

NATIONAL QUALITY FORUM
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PALLIATIVE CARE AND END OF LIFE CARE
STEERING COMMITTEE

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THURSDAY
JULY 21, 2011

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The Steering Committee met at the
Capitol Hilton, 1001 16th Street, N.W.,
Washington, D.C., at 9:00 a.m., R. Sean
Morrison and June Lunney, co-Chairs,
presiding.

PRESENT:

R. SEAN MORRISON, MD, Co-Chair
JUNE LUNNEY, PhD, RN, Co-Chair
RUSSELL ACEVEDO, MD, MD, FACP, FCCM, FCCP,
Crouse Hospital
EDUARDO BRUERA, MD, FAAHPM, The University of
Texas MD Anderson Cancer Center
DAVID CASARETT, MD, MA, University of

Pennsylvania School of Medicine
ROBERT FINE, MD, Baylor Health Care System
RICHARD GOLDSTEIN, MD, FAAP, Dana-Farber
Cancer Institute
SARAH HILL, MA, Ascension Health
PAMELA KALEN, National Business Group on
Health

NAOMI KARP, JD, AARP Public Policy Institute
MICHAEL LEPORE, PhD, Planetree
SOLOMON LIAO, MD, University of California,
Irvine
STEPHEN LUTZ, MD, Blanchard Valley Regional
Cancer Center
HELENE MARTEL, MA, Kaiser Permanente

NAOMI NAIERMAN, MPA, American Hospice
Foundation

DOUGLAS NEE, PharmD, MS, OptiMed, Inc.

KATHLEEN O'MALLEY, California HealthCare
Foundation

TINA PICCHI, MA, BCC, Supportive Care
Coalition

TRACY SCHROEPFER, PhD, University of
Wisconsin-Madison School of Social Work

DOUGLAS WHITE, MD, MAS, University of
Pittsburgh, Department of Critical Care
Medicine

NQF STAFF:

HEIDI BOSSLEY, MSN, MBA

HELEN BURSTIN, MD, MPH

ERIC COLCHAMIRO

CAREN A. GINSBERG, PhD

LINDSEY TIGHE, MS

ALSO PRESENT:

LAURA HANSON, University of North Carolina
Chapel Hill*

DALE LUPU, American Academy of Hospice and
Palliative Medicine

CAROL SPENCE, National Hospice and Palliative
Care Organization

MARTHA TECCA, Deyta

JOAN TENO, Brown Medical School

NEIL WENGER, RAND*

*Participating via teleconference

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

Page

Welcome, Recap of Day 1	4
Drs. Morrison and Lunney, Dr. Ginsberg	
Steering Committee Review: Care	10
Preferences (1626, 1641, 1647)	
Steering Committee Review (cont'd)	110
(0209, 1625)	
NQF Member/Public Comment	165
Steering Committee Review:	166
Comprehensive Measure	
(0208, 1623, 1632)	
Measure Report Framework and Discussion	232
of Measure Gaps	
NQF Member/Public Comment	263
Wrap-up/Next Steps	286
Dr. Ginsberg and Ms. Tighe	
Adjournment	290

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

2 9:01 a.m.

3 DR. MORRISON: Good morning,
4 everybody, and welcome to our second day.
5 Again, thanks to everybody for a really,
6 really productive session yesterday, after
7 what several people told me might have been a
8 little bit of a difficult start.

9 I do want to reassure you that I
10 think today -- he said, knock wood -- is going
11 to go very smoothly. We have -- Oh, don't
12 laugh. We have our measure developers
13 available to us to answer any questions. Most
14 of them present at the beginning measures, and
15 the preliminary scoring looks pretty
16 straightforward. So I think we are in very,
17 very good shape.

18 Just very, very quickly on today's
19 agenda, we are going to spend the morning on
20 reviewing one, two, three, four, five
21 measures. We are going to break for lunch.
22 We are going to have one, two, three, four,

1 five -- four measures -- three measures in the
2 afternoon. Then there will be a brief time to
3 discuss gaps, after which you guys have seen
4 everything here, and then for us to identify
5 for NQF what specific gaps are there, what we
6 didn't see, and what are the future
7 opportunities.

8 I need to apologize to the group.
9 I am going to be leaving about 12:45-1:00
10 o'clock to get a flight home. I have to get
11 my two kids to camp in Maine by tonight, and
12 this is the only way to do it. Unfortunately,
13 their camp schedule was scheduled before this
14 meeting. So June is going to take over and
15 run everything for the last part of the
16 afternoon.

17 Just a recap of yesterday. We
18 reviewed eight comprehensive -- or eight
19 measures. We approved seven of them, and we
20 tabled a number of measures for further
21 discussion.

22 Just for the group, June and I and

1 Lindsey, Karen and Heidi will be talking with
2 Dr. Earle next week by conference call. We,
3 hopefully, will get answers to all the
4 questions that you guys put forward to him.
5 We will circulate that back to the group.

6 Then we will reconvene by
7 electronic voting to go through the ASCO
8 measures and readdress those and, hopefully,
9 the answers that Dr. Earle gives us will give
10 you guys the confidence and the ability to
11 actually vote on those in a meaningful manner.

12 Make sense? Sir?

13 DR. BRUERA: Sean, I wanted some
14 clarification. Dr. Earle has changed his role
15 since this was done. So one of the questions
16 would be: Who is the ASCO person who could
17 further strengthen some of this work, because
18 if he has a different role and a different
19 scope, some of the very important questions
20 for this that I personally, coming from the
21 cancer perspective, feel are the most
22 important outcomes, might not be strengthened.

1 So what would be the process to
2 get the sponsor institution like ASCO to be
3 able to successfully address the comments that
4 we have to strengthen these measures for the
5 next application?

6 DR. MORRISON: You are exactly
7 right, and that is one of the issues that
8 Lindsey and I were talking about before the
9 meeting. Let me say it this way. There was
10 an opportunity to identify somebody from ASCO
11 before the meeting, and Dr. Earle didn't feel
12 that there was anybody at ASCO who could step
13 in for him.

14 I think that what I would like to
15 do with the NQF staff is reapproach that very
16 closely, because as you said, ASCO will be the
17 steward of these. ASCO is the steward of
18 these measures moving forward, and I think
19 that, given the fact that they have taken on
20 that responsibility, my perspective is that
21 it would be very helpful to have somebody from
22 ASCO step up to the plate, since they will be

1 stewarding these, and Dr. Earle is back in the
2 great white North where he is really not
3 connected to the American Society of Clinical
4 Oncology.

5 So I agree with you completely,
6 and I think it is something that we, with the
7 NQF staff, will try to explore really well,
8 because I completely agree with you, Eduardo.
9 It is critically important. There are some
10 important measures in an important population,
11 and we need to see if we can get them right.

12 MS. BOSSLEY: Just to add to it, I
13 actually have the text on my other phone that
14 I didn't see. There was an ASCO
15 representative on the phone listening. So I
16 think we have an opportunity to get a phone
17 call with Craig and also an ASCO
18 representative and talk this through, because
19 I think they have data that will help with
20 this. I think they are aware of it. I think
21 we just need to have a few more conversations.

22 The other thing is I think,

1 because you didn't have a very robust
2 discussion on all of the measures, we will try
3 to have Craig on a phone call with all of you
4 to go through those measures, and then have
5 you vote after that, and ASCO will also be on.

6 So that is something that Lindsey
7 and Eric and Karen and I will be working on
8 over the next week or two, to figure out when
9 we can do that.

10 DR. MORRISON: Everybody ready to
11 move forward? Did I miss anything else,
12 Heidi? Okay. Anybody have a conflict of
13 interest or disclosure that happened between
14 yesterday and today that needs -- Don't laugh.
15 The last NQF session, we had to do this all
16 over again. So just checking. It wasn't you.
17 No, no, it wasn't you.

18 All right. So we are going to
19 move to the first measure, which is 1626,
20 patients admitted to ICU who have care
21 preferences documented.

22 Do I have somebody from RAND on

1 the phone who can present? Anthony, do we
2 have anybody from RAND on the phone?

3 OPERATOR: Not at the moment, sir.

4 DR. MORRISON: Was that a yes?

5 OPERATOR: No, sir, not at the
6 moment.

7 DR. MORRISON: Not at the moment,
8 okay. So who do I have as the presenter?
9 Tracy. Thank you. So I have Tracy as the
10 presenter. So I am going to open it up to
11 Tracy to present. We could do that. Is Laura
12 on? Is Laura Hanson on the phone?

13 OPERATOR: She is joining shortly.

14 DR. MORRISON: She will be on
15 shortly? Okay. How about somebody from
16 Deyta? Yes. We are going to go down to 1647.
17 David Casarett, could I ask a favor? Could
18 you just move a little bit this way? Thank
19 you. Thank you, thank you, thank you.

20 So this is documentation of
21 spiritual/religious concerns, 1647.

22 MS. TECCA: That is right. I am

1 Martha Tecca from Deyta.

2 This is a measure -- Again, just
3 backing up briefly, what Deyta does -- I know
4 we are the only folks that are here sort of as
5 a vendor as opposed to as a researcher or more
6 commonly as a steward of measures.

7 This is not something that we have
8 done in this way before, but we have been
9 working to implement as many of the standard -
10 - what are evolving as standard measures as
11 possible among our clients who are using them
12 for performance improvement primarily, and in
13 some cases in some states, they are using them
14 for public reporting.

15 So we have actually captured data
16 from lots of hospices across the country for
17 many of the measures or different permutations
18 of many of the measures that are here.

19 When talking with folks in
20 advance, as I know many of you did, to figure
21 out whether or not we had a potential role
22 here, we were trying to determine which of the

1 categories of measures that we felt were
2 really important and in the conversations
3 appeared important, that there wasn't data,
4 that people were not going to be presenting
5 the measures from a research perspective.

6 So we selected this one measure,
7 because we felt -- to promote, we thought we
8 had a reasonable amount of data from actual
9 hospices who were using the measure, and
10 wanted to make sure that we were able to have
11 a real conversation about this particular
12 dimension of hospice care that we think is
13 important; and to the extent the NQF measures
14 of palliative and end of life care can be
15 looking at things that are core to those
16 services, this felt like a missing one in the
17 list that I had seen going forward. So that
18 is why this is here at all.

19 The data that we are presenting
20 for -- and the measure itself is one that was
21 promoted through the PEACE Project and then
22 the AIM project. So it isn't a measure that

1 we designed, but a measure that had been
2 promoted as a standard and that we have
3 captured data for, and we are presenting you
4 with the data from our clients over the course
5 of the time frame.

6 So it is a little bit of a
7 different -- Our application probably looks a
8 little bit different. I don't know if you
9 need more background than that, but we are
10 comfortable that it shows that there is, for
11 something that is required, documentation of
12 a spiritual conversation, required again by
13 the conditions of participation and,
14 certainly, a core aim and goal of this kind of
15 care, there is a surprising amount of
16 variation. So we thought it was useful to
17 have the conversation.

18 DR. MORRISON: Fantastic. Thank
19 you very much. Tina, I have you as the lead.

20 MS. PICCHI: Great. Thank you for
21 that background. So this is 1647, and the
22 measure is the percentage of hospice patients

1 with documentation in the clinical record of
2 a discussion of spiritual/religious concerns
3 or documentation that the patient or caregiver
4 did not want to discuss.

5 As Martha indicated, there really
6 is. Spiritual care has been shown to be a
7 critical element of quality of life at the end
8 of life and is of significance to 1.5 million
9 people who received services from
10 approximately 5,000 hospices in the U.S.

11 I am going to start at the end and
12 work back. Basically, I want to tell you, of
13 the six people who reviewed this measure, only
14 one recommended the measure for NQF
15 endorsement, and I think there is some
16 particular reasons why.

17 In terms of the demonstration,
18 there certainly has been pretty much of an
19 agreement of high impact, but the
20 demonstration of performance gap, there was a
21 variation in the reviewers' evaluation of
22 that.

1 The medium score shown in the data
2 was 78.2 percent in 2009, 73.6 percent in
3 2010. I think the concern is that the body of
4 evidence was rated very low by the majority of
5 the evaluators. There are no known studies,
6 and there didn't appear to be enough evidence
7 to demonstrate that this measure is
8 meaningful.

9 The data does come solely from
10 data and the system, though it comes from data
11 collected from 13,435 records in 2009 and
12 2010, and it does demonstrate a less than
13 optimal performance across the providers.

14 Now the citations for evidence of
15 impact include the NCP guidelines, which have
16 the eight domains of care, the NQF preferred
17 practices, and also it mentions the Consensus
18 Conference on Improving the Quality of
19 Spiritual Care as a dimension of palliative
20 care that was published in the Journal of
21 Palliative Medicine and later in its entirety
22 in the text written by Dr. Christina Puchalski

1 and Debbie Farrell entitled "Making Health
2 Care Whole."

3 Now my comments come to you also
4 as a board certified chaplain and someone who
5 has directed spiritual care in chaplaincy and
6 hospitals for the last 30 years.

7 It appears from my reading and the
8 other evaluators' that one of the important
9 elements that is missing that refers to the
10 preferred practices for the National Quality
11 Forum's preferred practices is the use of a
12 standardized instrument to measure spiritual
13 distress, spiritual pain, and to integrate
14 those findings into the care plan.

15 It appears that this measure falls
16 short of meeting the NCP guidelines and the
17 NQF preferred practices, because a
18 standardized instrument is not being used.
19 Also, there isn't any indication as to who
20 this assessment would be made -- who would be
21 making this assessment. Is it a spiritual
22 care professional? Is it someone else on the

1 hospice team, and are they qualified to make
2 this screening or is it an assessment? That
3 is another question.

4 The measure is a little vague in
5 its language, only that it requires
6 documentation that there was a discussion of
7 spiritual concerns or documentation that the
8 patient or family didn't want to discuss it.

9 It also doesn't meet some of the
10 other NCP guidelines in terms of ensuring
11 that, if there isn't indications of spiritual
12 distress or spiritual pain, there would be
13 then a referral to a qualified spiritual care
14 provider who would make an intervention, and
15 then integrate that into the care plan.

16 So based on that assessment, I
17 think that is why the measure was not strongly
18 recommended by the reviewers. However, I must
19 say as a spiritual care professional, it was
20 very heartening to see a measure being
21 proposed for this. So I really want to
22 applaud Deyta for putting that forward.

1 DR. MORRISON: Fantastic. Thank
2 you, Tina. That was very comprehensive. Open
3 for discussion. Dr. Casarett, Dr. Lunney, Dr.
4 Fine?

5 DR. CASARETT: I would like to
6 lead off with a question, but it is really
7 more of a comment or maybe a question to
8 consider in follow-up comments.

9 I wonder if we are letting the
10 perfect be the enemy of the good for this
11 measure. I understand all of those critiques
12 that you just shared, and I read through the
13 proposal just now and found some of my own,
14 but I also think back to some of the pain
15 measures we have looked at, and many of the
16 questions that we are asking now about this
17 spiritual assessment, we didn't ask about the
18 pain measures.

19 We didn't ask them to say who
20 would be doing the screening. We didn't ask
21 for a follow-up. We just said pain screening
22 is important. You can't really manage pain

1 unless you know it exists. Therefore, we
2 thought it was a good measure.

3 So while I recognize all of the
4 flaws that you just mentioned, I would ask us
5 in our comments to consider whether those
6 really are fatal flaws or whether this might
7 be a good first step.

8 DR. FINE: Yes. As the one guy
9 that voted for this, I saw this as a good
10 first step. I like to tell the people I train
11 that sooner or later death is not a medical
12 problem to be solved; it is a spiritual
13 problem to be faced.

14 In all, I see this as a screening
15 tool, not an assessment tool. It was maybe
16 not worded as well as it could be, but I echo
17 what David said, and that was my feeling when
18 I first read it. The evidence is not great,
19 if you look at the literature, but they
20 collected data on nearly 25,000 patients,
21 actually, over a couple of years. They showed
22 variability.

1 I view some of what we do as a
2 political tool, trying to move the public
3 debate, and I think it is important that we
4 ask hospices -- and I would again love to see
5 this eventually expanded into the acute care
6 setting and palliative care teams.

7 We on our palliative care teams at
8 Baylor Health Care in Texas -- you know, we
9 do, in fact, ask everybody if they have
10 spiritual concerns and, if they do, if they
11 wish to discuss them, what their faith is,
12 etcetera.

13 We all ask it in slightly
14 different ways. Some of us do the FICA
15 questions, some of us don't. Then based on
16 that, we may call in the chaplains. As a
17 Baptist health care system, we are swarming in
18 chaplains, and we have got a CP program. So
19 we never lack for spiritual professionals who
20 can come in and help.

21 I think you got to ask the
22 screening question and say it is a quality

1 measure. So I still say yea.

2 DR. MORRISON: Naomi.

3 MS. NAIERMAN: In our research
4 with consumers, we found two things. One is
5 that this is something they really want to
6 know about hospice when they are selecting a
7 hospice in advance: Will my family member,
8 will I, have this kind of support, if and when
9 I need it during my hospice experience?

10 We also found quite a bit of
11 variation among hospices. My sense is that it
12 is a kind of thing that can vary in terms of
13 resources allocation among hospices. It is
14 kind of fudgeable versus a nurse's aide or a
15 nurse. So I would vote for this myself,
16 despite the technical thoughts.

17 DR. MORRISON: Everybody will get
18 an opportunity to vote. Other comments,
19 questions from the group? Tina, I see you
20 moving there.

21 MS. PICCHI: The concern that I
22 have is it would be my hope that it would be

1 part of the initial screening assessment when
2 the patient was brought into hospice. My
3 concern could be that it could be hours before
4 death that there was documentation that a
5 clergy person was called in. So that was just
6 another part in terms of the timing that I
7 think could be improved.

8 DR. MORRISON: Naomi? Naomi,
9 Stephen, Bob, and Naomi again. Are you up or
10 down? Okay.

11 MS. KARP: This is just a wording
12 issue, but in the numerator statement, it just
13 says documentation of spiritual/religious
14 concerns; whereas, it seems to clearly be
15 talking about a discussion. So I don't know
16 if we have the ability to just amend that, to
17 add the word discussion of, because there
18 could be potentially -- you know, someone
19 might just make a remark to a staffperson, and
20 they note it, but there is not even a
21 discussion. So I would just want that to be
22 clear.

1 DR. MORRISON: Stephen.

2 DR. LUTZ: Yes. I am trying to
3 figure out how to word this. So if I don't
4 word it well, just ignore me and move on.

5 I am trying to share concerns that
6 some patients have voiced to me, if they are
7 in a system. Say they are in a system that
8 they know is a certain religious order, and
9 they are asked if they have any religious
10 concerns. I basically have patients say to
11 me, essentially, do you think it is going to
12 matter, I am in a Baptist hospital, and I said
13 I don't believe in God.

14 It sounds stupid, but I have
15 actually had this said. I am not trying to be
16 the unintended consequences guy for every
17 question, but I have had this concern brought
18 to me before. I don't know how else to voice
19 it other than to say some people take even the
20 question a little bit differently than maybe
21 we would intend it.

22 DR. MORRISON: I have got Bob and

1 Stephen. Every committee needs an unintended
2 consequences guy. So thank you for filling
3 that role.

4 DR. FINE: Tina, I just wanted to
5 respond to something you said. I didn't read
6 it and interpret it that it meant it had to be
7 a CP provider, a certified chaplain, which is
8 just interesting. I don't know why a nurse or
9 physician -- Again, I don't see it as an
10 assessment. If somebody sees this as an
11 assessment tool, it is not. It's lousy.

12 There is no assessment there at
13 all. It just says was there some kind of
14 discussion. Was the issue raised? That, to
15 me, doesn't have to be done by a chaplain, and
16 I wouldn't worry about the unintended
17 consequence of, oh, my god, they have just
18 been enrolled in hospice, they are dying, and
19 the chaplain hadn't shown up.

20 DR. MORRISON: Tracy?

21 DR. SCHROEPFER: I think the other
22 concern would be that spirituality wasn't

1 defined. I think that people struggle and
2 think that spirituality has to do with
3 religion, but it doesn't necessarily. It can,
4 and it cannot. So that oftentimes social
5 workers are doing the spiritual, because
6 people are talking about meaning and life,
7 which is spirituality. How do I -- What
8 legacy will I leave behind? Where do I fit
9 into this world? So those kind of questions.

10 So I think that I was more
11 concerned that it didn't define it well
12 enough, such that if it is not the chaplain or
13 if it is not religious, that then it would not
14 be counted, and that would concern me.

15 DR. MORRISON: I assume, Bob and
16 Stephen, you are okay. Right? It's okay. I
17 just want to make sure before I move forward.
18 I know it is early in the morning.

19 Other comments, questions, before
20 we move? I figured you had said everything,
21 Tracy. Other comments or questions before we
22 move to voting? Are people comfortable?

1 Okay. We are skipping the first question
2 again. We are skipping the first question
3 again, because we agree on the importance, and
4 we get an extra 45 seconds doing that all the
5 way through the day.

6 MR. COLCHAMIRO: On the
7 performance gap demonstrated by the measure,
8 12 high, four moderate, four low, and zero,
9 insufficient evidence.

10 DR. MORRISON: I am sorry. I
11 should be reading these. This is evidence or
12 outcome, importance to measure and report.
13 Everybody, try again. I am going to make
14 Lindsey sit in the middle of the circle here.
15 We could all go around one by one. All right,
16 everybody try one more time.

17 MR. COLCHAMIRO: Six, yes; 13, no.

18 DR. MORRISON: Okay. Are there
19 appropriate -- Is there a quantity of studies
20 in the body of evidence to support it?

21 MR. COLCHAMIRO: Two high, 11
22 moderate, 7 low, and zero insufficient

1 evidence.

2 DR. MORRISON: Importance of the
3 measure to report? Sorry, quality, quality,
4 quality. It is way too early in the morning.

5 MR. COLCHAMIRO: Three high, eight
6 moderate, eight low, one insufficient
7 evidence.

8 DR. MORRISON: Okay. Consistency
9 of results across the body of evidence?

10 MR. COLCHAMIRO: Four high, nine
11 moderate, six low, one insufficient evidence.

12 DR. MORRISON: Scientific
13 acceptability of the measure properties:
14 Reliability? Of course, we can go back. A
15 very good point, thank you.

16 MS. BOSSLEY: I just have a
17 question as well, because the evidence -- The
18 provider didn't hear it again. We will be
19 writing all of this up. So it will be helpful
20 to know. The evidence that is provided in here
21 is based on -- I think it is the NQF preferred
22 practice that we have.

1 There is very little else
2 provided, but all the ratings that I saw here
3 are showing that the quantity is moderate or
4 so, the quality is moderate or so. So I just
5 want to make sure that either you are voting
6 based on something that we don't have in front
7 of us, and your own expert opinion, which is
8 fine. I need to know that, so we can document
9 it, or we just need to probably have a little
10 more discussion on that. It would be helpful.

11 DR. MORRISON: David?

12 DR. CASARETT: I was curious about
13 that, too. I can give you my response, which
14 was, in thinking about the evidence, I was
15 thinking not just about what was in here, but
16 about the literature that exists that suggests
17 that patients do welcome the opportunity to
18 have these sorts of discussions.

19 DR. MORRISON: Other comments or
20 thoughts, because I think Heidi's point is
21 very well taken. There is very little
22 evidence supported, and I would add that,

1 remember, that the NQF framework is evidence
2 based, but certainly a substantial component
3 of the framework is expert opinion, and I
4 think this is one of the key issues where
5 there was not strong empirical data to support
6 it, and there was a lot of -- this was based
7 upon the expert opinion issue.

8 So as Helen keeps reminding me,
9 expert opinion does count as evidence, but
10 just make sure that what you -- and Heidi is
11 nodding. Just make sure that that is the
12 point. So I have got Naomi, and then Kate.

13 MS. NAIERMAN: Just quickly, to
14 repeat but with a little bit more information,
15 that in our study with consumers this was a
16 very valuable piece of information that they
17 wanted to know, in a public report, by the
18 way. That was the reason for our research.

19 If you would like a link to our
20 published report, I would be happy to direct
21 you there.

22 DR. MORRISON: Kate?

1 MS. O'MALLEY: I guess my question
2 would be, for the purpose of this particular
3 process, is it helpful to hear people say, in
4 my expert opinion, I think this is very
5 important; because I would say, in 20 years of
6 clinical practice in community settings, I
7 have found this work to be very significant to
8 patients and families.

9 DR. BURSTIN: And, actually, just
10 to remind you, the way the Evidence Task Force
11 has set this all up for us, obviously, we went
12 through the whole issue of quality, quantity,
13 consistency.

14 There is specifically an exception
15 to the empirical body of evidence, actually
16 more so for -- I guess for any kinds of
17 measures, -- where expert opinion
18 systematically assessed that benefits to
19 patients greatly outweigh potential harm. So
20 if that is the direction you want to go, you
21 just want to document that you are clearly
22 going in that direction.

1 DR. MORRISON: June?

2 DR. LUNNEY: I was just going to
3 comment that, in case you didn't read the
4 paper this morning, Harvey Chochinov made the
5 USA Today with his study. So that says
6 somebody is interested.

7 DR. MORRISON: Doug?

8 DR. WHITE: Just then for clarity
9 of how we should be voting on these, would we
10 be voting according to the evidence in the
11 room, and then there is a separate space where
12 we say, notwithstanding this evidence, that we
13 think, based on expert judgment, blah-blah-
14 blah?

15 DR. BURSTIN: Yes. I think you
16 all voted this sort of in the moderate range,
17 some more lows perhaps than we are necessarily
18 comfortable with, because why I think we will
19 qualify in the report that you continue to
20 evaluate the measure, because there was a
21 consensus on expert opinion that the benefits
22 outweigh the harms.

1 DR. WHITE: But is that where you
2 want us to go?

3 DR. BURSTIN: I think you should -
4 - If that feels right to you, in terms of the
5 process, yes.

6 DR. WHITE: This is just a
7 procedural question.

8 DR. BURSTIN: Yes. I think that
9 would be fine.

10 DR. WHITE: Should we vote
11 according to that or should we vote according
12 to what is in front of us, and then say, but
13 we still think it should go on? Is there a
14 later question where we can sort this out?

15 DR. BURSTIN: There is not a later
16 question, but it probably would be a good
17 straw vote, just a hand vote, just to see if
18 people are comfortable with that approach,
19 because you have already voted on the quality,
20 consistency and evidence.

21 DR. MORRISON: Can I see a show of
22 hands, who are comfortable with that approach,

1 to quote the good Dr. Burstin?

2 DR. BURSTIN: Would you state the
3 approach?

4 DR. MORRISON: All right. So I am
5 going to have to rephrase. So I think what I
6 am asking is that, based upon the -- We voted
7 to move this forward with a -- There was a
8 higher percentage of low/moderate than we have
9 typically seen that, I think, NQF staff feel
10 comfortable pushing forward.

11 What I would like to see is a show
12 of hands who feel that the benefits of this
13 measure far outweigh the potential of harms to
14 patients, that it is a measure that has very,
15 very few unintended consequences or harms for
16 patients, and the potential benefit is great.
17 So just a show of hands who believe that and
18 feel that we should move forward.

19 So I have got a strong majority.
20 So we can move forward? You guys are good?
21 Okay. We will move to the next question then.
22 Reliability?

1 MR. COLCHAMIRO: Three high, seven
2 moderate, nine low, one insufficient evidence.

3 DR. MORRISON: Validity?

4 MR. COLCHAMIRO: Three high, nine
5 moderate, eight low, zero insufficient
6 evidence.

7 DR. MORRISON: And disparities?

8 MR. COLCHAMIRO: One high, eight
9 moderate, seven low, four insufficient
10 evidence.

11 DR. MORRISON: I was going to
12 stop. We are going to have to have a
13 conversation now.

14 DR. BURSTIN: I think so.

15 DR. MORRISON: So do you want me
16 to read this one, Heidi?

17 MS. BOSSLEY: I think it would
18 actually help to have Lindsey or Eric just
19 read us back the ratings on reliability and
20 validity.

21 DR. MORRISON: That would be
22 helpful.

1 MS. BOSSLEY: I think it is not
2 clear it made it.

3 MR. COLCHAMIRO: So for
4 reliability, we had three high, seven
5 moderate, nine low, one insufficient evidence.

6 For validity, we had three high,
7 nine moderate, eight low, and zero
8 insufficient evidence.

9 MS. BOSSLEY: It may be helpful
10 maybe to talk a little bit more about why
11 people voted what they did for reliability and
12 then also validity, because I don't know that
13 we really got into the weeds of it on that.
14 So why don't we talk through that a bit? Does
15 that sound good to you?

16 DR. MORRISON: Yes, thank you.
17 Solomon?

18 DR. LIAO: So I think it may boil
19 down to whether we are thinking this is a
20 screening question or whether this is an
21 assessment.

22 DR. MORRISON: Sure. Yes, I am

1 not sure that -- Yes. Let's ask, because I am
2 not sure.

3 MS. TECCA: This is, again, one of
4 those odd places where I am calling the
5 developer. I am forwarding this measure that
6 was developed by PEACE, that was promoted by
7 AIM, and we have been using with hundreds of
8 hospices. I am not the developer of the
9 measure, but as others have described, it is
10 not an assessment. It is simply specifically
11 asking whether there was a general question --
12 whether the conversation and discussion had
13 been had about spiritual and religious
14 concerns, and the documentation of that, and
15 documentation of whether or not the family
16 refused.

17 It is actually very specific. It
18 is broad, but it is a very specific
19 definition. It is not about an assessment.
20 It is not about a specific assessment, not
21 about even necessarily screening. It is about
22 the documentation of the discussion.

1 DR. MORRISON: Anthony, could I
2 ask, is Laura Hanson on the phone?

3 DR. HANSON: I am.

4 DR. MORRISON: Okay. Laura, can I
5 put you on the spot?

6 DR. HANSON: Uh-oh.

7 DR. MORRISON: Because I have
8 heard several times that this was developed by
9 your group. I guess what I think it might be
10 helpful to the group is -- you know, I have
11 two questions as Chair's prerogative.

12 The first is a little bit about,
13 given that you guys developed it, why you
14 didn't submit it as a potential measure, and
15 perhaps you could answer some of the questions
16 that have arisen about the reliability and the
17 validity and the scientific merit of this,
18 given the committee's discussions about scores
19 that were in the very low to moderate range,
20 and help us with that? Doug, I have you next.

21 DR. HANSON: Okay. In the
22 development, really, our logic in the

1 development is precisely what has been
2 described, that the evidence base is very
3 strong for the importance of this domain and
4 addressing this domain in some way in the
5 clinical practice of hospice and palliative
6 care.

7 When we put it before the
8 technical expert panel for the PEACE Project,
9 it was rated highly, not as high as some
10 others, but certainly rated very high, over
11 four on a five-point rating scale overall.

12 The concerns all along were really
13 in the area of effective intervention to
14 address concerns, which I think the discussion
15 here has characterize well. So we ended up
16 not putting it forward mostly related to those
17 concerns, but we have some additional data
18 about inter-rated reliability that says it can
19 be reliably abstracted from medical records
20 and, certainly, data for the performance gap,
21 as I think has been comparably presented.

22 I think the discussion -- I have

1 been listening to the whole discussion, and I
2 think the discussion fit completely with what
3 we have learned in the process over the last
4 several years of looking at this particular
5 measure.

6 As I said, the rationale for us
7 not putting it forward had to do with still an
8 evidence gap between detecting spiritual
9 distress and then the nature of intervention
10 to relieve that distress. But we didn't find
11 a lot of evidence for harms about asking, and
12 I would characterize this as a screening
13 question or as a screen.

14 DR. MORRISON: So I just want to -
15 - So what I am hearing, just for the group, is
16 the question was that, as a process measure,
17 there wasn't -- there is not a clear link to
18 an outcome or an intervention that would
19 affect the outcome. Is that what I am hearing
20 specifically?

21 DR. HANSON: Right, exactly.

22 DR. MORRISON: I don't want to put

1 words in your mouth, but I think it is a
2 really important concept for the committee to
3 consider, particularly given the focus on
4 measurable interventions that can affect a
5 process. Okay.

6 So I've got a lot of people with
7 tent cards up. Let me start with Doug who was
8 up first. Then I've got Naomi. I've got
9 Kate. I've got June. I think that is it.

10 DR. WHITE: This is just a
11 comment sort of again about the process here.
12 So the question that had been asked is tell us
13 about why you voted the way you did, and I
14 voted the way I did, because I think it is
15 important for sort of an integrity based view
16 of NQF that we vote according to what is in
17 front of us, and then we have an opportunity
18 to say, notwithstanding this, here are the
19 reasons that we are going against the data
20 that is in front of us.

21 I would hate for the public to
22 look at our ratings and see a bunch of ones

1 and twos, and then look at what we based that
2 on, and say this is not a credible process.

3 DR. BURSTIN: Just one point,
4 though. That only applies to evidence. It
5 has nothing to do with scientific
6 acceptability. Scientific acceptability is
7 truly what is in front of you, and the only
8 question is whether you had sufficient
9 information that perhaps -- I don't know that
10 Laura could have provided additional
11 information than what is in front of you, but
12 again you have to act on what is in front of
13 you.

14 DR. WHITE: Yes. I am talking
15 more about the things around the measure
16 itself, the reliability, the validity,
17 etcetera, which is a central component of the
18 evaluation, I think.

19 MS. BOSSLEY: And part of what we
20 will do is -- Assuming this passes scientific
21 acceptability and you move forward through the
22 rest of it, what we try to do is then reflect

1 within the notes the Steering Committee's
2 rationale of why you did what you did, and you
3 all will see that. But we try to frame it so
4 that it doesn't sound like you -- You may have
5 known that you did something that may not look
6 like it followed the process. Happens all the
7 time. We are very good at writing notes to
8 reflect that you actually knew what you were
9 doing when you did it.

10 DR. MORRISON: The joys of being
11 in a public forum, Doug. I'm sorry, I've got
12 Naomi, Kate, and June.

13 MS. NAIERMAN: I want to make two
14 comments. First of all, Martha is right. She
15 is not the developer of this measure, and we
16 have just heard from the developer of this
17 measure. As far as I recall, she said it was
18 reliable and valid. It passes the test of
19 validity and reliability.

20 The other thing is that I am not
21 sure whether we are raising a higher bar for
22 this particular measure than we did for

1 previous measures where we just simply asked
2 for screening and assessment, and not outcome.

3 There is, clearly, an intervention
4 that could be applied if a screening showed
5 that someone wants to discuss spiritual care.
6 You just bring the chaplain in or whoever. So
7 I want to make sure we don't raise the bar any
8 further than we did for previous measures.

9 DR. MORRISON: Kate?

10 DR. HANSON: This is Laura.

11 DR. MORRISON: Sorry. Laura, I've
12 got a couple of committee members first, I'm
13 afraid, unless you are going to clarify.

14 DR. HANSON: I just want to
15 correct that statement, that we have data on
16 inter-rater reliability that shows good
17 reliability. We do not have data on validity.

18 DR. MORRISON: That is very
19 important. Thank you. Kate?

20 MS. O'MALLEY: I am adding my
21 voice to the access issue. It sounded from
22 Laura's descriptions they held back on the

1 intervention side, but when I was listening to
2 that, I also felt that we raised the bar a
3 little bit higher, thinking about pain
4 screenings. You can do a lot of pain
5 screening, but you don't necessarily know
6 always the quality of the intervention. So I
7 think that is an important consideration for
8 this work.

9 Also, in looking further at the
10 documentation, it does clearly say that it
11 documents a discussion about whether or not a
12 question took place about spiritual concerns.

13 DR. MORRISON: June?

14 DR. LUNNEY: I just wanted to ask
15 the NQF question, that I voted on my
16 reliability judgment without hearing Laura.

17 MS. BOSSLEY: One thing that we
18 could do is see if Laura would be willing to
19 provide that information, and then bring it
20 back to the committee. Then you can revote,
21 and we could probably even do that essentially
22 on the next phone call that we have with all

1 of you. So that would be the other option.

2 DR. BURSTIN: It still is a
3 concern, though, because measures at low
4 validity don't go through. So if there is
5 truly no validity testing, that is really
6 where it comes down to.

7 DR. MORRISON: Yes, and I do think
8 that is a very -- I am hearing that as an
9 important point. David, did you have a
10 comment? I'm sorry.

11 DR. CASARETT: No. I was just
12 going to make that same request, but although
13 I certainly believe Laura when she said it was
14 reliable, I think we need to see the numbers.

15 DR. MORRISON: Yes, and I do think
16 -- I'm sorry, Solomon? No, that's okay.

17 Heidi, I am not quite sure how to
18 proceed here, because I think as a committee
19 we need some information from Laura about the
20 scientific reliability, but what I am also
21 hearing is that we have no validity data at
22 all. I think, from -- Let me frame this.

1 From a scientific perspective, it is very hard
2 to push through a measure that has no validity
3 data behind it.

4 Let me rephrase that, because
5 Helen is saying it. It is impossible to put
6 through a measure that has no validity data
7 behind it, and I am not quite sure where we go
8 from here.

9 DR. BURSTIN: I would actually
10 suggest that it makes sense to actually allow
11 the developer to speak with Laura, see if
12 there is any additional information to provide
13 back to the committee, and just have you
14 review it offline. You don't have enough
15 information in front of you at the moment to
16 really make this assessment.

17 DR. MORRISON: June, and then
18 Doug.

19 DR. LUNNEY: Just to clarify,
20 validity for this purpose, we are looking at
21 whether or not the captured screening response
22 reflects the truth about what is in the

1 record? What are we trying to prove?

2 DR. WHITE: Yes, that's right.

3 Just to follow up on that, you can have --

4 From the standpoint of validity, you can have
5 an assessment of face validity. Does the same
6 measure -- what it appears to need to be
7 measuring? That could be via expert judgment,
8 or there could be the kind of question that
9 June is talking about.

10 So I would wonder if you can have
11 expert judgment of face validity as the
12 relevant validity testing?

13 DR. MORRISON: Solomon?

14 DR. LIAO: So again going back to
15 the issue of having consistent standard, we
16 have taken Laura's word on other measures and
17 not asked for her to have to provide the
18 numbers before we voted. So --

19 DR. BURSTIN: She actually
20 provided the numbers in the form she
21 submitted. The difference here is she didn't
22 submit this measure.

1 DR. LIAO: Exactly. So I guess I
2 am asking, do we need to table this or is this
3 something that we can take a preliminary vote
4 on today, or go back and revote this issue?

5 DR. MORRISON: I think we need to
6 confirm it, yes. We can do that. Tracy?

7 MS. TECCA: Can I just ask a quick
8 question? If we go forward, and I think it
9 would be terrific if the recommendation was
10 that Laura and I could sort of see how we can
11 present the data that is available in a
12 clearer form, but I would say I would love to
13 hear a sort of resolution to this question
14 about what validity -- what do you want to see
15 with regard to the validity, just in terms of
16 the data that would be helpful?

17 I don't know whether we have it in
18 our database or the combination, but it would
19 be helpful to know the question for sure that
20 we are trying to answer.

21 DR. BURSTIN: I think we can work
22 offline to provide that to you, but I think a

1 systematic assessment of face validity is one
2 element to get to at least moderate validity.
3 That is why I think more information here
4 would certainly get you closer.

5 MS. TECCA: I appreciate that,
6 yes.

7 DR. MORRISON: Last question,
8 Naomi.

9 MS. NAIERMAN: Just a quick
10 question. Would it help to have any
11 perspective from the AIM folks? Do they have
12 any data that -- because they selected this
13 measure. Just wondering. There may be
14 another source of information.

15 DR. MORRISON: Eduardo?

16 DR. BRUERA: Just a brief comment
17 about the issue of the validity and
18 reliability, because in experimental
19 conditions one can find things, and this is
20 going to be proposed for a quality measure for
21 clinical teams to work on, not for doing it
22 under the conditions of having a research

1 person or somebody who is particularly trained
2 to it.

3 So I think, if the body of
4 knowledge includes how these measures perform
5 in the real world when done by real
6 clinicians, that would be the important part
7 of the information, not whatever you did to
8 publish a paper, and we found with a JCAHO
9 pain fiasco that people can say anything they
10 want. When you tell them to say from zero to
11 10, they will adhere to any regulatory
12 measure.

13 Eighty percent of what I dictate
14 in every single medical chart is only for the
15 purpose of regulatory and billing issues, and
16 20 percent of that has any relationship with
17 patient care.

18 So we need to be aware that we
19 don't create paper tigers and that we ask for
20 the reliability and validity that, hopefully,
21 will be applicable to the real world clinical
22 scenario as much as possible.

1 Otherwise, we might run
2 consistently, not only when we talk about this
3 measure, but with any other measures of so
4 called quality, into backlashes of not really
5 improving outcomes.

6 DR. MORRISON: Tracy, I know you
7 got your thoughts together.

8 DR. SCHROEPFER: We have had
9 others where we have had the face validity at
10 least, and this one does talk about that it
11 has face validity.

12 I understand what people are
13 saying, but it just seems like validity -- I
14 mean, in this measure it is pretty much what
15 some of our other measures have been. It is
16 not like does it measure what it purports to
17 measure. It is a conversation was documented
18 or not, and how do you ever test for that.

19 It doesn't seem like validity
20 really applies so much with some of the more
21 rigorous tests. So this one says they
22 conducted face validity.

1 DR. MORRISON: Heidi, and then
2 Doug.

3 MS. BOSSLEY: The one thing with
4 the face validity, though, I would point out,
5 part of the criteria says it must be through
6 a systematic process. So they may have used
7 a systematic process, but it is not yet
8 documented in here. So that is something
9 that, I think, we need to go back and work
10 with them on, and see. But just stating that
11 it has face validity isn't enough to be able
12 to get even a low rating.

13 DR. MORRISON: Doug.

14 DR. WHITE: Just a measurement
15 issue, the difference between face validity
16 and criterion validity. We can all sit around
17 here and look at it and say it looks good; it
18 has face validity. But in the real world, the
19 other kind of validity is the criterion
20 validity.

21 Does the thing really measure what
22 it intends to measure compared to a gold

1 standard would require a chaplain or someone
2 who is really skilled in eliciting spiritual
3 needs separately doing that, going in there,
4 doing that, getting a sense of does this
5 patient really have any spiritual issues to be
6 addressed, and checking one or zero, yes or
7 no, and then comparing that to what you got on
8 your little screen.

9 I am not saying that we need to do
10 that. I am just sort of pointing out the
11 difference between face and criterion
12 validity.

13 DR. SCHROEPFER: And I agree with
14 you, and I understand that. I guess I am
15 thinking about our discussions yesterday
16 where, truly, we didn't hold that standard to
17 some of the measures yesterday. But, no, I
18 agree with you.

19 DR. WHITE: It is tricky when you
20 hear someone say the measure is valid. It is
21 such a thicket.

22 DR. MORRISON: All right, guys. I

1 think I am going to close discussion. I want
2 to just -- There are a couple of -- I think
3 there are a couple of issues that I want to
4 summarize on, and then I think a couple of
5 points that I want to sort of just clarify
6 before we move forward, if that is okay, and
7 I am trying to frame this so it will help in
8 terms of the -- because I think we are going
9 to move forward with voting or revoting.

10 So just a couple of things that I
11 have heard that would help, moving forward.
12 I think what I am hearing around the room is
13 everybody agrees that spirituality is a core
14 component, and I think that the importance of
15 that is -- and I think that the committee is
16 struggling hard with the idea that this is a
17 core component that we think needs to be
18 included.

19 I think that there are some
20 struggles and concerns about how the measure
21 is being put forward and some of the data
22 behind it. I think the relevance to yesterday

1 -- people talk about, well, we didn't hold
2 some of the pain standards, for example, to
3 that standard, but we have 20 years of data on
4 pain, and volumes and volumes and volumes of
5 it, how do you assess pain, what are the right
6 instruments, how are the questions asked.

7 I think that the evidence base for
8 spirituality is lacking. So I would not make
9 the link particularly to pain issues.

10 I think some of the issues that
11 have been raised, and Laura raised, I think,
12 for the committee are important ones.
13 Everybody understands the importance of
14 spirituality.

15 I think the problem is that,
16 unlike pain, again to use it, we don't have
17 clear links between the process of assessing
18 spirituality and then a good outcome that
19 addresses spiritual distress.

20 Even something as simple -- you
21 know, knowing this would be as a chaplaincy
22 consultation, we don't have outcomes data to

1 suggest what percentage of people who
2 identified spiritual distress are alleviated
3 or absolutely alleviated by a chaplaincy
4 visit, and we do have that data for pain.

5 We do know that, if you identify
6 pain in scale and you give opioids,
7 particularly if you have cancer pain, it
8 works. So I think that is some of the issues
9 that people are struggling with.

10 I think some of the scientific
11 validity issues that Doug pointed out are
12 very, very critical, that it really -- There
13 is a difference between face validity and
14 asking somebody do you have spiritual
15 distress, and understanding what that means.

16 As Doug said, there are ways of
17 getting at validity questions. You know, the
18 gold standard may be a chaplaincy
19 consultation, but there are other more
20 comprehensive assessments that get at
21 spiritual distress in a more comprehensive
22 way, and so that type of scientific criterion

1 validity that Doug presented, I think, are
2 very important in terms of making the
3 decision.

4 I think what you have heard from
5 Laura, which are going forward, is that there
6 is good reliability data, that people answer
7 the same way, that if you ask them this
8 question, they will answer the same way. That
9 is different from what does it mean by having
10 that answer, which comes back to the criterion
11 validity. I mean, what does it mean when they
12 say yes.

13 So what I would propose is we go
14 back and we revote on the reliability and
15 validity data. I think that we will assume
16 that Laura, because I trust her, has good
17 reliability data. I think for the committee,
18 for the purpose of the vote, I think you can
19 assume that criterion validity is not present,
20 and I think you have to vote your conscience
21 on the face validity piece.

22 Then what I would say is,

1 depending upon what we come back when we
2 revote based upon those specifics, then we
3 decide whether to move forward based upon the
4 voting, and I hear people's distress about
5 this one. I do think that this is one that
6 people are -- and I've got -- June is
7 distressed. I see distress.

8 DR. LUNNEY: I want to clarify.
9 This measure does not measure distress. It
10 measures whether or not a conversation
11 happened.

12 DR. MORRISON: No, I understand
13 that. I understand that, June. I understand
14 that, but I think what you are hearing is --

15 DR. LUNNEY: Then criterion to
16 distress assessment is inappropriate.

17 DR. FINE: I would like to ask the
18 question maybe of Doug. What would the
19 difference in a validity assessment be between
20 -- I see this as a screening question: Was
21 there a discussion or not? Nothing about the
22 quality of discussion, the meaning of

1 discussion, the outcome of the discussion. I
2 read it as a screening question.

3 What would validity testing look
4 like for a screening question versus an
5 assessment question? I am just trying to
6 understand this. I do not come with any
7 background in statistics.

8 DR. WHITE: I think June's point
9 is a very important clarification. But it
10 does -- Then it changes the importance of the
11 measure, I think.

12 If you are asking was any sort of
13 thing about spirituality questioned, that is
14 very different than was that a reliable and
15 valid screening tool for is there a spiritual
16 issue.

17 If we are not asking the latter --
18 and that is the point you are making -- then
19 I wonder about what is this thing? What is
20 the utility of the thing? We are not really
21 trying to sort of identify is there a real
22 problem for patients that needs to be followed

1 up on, i.e., is this a real screening tool for
2 a clinical issue.

3 If that is not what we are
4 measuring, then I guess I need to sort of
5 rethink how I had judged this.

6 DR. MORRISON: Naomi, and then
7 Helen.

8 MS. KARP: It seems to me that, if
9 we have this much confusion about what are we
10 even looking at for validity, is this
11 screening, what exactly does screening mean,
12 then there is something wrong with the
13 definition of the way this measure was framed.
14 It is too ambiguous. The wording is too
15 ambiguous. Even if they put the word
16 discussion in there, maybe that is too
17 ambiguous.

18 So what would be the process for
19 dealing with that? Do we have to reject the
20 whole measure or is there a way to give
21 somebody an opportunity to tweak the wording
22 and then have us look at it again?

1 DR. MORRISON: Helen, and then
2 Kate.

3 MS. MARTEL: Could someone from
4 NQF answer that as a process question?

5 DR. MORRISON: Yes.

6 DR. BURSTIN: We have before asked
7 a developer to go back and provide further
8 descriptions and refine the numerator
9 statement so that it is clearer, and include
10 definitions, anything like that. You can
11 request that, and I think that is actually
12 very reasonable here to provide more guidance
13 as to what you would expect to be documented
14 to be able to meet the measure. That is
15 perfectly appropriate.

16 DR. MORRISON: Helen?

17 MS. MARTEL: So I guess my
18 question would be, to follow on both of those,
19 is just that the clarification for are we
20 asking was the discussion raised? Was the
21 whole issue just raised in a discussion,
22 versus was there, as Doug said, a further --

1 you know, more depth to that screening than
2 did you even raise the topic of spiritual
3 dimension to a patient, or not.

4 DR. MORRISON: Kate?

5 MS. O'MALLEY: My question would
6 be to Helen. Since this question is in the
7 field and is used extensively in the Medicare
8 conditions of participation, when you ask this
9 question, what happens? Are we just asking
10 the question out in the wilderness, and the
11 tree falls, and nobody hears it, or does
12 something happen in relationship to this that
13 needs to be part of the process of considering
14 the value of this measure, this question?

15 DR. MORRISON: Helen, you want to
16 talk about it?

17 MS. MARTEL: Well, I guess that is
18 what I am asking the developer or the folks
19 who are promoting the measure, is exactly
20 that. It is to find that out. Is it just
21 raising the discussion, just raising the
22 issue, period, or is it then is there an

1 assumption that then you are doing something
2 about it? You are following through, and then
3 do an assessment, or something, or are you
4 just simply saying, you know, we are raising
5 the topic to give the opportunity for a
6 patient and family to express that they have
7 a spiritual concern, and the next step would
8 be further screening and assessment of
9 something?

10 MS. TECCA: Let me try to answer
11 that, to a certain extent. I think all of us
12 that are trying to measure hospice, look
13 broadly at the different kinds of things we
14 can measure in palliative care and hospice, we
15 are looking at, of course, not just screening,
16 but then what do you about getting to the
17 outcomes.

18 I think, if we look across the
19 various dimensions, there are lots of things
20 we don't know exactly why all the different
21 interventions that are gong on work, if they
22 work. So we acknowledge that.

1 Ideally, you would like to have:
2 Did you have a discussion? What exactly did
3 you ask? What did you do? You would like to
4 have all those pieces. So I think we
5 acknowledge that.

6 We started, however, this
7 particular measure because, if we go back to
8 the disparity data, which we haven't talked
9 about, but in fact this simple question of did
10 you document that you had the discussion, at
11 the median it is three-quarters of agencies
12 say yes to it, and 25 percent of them only
13 half the time are they documenting a required
14 discussion, in something that everyone here
15 says this is critical that we have this
16 discussion with our patients, everyone around
17 the table.

18 In the disparity we are noting
19 that, even on this first question, simple
20 screening question, only half of the people
21 are saying yes, 25 percent of the hospices,
22 so out of 100 different hospices that were

1 participating in this, and more, I know in
2 others.

3 So we don't have that next level.
4 Yes, sure, it would be nice to have the other
5 measures, but this is the first measure, which
6 it seems, based on the fact that we all
7 recognize it is important and we are seeing
8 from the disparity key data that the
9 discussions aren't happening in a lot of
10 hospices, just having a discussion would seem
11 to be important. So that is the -- Does that
12 answer the -- And the question earlier about
13 if asking this question -- Again, the question
14 is did you with that patient have the
15 discussion? That is the question.

16 DR. MORRISON: All right, Heidi.
17 What do I do?

18 MS. BOSSLEY: Put me on the spot.

19 DR. MORRISON: Of course.

20 MS. BOSSLEY: One thing we could
21 do -- So let me throw out a couple of options.
22 One thing we could do is, based on this

1 conversation, to me, either you can wait and
2 see if additional information from Laura would
3 be helpful.

4 The other thing to do is revote,
5 based on the conversation you have had,
6 looking at the information again. You could
7 do that, and then we could see where the votes
8 come out. Those, to me, would be two options.

9 DR. MORRISON: Strong feelings as
10 to should we revote? David?

11 DR. CASARETT: We spent so much
12 time on this discussion, and I confess, I am
13 actually less clear about this measure than I
14 was an hour ago. So although I was happy to
15 vote the first time, I think we need more
16 clarity and more information. I wouldn't feel
17 comfortable voting at this point.

18 DR. BURSTIN: We will take it
19 back.

20 DR. MORRISON: We will take it
21 back.

22 DR. BURSTIN: We will sit down,

1 and we have got the questions. We will get
2 the answers and get back to you.

3 DR. MORRISON: Does that feel good
4 with people? Good. Okay, onward and upward.
5 Great discussion, guys.

6 I had a feeling about that one. I
7 was hoping to go through the first two first,
8 so that we would be feeling really good before
9 we got it.

10 So I have got -- Is anybody from
11 RAND on the phone? It is ungodly early on the
12 West Coast. Anthony, do I have anybody from
13 RAND, either Neil, Carol? Neil is here?
14 Fantastic.

15 We are going to do measure 1626,
16 which is patients admitted to an intensive
17 care unit who have care preferences
18 documented. Would you like to give us a
19 little introduction to the measure? DR. WENGER:
20 Sure. So this measure I developed using the
21 RAND-UCLA methodology that we discussed
22 yesterday. This one is focused upon

1 preferences, and it is whether patients who
2 have been -- vulnerable elder patients who
3 were admitted to the intensive care unit have
4 documentation concerning care preferences
5 within 28 hours of ICU admission.

6 Documentation of care preferences
7 includes any of the following, including code
8 status: Preference for general aggressiveness
9 of care, mechanical ventilation, any sorts of
10 life sustaining treatment, including dialysis,
11 transfusion, feeding tube, a permanent feeding
12 tube, or that there has been documentation of
13 a care preference discussion, or that such a
14 discussion was attempted or why it couldn't be
15 carried out.

16 The denominator is simply all
17 vulnerable elders who are admitted to an ICU,
18 and who survived for 48 hours.

19 This measure has been implemented
20 a variety of times now, and there is a clear
21 performance gap in the three different
22 studies, some with very tiny ends. It is

1 satisfied less than a fifth of the time. In
2 the larger study it was satisfied 46 percent
3 of the time. That was published last year in
4 a sample of 369 patients.

5 It has excellent reliability. Its
6 validity derives from the process with which
7 it was developed, which is both literature
8 based and expert input, considering the
9 strength of the process/outcome link.

10 It also is part of a group of
11 measures that has been demonstrated to be
12 associated with better survival, which one
13 wouldn't expect this measure necessarily alone
14 to be associated with, but also better
15 functional outcome among vulnerable older
16 individuals.

17 We are not aware of any measures
18 with which it would need to be harmonized.

19 DR. MORRISON: Fantastic, Neil.
20 Thank you very much. Tracy, I think I have
21 you as the lead discussant on this. Right?

22 DR. SCHROEPFER: Yes. So he just

1 described the numerator and the denominator.
2 So I am just going to go into the summary of
3 the reviewers and how they felt, and I will
4 skip the high impact.

5 The opportunity for improvement,
6 the demonstrated performance gap: Pretty much
7 it was all highs except for one moderate and
8 a couple of insufficients. People felt this
9 performance gap was well documented. There
10 was a reasonable discussion of it.

11 The only question was that they
12 felt that the issue was important to all ICU
13 patients, not just the vulnerable. So they
14 questioned that.

15 In terms of the evidence, so here
16 in terms of the quantity, it was high to
17 moderate, and there was just a few in terms of
18 insufficient and low.

19 Quality, again, mostly moderate,
20 and consistency high to moderate. On the
21 positive side, felt studies demonstrated all
22 three, quantity, quality and consistency.

1 Even if there weren't clinical trials,
2 preferences are an important step in care
3 planning, and there was a code expert panel,
4 and then evidence.

5 On the other side, they felt like
6 there was only ungraded expert panel
7 recommendations. They felt the population and
8 preferences were vague, and that there was a
9 lack of information.

10 In terms of reliability, it was
11 high again, to moderate, but there were
12 actually three lows. They felt that the kappa
13 -- that is the inter-rater reliability -- that
14 was good, the measure well defined. The
15 numerator was reliable, but that the measure
16 itself was not directly tested, and this came
17 up several times, that it was tested as part
18 of a group of other measures.

19 Also, it was not clear to one
20 individual how to define care preferences,
21 because code status doesn't always match care
22 preferences.

1 In terms of validity, again expert
2 panel validity through a code, a code 3 and
3 assist, and so that was satisfactory, but some
4 people felt that the face validity was a low
5 level test. Again, items were not tested
6 directly, but part of a larger tool, and it
7 was hard to -- it would be hard to measure
8 whether, if there was a failure to attempt to
9 elicit the patient preferences, that would be
10 unknown, and that was very significant.

11 In terms of usability, this was
12 moderate. It has been used by the UCLA
13 Medical Center, and followed, but there really
14 wasn't enough information to determine about
15 the usefulness for public reporting. It is
16 just not clear how they would report, the
17 usefulness for quality improvement.

18 There was a feeling that it is not
19 clear how useful it would be, because of the
20 inconsistency in recording and documenting
21 whether there was a discussion. So there may
22 be a presence sometimes as an advance

1 directive, but in terms of this discussion
2 being recorded, there was concern, and they
3 felt that in that respect, it would not be
4 useful.

5 Feasibility: Feasibility, for the
6 most part, was moderate, and the feelings
7 there were that documentation of patient
8 preferences -- it is not consistent, and maybe
9 this would push for consistency, and one
10 person said, but it is being used at UCLA. So
11 that shows that it is feasible, but again
12 there is this concern about could you actually
13 capture this using electronic data capture.
14 Unless you did record progress notes
15 electronically, really, the data collection
16 would be a manual process, and that is going
17 to leave it open to errors and problems.

18 In terms of suitability, there were four
19 yeses and three no. Even in the yeses -- So
20 the yeses talked about that very much it
21 impacts a significant number of patients, and
22 knowing preferences can impact the treatment

1 decisions.

2 They felt that there was ample
3 documentation for implementing the measure,
4 and it could lead to improvement and better
5 standardization of documentation. But even
6 the yeses had some concerns, and that is that
7 the measure requires chart audits and some
8 documentation in paper charts. So again the
9 data collection could be burdensome.

10 The documenting professional
11 discipline was not specified. Physicians and
12 families -- so this is a comment, I think,
13 more than anything -- often know patient
14 preferences, and ignore them.

15 For the noes, more clarify and
16 evidence needed. Numerator: You can't count,
17 again, on the data being in the chart, being
18 reliable. So the numerator is not reliable,
19 and they felt that the reliability and
20 validity testing no strong. Then the
21 definition of care preferences was just too
22 broad to be meaningful.

1 They felt like in states where
2 there is a MOLST and POLST forms, it would be
3 easier to gather that information.

4 So that is pretty much it.

5 DR. MORRISON: thanks, Naomi.
6 Open for discussion. Russ, Rick. Russ?

7 DR. ACEVEDO: A lot of those
8 negative comments came from me. So I might as
9 well start. The determination of the patient
10 wishes and plans is crucial. So I want to
11 make sure that my other statements -- I am
12 just not sure this measure measures it, in
13 that one of the things that jumped out at me
14 is the code status, that if it is documented,
15 already your numerator, you have satisfied the
16 requirement, or it may have no relationship to
17 what the care plan for that patient is.

18 So that I immediately found as --
19 because my residents always tell me, oh, yes,
20 I talked to the family, and the patient is at
21 full code. Well, that still doesn't tell me
22 what the patient's goals of care are, what do

1 they want to accomplish, what things are
2 doable, not doable.

3 It is a long, meaningful
4 discussion that needs to occur, very important
5 to occur, but specifically the way this is
6 written, my residents had the discussion, yes,
7 we want resuscitation, I have met the
8 requirements of this measure.

9 So that is written too broad to be
10 meaningful. We are in a state that has a
11 MOLST form, which is very helpful when it is
12 filled out. So for instance, if this measure
13 were to go forward, then I think we will see
14 more use of the MOLST form.

15 Sorry, for those who don't know,
16 Medical Orders for Life Sustaining Treatment.
17 So it is a form where you essentially -- they
18 standardize the process of going over
19 treatment decisions. We talk about
20 resuscitation, ventilation, but you also talk
21 about artificial feeding, the whole host of
22 treatment decisions, and we have

1 documentation.

2 I think something like that -- If
3 this were to promote that, I would say yes,
4 but I think the way this is written now, I am
5 not sure I am going to capture the
6 information.

7 One last thing, and I will stop.
8 When I am having a discussion -- So a patient
9 gets admitted to my unit, and I am having a
10 discussion with either the patient or the
11 surrogate. We are discussing what our goals
12 of care are, and we are implementing it.

13 What this is going to -- So I have
14 had that discussion that is based on the
15 admitting plans, but there is not a specific
16 note there that says -- I mean, the note would
17 say that we have discussed the admitting plan.
18 I am not sure then that then satisfies that I
19 have specifically written down the patient's
20 preferences.

21 DR. MORRISON: Rick, and then
22 Naomi.

1 DR. GOLDSTEIN: I mostly have a
2 question, and it has to do with the usability
3 of this, this measure as it is prescribed. So
4 given the fact that a lot of these patient for
5 the first 48 hours in the ICU are not going to
6 be communicative -- I understand why it is
7 important to have on record even prior to
8 their transfer to the ICU that these
9 conversations have been held or that their
10 preferences are known, but what is the
11 strongest argument for this measure being
12 designed this particular way?

13 Is this really just an ICU
14 document, a documentation issue?

15 DR. MORRISON: Neil, can you
16 answer that, and can you also speak a little
17 bit to the issue that was raised before,
18 because I know you have provided some journal
19 publications supporting the feasibility,
20 reliability and validity of the measure, but
21 I think it might be helpful for the committee
22 to hear a little bit more what is in those

1 publications.

2 DR. WENGER: Right. I am not so
3 sure that I could hear the entire most recent
4 question. Can you paraphrase it?

5 DR. MORRISON: Let me try. Go
6 ahead, Rick.

7 DR. GOLDSTEIN: It is really a
8 usability issue for the measure as it is
9 written. So given the status of the majority
10 of these patients or many of these patients in
11 this first 48 hours in the ICU, why is this
12 measure as applied in this time frame
13 important?

14 Is it an ICU documentation need
15 or, really, shouldn't the question be asked
16 about the preferences for these patients even
17 prior to the transfer in the ICU?

18 DR. WENGER: There is no question
19 that, from a theoretical perspective, advance
20 care planning should be advanced. This
21 measure, like all of our quality measures,
22 attempts to hit at a very low bar, and when

1 it, therefore, is failed, it demonstrates
2 clear areas where improved care is needed.

3 The low bar is felt that, if
4 someone decompensates far enough and they are
5 a vulnerable individual receiving hospital
6 care, that for sure there ought to be
7 documentation concerning preferences within
8 two days in the intensive care unit.

9 That in no way discounts the fact
10 that there should have been documentation in
11 the outpatient setting before they ever got
12 admitted and early in hospitalization soon
13 after admission, but if you are trying to
14 identify a group of people where our expert
15 panels felt that there was no question that
16 there should be documentation concerning their
17 preferences to guide their care, it would be
18 within the first couple of days of intensive
19 care. So it is not a regulatory issue. It is
20 based on care needs.

21 To attempt to address the
22 usability issue a bit more: So only in one of

1 the three applications of this, albeit that
2 the other two were small, were UCLA records
3 used.

4 ACOVE-1 was from two large managed
5 care insurers, one in the northeast and one in
6 the southwest from a whole variety of
7 different hospitals, and the ASSIST measures
8 were also only partially measured at UCLA, but
9 also in other venues.

10 So this has been used in a variety
11 of different hospitals and different ICUs, and
12 there has been very little difficulty in
13 identifying documentation concerning
14 preferences, and even though there is a
15 concern that someone may simply jot down
16 something that doesn't reflect in depth
17 conversations, it occurs less than half the
18 time for this group.

19 DR. MORRISON: Naomi.

20 MS. KARP: I guess I would make
21 the point in response to that, that it doesn't
22 say that it requires a discussion of

1 preferences with the patient. I agree with
2 you that many, if not most, of the patients
3 couldn't have it, but it could come from an
4 advance directive. It could come from a
5 conversation with a legally authorized proxy,
6 a default surrogate.

7 So there is a potential to get the
8 information from a lot of different sources.
9 Also, I guess there was some discussion of
10 MOLST and POLST, but I just wanted to kind of
11 emphasizes that, to the degree -- You know, it
12 is a paradigm that is spreading, and 12 states
13 -- Kate, correct me if I am wrong. I think
14 about 12 states are endorsed POLST states, and
15 a lot of other states are implementing it.

16 To the extent that this measure
17 could really encourage the spread of POLST, I
18 think it is really important, because POLST is
19 a form that is very specific. It covers most
20 of these measures.

21 I agree, it is a problem if we are
22 just going to have one of these particular

1 kind of interventions documented, because that
2 is not going to get us that far, but if you
3 use a POLST or a MOLST or a POST or whatever
4 the state calls it as a form, you are going to
5 get it very comprehensively, in a defined way
6 that is going to be on a bright pink or yellow
7 piece of paper in the record or, hopefully,
8 one of these days electronically.

9 So I would really think this could
10 get us a long way toward the spread of POLST.

11 DR. MORRISON: Thanks, Naomi. I
12 have got Doug, and then I have got Kate.

13 DR. WHITE: I would just echo what
14 Naomi said. Speaking from the perspective of
15 an intensivist, this is a huge, huge problem.
16 The care that is delivered in ICU is often un-
17 patient centered with no documentation of
18 anything and no patient preferences, no
19 conversations with surrogates in those early
20 days.

21 Russell, I think your group does
22 better than most groups, even in just that,

1 yes, we got the code status. I certainly wish
2 the measure held people to a higher standard,
3 but thinking about where we are in the process
4 of nudging things along, I think this is a
5 pretty acceptable place to start, and relative
6 to a lot of other measures we have looked at
7 related to sort of what we do in ICUs, it is
8 unobjectionable, ethically.

9 There is just -- All the ethical
10 vectors point in the direction of you should
11 at least be doing that. It doesn't have
12 anything to do with what your outcomes are.
13 It is just this is a process measures; you
14 know, you should do this.

15 We've got lots of pretty good data
16 about reliability and validity. I mean, it
17 seems to me a little bit milk toast, but a
18 good measure, nonetheless, with enough
19 supporting scientific evidence that I look at
20 it favorably.

21 DR. MORRISON: Kate.

22 MS. O'MALLEY: A question for

1 Neil. I am just curious about hearing that
2 meeting the bar for this would be met, even if
3 you had code status in ICU patients. Since
4 this was a bundled measure when it was tested,
5 I am wondering if you know the degree to which
6 patients in ICUs don't have even a code status
7 determined for them in that setting.

8 DR. WENGER: More than half the
9 time.

10 DR. MORRISON: Neil, you are not
11 here, but there are a lot of people in sort of
12 stunned shock, and you know, I will tell you
13 that, speaking as a physician, it is
14 astounding. But, yes, that is what we see,
15 and it is stunning.

16 DR. WENGER: It is presumed.

17 DR. MORRISON: Other questions for
18 Neil? People comfortable moving to voting?
19 Again, really good discussion. So let's move
20 to voting.

21 All right, guys. Importance of
22 the measure: Performance gap, does it meet a

1 performance gap?

2 MR. COLCHAMIRO: Nineteen high,
3 one moderate, zero low, zero insufficient
4 evidence.

5 DR. MORRISON: Evidence or
6 outcome?

7 MR. COLCHAMIRO: Seven yes, 13 no.

8 MS. HILL: I think that people
9 aren't understanding that question.

10 DR. MORRISON: We are just going
11 to skip it.

12 DR. WHITE: It is a teachable
13 moment.

14 DR. MORRISON: You know what,
15 Doug? I will come back to the teachable
16 moment afterward. You are exactly right, but
17 I figured, since Helen and Heidi were not
18 giving me grief about it, I was just going to
19 let it fly. All right, we will come back to
20 the teachable moment.

21 Quantity of studies and body of
22 evidence? We will come back to the teachable

1 moment.

2 MR. COLCHAMIRO: Eleven high, nine
3 moderate, zero low, zero insufficient
4 evidence.

5 DR. MORRISON: Quality of the body
6 of evidence?

7 MR. COLCHAMIRO: Twelve high,
8 eight moderate, zero low, zero insufficient
9 evidence.

10 DR. MORRISON: Consistency?

11 MR. COLCHAMIRO: Fifteen high,
12 five moderate, zero low, zero insufficient
13 evidence.

14 DR. MORRISON: Reliability?

15 MR. COLCHAMIRO: Ten high, nine
16 moderate, one low, zero insufficient evidence.

17 DR. MORRISON: Validity?

18 MR. COLCHAMIRO: Seven high, 12
19 moderate, one low, zero insufficient evidence.

20 DR. MORRISON: Disparities?

21 MR. COLCHAMIRO: Nine high, seven
22 moderate, seven low, four insufficient

1 evidence.

2 DR. MORRISON: Usability?

3 MR. COLCHAMIRO: Ten high, eight
4 moderate, one low, one insufficient evidence.

5 DR. MORRISON: Feasibility?

6 MR. COLCHAMIRO: Seven high, eight
7 moderate, four low, one insufficient evidence.

8 DR. MORRISON: And overall for
9 endorsement? All right, would the uncertain
10 person out there please vote.

11 MR. COLCHAMIRO: Twenty yes, zero
12 no, zero abstentions.

13 DR. MORRISON: Terrific. Neil, I
14 think we have you for one more today. Is that
15 right?

16 DR. WENGER: Correct.

17 DR. MORRISON: Thanks very much.
18 As you know, it is endorsed, 20 people
19 endorsed, and I just wanted to thank you, and
20 would you just pass on your thanks to your
21 group who has done a really tremendous amount
22 of work to push this work forward.

1 DR. WENGER: Appreciate that.

2 DR. MORRISON: Okay, Doug. You
3 have your teachable moment.

4 DR. WHITE: Right. It's gone now.
5 What was it? What was the issue?

6 DR. MORRISON: What is an outcome
7 measure, sir? You have your teachable moment.

8 DR. WHITE: Right. A process of
9 feedback from on high, because I have a very,
10 very short attention span.

11 The issue we have all been voting
12 on, is this thing a health outcome or is this
13 a process measure along the way to a health
14 outcome? It seems like a lot of these things
15 where you are going to the chart and seeing,
16 there is a certain process of care
17 accomplished. That is not a health outcome.
18 That is a process of care.

19 DR. CASARETT: That is what people
20 have been voting on? I'm not sure how people
21 have been voting on that. Is that what people
22 have been doing, seeing these as outcome

1 measures?

2 DR. MORRISON: The question is, is
3 this an outcome measure? It is a straight yes
4 or no.

5 MS. BOSSLEY: We know that that
6 one needs a little work. We have been trying
7 to figure out what to do. We don't know what
8 to do. So I think, for the purposes of your
9 discussion today, we are probably going to --
10 You could skip over that one, and we are
11 probably going to throw out the responses on
12 that, because at this point I am not sure of
13 that.

14 We could even explain what you
15 would have been voting on and how you voted.
16 So I think we are going to --

17 DR. WHITE: So you are saying you
18 guys thought the question had face validity,
19 and in practice it turned out to not work?

20 MS. BOSSLEY: That is it. That's
21 it.

22 DR. MORRISON: Naomi?

1 MS. KARP: Just to clarify the
2 process, isn't that supposed to be a threshold
3 question, and it determines whether you then
4 go on to the next three?

5 DR. MORRISON: No. No.

6 DR. BURSTIN: Actually, just two
7 seconds. The logic of that question is that,
8 if it is an outcome, there is a bit of a pass
9 on evidence, particularly for adverse
10 outcomes, but for all -- Most of the measures
11 we've been talking about have been process
12 measures. So it is not a threshold, and you
13 move on and discuss the quality, consistency
14 anyway. Yes.

15 DR. MORRISON: Okay. The last
16 measure before our break: Dr. Hanson, we have
17 hospice and palliative care treatment
18 preferences. We are on a treatment
19 preferences roll. This comes from UNC Chapel
20 Hill group. Laura, are you with us on the
21 phone still, hanging in there?

22 DR. HANSON: Yes, I am.

1 DR. MORRISON: Would you like to
2 present this measure?

3 DR. HANSON: I can tell you
4 briefly about it. It is developed through the
5 same process as the other measures you have
6 heard from our group, a two-step process with
7 initial development and testing in a hospice
8 population, and then extension into a hospital
9 based, seriously ill population with hospital
10 based palliative care services.

11 This measure I really appreciated,
12 although -- I really appreciated the
13 discussion of the RAND measure, because I
14 think a lot of that discussion helped frame
15 the background for this quality measure as
16 well.

17 I would say that the operational
18 definition of the two quality measures is
19 quite comparable, but the denominator
20 population is different. The denominator
21 population for this quality measure is the
22 same as you have heard from our group before,

1 hospice and seriously ill hospitalized
2 patients with palliative care.

3 We have those same exclusions with
4 palliative care for at least one day, and
5 hospice enrollment for at least seven days.
6 The description of the numerator -- so the
7 documentation that is required for evidence
8 that there has been a discussion of life
9 sustaining treatment preferences -- includes
10 the presence of documentation of discussion of
11 those preferences with the patient or, if the
12 patient is not capable, with their designated
13 surrogate or review of advance directive, and
14 salient to, I think, some of the earlier
15 discussion, we have a specific description in
16 our operational description that a brief
17 statement that the patient is full code, for
18 example, is not accepted as evidence that a
19 discussion has occurred, or a brief statement
20 that the patient is do not resuscitate is not
21 accepted as evidence that their preferences
22 have been discussed.

1 This received a high rating from
2 our technical expert panel with a rating of
3 4.04 out of 5.00 possible points. Inter-rater
4 reliability was excellent, a kappa of one, and
5 we have evidence for a gap in performance. In
6 the hospice sample, this was documented for 82
7 percent of patients, and in the seriously ill
8 hospitalized sample for an overall level of 67
9 percent, and that overall level was
10 differential, depending on whether specialty
11 palliative care was involved. So when
12 specialty palliative care was involved, the
13 treatment preferences with goals of care and
14 evidence for discussion was documented 91
15 percent of the time.

16 Fantastic. Thank you so much,
17 Laura. Just to sort of frame this -- and,
18 Laura, correct me if I am wrong; I know you
19 were here for the prior discussion -- this is
20 a very similar measure to what the RAND group
21 proposed. It is a little more comprehensive,
22 as you said, that code status is not

1 acceptable, simple documentation. The major
2 difference is the denominator population is
3 different, and the setting is different.

4 As you pointed out, the bar may be
5 different in hospice and palliative care than
6 it currently is in the intensive care unit.
7 Actually, I think Doug and Neil pointed that
8 out.

9 So I have Bob as the leader for
10 the discussion, and then I will open it up to
11 comments from the group. Bob?

12 DR. FINE: This one was endorsed
13 by six of the nine people who reviewed it, and
14 the three people who said, no, we have
15 reservations, were concerned about chart
16 abstraction, kind of the ability to carry this
17 out across different settings by different
18 nurses. I think the steward, though, has kind
19 of answered that question, if I remember,
20 inter-rater reliability.

21 One of you all expressed concerns
22 about what was really included in the

1 numerator and the denominator exclusion of
2 less than seven days on hospice. We have
3 talked about that before. Overall, it got
4 high marks from people.

5 As a parenthetical aside and
6 related to some of our earlier discussion, I
7 think that it is interesting that their
8 benefit statement briefly explains the
9 benefits, improvements in quality envisioned
10 by use of this measure. Quote, "Use of the
11 treatment preference's quality measure will
12 improve attention to this important practice,"
13 which is kind of one of my whole points about
14 trying to just assess spirituality. Forget
15 about the quality of the assessment; just draw
16 attention to the -- I just thought it was
17 interesting. Couldn't resist putting that in.
18 So now I am just drawing attention to things.

19 I've got no other comments. It
20 was basically favorably reviewed, with a
21 couple of exceptions that just had some
22 worries about carrying it out.

1 DR. MORRISON: Thanks, Bob.

2 Appreciate the opinion. I've got Helen and
3 then Naomi, and then Doug.

4 MS. MARTEL: So my question is
5 about the denominator being patients in
6 specialty care in the acute care hospital.
7 Our inpatient teams follow patients from the
8 acute care into ICU, and they see them in both
9 places and consecutively.

10 So, to me, I was presuming there
11 was an overlap between this measure and the
12 last one. Is that not true?

13 DR. MORRISON: Let me try and
14 answer that, and I will turn to Heidi as well.
15 I think part of the issue, Helen, is, yes,
16 there is overlap. I think part of the problem
17 is that there are people there -- In terms of
18 the NQF endorsement process, the North
19 Carolina measures weren't tested in the ICU
20 population, and the ACOVE measure wasn't
21 tested outside of the ICU.

22 So you are right. You have a

1 potential overlapping Venn diagrams, but not -
2 - overlapping, but not the same, because are
3 were people cared for within palliative care
4 teams who are not in the ICU, and vice versa.

5 I'm sorry. Naomi, where did you
6 go? You are down. And David -- or, Doug, you
7 are up.

8 DR. WHITE: Laura, thanks. Again,
9 this seems like a great measure with lots of
10 face validity and scientific acceptability --
11 scientific testing and acceptability. So mine
12 is just a very small question, and I think the
13 inpatient palliative care consultation is
14 where the palliative care service is
15 consulted, because of difficulties around
16 goals of care, and what is documented as --
17 this is sort of for the vitalest patient.
18 This patient is full code.

19 It seems like that is a very clear
20 statement of preference that, just documented
21 in that way, is an appropriate documentation,
22 albeit controversial regarding the patient's

1 goals, but wouldn't fulfill your criteria for
2 having had a -- appropriately satisfied the
3 numerator conditions. Can you help us
4 understand that a little?

5 DR. HANSON: Because of the focus
6 of the quality measure on documenting patient
7 preferences, we required some evidence that
8 those preferences were brought forward, either
9 through an advance directive or through a
10 direct discussion with the patient or with the
11 patient's surrogate.

12 If the only documented statement
13 was this patient is full code, then we did not
14 accept that in the numerator. If the
15 documentation indicated "discussed with
16 patient, and patient is full code," we
17 accepted that in the numerator, and it was
18 really because of the need to make clear that
19 the goal is to document communication of
20 preferences or respect for preferences rather
21 than to write an order or make a medical
22 decision.

1 DR. WHITE: Thanks.

2 DR. MORRISON: Rick?

3 DR. GOLDSTEIN: I had had some
4 questions about inclusion criteria, and the
5 question that I -- The main sticking point I
6 have with this is that, if you wait -- If you
7 remove all the patients who have died in the
8 first seven days in hospice without a
9 conversation, you have lot 30 percent of the
10 patients that are referred to hospice. I just
11 wonder if that is too loose of a criteria.

12 Then in a minor way, in terms of
13 the inpatient palliative care programs, I
14 think, as certainly in pediatric palliative
15 care but also as programs mature, I think
16 having the DNR conversation at the first
17 meeting is not really what we do a lot of the
18 time.

19 A lot of times, we are really
20 there for clarification of goals, and if we
21 can have that conversation or not has sort of
22 more to do with whether we have made a full

1 assessment of where the family is or where the
2 patient is and how available they are to that
3 conversation.

4 So I am not so sure that its use
5 for palliative care in the first 24 hours is
6 really -- it has the same validity as we are
7 sort of imaging it to have.

8 DR. MORRISON: Solomon.

9 DR. LIAO: So mine is a follow-up
10 question to Doug and also to the reviewer's
11 concerns about feasibility. So, Laura, could
12 you help us to understand a little bit more
13 about the feasibility question of manually
14 extracting from the chart the distinction
15 between a simple full code order and a full
16 discussion about code status?

17 DR. HANSON: The basic operational
18 definition is pretty much as you see it in the
19 numerator details that are there, and our
20 nurse abstracters did not find any difficulty
21 and really had this very strong kappa of one
22 inter-rater reliability.

1 The criteria were really to look
2 for evidence that there was a statement like
3 "discussed," a statement of communication or
4 evidence that it was grounded in a written
5 advance directive that the provider had
6 reviewed.

7 I guess I don't know how to say
8 more than that. They did not find it difficult
9 from a feasibility standpoint beyond the usual
10 feasibility concerns of a requirement for
11 medical record review which, once you put that
12 in place, does ask for a little more time
13 commitment. But actually abstracting the
14 information, they did not find to be
15 difficult.

16 Remember, this is a two-step
17 process. So the inter-rater reliability was
18 done with nurse abstracters in a hospital
19 setting, but we also had a multitude of nurse
20 abstracters working in 22 different hospices
21 with different documentation methods, and they
22 did not find feasibility challenges with this

1 particular quality measure.

2 I want to go back to the comment
3 right before yours. The denominator excludes
4 palliative care patients who are seeing a
5 palliative care provider for less than one
6 day, but this measure is not time dependent.
7 it does not say that the documentation has to
8 be recorded within the first 24 hours, just
9 that it has to be recorded during the time
10 that palliative care is being delivered.

11 DR. MORRISON: Thanks for the
12 clarification, Laura. David, and then Rick.

13 DR. CASARETT: Hey, Laura, it is
14 Dave Casarett. Just a quick question about
15 reliability.

16 I notice that you had the kappa of
17 one, which is great, something to which all of
18 us aspire to, but if I am reading this right,
19 it is a kappa of one with two nurses in the
20 non-palliative care sample of 20 patients.

21 DR. HANSON: Correct. Small
22 sample.

1 DR. CASARETT: It seems like there
2 is more there. Do you have any sense, either
3 formally or informally, of more real world
4 kappas, either in a larger sample with other
5 nurses or things you have heard from hospices,
6 for instance, who have tried to implement
7 this, just to give us a sense of what it might
8 look like in the real world?

9 DR. HANSON: I wish I did, David.
10 I really can't answer that. That is the
11 extent of the inter-rater reliability data
12 that we have, and when the kappa was so good
13 with 20, we felt very comfortable with that,
14 but we don't have additional inter-rater
15 reliability, and I am not confident that other
16 people do, other than what you have heard from
17 Neil's measure right before this.

18 DR. MORRISON: Are folks
19 comfortable moving to a vote? Yes? Okay.
20 Lindsey has got it up already.

21 Performance gap?

22 MR. COLCHAMIRO: Sixteen high,

1 three moderate, one low, zero insufficient
2 evidence.

3 DR. MORRISON: Quantity of studies
4 in the body of evidence?

5 MR. COLCHAMIRO: Sixteen high,
6 four moderate, zero low, zero insufficient
7 evidence.

8 DR. MORRISON: Quality?

9 MR. COLCHAMIRO: Thirteen high,
10 seven moderate, zero low, and zero
11 insufficient evidence.

12 DR. MORRISON: Consistency of
13 results?

14 MR. COLCHAMIRO: Nineteen high,
15 one moderate, zero low, zero insufficient
16 evidence.

17 DR. MORRISON: Scientific
18 acceptability.

19 MR. COLCHAMIRO: Twelve high,
20 eight moderate, zero low, zero insufficient
21 evidence.

22 DR. MORRISON: Validity?

1 MR. COLCHAMIRO: Twelve high,
2 seven moderate, one low, zero insufficient
3 evidence.

4 DR. MORRISON: Disparities? I
5 need everybody to click one more time.
6 Thanks.

7 MR. COLCHAMIRO: Eight high, six
8 moderate, one low, five insufficient evidence.

9 DR. MORRISON: Usability?

10 MR. COLCHAMIRO: Thirteen high,
11 five moderate, one low, one insufficient
12 evidence.

13 DR. MORRISON: Feasibility?

14 MR. COLCHAMIRO: Eight high, 10
15 moderate, two low, zero insufficient evidence.

16 DR. MORRISON: And overall
17 endorsement?

18 MR. COLCHAMIRO: Nineteen yes, one
19 no, zero abstentions.

20 DR. MORRISON: So that brings us
21 to the break. Laura, I am sorry. Heidi has
22 got a --

1 MS. BOSSLEY: I'm sorry. I have
2 always got to come in. So I think the one
3 question is whether or not we have -- There
4 are two related measures. The question of
5 harmonization, of course, will come up.

6 The other piece, though, that we
7 will need to bring back to you on another call
8 is there is what I think would be either a
9 related or competing measure within the NQF
10 portfolio now that is endorsed on advance
11 care plans.

12 So that, actually, is in the
13 process. The developer is updating the form
14 right now, including evidence, etcetera,
15 because we plan on having that go through
16 maintenance in another project. We are
17 looking at whether we should move it into this
18 project and have you look at all three
19 measures on a conference call, and determine
20 what the next steps are, because that one is
21 ages 65, etcetera.

22 I will tell you now, and I will

1 say it on the other call, I developed that
2 measure way back when. So I am going to
3 recuse myself from that discussion when that
4 does occur, but that will be just heads up
5 coming to you a conference call soon.

6 DR. MORRISON: And I think, Heidi,
7 I know that there is also the issue about some
8 harmonization from some of the pain measures
9 yesterday between the UNC group and the RAND
10 group, and I know that there is -- now that
11 those are through, I think we can have that
12 discussion.

13 Laura, I think you are done with
14 us. Is that correct?

15 DR. HANSON: I am. I think I am
16 going to go see some palliative care patients.

17 DR. MORRISON: I wanted to again
18 express the committee's incredible thanks for
19 the work that you did as part of the PEACE
20 Project to get these measures forward to us,
21 and also to really thank you for the quality
22 of the work that you did on the application

1 process. It made it really, really easy to
2 review these. There was a tremendous amount
3 of data that you provided. It was
4 extraordinarily helpful, and thank you very,
5 very much for the work of you and your group
6 in terms of moving this forward, and enjoy the
7 North Carolina day. I hope it is cooler than
8 it is up here in D.C.

9 DR. HANSON: Well, it is 101.
10 Thank you all very much. I appreciate your
11 attention to this area. I am glad to be part
12 of it.

13 DR. MORRISON: So, guys, why don't
14 we take a 15-minute break, and reconvene at 10
15 minutes after the hour, which only puts us 10
16 minutes behind for the day, and Dr. Lunney is
17 not nearly as long-winded as I am. So she
18 will get us back on track.

19 (Whereupon, the foregoing matter
20 went off the record at 10:54 a.m. and resumed
21 at 11:14 a.m.)

22 DR. LUNNEY: All right. As we

1 reconvene, we are still continuing with the
2 Steering Committee discussion of care
3 preferences. We are now on measurement 0209,
4 comfortable dying.

5 Do we have a developer to comment
6 on this? Carol, do you want to comment on
7 this?

8 MS. SPENCE: Yes. This mic is
9 working okay? Great.

10 I just want to do a couple of
11 things. One is to give you just a little bit
12 of background on the development of this
13 measure. This measure actually has a very
14 long history. It was begun with the Outcomes
15 Forum Task Force, which convened back in 1998.
16 So the hospice community has been thinking
17 about quality and measurement of quality for
18 quite sometime.

19 That outcomes forum developed
20 actually a set of measures which were based on
21 a document that was called a Pathway for
22 Patient Care at the End of Life.

1 That document identified three end
2 result outcome measures, one of which was safe
3 and comfortable dying, and then this measure,
4 the specific comfortable dying measure, was
5 then developed by the Outcomes -- one of six
6 that were developed by the Outcomes Forum Task
7 Force. Then we moved ahead with ongoing data
8 collection after that.

9 So the focus of this measure is
10 that pain is brought to a comfortable level
11 within 48 hours of the initial assessment on
12 admission to hospice. So, obviously, it is
13 looking at pain management at the start of
14 hospice care, which addresses a basic aspect,
15 obviously, of hospice practice. But we also
16 feel that it is useful and meaningful for
17 consumers, providers, and payers as well.

18 So data collection is done on
19 admission with a follow-up very shortly
20 thereafter, and then NHPCO has been supporting
21 this measure for quite sometime in terms of
22 data submission by participating hospices, and

1 also then national reporting.

2 So the hospices that choose to --
3 and this is, again, voluntary data submission
4 -- will implement the measure and then give us
5 data on a quarterly basis. We then run an
6 analysis. They give us the data online. We
7 then run an analysis, and prepare a national
8 level result report, which we post, and then
9 the hospices are able to compare their results
10 to the national results.

11 So I just want to reiterate,
12 though, that when you look at the disparities
13 piece that this is a voluntary data
14 collection. I would expect to see even
15 greater disparities in performance among
16 hospices when this is implemented universally.
17 These are highly motivated hospices who
18 currently use this measure and give us the
19 data.

20 So the basic process for the
21 measure is two steps. On admission or, I
22 should say, at the initial assessment, the

1 nurse who is doing that initial physical
2 assessment asks the patient -- this is prior
3 to doing any pain assessment -- are you
4 uncomfortable because of pain.

5 So for patients who answer yes to
6 that question, they are entered into the
7 measure. The nurse goes on then to do the
8 comprehensive pain assessment as appropriate
9 for that patient, and then begins
10 intervention.

11 Then within 72 hours of that
12 initial assessment, the patient is contacted
13 and asked was their pain brought to a
14 comfortable level within 48 hours of the start
15 of hospice services, and then that becomes the
16 numerator.

17 We feel this measure aligns with
18 the HHS National Quality Strategy and that it
19 ensures patient choice for desired level of
20 treatment, because it truly reflects patient
21 goals for pain management.

22 Also, we feel that that is

1 probably the primary benefit of this measure,
2 the fact that it does reflect patient goals.
3 It is not setting a particular assessment --
4 or mandating a particular set of assessment
5 tools to be used. It allows the patient to
6 decide if they are comfortable or not, and
7 recognizes that, for example, on a rating
8 scale a three may not mean the same thing to
9 each patient.

10 Those rating scales are good for
11 looking at either populations or within
12 patient trending just to evaluate how you are
13 doing with that particular patient, but simply
14 asking the patient if they are comfortable and
15 then allowing them to -- The clinician is then
16 free to both assess with whatever tools are
17 appropriate for that patient, and also then
18 the patient gets to decide if a six
19 constitutes comfort for them, for example.

20 The other thing I just wanted to
21 mention in terms of the discussion previously
22 about what is an outcome -- This is an outcome

1 measure, and as such, based on conversation
2 with NQF -- yes, with NQF staff -- the
3 emphasis there was for structure and process
4 measures, presentation of evidence was
5 critical, linking it to an outcome; but this
6 was an outcome, the evidence requirements were
7 not as stringent.

8 So that was my understanding,
9 perhaps a misunderstanding, but that was our
10 understanding. So consequently, we did link
11 it to the -- well, the national -- the
12 palliative framework, the NQF palliative
13 framework, but did not provide a ton of
14 citations or other evidence for it, because it
15 was an outcome measure. But as previously
16 been discussed, there is a great deal of that
17 for pain and pain with hospice also available.

18 DR. LUNNEY: Thank you, Carol.
19 Sean, am I correct that you will introduce it
20 from our perspective?

21 DR. MORRISON: It is me. So Carol
22 has done a really nice job of presenting the

1 measure, and I am not going to go over
2 anything she repeated.

3 I think there was remarkable
4 consistency in terms of the preliminary
5 evaluations from the group. There was -- The
6 reviewers felt that there was a tremendous
7 opportunity for improvement with moderate to
8 high levels.

9 There was agreement, Carol, that
10 it was a health outcome, that the quantity of
11 the evidence was moderate to high with one
12 exception. The quality of the evidence was
13 rated as moderate to high with one reviewer
14 thinking it was low, and that the consistency
15 of the evidence, again, was moderate to high.

16 High level of reliability and
17 validity, some split voting in terms of the
18 disparities issues, and then very high
19 endorsement of both the usability and the
20 feasibility issues, I think, largely because
21 of the data that NHPCO provided for that.

22 All but one person recommended

1 this for endorsement. I think one of the
2 outside reviewers was concerned about only one
3 source of data, and he or she may or may not
4 want to feel comfortable about talking about
5 that.

6 I think, from my review
7 perspective, there are just two questions that
8 I have that, I think, would be helpful to
9 highlight, Carol, if you could -- actually,
10 one question, one statement.

11 So the statement is: This is --
12 It is a hospice population, I guess. The
13 question, Carol, is that when you have looked
14 at the performance of this measure, it looks
15 like 19 percent, plus or minus, of folks
16 achieve the goal of comfort after 48 hours.

17 My question to you, because this
18 came up in yesterday's conversation, is: I am
19 presuming that you guys -- that there is not
20 a number that you are targeting, and that this
21 is -- that we don't know what the right number
22 is.

1 MS. SPENCE: That is correct,
2 Sean, and thank you for bringing that up,
3 because I did mean to make that point. We
4 have not set a benchmark for this. In fact,
5 the discussion -- This was actually back
6 before I was even with NHPCO. I was on the
7 committee that developed this measure.

8 Our intention was never to expect
9 100 percent on this. In fact, when we have a
10 hospice coming in whose numbers come out to
11 100 percent, we look hard at that. We
12 actually in some cases will call them up and
13 check with them about their data.

14 Again, this was a wide expert
15 group that was together, but it was composed
16 of primarily clinicians who fully understand
17 no one expects that a patient with
18 uncontrolled neuropathic pain is going to
19 become comfortable within 48 hours. So that
20 would be a totally unreasonable expectation.

21 On the other side, we have not
22 attempted to set a benchmark for this. This

1 has definitely just been for hospices to
2 compare themselves against what other people,
3 other hospices, are doing.

4 DR. MORRISON: That is it for me,
5 June.

6 DR. LUNNEY: Do we have any
7 questions from the group? Naomi?

8 MS. NAIERMAN: I have two
9 questions. Obviously, this is chart based?

10 MS. SPENCE: It is chart based in
11 that, when the questions are asked, they are
12 recorded. However, there are various ways
13 that it can be extracted. There are a number
14 of software companies who do hospice software
15 who have incorporated the question into their
16 software. So it can be electronically
17 extracted.

18 There is also a measure sheet, a
19 measure tracking sheet that we provide that
20 hospices can use. So they don't have to make
21 it official part of the record. They can
22 insert that in there and use it, so it is more

1 readily, easily extractable if you do have a
2 paper record.

3 MS. NAIERMAN: So having seen it
4 as self-reported by the nurses, and they have
5 -- How is the bias, possible bias, controlled
6 here?

7 MS. SPENCE: Meaning that the
8 nurse -- because it is the nurses -- In the
9 same way as any other documentation. It is
10 open to a certain level of bias. They are
11 supposed to -- Again, the instructions, if
12 they are following, are -- We actually script
13 the question. They are supposed to ask the
14 question as written and specified by the
15 measure prior to beginning an assessment, and
16 that is part of the instructions. They are
17 not to infer or impute a patient's answer to
18 that question.

19 MS. NAIERMAN: Another question
20 has to do with those that are cognitively
21 impaired. I see that it is a little bit over
22 18 percent. So let's just round it as to

1 about one-fifth of the patients.

2 To the extent that hospices are
3 present in nursing homes, I wonder if there
4 has been any thought given to assessing pain
5 in folks with dementia, which would not rely
6 on their self-reporting.

7 MS. SPENCE: There are some
8 hospices that we know are doing that. That
9 would be for future testing for this, for
10 someone who was totally unable to respond,
11 although you do need to take into
12 consideration various levels of cognitive
13 impairment.

14 There are patients who cannot
15 respond using a zero to 10 scale, who can tell
16 you yes or no if they are comfortable. Again,
17 that is one of the, I think, advantages of
18 this measure, is that while you do need a
19 patient who can respond to you with a certain
20 level of understanding, it is more inclusive,
21 because it doesn't specify the assessment
22 tools to be used.

1 DR. LUNNEY: Thank you. Michael?

2 DR. LEPORE: T he current and
3 intended use of the measure is at least
4 partially for quality improvement, and I
5 wonder if you could speak to the fact that
6 over the two years of data being submitted,
7 the percent of patients reporting being
8 uncomfortable due to pain didn't change at
9 all. So to what extent is it being used
10 currently for quality improvement? It
11 certainly seems like it can.

12 MS. SPENCE: Yes, it can, and
13 again this is totally voluntary. We have got
14 -- Again, I can lay this more at the feet of
15 a marketing or lack thereof than anything
16 else, and it is more of a programmatic issue,
17 I believe, but we have in the last couple of
18 years really started looking very strongly at
19 material development and awareness, and if
20 this does move forward and if it does become
21 a CMS mandated measure, all of that is going
22 to change very drastically.

1 DR. LUNNEY: Doug?

2 DR. WHITE: This is sort of a
3 general question about the goals of the NQF as
4 it relates to measures that are not
5 benchmarked.

6 I remember one of our criteria had
7 to do with both can it be a quality measure
8 and its implications for public reporting.
9 How should we think about that when a measure
10 is not benchmarked?

11 MS. BOSSLEY: Great question. In
12 general, the criteria and our process does not
13 say that it has to have a benchmark, and for
14 the most part, most measures that we have
15 endorsed don't.

16 What you looked at yesterday
17 morning did recommend a benchmarking, but
18 again we don't require it. It is not
19 something that needs to be, and I think the
20 expectation from our viewpoint is most
21 measures are not specified to the point where
22 you could actually get 100 percent anyway.

1 So to us, the expectation is not
2 that that would occur. How others may
3 implement it is something that I think no one
4 knows how it will be, but the way it is being
5 used right now, from our viewpoint and the
6 criteria, is perfectly appropriate.

7 DR. LUNNEY: David?

8 DR. CASARETT: Thanks. I had a
9 question about the way that the responses are
10 coded. So pain, obviously, in this setting,
11 is often fluid, good days, bad days, good
12 hours, bad hours, break-through pain and so
13 on. So I am trying to get a sense of how
14 people respond to this question.

15 So if somebody is asked this
16 question and they had severe pain in the
17 morning, it is okay now -- I'm not sure what
18 the right answer is, but do you have a sense
19 of how people are actually answering this in
20 the setting of pain that may change?

21 MS. SPENCE: Well, again it is are
22 you uncomfortable, with the idea of then, as

1 the assessment moves forward, do you want us
2 to do something about it, is really, really
3 what that is getting at, is what is that
4 patient -- what are their goals. It really
5 opens the discussion of what are their goals
6 for pain management.

7 DR. LUNNEY: Martha, we can't --
8 sorry, no. I'm sorry -- or can we? I am
9 conflicted here. I am being told, yes, we can
10 invite your comment.

11 MS. BOSSLEY: If it would be
12 helpful to the conversation, I would say go
13 ahead, yes.

14 DR. LUNNEY: Go ahead, but be
15 helpful.

16 MS. TECCA: It is my goal. In
17 response to the issue about at this moment in
18 time, are you comfortable, the actual question
19 is to be asked 48 to 72 hours afterward, was
20 your pain brought to a comfortable level
21 within 48 hours. So it is not really like,
22 right now, how do you feel. It is asking them

1 to look at a -- It is that point in time, but
2 it is not that second how do you feel. So it
3 might make that a little bit better.

4 DR. CASARETT: I guess what I was
5 trying to -- I was trying to figure out how I
6 would answer that question, if I was asked
7 whether my pain was controlled to a
8 comfortable level within 48 hours, if I had
9 had some good hours and bad hours within that
10 time period. Again, I don't think there is a
11 right or wrong answer.

12 MS. TECCA: Well, again, you get
13 into that when you are doing -- depending on
14 what you are able to do with a patient -- the
15 comprehensive. If you are doing something
16 like the BPI, you are going to have a concept
17 of how the pain fluctuates over time, and when
18 you are looking at character and so forth on
19 an initial assessment, you are going to try to
20 go into that as fully as possible.

21 That will help elucidate what that
22 patient means by that first answer.

1 DR. LUNNEY: Are there any other
2 questions from the panel? One more.

3 MS. KALEN: I know that this
4 measure is designed to be assessed when the
5 patient is first evaluated on admission to
6 hospice, but we hope that people will be there
7 for more than 72 hours, and the goal is that
8 patients are getting to hospice 72 hours
9 before they die. So is this reassessed or is
10 this just a one-time assessment?

11 MS. SPENCE: The goal behind this
12 was to get hospices right out of the gate
13 working on pain for people that were
14 uncomfortable and wanted pain management. It
15 is similar to what Laura was saying yesterday.
16 This is only at assessment. It has no
17 implications for pain management down the
18 road.

19 DR. LUNNEY: Sean?

20 DR. MORRISON: Carol, a question
21 and just a comment. The question is: You
22 presented data, the 19 percent or 15 percent,

1 depending on the population, about groups.

2 But I just wanted to follow up on the question
3 about the quality improvement.

4 Do you have an understanding from
5 your dataset about whether there's individual
6 differences within the programs? I understand
7 that the mean stayed the same, but the
8 question is do individual programs change, and
9 maybe I just missed it.

10 MS. SPENCE: Individual changes
11 over --

12 DR. MORRISON: It goes back to the
13 issue about the quality improvement aspect of
14 this. One could say that the overall mean
15 stays the same, but you are bringing in more
16 and more hospices.

17 MS. SPENCE: Right, yes.

18 DR. MORRISON: So that there may
19 be, but do you have data on whether you look
20 at individual programs, whether that number
21 changes over time for those individual
22 programs?

1 MS. SPENCE: Yes, that is an
2 excellent -- We have not specifically done
3 that. I only know anecdotally. In talking to
4 some hospices, some are like, yes, we do the
5 measure. Do they do anything with it? Not
6 much.

7 On the other hand, we have a
8 couple of really good case studies where --
9 and I think I give the example in my material,
10 where the implementation of this measure
11 completely revamped their entire pain
12 management program down to developing brand
13 new competencies. I mean, it really got them
14 investigating how that hospice was doing pain
15 management.

16 There is your implications for
17 moving forward. While the measure doesn't
18 deal with it, the consequences can be such.
19 So they put together an incredible
20 communication process where there is actually
21 email alerts done every time a patient is
22 admitted where they answer yes to that

1 question, and they go to the medical director
2 who is going to be responsible for that
3 patient, and the whole team then gets alerted
4 that, yeah, this is something that we are now
5 putting in.

6 As I said, and then in looking at
7 how actually the pain management pieces, how
8 well they are doing, it led to total revamp of
9 their education around pain. So there's lots
10 of different things that can come out of it.
11 Right now, we haven't looked at the actual
12 scores across individual hospices.

13 DR. MORRISON: I guess my comment
14 is just a comment that follows from Naomi's
15 question. You know, my wonky pain researcher
16 hat says that, any patient self-reported
17 measure is going to be open for bias in the
18 clinical setting, and I just think we have to
19 live with that.

20 MS. SPENCE: I think, if you are
21 going to go back to the original -- pain is
22 what the patient says it is -- then we are

1 going to open ourselves up to some bias when
2 you start measuring in that respect.

3 DR. LUNNEY: Eduardo, I wasn't
4 able to detect you. Now I see how you hide.

5 DR. BRUERA: I think the crucial
6 aspect of this is what you defined as the fact
7 that we don't have the benchmarks, because as
8 you very well point out, the patient has the
9 right to call pain whatever they want to call
10 pain, but that doesn't mean that that is not
11 receptive input into the somatosensory
12 pathway, and therefore, not treatable with
13 pumps or opioids or sedatives, because what
14 you can generate is suffering being treated
15 with painkillers and adjuvants. And that
16 would not necessarily be a quality improvement
17 measure.

18 So part of the challenge is pain
19 by nature is multi-dimensional, and when you
20 summarize it to that nine, that number might
21 be the lack of dignity touching off or might
22 be your addictive disease that is causing you

1 to call it that way.

2 So it needs a bit of a more
3 thorough assessment. Not benchmarking a
4 number is a very smart way to do this.
5 Regrettably, if we have had this conversation,
6 we might have results that are different today
7 from yesterday with regard to the value of
8 really determining some quality improvement
9 measures without necessarily benchmarking that
10 30 percent or 20 percent or 60 percent is the
11 right number.

12 So while the effort is good, in
13 most cases coincide somatosensory nociceptive
14 afferents with your complaint, there is a wide
15 number in which that doesn't happen, and the
16 risk of being tied to a number and a
17 percentage is going to be as bad as not doing
18 it at all.

19 DR. LUNNEY: I see most tents. I
20 can't see them all. Are there any other on
21 this side? That makes me ask the question,
22 are we ready to vote? Okay.

1 The first question is: Is there a
2 performance gap demonstrated?

3 MR. COLCHAMIRO: Seventeen high,
4 three moderate, and zero low, zero
5 insufficient evidence.

6 DR. LUNNEY: Is it -- oops, we are
7 skipping this one.

8 MS. BOSSLEY: I think you can,
9 actually.

10 DR. LUNNEY: Now that we are
11 better judges of outcome measures, is this an
12 outcome measure?

13 MR. COLCHAMIRO: Nineteen yes, one
14 no.

15 DR. LUNNEY: Is there a quantity
16 of studies to support the evidence of this
17 measure?

18 DR. FINE: Can I ask a question?
19 If this is an outcome measure, why are we
20 voting on the quantity and quality? I thought
21 we didn't need to if it was an outcome
22 measure.

1 MS. BOSSLEY: It is a good point.
2 I think we've got into the habit.

3 DR. LUNNEY: Could we skip this?

4 MS. BOSSLEY: I think you can skip
5 -- Yes, we can go ahead and skip these.

6 DR. LUNNEY: And skip the next
7 two. Okay. Is the measure itself reliable?

8 MR. COLCHAMIRO: Twelve high,
9 eight moderate, zero low, zero insufficient
10 evidence.

11 DR. LUNNEY: Is this a valid
12 measure? Try one more time.

13 MR. COLCHAMIRO: Thirteen high,
14 seven moderate, zero low, zero insufficient
15 evidence.

16 DR. LUNNEY: So if there were
17 disparities, would this measure find them?

18 MR. COLCHAMIRO: Nine high, eight
19 moderate, one low, two insufficient evidence.

20 DR. LUNNEY: Is this a useful
21 measure for public reporting or QI?

22 MR. COLCHAMIRO: Eighteen high,

1 two moderate, zero low, zero insufficient
2 evidence.

3 DR. LUNNEY: And is it feasible to
4 use this measure? Try again, please.

5 MR. COLCHAMIRO: Fourteen high,
6 six moderate, zero low, zero insufficient
7 evidence.

8 DR. LUNNEY: Finally, do we
9 endorse the measure?

10 MR. COLCHAMIRO: Twenty yes, zero
11 no, zero abstentions.

12 DR. LUNNEY: Good job. Then I
13 think we are ready for measure number 1625,
14 which is a measure developed by RAND. Is
15 there anyone on the telephone from RAND who
16 would like to present this measure?

17 OPERATOR: We do have Neil Wenger
18 on the line.

19 DR. WENGER: Hi. I am here.

20 DR. LUNNEY: Good. Neil, we are
21 about to discuss the hospitalized patients who
22 die an expected death with an ICD that has

1 been deactivated. Would you like to present
2 an overview of that for us?

3 DR. WENGER: sure. I will be
4 brief with this one. This is a new measure,
5 which is in contrast to the measures that we
6 have presented before, which have been through
7 four different expert panels.

8 This measure went only through the
9 ASSIST expert panel. It did follow the same
10 RAND-UCLA methodology of linking process with
11 outcome based on what the literature and
12 clinical acumen would dictate.

13 This measure focuses on whether a
14 patient admitted to the hospital who died
15 after three or more days in the hospital and
16 who have an active ICD in place have
17 consideration of or deactivation undertaken
18 prior to death.

19 The measure is a chart abstraction
20 measure. It is a process measure, and it has
21 been implemented only one time, and that one
22 time was at a single institution at UCLA, and

1 I can't actually give you reliability data on
2 it, because all of our reliability charts that
3 were used -- none of them had an ICD in place.
4 So I can tell you the reliability is perfect
5 for detection of not having an ICD, but I
6 can't tell you the reliability of the
7 numerator.

8 There were 12 cases identified in
9 our chart abstraction. Only three of them had
10 consideration of turning off the ICD, which
11 would indicate, at least preliminarily, the
12 need for improvement in this area. But
13 actually, there are more data from other
14 publications, one that included 100 patients
15 entering hospice with an ICD where only 40
16 percent of the patients had had consideration
17 of turning off the ICD, and since then there
18 have actually been further publications
19 demonstrating that this is an area of great
20 need.

21 Concerning validity, I can offer
22 you the expert panel process as well as the

1 relationship of groups of measures to
2 important outcomes, but I cannot offer you any
3 validity for this specific measure as far as
4 process linking to outcome per se.

5 I think that this measure
6 represents sort of an emerging measure for an
7 area where there is lots of importance. There
8 are a number of specialty societies that have
9 indicated that this would be good process of
10 care, and there is no doubt that, based on the
11 emerging literature, that this is an area
12 where process has not caught up with what
13 those specialty societies would indicate.

14 I think that is probably about as
15 much as I can present.

16 DR. LUNNEY: And presenting it
17 from the evaluation perspective is Russell.

18 DR. ACEVEDO: Well, first let me
19 just define better what the numerator and
20 denominator were referring to.

21 First, as far as expected death,
22 expected death is defined as the physician

1 documentation, at least three days prior to
2 death, that the patient's illness was terminal
3 or that the patient had a grave prognosis, was
4 receiving comfort care, was receiving hospice
5 care, had a life threatening disease, or was
6 expected to die. So that is the --

7 So the numerator will be patients
8 from the denominator who had their ICD
9 deactivated prior to death, documentation why
10 this was not done, and then the denominator
11 would be those folks with an expected death
12 with an ICD in place.

13 The evidence was just mentioned.
14 There really are no certification to a
15 randomized controlled trial for this.
16 Currently, the concept is that the outcomes
17 would be better if the ICD were deactivated
18 prior to death, and this is recognized as good
19 practice.

20 I did pull up some of the clinical
21 practice guidelines, and as mentioned that
22 more and more have come out since this has

1 been presented.

2 Looking at our review, we had six
3 individuals who reviewed this, but the scores
4 for high impact and opportunities were
5 moderate. Perhaps the reviewers felt that the
6 quality and quantity of the data was low to
7 insufficient.

8 Both usability and feasibility
9 scored three out of six as moderate, and two
10 out of six as low. Four of the six reviewers
11 voted not to endorse this measure.

12 As far as the comments, it was
13 felt by the reviewers that this may be
14 important to the individual, but this is a
15 relatively small population, and efforts
16 should be directed toward larger patient
17 populations.

18 Also, they felt that conversations
19 were very difficult to put in an EMR, and that
20 this will require chart extraction to get the
21 data. Also, conversations on the deactivation
22 may have occurred in settings outside of the

1 hospital, i.e., the cardiologist's office or
2 the private physician's office.

3 The last comment was that a cancer
4 patient with a defibrillator may not die or
5 may not have V-tach or V-fib toward the end of
6 life.

7 DR. LUNNEY: Do we have any
8 questions coming from the panel? Sean, you
9 were up first.

10 DR. MORRISON: I am actually --
11 Russell, since I am the co-investigator on an
12 RO1 with randomized controlled trial about
13 turning these off, I disagree with you about
14 the possibility of doing that.

15 I am actually going to speak to
16 some of the body of evidence, because I have
17 been one of the people at Sinai who has been
18 doing -- mentoring Nate Goldstein who has done
19 a huge amount of work on turning off ICDs. So
20 I can speak a little bit to that, because we
21 have preliminary data that I can present to
22 the panel as part of that process.

1 There were preliminary data -- I
2 think Neil discussed this with the UCLA group
3 -- in the grant that we put and was funded by
4 NHLBI. The vast majority of people with ICDs
5 did not have a conversation about these. There
6 was a substantial number of ICDs that were not
7 turned off prior to death.

8 To raise the question again, and
9 it is painful, but I know these numbers, there
10 are about 100,000 people who have an ICD put
11 in every single year in this country. It is
12 now estimated that there are probably at any
13 given time 4 million people who are eligible
14 under Medicare eligibility for that, and the
15 growth of these devices is increasing
16 dramatically.

17 So that it is becoming -- It is
18 becoming a much more common device, and to
19 talk about my anecdote, one of my patients who
20 I saw last week had an enhanced pacemaker
21 placed, and I asked him what was an enhanced
22 pacemaker. He said, they put in something

1 called a defibrillator as well.

2 So it is becoming very common, and
3 I think that we are going to be seeing a lot
4 more people who are dying of other diseases
5 who have this incidentally. Anybody who has
6 witnessed one of these going off in the
7 setting of somebody dying, it is pretty
8 horrific.

9 DR. LUNNEY: David, I think you
10 were next.

11 DR. CASARETT: I will be quick.
12 So I guess this is really more of a
13 feasibility question, because we have
14 certainly had these instances in my hospice,
15 and they are bad, and they are awful, and they
16 are memorable in an awful way.

17 I am thinking about a hospital
18 that then would collect these data, and I
19 imagine those hospital QI folks going through
20 every chart to find an ICD patient, and then
21 looking in that subset to figure out what
22 happened.

1 So my question is, yeah, I know
2 400,000 who have these, many more who will,
3 but any idea what proportion of people who die
4 in the hospital have an ICD in place, because
5 I think that that number is very small. It
6 would be a lot of work to look through these
7 charts to get a small number of admittedly bad
8 outcomes, but a small number. Does anybody
9 know?

10 DR. WENGER: I can tell you, based
11 on our data, that it was a little bit over
12 five percent in 2006-2007, and in 2010-2011 we
13 just looked at the same question, and it is a
14 little bit over 12 percent. So it appears to
15 be rapidly increasing, and it is becoming not
16 that tiny.

17 Perhaps I can address one or two
18 of the other points that were just made. The
19 question of feasibility of the abstraction:
20 Actually, published last year in the Journal
21 of Palliative Medicine was the reliability of
22 identifying expected death, and it was

1 actually very high among a large number of
2 nurse abstracters with Kappas of about .7 or
3 higher.

4 The third point is that we are now
5 working with at least one EHR to put this
6 directly into their system, so that the
7 feasibility of this is going to become
8 electronic very rapidly.

9 DR. LUNNEY: Thank you, Neil.
10 Robert, you had a --

11 DR. FINE: Do we have any data on
12 how many patients with these devices actually
13 do have a painful shock at death? We hardly
14 ever -- At least at our shop, all politics is
15 local, and generally, our cardiologists are
16 turning these off before they call palliative
17 care or hospice. I am just curious.

18 I can't think of any of our
19 patients in the seven years at least when we
20 have had a formal palliative care service
21 where this has been an issue, where they have
22 actually -- They have either already been

1 turned off -- That is generally the case.

2 So I am just curious how much work
3 it takes to find these cases, how often there
4 is actually somebody who is getting shocked as
5 a result of these as they die.

6 DR. WENGER: Can I address that?
7 There may be someone there on the panel that
8 knows the answer to that question, and I
9 don't. But I would like to identify the
10 difference between patients who die in the
11 hospital with and without a palliative care
12 consult, as those that are receiving
13 palliative care consultations are very, very
14 different than the vast majority of patients
15 who die in the hospital who haven't received
16 palliative care attention.

17 DR. LUNNEY: Russell, I think you
18 have been waiting the most patiently.

19 DR. ACEVEDO: Sean, you said a
20 randomized controlled trial. What are you
21 randomizing?

22 DR. MORRISON: Can we have that

1 discussion at lunch, but I am happy to tell
2 you about it.

3 DR. ACEVEDO: Okay.

4 DR. LUNNEY: Naomi?

5 MS. KARP: I just have a question
6 about the denominator. I guess this is for
7 Neil or Sean or one of the medical experts
8 here, and it is just about the definition of
9 expected death. I just want to make sure that
10 that is not too broad, because it seems to
11 include a lot of different possibilities here
12 without any time limitations.

13 I am not necessarily advocating
14 for anything different, but I just want to
15 make sure that we are not having an over-broad
16 category of patients here. So does anyone
17 have anything they could add on that?

18 DR. LUNNEY: We have heard about
19 the reliability. Do we have any evidence of
20 the validity of this measure of expected
21 death?

22 DR. WHITE: Can I just a sort of a

1 -- My concern is the same. I think this may
2 be a too broad definition of expected death.
3 I think a lot of us have in our mind the
4 picture of a patient who enters hospice who is
5 dying, and it is very clear where this patient
6 is going and, of course, that patient could
7 have their ICD turned off. But this
8 definition allows for the patient -- allows
9 for and would count as an expected death the
10 patient who comes to the inpatient setting
11 with V-fib who has got stage 4 CHF, who comes
12 with V-fib who gets appropriately shocked and
13 who dies, who wanted to get cured and treated
14 or at least treated for their V-fib. That
15 would still be a ding.

16 So I worry about this. Yes, if
17 the patient came in and there was no
18 documented conversation and they have -- So I
19 worry about the life threatening illness part
20 of that definition of expected death. It
21 seems to raise a lot of problems that we might
22 be comparing apples and oranges within this

1 very broad denominator.

2 DR. LUNNEY: Sean?

3 DR. MORRISON: Just answer to one
4 of the questions that I asked before. Nate's
5 work, which I couldn't remember the numbers
6 which I pulled up, although the data are all
7 going back to 2004, when he looked at them,
8 they found that in 27 of 100 cases somebody
9 had discussed deactivating an ICD. It hadn't
10 been discussed in the others, and that 10
11 patients actively received a shock when they
12 were dying from their ICD at the end of their
13 life.

14 Doug, I think the measure here is
15 a conversation, not whether it was
16 deactivated. Am I not --

17 DR. WENGER: That is true.

18 DR. MORRISON: Is that true, Neil?
19 But I think it is about the report of a
20 discussion, whether somebody would want their
21 ICD deactivated in the setting of a
22 potentially expected death. Is that correct,

1 Neil, or am I not reading the measure right?

2 DR. WENGER: Correct. No, that is
3 right.

4 DR. LUNNEY: I heard Doug's
5 challenge to be the validity of the
6 denominator, not the numerator. Am I
7 mishearing you, Doug?

8 DR. WHITE: You are right. The
9 denominator question is the one that I first
10 asked. Sean's question was separate. If it
11 is really about conversation, I would ask why
12 is it not just -- Why is the measure not
13 hospitalized patients who have a conversation
14 about ICD before death, not -- There is some
15 normative judgment being made here that you
16 just definitely shouldn't be dying with it.

17 What I am wondering is would this
18 just be better stated as did you have the
19 conversation about it.

20 DR. WENGER: That would better
21 reflect the measure, that title, and the
22 numerator definition is the same as the title.

1 DR. WHITE: The only reason I
2 raised this life threatening illness thing as
3 part of the denominator is that there are some
4 times when you come in with CHF, and the right
5 thing to do is to keep your ICD on, and you
6 can have the conversation and die with ICD on,
7 and that is okay.

8 I think that there might be a
9 relatively large proportion in the inpatient
10 setting for whom that would be the case.

11 DR. LUNNEY: Well, the numerator
12 statement is an "or" statement. So it is a
13 deactivated ICD or documentation of why it was
14 not deactivated. David?

15 DR. CASARETT: I am having trouble
16 getting my head around this, but I guess (a)
17 I would urge us not to, on the fly, suggest
18 changes in the numerator because, obviously,
19 a lot of thought has gone into these, but also
20 related to that suggestion a discussion rather
21 than deactivation or a discussion, it seems to
22 me that you would get dinged if the discussion

1 happened in the cardiologist's office.

2 Patient comes in. It is
3 deactivated, but there is no discussion. So
4 you get dinged. I didn't quite think through
5 that, but I think that is an argument for not
6 making these sorts of hasty decisions now.

7 DR. WENGER: Right. Actually, the
8 way that you described it is precisely how the
9 measure is implemented. The reason that it
10 doesn't say discussion and deactivation is
11 that the way that medical record documentation
12 often works is that, if an action is taken,
13 there is no description of the discussion, but
14 if the action is not undertaken, there often
15 is a description about the discussion that led
16 to the choice not to take the action.

17 This is true across the board for
18 depression treatment on and on. So a
19 deactivation itself would satisfy, but the
20 vast majority of cases where the measure is
21 satisfied are documentations about discussions
22 not to deactivate.

1 DR. LUNNEY: We still don't have
2 clarity. Doug?

3 DR. WHITE: So now I am just
4 raising it. Does it seem to the group then
5 that -- I am thinking out loud about this,
6 just keeping in mind this inpatient class who
7 comes in with the goal of getting -- who come
8 in with V-fib and an ICD, for example. Do we
9 all still think that that should just be a
10 routine question, even when you are coming in,
11 in the acute setting, for cure or at least
12 resolution of the acute issue is the goal,
13 that you still have the conversation?

14 I could yes to that, I think, but
15 that is kind of what we are saying here, is
16 that even when it is pretty clear that the
17 patient is coming in with a quickly reversible
18 thing, you still have to have the
19 conversation.

20 DR. LUNNEY: I think we have to be
21 careful here, folks. We haven't had a
22 benchmark that absolutely everybody should

1 have this conversation or this deactivation,
2 and some of our measures have those cases
3 where we know from practice that it is not
4 feasible to do what we see as a quality
5 measure trying to measure.

6 So I think we just have to be
7 careful to try to -- Many of our side
8 conversations are about the difficulty of
9 being even-handed in our voting and even-
10 handed in the standard that we are using for
11 these measures, but we have had the
12 conversation several times over the two days
13 that some of these measures measure a complex
14 thing, and that we know that 100 percent is
15 not going to happen, and we don't know what
16 the right percent is that should happen.

17 Sean, you had a question?

18 DR. MORRISON: A clarifying
19 statement to Doug, because I admit, I do come
20 from it as a bias, because I am getting NIH
21 funding to actually do research in this area,
22 and think about this, and certainly have

1 published in this area.

2 I do want to clarify one thing
3 that you said, Doug, because I think the
4 population that you are specifically
5 describing is not what is in the denominator
6 population that is put forward to us. The
7 denominator population is hospitalization of
8 adult patients of at least three days duration
9 that ended in expected death.

10 Expected death is defined as
11 physician documentation at least three days
12 before death that the patient's illness was
13 terminal, whether the patient had a grave
14 prognosis, was receiving comfort care, was
15 receiving hospice care, had a life threatening
16 disease or was expected to die -- was expected
17 to die.

18 I would suggest to you that
19 anybody who has a life threatening disease --
20 and I think the data, both from the advanced
21 care planning literature and particularly the
22 work in the focus groups that have been done

1 with patients with ICDs, suggests that people,
2 the overwhelming majority -- no, it is not 100
3 percent as any benchmark -- do want to have
4 that discussion. They may not want to have it
5 turned off, but they at least want to have
6 that possibility raised.

7 So I don't have an issue with the
8 denominator population based on that, based
9 that the measure is documentation of a
10 discussion, and I do think there is a strong
11 body of evidence to suggest that our patients
12 do want to have that discussion.

13 DR. LUNNEY: Are we at a point of
14 clarity to vote? Oops, no, we are not. Kate?

15 MS. O'MALLEY: Just a feedback or
16 guidance. Since the numbers of people
17 impacted by this are so small, does that -- I
18 mean, I know we will have to make our own
19 decisions. It just seems from the discussion
20 that some of the information isn't really
21 there, and the evidence isn't as predominant
22 as might have been in other measures that we

1 have considered, although I certainly agree
2 that this should be done.

3 I am just wondering, based on the
4 conversation that has happened to date, do
5 people feel that we are ready to vote on this
6 measure, or would more information be helpful,
7 given the additional studies that you are
8 involved in, Sean? I just would like some
9 guidance on that.

10 DR. MORRISON: You know, Kate, I
11 think you are right. We are not going to have
12 data for another four years that we are going
13 to be able to submit. I can talk to you about
14 the preliminary pilot data that we did as part
15 of our ROI submission. I can talk about what
16 has been published, which Neil actually, I
17 think, has cited in the work here.

18 I think your point is extremely
19 well taken. What is the right percentage? We
20 have seen a doubling in the prevalence of
21 these devices over the past five years. Now
22 one in 10 people who die in the hospital has

1 one in place. It was five percent three to
2 four years ago.

3 You are right. We all have to
4 make an individual judgment of what is the
5 right prevalence, but it is 10 percent right
6 now. It is one in 10.

7 DR. LUNNEY: Naomi?

8 MS. KARP: At the risk of beating
9 the dead horse even deader, I guess I just
10 want to throw out one more time: Is there a
11 risk to patients who have a life threatening
12 disease but could potentially live for years
13 and are coming into the hospital for some --
14 I don't even know hypothetically what it would
15 be, but something unrelated to this device --
16 that by having a conversation, they might do
17 something that would shorten their life where
18 they -- Is that a risk or not? No? Okay,
19 good. Thank you.

20 DR. BRUERA: I guess one of the
21 questions is the benchmarking. That is, some
22 things do happen that you don't want to

1 happen, but in the previous discussion we
2 addressed the issue of controlling pain or
3 failing to control pain, and those events do
4 happen.

5 I think the question is, in one
6 case are we trying to figure out things that
7 are going to be a zero percent or are we
8 trying to figure out the frequency with which
9 some events occur, because that would give
10 peace of mind to a lot of us that some
11 situations in which somebody will die with
12 advanced disease and will have the
13 defibrillator go several times might happen,
14 and that might be quite okay. But when there
15 is a consistent trend for things like that to
16 happen, then you have the C-section scenario
17 of the person and the team perhaps not
18 performing at the best level.

19 So I am not sure that we are
20 tuning ourselves in the same way for every
21 single question, and in some cases we seem to
22 tune very high and in other cases we seem to

1 accept the fact that it is the benchmark that
2 will be defined over time, not that we are
3 defining it right now.

4 DR. WENGER: Is it appropriate for
5 me to respond to that?

6 DR. LUNNEY: Neil, yes.

7 DR. WENGER: I don't think the
8 question is whether it is okay for people to
9 get defibrillated numerous times before death.
10 I think that what this quality indicator is
11 trying to get at is whether that is okay
12 without a discussion having occurred.

13 DR. LUNNEY: I don't want to open
14 my mouth and stir anymore mud up from the
15 bottom of this water that might be settling
16 out. Is there some sense that we can now
17 vote? Good.

18 The first vote: Is there a
19 performance gap?

20 MR. COLCHAMIRO: Ten high, 10
21 moderate, zero low, zero insufficient
22 evidence.

1 DR. LUNNEY: So is this measure a
2 health outcome?

3 MR. COLCHAMIRO: Three yes, 17 no.

4 DR. LUNNEY: All right. Is there
5 a quantity of studies that support the need
6 for this measure?

7 MR. COLCHAMIRO: Three high, six
8 moderate, nine low, two insufficient evidence.

9 DR. LUNNEY: All right. There are
10 not a lot of studies. Are those that support
11 this measure of high quality?

12 MR. COLCHAMIRO: Five high, nine
13 moderate, three low, three insufficient
14 evidence.

15 DR. LUNNEY: All right. Of those
16 two measures of questionable quality, what is
17 the consistency? Please try again.

18 MR. COLCHAMIRO: Ten high, seven
19 moderate, zero low, three insufficient
20 evidence.

21 DR. LUNNEY: We passed the bar?
22 yes, we did. We go on.

1 MS. TIGHE: Heidi, I don't know if
2 it did.

3 MS. BOSSLEY: It did. So let's go
4 through the slides again, and we will walk
5 through it. I was tracking correctly.

6 So the quantity was, I would say,
7 moderate to low. But then if you go to the
8 quality, the majority said moderate. Right?
9 Then if you go to the consistency -- so if I
10 look at that, it would pass it, I think,
11 because again it says, if it is low quantity,
12 moderate to high quality, moderate
13 consistency, then yes as long as it is judged
14 that additional research is unlikely to change
15 the conclusion that the benefits to the
16 patient outweigh harms.

17 I think the conversation we had
18 was that you all agreed to that. So, yes, it
19 did.

20 DR. LUNNEY: Okay, now we are
21 looking at the measure properties itself. Do
22 we have evidence that it is a reliable measure?

1 MR. COLCHAMIRO: Five high, nine
2 moderator, three low, three insufficient
3 evidence.

4 DR. LUNNEY: Do we have evidence
5 that it is a valid measure?

6 MR. COLCHAMIRO: Five high, seven
7 moderate, six low, two insufficient evidence.

8 DR. LUNNEY: If there were
9 disparities in care, would this measure
10 capture it?

11 MR. COLCHAMIRO: Seven high, four
12 moderate, one low, eight insufficient
13 evidence.

14 DR. LUNNEY: Is this a usable
15 measure for either public reporting or quality
16 improvement -- or?

17 MR. COLCHAMIRO: Eleven high,
18 eight moderate, one low, zero insufficient
19 evidence.

20 DR. LUNNEY: We have a question?

21 DR. NEE: Yes, just sort of a
22 quick question. Could we go back to the

1 previous result? It seemed to me that, based
2 on the results of that, we still have a fair
3 amount of confusion in the group.

4 DR. LUNNEY: For the scientific
5 acceptability?

6 DR. NEE: The one where it was
7 equally high as it was insufficient.

8 DR. LUNNEY: The disparities?

9 DR. NEE: Disparities.

10 MS. BOSSLEY: It is not something
11 that needs to be met. It is one that,
12 especially if it is a new measure, I wouldn't
13 expect us to necessarily have this
14 information, but at the time of maintenance in
15 three years, I think we really would like to
16 see them having tracked the disparities
17 question.

18 DR. LUNNEY: Okay. so is it
19 feasible to use this measure?

20 MR. COLCHAMIRO: Seven high, eight
21 moderate, five low, zero insufficient
22 evidence.

1 DR. LUNNEY: And overall?

2 MR. COLCHAMIRO: Thirteen yes,
3 seven no, zero abstentions.

4 DR. LUNNEY: I believe we have
5 reached the point where we may go get some
6 lunch. Oh, public comments? Thank you. Are
7 there any people in the audience who would
8 like to make a comment on our session this
9 morning? Anthony, do we have anyone on the
10 phone that we would like to invite to make a
11 comment?

12 OPERATOR: All lines are open for
13 public discussion.

14 DR. LUNNEY: So this is a time
15 when, if there is anyone on the phone who
16 would like to make a comment about the session
17 this morning, they would be most welcomed.
18 They must have heard our stomachs growling.
19 We have 15 minutes to get some lunch and come
20 back, and we will talk and chew.

21 (Whereupon, the matter went off the record at
22 12:17 p.m. and resumed at 12:33 p.m.)

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A-F-T-E-R-N-O-O-N S-E-S-S-I-O-N

12:33 p.m.

DR. LUNNEY: This next measure is the family evaluation of hospice care. This is the moment that Joan has been waiting for.

DR. TENO: I am going to do it here, if that is okay with you.

I am a pure academic, and by definition a pure academic cannot go anywhere without PowerPoint slides. So I did submit PowerPoint slides. I was wondering if we could project those PowerPoint slides, please. I am more of an academic than a doctor at this point.

DR. MORRISON: She says that, but every time I call her she is seeing patients.

DR. TENO: I guess you just have to stop calling me on weekends, Sean.

So if you could just make it a little bigger. Okay. Can I have the next slide.

First of all, I realize that I

1 probably caused some confusion with the
2 committee, and I apologize for that. In
3 submitting both measures, we were trying to be
4 responsive to the precedents that Sean led and
5 put together, and our intent really was to
6 have an earlier version of the FEHC available
7 for the potential to be used in evaluation of
8 accountable care organizations or bundling in
9 payments.

10 So what I would like to do is just
11 sort of walk through with you both measures to
12 really highlight what the joint development
13 was and what the differences are, and we are
14 going to go out to take questions.

15 Both surveys are based on focus
16 groups that review guidelines, validation
17 studies with tests/retests, national survey
18 with evidence of discriminate validity on last
19 place of care.

20 The FEHC has been adapted to self-
21 administration with the mode test and some
22 elements of repeat validation, and with both

1 we tried to create as much as we can parallel
2 creation of a zero to 100 composite score.

3 Next slide, please.

4 Unlike what you have talked about
5 a lot this morning is this is patient and,
6 specifically in this case, bereaved family
7 members perceptions of the quality of care.
8 So one of the things that we have to think
9 about is how do we get evidence of what is
10 important from a bereaved family member's
11 standpoint?

12 In doing this project, we took an
13 analysis of 36 focus groups that were part of
14 a Robert Wood Johnson Foundation values
15 project, and then we supplemented those 36
16 focus groups with six focus groups of our own
17 that looked at various settings of care.

18 We currently have just completed
19 16 focus groups from five regions of the
20 country, and the initial survey was developed
21 with Director Jack Fowler of the UMass CAHPS
22 team, with the goal that each question asked

1 only about things that are important to the
2 quality of care for which the bereaved family
3 member, we feel, would be the best source of
4 information. Could I have the next slide,
5 please?

6 The conceptual model that we
7 developed was that high quality care at the
8 end of life is when health care institutions
9 provide the desired level of symptom
10 palliation and emotional support, treat the
11 patient with respect, promote shared decision
12 making, attend to needs of the caregiver for
13 information and skills in providing care for
14 the patient, provide emotional support to the
15 family before and after the patient death, and
16 coordinates care across settings of care.

17 This model was based on conceptual
18 guidelines, focus groups, and an expert panel.

19 One of the things I gave Lindsey
20 this morning, in addition to giving a copy of
21 my slides for you to take home and use as
22 liners for your bird cage, I have also given

1 you the table where we cross-walked the
2 conceptual model to the NQF preferred
3 guidelines, and started thinking the process
4 of that linkage between structure, process and
5 outcomes, and then showed you some of the
6 actual survey questions from either survey.

7 We have tried to be very careful,
8 realizing that we started on this in 1999.
9 The NQF preferred guidelines came out some
10 later. So our goal is to continue to grow the
11 core instrument and make sure that we are
12 staying with NQF and the National Consensus
13 Project. Could I have the next slide?

14 So we used family as expert
15 witnesses and to report the care that is
16 delivered to them. Only three questions of
17 the FEHC asks the family to act as a proxy.
18 I think we are all well aware that the World
19 Health Organization defined hospice and
20 palliative care as the unit of care of that
21 patient in the family.

22 We have chosen to focus on the

1 family just based on our experiences. It is
2 too burdensome to try to interview these
3 people in the last week of life, and also it
4 is difficult to predict when that last week of
5 life is. So that you get people at different
6 disease trajectories.

7 So let me just sort of review the
8 reliability and validity testing. Now the
9 reliability and validity testing is really
10 applicable to both instruments. We developed
11 the survey. We did a test/retest among 29
12 persons. We dropped some questions based on
13 them not meeting a satisfactory kappa.

14 We did an initial validation study
15 with 156 persons, i.e., bereaved family
16 members from hospice, nursing homes, and
17 hospital. We reviewed our work on validation
18 among 1380 persons. That was part of a
19 national study. In that study we published in
20 JAMA, we demonstrate some discriminate
21 validity by the last place of care.

22 In our work on the development of

1 this, we involved an expert panel. We have
2 tried to test construct, criteria, factorial
3 and discriminate validity. Next slide,
4 please.

5 So with adapting to the FEHC, we
6 simplified to skip patterns, and specifically
7 made some changes to the spiritual support
8 question. We now use the word hospice team.
9 We have a different time frame. The care
10 instrument refers to last two to seven days of
11 life, while the FEHC asks about the time the
12 patient was on hospice.

13 We expanded the self-efficacy
14 questions, which ask about the person's
15 reading of their competence in doing the task
16 by one, and we did mode testing comparing
17 self-administration versus telephone
18 administration, and did some revalidation of
19 the self-administered survey, mainly
20 consisting of internal consistency and
21 criterion validity. Next slide.

22 So this is the graphical picture

1 of the overall zero to 100 FEHC score, showing
2 a fairly good distribution, and I can give you
3 specifics of the mean mode, etcetera, if you
4 would like me to. Next slide.

5 Just to sort of highlight the
6 differences between the various composite
7 scores, just a minor correction: The scoring
8 of the FEHC is based on having at least 14 out
9 of 17 items present. We allow up to three
10 items to be missing. We use sort of a mode
11 substitution.

12 The constructs that are in the
13 composite score is again providing the desired
14 symptom control, emotional support, which is
15 three questions, attending to the caregivers
16 for information, skills is four questions on
17 self-efficacy, two questions on whether you
18 got enough information, knowledge about
19 various symptoms, information to the family
20 about the patient's condition and what to
21 expect while dying, two questions.

22 We have an emotional/spiritual

1 support which has three questions, and
2 coordination of care is three questions.

3 The Krumbach alpha is about .797.
4 We have monitored coordination with a single
5 rating of excellent, very good, fair, poor,
6 and as you can see, when we take a look at the
7 score, excellent has a 90.3; 76.2, good; 60.8
8 fair; 43.5 in poor; a 30.5 on a 100 score.

9 If a respondent says hospice is
10 too late, the mean score is 79.8; at the right
11 time, 87.1. So the care zero to 100 is based
12 on 14 items. It again has a similarity to the
13 FEHC in that we have three items on providing
14 desired comfort and emotional support, but we
15 include a treat the dying with respect with
16 one question, emotional support to the
17 caregiver with three questions, information
18 and skills to the caregiver with three
19 questions about self-efficacy, three on
20 information. Information continuity is one
21 question.

22 Internal consistency measured by

1 Krumbach alpha is .80. Correlation was
2 excellent, very good, fair, poor, .58.
3 Discriminate validity here by last place of
4 care: if you died in a nursing home, the zero
5 to 100 score is 71.2, versus home with hospice
6 services, 83.2.

7 You know, right now more than 1200
8 hospice programs are using it. We undertook
9 a process in terms of our measurement
10 maintenance where we did three rounds of focus
11 groups with end users, specifically quality
12 managers. We asked them to give us sort of
13 the bad, the ugly, and the good.

14 We are very pleased in those focus
15 groups. We heard some areas that we could --
16 they wanted to expand it. They wanted some
17 changes to the reporting structure, but the
18 FEHC has been adopted to be really sort of the
19 cornerstone of operation, staffing, quality,
20 and it is the foundation of what a lot of
21 hospices are currently doing for their
22 quality.

1 All alone, we have tried to
2 publish our results, noting the variation.
3 Just refer to a 2005 article of the FEHC from
4 the voluntary submission where we show
5 individual variation on item, composite
6 scores, and I previously had shown you
7 variation on the new zero to 100 score.

8 Then I am not going to go over
9 this in detail, but we are very committed to
10 updating this instrument. We currently have
11 a grant. We want to expand the instrument to
12 better cover the needs of the Hispanic
13 population. We are going to have a self-
14 administered Hispanic survey that will be
15 developed. We have a cultural anthropologist
16 working with us.

17 We are going to do some more
18 validity testing. We are also going to go to
19 the future of doing mode testing with
20 community administrations.

21 I think one of our goals as this
22 goes forward is to do some harmonization of

1 both the care and the FEHC instrument. So,
2 hopefully, I haven't confused you thoroughly
3 by now. Really appreciate the chance to
4 present both these measures on behalf of
5 myself and, really, Carol who has been working
6 with me now for eight or nine years as a
7 partner with the National Hospice and
8 Palliative Care Organization.

9 DR. LUNNEY: Thank you very much,
10 Joan. David, are you not the person who is
11 doing it from the evaluation perspective?

12 DR. CASARETT: I am, or I am not
13 "not the person," which means I am the person.
14 So, thanks, Joan, for doing all my work for
15 me. That was wonderful.

16 I have a full hospice unit of
17 patients who need to be seen tomorrow. So if
18 you want to put on your clinician hat, you
19 could see those patients for me, too. Much
20 appreciated.

21 I won't go over the FEHC
22 instruments, since you have already had the

1 graduate level course in that. So let me just
2 summarize the results and pull out three or
3 four points that came out in some of the
4 comments.

5 So nine raters. It was endorsed
6 by seven. Eight reviewers gave it a high
7 impact rating. Somewhat less enthusiasm, five
8 thought it was important, and I think there
9 were some questions there about whether this
10 was actually an outcome measure, which,
11 hopefully, we have laid to rest, but we can go
12 back and visit that one more time, if we have
13 to.

14 There was some uncertainty about
15 the evidence to support the measure. About
16 half, more or less, of reviewers gave it a
17 high rating for quantity, quality, and
18 consistency of evidence.

19 In terms of instrument properties,
20 there was more enthusiasm about its
21 reliability than its validity, than its
22 ability to distinguish among disparities.

1 Seven, five, and two raters respectively gave
2 it a high rating.

3 In general, reviewers thought it
4 was usable and feasible, six and five,
5 respectively, and as I said before, overall
6 seven people endorsed it.

7 So given those differences in
8 scores, I went back through and did a
9 qualitative analysis of the comments and came
10 up with four or five themes you might want to
11 address.

12 A couple of people raised
13 questions about nonresponse bias and the
14 impact on scoring. A couple of people raised
15 questions about whether this was measuring
16 proxy versus -- proxy for the patient versus
17 family experiences, which I think you just
18 addressed.

19 As I said before, ability to
20 discriminate between programs, given many of
21 the scores being fairly high. Two people
22 asked questions about, I think, about the use

1 of composite ratings for public reporting, so
2 not an issue of scientific validity but a
3 question of what would get reported to the
4 public eventually.

5 Then a couple of people had
6 questions about the equivalent of case mix
7 adjustment concerns, that there might be
8 differences in the way that different
9 populations answered these questions, and
10 whether or not that should be included in
11 adjustment.

12 DR. TENO: Okay. So I have five
13 questions to answer in two and a half minutes.
14 Right? No.

15 So why don't we just take them
16 from five and go backward. So we have thought
17 very hard about case mix adjustment. I guess
18 one of the things I didn't present in my
19 overview that I was amiss in saying is we have
20 published several articles about the
21 differences by each of the composite domains
22 by race, and that was published. It was

1 summarized much better in the Care instrument
2 application.

3 It could have been -- We can beef
4 up the FEHC part of the measure at maintenance
5 to put in references and the actual findings
6 of the article, but needless to say, we do see
7 differences by race in terms of African
8 American versus white, and also Hispanic
9 versus white.

10 To give you sort of a magnitude,
11 the differences on Hispanics, I think, is
12 fairly close to three points on the mean
13 between white versus Hispanic. African
14 American, I think, is two or one. It is not
15 as predominant.

16 I am sorry, David. What was the
17 question about the composite score?

18 DR. CASARETT: It was not, as near
19 as I could tell, concerns about validity that
20 were raised. It was the question of what the
21 public would like to see, which may actually
22 be beyond the bounds of what we want to

1 discuss here.

2 DR. TENO: I think that is a very
3 good empirical question that needs to be
4 addressed. From our standpoint, we provide
5 people who -- hospices that voluntarily
6 participate in the FEHC repository both sets
7 of information. We provide them a composite
8 zero to 100 score, as well as the individual
9 items, as well as the individual domains. We
10 try to provide them with benchmark data so
11 that they can compare their performance and,
12 hopefully, improve their performance.

13 I think proxy versus patient I
14 addressed, and the issue of nonresponse bias.
15 So in the past we have compared the Medicare
16 claims files, hospice providers, with those
17 people age 65 and older who participate in the
18 FEHC.

19 We found that we underrepresent
20 African Americans and have a tendency to
21 represent larger hospice programs in the
22 measure. So that is sort of the bad news.

1 The good news is, when you compare
2 us to other voluntary programs, we have a
3 participation rate of around 42 to 43 percent.
4 If you look at what the HCAHPS is doing, it is
5 like eight or nine percent. So it is always
6 amazing that with one mailed out survey, we
7 are getting a fairly good return on the
8 survey.

9 Then you had a question about
10 programs, David?

11 DR. CASARETT: A couple of the
12 reviewers raised questions about the ability
13 to discriminate among programs. Again, this
14 is my synthesis of the qualitative comments,
15 but I think it was getting into issues of high
16 scores across the board.

17 MS. SPENCE: Well, we ran -- If
18 you look at individual questions, there are
19 some questions that hospices performed very
20 well on as a group, and there are others where
21 there is more variation, but for purposes of
22 the submission, we focused on the composite

1 score, the large composite, that zero to 100
2 that Joan was talking about, which
3 incorporates 17 of the questions.

4 We found, actually -- We did
5 announce a variance and found that there was
6 a statistically significant difference. We
7 had a minimum mean of 73.3 and a maximum of
8 96.3, and with a mean of 86.6, and again that
9 was statistically significant.

10 So I think that is pretty good
11 evidence that it can discriminate.

12 DR. LUNNEY: Are there questions
13 from the panel members? Rick?

14 DR. GOLDSTEIN: So can I just
15 present a scenario, because I would be very
16 interested in hearing -- I am sure you thought
17 about it. So I am interested in hearing how
18 you see the FEHC affecting this issue.

19 Let's say you are in a medium size
20 town, and there are two hospices. One says
21 the FEHC is very important, and I am just
22 going to go with my bread and butter hospice

1 patients, and I am not going to take -- I am
2 not going to try to get to higher risk groups.

3 Another hospice says, you know
4 what, we are going to take care of everybody
5 else. We are gong to take care of the black
6 families. We are going to take care of the
7 Hispanic families who -- and we are not any
8 better than the other hospice. So our
9 performance profile is probably going to be
10 muddied by the fact that we are taking on
11 those patients.

12 How does the FEHC -- Does the
13 FEHC ding the people that sort of go at an at-
14 risk population, and have you thought about
15 that at all? I worry about this as a tool
16 that is kind of a disincentive for more
17 complicated patients, as well as not really
18 addressing the disparities issue that is so
19 problematic in hospice care anyway.

20 DR. TENO: So, you know, I think
21 you are hitting on a really important
22 question, which I am going to answer

1 philosophically. The question is should you
2 put race into the multivariate model?

3 I think the first thing, before I
4 address the race issue, is we have looked at
5 a number of factors that relate to the zero to
6 100 score, and we found age, who the
7 respondent was, number of times they have
8 contact with the person in the last week of
9 life, really don't predict how they are going
10 to respond.

11 The one thing that does really
12 predict how someone is going to respond is
13 whether they are black or whether they are
14 Hispanic. So the question is, is there
15 something inherent about someone's skin color
16 or the pigment in their skin that results them
17 in doing a different rating score or is there
18 something about the actual quality of care
19 that they are receiving?

20 I actually think there are
21 differences on quality of care, and I wouldn't
22 want to adjust away those differences. I

1 would rather have those differences out there
2 as targets for improvement and having hospice
3 programs think about how do we reach this very
4 important population, how do we take our
5 services and provide it to them in a
6 culturally sensitive manner?

7 So as someone who has thought
8 about this, I have decided on not using a risk
9 adjustment for this, and really trying to put
10 it out there for the emphasis that we need to
11 improve hospice care for this part. Carol?

12 MS. SPENCE: I am going to take
13 the prerogative of doing double time on this,
14 since we are presenting two surveys together.
15 Just to build a little bit on what Joan said,
16 I think there is something inherently
17 different about risk adjustment, because you
18 have complicated diagnoses, and if you are in
19 a hospital and this is the patient population,
20 very sick patient population you serve, versus
21 if you survey predominantly black community,
22 and you are getting lower scores on FEHC, I

1 think it is on the hospice to figure out how
2 to better serve -- how to meet better the
3 needs of that community rather than going in
4 initially and risk adjusting.

5 We don't know enough. We haven't
6 looked into it. Right now with the hospices
7 that are participating, you have to aggregate
8 at a national level, and sometimes over more
9 than just a quarter, to really have enough --
10 a big enough n in the minorities to really
11 start looking at differences.

12 So I am not saying there is not
13 work to be done there. There is, but as it
14 stands right now, I don't think we have enough
15 information to say that we are putting
16 hospices at a disadvantage by not risk
17 adjusting based on race.

18 DR. GOLDSTEIN: But isn't -- May I
19 just follow up? But isn't there a converse to
20 that, which is doesn't this end up being a
21 disincentive for hospices to go out and pursue
22 these more complicated patients?

1 DR. CASARETT: I can try to answer
2 that. That was actually the point I wanted to
3 make before. That actually really worried me
4 when I was reviewing this, but the more I
5 thought about it, t hat is something that, I
6 think, applies to all the measures.

7 The pain measure that we just
8 looked at, that could arguably create a
9 disincentive to enroll patients with pain. So
10 I think all of these measures, virtually all
11 of them except if you have a very fixed
12 denominator beyond providers' control, would
13 be susceptible to that.

14 So it seems like at least my take
15 on this is that is a concern with the FEHC.
16 I am not sure it is a greater concern than it
17 is for some of the other measures. That was
18 the way I interpreted it.

19 DR. LUNNEY: I just wanted to make
20 sure that the question about public reporting
21 was answered. I kind of, I guess, in my own
22 mind wonder about the ability for the public

1 to understand the complexity of this measure.

2 DR. TENO: Sure. I have not been
3 involved currently in efforts to public report
4 this measure. It is being publicly reported
5 in Florida right now. While I have given full
6 blessing -- You know, I've put this measure
7 out there to let anybody use this measure free
8 of charge, as long as they don't sort of start
9 selling it or doing something wholesale wrong
10 with it.

11 So Florida is publicly reporting
12 it. I know the American Hospice Foundation
13 has worked with data to design a public report
14 card which Shoshanna Sofaer has done some
15 initial testing, not the composite but
16 individual domains, on that. There, I
17 believe, might be a paper being written.

18 When I corresponded with Shoshanna
19 over the summer, she was not at the point
20 where -- She told me some of the issues they
21 encountered, but it really wasn't issues with
22 the measure. It actually was the issue with

1 the public understanding what hospice is
2 rather than the actual measure itself.

3 I think, if this goes forward for
4 public reporting, just like any of the HCAHPS,
5 the Consumer Health Plan Assessment measures,
6 there needs to be some empirical work done to
7 report the measure in a such a way that it is
8 understandable to consumers.

9 I can tell you, as someone who has
10 really sort of thought about this over time,
11 we really tried to capture information that we
12 thought would be valuable to consumers, that
13 experts would endorse, and we tried to really
14 emphasize the face validity of the
15 instrument, so that when a clinician hears the
16 measure, it has sort of a, well, we got to do
17 better, has that sort of clinical face
18 validity.

19 Can I sit here and tell you right
20 now that I have done this research to design
21 a report, have gone out and tested? No. I
22 think Shoshanna is the right person with her

1 extensive experience with the CAHPS team to
2 test this, and I wholesalely support the
3 efforts to go ahead and do that.

4 So in a way, I am not able to
5 directly answer your question, but I am
6 concerned about it, and we want to proceed
7 forward.

8 DR. LUNNEY: No, you did. Thank
9 you. Kate, you had a question?

10 MS. O'MALLEY: Just a comment.
11 There is about 200 hospice providers in
12 California, and about a third of them collect
13 FEHC data, either through a vendor or through
14 their own efforts.

15 The California HealthCare
16 Foundation has a consumer facing website that
17 displays information about quality of care
18 providers, including hospice. So we are
19 working now with Naomi's group at the American
20 Hospice Foundation to test the feasibility of
21 putting FEHC data on our consumer facing
22 website using a lot of the groundwork that

1 they have already done in their experience in
2 Florida.

3 We are surveying hospices now to
4 see if they would be willing to participate
5 with us, knowing that this data would
6 eventually be reported publicly. So the
7 surveys in the field, and I think we have got,
8 I don't know, almost 90 hospices. Almost half
9 of hospices are responding to our inquiry of
10 whether or not they would participate in
11 public reporting.

12 So just to let you know, the
13 marble is continuing to roll forward, and
14 there is a lot of interest in this measure in
15 the field.

16 DR. LUNNEY: Are there any other
17 comments or questions from the community?

18 MS. NAIERMAN: I should clarify
19 that, when we worked with Shoshanna, she did
20 a whole lot of cognitive testing of a report
21 card design that she developed for consumers
22 especially, and she did come across the

1 stumbling block that most people that she
2 tested with, consumers, really didn't
3 understand hospice and, if they did, they were
4 convinced it is a place.

5 So we were convinced then that any
6 public report that is issued or that is
7 published should be accompanied or should
8 include an educational component that she
9 designed based on the misconception she had
10 found, and she cognitively tested several
11 times over.

12 So our report card is posted on
13 our website, AmericanHospice.org, under the
14 tab Report Card, and you will get an overview
15 of the work that she has put into it, and you
16 will have an interactive model of how it
17 works.

18 DR. LUNNEY: Thank you. I don't
19 detect any other -- I have a better set of
20 eyes next to me. Oops, Michael.

21 DR. LEPORE: From the sense of
22 disclosure of interest, I am appointed in the

1 Department where Joan is employed. I know
2 this is being submitted by NHPCO, but I do
3 work in the Center for Gerontology and Health
4 Care Research where Joan also works.

5 DR. LUNNEY: Then seeing no more
6 comments or questions, I think we are ready to
7 vote.

8 MS. BOSSLEY: But just so everyone
9 knows, you are only voting on the first
10 measure, 0208, not both, because I think we
11 need to -- unless you disagree -- probably
12 discuss both of them, because one is
13 maintenance. So it is a little bit different
14 looking at the public reporting, etcetera.
15 The other one is a new one for you.

16 MS. NAIERMAN: When you say
17 maintenance, when the FEHC was originally
18 endorsed, it wasn't in composite form. Is
19 that true?

20 MS. BOSSLEY: I would have to go
21 back and look. Karen, did you --

22 MS. NAIERMAN: Joan would know,

1 because she was --

2 MS. BOSSLEY: Joan will know. I
3 don't remember.

4 MS. SPENCE: We hadn't done the
5 composite at that point. So it was actually
6 the survey, but since it was very clear that
7 NQF isn't in the business of endorsing
8 surveys, at this point we submitted the
9 composite, because that was the way to have a
10 single score that included the maximum number
11 of questions.

12 MS. NAIERMAN: So just another
13 clarification: When we are voting on a
14 composite, is it by implication that we are
15 voting for each of the questions within the
16 survey?

17 MS. BOSSLEY: This is where it
18 gets fun. Okay. So they have put forward it
19 as a composite, not with the individual
20 questions pulled out to be reported
21 separately. So you are really voting on that
22 composite score of this as a result of the

1 survey.

2 So everything you look at should
3 be framed within that. Is that answering your
4 question or -- I'm almost. I feel like I am
5 almost.

6 MS. NAIERMAN: Well, for example,
7 for me it was a little difficult to figure out
8 about the usability. From our experience, the
9 usability is the individual component. Now
10 will the hospice be available 24 hours a day,
11 or will they respect my loved one.

12 A composite is not as usable. So
13 the rating for me would be different.

14 MS. BOSSLEY: So I think, because
15 that is what is before you, you need to
16 evaluate the usability of the composite
17 itself, but I think you also need to keep in
18 mind you are hearing that there is work on how
19 to make this -- I mean, you yourself said it -
20 - to make this understandable to individuals,
21 although it sounds like you are using the
22 individual components for public reporting.

1 But again --

2 MS. NAIERMAN: Yes, we are. But
3 if this FEHC measure, FEHC tool, has already
4 been endorsed by NQF, including its individual
5 measures, can we not take it for granted that
6 it has been approved by NQF already? I am
7 talking about the individual measures -- the
8 individual questions.

9 MS. BOSSLEY: Right. So the
10 measure is up for maintenance now. Now I
11 think this was -- I don't remember how many
12 years before when it was actually the survey
13 that was submitted, but as was clarified, we
14 don't endorse surveys. We endorse the
15 measures that result from that.

16 So we are not endorsing the
17 individual measures right now, other than how
18 they construct the composite. So what you
19 would want to have happen, and this is part of
20 our composite framework that we typically show
21 and we can distribute to all of you so you see
22 it, is that the individual components within

1 that composite must meet the criteria, must
2 show that they meet all four things, which I
3 think, again because it was reviewed
4 previously and I don't think there has been
5 any significant changes, I think we can say
6 that that has occurred.

7 Those can be and should be -- you
8 should be able to drill down and look at the
9 results of those individuals, but before you
10 today is the composite, looking at the rollup.

11 DR. CASARETT: Just a quick
12 usability clarification or question. I
13 understand that we are supposed to rate
14 feasibility based on the composite, but my
15 understanding is that hospices would get each
16 one of those individual items. So each one of
17 those items that make up the composite would
18 be actionable.

19 It seems kind of unfair maybe to
20 penalize this based on usability, if hospices
21 are seeing everything. Does that make sense?

22 MS. BOSSLEY: I wouldn't penalize

1 this measure based on the usability at all, as
2 long as you can drill down. It is clear that
3 there is work underway to look at how, when
4 you get to the point of public reporting,
5 which is where we really want this to head --
6 how do you then display that information.

7 Again, we may not rate this high
8 because of that, but I wouldn't in any way
9 factor of that into your rating.

10 DR. LUNNEY: With that final
11 clarification, we are ready to vote. Is there
12 a performance gap that this measure addresses?

13 MR. COLCHAMIRO: Seventeen high,
14 one moderate, one low, zero insufficient
15 evidence.

16 DR. LUNNEY: Is this measure a
17 process or outcome?

18 MR. COLCHAMIRO: Eleven yes, eight
19 no.

20 DR. LUNNEY: All right. Now in
21 terms of the importance to measure and report
22 this, is there a quantity of studies to

1 support it?

2 MR. COLCHAMIRO: Twelve high, six
3 moderate, zero low, one insufficient evidence.

4 DR. LUNNEY: Does that body of
5 evidence have quality?

6 MR. COLCHAMIRO: Thirteen high,
7 six moderate, zero low, zero insufficient
8 evidence.

9 DR. LUNNEY: And are there
10 consistent results?

11 MR. COLCHAMIRO: Fourteen high,
12 four moderate, one low, zero insufficient
13 evidence.

14 DR. LUNNEY: In terms of
15 reliability?

16 MR. COLCHAMIRO: Fifteen high,
17 four moderate, zero low, zero insufficient
18 evidence.

19 DR. LUNNEY: Is it a valid
20 measure?

21 MR. COLCHAMIRO: Fifteen high,
22 three moderate, one low, zero insufficient

1 evidence.

2 DR. LUNNEY: If there are
3 disparities out there, would this measure
4 capture it?

5 MR. COLCHAMIRO: Eleven high, six
6 moderate, one low, one insufficient evidence.

7 DR. LUNNEY: Is it usable and
8 understandable for public reporting?

9 MR. COLCHAMIRO: Ten high, nine
10 moderate, zero low, zero insufficient
11 evidence.

12 DR. LUNNEY: Is it feasible to use
13 this document -- measure?

14 MR. COLCHAMIRO: Twelve high, six
15 moderate, one low, zero insufficient evidence.

16 DR. LUNNEY: And finally, do we
17 endorse this measure?

18 MR. COLCHAMIRO: Nineteen yes,
19 zero no, zero abstentions.

20 DR. LUNNEY: All right. We could
21 move from here to measure 1623, the Bereaved
22 Family Survey. Do we have a developer to

1 present this to us? Okay, we will skip over
2 and move to 1632. Do we need to hear more
3 from the developers? Okay, Naomi is the one
4 presenting this.

5 MS. KARP: Okay. So you have
6 heard Joan's detailed pitch, and so I won't go
7 over any of the characteristics of it. I will
8 just talk about the people who reviewed it.

9 Seven people reviewed the measure.
10 The bottom line was that five of the reviewers
11 recommended approval, and two recommended
12 against. Most of the ratings in most of the
13 categories were in the high and moderate
14 range. So I am just going to flat the
15 concerns and the questions that were raised.

16 It seemed to me that the main
17 concerns of the two naysayers appeared to have
18 to do with feasibility. One mentioned that it
19 was not easy to implement massively. Even
20 some who recommended approval noted that it
21 was ambitious, that more is needed to
22 understand feasibility and optimal

1 implementation strategy.

2 Some of the other questions raised
3 were: Someone said the zero to 100 scale may
4 be too much information for the public. I am
5 not sure I really understand that. So whoever
6 said that maybe could explain it.

7 There was a question about whether
8 the survey instrument might be too long.
9 There was a question about what is the
10 interval between the time of death of the
11 patient and the administration of the survey,
12 and is that too long of an interval? I am not
13 sure whether that time interval was specified
14 in there. I believe in the published study
15 that you attended, you talked about a nine
16 month interval, which seems like a long time.

17 Then someone noted the fact that,
18 unlike the FEHC, which is just for hospices,
19 this is meant to be administered in several
20 different settings of care, and there was a
21 question raised about whether hospitals would
22 really be willing to devote the time needed to

1 this, that hospitals were very different from
2 hospices, and also that families of people who
3 die in the hospital may not be as focused on
4 the quality of the care at death as people
5 with patients in hospices.

6 DR. LUNNEY: Would the developers
7 like to respond to those?

8 DR. TENO: You know, actually, I
9 am going to go last and get confused as usual.
10 Our experience along with this national
11 fielding of the survey we actually did 100 in
12 depth narratives, and that is just not
13 something we saw.

14 Irregardless of the site of care,
15 the dying of a loved one is a sentinel event
16 that really does impact. When it goes wrong,
17 it really leaves an impact on people that you
18 can recall those memories up to two years
19 later.

20 We chose nine months for the study
21 based on when we could get the death
22 certificates. It is a research goal right now

1 for us as part of the development of the FEHC
2 to look at early versus late administration,
3 look at stability and responses over time. It
4 is on our agenda. We, hopefully, will have
5 that answer to you by the time of the next
6 measurement maintenance, and make more solid
7 recommendations.

8 The feasibility: We agree with
9 you that our intent and the reason that I have
10 put this forward was at the request of the
11 NCPRC. So that if we do have a demonstration
12 going forward regarding accountable care
13 organizations or bundling of payments, we
14 wanted to have a measure out there that could
15 capture the consumer's perspective; because
16 you realize that all of these changes in how
17 we finance our health care system, the people
18 at most risk is the dying, because those are
19 the high cost patients.

20 So our intent with this measure
21 was to fill a void, because initially this was
22 not something I was going to do. I was sort

1 of drafted in doing it. I want to make it
2 available as an ACO.

3 This is a measure that, if it gets
4 picked up and gets used, I am going to try to
5 harmonize it back to the work of the FEHC.

6 DR. LUNNEY: Are there any other -
7 - Yes, Eduardo.

8 DR. BRUERA: Just for
9 clarification, Joan, is this a copyrighted
10 tool or is this going to freely available to
11 everybody who wants to use it for their
12 clinical programs?

13 DR. TENO: My life is online.
14 Seriously, I have been very fortunate to work
15 as a health services researcher for 25 years,
16 and I really believe the onus on me is to give
17 back to the field. All my work is done
18 through either taxpayer money or public
19 philanthropy.

20 So from the very beginning, I have
21 put everything out there on websites, made the
22 information accessible. The instrument

1 currently is being used in Australia. I get
2 these wonderful emails from the person in
3 Australia who is using it.

4 I have let people sort of adapt
5 it. It has been translated into various
6 languages. I have done freely. I just think
7 it is a service that we do, because all this
8 work comes from really either federal or, in
9 this case, philanthropic money.

10 DR. LUNNEY: Robert?

11 DR. FINE: Joan, a question. Is
12 this just for veterans or is this for anybody,
13 because it refers to veterans?

14 DR. TENO: No, that is 23.

15 DR. FINE: Ah, that is why I am
16 confused. Thank you.

17 DR. LUNNEY: We are on measure
18 0208, the care measure.

19 MS. BOSSLEY: This is 1632, and 23
20 is the veterans, I believe.

21 DR. LUNNEY: Naomi.

22 MS. NAIERMAN: I have a point of

1 clarification. Picking up on what I asked
2 earlier about the individual components, being
3 that this -- I hope I am getting this right.
4 This is similar to the FEHC. One is the
5 mother of the other, and we are asked here to
6 consider all the individual components and not
7 the composite. Right?

8 DR. TENO: This is something I
9 would like NQF guidance on, because obviously,
10 the team struggled on how to write this up,
11 and struggled with this whole notion of
12 maintenance.

13 I did this in Seattle, and I
14 decided to give you the maximum information,
15 not only to give you the zero to 100, but to
16 show you each of the subdomains that we have;
17 because I actually think they are both
18 important, and that as you go forward in
19 public reporting.

20 If the NQF agrees, I would like to
21 update, with Carol's permission without her
22 hitting me -- I would like to update the FEHC

1 to have a very similar -- you know, talking
2 about how the FEHC really, in addition to
3 having the zero to 100, also does have
4 components, which I would like to make that
5 information available, but she is not going --

6 MS. SPENCE: No, I mean, that is -
7 - We had a telephone call, and we discussed
8 that point -- we, NQF and NHPCO had a
9 telephone call, and we were told very clearly
10 that, if we wanted to do individual questions,
11 there had to be a separate submission for each
12 individual question.

13 So from a practical standpoint,
14 that was also part of my decision to go with
15 the composite. I don't know if there is a
16 difference between that being a maintenance
17 measure versus this being --

18 DR. LUNNEY: So this is something
19 that I will say even as NQF staff, we have
20 spent quite a bit of time and went through our
21 Consensus Standards Approval Committee, to
22 talk it through as well, because it is again

1 an evolving art, I think, in measurement,
2 looking at surveys.

3 So there are several ways that
4 this could be put forward, and I think we can
5 talk offline if there are ways that you want
6 to further pull out either the domains or the
7 questions that you feel that are relevant for
8 public reporting and accountability.

9 What we have before us is the
10 composite, which is the rollup, for both the
11 FEHC and the care. Correct? I want to make
12 sure I am understanding, because it is not
13 necessarily clear.

14 DR. TENO: Sure. To be clear,
15 Carol, listened to you -- I didn't. Carol
16 gave you the composite. I actually gave you
17 the composite and the psychometric properties
18 of all the domains as well, and I provided you
19 with all the validity testing that we have
20 done with each of the items. But that is
21 because I have obsessed about this for about
22 12 years now.

1 MS. BOSSLEY: Right. So we want
2 all the information underlying the composite
3 that shows how everything pulled together into
4 that composite. So the individual, the
5 domains, all of that, we would want. So what
6 you have done is correct. I think both of you
7 have done that.

8 What I think is the question that
9 we may need to take offline and then bring
10 back to the committee is whether just the
11 composite that we have in front of us, because
12 I think that is how the committee has been
13 voting, and that is what we have looked at for
14 both of them, then needs to be further broken
15 out into either domains or something.

16 I guess part of what would be
17 helpful for you all to think about is are
18 there specific domains or questions within the
19 survey that makes sense to pull out and be
20 reported on their own.

21 That would be the part that, I
22 think, you would need to tell us. It could be

1 all of them, and then we will figure out with
2 you how to help get that information into what
3 we need.

4 DR. TENO: Personally, I will be
5 very glad to work with you on that.

6 DR. LUNNEY: Are we clear on this?

7 MS. BOSSLEY: So you all know what
8 you have in front of you today. In front of
9 you today, I would say, is the composite. So
10 it is the rollup of everything. You have
11 discussed it for the first one, 0208.

12 Now you are discussing it for
13 1613. What we need to figure out, and we will
14 do it with Joan and Carol, is whether or not
15 we are going to bring back to you the
16 individual questions or some domains that
17 would be pulled out and actually be endorsed
18 as separate measures that could be reported
19 out on patient experience -- or family
20 experience.

21 DR. LUNNEY: I just want to
22 clarify that I am understanding the

1 denominator correctly, and this is intended as
2 a follow-back survey that could capture next
3 of kin of anyone who died in any setting that
4 was not traumatic.

5 DR. TENO: Non-traumatic deaths,
6 and the next of kin has to say they were the
7 person most involved in the care and would
8 have, or did, make medical decisions.

9 DR. LUNNEY: Okay. Let us proceed
10 with our voting. Is there something? Come
11 on, Doug, hurry up. All right.

12 Has there been a performance gap
13 identified to support the importance of this
14 tool?

15 MR. COLCHAMIRO: Fourteen high,
16 five moderate, zero low, zero insufficient
17 evidence.

18 DR. LUNNEY: Is this measure and
19 outcome measure or a process measure? Is it
20 an outcome measure?

21 MR. COLCHAMIRO: Eight yes, 11 no.

22 DR. LUNNEY: All right. Is the

1 evidence to support the importance of this
2 measure -- is there a quantity of studies
3 available?

4 MR. COLCHAMIRO: Nine high, nine
5 moderate, one low, zero insufficient evidence.

6 DR. LUNNEY: Again, in the
7 evidence that supports the importance of this
8 measure, is there quality evidence?

9 MR. COLCHAMIRO: Eight high, 10
10 moderate, zero low, zero insufficient
11 evidence.

12 DR. LUNNEY: Among the studies
13 supporting the importance of this measure, is
14 there consistency?

15 MR. COLCHAMIRO: Ten high, nine
16 moderate, zero low, zero insufficient
17 evidence.

18 DR. LUNNEY: Now looking at the
19 measurement properties, is there evidence that
20 this is reliable measure?

21 MR. COLCHAMIRO: Eleven high,
22 eight moderate, zero low, zero insufficient

1 evidence.

2 DR. LUNNEY: Is there evidence
3 supporting the validity of the measure?

4 MR. COLCHAMIRO: Nine high, 10
5 moderate, zero low, zero insufficient
6 evidence.

7 DR. LUNNEY: If there are
8 disparities out there, will this measure catch
9 them?

10 MR. COLCHAMIRO: Ten high, nine
11 moderate, zero low, zero insufficient
12 evidence.

13 DR. LUNNEY: Is this a useful
14 measure for public disclosure or quality
15 improvement?

16 MR. COLCHAMIRO: Nine high, nine
17 moderate, zero low, one insufficient evidence.

18 DR. LUNNEY: And is it feasible to
19 use this measure?

20 MR. COLCHAMIRO: Seven high, 10
21 moderate, two low, zero insufficient evidence.

22 DR. LUNNEY: Finally, do we

1 endorse this measure?

2 MR. COLCHAMIRO: Nineteen yes,
3 zero no, zero abstentions.

4 DR. LUNNEY: I think we are ready
5 for our last instrument that we are going to
6 deal with today, number 1623 from the PROMISE
7 Center, the Bereaved Family Survey. Do we
8 have a developer? Is the developer available?

9 MS. TIGHE: Anthony, is there a
10 developer from the PROMISE Center on the line?
11 I think the name is Heim Lu.

12 OPERATOR: We do not have that
13 company on.

14 MS. TIGHE: Thanks.

15 DR. LUNNEY: Then, Rick, over to
16 you.

17 DR. GOLDSTEIN: So the BFS is a
18 comprehensive measure intended for use by the
19 VA for quality improvement in the care of
20 veterans who die in inpatient VA facilities,
21 and it assesses families' perceptions of the
22 quality of care for those veterans who -- and

1 the care was during their last month of life,
2 with a follow-back study administered to
3 identified next of kin six to 10 weeks
4 following death, and its elements focus on
5 communication, emotional and spiritual
6 support, pain management, and personal care
7 needs.

8 It also has sections that ask
9 about the presence of PTSD at end of life,
10 which is of interest to the VA, and also
11 family awareness of entitled benefits.

12 Its numerator is completed
13 surveys, completed being 12 of 17 items, with
14 optimal responses to a global assessment of
15 care score, with additional breakdown of
16 tested elements. The denominator is the total
17 completed surveys from the family member with
18 the VA inpatient death.

19 They excluded patients without
20 identified or contactable next of kin and
21 acute fatalities, and six of us completed
22 evaluations.

1 In summary, it provides a
2 performance gap. We all rated it highly. We
3 were split about whether this was an outcome
4 measure, and if it was, it would have scared
5 us from the evidence presentation. However,
6 the measure designer didn't feel that the
7 structure was -- that structure
8 process/outcome relationship applied in this
9 case, but then later cited the measure's
10 discriminate validity and showed a
11 relationship, a testable relationship.

12 There is only one study cited, but
13 the measure is based on FATE and FATE-S for
14 which there was more evidence, and you can see
15 from the scores that we were all over the
16 place in assessing quantity, quality and
17 consistency.

18 It has been tested, pilot tested.
19 The measure has been pilot tested with
20 suitable operational characteristics. There
21 is general agreement that the measure was
22 usable, but less agreement that it is

1 feasible, mostly due to the fact that it is an
2 add-on process.

3 In terms of specific comments, it
4 was noted that crucial aspects at the end of
5 life care are not included in the measure,
6 things like advance care planning,
7 coordination of care, and family burden.

8 The designers have noted that the
9 care of veterans without next of kin and
10 families is more costly and tends to have
11 poorer outcomes, and this measure does nothing
12 to address that.

13 There was some question about the
14 measure's use in the general population, and
15 that concern led to the only exception to all
16 other reviewers vis a vis it is a suitable
17 measure for endorsement.

18 I think this is really just
19 intended for the VA, and that they are asking
20 for endorsement.

21 DR. LUNNEY: Given my side
22 question, does the NQF address measures

1 intended for specific populations, and the
2 answer is yes.

3 MS. BOSSLEY: Right. Let me just
4 add, though, I guess the other question would
5 be is there anything that this survey perhaps
6 addresses that couldn't be addressed by the
7 other ones you have looked at in that
8 population? I think, to have you have discuss
9 that -- So some of the other ones kind of
10 could be potentially applied to this
11 population, perhaps not because of the group
12 we are talking about. That may be helpful, to
13 give us a little feedback on that.

14 DR. LUNNEY: Is anyone familiar
15 with this to know whether there are aspects of
16 the other instruments that were deliberately
17 left out or anything added that was not
18 covered by the other -- the FEHC or the CARE?

19 DR. GOLDSTEIN: There are some
20 specific VA measures. So there are two
21 questions about PTSD, and there are about
22 three questions, if I remember correctly,

1 about whether there were death benefits,
2 burial benefits, and family benefits that
3 follow.

4 I would also say that the language
5 of this, which I think is the strength of the
6 way the questionnaire is constructed -- It is
7 a telephone survey, but it is very accessible,
8 and I am just guessing that, if we tried to
9 estimate sort of an educational level, it is
10 at a lower level than what I reviewed from the
11 others.

12 Then in terms of what wasn't
13 there, things like coordination -- the same
14 things I just talked about. Coordination of
15 care and advance care planning, and family
16 burden are not included.

17 DR. LUTZ: And you may have just
18 answered this, and I maybe didn't understand.
19 But you said that NQF can look at something
20 that is just for a specific subset of health
21 care, but then we also have the charge that,
22 if there are two competing things, we are

1 supposed to pick the better.

2 Does that mean this can be
3 separate altogether or does it mean that one
4 has to be the better?

5 MS. BOSSLEY: I would say, given
6 the population we are talking about, I think
7 that it is a unique enough population that it
8 makes sense to have a separate survey and a
9 separate measure.

10 So if you all agree with that,
11 that is how the recommendation would go
12 forward, that it is appropriate to have two.

13 DR. LUNNEY: Let's see. Tina?

14 MS. PICCHI: One concern I had was
15 the small group of people that it was
16 addressing. Only 27,000 of the veterans in
17 2000 who were in veteran facilities had this
18 survey administered, and the other 77,000 who
19 died were not included in this survey.

20 I didn't know if there was a -- I
21 know that they have been trying to tie this as
22 a quality indicator to the palliative care

1 programs that they have implemented in the VA,
2 and so it is specific to the facilities.
3 Nonetheless, there is a large population of
4 veterans' families who would not be surveyed
5 with this.

6 MS. NAIERMAN: I think I could
7 answer that partially. To the extent that VA
8 facilities refer out to hospice, they may be -
9 - veterans may have been captured in a
10 hospice setting versus dying in the inpatient
11 facility. So the 27,000 is a little bit
12 deceiving. Of course, the rest of it may be
13 that they didn't have a family member that can
14 be contacted.

15 DR. LUNNEY: David?

16 DR. CASARETT: I think I can add
17 to that a bit. although I am not familiar with
18 all the details. Two issues, problems, I
19 could see. One is I think it is very, very
20 difficult to identify people who die outside
21 of facilities. Some veteran who dies
22 somewhere in the community, figuring out that

1 they have died is difficult.

2 The other issue is I believe that
3 NHPCO is developing a version of the FEHC or
4 a module of the FEHC that uses some of these
5 questions as a way of getting at some of those
6 patients.

7 DR. LUNNEY: I am not sure I quite
8 understood that, David. Are you saying,
9 therefore, that in the future the FEHC or the
10 CARE will make this not needed?

11 DR. CASARETT: No, I don't think
12 so. I just looked at Carol who, I guess, is
13 not allowed to speak. So I am going to
14 channel Carol for a second, if I can.

15 So the FEHC is administered to
16 people who die in hospice, some of whom are
17 veterans. So I believe NHPCO is working to
18 identify those veterans and ensure that those
19 veterans get an additional module. That would
20 be different than those veterans who die in a
21 VA facility, a nursing home, for which I think
22 the BFS is directed.

1 DR. LUNNEY: All right. You can
2 nod.

3 DR. CASARETT: Carol can nod.

4 DR. LUNNEY: And presumably, the
5 concerns in the VA facility are slightly
6 different from the concerns that might be had
7 if the veteran was out in the general
8 population. So, okay. I think I am clear.

9 DR. GOLDSTEIN: I just wanted to
10 make one other comment in favor of not
11 harmonizing this too early. It has to do with
12 the VA system. They don't have problems with
13 access. SES is lower. Increasingly, the
14 demographic mix is traditionally a much harder
15 group to capture in our studies.

16 So I would be very interested to
17 see what they find, and I think that they
18 should be able to pull out a lot of
19 interesting information.

20 DR. LUNNEY: Are there any other
21 questions before we vote?

22 MS. O'MALLEY: I just had a

1 question. This is just more of a wonderment
2 kind of a question of the purpose of seeking
3 NQF endorsement for this particular measure,
4 because the thought that comes to mind is that
5 the VA is the federal government, and if you
6 are thinking about NQF's endorsement as a
7 launching pad for promoting uptake and
8 promoting the quality and people's interest
9 and engagement in quality processes and public
10 reporting, I am just wondering why this
11 measure would need NQF endorsement.

12 If it is the federal government,
13 you just say do it, as your measure.

14 MS. BOSSLEY: Well, I would have
15 to ask the VA why they submitted it, but part
16 of the -- The government is actually required
17 through AHRQ and other legislation to use NQF
18 endorsed measures wherever possible. I think
19 that would indeed apply to the VA as well.

20 So my assumption would be that may
21 be part of why you see this measure before you
22 now. My other assumption would be a lot of

1 people really look to that multi-stakeholder
2 input that the NQF process has, and does find
3 value in it. But again, I can't speak for the
4 developer themselves, but I think that may be
5 two factors why you do see the measure before
6 you.

7 DR. CASARETT: I don't think I
8 could speak for the developer either, but
9 there is a rhetorical process that goes on in
10 both convincing people that a measure should
11 be used within the VA, given that right now
12 there are something like 200 quality measures
13 the VA use.

14 You need to convince people that
15 you really need a 201st, and this costs money.
16 As people have mentioned, there is a
17 commitment by the VA to do this survey for
18 every single inpatient death across the
19 country, which is expensive, and it becomes
20 easier, I think, to argue for that expense for
21 an NQF measure. So I think it is those
22 things, too.

1 MS. NAIERMAN: I just have a quick
2 comment. Someone said earlier that this may
3 not be totally feasible, because it is an add-
4 on, but to Kate's comment, if they are told to
5 do it, they are going to; and if the funds are
6 satisfied, they will do it. So add-on or not,
7 seems to me, it will be done.

8 DR. LIAO: So, David, can I just
9 ask a clarification question. So the VA has
10 200 quality measures. They don't -- Each VA
11 hospital does not have to implement or use all
12 200, right? They select which ones they are
13 going to use?

14 DR. CASARETT: I am no longer in
15 the VA, a factor for which I thank my lucky
16 stars every time I wake up in the morning. So
17 I don't know what the latest count was. I do
18 know that, when I used to work in the VA, the
19 question always was we are being held
20 accountable for way too many things for us to
21 keep track of; don't give us another one.

22 DR. LIAO: At least I know my

1 local VA -- the director gets to pick which
2 ones sort of that they are going to use and
3 report, for whatever their incentive program
4 is. So, yes, they don't have to use -- I
5 guess that is why --

6 DR. LUNNEY: However, I don't
7 think it is our purpose to worry about what
8 the VA is going to do with this. I think our
9 purpose is to determine whether this is a
10 measure that we think warrants endorsement by
11 this panel as a measure that has substantial
12 evidence supporting the need for something to
13 measure and document performance gaps, has the
14 liability and validity that we would expect of
15 a measure that was to do that, is feasible and
16 is useful. Is that fair?

17 How they choose to work with our
18 endorsement or not is not for us to deal with.

19 So having preached, are we ready
20 to vote? Is there a performance gap?

21 MR. COLCHAMIRO: Fifteen high,
22 four moderate, zero low, zero insufficient

1 evidence.

2 DR. LUNNEY: Is this measure
3 process or outcome?

4 MR. COLCHAMIRO: Ten yes, nine no.

5 DR. LUNNEY: All right. In terms
6 of the importance to measure and report, is
7 there a quantity of studies?

8 MR. COLCHAMIRO: Eight high, 10
9 moderate, one low, zero insufficient evidence.

10 DR. LUNNEY: Is there quality in
11 those studies?

12 MR. COLCHAMIRO: Six high, 12
13 moderate, one low, zero insufficient evidence.

14 DR. LUNNEY: And is there
15 consistency among those studies? If you have
16 made up your mind, try again.

17 MR. COLCHAMIRO: Seven high, 11
18 moderate, one low, zero insufficient evidence.

19 DR. LUNNEY: So is there evidence
20 that this is a reliable measure?

21 MR. COLCHAMIRO: Seven high, 10
22 moderate, two low, zero insufficient evidence.

1 DR. LUNNEY: Is there evidence
2 that it is a valid measure?

3 MR. COLCHAMIRO: Seven high, 11
4 moderate, one low, zero insufficient evidence.

5 DR. LUNNEY: If there were
6 disparities, would this catch it?

7 MR. COLCHAMIRO: Eight high, nine
8 moderate, zero low, two insufficient evidence.

9 DR. LUNNEY: Is this useful for
10 public reporting or quality improvement?

11 MR. COLCHAMIRO: Twelve high, six
12 moderate, zero low, one insufficient evidence.

13 DR. LUNNEY: Is it feasible to use
14 this?

15 MR. COLCHAMIRO: Eight high, 11
16 moderate, zero low, zero insufficient
17 evidence.

18 DR. LUNNEY: And overall do we
19 endorse it?

20 MR. COLCHAMIRO: Nineteen yes, no
21 zero, no abstentions.

22 DR. LUNNEY: I believe that allows

1 us to set these things down for the day.

2 Before public comment, we are going to have
3 the framework discussion.

4 So at this point, I will turn it
5 over to Heidi for a discussion of the report's
6 framework.

7 MS. BOSSLEY: So just one thing we
8 wanted to -- and this will be very brief,
9 because again I think we will continue to have
10 conversations about this. Did send around the
11 preferred practices, that report from the last
12 maintenance -- or endorsement? I don't think
13 we did.

14 So what we will do is we are going
15 to send around the last projects that we did
16 related to palliative and end of life care.
17 In there, it looks at both measures as well as
18 defining preferred practices, and created some
19 domains with which you would kind of frame the
20 whole spectrum of care in this arena.

21 We would like to see if you wanted
22 to still think that is relevant. Do those

1 domains continue to capture what we are
2 looking for, and then we will begin to
3 structure the report around that. If not,
4 though, we wanted to get your feedback on
5 that, because there are several groups out
6 there currently trying to also kind of capture
7 how care in the domains with which care is
8 provided in this area.

9 So, for example, CMS has a
10 technical expert panel currently looking at
11 developing measures, identifying gaps, and
12 they have come up with several domains, as
13 well as the Long Term Quality Alliance has
14 also done the same.

15 So we will distribute all that
16 information to you, and then would like to
17 propose that we use the same structure and
18 format that we did in the last report. We
19 want to make sure that we are still relevant
20 to how care is delivered now.

21 So just a heads up that that will
22 be coming to you on how we re thinking of

1 framing this report.

2 The other piece, though -- and I
3 am going to let June run this -- is we always
4 like to spend some time after you have gotten
5 into the weeds on the measures to kind of step
6 back and take a look and see, within care for
7 palliative/end of life, where are we in the
8 set of measures that you would like to see to
9 be able to show the quality that is being
10 delivered to patients, and what gaps are
11 there? I suspect there are a lot.

12 So I would like to just begin a
13 conversation today, because a part of what we
14 include in all our reports is here are the
15 measures you put forward, but here is where we
16 still need measurement and quality improvement
17 focus.

18 DR. LUNNEY: I actually would like
19 to just say it is easy to get caught up in the
20 sense that we are packing up and, yes, okay,
21 we are through with our laptops maybe, but
22 please don't be through with your brain,

1 because I think this section of our meeting
2 could be very valuable in terms of our
3 stopping now.

4 Go up to the 10,000 level, look
5 over the set of measures that we have
6 evaluated in the past two days and those that
7 we have endorsed. What is missing?

8 All right. Doug was the quickest
9 that I saw, but maybe I was just looking
10 straight ahead.

11 DR. WHITE: I will just start with
12 one to get the ball rolling. Last night I
13 looked at some of the consensus guidelines
14 specific to the acute inpatient setting
15 related to decision making about life support
16 and goals of care.

17 One of the things that struck me
18 is that, especially in the critically ill
19 population and the acutely ill population,
20 there is a need to assess not just whether
21 there is this one conversation, because we
22 know in the inpatient setting often it is the

1 act of talking early and talking often that is
2 important.

3 In fact, a lot of the good work
4 that Judy Nelson has recently been doing is
5 about how can we get people to talk serially
6 over the arc of an illness in the inpatient
7 setting, and she has proposed that, and
8 recently they tried to use that as a quality
9 measure in a project, I guess, in Rhode Island
10 was one of the big things, and it just failed
11 miserably. They weren't able to get people to
12 talk more serially over the course of a
13 hospitalization with the patient or the
14 surrogate.

15 So that would be one, thinking
16 about ways -- Can we document? Can we have a
17 measure that talks about serial conversations,
18 maybe within 48 hours and then within weekly
19 within the ICU?

20 DR. LUTZ: I just wanted to echo
21 what Eduardo said earlier. I think part of
22 the concern I have as an oncologist coming

1 here is that there are a lot of issues, and I
2 sort of feel like we are putting the computers
3 back in the bag, and because there was sort of
4 an absence of someone to carry the ball for
5 the ASCO issues.

6 You know, we've got to the point
7 where we said we had one or two favorites, but
8 that doesn't give me a lot of closure. It
9 leaves me believing that, unless someone can
10 bring those to the finish line, we have not
11 taken the opportunity to help ourselves
12 through what is a very difficult time in
13 oncology, as oncology struggles a great deal
14 with what to do with end of life care.

15 There seems to be a wide schism
16 even in the societies. We can't predict that
17 well when someone is going to die of cancer,
18 but we can more so than many of the other
19 things that lead people to hospice. We still
20 don't have very good measures.

21 So I feel a little empty that
22 those didn't get done.

1 MS. BOSSLEY: Just to say that you
2 are going to have more conversations on this.
3 So please go away feeling better. We are not
4 done yet.

5 DR. FINE: So my hope is that at
6 some point tools might be developed that look
7 at the quality of care at the end of life for
8 all patients and not just those seen by
9 palliative care and/or hospice teams.

10 I understand the need to focus on
11 the quality of what we who are palliative care
12 practitioners or hospice practitioners do, but
13 it strikes me that we will never see all
14 patients who face the end of life or there is
15 certainly a period of time where we are not
16 yet involved, and yet there are qualitative
17 issues.

18 It seems to me the tools in
19 general seem to place in their denominator in
20 general patients that are kind of already
21 identified as palliative care appropriate.

22 DR. LUNNEY: Thank you. You might

1 straighten your table cards, if it is
2 appropriate, only if it is appropriate, so
3 that I can keep some track. I am going to
4 continue, if you don't mind, going around the
5 room, and I will come back. So, Kate, I think
6 you are the next whose tent I see.

7 MS. O'MALLEY: One thought that
8 comes to mind as I look back on the work that
9 we did, it seems that our measures sort of
10 conform with the fragmentation that we have in
11 our health care system.

12 In relationship to Bob's comment,
13 would really encourage the development of
14 measures that go across the continuum of care.
15 I think specifically about the outpatient
16 setting like medical groups in California that
17 deal with elders or nursing homes.

18 You know, in California 22 percent
19 of frail elders die in nursing homes, and when
20 we look at discharge data from nursing homes,
21 38 percent of nursing home discharges are
22 hospital admissions, and hospital deaths --

1 about 20 percent of them were preceded by a
2 nursing home stay.

3 So there is an enormous amount of
4 churn out there, and I think people are very
5 well aware of that. I don't know yet exactly
6 what the role of quality measures can play,
7 but finding things to support in studies and
8 to look at settings of care, particular
9 nursing homes, I think, would be very valuable
10 to have a higher degree of quality scrutiny
11 and ability to measure in those settings.

12 DR. LUNNEY: Thank you. Eduardo.

13 DR. BRUERA: I think our challenge
14 is going to be to find very hard outcomes, and
15 basically, as you know, if I fly tomorrow and
16 my plane lands, 80 percent of the people are
17 going to be delighted with the flight, even
18 though the food was awful, it landed three
19 hours late. We are alive. We landed, that's
20 fine.

21 Mom is sick. Mom got admitted.
22 Mom died. So the question I have is it is very

1 hard sometimes to pose the question on the
2 people who are the recipients or who are
3 suffering through the problem at that point,
4 and there is nothing inherently wrong with
5 that, but we need to go much more hard in the
6 outcomes.

7 There are things that people are
8 undergoing that should be the real outcomes.
9 The reason why we are going bankrupt is not
10 because we are having some chance -- it is
11 because of things we are doing and the results
12 of those.

13 So I think we need to step back a
14 little bit and look at exactly what the things
15 are that are low hanging fruit, that are very
16 hard outcomes.

17 I would like to echo some of the
18 issues, that I don't go home with the feeling
19 that asking this question or asking that
20 question is really going to change end of life
21 care in this country. So measuring hard
22 benchmarks that are out there and getting the

1 consensus that we don't have to feel bad or
2 paranoid about them -- they are benchmarks
3 that will be defined, the same as the C-
4 Section was defined. But if we don't put
5 those on the table, asking this or that
6 question -- I ask questions to death to my
7 patients, but I am not sure the answer is that
8 is what we do to people, that we need to put
9 back on the table.

10 DR. LUNNEY: And I am going to
11 take my place around the table, and
12 particularly because -- oops, Naomi.

13 MS. KARP: I guess I want to focus
14 on advance care planning and documentation.
15 Admittedly, I haven't seen the NQF advance
16 care planning measure. So I don't know what
17 is in it.

18 I guess, to Doug's point, I want
19 to -- and I think that you were talking more
20 about the hospital setting, but I agree with
21 you about advance care planning is not a one
22 stop shop, and so we should look at a measure

1 that goes across a longer time frame. But I
2 also think we should do that in more settings
3 of care. So we should expand it to outpatient
4 medical practices, nursing homes, home care,
5 etcetera.

6 I guess the specific one -- I
7 haven't really thought about this before, but
8 we were talking about POLST before, and I
9 wonder whether the use of the POLST could be
10 amenable to actually being a quality measure.

11 In many states, it needs some kind
12 of legislation or regulation, but it is still
13 -- even without that, it is a form and a
14 protocol that can be used within a facility,
15 and is not necessarily dependent upon that.
16 So that might be something very concrete and
17 tangible that we could look at.

18 DR. LUNNEY: And what I wanted to
19 bring up -- and it is ironic, because Naomi
20 reminded me of a mutual friend who, if she was
21 here, would certainly bring it up as well, and
22 that is the fact that the National Mortality

1 Follow-back Survey is dead on the vine for
2 federal funding, but at least one of our
3 measures today had a very broad denominator
4 that would have caught many more people who
5 died than those that we saw it coming.

6 It does become a real issue,
7 because some of the questions that you want to
8 ask, you then can't turn around and change
9 care, because if you didn't see it coming, you
10 didn't know you were caring for someone who
11 was dying. But most of the questions that we
12 ask are questions that would indicate whether
13 health care was of high quality, whether the
14 person was headed to a end or not.

15 So I would like to say that I
16 think we could develop some good mortality
17 follow-back survey questions and encourage
18 their use, even outside of the federally
19 supported nationally representative survey.

20 Around the table. Did I skip you?
21 I'm sorry.

22 DR. GOLDSTEIN: You did. That is

1 okay.

2 DR. LUNNEY: I don't do vertical
3 versus horizontal.

4 DR. GOLDSTEIN: I think POLST is
5 really something that is important, not just
6 in hospitals but in terms of transitions in
7 care, and also continuance of care, and it
8 seems like it a ripe fruit that is ready to be
9 plucked. So I would say that.

10 There were really no process
11 measures related to communication of
12 critically ill patients. So something like
13 ICU family meetings might be an interesting
14 benchmark to explore.

15 Then just from where I sit, there
16 really are no measures either specific or
17 attempting to address children and young
18 adults and issues like minors with decision
19 making capacity, the presence or availability
20 of hospices with expertise to take care of
21 children, or even the availability of
22 functional services. OT, PT, child life

1 educational support services in the community
2 for critically ill children and families are
3 things that I just feel are missing.

4 DR. SCHROEPFER: I have two areas
5 I wanted to raise. The first is in terms of
6 the role of culture. My research focuses
7 working with medically underserved
8 communities. I work with a number of tribes
9 in Wisconsin, Amish, Hmong, so different
10 communities.

11 In working with the communities
12 around end of life, I have learned that how we
13 measure things, we are not really going to
14 capture what we are seeking with regard to
15 some populations.

16 One of the examples I can think of
17 is working with the Shakopee Nation in
18 Minnesota, what came out of the research was
19 that stoicism is so key for elders. So an
20 elder can be in pain, and the chart that they
21 use there, have been using in that area, are
22 ones with the faces where you are happy. You

1 have no pain down. So you have the miserable
2 face, and an elder will always choose the
3 middle.

4 An elder will never talk about not
5 being able to access care at end of life,
6 because the Indian Health Services and the
7 limited amount of funds that come in. They
8 run out of funds halfway through the year. So
9 elders don't seek services, because they save
10 them for the children.

11 There is also the issue of some of
12 the tribes I have worked with -- their tribal
13 docs are doing a really good job of working
14 with the more mainstream doctors, and some of
15 the things that they talk about that are
16 important -- like for example, in cancer, what
17 is needed from the traditional docs before
18 they can go with the more mainstream doc, if
19 you are going to talk to them about quality of
20 care, both of those things have to be
21 measured.

22 Language is another thing.

1 Language is a huge issue, and the quality of
2 care that someone who is Hmong -- I work with
3 immigrants from 15 countries, Latin countries,
4 and for them language is a huge issue, and it
5 definitely impacts their care.

6 I could go on and on with stories,
7 Amish. I just think that oftentimes that --
8 When I started in end of life in the Eighties,
9 the thing that I always heard was back then
10 people were trying to define a good death, and
11 we really felt we could define this good
12 death.

13 What I have learned through the
14 years with my research is everybody defines a
15 good death differently, and culture -- Color
16 is not culture, but culture is really
17 important, and I just think oftentimes that we
18 need to look through a different set of eyes.

19 My last thing has to do with
20 holistic. So I am a social worker, and I know
21 the frustration of being a social worker in
22 the field of palliative care and end of life,

1 and I speak for my many, many students that
2 have graduated and work in the field.

3 One of the things consistently is
4 that sometimes there is such a medical focus,
5 and I am not saying that the medical focus
6 isn't important. Of course, it is important,
7 but my research and research of others, when
8 you look at the information that is out there,
9 shows that psychosocial is key.

10 In my research I have found that
11 pain is not even a significant variable, if
12 you haven't addressed social support and other
13 aspects of the psychosocial and the spiritual.

14 So I just think I was glad that we
15 had Joan's work at the end, but mostly we did
16 not have a lot in terms of the psychosocial,
17 the spiritual, and I just think more is needed
18 of that, if we are really going to get at a
19 quality dying process.

20 DR. LUNNEY: Naomi?

21 MS. NAIERMAN: Understandably, we
22 are making the first baby step in this field,

1 and we do have some process measures that get
2 us started with screening, assessment,
3 discussions and so on. So I would like to
4 prioritize those process measures to be
5 followed by outcomes.

6 So having screened and assessed
7 for pain, what are the outcomes of those? I
8 think having done the basics for it, I don't
9 think it will go very far, as Eduardo said, if
10 we don't aim to complete that cycle toward
11 outcomes.

12 The other thing I would stitch
13 together is in hospice we think a lot about
14 wasted resources, minimizing unnecessary
15 hospitalizations, ER visits and so on. I
16 don't think -- and yet, I don't think it is
17 really coordinated with the other priorities
18 that the health care system as a whole looks
19 at.

20 So, for example, NQF has an NPP
21 around use of care. I am not sure exactly
22 what the language is. But I am not sure to

1 what extent it has been stitched together with
2 coordination efforts and outcome measures in
3 the setting of end of life care.

4 So if you looked across the
5 continuum, you will see that, when hospice is
6 involved in a nursing home setting, more than
7 likely you will see fewer unscheduled
8 hospitalizations and emergency room visits.
9 I think that is huge, because we are so
10 consumed with reducing the deficit, reducing
11 health care costs, and that is where the big
12 money is.

13 So to the extent that quality can
14 drive better resource use, I would put a high
15 priority on that as well.

16 DR. LUNNEY: Solomon, I think.

17 DR. LIAO: I think one of the big
18 topics in palliative medicine or palliative
19 care that we haven't talked about is
20 artificial hydration and nutrition.

21 I know that some people have
22 looked at, for example, feeding tube

1 placements as a quality measure, and so I am
2 glad to see, for example, the consideration of
3 turning off defibrillators and not giving
4 chemotherapy in the last few weeks of life.
5 So maybe this next time around it could fit
6 under the same type of thinking or thought.

7 DR. LUNNEY: Thank you. Coming
8 around again, Naomi, are you still --

9 MS. KARP: It is really just a
10 question, because it is my first time doing
11 this, and it seems to me that the Steering
12 Committees are reactive in that we have to
13 only react to the measures that are submitted,
14 but now we are having this discussion about
15 gaps. So I wonder what is the process for how
16 we fill them, and is there anything we can do
17 that is proactive?

18 I am not a researcher. I don't do
19 this kind of research. So I couldn't be a
20 measure developer, but what can we and NQF do?

21 MS. BOSSLEY: It is a really good
22 question, and I think it is something that we

1 are seeing continuing to evolve. Part of this
2 is just putting it within the framework of
3 this report. So these are the measures you
4 received, and this is always one of the things
5 most committees struggle with.

6 You have to work with what you
7 have in front of you, and that often is
8 limited within the scope of the project.

9 One thing that we are starting to
10 do now, and it is throughout several of the
11 activities that NQF has, is starting to look
12 at the gaps. How do we begin to pull that
13 together into reports or some way, so that it
14 is out for others to take a look at in a more
15 accessible, easy way.

16 So we are working on that now. We
17 have actually been charged through our HHS
18 contracts to actually develop a report on gaps
19 at the end of this year. So the hope is that,
20 as it becomes more publicly available out
21 there, not only buried kind of in the report
22 but also within a true focused document on

1 gaps, that is part of it.

2 We are also trying to think, just
3 as staff and performance measures: How do we
4 really start feeding this information back to
5 the measure developers, begin to know what
6 they have in their pipeline, because often we
7 struggle with not knowing all the groups out
8 there that work on these issues. How do we
9 get to them early so that they understand kind
10 of the criteria we have, the issues that you
11 all have faced, the other groups have faced
12 looking at these measures, so that they can
13 make sure they address those things.

14 So we are trying to figure out how
15 to do that best, but it is a challenge. If
16 you have any ideas in addition to what I have
17 mentioned, please mention it, because we
18 continue to try to figure out how to keep this
19 moving.

20 DR. LUNNEY: Michael?

21 DR. LEPORE: An area around end of
22 life care that we didn't address at all is

1 really after death. I don't know to what
2 extent it would fit in here, but treatment of
3 the body and treatment of the family after the
4 individual has died has not been addressed and
5 does seem important.

6 DR. LUNNEY: And then ironically,
7 I would just like to raise sort of the counter
8 issue. I understand I was in part asked to
9 co-chair to make sure we kept an end of life
10 focus as well as a palliative focus, and I
11 kind of think we drifted heavily to end of
12 life.

13 I kind of look back now and say,
14 even those of you involved in hospice, think
15 for a minute about palliative care from
16 initial diagnosis. Are there gaps in what we
17 would see as good care of people who are
18 dealing with a serious illness that may live.

19 I think we hit on pain, dyspnea,
20 constipation with opioids. There is something
21 missing from that equation. I mean, people
22 who when they come into the health care system

1 with a serious illness and they are
2 struggling, let's think they are going to be
3 alive in five years. What is the kind of care
4 that really would mark good palliative care?

5 Rick?

6 DR. GOLDSTEIN: I don't know about
7 in adults, but the importance of clear
8 prognosis is -- It is probably the most
9 determinant of how that course goes, and
10 actually, it would be a very hard quality
11 measure to assess, although plenty of people
12 don't feel that they even have received
13 prognosis -- I mean communication issues
14 related to those patients are important.

15 MS. PICCHI: Actually, I wanted --
16 I had my card up for a little bit. I wanted
17 to make one more comment about the previous
18 conversation, and then address your question
19 as well.

20 I was sitting here looking at the
21 NQF preferred practices, and one of the areas
22 that I think is really significant for

1 families is item number 27 about educating
2 family on a timely basis regarding the signs
3 and symptoms of imminent death.

4 That has huge ramifications,
5 obviously, for what happens with loved ones in
6 those last days and hours, and also the whole
7 bereavement process following and a need to
8 really be able to attend to the psychosocial
9 and the spiritual dimensions of the life of
10 that family. So I would love to see a measure
11 around that.

12 In answer to your question, I also
13 would like to echo something that Tracy said
14 earlier. That is, from the palliative care
15 perspective, palliative care truly is an
16 interdisciplinary art, and I don't know if we
17 have done as much as we can and should in
18 making sure that we have the right people that
19 are certified and on palliative care teams
20 available to do those initial assessments as
21 well as follow-throughs, including not only
22 the medical dimension but the psychosocial and

1 the spiritual assessments and care planning
2 that needs to be fully implemented into the
3 continuum of care plan.

4 DR. LUNNEY: Thank you, Tina.
5 Back over here, I will start, I guess, to the
6 left, and work to the right, if that is fair.

7 DR. SCHROEPFER: I have such a big
8 mouth, I forget. What Tina said -- I think
9 one of the things that we don't -- I think
10 that would be a good measure, too, is the
11 training. We need more training around
12 interdisciplinary teams and how they can truly
13 not be hierarchical but actually work together
14 and value each other's contribution. So that
15 would be a wonderful outcome measure.

16 To your comment: My research
17 focuses a lot on talking with people about
18 whether they have considered hastening death
19 and, if so, why and, if not, why not. One of
20 the things that does come up is that, for
21 people who have not -- so this is palliation,
22 not talking about end of life care, but for

1 people who are being told that they have some
2 kind of disease, it could be -- no, it could
3 be life limiting, but certain, it is going to
4 be difficult to deal with. It could be that
5 they are going to be on dialysis or whatever.

6 The important point is that what I
7 found is that without support at the time of
8 diagnosis -- so not just the conversation with
9 the physician saying this is what you have
10 and, you know, we are going to work with you,
11 but more of the psychosocial, more support
12 that way, that they often just feel like I
13 just want to go ahead and hasten my death, get
14 it done, because life is going to be horrible.

15 So having more after that
16 conversation and making that a part of care,
17 and how we can do that, I think, is important.

18 MS. NAIERMAN: I just wanted to
19 respond to Tina. I believe that one of the
20 FEHC measures is a conversation, communication
21 around imminent death, and of course, integral
22 to that is training the family about how to

1 deal with the -- how to help and support the
2 dying person in the home, but there is a
3 measure within the FEHC, as I recall,
4 hopefully, correctly. So we are measuring it,
5 having endorsed the FEHC now.

6 DR. LUTZ: I think, thinking a
7 little bit farther upstream, I think the
8 biggest unmet need in palliative care is, if
9 you consider from the time someone is
10 diagnosed, they may have a chronic dying
11 illness, four or five years, and we have
12 discussed a lot of measures that have to do
13 with end of life or have to do with specific
14 topics.

15 There is not much out there about
16 education of or support of caregivers. As we
17 have 78 million Baby Boomers enter a time
18 period when there is not enough money to put
19 everybody in nursing homes or to have personal
20 caregivers, it is going to be perhaps much
21 like it was 100 years ago. It will fall to
22 the family or someone who cares.

1 Those people -- We people when we
2 are in those circumstances helping someone
3 don't have a whole lot of resources to go to
4 essentially to help the caregiver understand
5 and get support. I think it is a huge issue.

6 MS. O'MALLEY: Oftentimes, in
7 California hospitals in the conversation
8 around goals of care, people who are not --
9 who don't speak English well, oftentimes
10 interpreters are brought in. One of the areas
11 that we are working on in our public hospital
12 initiative to support palliative care is
13 education of interpreters about how to
14 effective in the palliative care conversation.

15 As part of doing that, we looked
16 nationally for anything we could find, and we
17 really found very little on how to help
18 interpreters really learn a language and
19 really be comfortable. When you think about
20 the life of an interpreter, they go from the
21 well baby clinic to the bedside with relatives
22 breaking news about terminal illness.

1 So if there is a way to really
2 look at the quality of the conversation for
3 patients with whom English is not their
4 primary language, who need interpreters, that
5 are trained or certified -- a trained
6 interpreter in palliative care is available
7 for that conversation.

8 DR. LUNNEY: Then let's open it
9 now to public comment and start with people in
10 the room who might want to add to our
11 discussion. I think I will first call on the
12 first hand, which was behind you, Joan.

13 DR. LUPU: Hi. Dale Lupu. I am
14 the consultant who works with the American
15 Academy of Hospice and palliative Medicine on
16 quality issues, and it has been a privilege to
17 see the depth of the conversation today, which
18 was really fun.

19 I can't bear not saying this.
20 There is sort of a half-empty/half-full sense
21 that I have right now. Part of me is so
22 proud, having watched the field since its

1 inception, that here we are having -- That we
2 have any measures for you guys to look at is
3 just, I think, a course of celebration, and I
4 want to sort of say to the glass half-full,
5 yeah. It is incredible. Then, of course, the
6 glass half-empty is really seeing how far we
7 have to go.

8 So on how far we have to go in
9 gaps: I want to now talk -- I was kind of a
10 staff participant with the group that is the
11 NPCRC, the National Palliative Care Research
12 Center, pulled together, key researchers, to
13 bring together this package to you.

14 There is a letter that you
15 received, and I just want to commend to you
16 and maybe talk about two of those points that
17 the researchers, in conjunction with Brookings
18 and the Long Term Care Quality Alliance -- The
19 two things that became evident as the measure
20 development community was trying to pull
21 together a comprehensive set of measures --
22 There were two things that became evident.

1 So one is, well, just conceptually
2 -- and you guys have said this, but just
3 conceptually I think of hospice and palliative
4 care as having two components. There is what
5 I would call the specialty level, which is the
6 specialty services. So that is the patients
7 getting hospice specialty care or palliative
8 care/specialty care.

9 The primary level is all those
10 other folks out there. You guys were talking
11 about it. But I think it is helpful to
12 remember that we need quality measures that
13 address both of those slices of patients, both
14 patient populations or both care delivery
15 places.

16 When we looked at the set of
17 measures that was coming to you that was more
18 focused on specialty level care, so really
19 measuring hospice and palliative care, the
20 thing that was very apparent is that we have
21 carved up the denominators in these small
22 pieces. So we have the ASSESS or we have

1 ACOVE.

2 Not faulting it, but because of
3 the NQF process, those could only come forward
4 with the denominators that have been tested.
5 So we are very much hoping that you will put
6 forward in the gaps -- You guys were even
7 trying to do it. I mean, it is very evident
8 that this is, in some sense, a low hanging
9 fruit, that some of these measures are now
10 ready to be just have the denominator
11 broadened and be able to apply either across
12 all the specialty level care or even be pushed
13 out farther.

14 So that is one gap, is let's
15 define some common denominators, and let's get
16 some of these measures tested, but we need the
17 resources for the community to do that. I
18 think that is where the report could be
19 helpful, is saying we are really ready for
20 this now. So that is one.

21 Then two is -- This is a little
22 more subtle. That is how often we look at the

1 other measures that are out there that are
2 purporting to measure quality and how
3 frequently they are completely silent about
4 any of the hospice and palliative care
5 domains.

6 Sometimes it is not intentional.
7 Sometimes it is a lot about -- Well, for
8 instance, in HCAHPS the way the sampling frame
9 is set up, nobody who has died is in the
10 sampling frame.

11 So there are a lot of places in
12 which, not so much palliative care -- well,
13 even really seriously ill folks, but
14 especially the end of life patient population
15 is simply excluded from the measure, both from
16 the population, and then those concerns aren't
17 built into those broader measures of nursing
18 home care, of hospital care.

19 So that is a different way of
20 looking at a gap, and we would suggest that
21 that be part of the report as well. So thank
22 you.

1 DR. LUNNEY: Thank you, Dale.

2 Joan?

3 DR. TENO: I have three quick
4 things to say. I actually think there is a
5 really urgent need to define some baby steps
6 in terms of the psychosocial outcomes and
7 spiritual outcomes. If we don't start on that
8 pathway, I won't have a chaplain at my IDD
9 table.

10 I think we are going to have to
11 realize that where we are going to have to
12 start is sort of almost like a RAND-like
13 process, Delphi panel that comes up with some
14 things that are based on expert opinions and
15 the best available evidence to get something
16 out there, and we are going to need to really
17 think about at least having our best guess of
18 what the right thing is here, because
19 gathering the evidence is going to take time.

20 My concern is, as we start sort of
21 figuring out how to redo our health care
22 system, we are going to go from my internship

1 year where I used to have social workers in
2 the hospital, where all I see is discharge
3 planners. So I think there is some real
4 things.

5 I think a real low lying fruit is
6 grief and post-traumatic stress disorders. I
7 think we haven't realized just sort of what
8 you were saying before, how we manage that
9 dying episode and what that caregiver sees and
10 how that caregiver is educated and trained has
11 a tremendous impact on their grief and
12 bereavement period.

13 While we want to always go
14 upstream, we need to not forget that the
15 actual last days of life is a huge event to
16 these caregivers, and it is a huge impact on
17 their future life.

18 Then I think one of the challenges
19 is you have people like me who are academics
20 who tend to be the types who like granola
21 cereal, flip-flops during the summer. We
22 don't do really good at coming up with

1 business plans on how to get these measures
2 out to people and how to do maintenance.

3 We are more the people who do
4 start-ups. We need to have some way of
5 creating marriages for people who like
6 starting things up to hand it off to other
7 people to fully implement. As we go forward
8 in this process, I think a lot of the people
9 you heard present today are starter-uppers.
10 They may not be the best person to do the
11 maintaining.

12 So I think we need to think about
13 how we can create some creative marriages to
14 not only get the measures out there, but how
15 to maintain them, get them used, and take it
16 to the next level.

17 DR. LUNNEY: Thank you, Joan. Any
18 other comments in the room?

19 Anthony, are the phone lines open,
20 and do we have any comments from people on the
21 phone?

22 OPERATOR: All lines are open.

1 DR. LUNNEY: Hearing no -- Oops.

2 DR. WHITE: Are we going to have a
3 time for sort of process talk, like talking
4 about how this went and what we can to improve
5 it?

6 DR. LUNNEY: That would be very
7 helpful.

8 DR. WHITE: Is now a good time?

9 MS. BOSSLEY: I think -- Yes.
10 June agrees, yes, now it is time. I have been
11 at least hearing and participating in quite a
12 few side conversations, and I would think it
13 would be very important to put it out here in
14 the center of the room.

15 DR. WHITE: Okay. It seems like a
16 lot of our conversations hinged on just
17 definitional uncertainty today. We had lots
18 of questions about what is what. What is
19 reliability; what is validity.

20 I think I talked a little bit
21 about a cheat sheet yesterday. It would be
22 great to see for each of the key criteria that

1 we are supposed to be using to evaluate this
2 a very pithy summary of what is reliability.
3 What are you looking for. What are examples
4 of good evidence, moderate evidence, poor
5 evidence.

6 I know that we got this very long
7 packet, but it was -- It didn't sort of
8 fulfill the brevity need, the sort of pithy --
9 Give us the summary that we need to sort
10 things out.

11 MS. BOSSLEY: We often struggle
12 with that. I will admit it. Any thoughts you
13 may have on how to go about doing that,
14 because you are the end users -- We are in the
15 weeds on this all the time. So I think
16 sometimes it is harder for us to get out of it
17 and think, if I were someone new to this, what
18 would be useful.

19 So any thoughts you may have are
20 welcome, because we know that this is an
21 evolving process.

22 DR. WHITE: Two quick ones. Some

1 of us are, and some of us aren't, researchers,
2 and even among those of us who are
3 researchers, not all of us have really thought
4 about reliability and validity, and yet these
5 are central concepts. So maybe just a little
6 pithy primers on what is reliability, what is
7 validity, what are the different kinds of
8 validity, and what is most important.

9 DR. CASARETT: I actually had a
10 thought along those lines. Although I really
11 appreciate the free flowing nature of these
12 discussions with back and forth, bouncing
13 around, part of me, though, would welcome more
14 NIH-like study section structure in which you
15 walk through set criteria and say, in general
16 the group thought that this met these
17 criteria, validity, reliability, because of
18 this, and maybe even, going out on a limb,
19 preliminary reviews, so we have in front of us
20 as we are voting a reminder that the
21 reliability was thought to be good because of
22 this correlation coefficient, based on this

1 number of samples.

2 I am not sure if that is -- That
3 may be too much structure, but I think a
4 little bit more structure might help.

5 MS. BOSSLEY: No, it is a good
6 point. The other thing I will mention to you
7 is we are looking at having outside
8 consultants provide an analysis of the
9 reliability and the validity testing, moving
10 forward.

11 So, actually, every measure would
12 have -- and we have done it in certain
13 projects. We had an outcomes project last
14 year, and we have a resource use project this
15 year that we have actually provided that type
16 of information, so that you have an outside
17 expert taking a look at that.

18 So it sounds like moving in that
19 direction might be a good thing on all
20 projects, which is, I think, where we are
21 headed.

22 DR. LUNNEY: Thank you, David.

1 Robert?

2 DR. FINE: My question, and I had
3 asked Karen early on when I was about to veto
4 all of these things in previous review, and
5 said why am I going to D.C. if I am going to
6 vote against all of them.

7 There is this whole section on
8 staff notes. It wasn't completed, and the
9 answer, I think, Caren gave is, well, we are
10 not sure we had time, but I am curious what
11 the purpose of that is.

12 I could see it being very useful,
13 that if there was someone with expertise in
14 looking at these -- I kind of consider myself
15 a reasonable content expert after 25 years of
16 working at the interface between life and
17 death, pretty good on that, but I am not a
18 statistician.

19 I don't know those other things,
20 and because I have not been a researcher -- I
21 have been a clinician and really tried to
22 implement what researchers do out in the

1 private sector where everything has a really
2 strong financial model. It doesn't happen in
3 my sector.

4 I wish those staff notes had been
5 filled in. I think that might have helped me,
6 given my deficits in some of the areas of
7 statistics and all, if that is someplace where
8 they would have put that in.

9 DR. LUNNEY: Naomi, on the left.

10 MS. NAIERMAN: Very quickly, the
11 slides that you had did give a very brief
12 outline of each of the measures, and I found
13 June's pithy words about each one of those
14 technical language descriptions even more
15 helpful.

16 So I think, if you put even a
17 sentence after you have put the criteria in
18 one or two words, that may be a start toward
19 a brief cheat sheet.

20 DR. LUNNEY: Naomi, on the right.

21 MS. KARP: I think most of my
22 points have been made, but I am going to just

1 chime in with the -- I know a lot of substance
2 about this, but I am not a statistician. I
3 don't know that language.

4 I think you perhaps erred on the
5 side of you gave us so many tables and charts
6 and so much material that, when I started to
7 do the process, I was just overwhelmed. You
8 know, I had so many documents open on my
9 computer that I didn't know how to toggle back
10 and forth between them.

11 So I guess I will echo what
12 everyone else said: The cheat sheet, that
13 plain spoken sentence or two about what does
14 this really mean. It would have helped me a
15 lot get over the psychological hurdle of, oh,
16 my god, I don't know what kappa means. So how
17 can I do this?

18 DR. LUNNEY: Thank you. Eduardo.

19 DR. BRUERA: I personally had much
20 -- I had limited problems with the
21 reliability, validation and all that, and I
22 think our voting suggested that that generally

1 was okay.

2 The problem is when you have
3 outcomes that are not measured by psychometric
4 analysis, like getting chemo before you die,
5 going to the ICU, disconnecting your
6 defibrillator. I mean, you don't need
7 reliability, validity to turn off or to put a
8 magnet on a machine. It is just something that
9 you do or you don't do.

10 So the results are looked in
11 different ways. The outcomes are measured in
12 different ways than reliability, validity of
13 psychometrics. I find that the analysis of
14 the literature for that is way more complex,
15 because you have multiple sources.

16 I would have loved to see that we
17 got a little bit more kind of bouncing back
18 and forth with the instrument developers about
19 what is missing there, and I don't know if the
20 peer review process before presentation to
21 make sure that the methodology followed this
22 more solid would help the process of this

1 meeting coming together, because in some cases
2 what was missing was a lot of information that
3 I had to go and do some PubMed searches and
4 look around myself, and the research was done
5 by other groups, and sometimes with totally
6 different questions.

7 so it gave me satisfaction that I
8 understood the problem, but you know, these
9 are volunteer groups submitting volunteer
10 information to other volunteer groups, and
11 perhaps getting some peer review where it has
12 been submitted would help us an awful lot in
13 the fact that when outcomes are used rather
14 than the pure methodology of the instrument
15 development, you have to go a little bit
16 deeper, and that takes hours of work.

17 DR. LUNNEY: Kate. Sorry.

18 MS. KALEN: I guess part of what I
19 reflected on over the course of the two days
20 was the bouncing a little bit back and forth
21 when we were reviewing the measures between
22 how strict did we have to be to adhere to

1 exactly what was presented to us in the
2 materials versus the expert opinion that we
3 have in the room, where we might not be
4 specifically citing other studies that would
5 support a deficit where there was a known
6 deficit in the materials presented that
7 someone here might have been able to fill in
8 the pieces.

9 That kind of shifted back and
10 forth across the two days, and I think created
11 some uncertainty as to, for the reviewers, how
12 much latitude did we have, if there was no
13 information presented for disparities or
14 something and the developer doesn't address it
15 in the conversation, and yet we know e can
16 connect the dots to know that particular
17 measure could be used to -- you could use it
18 and figure out the disparity question later.

19 I guess there wasn't enough
20 clarification for me on that.

21 DR. LUNNEY: Thank you, Kate.

22 Sorry, I didn't really skip you. I just saw

1 hers first.

2 MS. O'MALLEY: A couple of
3 concrete suggestions. I think this is a
4 process that would be enhanced by some kind of
5 a checklist, particularly for people who have
6 never done it before. It would have really
7 helped me organize my thinking. Like Naomi,
8 I was like where do I start on something like
9 this.

10 Something else, if you have the
11 resources, that might be helpful for people
12 who are not health services researchers is to
13 have a fast paced tutorial that you could just
14 go through on the web, that would be like this
15 is what this is, this is what we are looking
16 for, and within that to embed some examples of
17 best practices: This is the best answer we
18 have seen to this question, also paired with
19 this is the worst answer we have seen to this
20 question. So you know if you are voting
21 somewhere in the middle, you know what your
22 conscience is telling you to do actually has

1 some face validity to it.

2 Then I think also it would have
3 been really helpful -- I am thinking about all
4 the ASCO back and forth that we had yesterday,
5 and I as part of the I team looking at this,
6 realizing that I thought a lot of it was
7 insufficient.

8 It might have been helpful to have
9 it stopped at the gates; you know, to have a
10 staffperson say this is a maintenance measure
11 that is coming back; we have a new set of
12 criteria, and send it back to the developer
13 and say we don't think this is going to get
14 very far in the process unless you consider X,
15 Y and Z might be a kind thing to do, rather
16 than bring it forward and then have it go back
17 anyway.

18 You on the inside, knowing much
19 better than we do what your processes are, now
20 in hindsight, I am saying, gosh, why did we
21 even spend so much time. It probably would
22 have been kinder to send it back to the

1 developer and say we need a little bit more
2 substance here before we feel it is going to
3 meet the new criteria.

4 So a couple of suggestions.

5 DR. LUNNEY: Solomon.

6 DR. LIAO: I also have a couple of
7 back and forth suggestions. So along that
8 same line, if I can ask that when we do the
9 first measure that we do it with a developer
10 that is actually in the room or at least
11 available -- an easy one, an old one that you
12 are virtually guaranteed consensus and all
13 that.

14 MS. BOSSLEY: We typically do do
15 that. For whatever reason, it didn't happen
16 this time. So I apologize.

17 DR. LIAO: Then secondly, in
18 terms of our orientation, I would have found
19 it very helpful that, instead of having a
20 staff member walk us through -- or maybe in
21 addition to the staff member walking us
22 through the review process, to actually have

1 a prior committee member who has actually
2 reviewed these show us their thinking process,
3 going through it.

4 DR. LUNNEY: And I am particularly
5 guilty of having changed considerably my
6 review in this room from my review ahead of
7 time, because I was under the understanding
8 that, if it wasn't on the paper in front of
9 me, that I didn't have to presume that it
10 existed somewhere and go looking for it.

11 I think that is a real tough
12 issue. There were some real differences here
13 in how much trouble people went to to complete
14 their application, and I, with my NIH
15 background, get annoyed with people who don't
16 want to take the time to provide that
17 information for me, but expect me to already
18 know what they know.

19 So I wish that could be evened out
20 a little.

21 Do you have another?

22 DR. WHITE: Just a quick follow-up

1 on that point exactly. It is the same point,
2 for sure. Can I just round up that one.

3 I came to this late. So I wasn't
4 part of the early calls, and maybe you guys
5 did this, but it would be one thing to
6 consider about how to get us all on the same
7 page about how to do the evaluations is to
8 devote 15 minutes and say, you guys are going
9 to in the next month be asked to do all these
10 evaluations; here is -- we will take you
11 through one.

12 DR. LUNNEY: Over here. Go ahead.

13 DR. SCHROEPFER: I have a
14 question, and maybe I missed it. When we
15 entered on Survey Monkey, was there a way to
16 save part-way through? No. I had an
17 emergency with a student, and I had to go, and
18 I had put half of my stuff in, and then my
19 computer restarted with an update, and I lost
20 everything, and I had to start all over again.

21 So I think having that Save button
22 would be like the most wonderful thing.

1 The other thing, I think,
2 yesterday I felt like when we came in that it
3 was kind of the agenda was set out for us to
4 start right away with the measures, but some
5 of what I think happened, too, was just the
6 need to kind of debrief for a moment, just to
7 kind of talk about some of the ground rules
8 and how we were going to proceed.

9 So I think that some of that,
10 sticking with that first measure was actually
11 us seeking, whether we were conscious of it or
12 not, really trying to figure out what did that
13 mean. What was it going to look like.

14 DR. LUNNEY: Any other tents?

15 DR. CASARETT: If there is a way
16 to do that in advance at future meetings, that
17 would be great, because time when we are
18 actually here is really valuable, and that is
19 something that could be -- at least be done on
20 a call.

21 DR. LUNNEY: I don't see any
22 sideways tents. Then I think it is time for

1 you guys to tell us --

2 MS. BOSSLEY: Thank you for these
3 comments on the process, because we appreciate
4 -- You are the first ones actually going
5 through the new criteria, which was why you
6 kind of see Helen and Caren and myself going,
7 is this working the right way or not; because,
8 unfortunately, you were the guinea pigs.

9 If you, over the next few days,
10 reflect back and have any other suggestions,
11 please tell us. We have another committee on
12 renal disease that will meet in August. So we
13 have got to huddle now and figure out how do
14 we keep improving the process, trying to
15 reflect what our business is, to make sure
16 that we do it with our committees as well.

17 So thank you for everything. For
18 next steps, I think, Caren, do you want me to
19 go over something, or do you? Okay, I will
20 Caren go over.

21 DR. GINSBERG: The list -- to-do
22 list from yesterday was to get back to Craig

1 Earle about the one, two, three, four, five,
2 six, seven measures we need input on.

3 We have to talk about harmonizing
4 pain measures and finding a common
5 denominator, a numerator for different
6 denominators.

7 We tabled the spirituality
8 measure, and we need more information from the
9 developers on that.

10 We have to talk about the
11 treatment preferences; measures. There are
12 three that have to be harmonized, two from
13 this meeting and one, an existing measure 326
14 on care preferences.

15 Then everything else you just said
16 to us in the past few minutes go on the to-do
17 list, too. We have to work through that as
18 well. Thank you for those comments.

19 Is there anything else that we
20 need to get back to you on immediately about
21 the measures?

22 We need to reschedule. Sean has

1 another commitment. So we will have to
2 reschedule. We were hoping to do it in
3 August.

4 MS. TIGHE: We are looking to
5 schedule it about three weeks from now. So I
6 will be in touch to figure out a date that
7 works.

8 MS. BOSSLEY: And keep in mind, I
9 have the feeling, because we have seven
10 measures that we tabled, we will probably have
11 to have either multiple email exchanges or
12 potentially a second call.

13 So we will just have to play that
14 be ear and see how we move forward, but I
15 think, given the amount of work that you may
16 have in front of you still, you may have two
17 calls coming.

18 DR. GINSBERG: If you could get
19 any questions you have for Craig Earle to me
20 or Lindsey or Heidi within the next couple of
21 days, certainly by Tuesday -- we are trying
22 to set up a call now. So if you have

1 questions you need answered, just get them to
2 us.

3 MS. TIGHE: Actually, if you could
4 do it before the weekend, one of the potential
5 times to speak with him is on Monday
6 afterwards.

7 DR. GINSBERG: All right,
8 tomorrow. I was trying to be nice.

9 (Whereupon, the foregoing matter
10 went off the record at 2:52 p.m.)

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absence 238:4	accountable 167:8 206:12 229:20
absolutely 56:3 153:22	ACEVEDO 1:13 75:7 138:18 146:19 147:3
abstentions 88:12 106:19 135:11 165:3 202:19 217:3 232:21	achieve 117:16
abstracted 38:19	acknowledge 63:22 64:5
abstracters 101:20 102:18,20 145:2	ACO 207:2
abstracting 102:13	ACOVE 97:20 266:1
abstraction 95:16 136:19 137:9 144:19	ACOVE-1 81:4
academic 166:8,9 166:13	act 41:12 170:17 237:1
academics 269:19	action 152:12,14,16
Academy 2:14 263:15	actionable 199:18
accept 99:14 160:1	active 136:16
acceptability 27:13 41:6,6,21 98:10 98:11 105:18 164:5	actively 149:11
acceptable 84:5 95:1	activities 254:11
accepted 93:18,21 99:17	actual 12:8 125:18 130:11 170:6 181:5 186:18 191:2 269:15
access 43:21 226:13 248:5	acumen 136:12
accessible 207:22 222:7 254:15	acute 20:5 97:6,8 153:11,12 218:21 236:14
accompanied 194:7	acutely 236:19
	adapt 208:4
	adapted 167:20
	adapting 172:5
	add 8:12 22:17 28:22 147:17 221:4 224:16 229:3 263:10
	added 221:17
	addictive 131:22
	adding 43:20
	addition 169:20 210:2 255:16 283:21
	additional 38:17
	41:10 46:12 66:2 104:14 157:7 162:14 218:15 225:19
	address 7:3 38:14 80:21 144:17 146:6 179:11 186:4 220:12,22 246:17 255:13,22 257:18 265:13 280:14
	addressed 53:6 159:2 179:18 182:4,14 221:6 250:12 256:4
	addresses 55:19 111:14 200:12 221:6
	addressing 38:4 185:18 223:16
	add-on 220:2 229:6
	adhere 50:11 279:22
	Adjournment 3:22
	adjust 186:22
	adjusting 188:4,17
	adjustment 180:7 180:11,17 187:9 187:17
	adjuvants 131:15
	administered 176:14 204:19 218:2 223:18 225:15
	administration 167:21 172:18 204:11 206:2
	administrations 176:20
	admission 68:5 80:13 111:12,19 112:21 127:5
	admissions 240:22
	admit 154:19 272:12
	admitted 9:20 67:16 68:3,17
	77:9 80:12 129:22 136:14 241:21
	admittedly 144:7 243:15
	admitting 77:15,17
	adopted 175:18
	adult 155:8
	adults 246:18 257:7
	advance 11:20 21:7 72:22 79:19 82:4 93:13 99:9 102:5 107:10 220:6 222:15 243:14,15 243:21 286:16
	advanced 79:20 155:20 159:12
	advantages 121:17
	adverse 91:9
	advocating 147:13
	affect 39:19 40:4
	afferents 132:14
	afraid 43:13
	African 181:7,13 182:20
	afternoon 5:2,16
	afterward 86:16 125:19
	age 182:17 186:6
	agencies 64:11
	agenda 4:19 206:4 286:3
	ages 107:21
	aggregate 188:7
	aggressiveness 68:8
	ago 66:14 158:2 261:21
	agree 8:5,8 26:3 53:13,18 82:1,21 157:1 206:8 223:10 243:20
	agreed 162:18
	agreement 14:19 116:9 219:21,22
	agrees 54:13 209:20 271:10
	Ah 208:15
	ahead 79:6 111:7 125:13,14 134:5 192:3 236:10 260:13 284:6 285:12
	AHRQ 227:17
	aide 21:14
	aim 12:22 13:14 36:7 49:11 251:10
	albeit 81:1 98:22
	alerted 130:3
	alerts 129:21
	aligns 113:17
	alive 241:19 257:3
	alleviated 56:2,3
	Alliance 234:13 264:18
	allocation 21:13
	allow 46:10 173:9
	allowed 225:13
	allowing 114:15
	allows 114:5 148:8 148:8 232:22
	alpha 174:3 175:1
	altogether 223:3
	amazing 183:6
	ambiguous 60:14 60:15,17
	ambitious 203:21
	amenable 244:10
	amend 22:16
	American 1:24 2:14 8:3 181:8,14 190:12 192:19 263:14
	AmericanHospic... 194:13
	Americans 182:20
	Amish 247:9 249:7
	amiss 180:19
	amount 12:8 13:15 88:21 109:2 141:19 164:3 241:3 248:7 289:15
	ample 74:2

analysis 112:6,7 168:13 179:9 274:8 278:4,13	appeared 12:3 203:17	247:4 257:21 262:10 276:6	127:4 251:6	Australia 208:1,3
Anderson 1:15	appears 16:7,15 47:6 144:14	arena 233:20	assesses 217:21	authorized 82:5
and/or 239:9	applaud 17:22	arguably 189:8	assessing 55:17 121:4 219:16	availability 246:19 246:21
anecdotally 129:3	apples 148:22	argue 228:20	assessment 16:20 16:21 17:2,16 18:17 19:15 22:1 24:10,11,12 35:21 36:10,19,20 43:2 46:16 47:5 49:1 58:16,19 59:5 63:3,8 96:15 101:1 111:11 112:22 113:2,3,8 113:12 114:3,4 120:15 121:21 125:1 126:19 127:10,16 132:3 191:5 218:14 251:2	available 4:13 48:11 101:2 115:17 167:6 197:10 207:2,10 210:5 215:3 217:8 254:20 258:20 263:6 268:15 283:11
anecdote 142:19	applicable 50:21 171:10	argument 78:11 152:5	assessments 56:20 258:20 259:1	aware 8:20 50:18 69:17 170:18 241:5
announce 184:5	application 7:5 13:7 108:22 181:2 284:14	arisen 37:16	assist 72:3 81:7 136:9	awareness 122:19 218:11
annoyed 284:15	applications 81:1	art 211:1 258:16	associated 69:12,14	awful 143:15,16 241:18 279:12
answer 4:13 37:15 48:20 57:6,8,10 61:4 63:10 65:12 78:16 97:14 104:10 113:5 120:17 124:18 126:6,11,22 129:22 146:8 149:3 180:13 185:22 189:1 192:5 206:5 221:2 224:7 243:7 258:12 275:9 281:17,19	applied 43:4 79:12 219:8 221:10	articles 176:3 181:6	assume 25:15 57:15,19	A-F-T-E-R-N-O-... 166:1
answered 95:19 180:9 189:21 222:18 290:1	applies 41:4 51:20 189:6	artificial 76:21 252:20	Assuming 41:20	a.m 1:9 4:2 109:20 109:21
answers 6:3,9 67:2	appoint 227:19 266:11	Ascension 1:18	assumption 63:1 227:20,22	<hr/> B <hr/>
Anthony 10:1 37:1 67:12 165:9 217:9 270:19	appointed 194:22	ASCO 6:7,16 7:2 7:10,12,16,17,22 8:14,17 9:5 238:5 282:4	astounding 85:14	baby 250:22 261:17 262:21 268:5
answering 124:19 197:3	appreciate 49:5 89:1 97:2 109:10 177:3 273:11 287:3	asking 18:16 33:6 36:11 39:11 48:2 56:14 59:12,17 61:20 62:9,18 65:13 114:14 125:22 220:19 242:19,19 243:5	attempt 72:8 80:21	back 6:5 8:1 14:12 18:14 27:14 34:19 43:22 44:20 46:13 47:14 48:4 52:9 57:10,14 58:1 61:7 64:7 66:19 66:21 67:2 86:15 86:19,22 103:2 107:7 108:2 109:18 110:15 118:5 128:12 130:21 149:7 163:22 165:20 178:12 179:8 195:21 207:5,17 212:10 213:15 235:6 238:3 240:5 240:8 242:13 243:9 249:9 255:4
answers 6:3,9 67:2	appreciated 92:11 92:12 177:20	asks 113:2 170:17 172:11	attempted 68:14 118:22	
anybody 7:12 9:12 10:2 67:10,12 143:5 144:8 155:19 190:7 208:12	approach 32:18,22 33:3	aspect 111:14 128:13 131:6	attempting 246:17	
anyway 91:14 123:22 185:19 282:17	appropriate 26:19 61:15 98:21 113:8 114:17 124:6 160:4 223:12 239:21 240:2,2	aspects 220:4 221:15 250:13	attempts 79:22	
apologize 5:8 167:2 283:16	approval 203:11,20 210:21	aspire 103:18	attend 169:12 258:8	
apparent 265:20	approved 5:19 198:6	assess 55:5 96:14 114:16 236:20 257:11 265:22	attended 204:15	
appear 15:6	approximately 14:10	assessed 30:18	attending 173:15	
	arc 237:6		attention 89:10 96:12,16,18 109:11 146:16	
	area 38:13 109:11 137:12,19 138:7 138:11 154:21 155:1 234:8 247:21 255:21		audience 165:7	
	areas 80:2 175:15		audits 74:7	
			August 287:12 289:3	

256:13 259:5	241:15	best 159:18 169:3	board 16:4 152:17	brief 5:2 49:16
273:12 277:9	basics 251:8	255:15 268:15,17	183:16	93:16,19 136:4
278:17 279:20	basis 112:5 258:2	270:10 281:17,17	Bob 22:9 23:22	233:8 276:11,19
280:9 282:4,11,12	Baylor 1:17 20:8	better 69:12,14	25:15 95:9,11	briefly 11:3 92:4
282:16,22 283:7	BCC 2:2	74:4 83:22 126:3	97:1	96:8
287:10,22 288:20	bear 263:19	133:11 138:19	Bob's 240:12	bright 83:6
background 13:9	beating 158:8	139:17 150:18,20	body 15:3 26:20	bring 43:6 44:19
13:21 59:7 92:15	becoming 142:17	176:12 181:1	27:9 30:15 50:3	107:7 212:9
110:12 284:15	142:18 143:2	185:8 188:2,2	86:21 87:5 105:4	213:15 238:10
backing 11:3	144:15	191:17 194:19	141:16 156:11	244:19,21 264:13
backlashes 51:4	bedside 262:21	223:1,4 239:3	201:4 256:3	282:16
backward 180:16	beef 181:3	252:14 282:19	boil 35:18	bringing 118:2
bad 124:11,12	beginning 4:14	beyond 102:9	Boomers 261:17	128:15
126:9 132:17	120:15 207:20	181:22 189:12	BOSSLEY 2:8 8:12	brings 106:20
143:15 144:7	begins 113:9	BFS 217:17 225:22	27:16 34:17 35:1	broad 36:18 74:22
175:13 182:22	begun 110:14	bias 120:5,5,10	35:9 41:19 44:17	76:9 147:10 148:2
243:1	behalf 177:4	130:17 131:1	52:3 65:18,20	149:1 245:3
bag 238:3	believe 23:13 33:17	154:20 179:13	90:5,20 107:1	broadened 266:11
ball 236:12 238:4	45:13 122:17	182:14	123:11 125:11	broader 267:17
bankrupt 242:9	165:4 190:17	big 188:10 237:10	133:8 134:1,4	broadly 63:13
Baptist 20:17 23:12	204:14 207:16	252:11,17 259:7	162:3 164:10	broken 212:14
bar 42:21 43:7 44:2	208:20 225:2,17	bigger 166:20	195:8,20 196:2,17	Brookings 264:17
79:22 80:3 85:2	232:22 260:19	biggest 261:8	197:14 198:9	brought 22:2 23:17
95:4 161:21	believing 238:9	billing 50:15	199:22 208:19	99:8 111:10
base 38:2 55:7	benchmark 118:4	bird 169:22	212:1 213:7 221:3	113:13 125:20
based 17:16 20:15	118:22 123:13	bit 4:8 10:18 13:6,8	223:5 227:14	262:10
27:21 28:6 29:2,6	153:22 156:3	21:10 23:20 29:14	233:7 239:1	Brown 2:19
31:13 33:6 40:15	160:1 182:10	35:10,14 37:12	253:21 271:9	BRUERA 1:14
41:1 58:2,3 65:6	246:14	44:3 78:17,22	272:11 274:5	6:13 49:16 131:5
65:22 66:5 69:8	benchmarked	80:22 84:17 91:8	283:14 287:2	158:20 207:8
77:14 80:20 92:9	123:5,10	101:12 110:11	289:8	241:13 277:19
92:10 110:20	benchmarking	120:21 126:3	bottom 160:15	build 187:15
115:1 119:9,10	123:17 132:3,9	132:2 141:20	203:10	built 267:17
136:11 138:10	158:21	144:11,14 187:15	bouncing 273:12	bunch 40:22
144:10 156:8,8	benchmarks 131:7	195:13 210:20	278:17 279:20	bundled 85:4
157:3 164:1	242:22 243:2	224:11,17 242:14	bounds 181:22	bundling 167:8
167:15 169:17	benefit 33:16 96:8	257:16 261:7	BPI 126:16	206:13
171:1,12 173:8	114:1	271:20 274:4	brain 235:22	burden 220:7
174:11 188:17	benefits 30:18	278:17 279:15,20	brand 129:12	222:16
194:9 199:14,20	31:21 33:12 96:9	283:1	bread 184:22	burdensome 74:9
200:1 205:21	162:15 218:11	black 185:5 186:13	break 4:21 91:16	171:2
219:13 268:14	222:1,2,2	187:21	106:21 109:14	burial 222:2
273:22	bereaved 168:6,10	blah 31:14	breakdown 218:15	buried 254:21
basic 101:17	169:2 171:15	blah-blah 31:13	breaking 262:22	Burstin 2:8 30:9
111:14 112:20	202:21 217:7	Blanchard 1:22	break-through	31:15 32:3,8,15
basically 14:12	bereavement 258:7	blessing 190:6	124:12	33:1,2 34:14 41:3
23:10 96:20	269:12	block 194:1	brevity 272:8	45:2 46:9 47:19

48:21 61:6 66:18 66:22 91:6 business 1:19 196:7 270:1 287:15 butter 184:22 button 285:21	cardiologist's 141:1 152:1 cards 40:7 240:1 care 1:3,3,17 2:2,5 2:16 3:4 9:20 12:12,14 13:15 14:6 15:16,19,20 16:2,5,14,22 17:13,15,19 20:5 20:6,7,8,17 38:6 43:5 50:17 63:14 67:17,17 68:3,4,6 68:9,13 71:2,20 71:21 74:21 75:17 75:22 77:12 79:20 80:2,6,8,17,19,20 81:5 83:16 89:16 89:18 91:17 92:10 93:2,4 94:11,12 94:13 95:5,6 97:6 97:6,8 98:3,13,14 98:16 100:13,15 101:5 103:4,5,10 103:20 107:11 108:16 110:2,22 111:14 138:10 139:4,5 145:17,20 146:11,13,16 155:14,15,21 163:9 166:4 167:8 167:19 168:7,17 169:2,7,8,13,16 169:16 170:15,20 170:20 171:21 172:9 174:2,11 175:4 177:1,8 181:1 185:4,5,6 185:19 186:18,21 187:11 192:17 195:4 204:20 205:4,14 206:12 206:17 208:18 211:11 214:7 217:19,22 218:1,6 218:15 220:5,6,7 220:9 221:18 222:15,15,21	223:22 225:10 233:16,20 234:7,7 234:20 235:6 236:16 238:14 239:7,9,11,21 240:11,14 241:8 242:21 243:14,16 243:21 244:3,4 245:9,13 246:7,7 246:20 248:5,20 249:2,5,22 251:18 251:21 252:3,11 252:19 255:22 256:15,17,22 257:3,4 258:14,15 258:19 259:1,3,22 260:16 261:8 262:8,12,14 263:6 264:11,18 265:4,7 265:8,14,18,19 266:12 267:4,12 267:18,18 268:21 288:14 cared 98:3 careful 153:21 154:7 170:7 caregiver 14:3 169:12 174:17,18 262:4 269:9,10 caregivers 173:15 261:16,20 269:16 Caren 2:9 275:9 287:6,18,20 cares 261:22 care/specialty 265:8 caring 245:10 Carol 2:15 67:13 110:6 115:18,21 116:9 117:9,13 127:20 177:5 187:11 211:15,15 213:14 225:12,14 226:3 Carolina 2:13 97:19 109:7 Carol's 209:21	carried 68:15 carry 95:16 238:4 carrying 96:22 carved 265:21 Casarett 1:15 10:17 18:3,5 28:12 45:11 66:11 89:19 103:13,14 104:1 124:8 126:4 143:11 151:15 177:12 181:18 183:11 189:1 199:11 224:16 225:11 226:3 228:7 229:14 273:9 286:15 case 31:3 129:8 146:1 151:10 159:6 168:6 180:6 180:17 208:9 219:9 cases 11:13 118:12 132:13 137:8 146:3 149:8 152:20 154:2 159:21,22 279:1 catch 216:8 232:6 categories 12:1 203:13 category 147:16 caught 138:12 235:19 245:4 caused 167:1 causing 131:22 celebration 264:3 center 1:15,23 72:13 195:3 217:7 217:10 264:12 271:14 centered 83:17 central 41:17 273:5 cereal 269:21 certain 23:8 63:11 89:16 120:10 121:19 260:3 274:12 certainly 13:14	14:18 29:2 38:10 38:20 45:13 49:4 84:1 100:14 122:11 143:14 154:22 157:1 239:15 244:21 289:21 certificates 205:22 certification 139:14 certified 16:4 24:7 258:19 263:5 Chair's 37:11 challenge 131:18 150:5 241:13 255:15 challenges 102:22 269:18 chance 177:3 242:10 change 122:8,22 124:20 128:8 162:14 242:20 245:8 changed 6:14 284:5 changes 59:10 128:10,21 151:18 172:7 175:17 199:5 206:16 channel 225:14 Chapel 2:13 91:19 chaplain 16:4 24:7 24:15,19 25:12 43:6 53:1 268:8 chaplaincy 16:5 55:21 56:3,18 chaplains 20:16,18 character 126:18 characteristics 203:7 219:20 characterize 38:15 39:12 charge 190:8 222:21 charged 254:17 chart 50:14 74:7,17 89:15 95:15
--	--	---	---	---

101:14 119:9,10 136:19 137:9 140:20 143:20 247:20 charts 74:8 137:2 144:7 277:5 cheat 271:21 276:19 277:12 check 118:13 checking 9:16 53:6 checklist 281:5 chemo 278:4 chemotherapy 253:4 chew 165:20 CHF 148:11 151:4 child 246:22 children 246:17,21 247:2 248:10 chime 277:1 Chochinov 31:4 choice 113:19 152:16 choose 112:2 230:17 248:2 chose 205:20 chosen 170:22 Christina 15:22 chronic 261:10 churn 241:4 circle 26:14 circulate 6:5 circumstances 262:2 citations 15:14 115:14 cited 157:17 219:9 219:12 citing 280:4 claims 182:16 clarification 6:14 59:9 61:19 100:20 103:12 196:13 199:12 200:11 207:9 209:1 229:9 280:20 clarified 198:13	clarify 43:13 46:19 54:5 58:8 74:15 91:1 155:2 193:18 213:22 clarifying 154:18 clarity 31:8 66:16 153:2 156:14 class 153:6 clear 22:22 35:2 39:17 55:17 66:13 68:20 71:19 72:16 72:19 80:2 98:19 99:18 148:5 153:16 196:6 200:2 211:13,14 213:6 226:8 257:7 clearer 48:12 61:9 clearly 22:14 30:21 43:3 44:10 210:9 clergy 22:5 click 106:5 clients 11:11 13:4 clinic 262:21 clinical 8:3 14:1 30:6 38:5 49:21 50:21 60:2 71:1 130:18 136:12 139:20 191:17 207:12 clinician 114:15 177:18 191:15 275:21 clinicians 50:6 118:16 close 54:1 181:12 closely 7:16 closer 49:4 closure 238:8 CMS 122:21 234:9 Coalition 2:3 Coast 67:12 code 68:7 71:3,21 72:2,2 75:14,21 84:1 85:3,6 93:17 94:22 98:18 99:13 99:16 101:15,16 coded 124:10	coefficient 273:22 cognitive 121:12 193:20 cognitively 120:20 194:10 coincide 132:13 COLCHAMIRO 2:9 26:6,17,21 27:5,10 34:1,4,8 35:3 86:2,7 87:2,7 87:11,15,18,21 88:3,6,11 104:22 105:5,9,14,19 106:1,7,10,14,18 133:3,13 134:8,13 134:18,22 135:5 135:10 160:20 161:3,7,12,18 163:1,6,11,17 164:20 165:2 200:13,18 201:2,6 201:11,16,21 202:5,9,14,18 214:15,21 215:4,9 215:15,21 216:4 216:10,16,20 217:2 230:21 231:4,8,12,17,21 232:3,7,11,15,20 collect 143:18 192:12 collected 15:11 19:20 collection 73:15 74:9 111:8,18 112:14 color 186:15 249:15 combination 48:18 come 15:9 16:3 20:20 58:1 59:6 66:8 82:3,4 86:15 86:19,22 107:2,5 118:10 130:10 139:22 151:4 153:7 154:19 165:19 193:22	214:10 234:12 240:5 248:7 256:22 259:20 266:3 comes 15:10 45:6 57:10 91:19 148:10,11 152:2 153:7 208:8 227:4 240:8 268:13 comfort 114:19 117:16 139:4 155:14 174:14 comfortable 13:10 25:22 31:18 32:18 32:22 33:10 66:17 85:18 104:13,19 110:4 111:3,4,10 113:14 114:6,14 117:4 118:19 121:16 125:18,20 126:8 262:19 coming 6:20 108:5 118:10 141:8 153:10,17 158:13 234:22 237:22 245:5,9 253:7 265:17 269:22 279:1 282:11 289:17 commend 264:15 comment 3:8,17 18:7 31:3 40:11 45:10 49:16 74:12 103:2 110:5,6 125:10 127:21 130:13,14 141:3 165:8,11,16 192:10 226:10 229:2,4 233:2 240:12 257:17 259:16 263:9 comments 7:3 16:3 18:8 19:5 21:18 25:19,21 28:19 42:14 75:8 95:11 96:19 140:12 165:6 178:4 179:9	183:14 193:17 195:6 220:3 270:18,20 287:3 288:18 commitment 102:13 228:17 289:1 committed 176:9 committee 1:4,8 3:4,6,9 24:1 40:2 43:12 44:20 45:18 46:13 54:15 55:12 57:17 78:21 110:2 118:7 167:2 210:21 212:10,12 284:1 287:11 committees 253:12 254:5 287:16 committee's 37:18 42:1 108:18 common 142:18 143:2 266:15 288:4 commonly 11:6 communication 99:19 102:3 129:20 218:5 246:11 257:13 260:20 communicative 78:6 communities 247:8 247:10,11 community 30:6 110:16 176:20 187:21 188:3 193:17 224:22 247:1 264:20 266:17 companies 119:14 company 217:13 comparable 92:19 comparably 38:21 compare 112:9 119:2 182:11 183:1 compared 52:22
--	--	--	--	---

182:15 comparing 53:7 148:22 172:16 competence 172:15 competencies 129:13 competing 107:9 222:22 complaint 132:14 complete 251:10 284:13 completed 168:18 218:12,13,17,21 275:8 completely 8:5,8 39:2 129:11 267:3 complex 154:13 278:14 complexity 190:1 complicated 185:17 187:18 188:22 component 29:2 41:17 54:14,17 194:8 197:9 components 197:22 198:22 209:2,6 210:4 265:4 composed 118:15 composite 168:2 173:6,13 176:5 180:1,21 181:17 182:7 183:22 184:1 190:15 195:18 196:5,9,14 196:19,22 197:12 197:16 198:18,20 199:1,10,14,17 209:7 210:15 211:10,16,17 212:2,4,11 213:9 comprehensive 3:10 5:18 18:2 56:20,21 94:21 113:8 126:15 217:18 264:21 comprehensively	83:5 computer 277:9 285:19 computers 238:2 concept 40:2 126:16 139:16 concepts 273:5 conceptual 169:6 169:17 170:2 conceptually 265:1 265:3 concern 15:3 21:21 22:3 23:17 24:22 25:14 45:3 63:7 73:2,12 81:15 148:1 189:15,16 220:15 223:14 237:22 268:20 concerned 25:11 95:15 117:2 192:6 concerning 68:4 80:7,16 81:13 137:21 concerns 10:21 14:2 17:7 20:10 22:14 23:5,10 36:14 38:12,14,17 44:12 54:20 74:6 95:21 101:11 102:10 180:7 181:19 203:15,17 226:5,6 267:16 conclusion 162:15 concrete 244:16 281:3 condition 173:20 conditions 13:13 49:19,22 62:8 99:3 conducted 51:22 conference 6:2 15:18 107:19 108:5 confess 66:12 confidence 6:10 confident 104:15 confirm 48:6	conflict 9:12 conflicted 125:9 conform 240:10 confused 177:2 205:9 208:16 confusion 60:9 164:3 167:1 conjunction 264:17 connect 280:16 connected 8:3 conscience 57:20 281:22 conscious 286:11 consecutively 97:9 consensus 15:17 31:21 170:12 210:21 236:13 243:1 283:12 consequence 24:17 consequences 23:16 24:2 33:15 129:18 consequently 115:10 consider 18:8 19:5 40:3 209:6 261:9 275:14 282:14 285:6 considerably 284:5 consideration 44:7 121:12 136:17 137:10,16 253:2 considered 157:1 259:18 considering 62:13 69:8 consistency 27:8 30:13 32:20 70:20 70:22 73:9 87:10 91:13 105:12 116:4,14 161:17 162:9,13 172:20 174:22 178:18 215:14 219:17 231:15 consistent 47:15 73:8 159:15	201:10 consistently 51:2 250:3 consisting 172:20 constipation 256:20 constitutes 114:19 construct 172:2 198:18 constructed 222:6 constructs 173:12 consult 146:12 consultant 263:14 consultants 274:8 consultation 55:22 56:19 98:13 consultations 146:13 consulted 98:15 consumed 252:10 consumer 191:5 192:16,21 consumers 21:4 29:15 111:17 191:8,12 193:21 194:2 consumer's 206:15 contact 186:8 contactable 218:20 contacted 113:12 224:14 content 275:15 continuance 246:7 continue 31:19 170:10 233:9 234:1 240:4 255:18 continuing 110:1 193:13 254:1 continuity 174:20 continuum 240:14 252:5 259:3 contracts 254:18 contrast 136:5 contribution 259:14 control 159:3	173:14 189:12 controlled 120:5 126:7 139:15 141:12 146:20 controlling 159:2 controversial 98:22 cont'd 3:6 convened 110:15 conversation 12:11 13:12,17 34:13 36:12 51:17 58:10 66:1,5 82:5 100:9 100:16,21 101:3 115:1 117:18 125:12 132:5 142:5 148:18 149:15 150:11,13 150:19 151:6 153:13,19 154:1 154:12 157:4 158:16 162:17 235:13 236:21 257:18 260:8,16 260:20 262:7,14 263:2,7,17 280:15 conversations 8:21 12:2 78:9 81:17 83:19 140:18,21 154:8 233:10 237:17 239:2 271:12,16 converse 188:19 convince 228:14 convinced 194:4,5 convincing 228:10 cooler 109:7 coordinated 251:17 coordinates 169:16 coordination 174:2 174:4 220:7 222:13,14 252:2 copy 169:20 copyrighted 207:9 core 12:15 13:14 54:13,17 170:11 cornerstone 175:19 correct 43:15 82:13
--	---	---	--	---

88:16 94:18	CP 20:18 24:7	190:3 208:1 234:6	224:15 225:8	258:3 259:18
103:21 108:14	Craig 8:17 9:3	234:10	229:8 274:22	260:13,21 275:17
115:19 118:1	287:22 289:19	cycle 251:10	day 3:2 4:4 26:5	deaths 214:5
149:22 150:2	create 50:19 168:1	C-O-N-T-E-N-T-S	93:4 103:6 109:7	240:22
211:11 212:6	189:8 270:13	3:1	109:16 197:10	debate 20:3
correction 173:7	created 233:18	C-section 159:16	233:1	Debbie 16:1
correctly 162:5	280:10		days 80:8,18 83:8	debrief 286:6
214:1 221:22	creating 270:5	D	83:20 93:5 96:2	deceiving 224:12
261:4	creation 168:2	Dale 2:14 263:13	100:8 124:11,11	decide 58:3 114:6
correlation 175:1	creative 270:13	268:1	136:15 139:1	114:18
273:22	credible 41:2	Dana-Farber 1:17	154:12 155:8,11	decided 187:8
corresponded	criteria 52:5 99:1	data 8:19 11:15	172:10 236:6	209:14
190:18	100:4,11 102:1	12:3,8,19 13:3,4	258:6 269:15	decision 57:3 99:22
cost 206:19	123:6,12 124:6	15:1,9,10,10	279:19 280:10	169:11 210:14
costly 220:10	172:2 199:1	19:20 29:5 38:17	287:9 289:21	236:15 246:18
costs 228:15 252:11	255:10 271:22	38:20 40:19 43:15	deactivate 152:22	decisions 74:1
count 29:9 74:16	273:15,17 276:17	43:17 45:21 46:3	deactivated 136:1	76:19,22 152:6
148:9 229:17	282:12 283:3	46:6 48:11,16	139:9,17 149:16	156:19 214:8
counted 25:14	287:5	49:12 54:21 55:3	149:21 151:13,14	decompensates
counter 256:7	criterion 52:16,19	55:22 56:4 57:6	152:3	80:4
countries 249:3,3	53:11 56:22 57:10	57:15,17 64:8	deactivating 149:9	deeper 279:16
country 11:16	57:19 58:15	65:8 73:13,15	deactivation	default 82:6
142:11 168:20	172:21	74:9,17 84:15	136:17 140:21	defibrillated 160:9
228:19 242:21	critical 2:5 14:7	104:11 109:3	151:21 152:10,19	defibrillator 141:4
couple 19:21 43:12	56:12 64:15 115:5	111:7,18,22 112:3	154:1	143:1 159:13
54:2,3,4,10 65:21	critically 8:9	112:5,6,13,19	dead 158:9 245:1	278:6
70:8 80:18 96:21	236:18 246:12	116:21 117:3	deader 158:9	defibrillators 253:3
110:10 122:17	247:2	118:13 122:6	deal 115:16 129:18	deficit 252:10
129:8 179:12,14	critiques 18:11	127:22 128:19	217:6 230:18	280:5,6
180:5 183:11	cross-walked 170:1	137:1,13 140:6,21	238:13 240:17	deficits 276:6
281:2 283:4,6	Crouse 1:14	141:21 142:1	260:4 261:1	define 25:11 71:20
289:20	crucial 75:10 131:5	143:18 144:11	dealing 60:19	138:19 249:10,11
course 13:4 27:14	220:4	145:11 149:6	256:18	266:15 268:5
63:15 65:19 107:5	cultural 176:15	155:20 157:12,14	death 19:11 22:4	defined 25:1 71:14
148:6 178:1	culturally 187:6	182:10 190:13	135:22 136:18	83:5 131:6 138:22
224:12 237:12	culture 247:6	192:13,21 193:5	138:21,22 139:2,9	155:10 160:2
250:6 257:9	249:15,16,16	240:20	139:11,18 142:7	170:19 243:3,4
260:21 264:3,5	cure 153:11	database 48:18	144:22 145:13	defines 249:14
279:19	cured 148:13	dataset 128:5	147:9,21 148:2,9	defining 160:3
cover 176:12	curious 28:12 85:1	date 157:4 289:6	148:20 149:22	233:18
covered 221:18	145:17 146:2	Dave 103:14	150:14 155:9,10	definitely 119:1
covers 82:19	275:10	David 1:15 10:17	155:12 160:9	150:16 249:5
co-chair 1:12,13	current 122:2	19:17 28:11 45:9	169:15 204:10	definition 36:19
256:9	currently 95:6	66:10 98:6 103:12	205:4,21 218:4,18	60:13 74:21 92:18
co-Chairs 1:10	112:18 122:10	104:9 124:7 143:9	222:1 228:18	101:18 147:8
co-investigator	139:16 168:18	151:14 177:10	243:6 249:10,12	148:2,8,20 150:22
141:11	175:21 176:10	181:16 183:10	249:15 256:1	166:9

definitional 271:17	205:12 263:17	61:7 62:18 107:13	dies 148:13 224:21	dinged 151:22
definitions 61:10	derives 69:6	110:5 202:22	difference 47:21	152:4
degree 82:11 85:5	described 36:9	217:8,8,10 228:4	52:15 53:11 56:13	direct 29:20 99:10
241:10	38:2 70:1 152:8	228:8 253:20	58:19 95:2 146:10	directed 16:5
deliberately 221:16	describing 155:5	280:14 282:12	184:6 210:16	140:16 225:22
delighted 241:17	description 93:6,15	283:1,9	differences 128:6	direction 30:20,22
delivered 83:16	93:16 152:13,15	developers 4:12	167:13 173:6	84:10 274:19
103:10 170:16	descriptions 43:22	203:3 205:6 255:5	179:7 180:8,21	directive 73:1 82:4
234:20 235:10	61:8 276:14	278:18 288:9	181:7,11 186:21	93:13 99:9 102:5
delivery 265:14	design 190:13	developing 129:12	186:22 187:1	directly 71:16 72:6
Delphi 268:13	191:20 193:21	225:3 234:11	188:11 284:12	145:6 192:5
dementia 121:5	designated 93:12	development 37:22	different 6:18,18	director 130:1
demographic	designed 13:1	38:1 92:7 110:12	11:17 13:7,8	168:21 230:1
226:14	78:12 127:4 194:9	122:19 167:12	20:14 57:9 59:14	disadvantage
demonstrate 15:7	designer 219:6	171:22 206:1	63:13,20 64:22	188:16
15:12 171:20	designers 220:8	240:13 264:20	68:21 81:7,11,11	disagree 141:13
demonstrated 26:7	desired 113:19	279:15	82:8 92:20 95:3,3	195:11
69:11 70:6,21	169:9 173:13	device 142:18	95:5,17,17 102:20	discharge 240:20
133:2	174:14	158:15	102:21 130:10	269:2
demonstrates 80:1	despite 21:16	devices 142:15	132:6 136:7	discharges 240:21
demonstrating	detail 176:9	145:12 157:21	146:14 147:11,14	discipline 74:11
137:19	detailed 203:6	devote 204:22	171:5 172:9 180:8	disclosure 9:13
demonstration	details 101:19	285:8	186:17 187:17	194:22 216:14
14:17,20 206:11	224:18	Deyta 2:18 10:16	195:13 197:13	disconnecting
denominator 68:16	detect 131:4 194:19	11:1,3 17:22	204:20 205:1	278:5
70:1 92:19,20	detecting 39:8	diagnosed 261:10	225:20 226:6	discounts 80:9
95:2 96:1 97:5	detection 137:5	diagnoses 187:18	247:9 249:18	discriminate
103:3 138:20	determinant 257:9	diagnosis 256:16	267:19 273:7	167:18 171:20
139:8,10 147:6	determination 75:9	260:8	278:11,12 279:6	172:3 175:3
149:1 150:6,9	determine 11:22	diagrams 98:1	288:5	179:20 183:13
151:3 155:5,7	72:14 107:19	dialysis 68:10	differential 94:10	184:11 219:10
156:8 189:12	230:9	260:5	differently 23:20	discuss 5:3 14:4
214:1 218:16	determined 85:7	dictate 50:13	249:15	17:8 20:11 43:5
239:19 245:3	determines 91:3	136:12	difficult 4:8 102:8	91:13 135:21
266:10 288:5	determining 132:8	die 127:9 135:22	102:15 140:19	182:1 195:12
denominators	develop 245:16	139:6 141:4 144:3	171:4 197:7	221:8
265:21 266:4,15	254:18	146:5,10,15 151:6	224:20 225:1	discussant 69:21
288:6	developed 36:6	155:16,17 157:22	238:12 260:4	discussed 67:21
Department 2:5	37:8,13 67:20	159:11 205:3	difficulties 98:15	77:17 93:22 99:15
195:1	69:7 92:4 108:1	217:20 224:20	difficulty 81:12	102:3 115:16
dependent 103:6	110:19 111:5,6	225:16,20 238:17	101:20 154:8	142:2 149:9,10
244:15	118:7 135:14	240:19 278:4	dignity 131:21	210:7 213:11
depending 58:1	168:20 169:7	died 100:7 136:14	dimension 12:12	261:12
94:10 126:13	171:10 176:15	175:4 214:3	15:19 62:3 258:22	discussing 77:11
128:1	193:21 239:6	223:19 225:1	dimensions 63:19	213:12
depression 152:18	developer 36:5,8	241:22 245:5	258:9	discussion 3:13
depth 62:1 81:16	42:15,16 46:11	256:4 267:9	ding 148:15 185:13	5:21 9:2 14:2

17:6 18:3 22:15 22:17,21 24:14 28:10 36:12,22 38:14,22 39:1,2 44:11 54:1 58:21 58:22 59:1,1 60:16 61:20,21 62:21 64:2,10,14 64:16 65:10,15 66:12 67:5 68:13 68:14 70:10 72:21 73:1 75:6 76:4,6 77:8,10,14 81:22 82:9 85:19 90:9 92:13,14 93:8,10 93:15,19 94:14,19 95:10 96:6 99:10 101:16 108:3,12 110:2 114:21 118:5 125:5 147:1 149:20 151:20,21 151:22 152:3,10 152:13,15 156:4 156:10,12,19 159:1 160:12 165:13 233:3,5 253:14 263:11 discussions 28:18 37:18 53:15 65:9 152:21 251:3 273:12 disease 131:22 139:5 155:16,19 158:12 159:12 171:6 260:2 287:12 diseases 143:4 disincentive 185:16 188:21 189:9 disorders 269:6 disparities 34:7 87:20 106:4 112:12,15 116:18 134:17 163:9 164:8,9,16 178:22 185:18 202:3 216:8 232:6	280:13 disparity 64:8,18 65:8 280:18 display 200:6 displays 192:17 distinction 101:14 distinguish 178:22 distress 16:13 17:12 39:9,10 55:19 56:2,15,21 58:4,7,9,16 distressed 58:7 distribute 198:21 234:15 distribution 173:2 DNR 100:16 doable 76:2,2 doc 248:18 docs 248:13,17 doctor 166:13 doctors 248:14 document 28:8 30:21 64:10 78:14 99:19 110:21 111:1 202:13 230:13 237:16 254:22 documentation 10:20 13:11 14:1 14:3 17:6,7 22:4 22:13 36:14,15,22 44:10 68:4,6,12 73:7 74:3,5,8 77:1 78:14 79:14 80:7 80:10,16 81:13 83:17 93:7,10 95:1 98:21 99:15 102:21 103:7 120:9 139:1,9 151:13 152:11 155:11 156:9 243:14 documentations 152:21 documented 9:21 51:17 52:8 61:13 67:18 70:9 75:14	83:1 94:6,14 98:16,20 99:12 148:18 documenting 64:13 72:20 74:10 99:6 documents 44:11 277:8 doing 18:20 25:5 26:4 42:9 49:21 53:3,4 63:1 84:11 89:22 113:1,3 114:13 119:3 121:8 126:13,15 129:14 130:8 132:17 141:14,18 168:12 172:15 175:21 176:19 177:11,14 183:4 186:17 187:13 190:9 207:1 237:4 242:11 248:13 253:10 262:15 272:13 domain 38:3,4 domains 15:16 180:21 182:9 190:16 211:6,18 212:5,15,18 213:16 233:19 234:1,7,12 267:5 dots 280:16 double 187:13 doubling 157:20 doubt 138:10 Doug 31:7 37:20 40:7 42:11 46:18 52:2,13 56:11,16 57:1 58:18 61:22 83:12 86:15 89:2 95:7 97:3 98:6 101:10 123:1 149:14 150:7 153:2 154:19 155:3 214:11 236:8 DOUGLAS 2:1,5 Doug's 150:4	243:18 Dr 3:3,20 4:3 6:2,9 6:13,14 7:6,11 8:1 9:10 10:4,7,14 13:18 15:22 18:1 18:3,3,3,5 19:8 21:2,17 22:8 23:1 23:2,22 24:4,20 24:21 25:15 26:10 26:18 27:2,8,12 28:11,12,19 29:22 30:9 31:1,2,7,8,15 32:1,3,6,8,10,15 32:21 33:1,2,4 34:3,7,11,14,15 34:21 35:16,18,22 37:1,3,4,6,7,21 39:14,21,22 40:10 41:3,14 42:10 43:9,10,11,14,18 44:13,14 45:2,7 45:11,15 46:9,17 46:19 47:2,13,14 47:19 48:1,5,21 49:7,15,16 51:6,8 52:1,13,14 53:13 53:19,22 58:8,12 58:15,17 59:8 60:6 61:1,5,6,16 62:4,15 65:16,19 66:9,11,18,20,22 67:3,19 69:19,22 75:5,7 77:21 78:1 78:15 79:2,5,7,18 81:19 83:11,13 84:21 85:8,10,16 85:17 86:5,10,12 86:14 87:5,10,14 87:17,20 88:2,5,8 88:13,16,17 89:1 89:2,4,6,8,19 90:2 90:17,22 91:5,6 91:15,16,22 92:1 92:3 95:12 97:1 97:13 98:8 99:5 100:1,2,3 101:8,9 101:17 103:11,13	103:21 104:1,9,18 105:3,8,12,17,22 106:4,9,13,16,20 108:6,15,17 109:9 109:13,16,22 115:18,21 119:4,6 122:1,2 123:1,2 124:7,8 125:7,14 126:4 127:1,19,20 128:12,18 130:13 131:3,5 132:19 133:6,10,15,18 134:3,6,11,16,20 135:3,8,12,19,20 136:3 138:16,18 141:7,10 143:9,11 144:10 145:9,11 146:6,17,19,22 147:3,4,18,22 149:2,3,17,18 150:2,4,8,20 151:1,11,15 152:7 153:1,3,20 154:18 156:13 157:10 158:7,20 160:4,6 160:7,13 161:1,4 161:9,15,21 162:20 163:4,8,14 163:20,21 164:4,6 164:8,9,18 165:1 165:4,14 166:3,6 166:15,17 177:9 177:12 180:12 181:18 182:2 183:11 184:12,14 185:20 188:18 189:1,19 190:2 192:8 193:16 194:18,21 195:5 199:11 200:10,16 200:20 201:4,9,14 201:19 202:2,7,12 202:16,20 205:6,8 207:6,8,13 208:10 208:11,14,15,17 208:21 209:8 210:18 211:14
---	---	---	--	--

213:4,6,21 214:5 214:9,18,22 215:6 215:12,18 216:2,7 216:13,18,22 217:4,15,17 220:21 221:14,19 222:17 223:13 224:15,16 225:7 225:11 226:1,3,4 226:9,20 228:7 229:8,14,22 230:6 231:2,5,10,14,19 232:1,5,9,13,18 232:22 235:18 236:11 237:20 239:5,22 241:12 241:13 243:10 244:18 245:22 246:2,4 247:4 250:20 252:16,17 253:7 255:20,21 256:6 257:6 259:4 259:7 261:6 263:8 263:13 268:1,3 270:17 271:1,2,6 271:8,15 272:22 273:9 274:22 275:2 276:9,20 277:18,19 279:17 280:21 283:5,6,17 284:4,22 285:12 285:13 286:14,15 286:21 287:21 289:18 290:7	dying 24:18 110:4 111:3,4 143:4,7 148:5 149:12 150:16 173:21 174:15 205:15 206:18 224:10 245:11 250:19 261:2,10 269:9 dyspnea 256:19 D.C 1:9 109:8 275:5	efforts 140:15 190:3 192:3,14 252:2 EHR 145:5 eight 5:18,18 15:16 27:5,6 34:5,8 35:7 87:8 88:3,6 105:20 106:7,14 134:9,18 163:12 163:18 164:20 177:6 178:6 183:5 200:18 214:21 215:9,22 231:8 232:7,15 Eighteen 134:22 Eighties 249:8 Eighty 50:13 either 28:5 66:1 67:13 77:10 99:8 104:2,4 107:8 114:11 145:22 163:15 170:6 192:13 207:18 208:8 211:6 212:15 228:8 246:16 266:11 289:11 elder 68:2 247:20 248:2,4 elders 68:17 240:17 240:19 247:19 248:9 electronic 6:7 73:13 145:8 electronically 73:15 83:8 119:16 element 14:7 49:2 elements 16:9 167:22 218:4,16 Eleven 87:2 163:17 200:18 202:5 215:21 elicit 72:9 eliciting 53:2 eligibility 142:14 eligible 142:13 elucidate 126:21	email 129:21 289:11 emails 208:2 embed 281:16 emergency 252:8 285:17 emerging 138:6,11 emotional 169:10 169:14 173:14 174:14,16 218:5 emotional/spiritu... 173:22 emphasis 115:3 187:10 emphasizes 82:11 191:14 empirical 29:5 30:15 182:3 191:6 employed 195:1 empty 238:21 EMR 140:19 encountered 190:21 encourage 82:17 240:13 245:17 ended 38:15 155:9 endorse 135:9 140:11 191:13 198:14,14 202:17 217:1 232:19 endorsed 82:14 88:18,19 95:12 107:10 123:15 178:5 179:6 195:18 198:4 213:17 227:18 236:7 261:5 endorsement 14:15 88:9 97:18 106:17 116:19 117:1 220:17,20 227:3,6 227:11 230:10,18 233:12 endorsing 196:7 198:16 ends 68:22 enemy 18:10	engagement 227:9 English 262:9 263:3 enhanced 142:20 142:21 281:4 enjoy 109:6 enormous 241:3 enroll 189:9 enrolled 24:18 enrollment 93:5 ensure 225:18 ensures 113:19 ensuring 17:10 enter 261:17 entered 113:6 285:15 entering 137:15 enters 148:4 enthusiasm 178:7 178:20 entire 79:3 129:11 entirety 15:21 entitled 16:1 218:11 envisioned 96:9 episode 269:9 equally 164:7 equation 256:21 equivalent 180:6 ER 251:15 Eric 2:9 9:7 34:18 erred 277:4 errors 73:17 especially 164:12 193:22 236:18 267:14 essentially 23:11 44:21 76:17 262:4 estimate 222:9 estimated 142:12 etcetera 20:12 41:17 107:14,21 173:3 195:14 244:5 ethical 84:9 ethically 84:8 evaluate 31:20
	E			
drafted 207:1 dramatically 142:16 drastically 122:22 draw 96:15 drawing 96:18 drifted 256:11 drill 199:8 200:2 drive 252:14 dropped 171:12 Drs 3:3 due 122:8 220:1 duration 155:8	e 280:15 ear 289:14 Earle 6:2,9,14 7:11 8:1 288:1 289:19 earlier 65:12 93:14 96:6 167:6 209:2 229:2 237:21 258:14 early 25:18 27:4 67:11 80:12 83:19 206:2 226:11 237:1 255:9 275:3 285:4 easier 75:3 228:20 easily 120:1 easy 109:1 203:19 235:19 254:15 283:11 echo 19:16 83:13 237:20 242:17 258:13 277:11 Eduardo 1:14 8:8 49:15 131:3 207:7 237:21 241:12 251:9 277:18 educated 269:10 educating 258:1 education 130:9 261:16 262:13 educational 194:8 222:9 247:1 effective 38:13 262:14 effort 132:12			

114:12 197:16 272:1 evaluated 127:5 236:6 evaluation 14:21 41:18 138:17 166:4 167:7 177:11 evaluations 116:5 218:22 285:7,10 evaluators 15:5 16:8 evened 284:19 event 205:15 269:15 events 159:3,9 eventually 20:5 180:4 193:6 even-handed 154:9 everybody 4:4,5 9:10 20:9 21:17 26:13,16 54:13 55:13 106:5 153:22 185:4 207:11 249:14 261:19 evidence 15:4,6,14 19:18 26:9,11,20 27:1,7,9,11,17,20 28:14,22 29:1,9 30:10,15 31:10,12 32:20 34:2,6,10 35:5,8 38:2 39:8 39:11 41:4 55:7 70:15 71:4 74:16 84:19 86:4,5,22 87:4,6,9,13,16,19 88:1,4,7 91:9 93:7 93:18,21 94:5,14 99:7 102:2,4 105:2,4,7,11,16 105:21 106:3,8,12 106:15 107:14 115:4,6,14 116:11 116:12,15 133:5 133:16 134:10,15 134:19 135:2,7	139:13 141:16 147:19 156:11,21 160:22 161:8,14 161:20 162:22 163:3,4,7,13,19 164:22 167:18 168:9 178:15,18 184:11 200:15 201:3,5,8,13,18 202:1,6,11,15 214:17 215:1,5,7 215:8,11,17,19 216:1,2,6,12,17 216:21 219:5,14 230:12 231:1,9,13 231:18,19,22 232:1,4,8,12,17 268:15,19 272:4,4 272:5 evident 264:19,22 266:7 evolve 254:1 evolving 11:10 211:1 272:21 exactly 7:6 39:21 48:1 60:11 62:19 63:20 64:2 86:16 241:5 242:14 251:21 280:1 285:1 example 55:2 93:18 114:7,19 129:9 153:8 197:6 234:9 248:16 251:20 252:22 253:2 examples 247:16 272:3 281:16 excellent 69:5 94:4 129:2 174:5,7 175:2 exception 30:14 116:12 220:15 exceptions 96:21 exchanges 289:11 excluded 218:19 267:15 excludes 103:3	exclusion 96:1 exclusions 93:3 existed 284:10 existing 288:13 exists 19:1 28:16 expand 175:16 176:11 244:3 expanded 20:5 172:13 expect 61:13 69:13 112:14 118:8 164:13 173:21 230:14 284:17 expectation 118:20 123:20 124:1 expected 135:22 138:21,22 139:6 139:11 144:22 147:9,20 148:2,9 148:20 149:22 155:9,10,16,16 expects 118:17 expense 228:20 expensive 228:19 experience 21:9 192:1 193:1 197:8 205:10 213:19,20 experiences 171:1 179:17 experimental 49:18 expert 28:7 29:3,7 29:9 30:4,17 31:13,21 38:8 47:7,11 69:8 71:3 71:6 72:1 80:14 94:2 118:14 136:7 136:9 137:22 169:18 170:14 172:1 234:10 268:14 274:17 275:15 280:2 expertise 246:20 275:13 experts 147:7 191:13 explain 90:14 204:6	explains 96:8 explore 8:7 246:14 express 63:6 108:18 expressed 95:21 extension 92:8 extensive 192:1 extensively 62:7 extent 12:13 63:11 82:16 104:11 121:2 122:9 224:7 252:1,13 256:2 extra 26:4 extractable 120:1 extracted 119:13 119:17 extracting 101:14 extraction 140:20 extraordinarily 109:4 extremely 157:18 eyes 194:20 249:18	185:10 204:17 220:1 237:3 244:22 279:13 factor 200:9 229:15 factorial 172:2 factors 186:5 228:5 failed 80:1 237:10 failing 159:3 failure 72:8 fair 164:2 174:5,8 175:2 230:16 259:6 fairly 173:2 179:21 181:12 183:7 faith 20:11 fall 261:21 falls 16:15 62:11 familiar 221:14 224:17 families 30:8 74:12 185:6,7 205:2 217:21 220:10 224:4 247:2 258:1 family 17:8 21:7 36:15 63:6 75:20 101:1 166:4 168:6 168:10 169:2,15 170:14,17,21 171:1,15 173:19 179:17 202:22 213:19 217:7 218:11,17 220:7 222:2,15 224:13 246:13 256:3 258:2,10 260:22 261:22 Fantastic 13:18 18:1 67:14 69:19 94:16 far 33:13 42:17 80:4 83:2 138:3 138:21 140:12 251:9 264:6,8 282:14 Farrell 16:1 farther 261:7 266:13
F				
FAAHPM 1:14				
FAAP 1:17				
face 47:5,11 49:1 51:9,11,22 52:4 52:11,15,18 53:11 56:13 57:21 72:4 90:18 98:10 191:14,17 239:14 248:2 282:1				
faced 19:13 255:11 255:11				
faces 247:22				
facilities 217:20 223:17 224:2,8,21				
facility 224:11 225:21 226:5 244:14				
facing 192:16,21				
FACP 1:13				
fact 7:19 20:9 64:9 65:6 78:4 80:9 114:2 118:4,9 122:5 131:6 160:1				

fast 281:13	72:18 239:3	268:21	five 4:20 5:1 87:12	following 63:2 68:7
fatal 19:6	242:18 289:9	files 182:16	106:8,11 144:12	120:12 218:4
fatalities 218:21	feelings 66:9 73:6	fill 206:21 253:16	157:21 158:1	258:7
FATE 219:13	feels 32:4	280:7	161:12 163:1,6	follows 130:14
FATE-S 219:13	feet 122:14	filled 76:12 276:5	164:21 168:19	follow-back 214:2
faulting 266:2	FEHC 167:6,20	filling 24:2	178:7 179:1,4,10	218:2 245:1,17
favor 10:17 226:10	170:17 172:5,11	final 200:10	180:12,16 203:10	follow-throughs
favorably 84:20	173:1,8 174:13	finally 135:8	214:16 257:3	258:21
96:20	175:18 176:3	202:16 216:22	261:11 288:1	follow-up 18:8,21
favorites 238:7	177:1,21 181:4	finance 206:17	five-point 38:11	101:9 111:19
FCCM 1:13	182:6,18 184:18	financial 276:2	fixed 189:11	284:22
FCCP 1:13	184:21 185:12,13	find 39:10 49:19	flat 203:14	food 241:18
feasibility 73:5,5	187:22 189:15	62:20 101:20	flaws 19:4,6	Force 30:10 110:15
78:19 88:5 101:11	192:13,21 195:17	102:8,14,22	flight 5:10 241:17	111:7
101:13 102:9,10	198:3,3 204:18	134:17 143:20	flip-flops 269:21	foregoing 109:19
102:22 106:13	206:1 207:5 209:4	146:3 226:17	Florida 190:5,11	290:9
116:20 140:8	209:22 210:2	228:2 241:14	193:2	forget 96:14 259:8
143:13 144:19	211:11 221:18	262:16 278:13	flowing 273:11	269:14
145:7 192:20	225:3,4,9,15	finding 241:7 288:4	fluctuates 126:17	form 47:20 48:12
199:14 203:18,22	260:20 261:3,5	findings 16:14	fluid 124:11	76:11,14,17 82:19
206:8	felt 12:1,7,16 44:2	181:5	fly 86:19 151:17	83:4 107:13
feasible 73:11	70:3,8,12,21 71:5	fine 1:17 18:4 19:8	241:15	195:18 244:13
135:3 154:4	71:7,12 72:4 73:3	24:4 28:8 32:9	focus 40:3 99:5	formal 145:20
164:19 179:4	74:2,19 75:1 80:3	58:17 95:12	111:9 155:22	formally 104:3
202:12 216:18	80:15 104:13	133:18 145:11	167:15 168:13,16	format 234:18
220:1 229:3	116:6 140:5,13,18	208:11,15 239:5	168:16,19 169:18	forms 75:2
230:15 232:13	249:11 286:2	241:20 275:2	170:22 175:10,14	forth 126:18
federal 208:8 227:5	fewer 252:7	finish 238:10	218:4 235:17	273:12 277:10
227:12 245:2	fiasco 50:9	first 9:19 19:7,10	239:10 243:13	278:18 279:20
federally 245:18	FICA 20:14	19:18 26:1,2	250:4,5 256:10,10	280:10 282:4
feedback 89:9	field 62:7 193:7,15	37:12 40:8 42:14	focused 67:22	283:7
156:15 221:13	207:17 249:22	43:12 64:19 65:5	183:22 205:3	fortunate 207:14
234:4	250:2,22 263:22	66:15 67:7,7 78:5	254:22 265:18	forum 1:1 42:11
feeding 68:11,11	fielding 205:11	79:11 80:18 100:8	focuses 136:13	110:15,19 111:6
76:21 252:22	Fifteen 87:11	100:16 101:5	247:6 259:17	Forum's 16:11
255:4	201:16,21 230:21	103:8 126:22	folks 11:4,19 49:11	forward 6:4 7:18
feel 6:21 7:11 33:9	fifth 69:1	127:5 133:1	62:18 104:18	9:11 12:17 17:22
33:12,18 66:16	figure 9:8 11:20	138:18,21 141:9	117:15 121:5	25:17 33:7,10,18
67:3 111:16	23:3 90:7 126:5	150:9 160:18	139:11 143:19	33:20 38:16 39:7
113:17,22 117:4	143:21 159:6,8	166:22 186:3	153:21 265:10	41:21 48:8 54:6,9
125:22 126:2	188:1 197:7 213:1	195:9 213:11	267:13	54:11,21 57:5
157:5 169:3 197:4	213:13 255:14,18	247:5 250:22	follow 47:3 61:18	58:3 76:13 88:22
211:7 219:6 238:2	280:18 286:12	253:10 263:11,12	97:7 128:2 136:9	99:8 108:20 109:6
238:21 243:1	287:13 289:6	281:1 283:9	188:19 222:3	122:20 125:1
247:3 257:12	figured 25:20	286:10 287:4	followed 42:6	129:17 155:6
260:12 283:2	86:17	fit 25:8 39:2 253:5	59:22 72:13 251:5	176:22 191:3
feeling 19:17 67:6,8	figuring 224:22	256:2	278:21	192:7 193:13

196:18 206:10,12 209:18 211:4 223:12 235:15 266:3,6 270:7 274:10 282:16 289:14 forwarding 36:5 found 18:13 21:4 21:10 30:7 50:8 75:18 149:8 182:19 184:4,5 186:6 194:10 250:10 260:7 262:17 276:12 283:18 foundation 1:25 2:2 168:14 175:20 190:12 192:16,20 four 4:20,22 5:1 26:8,8 27:10 34:9 38:11 73:18 87:22 88:7 105:6 136:7 140:10 157:12 158:2 163:11 173:16 178:3 179:10 199:2 201:12,17 230:22 261:11 288:1 Fourteen 135:5 201:11 214:15 Fowler 168:21 fragmentation 240:10 frail 240:19 frame 13:5 42:3 45:22 54:7 79:12 92:14 94:17 172:9 233:19 244:1 267:8,10 framed 60:13 197:3 framework 3:13 29:1,3 115:12,13 198:20 233:3,6 254:2 framing 235:1 free 114:16 190:7	273:11 freely 207:10 208:6 frequency 159:8 frequently 267:3 friend 244:20 front 28:6 32:12 40:17,20 41:7,11 41:12 46:15 212:11 213:8,8 254:7 273:19 284:8 289:16 fruit 242:15 246:8 266:9 269:5 frustration 249:21 fudgeable 21:14 fulfill 99:1 272:8 full 75:21 93:17 98:18 99:13,16 100:22 101:15,15 177:16 190:5 fully 118:16 126:20 259:2 270:7 fun 196:18 263:18 functional 69:15 246:22 funded 142:3 funding 154:21 245:2 funds 229:5 248:7 248:8 further 5:20 6:17 43:8 44:9 61:7,22 63:8 137:18 211:6 212:14 future 5:6 121:9 176:19 225:9 269:17 286:16	gaps 3:15 5:3,5 230:13 234:11 235:10 253:15 254:12,18 255:1 256:16 264:9 266:6 gate 127:12 gates 282:9 gather 75:3 gathering 268:19 general 36:11 68:8 123:3,12 179:3 219:21 220:14 226:7 239:19,20 273:15 generally 145:15 146:1 277:22 generate 131:14 Gerontology 195:3 getting 53:4 56:17 63:16 125:3 127:8 146:4 151:16 153:7 154:20 183:7,15 187:22 209:3 225:5 242:22 265:7 278:4 279:11 Ginsberg 2:9 3:3 3:20 287:21 289:18 290:7 give 6:9 28:13 56:6 60:20 63:5 67:18 104:7 110:11 112:4,6,18 129:9 137:1 159:9 173:2 175:12 181:10 207:16 209:14,15 221:13 229:21 238:8 272:9 276:11 given 7:19 37:13,18 40:3 78:4 79:9 121:4 142:13 157:7 169:22 179:7,20 190:5 220:21 223:5 228:11 276:6	289:15 gives 6:9 giving 86:18 169:20 253:3 glad 109:11 213:5 250:14 253:2 glass 264:4,6 global 218:14 go 4:11 6:7 9:4 10:16 26:15 27:14 30:20 32:2,13 45:4 46:7 48:4,8 52:9 57:13 61:7 64:7 67:7 70:2 76:13 79:5 91:4 98:6 103:2 107:15 108:16 116:1 125:12,14 126:20 130:1,21 134:5 159:13 161:22 162:3,7,9 163:22 165:5 166:9 167:14 176:8,18 177:21 178:11 180:16 184:22 185:13 188:21 192:3 195:20 203:6 205:9 209:18 210:14 223:11 236:4 239:3 240:14 242:5,18 248:18 249:6 251:9 260:13 262:3,20 264:7,8 268:22 269:13 270:7 272:13 279:3,15 281:14 282:16 284:10 285:12,17 287:19,20 288:16 goal 13:14 99:19 117:16 125:16 127:7,11 153:7,12 168:22 170:10 205:22 goals 75:22 77:11 94:13 98:16 99:1	100:20 113:21 114:2 123:3 125:4 125:5 176:21 236:16 262:8 god 23:13 24:17 277:16 goes 113:7 128:12 176:22 191:3 205:16 228:9 244:1 257:9 going 4:10,19,21,22 5:9,14 9:18 10:10 10:16 12:4,17 14:11 23:11 26:13 30:22 31:2 33:5 34:11,12 40:19 43:13 45:12 47:14 49:20 53:3 54:1,8 57:5 67:15 70:2 73:16 76:18 77:5 77:13 78:5 82:22 83:2,4,6 86:10,18 89:15 90:9,11,16 108:2,16 116:1 118:18 122:21 126:16,19 130:2 130:17,21 131:1 132:17 141:15 143:3,6 145:7 148:6 149:7 154:15 157:11,12 159:7 166:6 167:14 176:8,13 176:17,18 184:22 185:1,2,4,6,9,22 186:9,12 187:12 188:3 203:14 205:9 206:12,22 207:4,10 210:5 213:15 217:5 225:13 229:5,13 230:2,8 233:2,14 235:3 238:17 239:2 240:3,4 241:14,17 242:9 242:20 243:10 247:13 248:19
G				
gap 14:20 26:7 38:20 39:8 68:21 70:6,9 85:22 86:1 94:5 104:21 133:2 160:19 200:12 214:12 219:2 230:20 266:14 267:20				

250:18 257:2	227:12,16	guaranteed 283:12	half-full 264:4	hasten 260:13
260:3,5,10,14	graduate 178:1	guess 30:1,16 37:9	hand 32:17 129:7	hastening 259:18
261:20 268:10,11	graduated 250:2	48:1 53:14 60:4	263:12 270:6	hasty 152:6
268:16,19,22	granola 269:20	61:17 62:17 81:20	handed 154:10	hat 130:16 177:18
271:2 273:18	grant 142:3 176:11	82:9 102:7 117:12	hands 32:22 33:12	189:5
275:5,5 276:22	granted 198:5	126:4 130:13	33:17	hate 40:21
278:5 282:13	graphical 172:22	143:12 147:6	hanging 91:21	HCAHPS 183:4
283:2 284:3 285:8	grave 139:3 155:13	151:16 158:9,20	242:15 266:8	191:4 267:8
286:8,13 287:4,6	great 8:2 13:20	166:17 180:17	Hanson 2:13 10:12	head 151:16 200:5
gold 52:22 56:18	19:18 33:16 67:5	189:21 212:16	37:2,3,6,21 39:21	headed 245:14
Goldstein 1:17	98:9 103:17 110:9	221:4 225:12	43:10,14 91:16,22	274:21
78:1 79:7 100:3	115:16 123:11	230:5 237:9	92:3 99:5 101:17	heads 108:4 234:21
141:18 184:14	137:19 238:13	243:13,18 244:6	103:21 104:9	health 1:17,18,19
188:18 217:17	271:22 286:17	259:5 268:17	108:15 109:9	16:1 20:8,17
221:19 226:9	greater 112:15	277:11 279:18	happen 62:12	89:12,13,17
245:22 246:4	189:16	280:19	132:15 154:15,16	116:10 161:2
257:6	greatly 30:19	guessing 222:8	158:22 159:1,4,13	169:8 170:19
gong 63:21 143:19	grief 86:18 269:6	guidance 61:12	159:16 198:19	191:5 195:3
185:5	269:11	156:16 157:9	276:2 283:15	206:17 207:15
good 4:3,17 18:10	ground 286:7	209:9	happened 9:13	222:20 240:11
19:2,7,9 27:15	grounded 102:4	guide 80:17	58:11 143:22	245:13 248:6
32:16 33:1,20	groundwork	guidelines 15:15	152:1 157:4 286:5	251:18 252:11
35:15 42:7 43:16	192:22	16:16 17:10	happening 65:9	256:22 268:21
52:17 55:18 57:6	group 1:19 5:8,22	139:21 167:16	happens 42:6 62:9	281:12
57:16 67:3,4,8	6:5 21:19 37:9,10	169:18 170:3,9	258:5	HealthCare 2:1
71:14 84:15,18	39:15 69:10 71:18	236:13	happy 29:20 66:14	192:15
85:19 104:12	80:14 81:18 83:21	guilty 284:5	147:1 247:22	hear 27:18 30:3
114:10 124:11,11	88:21 91:20 92:6	guinea 287:8	hard 46:1 54:16	48:13 53:20 58:4
126:9 129:8	92:22 94:20 95:11	guy 19:8 23:16 24:2	72:7,7 118:11	78:22 79:3 203:2
132:12 134:1	108:9,10 109:5	guys 5:3 6:4,10	180:17 241:14	heard 37:8 42:16
135:12,20 138:9	116:5 118:15	33:20 37:13 53:22	242:1,5,16,21	54:11 57:4 92:6
139:18 158:19	119:7 142:2 153:4	67:5 85:21 90:18	257:10	92:22 104:5,16
160:17 173:2	164:3 183:20	109:13 117:19	harder 226:14	147:18 150:4
174:5,7 175:2,13	192:19 221:11	264:2 265:2,10	272:16	165:18 175:15
182:3 183:1,7	223:15 226:15	266:6 285:4,8	harm 30:19	203:6 249:9 270:9
184:10 237:3	264:10 273:16	287:1	harmonization	hearing 39:15,19
238:20 245:16	groups 83:22 128:1		107:5 108:8	44:16 45:8,21
248:13 249:10,11	138:1 155:22	H	176:22	54:12 58:14 85:1
249:15 253:21	167:16 168:13,16	habit 134:2	harmonize 207:5	184:16,17 197:18
256:17 257:4	168:16,19 169:18	half 64:13,20 81:17	harmonized 69:18	271:1,11
259:10 269:22	175:11,15 185:2	85:8 178:16	288:12	hears 62:11 191:15
271:8 272:4	234:5 240:16	180:13 193:8	harmonizing	heartening 17:20
273:21 274:5,19	255:7,11 279:5,9	285:18	226:11 288:3	heavily 256:11
275:17	279:10	halfway 248:8	harms 31:22 33:13	Heidi 2:8 6:1 9:12
gosh 282:20	grow 170:10	half-empty 264:6	33:15 39:11	29:10 34:16 45:17
gotten 235:4	growling 165:18	half-empty/half-f...	162:16	52:1 65:16 86:17
government 227:5	growth 142:15	263:20	Harvey 31:4	97:14 106:21

108:6 162:1 233:5 289:20 Heidi's 28:20 Heim 217:11 held 43:22 78:9 84:2 229:19 Helen 2:8 29:8 46:5 60:7 61:1,16 62:6 62:15 86:17 97:2 97:15 287:6 HELENE 1:23 help 8:19 20:20 34:18 37:20 49:10 54:7,11 99:3 101:12 126:21 213:2 238:11 261:1 262:4,17 274:4 278:22 279:12 helped 92:14 276:5 277:14 281:7 helpful 7:21 27:19 28:10 30:3 34:22 35:9 37:10 48:16 48:19 66:3 76:11 78:21 109:4 117:8 125:12,15 157:6 212:17 221:12 265:11 266:19 271:7 276:15 281:11 282:3,8 283:19 helping 262:2 Hey 103:13 HHS 113:18 254:17 Hi 135:19 263:13 hide 131:4 hierarchical 259:13 high 14:19 26:8,21 27:5,10 34:1,4,8 35:4,6 38:9,10 70:4,16,20 71:11 86:2 87:2,7,11,15 87:18,21 88:3,6 89:9 94:1 96:4	104:22 105:5,9,14 105:19 106:1,7,10 106:14 116:8,11 116:13,15,16,18 133:3 134:8,13,18 134:22 135:5 140:4 145:1 159:22 160:20 161:7,11,12,18 162:12 163:1,6,11 163:17 164:7,20 169:7 178:6,17 179:2,21 183:15 200:7,13 201:2,6 201:11,16,21 202:5,9,14 203:13 206:19 214:15 215:4,9,15,21 216:4,10,16,20 230:21 231:8,12 231:17,21 232:3,7 232:11,15 245:13 252:14 higher 33:8 42:21 44:3 84:2 145:3 185:2 241:10 highlight 117:9 167:12 173:5 highly 38:9 112:17 219:2 highs 70:7 Hill 1:18 2:13 86:8 91:20 Hilton 1:9 hindsight 282:20 hinged 271:16 Hispanic 176:12,14 181:8,13 185:7 186:14 Hispanics 181:11 history 110:14 hit 79:22 256:19 hitting 185:21 209:22 Hmong 247:9 249:2 hold 53:16 55:1	holistic 249:20 home 5:10 169:21 175:4,5 225:21 240:21 241:2 242:18 244:4 252:6 261:2 267:18 homes 121:3 171:16 240:17,19 240:20 241:9 244:4 261:19 hope 21:22 109:7 127:6 209:3 239:5 254:19 hopefully 6:3,8 50:20 83:7 177:2 178:11 182:12 206:4 261:4 hoping 67:7 266:5 289:2 horizontal 246:3 horrible 260:14 horrific 143:8 horse 158:9 hospice 1:24 2:14 2:15 12:12 13:22 17:1 21:6,7,9 22:2 24:18 38:5 63:12 63:14 91:17 92:7 93:1,5 94:6 95:5 96:2 100:8,10 110:16 111:12,14 111:15 113:15 115:17 117:12 118:10 119:14 127:6,8 129:14 137:15 139:4 143:14 145:17 148:4 155:15 166:4 170:19 171:16 172:8,12 174:9 175:5,8 177:7,16 182:16 182:21 184:22 185:3,8,19 187:2 187:11 188:1 190:12 191:1	192:11,18,20 194:3 197:10 224:8,10 225:16 238:19 239:9,12 251:13 252:5 256:14 263:15 265:3,7,19 267:4 hospices 11:16 12:9 14:10 20:4 21:11 21:13 36:8 64:21 64:22 65:10 102:20 104:5 111:22 112:2,9,16 112:17 119:1,3,20 121:2,8 127:12 128:16 129:4 130:12 175:21 182:5 183:19 184:20 188:6,16 188:21 193:3,8,9 199:15,20 204:18 205:2,5 246:20 hospital 1:14 23:12 80:5 92:8,9 97:6 102:18 136:14,15 141:1 143:17,19 144:4 146:11,15 157:22 158:13 171:17 187:19 205:3 229:11 240:22,22 243:20 262:11 267:18 269:2 hospitalization 80:12 155:7 237:13 hospitalizations 251:15 252:8 hospitalized 93:1 94:8 135:21 150:13 hospitals 16:6 81:7 81:11 204:21 205:1 246:6 262:7 host 76:21 hour 66:14 109:15 hours 22:3 68:5,18	78:5 79:11 101:5 103:8 111:11 113:11,14 117:16 118:19 124:12,12 125:19,21 126:8,9 126:9 127:7,8 197:10 237:18 241:19 258:6 279:16 huddle 287:13 huge 83:15,15 141:19 249:1,4 252:9 258:4 262:5 269:15,16 hundreds 36:7 hurdle 277:15 hurry 214:11 hydration 252:20 hypothetically 158:14 <hr/> I <hr/> ICD 135:22 136:16 137:3,5,10,15,17 139:8,12,17 142:10 143:20 144:4 148:7 149:9 149:12,21 150:14 151:5,6,13 153:8 ICDs 141:19 142:4 142:6 156:1 ICU 9:20 68:5,17 70:12 78:5,8,13 79:11,14,17 83:16 85:3 97:8,19,21 98:4 237:19 246:13 278:5 ICUs 81:11 84:7 85:6 IDD 268:8 idea 54:16 124:22 144:3 Ideally 64:1 ideas 255:16 identified 56:2 111:1 137:8 214:13 218:3,20
--	--	--	--	---

239:21	importance 26:3	incentive 230:3	210:10,12 212:4	input 69:8 131:11
identify 5:4 7:10	26:12 27:2 38:3	inception 264:1	213:16 256:4	228:2 288:2
56:5 59:21 80:14	54:14 55:13 59:10	incidentally 143:5	individuals 69:16	inquiry 193:9
146:9 224:20	85:21 138:7	include 15:15 61:9	140:3 197:20	insert 119:22
225:18	200:21 214:13	147:11 174:15	199:9	inside 282:18
identifying 81:13	215:1,7,13 231:6	194:8 235:14	infer 120:17	instance 76:12
144:22 234:11	257:7	included 54:18	informally 104:3	104:6 267:8
ignore 23:4 74:14	important 6:19,22	95:22 137:14	information 29:14	instances 143:14
ill 92:9 93:1 94:7	8:9,10,10 12:2,3	180:10 196:10	29:16 41:9,11	Institute 1:18,20
236:18,19 246:12	12:13 16:8 18:22	220:5 222:16	44:19 45:19 46:12	institution 7:2
247:2 267:13	20:3 30:5 40:2,15	223:19	46:15 49:3,14	136:22
illness 139:2	43:19 44:7 45:9	includes 50:4 68:7	50:7 66:2,6,16	institutions 169:8
148:19 151:2	50:6 55:12 57:2	93:9	71:9 72:14 75:3	instructions 120:11
155:12 237:6	59:9 65:7,11	including 68:7,10	77:6 82:8 102:14	120:16
256:18 257:1	70:12 71:2 76:4	107:14 192:18	156:20 157:6	instrument 16:12
261:11 262:22	78:7 79:13 82:18	198:4 258:21	164:14 169:4,13	16:18 170:11
imagine 143:19	96:12 138:2	inclusion 100:4	173:16,18,19	172:10 176:10,11
imaging 101:7	140:14 168:10	inclusive 121:20	174:17,20,20	177:1 178:19
immediately 75:18	169:1 178:8	inconsistency	182:7 188:15	181:1 191:15
288:20	184:21 185:21	72:20	191:11 192:17	204:8 207:22
immigrants 249:3	187:4 209:18	incorporated	200:6 204:4	217:5 278:18
imminent 258:3	237:2 246:5	119:15	207:22 209:14	279:14
260:21	248:16 249:17	incorporates 184:3	210:5 212:2 213:2	instruments 55:6
impact 14:19 15:15	250:6,6 256:5	increasing 142:15	226:19 234:16	171:10 177:22
70:4 73:22 140:4	257:14 260:6,17	144:15	250:8 255:4	221:16
178:7 179:14	271:13 273:8	Increasingly	274:16 279:2,10	insufficient 26:9,22
205:16,17 269:11	impossible 46:5	226:13	280:13 284:17	27:6,11 34:2,5,9
269:16	improve 96:12	incredible 108:18	288:8	35:5,8 70:18 86:3
impacted 156:17	182:12 187:11	129:19 264:5	inherent 186:15	87:3,8,12,16,19
impacts 73:21	271:4	Indian 248:6	inherently 187:16	87:22 88:4,7
249:5	improved 22:7	indicate 137:11	242:4	105:1,6,11,15,20
impaired 120:21	80:2	138:13 245:12	initial 22:1 92:7	106:2,8,11,15
impairment 121:13	improvement	indicated 14:5	111:11 112:22	133:5 134:9,14,19
implement 11:9	11:12 70:5 72:17	99:15 138:9	113:1,12 126:19	135:1,6 140:7
104:6 112:4 124:3	74:4 116:7 122:4	indication 16:19	168:20 171:14	160:21 161:8,13
203:19 229:11	122:10 128:3,13	indications 17:11	190:15 256:16	161:19 163:2,7,12
270:7 275:22	131:16 132:8	indicator 160:10	258:20	163:18 164:7,21
implementation	137:12 163:16	223:22	initially 188:4	200:14 201:3,7,12
129:10 204:1	187:2 216:15	individual 71:20	206:21	201:17,22 202:6
implemented 68:19	217:19 232:10	80:5 128:5,8,10	initiative 262:12	202:10,15 214:16
112:16 136:21	235:16	128:20,21 130:12	inpatient 97:7	215:5,10,16,22
152:9 224:1 259:2	improvements 96:9	140:14 158:4	98:13 100:13	216:5,11,17,21
implementing 74:3	improving 15:18	176:5 182:8,9	148:10 151:9	230:22 231:9,13
77:12 82:15	51:5 287:14	183:18 190:16	153:6 217:20	231:18,22 232:4,8
implication 196:14	impute 120:17	196:19 197:9,22	218:18 224:10	232:12,16 282:7
implications 123:8	inappropriate	198:4,7,8,17,22	228:18 236:14,22	insufficients 70:8
127:17 129:16	58:16	199:16 209:2,6	237:6	insurers 81:5

integral 260:21	inter-rater 43:16	263:16	K	239:20 244:11
integrate 16:13	71:13 94:3 95:20	item 176:5 258:1	Kaiser 1:23	253:19 254:21
17:15	101:22 102:17	items 72:5 173:9,10	KALEN 1:19 127:3	255:9 256:11,13
integrity 40:15	104:11,14	174:12,13 182:9	279:18	257:3 260:2 264:9
intend 23:21	introduce 115:19	199:16,17 211:20	kappa 71:12 94:4	275:14 278:17
intended 122:3	introduction 67:19	218:13	101:21 103:16,19	280:9 281:4
214:1 217:18	investigating	i.e 60:1 141:1	104:12 171:13	282:15 286:3,6,7
220:19 221:1	129:14	171:15	277:16	287:6
intends 52:22	invite 125:10	J	kappas 104:4 145:2	kinder 282:22
intensive 67:16	165:10	Jack 168:21	Karen 6:1 9:7	kinds 30:16 63:13
68:3 80:8,18 95:6	involved 94:11,12	JAMA 171:20	195:21 275:3	273:7
intensivist 83:15	157:8 172:1 190:3	JCAHO 50:8	KARP 1:20 22:11	knew 42:8
intent 167:5 206:9	214:7 239:16	JD 1:20	60:8 81:20 91:1	knock 4:10
206:20	252:6 256:14	Joan 2:19 166:5	147:5 158:8 203:5	know 11:3,20 13:8
intention 118:8	ironic 244:19	177:10,14 184:2	243:13 253:9	19:1 20:8 21:6
intentional 267:6	ironically 256:6	187:15 195:1,4,22	276:21	22:15,18 23:8,18
interactive 194:16	Irregardless	196:2 207:9	Kate 29:12,22 40:9	24:8 25:18 27:20
interdisciplinary	205:14	208:11 213:14	42:12 43:9,19	28:8 29:17 35:12
258:16 259:12	Irvine 1:22	263:12 268:2	61:2 62:4 82:13	37:10 41:9 44:5
interest 9:13	Island 237:9	270:17	83:12 84:21	48:17,19 51:6
193:14 194:22	issue 22:12 24:14	Joan's 203:6	156:14 157:10	55:21 56:5,17
218:10 227:8	29:7 30:12 43:21	250:15	192:9 240:5	62:1 63:4,20 65:1
interested 31:6	47:15 48:4 49:17	job 115:22 135:12	279:17 280:21	74:13 76:15 78:18
184:16,17 226:16	52:15 59:16 60:2	248:13	Kate's 229:4	82:11 84:14 85:5
interesting 24:8	61:21 62:22 70:12	Johnson 168:14	KATHLEEN 2:1	85:12 86:14 88:18
96:7,17 226:19	78:14,17 79:8	joining 10:13	keep 151:5 197:17	90:5,7 94:18
246:13	80:19,22 89:5,11	joint 167:12	229:21 240:3	102:7 108:7,10
interface 275:16	97:15 108:7	jot 81:15	255:18 287:14	117:21 121:8
internal 172:20	122:16 125:17	journal 15:20	289:8	127:3 129:3
174:22	128:13 145:21	78:18 144:20	keeping 153:6	130:15 142:9
internship 268:22	153:12 156:7	joys 42:10	keeps 29:8	144:1,9 154:3,14
interpret 24:6	159:2 180:2	judged 60:5 162:13	kept 256:9	154:15 156:18
interpreted 189:18	182:14 184:18	judges 133:11	key 29:4 65:8	157:10 158:14
interpreter 262:20	185:18 186:4	judgment 31:13	247:19 250:9	162:1 175:7 185:3
263:6	190:22 225:2	44:16 47:7,11	264:12 271:22	185:20 188:5
interpreters 262:10	245:6 248:11	150:15 158:4	kids 5:11	190:6,12 193:8,12
262:13,18 263:4	249:1,4 256:8	Judy 237:4	kin 214:3,6 218:3	195:1,22 196:2
interval 204:10,12	262:5 284:12	JULY 1:6	218:20 220:9	205:8 210:1,15
204:13,16	issued 194:6	jumped 75:13	kind 13:14 21:8,12	213:7 221:15
intervention 17:14	issues 7:7 29:4	June 1:10,13 5:14	21:14 24:13 25:9	223:20,21 229:17
38:13 39:9,18	50:15 53:5 54:3	5:22 31:1 40:9	47:8 52:19 82:10	229:18,22 236:22
43:3 44:1,6	55:9,10 56:8,11	42:12 44:13 46:17	83:1 95:16,18	238:6 240:18
113:10	116:18,20 183:15	47:9 58:6,13	96:13 153:15	241:5,15 243:16
interventions 40:4	190:20,21 224:18	119:5 235:3	185:16 189:21	245:10 249:20
63:21 83:1	238:1,5 239:17	271:10	199:19 221:9	252:21 255:5
interview 171:2	242:18 246:18	June's 59:8 276:13	227:2 233:19	256:1 257:6
inter-rated 38:18	255:8,10 257:13		234:6 235:5	258:16 260:10

272:6,20 275:19 277:1,3,8,9,16 278:19 279:8 280:15,16 281:20 281:21 282:9 284:18,18 knowing 55:21 73:22 193:5 255:7 282:18 knowledge 50:4 173:18 known 15:5 42:5 78:10 280:5 knows 124:4 146:8 195:9 Krumbach 174:3 175:1	41:10 43:10,11 44:16,18 45:13,19 46:11 48:10 55:11 57:5,16 66:2 91:20 94:17,18 98:8 101:11 103:12,13 106:21 108:13 127:15 Laura's 43:22 47:16 lay 122:14 lead 13:19 18:6 69:21 74:4 238:19 leader 95:9 learn 262:18 learned 39:3 247:12 249:13 leave 25:8 73:17 leaves 205:17 238:9 leaving 5:9 led 130:8 152:15 167:4 220:15 left 221:17 259:6 276:9 legacy 25:8 legally 82:5 legislation 227:17 244:12 LEPORE 1:21 122:2 194:21 255:21 letter 264:14 letting 18:9 let's 36:1 85:19 120:22 162:3 184:19 223:13 257:2 263:8 266:14,15 level 65:3 72:5 94:8 94:9 111:10 112:8 113:14,19 116:16 120:10 121:20 125:20 126:8 159:18 169:9 178:1 188:8 222:9 222:10 236:4 265:5,9,18 266:12	270:16 levels 116:8 121:12 liability 230:14 LIAO 1:21 35:18 47:14 48:1 101:9 229:8,22 252:17 283:6,17 life 1:3 12:14 14:7 14:8 25:6 68:10 76:16 93:8 110:22 139:5 141:6 148:19 149:13 151:2 155:15,19 158:11,17 169:8 171:3,5 172:11 186:9 207:13 218:1,9 220:5 233:16 235:7 236:15 238:14 239:7,14 242:20 246:22 247:12 248:5 249:8,22 252:3 253:4 255:22 256:9,12 258:9 259:22 260:3,14 261:13 262:20 267:14 269:15,17 275:16 limb 273:18 limitations 147:12 limited 248:7 254:8 277:20 limiting 260:3 Lindsey 2:10 6:1 7:8 9:6 26:14 34:18 104:20 169:19 289:20 line 135:18 203:10 217:10 238:10 283:8 liners 169:22 lines 165:12 270:19 270:22 273:10 link 29:19 39:17 55:9 69:9 115:10 linkage 170:4 linking 115:5	136:10 138:4 links 55:17 list 12:17 287:21,22 288:17 listened 211:15 listening 8:15 39:1 44:1 literature 19:19 28:16 69:7 136:11 138:11 155:21 278:14 little 4:8 10:18 13:6 13:8 17:4 23:20 28:1,9,21 29:14 35:10 37:12 44:3 53:8 67:19 78:16 78:22 81:12 84:17 90:6 94:21 99:4 101:12 102:12 110:11 120:21 126:3 141:20 144:11,14 166:20 187:15 195:13 197:7 221:13 224:11 238:21 242:14 257:16 261:7 262:17 266:21 271:20 273:5 274:4 278:17 279:15,20 283:1 284:20 live 130:19 158:12 256:18 local 145:15 230:1 logic 37:22 91:7 long 76:3 83:10 110:14 162:13 190:8 200:2 204:8 204:12,16 234:13 264:18 272:6 longer 229:14 244:1 long-winded 109:17 look 19:19 40:22 41:1 42:5 52:17 59:3 60:22 63:12	63:18 84:19 102:1 104:8 107:18 112:12 118:11 126:1 128:19 144:6 162:10 174:6 183:4,18 195:21 197:2 199:8 200:3 206:2 206:3 222:19 228:1 235:6 236:4 239:6 240:8,20 241:8 242:14 243:22 244:17 249:18 250:8 254:11,14 256:13 263:2 264:2 266:22 274:17 279:4 286:13 looked 18:15 84:6 117:13 123:16 130:11 144:13 149:7 168:17 186:4 188:6 189:8 212:13 221:7 225:12 236:13 252:4,22 262:15 265:16 278:10 looking 12:15 39:4 44:9 46:20 60:10 63:15 66:6 107:17 111:13 114:11 122:18 126:18 130:6 140:2 143:21 162:21 188:11 195:14 199:10 211:2 215:18 234:2,10 236:9 255:12 257:20 267:20 272:3 274:7 275:14 281:15 282:5 284:10 289:4 looks 4:15 13:7 52:17 117:14 233:17 251:18 loose 100:11
L				
lack 20:19 71:9 122:15 131:21 lacking 55:8 laid 178:11 landed 241:18,19 lands 241:16 language 17:5 222:4 248:22 249:1,4 251:22 262:18 263:4 276:14 277:3 languages 208:6 laptops 235:21 large 81:4 145:1 151:9 184:1 224:3 largely 116:20 larger 69:2 72:6 104:4 140:16 182:21 late 174:10 206:2 241:19 285:3 latest 229:17 Latin 249:3 latitude 280:12 laugh 4:12 9:14 launching 227:7 Laura 2:13 10:11 10:12 37:2,4				

lost 285:19	214:16 215:5,10	215:18 216:2,7,13	270:2 282:10	MBA 2:8
lot 29:6 39:11 40:6	215:16,22 216:5	216:18,22 217:4	major 95:1	MD 1:12,13,13,14
44:4 65:9 75:7	216:11,17,21	217:15 220:21	majority 15:4	1:15,15,17,17,21
78:4 82:8,15 84:6	230:22 231:9,13	221:14 223:13	33:19 79:9 142:4	1:22 2:5,8
85:11 89:14 92:14	231:18,22 232:4,8	224:15 225:7	146:14 152:20	mean 51:14 57:9,11
100:9,17,19 143:3	232:12,16 242:15	226:1,4,20 230:6	156:2 162:8	57:11 60:11 77:16
144:6 147:11	266:8 269:5	231:2,5,10,14,19	making 16:1,21	84:16 114:8 118:3
148:3,21 151:19	lower 187:22	232:1,5,9,13,18	57:2 59:18 152:6	128:7,14 129:13
159:10 161:10	222:10 226:13	232:22 235:18	169:12 236:15	131:10 156:18
168:5 175:20	lows 31:17 71:12	239:22 241:12	246:19 250:22	173:3 174:10
192:22 193:14,20	low/moderate 33:8	243:10 244:18	258:18 260:16	181:12 184:7,8
226:18 227:22	Lu 217:11	246:2 250:20	manage 18:22	197:19 210:6
235:11 237:3	lucky 229:15	252:16 253:7	269:8	223:2,3 256:21
238:1,8 250:16	lunch 4:21 147:1	255:20 256:6	managed 81:4	257:13 266:7
251:13 259:17	165:6,19	259:4 263:8 268:1	management	277:14 278:6
261:12 262:3	Lunney 1:10,13 3:3	270:17 271:1,6	111:13 113:21	286:13
267:7,11 270:8	18:3 31:2 44:14	274:22 276:9,20	125:6 127:14,17	meaning 25:6
271:16 277:1,15	46:19 58:8,15	277:18 279:17	129:12,15 130:7	58:22 120:7
279:2,12 282:6	109:16,22 115:18	280:21 283:5	218:6	meaningful 6:11
lots 11:16 63:19	119:6 122:1 123:1	284:4 285:12	managers 175:12	15:8 74:22 76:3
84:15 98:9 130:9	124:7 125:7,14	286:14,21	mandated 122:21	76:10 111:16
138:7 271:17	127:1,19 131:3	Lupu 2:14 263:13	mandating 114:4	means 56:15
loud 153:5	132:19 133:6,10	263:13	manner 6:11 187:6	126:22 177:13
lousy 24:11	133:15 134:3,6,11	LUTZ 1:22 23:2	manual 73:16	277:16
love 20:4 48:12	134:16,20 135:3,8	222:17 237:20	manually 101:13	meant 24:6 204:19
258:10	135:12,20 138:16	261:6	marble 193:13	measurable 40:4
loved 197:11	141:7 143:9 145:9	lying 269:5	mark 257:4	measure 3:10,13,15
205:15 258:5	146:17 147:4,18		marketing 122:15	4:12 9:19 11:2
278:16	149:2 150:4	M	marks 96:4	12:6,9,20,22 13:1
low 15:4 26:8,22	151:11 153:1,20	MA 1:15,18,23 2:2	marriages 270:5,13	13:22 14:13,14
27:6,11 34:2,5,9	156:13 158:7	machine 278:8	MARTEL 1:23	15:7 16:12,15
35:5,7 37:19 45:3	160:6,13 161:1,4	magnet 278:8	61:3,17 62:17	17:4,17,20 18:11
52:12 70:18 72:4	161:9,15,21	magnitude 181:10	97:4	19:2 21:1 26:7,12
79:22 80:3 86:3	162:20 163:4,8,14	mailed 183:6	Martha 2:18 11:1	27:3,13 31:20
87:3,8,12,16,19	163:20 164:4,8,18	main 100:5 203:16	14:5 42:14 125:7	33:13,14 36:5,9
87:22 88:4,7	165:1,4,14 166:3	Maine 5:11	MAS 2:5	37:14 39:5,16
105:1,6,10,15,20	177:9 184:12	mainstream 248:14	massively 203:19	41:15 42:15,17,22
106:2,8,11,15	189:19 192:8	248:18	match 71:21	46:2,6 47:6,22
116:14 133:4	193:16 194:18	maintain 270:15	material 122:19	49:13,20 50:12
134:9,14,19 135:1	195:5 200:10,16	maintaining	129:9 277:6	51:3,14,16,17
135:6 140:6,10	200:20 201:4,9,14	270:11	materials 280:2,6	52:21,22 53:20
160:21 161:8,13	201:19 202:2,7,12	maintenance	matter 23:12	54:20 58:9,9
161:19 162:7,11	202:16,20 205:6	107:16 164:14	109:19 165:21	59:11 60:13,20
163:2,7,12,18	207:6 208:10,17	175:10 181:4	290:9	61:14 62:14,19
164:21 200:14	208:21 210:18	195:13,17 198:10	mature 100:15	63:12,14 64:7
201:3,7,12,17,22	213:6,21 214:9,18	206:6 209:12	maximum 184:7	65:5 66:13 67:15
202:6,10,15	214:22 215:6,12	210:16 233:12	196:10 209:14	67:19,20 68:19

69:13 71:14,15 72:7 74:3,7 75:12 76:8,12 78:3,11 78:20 79:8,12,21 82:16 84:2,18 85:4,22 89:7,13 90:3 91:16 92:2 92:11,13,15,21 94:20 96:10,11 97:11,20 98:9 99:6 103:1,6 104:17 107:9 108:2 110:13,13 111:3,4,9,21 112:4,18,21 113:7 113:17 114:1 115:1,15 116:1 117:14 118:7 119:18,19 120:15 121:18 122:3,21 123:7,9 127:4 129:5,10,17 130:17 131:17 133:12,17,19,22 134:7,12,17,21 135:4,9,13,14,16 136:4,8,13,19,20 136:20 138:3,5,6 140:11 147:20 149:14 150:1,12 150:21 152:9,20 154:5,5,13 156:9 157:6 161:1,6,11 162:21,22 163:5,9 163:15 164:12,19 166:3 178:10,15 181:4 182:22 189:7 190:1,4,6,7 190:22 191:2,7,16 193:14 195:10 198:3,10 200:1,12 200:16,21 201:20 202:3,13,17,21 203:9 206:14,20 207:3 208:17,18 210:17 214:18,19 214:19,20 215:2,8	215:13,20 216:3,8 216:14,19 217:1 217:18 219:4,6,13 219:19,21 220:5 220:11,17 223:9 227:3,11,13,21 228:5,10,21 230:10,11,13,15 231:2,6,20 232:2 237:9,17 241:11 243:16,22 244:10 247:13 253:1,20 255:5 257:11 258:10 259:10,15 261:3 264:19 267:2,15 274:11 280:17 282:10 283:9 286:10 288:8,13 measured 81:8 174:22 248:21 278:3,11 measurement 52:14 110:3,17 175:9 206:6 211:1 215:19 235:16 measures 4:14,21 5:1,1,19,20 6:8 7:4,18 8:10 9:2,4 11:6,10,17,18 12:1,5,13 18:15 18:18 30:17 43:1 43:8 45:3 47:16 50:4 51:3,15 53:17 58:10 65:5 69:11,17 71:18 75:12 79:21 81:7 82:20 84:6,13 90:1 91:10,12 92:5,18 97:19 107:4,19 108:8,20 110:20 111:2 115:4 123:4,14,21 132:9 133:11 136:5 138:1 154:2 154:11,13 156:22 161:16 167:3,11	177:4 189:6,10,17 191:5 198:5,7,15 198:17 213:18 220:22 221:20 227:18 228:12 229:10 233:17 234:11 235:5,8,15 236:5 238:20 240:9,14 241:6 245:3 246:11,16 251:1,4 252:2 253:13 254:3 255:3,12 260:20 261:12 264:2,21 265:12,17 266:9 266:16 267:1,17 270:1,14 276:12 279:21 286:4 288:2,4,11,21 289:10 measure's 219:9 220:14 measuring 47:7 60:4 131:2 179:15 242:21 261:4 265:19 mechanical 68:9 median 64:11 medical 2:19 19:11 38:19 50:14 72:13 76:16 99:21 102:11 130:1 147:7 152:11 214:8 240:16 244:4 250:4,5 258:22 medically 247:7 Medicare 62:7 142:14 182:15 medicine 1:16 2:6 2:14 15:21 144:21 252:18 263:15 medium 15:1 184:19 meet 17:9 61:14 85:22 188:2 199:1 199:2 283:3	287:12 meeting 5:14 7:9 7:11 16:16 85:2 100:17 171:13 236:1 279:1 288:13 meetings 246:13 286:16 member 21:7 169:3 218:17 224:13 283:20,21 284:1 members 43:12 168:7 171:16 184:13 member's 168:10 Member/Public 3:8,17 memorable 143:16 memories 205:18 mention 114:21 255:17 274:6 mentioned 19:4 139:13,21 203:18 228:16 255:17 mentions 15:17 mentoring 141:18 merit 37:17 met 1:8 76:7 85:2 164:11 273:16 methodology 67:21 136:10 278:21 279:14 methods 102:21 mic 110:8 Michael 1:21 122:1 194:20 255:20 middle 26:14 248:3 281:21 milk 84:17 million 14:8 142:13 261:17 mind 148:3 153:6 159:10 189:22 197:18 227:4 231:16 240:4,8 289:8 mine 98:11 101:9	minimizing 251:14 minimum 184:7 Minnesota 247:18 minor 100:12 173:7 minorities 188:10 minors 246:18 minus 117:15 minute 256:15 minutes 109:15,16 165:19 180:13 285:8 288:16 misconception 194:9 miserable 248:1 miserably 237:11 mishearing 150:7 missed 128:9 285:14 missing 12:16 16:9 173:10 236:7 247:3 256:21 278:19 279:2 misunderstanding 115:9 mix 180:6,17 226:14 mode 167:21 172:16 173:3,10 176:19 model 169:6,17 170:2 186:2 194:16 276:2 moderate 26:8,22 27:6,11 28:3,4 31:16 34:2,5,9 35:5,7 37:19 49:2 70:7,17,19,20 71:11 72:12 73:6 86:3 87:3,8,12,16 87:19,22 88:4,7 105:1,6,10,15,20 106:2,8,11,15 116:7,11,13,15 133:4 134:9,14,19 135:1,6 140:5,9 160:21 161:8,13
---	---	--	---	---

161:19 162:7,8,12 162:12 163:7,12 163:18 164:21 200:14 201:3,7,12 201:17,22 202:6 202:10,15 203:13 214:16 215:5,10 215:16,22 216:5 216:11,17,21 230:22 231:9,13 231:18,22 232:4,8 232:12,16 272:4 moderator 163:2 module 225:4,19 MOLST 75:2 76:11,14 82:10 83:3 Mom 241:21,21,22 moment 10:3,6,7 46:15 86:13,16,20 87:1 89:3,7 125:17 166:5 286:6 Monday 290:5 money 207:18 208:9 228:15 252:12 261:18 monitored 174:4 Monkey 285:15 month 204:16 218:1 285:9 months 205:20 morning 4:3,19 25:18 27:4 31:4 123:17 124:17 165:9,17 168:5 169:20 229:16 Morrison 1:10,12 3:3 4:3 7:6 9:10 10:4,7,14 13:18 18:1 21:2,17 22:8 23:1,22 24:20 25:15 26:10,18 27:2,8,12 28:11 28:19 29:22 31:1 31:7 32:21 33:4 34:3,7,11,15,21	35:16,22 37:1,4,7 39:14,22 42:10 43:9,11,18 44:13 45:7,15 46:17 47:13 48:5 49:7 49:15 51:6 52:1 52:13 53:22 58:12 60:6 61:1,5,16 62:4,15 65:16,19 66:9,20 67:3 69:19 75:5 77:21 78:15 79:5 81:19 83:11 84:21 85:10 85:17 86:5,10,14 87:5,10,14,17,20 88:2,5,8,13,17 89:2,6 90:2,22 91:5,15 92:1 97:1 97:13 100:2 101:8 103:11 104:18 105:3,8,12,17,22 106:4,9,13,16,20 108:6,17 109:13 115:21 119:4 127:20 128:12,18 130:13 141:10 146:22 149:3,18 154:18 157:10 166:15 mortality 244:22 245:16 mother 209:5 motivated 112:17 mouth 40:1 160:14 259:8 move 9:11,19 10:18 20:2 23:4 25:17 25:20,22 33:7,18 33:20,21 41:21 54:6,9 58:3 85:19 91:13 107:17 122:20 202:21 203:2 289:14 moved 111:7 moves 125:1 moving 7:18 21:20 54:11 85:18	104:19 109:6 129:17 255:19 274:9,18 MPA 1:24 MPH 2:8 MSN 2:8 mud 160:14 muddied 185:10 multiple 278:15 289:11 multitude 102:19 multivariate 186:2 multi-dimensional 131:19 multi-stakeholder 228:1 mutual 244:20 <hr/> N <hr/> n 188:10 NAIERMAN 1:24 21:3 29:13 42:13 49:9 119:8 120:3 120:19 193:18 195:16,22 196:12 197:6 198:2 208:22 224:6 229:1 250:21 260:18 276:10 name 217:11 Naomi 1:20,24 21:2 22:8,8,9 29:12 40:8 42:12 49:8 60:6 75:5 77:22 81:19 83:11,14 90:22 97:3 98:5 119:7 147:4 158:7 203:3 208:21 243:12 244:19 250:20 253:8 276:9,20 281:7 Naomi's 130:14 192:19 narratives 205:12 Nate 141:18 Nate's 149:4 Nation 247:17	national 1:1,19 2:15 16:10 112:1 112:7,10 113:18 115:11 167:17 170:12 171:19 177:7 188:8 205:10 244:22 264:11 nationally 245:19 262:16 nature 39:9 131:19 273:11 naysayers 203:17 NCP 15:15 16:16 17:10 NCPRC 206:11 near 181:18 nearly 19:20 109:17 necessarily 25:3 31:17 36:21 44:5 69:13 131:16 132:9 147:13 164:13 211:13 244:15 NEE 2:1 163:21 164:6,9 need 5:8 8:11,21 13:9 21:9 28:8,9 45:14,19 47:6 48:2,5 50:18 52:9 53:9 60:4 66:15 69:18 79:14 99:18 106:5 107:7 121:11,18 133:21 137:12,20 161:5 177:17 187:10 195:11 197:15,17 203:2 212:9,22 213:3,13 227:11 228:14,15 230:12 235:16 236:20 239:10 242:5,13 243:8 249:18 258:7 259:11 261:8 263:4 265:12 266:16	268:5,16 269:14 270:4,12 272:8,9 278:6 283:1 286:6 288:2,8,20,22 290:1 needed 74:16 80:2 203:21 204:22 225:10 248:17 250:17 needless 181:6 needs 9:14 24:1 53:3 54:17 59:22 62:13 76:4 80:20 90:6 123:19 132:2 164:11 169:12 176:12 182:3 188:3 191:6 212:14 218:7 244:11 259:2 negative 75:8 Neil 2:20 67:13,13 69:19 78:15 85:1 85:10,18 88:13 95:7 135:17,20 142:2 145:9 147:7 149:18 150:1 157:16 160:6 Neil's 104:17 Nelson 237:4 neuropathic 118:18 never 20:19 118:8 239:13 248:4 281:6 new 129:13 136:4 164:12 176:7 195:15 272:17 282:11 283:3 287:5 news 182:22 183:1 262:22 NHLBI 142:4 NHPCO 111:20 116:21 118:6 195:2 210:8 225:3 225:17 nice 65:4 115:22
---	--	--	---	--

290:8	16:17 27:21 29:1	171:16 175:4	old 283:11	70:5 116:7 238:11
night 236:12	33:9 40:16 44:15	225:21 240:17,19	older 69:15 182:17	opposed 11:5
NIH 154:20 284:14	61:4 97:18 107:9	240:20,21 241:2,9	once 102:11	optimal 15:13
NIH-like 273:14	115:2,2,12 123:3	244:4 252:6	oncologist 237:22	203:22 218:14
nine 27:10 34:2,4	170:2,9,12 196:7	261:19 267:17	oncology 8:4	OptiMed 2:1
35:5,7 87:2,15,21	198:4,6 209:9,20	nutrition 252:20	238:13,13	option 45:1
95:13 131:20	210:8,19 220:22	N.W 1:9	ones 40:22 55:12	options 65:21 66:8
134:18 161:8,12	222:19 227:3,11		221:7,9 229:12	oranges 148:22
163:1 177:6 178:5	227:17 228:2,21	O	230:2 247:22	order 23:8 99:21
183:5 202:9	243:15 251:20	obsessed 211:21	258:5 272:22	101:15
204:15 205:20	253:20 254:11	obviously 30:11	287:4	Orders 76:16
215:4,4,15 216:4	257:21 266:3	111:12,15 119:9	one-fifth 121:1	Organization 2:16
216:10,16,16	NQF's 227:6	124:10 151:18	one-time 127:10	170:19 177:8
231:4 232:7	nudging 84:4	209:9 258:5	ongoing 111:7	organizations
Nineteen 86:2	number 5:20 73:21	occur 76:4,5 108:4	online 112:6	167:8 206:13
105:14 106:18	117:20,21 119:13	124:2 159:9	207:13	organize 281:7
133:13 202:18	128:20 131:20	occurred 93:19	onus 207:16	orientation 283:18
217:2 232:20	132:4,11,15,16	140:22 160:12	onward 67:4	original 130:21
nociceptive 132:13	135:13 138:8	199:6	oops 133:6 156:14	originally 195:17
nod 226:2,3	142:6 144:5,7,8	occurs 81:17	194:20 243:12	OT 246:22
nodding 29:11	145:1 186:5,7	odd 36:4	271:1	other's 259:14
noes 74:15	196:10 217:6	offer 137:21 138:2	open 10:10 18:2	ought 80:6
nonresponse	247:8 258:1 274:1	office 141:1,2 152:1	73:17 75:6 95:10	outcome 26:12
179:13 182:14	numbers 45:14	official 119:21	120:10 130:17	39:18,19 43:2
non-palliative	47:18,20 118:10	offline 46:14 48:22	131:1 160:13	55:18 59:1 69:15
103:20	142:9 149:5	211:5 212:9	165:12 263:8	86:6 89:6,12,14
Non-traumatic	156:16	oftentimes 25:4	270:19,22 277:8	89:17,22 90:3
214:5	numerator 22:12	249:7,17 262:6,9	opens 125:5	91:8 111:2 114:22
normative 150:15	61:8 70:1 71:15	oh 4:11 24:17 75:19	operation 175:19	114:22 115:5,6,15
North 2:13 8:2	74:16,18 75:15	165:6 277:15	operational 92:17	116:10 133:11,12
97:18 109:7	93:6 96:1 99:3,14	okay 9:12 10:8,15	93:16 101:17	133:19,21 136:11
northeast 81:5	99:17 101:19	22:10 25:16,16	219:20	138:4 161:2
note 22:20 77:16,16	113:16 137:7	26:1,18 27:8	OPERATOR 10:3	178:10 200:17
noted 203:20	138:19 139:7	33:21 37:4,21	10:5,13 135:17	214:19,20 219:3
204:17 220:4,8	150:6,22 151:11	40:5 45:16 54:6	165:12 217:12	231:3 252:2
notes 42:1,7 73:14	151:18 218:12	67:4 89:2 91:15	270:22	259:15
275:8 276:4	288:5	104:19 110:9	opinion 28:7 29:3,7	outcomes 6:22 51:5
notice 103:16	numerous 160:9	124:17 132:22	29:9 30:4,17	55:22 63:17 84:12
noting 64:18 176:2	nurse 21:15 24:8	134:7 147:3 151:7	31:21 97:2 280:2	91:10 110:14,19
notion 209:11	101:20 102:18,19	158:18 159:14	opinions 268:14	111:5,6 138:2
notwithstanding	113:1,7 120:8	160:8,11 162:20	opioids 56:6 131:13	139:16 144:8
31:12 40:18	145:2	164:18 166:7,20	256:20	170:5 220:11
NPCRC 264:11	nurses 95:18	180:12 196:18	opportunities 5:7	241:14 242:6,8,16
NPP 251:20	103:19 104:5	203:1,3,5 214:9	140:4	251:5,7,11 268:6
NQF 2:7 3:8,17 5:5	120:4,8	226:8 235:20	opportunity 7:10	268:7 274:13
7:15 8:7 9:15	nurse's 21:14	246:1 271:15	8:16 21:18 28:17	278:3,11 279:13
12:13 14:14 15:16	nursing 121:3	278:1 287:19	40:17 60:21 63:5	outline 276:12

outpatient 80:11 240:15 244:3	125:6,20 126:7,17 127:13,14,17	paper 31:4 50:8,19 74:8 83:7 120:2 190:17 284:8	91:9 155:21 243:12 281:5 284:4	73:21 79:10,10,16 82:2 85:3,6 93:2 94:7 97:5,7 100:7 100:10 103:4,20 108:16 113:5 121:1,14 122:7 127:8 135:21 137:14,16 139:7 142:19 145:12,19 146:10,14 147:16 149:11 150:13 155:8 156:1,11 158:11 166:16 177:17,19 185:1 185:11,17 188:22 189:9 205:5 206:19 218:19 225:6 235:10 239:8,14,20 243:7 246:12 257:14 263:3 265:6,13
outside 97:21 117:2 140:22 224:20 245:18 274:7,16	129:11,14 130:7,9 130:15,21 131:9 131:10,18 159:2,3 189:7,9 218:6 247:20 248:1 250:11 251:7 256:19 288:4	paradigm 82:12 parallel 168:1 paranoid 243:2 paraphrase 79:4 parenthetical 96:5 part 5:15 22:1,6 41:19 50:6 52:5 62:13 69:10 71:17 72:6 73:6 97:15 97:16 108:19 109:11 119:21 120:16 123:14 131:18 141:22 148:19 151:3 157:14 168:13 171:18 181:4 187:11 198:19 206:1 210:14 212:16,21 227:15 227:21 235:13 237:21 254:1 255:1 256:8 260:16 262:15 263:21 267:21 273:13 279:18 282:5 285:4	partner 177:7 part-way 285:16 pass 88:20 91:8 162:10 passed 161:21 passes 41:20 42:18 pathway 110:21 131:12 268:8 patient 14:3 17:8 22:2 50:17 53:5 62:3 63:6 65:14 72:9 73:7 74:13 75:9,17,20 77:8 77:10 78:4 82:1 83:17,18 93:11,12 93:17,20 98:17,18 99:6,10,13,16,16 101:2 110:22 113:2,9,12,19,20 114:2,5,9,12,13 114:14,17,18 118:17 121:19 125:4 126:14,22 127:5 129:21 130:3,16,22 131:8 136:14 139:3 140:16 141:4 143:20 148:4,5,6 148:8,10,17 152:2 153:17 155:13 162:16 168:5 169:11,14,15 170:21 172:12 179:16 182:13 187:19,20 204:11 213:19 237:13 265:14 267:14 patiently 146:18 patients 9:20 13:22 19:20 23:6,10 28:17 30:8,19 33:14,16 59:22 64:16 67:16 68:1 68:2 69:4 70:13	patient's 75:22 77:19 98:22 99:11 120:17 139:2 155:12 173:20 patterns 172:6 payers 111:17 payments 167:9 206:13 peace 12:21 36:6 38:8 108:19 159:10 pediatric 100:14 peer 278:20 279:11 penalize 199:20,22 Pennsylvania 1:16 people 4:7 12:4 14:9,13 19:10 23:19 25:1,6,22 30:3 32:18 35:11 40:6 50:9 51:12 55:1 56:1,9 57:6 58:6 64:20 67:4 70:8 72:4 80:14 84:2 85:11,18 86:8 88:18 89:19 89:20,21 95:13,14
outweigh 30:19 31:22 33:13 162:16				
overall 38:11 88:8 94:8,9 96:3 106:16 128:14 165:1 173:1 179:5 232:18	painful 142:9 145:13 painkillers 131:15 paired 281:18 palliation 169:10 259:21 palliative 1:3 2:14 2:15 12:14 15:19 15:21 20:6,7 38:5 63:14 91:17 92:10 93:2,4 94:11,12 95:5 98:3,13,14 100:13,14 101:5 103:4,5,10 108:16 115:12,12 144:21 145:16,20 146:11 146:13,16 170:20 177:8 223:22 233:16 239:9,11 239:21 249:22 252:18,18 256:10 256:15 257:4 258:14,15,19 261:8 262:12,14 263:6,15 264:11 265:3,7,19 267:4 267:12			
overlap 97:11,16 overlapping 98:1,2 overview 136:2 180:19 194:14				
overwhelmed 277:7				
overwhelming 156:2				
over-broad 147:15 o'clock 5:10 O'MALLEY 2:1 30:1 43:20 62:5 84:22 156:15 192:10 226:22 240:7 262:6 281:2				
<hr/> P <hr/>				
paced 281:13 pacemaker 142:20 142:22 package 264:13 packet 272:7 packing 235:20 pad 227:7 page 3:1 285:7 pain 16:13 17:12 18:14,18,21,22 44:3,4 50:9 55:2,4 55:5,9,16 56:4,6,7 108:8 111:10,13 113:3,4,8,13,21 115:17,17 118:18 121:4 122:8 124:10,12,16,20	palliative/end 235:7 PAMELA 1:19 panel 38:8 71:3,6 72:2 94:2 127:2 136:9 137:22 141:8,22 146:7 169:18 172:1 184:13 230:11 234:10 268:13 panels 80:15 136:7	partially 81:8 122:4 224:7 participant 264:10 participate 182:6 182:17 193:4,10 participating 2:22 65:1 111:22 188:7 271:11 participation 13:13 62:8 183:3 particular 12:11 14:16 30:2 39:4 42:22 64:7 78:12 82:22 103:1 114:3 114:4,13 227:3 241:8 280:16 particularly 40:3 50:1 55:9 56:7		

96:4 97:17 98:3 104:16 119:2 124:14,19 127:6 127:13 141:17 142:4,10,13 143:4 144:3 156:1,16 157:5,22 160:8 165:7 171:3,5 179:6,12,14,21 180:5 182:5,17 185:13 194:1 203:8,9 205:2,4 205:17 206:17 208:4 223:15 224:20 225:16 228:1,10,14,16 237:5,11 238:19 241:4,16 242:2,7 243:8 245:4 249:10 252:21 256:17,21 257:11 258:18 259:17,21 260:1 262:1,1,8 263:9 269:19 270:2,3,5,7,8,20 281:5,11 284:13 284:15 people's 58:4 227:8 percent 15:2,2 50:13,16 64:12,21 69:2 94:7,9,15 100:9 117:15 118:9,11 120:22 122:7 123:22 127:22,22 132:10 132:10,10 137:16 144:12,14 154:14 154:16 156:3 158:1,5 159:7 183:3,5 240:18,21 241:1,16 percentage 13:22 33:8 56:1 132:17 157:19 perceptions 168:7 217:21 perfect 18:10 137:4	perfectly 61:15 124:6 perform 50:4 performance 11:12 14:20 15:13 26:7 38:20 68:21 70:6 70:9 85:22 86:1 94:5 104:21 112:15 117:14 133:2 160:19 182:11,12 185:9 200:12 214:12 219:2 230:13,20 255:3 performed 183:19 performing 159:18 period 62:22 126:10 239:15 261:18 269:12 permanent 68:11 Permanente 1:23 permission 209:21 permutations 11:17 person 6:16 22:5 50:1 73:10 88:10 116:22 159:17 177:10,13,13 186:8 191:22 208:2 214:7 245:14 261:2 270:10 personal 218:6 261:19 personally 6:20 213:4 277:19 persons 171:12,15 171:18 person's 172:14 perspective 6:21 7:20 12:5 46:1 49:11 79:19 83:14 115:20 117:7 138:17 177:11 206:15 258:15 PharmD 2:1 PhD 1:13,21 2:4,9	philanthropic 208:9 philanthropy 207:19 philosophically 186:1 phone 8:13,15,16 9:3 10:1,2,12 37:2 44:22 67:11 91:21 165:10,15 270:19 270:21 physical 113:1 physician 24:9 85:13 138:22 155:11 260:9 Physicians 74:11 physician's 141:2 PICCHI 2:2 13:20 21:21 223:14 257:15 pick 223:1 230:1 picked 207:4 Picking 209:1 picture 148:4 172:22 piece 29:16 57:21 83:7 107:6 112:13 235:2 pieces 64:4 130:7 265:22 280:8 pigment 186:16 pigs 287:8 pilot 157:14 219:18 219:19 pink 83:6 pipeline 255:6 pitch 203:6 pithy 272:2,8 273:6 276:13 Pittsburgh 2:5 place 44:12 84:5 102:12 136:16 137:3 139:12 144:4 158:1 167:19 171:21 175:3 194:4 219:16 239:19	243:11 placed 142:21 placements 253:1 places 36:4 97:9 265:15 267:11 plain 277:13 plan 16:14 17:15 75:17 77:17 107:15 191:5 259:3 plane 241:16 Planetree 1:21 planners 269:3 planning 71:3 79:20 155:21 220:6 222:15 243:14,16,21 259:1 plans 75:10 77:15 107:11 270:1 plate 7:22 play 241:6 289:13 please 88:10 135:4 161:17 166:12 168:3 169:5 172:4 235:22 239:3 255:17 287:11 pleased 175:14 plenty 257:11 plucked 246:9 plus 117:15 point 27:15 28:20 29:12 41:3 45:9 52:4 59:8,18 66:17 81:21 84:10 90:12 100:5 118:3 123:21 126:1 131:8 134:1 145:4 156:13 157:18 165:5 166:14 189:2 190:19 196:5,8 200:4 208:22 210:8 233:4 238:6 239:6 242:3 243:18 260:6 274:6 285:1 285:1	pointed 56:11 95:4 95:7 pointing 53:10 points 54:5 94:3 96:13 144:18 178:3 181:12 264:16 276:22 Policy 1:20 political 20:2 politics 145:14 POLST 75:2 82:10 82:14,17,18 83:3 83:10 244:8,9 246:4 poor 174:5,8 175:2 272:4 poorer 220:11 population 8:10 71:7 92:8,9,20,21 95:2 97:20 117:12 128:1 140:15 155:4,6,7 156:8 176:13 185:14 187:4,19,20 220:14 221:8,11 223:6,7 224:3 226:8 236:19,19 267:14,16 populations 114:11 140:17 180:9 221:1 247:15 265:14 portfolio 107:10 pose 242:1 positive 70:21 possibilities 147:11 possibility 141:14 156:6 possible 11:11 50:22 94:3 120:5 126:20 227:18 post 83:3 112:8 posted 194:12 post-traumatic 269:6 potential 11:21 30:19 33:13,16
---	--	---	--	--

37:14 82:7 98:1 167:7 290:4 potentially 22:18 149:22 158:12 221:10 289:12 PowerPoint 166:10 166:11,12 practical 210:13 practice 27:22 30:6 38:5 90:19 96:12 111:15 139:19,21 154:3 practices 15:17 16:10,11,17 233:11,18 244:4 257:21 281:17 practitioners 239:12,12 preached 230:19 preceded 241:1 precedents 167:4 precisely 38:1 152:8 predict 171:4 186:9 186:12 238:16 predominant 156:21 181:15 predominantly 187:21 preference 68:8,13 98:20 preferences 3:5 9:21 67:17 68:1,4 68:6 71:2,8,20,22 72:9 73:8,22 74:14,21 77:20 78:10 79:16 80:7 80:17 81:14 82:1 83:18 91:18,19 93:9,11,21 94:13 99:7,8,20,20 110:3 288:11,14 preference's 96:11 preferred 15:16 16:10,11,17 27:21 170:2,9 233:11,18 257:21	preliminarily 137:11 preliminary 4:15 48:3 116:4 141:21 142:1 157:14 273:19 prepare 112:7 prerogative 37:11 187:13 prescribed 78:3 presence 72:22 93:10 218:9 246:19 present 1:12 2:12 4:14 10:1,11 48:11 57:19 92:2 121:3 135:16 136:1 138:15 141:21 173:9 177:4 180:18 184:15 203:1 270:9 presentation 115:4 219:5 278:20 presented 38:21 57:1 127:22 136:6 140:1 280:1,6,13 presenter 10:8,10 presenting 12:4,19 13:3 115:22 138:16 187:14 203:4 presiding 1:10 presumably 226:4 presume 284:9 presumed 85:16 presuming 97:10 117:19 pretty 4:15 14:18 51:14 70:6 75:4 84:5,15 101:18 143:7 153:16 184:10 275:17 prevalence 157:20 158:5 previous 43:1,8 159:1 164:1	257:17 275:4 previously 114:21 115:15 176:6 199:4 primarily 11:12 118:16 primary 114:1 263:4 265:9 primers 273:6 prior 78:7 79:17 94:19 113:2 120:15 136:18 139:1,9,18 142:7 284:1 priorities 251:17 prioritize 251:4 priority 252:15 private 141:2 276:1 privilege 263:16 proactive 253:17 probably 13:7 28:9 32:16 44:21 90:9 90:11 114:1 138:14 142:12 167:1 185:9 195:11 257:8 282:21 289:10 problem 19:12,13 55:15 59:22 82:21 83:15 97:16 242:3 278:2 279:8 problematic 185:19 problems 73:17 148:21 224:18 226:12 277:20 procedural 32:7 proceed 45:18 192:6 214:9 286:8 process 7:1 30:3 32:5 39:3,16 40:5 40:11 41:2 42:6 52:6,7 55:17 60:18 61:4 62:13 69:6 73:16 76:18 84:3,13 89:8,13 89:16,18 91:2,11	92:5,6 97:18 102:17 107:13 109:1 112:20 115:3 123:12 129:20 136:10,20 137:22 138:4,9,12 141:22 170:3,4 175:9 200:17 214:19 220:2 228:2,9 231:3 246:10 250:19 251:1,4 253:15 258:7 266:3 268:13 270:8 271:3 272:21 277:7 278:20,22 281:4 282:14 283:22 284:2 287:3,14 processes 227:9 282:19 process/outcome 69:9 219:8 productive 4:6 professional 16:22 17:19 74:10 professionals 20:19 profile 185:9 prognosis 139:3 155:14 257:8,13 program 20:18 129:12 230:3 programmatic 122:16 programs 100:13 100:15 128:6,8,20 128:22 175:8 179:20 182:21 183:2,10,13 187:3 207:12 224:1 progress 73:14 project 12:21,22 38:8 107:16,18 108:20 166:12 168:12,15 170:13 237:9 254:8 274:13,14	projects 233:15 274:13,20 PROMISE 217:6 217:10 promote 12:7 77:3 169:11 promoted 12:21 13:2 36:6 promoting 62:19 227:7,8 properties 27:13 162:21 178:19 211:17 215:19 proportion 144:3 151:9 proposal 18:13 propose 57:13 234:17 proposed 17:21 49:20 94:21 237:7 protocol 244:14 proud 263:22 prove 47:1 provide 44:19 46:12 47:17 48:22 61:7,12 115:13 119:19 169:9,14 182:4,7,10 187:5 274:8 284:16 provided 27:20 28:2 41:10 47:20 78:18 109:3 116:21 211:18 234:8 274:15 provider 17:14 24:7 27:18 102:5 103:5 providers 15:13 111:17 182:16 189:12 192:11,18 provides 219:1 providing 169:13 173:13 174:13 proxy 82:5 170:17 179:16,16 182:13 psychological 277:15
---	--	--	---	---

<p>psychometric 211:17 278:3</p> <p>psychometrics 278:13</p> <p>psychosocial 250:9 250:13,16 258:8 258:22 260:11 268:6</p> <p>PT 246:22</p> <p>PTSD 218:9 221:21</p> <p>public 1:20 11:14 20:2 29:17 40:21 42:11 72:15 123:8 134:21 163:15 165:6,13 180:1,4 181:21 189:20,22 190:3,13 191:1,4 193:11 194:6 195:14 197:22 200:4 202:8 204:4 207:18 209:19 211:8 216:14 227:9 232:10 233:2 262:11 263:9</p> <p>publications 78:19 79:1 137:14,18</p> <p>publicly 190:4,11 193:6 254:20</p> <p>publish 50:8 176:2</p> <p>published 15:20 29:20 69:3 144:20 155:1 157:16 171:19 180:20,22 194:7 204:14</p> <p>PubMed 279:3</p> <p>Puchalski 15:22</p> <p>pull 139:20 178:2 211:6 212:19 226:18 254:12 264:20</p> <p>pulled 149:6 196:20 212:3 213:17 264:12</p> <p>pumps 131:13</p> <p>pure 166:8,9 279:14</p>	<p>purporting 267:2</p> <p>purports 51:16</p> <p>purpose 30:2 46:20 50:15 57:18 227:2 230:7,9 275:11</p> <p>purposes 90:8 183:21</p> <p>pursue 188:21</p> <p>push 46:2 73:9 88:22</p> <p>pushed 266:12</p> <p>pushing 33:10</p> <p>put 6:4 37:5 38:7 39:22 46:5 54:21 60:15 65:18 102:11 129:19 140:19 142:3,10 142:22 145:5 155:6 167:5 177:18 181:5 186:2 187:9 190:6 194:15 196:18 206:10 207:21 211:4 235:15 243:4,8 252:14 261:18 266:5 271:13 276:8,16 276:17 278:7 285:18</p> <p>puts 109:15</p> <p>putting 17:22 38:16 39:7 96:17 130:5 188:15 192:21 238:2 254:2</p> <p>P-R-O-C-E-E-D-... 4:1</p> <p>p.m 165:22,22 166:2 290:10</p> <hr/> <p style="text-align: center;">Q</p> <hr/> <p>QI 134:21 143:19</p> <p>qualified 17:1,13</p> <p>qualify 31:19</p> <p>qualitative 179:9 183:14 239:16</p> <p>quality 1:1 14:7</p>	<p>15:18 16:10 20:22 27:3,3,4 28:4 30:12 32:19 44:6 49:20 51:4 58:22 70:19,22 72:17 79:21 87:5 91:13 92:15,18,21 96:9 96:11,15 99:6 103:1 105:8 108:21 110:17,17 113:18 116:12 122:4,10 123:7 128:3,13 131:16 132:8 133:20 140:6 154:4 160:10 161:11,16 162:8,12 163:15 168:7 169:2,7 175:11,19,22 178:17 186:18,21 192:17 201:5 205:4 215:8 216:14 217:19,22 219:16 223:22 227:8,9 228:12 229:10 231:10 232:10 234:13 235:9,16 237:8 239:7,11 241:6,10 244:10 245:13 248:19 249:1 250:19 252:13 253:1 257:10 263:2,16 264:18 265:12 267:2</p> <p>quantity 26:19 28:3 30:12 70:16 70:22 86:21 105:3 116:10 133:15,20 140:6 161:5 162:6 162:11 178:17 200:22 215:2 219:16 231:7</p> <p>quarter 188:9</p> <p>quarterly 112:5</p> <p>question 17:3 18:6 18:7 20:22 23:17</p>	<p>23:20 26:1,2 27:17 30:1 32:7 32:14,16 33:21 35:20 36:11 39:13 39:16 40:12 41:8 44:12,15 47:8 48:8,13,19 49:7 49:10 57:8 58:18 58:20 59:2,4,5 61:4,18 62:5,6,9 62:10,14 64:9,19 64:20 65:12,13,13 65:15 70:11 78:2 79:4,15,18 80:15 84:22 86:9 90:2 90:18 91:3,7 95:19 97:4 98:12 100:5 101:10,13 103:14 107:3,4 113:6 117:10,13 117:17 119:15 120:13,14,18,19 123:3,11 124:9,14 124:16 125:18 126:6 127:20,21 128:2,8 130:1,15 132:21 133:1,18 142:8 143:13 144:1,13,19 146:8 147:5 150:9,10 153:10 154:17 159:5,21 160:8 163:20,22 164:17 168:22 172:8 174:16,21 180:3 181:17,20 182:3 183:9 185:22 186:1,14 189:20 192:5,9 197:4 199:12 204:7,9,21 208:11 210:12 212:8 220:13,22 221:4 227:1,2 229:9,19 241:22 242:1,19,20 243:6 253:10,22 257:18 258:12 275:2</p>	<p>280:18 281:18,20 285:14</p> <p>questionable 161:16</p> <p>questioned 59:13 70:14</p> <p>questionnaire 222:6</p> <p>questions 4:13 6:4 6:15,19 18:16 20:15 21:19 25:9 25:19,21 37:11,15 55:6 56:17 67:1 85:17 100:4 117:7 119:7,9,11 127:2 141:8 149:4 158:21 167:14 170:6,16 171:12 172:14 173:15,16 173:17,21 174:1,2 174:17,19 178:9 179:13,15,22 180:6,9,13 183:12 183:18,19 184:3 184:12 193:17 195:6 196:11,15 196:20 198:8 203:15 204:2 210:10 211:7 212:18 213:16 221:21,22 225:5 226:21 243:6 245:7,11,12,17 271:18 279:6 289:19 290:1</p> <p>quick 48:7 49:9 103:14 143:11 163:22 199:11 229:1 268:3 272:22 284:22</p> <p>quickest 236:8</p> <p>quickly 4:18 29:13 153:17 276:10</p> <p>quite 21:10 45:17 46:7 92:19 110:18 111:21 152:4 159:14 210:20</p>
--	---	---	---	--

225:7 271:11	40:22 180:1	125:21 129:8,13	146:15 149:11	reflected 279:19
quote 33:1 96:10	203:12	132:8 139:14	254:4 257:12	reflects 46:22
R	rationale 39:6 42:2	143:12 150:11	264:15	113:20
R 1:9,12	reach 187:3	156:20 164:15	receiving 80:5	refused 36:16
race 180:22 181:7	reached 165:5	167:5,12 171:9	139:4,4 146:12	regard 48:15 132:7
186:2,4 188:17	react 253:13	175:18 177:3,5	155:14,15 186:19	247:14
raise 43:7 62:2	reactive 253:12	185:17,21 186:9	receptive 131:11	regarding 98:22
142:8 148:21	read 18:12 19:18	186:11 187:9	recipients 242:2	206:12 258:2
247:5 256:7	24:5 31:3 34:16	188:9,10 189:3	recognize 19:3 65:7	Regional 1:22
raised 24:14 44:2	34:19 59:2	190:21 191:10,11	recognized 139:18	regions 168:19
55:11,11 61:20,21	readdress 6:8	191:13 194:2	recognizes 114:7	Regrettably 132:5
78:17 151:2 156:6	readily 120:1	196:21 200:5	recommend 123:17	regulation 244:12
179:12,14 181:20	reading 16:7 26:11	204:5,22 205:16	recommendation	regulatory 50:11
183:12 203:15	103:18 150:1	205:17 207:16	48:9 223:11	50:15 80:19
204:2,21	172:15	208:8 210:2	recommendations	reiterate 112:11
raising 42:21 62:21	ready 9:10 132:22	220:18 228:1,15	71:7 206:7	reject 60:19
62:21 63:4 153:4	135:13 157:5	240:13 242:20	recommended	relate 186:5
ramifications	195:6 200:11	244:7 246:5,10,16	14:14 17:18	related 38:16 84:7
258:4	217:4 230:19	247:13 248:13	116:22 203:11,11	96:6 107:4,9
ran 183:17	246:8 266:10,19	249:11,16 250:18	203:20	151:20 233:16
RAND 2:20 9:22	real 12:11 50:5,5	251:17 253:9,21	reconvene 6:6	236:15 246:11
10:2 67:11,13	50:21 52:18 59:21	255:4 256:1 257:4	109:14 110:1	257:14
92:13 94:20 108:9	60:1 104:3,8	257:22 258:8	record 14:1 47:1	relates 123:4
135:14,15	242:8 245:6 269:3	262:17,18,19	73:14 78:7 83:7	relationship 50:16
randomized 139:15	269:5 284:11,12	263:1,18 264:6	102:11 109:20	62:12 75:16 138:1
141:12 146:20	realize 166:22	265:18 266:19	119:21 120:2	219:8,11,11
randomizing	206:16 268:11	267:13 268:5,16	152:11 165:21	240:12
146:21	realized 269:7	269:22 273:3,10	290:10	relative 84:5
RAND-like 268:12	realizing 170:8	275:21 276:1	recorded 73:2	relatively 140:15
RAND-UCLA	282:6	277:14 280:22	103:8,9 119:12	151:9
67:21 136:10	really 4:5,6 8:2,7	281:6 282:3	recording 72:20	relatives 262:21
range 31:16 37:19	12:2 14:5 17:21	286:12,18	records 15:11	relevance 54:22
203:14	18:6,22 19:6 21:5	reapproach 7:15	38:19 81:2	relevant 47:12
rapidly 144:15	35:13 37:22 38:12	reason 29:18 151:1	recuse 108:3	211:7 233:22
145:8	40:2 45:5 46:16	152:9 206:9 242:9	redo 268:21	234:19
rate 183:3 199:13	51:4,20 52:21	283:15	reducing 252:10,10	reliability 27:14
200:7	53:2,5 56:12	reasonable 12:8	refer 176:3 224:8	33:22 34:19 35:4
rated 15:4 38:9,10	59:20 67:8 72:13	61:12 70:10	references 181:5	35:11 37:16 38:18
116:13 219:2	73:15 78:13 79:7	275:15	referral 17:13	41:16 42:19 43:16
raters 178:5 179:1	79:15 82:17,18	reasons 14:16	referred 100:10	43:17 44:16 45:20
rating 38:11 52:12	83:9 85:19 88:21	40:19	referring 138:20	49:18 50:20 57:6
94:1,2 114:7,10	92:11,12 95:22	reassessed 127:9	refers 16:9 172:10	57:14,17 69:5
174:5 178:7,17	99:18 100:17,19	reassure 4:9	208:13	71:10,13 74:19
179:2 186:17	101:6,21 102:1	recall 42:17 205:18	refine 61:8	78:20 84:16 87:14
197:13 200:9	104:10 108:21	261:3	reflect 41:22 42:8	94:4 95:20 101:22
ratings 28:2 34:19	109:1,1 115:22	recap 3:2 5:17	81:16 114:2	102:17 103:15
	122:18 125:2,2,4	received 14:9 94:1	150:21 287:10,15	104:11,15 116:16

137:1,2,4,6	190:4 193:6	253:18 275:20	201:10 242:11	79:6 100:2 103:12
144:21 147:19	196:20 212:20	researchers 264:12	278:10	184:13 217:15
171:8,9 178:21	213:18	264:17 273:1,3	resumed 109:20	257:5
201:15 271:19	reporting 11:14	275:22 281:12	165:22	right 7:7 8:11 9:18
272:2 273:4,6,17	72:15 112:1 122:7	reservations 95:15	resuscitate 93:20	10:22 25:16 26:15
273:21 274:9	123:8 134:21	residents 75:19	resuscitation 76:7	32:4 33:4 39:21
277:21 278:7,12	163:15 175:17	76:6	76:20	42:14 47:2 53:22
reliable 42:18	180:1 189:20	resist 96:17	rethink 60:5	55:5 65:16 69:21
45:14 59:14 71:15	190:11 191:4	resolution 48:13	return 183:7	79:2 85:21 86:16
74:18,18 134:7	193:11 195:14	153:12	revalidation	86:19 88:9,15
162:22 215:20	197:22 200:4	resource 252:14	172:18	89:4,8 97:22
231:20	202:8 209:19	274:14	revamp 130:8	103:3,18 104:17
reliably 38:19	211:8 227:10	resources 21:13	revamped 129:11	107:14 109:22
relieve 39:10	232:10	251:14 262:3	reversible 153:17	117:21 124:5,18
religion 25:3	reports 235:14	266:17 281:11	review 3:4,6,9	125:22 126:11
religious 23:8,9	254:13	respect 73:3 99:20	46:14 93:13	127:12 128:17
25:13 36:13	report's 233:5	131:2 169:11	102:11 109:2	130:11 131:9
rely 121:5	repository 182:6	174:15 197:11	117:6 140:2	132:11 150:1,3,8
remark 22:19	represent 182:21	respectively 179:1	167:16 171:7	151:4 152:7
remarkable 116:3	representative 8:15	179:5	275:4 278:20	154:16 157:11,19
remember 29:1	8:18 245:19	respond 24:5	279:11 283:22	158:3,5,5 160:3
95:19 102:16	represents 138:6	121:10,15,19	284:6,6	161:4,9,15 162:8
123:6 149:5 196:3	request 45:12	124:14 160:5	reviewed 5:18	174:10 175:7
198:11 221:22	61:11 206:10	186:10,12 205:7	14:13 95:13 96:20	180:14 188:6,14
265:12	require 53:1	260:19	102:6 140:3	190:5 191:19,22
remind 30:10	123:18 140:20	respondent 174:9	171:17 199:3	198:9,17 200:20
reminded 244:20	required 13:11,12	186:7	203:8,9 222:10	202:20 205:22
reminder 273:20	64:13 93:7 99:7	responding 193:9	284:2	209:3,7 212:1
reminding 29:8	227:16	response 28:13	reviewer 116:13	214:11,22 221:3
remove 100:7	requirement 75:16	46:21 81:21	reviewers 14:21	226:1 228:11
renal 287:12	102:10	125:17	17:18 70:3 116:6	229:12 231:5
repeat 29:14	requirements 76:8	responses 90:11	117:2 140:5,10,13	236:8 258:18
167:22	115:6	124:9 206:3	178:6,16 179:3	259:6 263:21
repeated 116:2	requires 17:5 74:7	218:14	183:12 203:10	268:18 276:20
rephrase 33:5 46:4	81:22	responsibility 7:20	220:16 280:11	286:4 287:7 290:7
report 3:13 26:12	reschedule 288:22	responsible 130:2	reviewer's 101:10	rigorous 51:21
27:3 29:17,20	289:2	responsive 167:4	reviewing 4:20	ripe 246:8
31:19 72:16 112:8	research 12:5 21:3	rest 41:22 178:11	189:4 279:21	risk 132:16 158:8
149:19 170:15	29:18 49:22	224:12	reviews 273:19	158:11,18 185:2
190:3,13 191:7,21	154:21 162:14	restarted 285:19	revote 44:20 48:4	185:14 187:8,17
193:20 194:6,12	191:20 195:4	result 111:2 112:8	57:14 58:2 66:4	188:4,16 206:18
194:14 200:21	205:22 247:6,18	146:5 164:1	66:10	RN 1:13
230:3 231:6	249:14 250:7,7,10	196:22 198:15	revoting 54:9	road 127:18
233:11 234:3,18	253:19 259:16	results 27:9 105:13	rhetorical 228:9	Robert 1:17 145:10
235:1 254:3,18,21	264:11 279:4	112:9,10 132:6	Rhode 237:9	168:14 208:10
266:18 267:21	researcher 11:5	164:2 176:2 178:2	RICHARD 1:17	275:1
reported 180:3	130:15 207:15	186:16 199:9	Rick 75:6 77:21	robust 9:1

role 6:14,18 11:21 24:3 241:6 247:6	53:9 63:4 64:21 90:17 127:15	179:21 183:16 187:22 219:15	108:16 112:14 120:21 131:4	282:12,22
roll 91:19 193:13	153:15 180:19	scoring 4:15 173:7	132:19,20 154:4	sense 6:12 21:11
rolling 236:12	188:12 225:8	179:14	164:16 174:6	46:10 53:4 104:2
rollup 199:10	250:5 260:9	screen 39:13 53:8	177:19 181:6,21	104:7 124:13,18
211:10 213:10	263:19 266:19	screened 251:6	184:18 193:4	160:16 194:21
room 31:11 54:12	269:8 282:20	screening 17:2	198:21 219:14	199:21 212:19
240:5 252:8	says 22:13 24:13	18:20,21 19:14	223:13 224:19	223:8 235:20
263:10 270:18	31:5 38:18 51:21	20:22 22:1 35:20	226:17 227:21	263:20 266:8
271:14 280:3	52:5 64:15 77:16	36:21 39:12 43:2	228:5 233:21	sensitive 187:6
283:10 284:6	130:16,22 162:11	43:4 44:5 46:21	235:6,8 239:13	sentence 276:17
round 120:22	166:15 174:9	58:20 59:2,4,15	240:6 245:9 252:5	277:13
285:2	184:20 185:3	60:1,11,11 62:1	252:7 253:2	sentinel 205:15
rounds 175:10	scale 38:11 56:6	63:8,15 64:20	256:17 258:10	separate 31:11
routine 153:10	114:8 121:15	251:2	263:17 269:2	150:10 210:11
RO1 141:12 157:15	204:3	screenings 44:4	271:22 275:12	213:18 223:3,8,9
rules 286:7	scales 114:10	script 120:12	278:16 286:21	separately 53:3
run 5:15 51:1 112:5	scared 219:4	scrutiny 241:10	287:6 289:14	196:21
112:7 235:3 248:8	scenario 50:22	se 138:4	seeing 65:7 89:15	serial 237:17
Russ 75:6,6	159:16 184:15	Sean 1:9,12 6:13	89:22 103:4 143:3	serially 237:5,12
Russell 1:13 83:21	schedule 5:13	115:19 118:2	166:16 195:5	serious 256:18
138:17 141:11	289:5	127:19 141:8	199:21 254:1	257:1
146:17	scheduled 5:13	146:19 147:7	264:6	seriously 92:9 93:1
	schism 238:15	149:2 154:17	seek 248:9	94:7 207:14
S	School 1:16 2:4,19	157:8 166:18	seeking 227:2	267:13
safe 111:2	SCHROEPFER	167:4 288:22	247:14 286:11	serve 187:20 188:2
salient 93:14	2:4 24:21 51:8	Sean's 150:10	seen 5:3 12:17 33:9	service 98:14
sample 69:4 94:6,8	53:13 69:22 247:4	searches 279:3	120:3 157:20	145:20 208:7
103:20,22 104:4	259:7 285:13	Seattle 209:13	177:17 239:8	services 12:16 14:9
samples 274:1	scientific 27:12	second 4:4 126:2	243:15 281:18,19	92:10 113:15
sampling 267:8,10	37:17 41:5,6,20	225:14 289:12	sees 24:10 269:9	175:6 187:5
SARAH 1:18	45:20 46:1 56:10	secondly 283:17	select 229:12	207:15 246:22
satisfaction 279:7	56:22 84:19 98:10	seconds 26:4 91:7	selected 12:6 49:12	247:1 248:6,9
satisfactory 72:3	98:11 105:17	section 236:1 243:4	selecting 21:6	265:6 281:12
171:13	164:4 180:2	273:14 275:7	self 167:20 176:13	SES 226:13
satisfied 69:1,2	scope 6:19 254:8	sections 218:8	self-administered	session 4:6 9:15
75:15 99:2 152:21	score 15:1 168:2	sector 276:1,3	172:19	165:8,16
229:6	173:1,13 174:7,8	sedatives 131:13	self-administrati...	set 30:11 110:20
satisfies 77:18	174:10 175:5	see 5:6 8:11,14	172:17	114:4 118:4,22
satisfy 152:19	176:7 181:17	17:20 19:14 20:4	self-efficacy 172:13	194:19 233:1
save 248:9 285:16	182:8 184:1 186:6	21:19 24:9 32:17	173:17 174:19	235:8 236:5
285:21	186:17 196:10,22	32:21 33:11 40:22	self-reported 120:4	249:18 264:21
saw 19:9 28:2	218:15	42:3 44:18 45:14	130:16	265:16 267:9
142:20 205:13	scored 140:9	46:11 48:10,14	self-reporting	273:15 282:11
236:9 245:5	scores 37:18	52:10 58:7,20	121:6	286:3 289:22
280:22	130:12 140:3	66:2,7 76:13	selling 190:9	sets 182:6
saying 46:5 51:13	173:7 176:6 179:8	85:14 97:8 101:18	send 233:10,15	setting 20:6 80:11
				85:7 95:3 102:19

114:3 124:10,20 130:18 143:7 148:10 149:21 151:10 153:11 214:3 224:10 236:14,22 237:7 240:16 243:20 252:3,6 settings 30:6 95:17 140:22 168:17 169:16 204:20 241:8,11 244:2 settling 160:15 seven 5:19 34:1,9 35:4 86:7 87:18 87:21,22 88:6 93:5 96:2 100:8 105:10 106:2 134:14 145:19 161:18 163:6,11 164:20 165:3 172:10 178:6 179:1,6 203:9 216:20 231:17,21 232:3 288:2 289:9 Seventeen 133:3 200:13 severe 124:16 Shakopee 247:17 shape 4:17 share 23:5 shared 18:12 169:11 sheet 119:18,19 271:21 276:19 277:12 shifted 280:9 shock 85:12 145:13 149:11 shocked 146:4 148:12 shop 145:14 243:22 short 16:16 89:10 shorten 158:17 shortly 10:13,15 111:19 Shoshanna 190:14	190:18 191:22 193:19 show 32:21 33:11 33:17 176:4 198:20 199:2 209:16 235:9 284:2 showed 19:21 43:4 170:5 219:10 showing 28:3 173:1 shown 14:6 15:1 24:19 176:6 shows 13:10 43:16 73:11 212:3 250:9 sick 187:20 241:21 side 44:1 70:21 71:5 118:21 132:21 154:7 220:21 271:12 277:5 sideways 286:22 significance 14:8 significant 30:7 72:10 73:21 184:6 184:9 199:5 250:11 257:22 signs 258:2 silent 267:3 similar 94:20 127:15 209:4 210:1 similarity 174:12 simple 55:20 64:9 64:19 95:1 101:15 simplified 172:6 simply 36:10 43:1 63:4 68:16 81:15 114:13 267:15 Sinai 141:17 single 50:14 136:22 142:11 159:21 174:4 196:10 228:18 sir 6:12 10:3,5 89:7 sit 26:14 52:16 66:22 191:19 246:15	site 205:14 sitting 257:20 situations 159:11 six 14:13 26:17 27:11 95:13 106:7 111:5 114:18 135:6 140:2,9,10 140:10 161:7 163:7 168:16 179:4 201:2,7 202:5,14 218:3,21 231:12 232:11 288:2 Sixteen 104:22 105:5 size 184:19 skilled 53:2 skills 169:13 173:16 174:18 skin 186:15,16 skip 70:4 86:11 90:10 134:3,4,5,6 172:6 203:1 245:20 280:22 skipping 26:1,2 133:7 slices 265:13 slide 166:21 168:3 169:4 170:13 172:3,21 173:4 slides 162:4 166:10 166:11,12 169:21 276:11 slightly 20:13 226:5 small 81:2 98:12 103:21 140:15 144:5,7,8 156:17 223:15 265:21 smart 132:4 smoothly 4:11 social 2:4 25:4 249:20,21 250:12 269:1 societies 138:8,13 238:16 Society 8:3	Sofaer 190:14 software 119:14,14 119:16 solely 15:9 solid 206:6 278:22 Solomon 1:21 35:17 45:16 47:13 101:8 252:16 283:5 solved 19:12 somatosensory 131:11 132:13 somebody 7:10,21 9:22 10:15 24:10 31:6 50:1 56:14 60:21 124:15 143:7 146:4 149:8 149:20 159:11 someone's 186:15 someplace 276:7 Somewhat 178:7 soon 80:12 108:5 sooner 19:11 sorry 26:10 27:3 42:11 43:11 45:10 45:16 76:15 98:5 106:21 107:1 125:8,8 181:16 245:21 279:17 280:22 sort 11:4 31:16 32:14 40:11,15 48:10,13 53:10 54:5 59:12,21 60:4 84:7 85:11 94:17 98:17 100:21 101:7 123:2 138:6 147:22 163:21 167:11 171:7 173:5,10 175:12 175:18 181:10 182:22 185:13 190:8 191:10,16 191:17 206:22 208:4 222:9 230:2 238:2,3 240:9	256:7 263:20 264:4 268:12,20 269:7 271:3 272:7 272:8,9 sorts 28:18 68:9 152:6 sound 35:15 42:4 sounded 43:21 sounds 23:14 197:21 274:18 source 49:14 117:3 169:3 sources 82:8 278:15 southwest 81:6 space 31:11 span 89:10 speak 46:11 78:16 122:5 141:15,20 225:13 228:3,8 250:1 262:9 290:5 speaking 83:14 85:13 specialty 94:10,12 97:6 138:8,13 265:5,6,7,18 266:12 specific 5:5 36:17 36:18,20 77:15 82:19 93:15 111:4 138:3 212:18 220:3 221:1,20 222:20 224:2 236:14 244:6 246:16 261:13 specifically 30:14 36:10 39:20 76:5 77:19 129:2 155:4 168:6 172:6 175:11 240:15 280:4 specifics 58:2 173:3 specified 74:11 120:14 123:21 204:13 specify 121:21 spectrum 233:20
--	---	---	--	--

SPENCE 2:15 110:8 118:1 119:10 120:7 121:7 122:12 124:21 127:11 128:10,17 129:1 130:20 183:17 187:12 196:4 210:6 spend 4:19 235:4 282:21 spent 66:11 210:20 spiritual 13:12 14:6 15:19 16:5 16:12,13,21 17:7 17:11,12,13,19 18:17 19:12 20:10 20:19 25:5 36:13 39:8 43:5 44:12 53:2,5 55:19 56:2 56:14,21 59:15 62:2 63:7 172:7 218:5 250:13,17 258:9 259:1 268:7 spirituality 24:22 25:2,7 54:13 55:8 55:14,18 59:13 96:14 288:7 spiritual/religious 10:21 14:2 22:13 split 116:17 219:3 spoken 277:13 sponsor 7:2 spot 37:5 65:18 spread 82:17 83:10 spreading 82:12 stability 206:3 staff 2:7 7:15 8:7 33:9 115:2 210:19 255:3 264:10 275:8 276:4 283:20,21 staffing 175:19 staffperson 22:19 282:10 stage 148:11 standard 11:9,10	13:2 47:15 53:1 53:16 55:3 56:18 84:2 154:10 standardization 74:5 standardize 76:18 standardized 16:12 16:18 standards 55:2 210:21 standpoint 47:4 102:9 168:11 182:4 210:13 stands 188:14 stars 229:16 start 4:8 14:11 40:7 75:9 84:5 111:13 113:14 131:2 188:11 190:8 236:11 255:4 259:5 263:9 268:7 268:12,20 276:18 281:8 285:20 286:4 started 64:6 122:18 170:3,8 249:8 251:2 277:6 starter-uppers 270:9 starting 254:9,11 270:6 start-ups 270:4 state 33:2 76:10 83:4 stated 150:18 statement 22:12 43:15 61:9 93:17 93:19 96:8 98:20 99:12 102:2,3 117:10,11 151:12 151:12 154:19 statements 75:11 states 11:13 75:1 82:12,14,14,15 244:11 stating 52:10 statistically 184:6,9	statistician 275:18 277:2 statistics 59:7 276:7 status 68:8 71:21 75:14 79:9 84:1 85:3,6 94:22 101:16 stay 241:2 stayed 128:7 staying 170:12 stays 128:15 Steering 1:4,8 3:4,6 3:9 42:1 110:2 253:11 step 7:12,22 19:7 19:10 63:7 71:2 235:5 242:13 250:22 Stephen 1:22 22:9 23:1 24:1 25:16 steps 3:19 107:20 112:21 268:5 287:18 steward 7:17,17 11:6 95:18 stewarding 8:1 sticking 100:5 286:10 stir 160:14 stitch 251:12 stitched 252:1 stoicism 247:19 stomachs 165:18 stop 34:12 77:7 166:18 243:22 stopped 282:9 stopping 236:3 stories 249:6 straight 90:3 236:10 straighten 240:1 straightforward 4:16 strategy 113:18 204:1 straw 32:17	Street 1:9 strength 69:9 222:5 strengthen 6:17 7:4 strengthened 6:22 stress 269:6 strict 279:22 strikes 239:13 stringent 115:7 strong 29:5 33:19 38:3 66:9 74:20 101:21 156:10 276:2 strongest 78:11 strongly 17:17 122:18 struck 236:17 structure 115:3 170:4 175:17 219:7,7 234:3,17 273:14 274:3,4 struggle 25:1 254:5 255:7 272:11 struggled 209:10 209:11 struggles 54:20 238:13 struggling 54:16 56:9 257:2 student 285:17 students 250:1 studies 15:5 26:19 68:22 70:21 86:21 105:3 129:8 133:16 157:7 161:5,10 167:17 200:22 215:2,12 226:15 231:7,11 231:15 241:7 280:4 study 29:15 31:5 69:2 171:14,19,19 204:14 205:20 218:2 219:12 273:14 stuff 285:18 stumbling 194:1 stunned 85:12	stunning 85:15 stupid 23:14 subdomains 209:16 submission 111:22 112:3 157:15 176:4 183:22 210:11 submit 37:14 47:22 157:13 166:10 submitted 47:21 122:6 195:2 196:8 198:13 227:15 253:13 279:12 submitting 167:3 279:9 subset 143:21 222:20 substance 277:1 283:2 substantial 29:2 142:6 230:11 substitution 173:11 subtle 266:22 successfully 7:3 suffering 131:14 242:3 sufficient 41:8 suggest 46:10 56:1 151:17 155:18 156:11 267:20 suggested 277:22 suggestion 151:20 suggestions 281:3 283:4,7 287:10 suggests 28:16 156:1 suitability 73:18 suitable 219:20 220:16 summarize 54:4 131:20 178:2 summarized 181:1 summary 70:2 219:1 272:2,9 summer 190:19 269:21 supplemented
---	--	---	--	---

168:15	237:14	tab 194:14	265:10 271:3	190:2 205:8
support 21:8 26:20	surrogates 83:19	table 48:2 64:17	talks 237:17	207:13 208:14
29:5 133:16 161:5	survey 167:17	170:1 240:1 243:5	tangible 244:17	209:8 211:14
161:10 169:10,14	168:20 170:6,6	243:9,11 245:20	targeting 117:20	213:4 214:5 268:3
172:7 173:14	171:11 172:19	268:9	targets 187:2	tent 40:7 240:6
174:1,14,16	176:14 183:6,8	tabled 5:20 288:7	task 30:10 110:15	tents 132:19 286:14
178:15 192:2	187:21 196:6,16	289:10	111:6 172:15	286:22
201:1 214:13	197:1 198:12	tables 277:5	taxpayer 207:18	Term 234:13
215:1 218:6	202:22 204:8,11	take 5:14 23:19	teachable 86:12,15	264:18
236:15 241:7	205:11 212:19	48:3 66:18,20	86:20,22 89:3,7	terminal 139:2
247:1 250:12	214:2 217:7 221:5	109:14 121:11	team 17:1 130:3	155:13 262:22
260:7,11 261:1,16	222:7 223:8,18,19	152:16 167:14	159:17 168:22	terms 14:17 17:10
262:5,12 280:5	228:17 245:1,17	169:21 174:6	172:8 192:1	21:12 22:6 32:4
supported 28:22	245:19 285:15	180:15 185:1,4,5	209:10 282:5	48:15 54:8 57:2
245:19	surveyed 224:4	185:6 187:4,12	teams 20:6,7 49:21	70:15,16,17 71:10
supporting 78:19	surveying 193:3	189:14 198:5	97:7 98:4 239:9	72:1,11 73:1,18
84:19 111:20	surveys 167:15	212:9 235:6	258:19 259:12	97:17 100:12
215:13 216:3	187:14 193:7	243:11 246:20	Tecca 2:18 10:22	109:6 111:21
230:12	196:8 198:14	254:14 268:19	11:1 36:3 48:7	114:21 116:4,17
Supportive 2:2	211:2 218:13,17	270:15 284:16	49:5 63:10 125:16	175:9 178:19
supports 215:7	survival 69:12	285:10	126:12	181:7 200:21
supposed 91:2	survived 68:18	taken 7:19 28:21	technical 21:16	201:14 220:3
120:11,13 199:13	susceptible 189:13	47:16 152:12	38:8 94:2 234:10	222:12 231:5
223:1 272:1	suspect 235:11	157:19 238:11	276:14	236:2 246:6 247:5
sure 12:10 25:17	sustaining 68:10	takes 146:3 279:16	teleconference 2:22	250:16 268:6
28:5 29:10,11	76:16 93:9	talk 8:18 35:10,14	telephone 135:15	283:18
35:22 36:1,2	swarming 20:17	51:2,10 55:1	172:17 210:7,9	terrific 48:9 88:13
42:21 43:7 45:17	symptom 169:9	62:16 76:19,20	222:7	test 42:18 51:18
46:7 48:19 65:4	173:14	142:19 157:13,15	tell 14:12 19:10	72:5 167:21 172:2
67:20 75:11,12	symptoms 173:19	165:20 203:8	40:12 50:10 75:19	192:2,20
77:5,18 79:3 80:6	258:3	210:22 211:5	75:21 85:12 92:3	testable 219:11
89:20 90:12 101:4	synthesis 183:14	237:5,12 248:4,15	107:22 121:15	tested 71:16,17
124:17 136:3	system 1:17 15:10	248:19 264:9,16	137:4,6 144:10	72:5 85:4 97:19
147:9,15 159:19	20:17 23:7,7	271:3 286:7 288:3	147:1 181:19	97:21 191:21
170:11 184:16	145:6 206:17	288:10	191:9,19 212:22	194:2,10 218:16
189:16,20 190:2	226:12 240:11	talked 64:8 73:20	287:1,11	219:18,18,19
204:5,13 211:12	251:18 256:22	75:20 96:3 168:4	telling 281:22	266:4,16
211:14 225:7	268:22	204:15 222:14	Ten 87:15 88:3	testing 45:5 47:12
234:19 243:7	systematic 49:1	252:19 271:20	160:20 161:18	59:3 74:20 92:7
251:21,22 255:13	52:6,7	talking 6:1 7:8	202:9 215:15	98:11 121:9 171:8
256:9 258:18	systematically	11:19 22:15 25:6	216:10 231:4	171:9 172:16
274:2 275:10	30:18	41:14 47:9 91:11	tend 269:20	176:18,19 190:15
278:21 285:2	S-E-S-S-I-O-N	117:4 129:3 184:2	tendency 182:20	193:20 211:19
287:15	166:1	198:7 210:1	tends 220:10	274:9
surprising 13:15	_____	221:12 223:6	TENO 2:19 166:6	tests 51:21
surrogate 77:11	T	237:1,1 243:19	166:17 180:12	tests/retests 167:17
82:6 93:13 99:11	_____	244:8 259:17,22	182:2 185:20	test/retest 171:11
	t 122:2 189:5			

Texas 1:15 20:8	76:1 84:4 89:14	88:14 90:8,16	245:16 246:4	282:6
text 8:13 15:22	96:18 104:5	92:14 93:14 95:7	247:16 249:7,17	thoughts 21:16
thank 10:9,18,19	110:11 130:10	95:18 96:7 97:15	250:14,17 251:8,9	28:20 51:7 272:12
10:19,19 13:18,20	158:22 159:6,15	97:16 98:12	251:13,16,16	272:19
18:1 24:2 27:15	168:8 169:1,19	100:14,15 107:2,8	252:9,16,17	threatening 139:5
35:16 43:19 69:20	180:18 199:2	108:6,11,13,15	253:22 255:2	148:19 151:2
88:19 94:16	220:6 222:13,14	116:3,20 117:1,6	256:11,14,19	155:15,19 158:11
108:21 109:4,10	222:22 228:22	117:8 121:17	257:2,22 259:8,9	three 4:20,22 5:1
115:18 118:2	229:20 233:1	123:9,19 124:3	260:17 261:6,7	27:5 34:1,4 35:4,6
122:1 145:9	236:17 237:10	126:10 129:9	262:5,19 263:11	68:21 70:22 71:12
158:19 165:6	238:19 241:7	130:18,20 131:5	264:3 265:3,11	73:19 81:1 91:4
177:9 192:8	242:7,11,14 247:3	133:8 134:2,4	266:18 268:4,10	95:14 105:1
194:18 208:16	247:13 248:15,20	135:13 138:5,14	268:17 269:3,5,7	107:18 111:1
229:15 239:22	250:3 254:4	142:2 143:3,9	269:18 270:8,12	114:8 133:4
241:12 253:7	255:13 259:9,20	144:5 145:18	270:12 271:9,12	136:15 137:9
259:4 267:21	264:19,22 268:4	146:17 148:1,3	271:20 272:15,17	139:1 140:9 155:8
268:1 270:17	268:14 269:4	149:14,19 151:8	274:3,20 275:9	155:11 158:1
274:22 277:18	270:6 272:10	152:4,5 153:9,14	276:5,16,21 277:4	161:3,7,13,13,19
280:21 287:2,17	275:4,19	153:20 154:6,22	277:22 280:10	163:2,2 164:15
288:18	think 4:10,16 7:14	155:3,20 156:10	281:3 282:2,13	170:16 173:9,15
thanks 4:5 75:5	7:18 8:6,16,19,20	157:11,17,18	284:11 285:21	174:1,2,13,17,18
83:11 88:17,20	8:20,22 12:12	159:5 160:7,10	286:1,5,9,22	174:19 175:10
97:1 98:8 100:1	14:15 15:3 17:17	162:10,17 164:15	287:18 289:15	178:2 181:12
103:11 106:6	18:14 20:3,21	168:8 170:18	thinking 28:14,15	201:22 221:22
108:18 124:8	22:7 23:11 24:21	176:21 178:8	35:19 44:3 53:15	241:18 268:3
177:14 217:14	25:1,2,10 27:21	179:17,22 181:11	84:3 110:16	288:1,12 289:5
themes 179:10	28:20 29:4 30:4	181:14 182:2,13	116:14 143:17	three-quarters
theoretical 79:19	31:13,15,18 32:3	183:15 184:10	153:5 170:3 227:6	64:11
thereof 122:15	32:8,13 33:5,9	185:20 186:3,20	234:22 237:15	threshold 91:2,12
thicket 53:21	34:14,17 35:1,18	187:3,16 188:1,14	253:6 261:6 281:7	throw 65:21 90:11
thing 8:22 21:12	37:9 38:14,21,22	189:6,10 191:3,22	282:3 284:2	158:10
42:20 44:17 52:3	39:2 40:1,9,14	193:7 195:6,10	third 145:4 192:12	THURSDAY 1:6
52:21 59:13,19,20	41:18 44:7 45:7	197:14,17 198:11	Thirteen 105:9	tie 223:21
65:20,22 66:4	45:14,15,18,22	199:3,4,5 208:6	106:10 134:13	tied 132:16
77:7 89:12 114:8	48:5,8,21,22 49:3	209:17 211:1,4	165:2 201:6	tigers 50:19
114:20 151:2,5	50:3 52:9 54:1,2,4	212:6,8,12,17,22	thorough 132:3	Tighe 2:10 3:20
153:18 154:14	54:8,12,14,15,17	217:4,11 220:18	thoroughly 177:2	162:1 217:9,14
155:2 186:3,11	54:19,22 55:7,10	221:8 222:5 223:6	thought 12:7 13:16	289:4 290:3
233:7 248:22	55:11,15 56:8,10	224:6,16,19	19:2 90:18 96:16	time 5:2 13:5 26:16
249:9,19 251:12	57:1,4,15,17,18	225:11,21 226:8	121:4 133:20	42:7 64:13 66:12
254:9 265:20	57:20 58:5,14	226:17 227:18	151:19 178:8	66:15 69:1,3
268:18 274:6,19	59:8,11 61:11	228:4,7,20,21	179:3 180:16	79:12 81:18 85:9
282:15 285:5,22	63:11,18 64:4	230:7,8,10 233:9	184:16 185:14	94:15 100:18
286:1	66:15 69:20 74:12	233:12,22 236:1	187:7 189:5	102:12 103:6,9
things 12:15 21:4	76:13 77:2,4	237:21 240:5,15	191:10,12 227:4	106:5 125:18
41:15 49:19 54:10	78:21 82:13,18	241:4,9,13 242:13	240:7 244:7 253:6	126:1,10,17
63:13,19 75:13	83:9,21 84:4 86:8	243:19 244:2	273:3,10,16,21	128:21 129:21

134:12 136:21,22	tonight 5:11	73:22 76:16,19,22	223:21 234:6	266:21 272:22
142:13 147:12	tool 19:15,15 20:2	91:17,18 93:9	249:10 255:2,14	276:18 277:13
158:10 160:2	24:11 59:15 60:1	94:13 96:11	264:20 266:7	279:19 280:10
164:14 165:14	72:6 185:15 198:3	113:20 152:18	286:12 287:14	288:1,12 289:16
166:16 172:9,11	207:10 214:14	256:2,3 288:11	289:21 290:8	twos 41:1
174:11 178:12	tools 114:5,16	tree 62:11	tube 68:11,12	two-step 92:6
187:13 191:10	121:22 239:6,18	tremendous 88:21	252:22	102:16
204:10,13,16,22	topic 62:2 63:5	109:2 116:6	Tuesday 289:21	type 56:22 253:6
206:3,5 210:20	topics 252:18	269:11	tune 159:22	274:15
229:16 235:4	261:14	trend 159:15	tuning 159:20	types 269:20
238:12 239:15	total 130:8 218:16	trending 114:12	turn 97:14 233:4	typically 33:9
244:1 253:5,10	totally 118:20	trial 139:15 141:12	245:8 278:7	198:20 283:14
260:7 261:9,17	121:10 122:13	146:20	turned 90:19 142:7	
268:19 271:3,8,10	229:3 279:5	trials 71:1	146:1 148:7 156:5	U
272:15 275:10	touch 289:6	tribal 248:12	turning 137:10,17	UCLA 72:12 73:10
282:21 283:16	touching 131:21	tribes 247:8 248:12	141:13,19 145:16	81:2,8 136:22
284:7,16 286:17	tough 284:11	tricky 53:19	253:3	142:2
286:22	town 184:20	tried 104:6 168:1	tutorial 281:13	ugly 175:13
timely 258:2	to-do 287:21	170:7 172:2 176:1	tweak 60:21	Uh-oh 37:6
times 37:8 68:20	288:16	191:11,13 222:8	Twelve 87:7 105:19	UMass 168:21
71:17 100:19	track 109:18	237:8 275:21	106:1 134:8 201:2	un 83:16
151:4 154:12	229:21 240:3	trouble 151:15	202:14 232:11	unable 121:10
159:13 160:9	tracked 164:16	284:13	Twenty 88:11	UNC 91:19 108:9
186:7 194:11	tracking 119:19	true 97:12 149:17	135:10	uncertain 88:9
290:5	162:5	149:18 152:17	two 4:20,22 5:11	uncertainty 178:14
timing 22:6	Tracy 2:4 10:9,9,11	195:19 254:22	9:8 21:4 26:21	271:17 280:11
Tina 2:2 13:19 18:2	24:20 25:21 48:6	truly 41:7 45:5	37:11 42:13 66:8	uncomfortable
21:19 24:4 223:13	51:6 69:20 258:13	53:16 113:20	67:7 80:8 81:2,4	113:4 122:8
259:4,8 260:19	traditional 248:17	258:15 259:12	91:6 92:18 103:19	124:22 127:14
tiny 68:22 144:16	traditionally	trust 57:16	106:15 107:4	uncontrolled
title 150:21,22	226:14	truth 46:22	112:21 117:7	118:18
toast 84:17	train 19:10	try 8:7 9:2 26:13,16	119:8 122:6 134:7	undergoing 242:8
today 4:10 9:14	trained 50:1 263:5	41:22 42:3 63:10	134:19 135:1	underlying 212:2
31:5 48:4 88:14	263:5 269:10	79:5 97:13 126:19	140:9 144:17	underrepresent
90:9 132:6 199:10	training 259:11,11	134:12 135:4	154:12 161:8,16	182:19
213:8,9 217:6	260:22	154:7 161:17	163:7 172:10	underserved 247:7
235:13 245:3	trajectories 171:6	171:2 182:10	173:17,21 179:1	understand 18:11
263:17 270:9	transfer 78:8 79:17	185:2 189:1 207:4	179:21 180:13	51:12 53:14 58:12
271:17	transfusion 68:11	231:16 255:18	181:14 184:20	58:13,13 59:6
today's 4:18	transitions 246:6	trying 11:22 20:2	187:14 203:11,17	78:6 99:4 101:12
toggle 277:9	translated 208:5	23:2,5,15 47:1	205:18 216:21	118:16 128:6
told 4:7 125:9	traumatic 214:4	48:20 54:7 59:5	221:20 222:22	190:1 194:3
190:20 210:9	treat 169:10 174:15	59:21 63:12 80:13	223:12 224:18	199:13 203:22
229:4 260:1	treatable 131:12	90:6 96:14 124:13	228:5 231:22	204:5 222:18
tomorrow 177:17	treated 131:14	126:5,5 154:5	232:8 236:6 238:7	239:10 255:9
241:15 290:8	148:13,14	159:6,8 160:11	247:4 264:16,19	256:8 262:4
ton 115:13	treatment 68:10	167:3 187:9	264:22 265:4	understandable

191:8 197:20 202:8 Understandably 250:21 understanding 56:15 86:9 115:8 115:10 121:20 128:4 191:1 199:15 211:12 213:22 284:7 understands 55:13 understood 225:8 279:8 undertaken 136:17 152:14 undertook 175:8 underway 200:3 unfair 199:19 unfortunately 5:12 287:8 ungodly 67:11 ungraded 71:6 unintended 23:16 24:1,16 33:15 unique 223:7 unit 67:17 68:3 77:9 80:8 95:6 170:20 177:16 universally 112:16 University 1:14,15 1:21 2:4,5,13 unknown 72:10 unmet 261:8 unnecessary 251:14 unobjectionable 84:8 unreasonable 118:20 unrelated 158:15 unscheduled 252:7 update 209:21,22 285:19 updating 107:13 176:10 upstream 261:7 269:14	uptake 227:7 upward 67:4 urge 151:17 urgent 268:5 USA 31:5 usability 72:11 78:2 79:8 80:22 88:2 106:9 116:19 140:8 197:8,9,16 199:12,20 200:1 usable 163:14 179:4 197:12 202:7 219:22 use 16:11 55:16 76:14 83:3 96:10 96:10 101:4 112:18 119:20,22 122:3 135:4 164:19 169:21 172:8 173:10 179:22 190:7 202:12 207:11 216:19 217:18 220:14 227:17 228:13 229:11,13 230:2,4 232:13 234:17 237:8 244:9 245:18 247:21 251:21 252:14 274:14 280:17 useful 13:16 72:19 73:4 111:16 134:20 216:13 230:16 232:9 272:18 275:12 usefulness 72:15,17 users 175:11 272:14 uses 225:4 usual 102:9 205:9 utility 59:20 U.S 14:10 <hr/> V <hr/> VA 217:19,20 218:10,18 220:19	221:20 224:1,7 225:21 226:5,12 227:5,15,19 228:11,13,17 229:9,10,15,18 230:1,8 vague 17:4 71:8 valid 42:18 53:20 59:15 134:11 163:5 201:19 232:2 validation 167:16 167:22 171:14,17 277:21 validity 34:3,20 35:6,12 37:17 41:16 42:19 43:17 45:4,5,21 46:2,6 46:20 47:4,5,11 47:12 48:14,15 49:1,2,17 50:20 51:9,11,13,19,22 52:4,11,15,16,18 52:19,20 53:12 56:11,13,17 57:1 57:11,15,19,21 58:19 59:3 60:10 69:6 72:1,2,4 74:20 78:20 84:16 87:17 90:18 98:10 101:6 105:22 116:17 137:21 138:3 147:20 150:5 167:18 171:8,9,21 172:3 172:21 175:3 176:18 178:21 180:2 181:19 191:14,18 211:19 216:3 219:10 230:14 271:19 273:4,7,8,17 274:9 278:7,12 282:1 Valley 1:22 valuable 29:16 191:12 236:2	241:9 286:18 value 62:14 132:7 228:3 259:14 values 168:14 variability 19:22 variable 250:11 variance 184:5 variation 13:16 14:21 21:11 176:2 176:5,7 183:21 variety 68:20 81:6 81:10 various 63:19 119:12 121:12 168:17 173:6,19 208:5 vary 21:12 vast 142:4 146:14 152:20 vectors 84:10 vendor 11:5 192:13 Venn 98:1 ventilation 68:9 76:20 venues 81:9 versa 98:4 version 167:6 225:3 versus 21:14 59:4 61:22 172:17 175:5 179:16,16 181:8,9,13 182:13 187:20 206:2 210:17 224:10 246:3 280:2 vertical 246:2 veteran 223:17 224:21 226:7 veterans 208:12,13 208:20 217:20,22 220:9 223:16 224:4,9 225:17,18 225:19,20 veto 275:3 vice 98:4 view 20:1 40:15 viewpoint 123:20	124:5 vine 245:1 virtually 189:10 283:12 vis 220:16,16 visit 56:4 178:12 visits 251:15 252:8 vitalist 98:17 voice 23:18 43:21 voiced 23:6 void 206:21 volumes 55:4,4,4 voluntarily 182:5 voluntary 112:3,13 122:13 176:4 183:2 volunteer 279:9,9 279:10 vote 6:11 9:5 21:15 21:18 32:10,11,17 32:17 40:16 48:3 57:18,20 66:15 88:10 104:19 132:22 156:14 157:5 160:17,18 195:7 200:11 226:21 230:20 275:6 voted 19:9 31:16 32:19 33:6 35:11 40:13,14 44:15 47:18 90:15 140:11 votes 66:7 voting 6:7 25:22 28:5 31:9,10 54:9 58:4 66:17 85:18 85:20 89:11,20,21 90:15 116:17 133:20 154:9 195:9 196:13,15 196:21 212:13 214:10 273:20 277:22 281:20 vulnerable 68:2,17 69:15 70:13 80:5 V-fib 141:5 148:11
---	--	---	--	--

V-tach 141:5	260:18	weekends 166:18	104:9 276:4	193:19 248:12
<hr/> W <hr/>	wants 43:5 207:11	weekly 237:18	284:19	worker 249:20,21
wait 66:1 100:6	warrants 230:10	weeks 218:3 253:4	wishes 75:10	workers 25:5 269:1
waiting 146:18	Washington 1:9	289:5	witnessed 143:6	working 9:7 11:9
166:5	wasn't 9:16,17 12:3	welcome 3:2 4:4	witnesses 170:15	102:20 110:9
wake 229:16	24:22 39:17 72:14	28:17 272:20	wonder 18:9 47:10	127:13 145:5
walk 162:4 167:11	97:20 131:3	273:13	59:19 100:11	176:16 177:5
273:15 283:20	190:21 195:18	welcomed 165:17	121:3 122:5	192:19 225:17
walking 283:21	222:12 275:8	Wenger 2:20 67:19	189:22 244:9	247:7,11,17
want 4:9 14:4,12	280:19 284:8	79:2,18 85:8,16	253:15	248:13 254:16
17:8,21 21:5	285:3	88:16 89:1 135:17	wonderful 177:15	262:11 275:16
22:21 25:17 28:5	wasted 251:14	135:19 136:3	208:2 259:15	287:7
30:20,21 32:2	watched 263:22	144:10 146:6	285:22	works 56:8 152:12
34:15 39:14,22	water 160:15	149:17 150:2,20	wondering 49:13	194:17 195:4
42:13 43:7,14	way 5:12 7:9 10:18	152:7 160:4,7	85:5 150:17 157:3	263:14 289:7
48:14 50:10 54:1	11:8 26:5 27:4	went 30:11 109:20	166:11 227:10	world 25:9 50:5,21
54:3,5 58:8 62:15	29:18 30:10 38:4	136:8 165:21	wonderment 227:1	52:18 104:3,8
75:10 76:1,7	40:13,14 56:22	179:8 210:20	wonky 130:15	170:18
103:2 110:6,10	57:7,8 60:13,20	271:4 284:13	wood 4:10 168:14	worried 189:3
112:11 117:4	76:5 77:4 78:12	290:10	word 22:17 23:3,4	worries 96:22
125:1 131:9 147:9	80:9 83:5,10	weren't 71:1 97:19	47:16 60:15 172:8	worry 24:16 148:16
147:14 149:20	89:13 98:21	237:11	worded 19:16	148:19 185:15
155:2 156:3,4,5	100:12 108:2	West 67:12	wording 22:11	230:7
156:12 158:10,22	120:9 124:4,9	we've 84:15 91:11	60:14,21	worst 281:19
160:13 176:11	132:1,4 143:16	134:2 238:6	words 40:1 276:13	wouldn't 24:16
177:18 179:10	152:8,11 159:20	white 2:5 8:2 31:8	276:18	66:16 69:13 99:1
181:22 186:22	180:8 189:18	32:1,6,10 40:10	work 2:4 6:17	164:12 186:21
192:6 198:19	191:7 192:4 196:9	41:14 47:2 52:14	14:12 30:7 44:8	199:22 200:8
200:5 207:1 211:5	200:8 222:6 225:5	53:19 59:8 83:13	48:21 49:21 52:9	Wrap-up/Next
211:11 212:1,5	229:20 254:13,15	86:12 89:4,8	63:21,22 88:22,22	3:19
213:21 234:19	260:12 263:1	90:17 98:8 100:1	90:6,19 108:19,22	write 99:21 209:10
243:13,18 245:7	267:8,19 270:4	123:2 147:22	109:5 141:19	writing 27:19 42:7
260:13 263:10	278:14 285:15	150:8 151:1 153:3	144:6 146:2 149:5	written 15:22 76:6
264:4,9,15 269:13	286:15 287:7	181:8,9,13 236:11	155:22 157:17	76:9 77:4,19 79:9
284:16 287:18	ways 20:14 56:16	271:2,8,15 272:22	171:17,22 177:14	102:4 120:14
wanted 6:13 12:10	119:12 211:3,5	284:22	188:13 191:6	190:17
24:4 29:17 44:14	237:16 278:11,12	wholesale 190:9	194:15 195:3	wrong 60:12 82:13
82:10 88:19	web 281:14	wholesalely 192:2	197:18 200:3	94:18 126:11
108:17 114:20	website 192:16,22	wide 118:14 132:14	207:5,14,17 208:8	190:9 205:16
127:14 128:2	194:13	238:15	213:5 229:18	242:4
148:13 175:16,16	websites 207:21	wilderness 62:10	230:17 237:3	<hr/> X <hr/>
189:2,19 206:14	weeds 35:13 235:5	willing 44:18 193:4	240:8 247:8 249:2	X 282:14
210:10 226:9	272:15	204:22	250:2,15 254:6	<hr/> Y <hr/>
233:8,21 234:4	week 6:2 9:8	Wisconsin 247:9	255:8 259:6,13	Y 282:15
237:20 244:18	142:20 171:3,4	Wisconsin-Madi...	260:10 279:16	yea 21:1
247:5 257:15,16	186:8	2:4	288:17 289:15	yeah 130:4 144:1
	weekend 290:4	wish 20:11 84:1	worked 190:13	

264:5	186:5 200:14	144:14 211:22	2009 15:2,11	5
year 69:3 142:11	201:3,7,7,12,17	218:13 231:12	201st 228:15	5,000 14:10
144:20 248:8	201:17,22 202:10	12:17 165:22	2010 15:3,12	5.00 94:3
254:19 269:1	202:10,15,19,19	12:33 165:22 166:2	2010-2011 144:12	58 175:2
274:14,15	204:3 209:15	12:45-1:00 5:9	2011 1:6	6
years 16:6 19:21	210:3 214:16,16	1200 175:7	21 1:6	60 132:10
30:5 39:4 55:3	215:5,10,10,16,16	13 26:17 86:7	22 102:20 240:18	60.8 174:7
122:6,18 145:19	215:22,22 216:5,5	13,435 15:11	23 208:14,19	65 107:21 182:17
157:12,21 158:2	216:11,11,17,21	1380 171:18	232 3:13	67 94:8
158:12 164:15	217:3,3 230:22,22	14 173:8 174:12	24 101:5 103:8	7
177:6 198:12	231:9,13,18,22	15 127:22 165:19	197:10	7 26:22 145:2
205:18 207:15	232:4,8,12,16,16	249:3 285:8	25 64:12,21 207:15	71.2 175:5
211:22 249:14	232:21	15-minute 109:14	275:15	72 113:11 125:19
257:3 261:11,21	0	156 171:15	25,000 19:20	127:7,8
275:15	0208 3:11 195:10	16 168:19	263 3:17	73.3 184:7
yellow 83:6	208:18 213:11	16th 1:9	27 149:8 258:1	73.6 15:2
yeses 73:19,19,20	0209 3:6 110:3	1613 213:13	27,000 223:16	76.2 174:7
74:6	1	1623 3:11 202:21	224:11	77,000 223:18
yesterday 4:6 5:17	1 3:2	217:6	28 68:5	78 261:17
9:14 53:15,17	1.5 14:8	1625 3:6 135:13	286 3:19	78.2 15:2
54:22 67:22 108:9	10 3:4 50:11 106:14	1626 3:5 9:19 67:15	29 171:11	79.8 174:10
123:16 127:15	109:14,15 121:15	1632 3:11 203:2	290 3:22	797 174:3
132:7 271:21	149:10 157:22	208:19	3	8
282:4 286:2	158:5,6 160:20	1641 3:5	3 72:2	80 175:1 241:16
287:22	215:9 216:4,20	1647 3:5 10:16,21	30 16:6 100:9	82 94:6
yesterday's 117:18	218:3 231:8,21	13:21	132:10	83.2 175:6
young 246:17	10,000 236:4	165 3:8	30.5 174:8	86.6 184:8
Z	10:54 109:20	166 3:9	326 288:13	87.1 174:11
Z 282:15	100 64:22 118:9,11	17 161:3 173:9	36 168:13,15	9
zero 26:8,22 34:5	123:22 137:14	184:3 218:13	369 69:4	9:00 1:9
35:7 50:10 53:6	149:8 154:14	18 120:22	38 240:21	9:01 4:2
86:3,3 87:3,3,8,8	156:2 168:2 173:1	19 117:15 127:22	4	90 193:8
87:12,12,16,19	174:8,11 175:5	1998 110:15	4 3:2 142:13 148:11	90.3 174:7
88:11,12 105:1,6	176:7 182:8 184:1	1999 170:8	4.04 94:3	91 94:14
105:6,10,10,15,15	186:6 204:3	2	40 137:15	96.3 184:8
105:20,20 106:2	205:11 209:15	2:52 290:10	400,000 144:2	
106:15,19 121:15	210:3 261:21	20 30:5 50:16 55:3	42 183:3	
133:4,4 134:9,9	100,000 142:10	88:18 103:20	43 183:3	
134:14,14 135:1,1	1001 1:9	104:13 132:10	43.5 174:8	
135:6,6,10,11	101 109:9	241:1	45 26:4	
159:7 160:21,21	11 26:21 214:21	200 192:11 228:12	46 69:2	
161:19 163:18	231:17 232:3,15	229:10,12	48 68:18 78:5 79:11	
164:21 165:3	11:14 109:21	2000 223:17	111:11 113:14	
168:2 173:1	110 3:6	2004 149:7	117:16 118:19	
174:11 175:4	12 26:8 82:12,14	2005 176:3	125:19,21 126:8	
176:7 182:8 184:1	87:18 137:8	2006-2007 144:12	237:18	

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This is to certify that the foregoing transcript


In the matter of: Palliative Care

Before: NQF

Date: 07-21-11

Place: Washington, DC

was duly recorded and accurately transcribed under my direction; further, that said transcript is a true and accurate record of the proceedings.



Court Reporter

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