

NATIONAL QUALITY FORUM

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MEASURING AFFORDABLE CARE EXPERT PANEL

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FRIDAY, MARCH 28, 2014

The Panel met at the National Quality Forum, 9th Floor Conference Room, 1030 15th Street, N.W., Washington, D.C., at 9:00 a.m., Elizabeth Mort and Melissa Thomason, Co-Chairs, presiding.

PRESENT:

ELIZABETH MORT, Partners HealthCare System,
Inc., Chair

MELISSA THOMASON, Vidant Health, Chair

DEB DAHL, Banner Health

MAUREEN EDIGER, Children's Hospital of
Colorado

TINA FRONTERA, Minnesota Community Measurement

JESSICA GREENE, George Washington University

ALYSSA KEEFE, California Hospital Association

LISA LATTS, LML Health Solution, LLC

TAYLER LOFQUIST, Beekeeper Group

CARRIE NELSON, Advocate Health Care

MARCI NIELSEN, Patient-Centered Primary Care
Collaborative

CYNTHIA ROLFE, Blue Cross Blue Shield
Association

ALISON SHIPPY, National Partnership for Women
& Families

PAUL SIERZENSKI, American College of Emergency
Physicians

JOE SINGER, HealthCore, Inc.

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

2 (9:05 a.m.)

3 MR. AMIN: Good morning. So, is
4 everybody ready for an exciting Day 2? Great.
5 Ron, looking good. All right. So just wanted
6 to get started by doing a quick recap of Day
7 1, of where we've been. And then I'll sort of
8 ask for some reflections from the Chair about
9 yesterday.

10 And then I'll ask Erin to give us
11 a sense of today's agenda, talk through how
12 we'll do these case studies, what folks can
13 expect. And if there's any other thoughts
14 from the NQF, we would welcome that.

15 So yesterday we began our session
16 by walking through the consumer experience,
17 discussing definitions of affordability. And
18 really talking through the three different
19 phases.

20 So some reflections from yesterday
21 around the population at risk, which we sort
22 of redefined as being, they're staying

1 healthy. We identified, the structure that we
2 used yesterday was to really talk through the
3 decisions at various points in time. And then
4 the types of information that we would need.

5 And at the staying health phase we
6 really talked about, why should I get the
7 care? You know, why should I get care in a
8 period where I'm actually generally healthy?
9 Making decisions around selecting a health
10 plan and selecting services.

11 We also talked about, as a
12 precursor to the population at risk, or
13 staying health phase, various consumer
14 attributes that were present for most of the
15 panel, around cultural expectations, age,
16 other patient utilities that would affect the
17 way that consumers would make decisions.

18 In the evaluation and ongoing
19 management phase, which we redefined as the
20 getting well phase, we discussed the
21 importance of the distinction between emergent
22 and non-emergent types of care. And also

1 discussed, thanks to Marci, the Health Belief
2 Model, which seemed to resonate with folks
3 around the perceived susceptibility, severity,
4 benefits, barriers and actions, as part of the
5 decision making process for when to seek care.

6 The primary decision that emerged
7 during this conversation that I, you know,
8 that Liz reflected on yesterday as well, in
9 terms of Maureen's input around, do I really
10 need to go? And making, and how do I make
11 that decision about when I need to go?

12 Weighing different types of cost
13 trade-offs, trade-offs of other emotional
14 factors, and family factors. Additionally,
15 another decision point at the decision of
16 getting well is, how do I choose my doctor?

17 And then finally, we discussed the
18 following-up phase, which we broadened to
19 include living with chronic illness and coping
20 with end of life care. And the decisions
21 really focused around how to coordinate my
22 multiple providers, the selection of those

1 providers, and assessing the appropriateness
2 of care, in addition to selection of
3 specialists.

4 And across those various different
5 time periods we discussed various different
6 pieces of information that would be needed
7 along the lines of co-pays, deductibles and
8 lifetime caps. So that's a reflection of
9 where we were yesterday.

10 We achieved quite a bit. It was
11 very helpful, very rich discussion yesterday.
12 And so I will turn it over the Chairs. Liz,
13 or Melissa, do you have anything to add around
14 where we were yesterday? I would also welcome
15 comments from the NQF staff, or anyone else on
16 the panel that has any other thoughts about
17 yesterday's discussion.

18 CHAIR MORT: Thank you, Taroon.
19 Again, a wonderful, I think, summary of what
20 we did yesterday. And from my perspective, I
21 came to this meeting bringing quality and
22 safety health services research, thinking

1 about measures hat.

2 And I took it off after about 15
3 minutes, because I was so moved by the
4 scenarios and the stories that consumers and
5 patients brought forward. And for the rest of
6 the meeting I tried to suspend those
7 frameworks and ways of thinking about things,
8 and just listen.

9 And I think what I heard were some
10 very profound things from my perspective.
11 They were probably self evident from everyone
12 who was speaking, Melissa. But just the whole
13 idea of navigation of this health care system,
14 that this delivery of care and the payment of
15 care, unlike when I was a kid, has gotten
16 really complicated.

17 The other, the thing I would bring
18 out that you didn't mention, Taroon, is the
19 importance of insurance. And how just getting
20 into the game as a patient and a consumer, the
21 insurance maze is such a challenge that
22 there's going to be a lot of work that needs

1 to be done.

2 Although, I was reassured to hear
3 by Joe and Cynthia that there is a lot of good
4 work. So there's a lot of models on which to
5 build and generalize. The indirect costs of
6 accessing care, once you have the insurance,
7 also is something that was just a real wake up
8 call for me.

9 And Helen and I were talking
10 about, as doctors, thinking about how we
11 organize our practice, make ourselves and our
12 knowledge available, could go a long way
13 towards helping patients decide whether they
14 need to go to the emergency room, take a day
15 off work, et cetera. We've covered those
16 grounds pretty thoroughly I'd say.

17 And I think in summary what I
18 would say about yesterday, you know, coming
19 in. And the title of our workgroup is
20 specifically, let me just refer to it,
21 "Measuring Affordable Care". I think I'm
22 thinking about this more as assessing

1 affordability.

2 It's not going to be a measure or
3 a group of measures. We're nowhere near that
4 level of understanding. It's really
5 understanding the issues, the taxonomy, some
6 labels, where to get the information.

7 And there's measurement in there.
8 But it's more of an assessment exercise,
9 rather than a measurement exercise. So this
10 has been a wonderful session so far. And I
11 can't wait for today.

12 CHAIR THOMASON: I think that's a
13 great point. And we had, even as consumers we
14 sort of had that same feeling. It was that
15 we're not necessarily at the place for
16 measures. But I think we did a great job
17 yesterday of beginning to define portability.
18 So, I talked to my other consumers. And this
19 is kind of what we felt going into today.

20 The first, I'm not sure if there
21 was really an oversight on -- I wish I had
22 mentioned it before today. But I didn't know

1 until I got here. I really wish that we had
2 a consumer on this panel who has absolutely,
3 is perfectly healthy. Because we have a
4 skewed version of --

5 Just like Marci was saying
6 yesterday, we're all patients, frequent
7 flyers. Even Tayler, with her experiences in
8 having to choose, we have entirely different
9 experiences. And I know that it sort of skews
10 our viewpoint.

11 And most of our population, I
12 understand it's not like us and our
13 experiences. They're healthy. And I will add
14 though that I started that way. And, you
15 know, I was healthy. And so I try to think
16 back to when I was in that first bubble, and
17 the decisions I made back then.

18 And really, I didn't access the
19 health care system. For many years I had no
20 insurance at all, because affordability was
21 such an issue. And my husband didn't work for
22 a large corporation at that time. And I

1 volunteered full time after college.

2 So I just didn't go to the doctor,
3 even if I got sick. I completely did not
4 access the system. And once my husband began
5 working for a large corporation and affordable
6 insurance was an option, and I knew I would
7 want to have a baby in the next couple of
8 years, I said, yes, let's do insurance.

9 And thank goodness we did, right,
10 going into everything. But I remember what it
11 was like to be in that first bubble. And I
12 want us to keep those people in mind also.

13 Adam made a good point. He said
14 that he wanted to make sure that we kept those
15 definitions that we visited yesterday in mind.
16 And that we still reflect on those from a
17 consumer's perspective.

18 Because coming out of this, we
19 still want a consumer to be able to read that
20 paper and say, yes, I should probably look for
21 those things when I choose a provider. And if
22 they're defined from the consumer's

1 perspective they'll be able to do that. But
2 if they're not it really won't be usable.

3 Adam was saying, well, do we have
4 all these measures and all these information
5 in place? Probably. And it's, a lot of these
6 definitions, probably. And it doesn't mean
7 they're wrong. Maybe we're just not doing a
8 great job of educating the population, and
9 translating it very well.

10 And we probably need to keep that
11 in mind. We talked a lot, y'all. Okay. We
12 use the word y'all in North Carolina, by the
13 way. And this is another comment. So, Cory
14 was saying that, he said, you know, Melissa,
15 I don't know if even our insurance company
16 reps here, he's like, I don't know if they
17 even understand why we even care about
18 affordability, or like the price of it all.

19 Because they're picking up so much
20 of it. And so, from my perspective, I can't
21 speak for everyone, but I do want to sort of
22 address that. From my point of view, and you

1 can certainly correct me if I'm wrong. But
2 from my consumer perspective, the insurance
3 company picks up a lot of the bill when I go
4 to the hospital.

5 But in my eyes they have a lot of
6 money. And from my perspective the percentage
7 of my income that then I am expected to pay is
8 a lot, compared to the income we then receive.
9 So even though I don't have a \$400,000 dollar
10 bill to pay, that \$6,000 dollars a year hits
11 me probably even harder than, you know, large
12 companies, and things like that.

13 So it does matter to me from a
14 financial standpoint. But then it matters to
15 me too as an advisor and a patient. I do a
16 lot of work with patient engagement and
17 patient and family centered care. And we talk
18 a lot about patient family centered care
19 perspectives.

20 And then I thought, well this work
21 is probably going to be very different from
22 what I've done. But when I sat here yesterday

1 and listened, we talked about the exact same
2 things. We talked about transparency. We
3 talked about respect. We talked about
4 educating the public. We talked about asking
5 the hard questions and listening.

6 So this to me is just another area
7 of patient and family centered care. And I
8 think when we start to break some of those
9 barriers of affordability down, then it will
10 break a lot of those communication barriers
11 and trust barriers that the general population
12 has when they're seeking providers, and when
13 they're engaging with them.

14 So that was kind of our consumer
15 perspective. Maureen did want to share really
16 quickly a model that they talked about at
17 Children's, and the conclusion they reached.

18 MEMBER EDIGER: I talked about it
19 very briefly yesterday. I just think it's
20 worth mentioning, because I think it's a
21 really unique -- Maybe it's not. You guys can
22 tell me if other hospitals do some more

1 exercises.

2 But the conversation around the
3 costs with high risk spinal surgery started in
4 our Quality and Safety Committee, mostly as a
5 safety concern. And just the outcomes, the
6 percentage of outcomes that are not good,
7 including death, or being bedridden for life,
8 or serious infection keeping you in the
9 hospital for months at a time.

10 So the ethics committee at the
11 Children's Hospital of Colorado took this
12 issue, and organized a conference for a couple
13 of days that had -- I just felt like it was
14 really inclusive.

15 Because it had the orthopedic
16 doctors, it had the spine surgeons. It had,
17 the Chief Financial Officer from the hospital
18 was there. We had budget people there. We
19 had inpatients. We had quite a few parents,
20 and even some of the kids that had done the
21 surgery.

22 But the question really came down

1 to, at what point is it appropriate for the
2 full cost of the surgery to be discussed? Is
3 that something that parents and patients want
4 to know when they're making a decision whether
5 or not?

6 Because a lot of these kids, and,
7 I mean, Carrie talked about her niece
8 yesterday. For a lot of these kids, like, not
9 having the surgery means being uncomfortable,
10 a possibly being a lot less mobile for the
11 rest of their life.

12 But even 50 percent of them have
13 the surgery, and they have a long
14 hospitalization and infection. And still
15 spend a lot of their life in a very non-mobile
16 state. And so, what is the obligation of the
17 doctors, the hospital, to present this
18 information to parents?

19 And it was just fascinating.
20 Because all the parents in the room were
21 saying, absolutely we want this information.
22 Because for us, knowing the full costs, not

1 just, you know, the surgery is costing, you
2 know, it was \$25 million dollars, which seemed
3 like a really big number.

4 And then the accountants assured
5 it's only two percent of the overall budget.
6 But it was just fascinating watching how like
7 doctors reacted to those numbers. Because
8 they're going, \$25 million, oh my gosh. And
9 that number meant one thing to them.

10 The accountants were like, no, no,
11 it's perspective of the bigger piece of pie.
12 And parents are thinking, well that's not me.
13 That's the other, you know, hundreds of people
14 having the surgery done each year. But being
15 able to put it in perspective, with everybody
16 at the table at the same time, it was
17 fascinating.

18 And the conclusion, the outcome of
19 this was, okay, the now what, that the parents
20 want to hear about the issues of affordability
21 from their physicians. They don't want it to
22 be a representative from the insurance company

1 calling and saying, we wanted to talk to you.

2 Like, as helpful as it was,
3 whoever had the, you know, you can have your
4 MRI at this place. Like, for something this
5 serious, like parents and kids want to hear
6 this from their doctor. They want to know
7 that they're going to have a conversation
8 that's going to last longer than two minutes
9 about it.

10 They want to be able to ask
11 questions, revisit it if they need to. And I
12 think doctors and administrators were both
13 surprised at how willing patients were, and
14 parents, to having that conversation. So that
15 was the takeaway. And I can certainly send
16 you the paper that will come out of that, and
17 sort of the outcomes.

18 MEMBER NELSON: Can I ask a couple
19 of questions on that? So, have you guys made
20 a change? Have you implemented a change, to
21 where you're actually incorporating that into,
22 you could consider it sort of a risk benefit

1 conversation?

2 MEMBER EDIGER: Yes, I think so.
3 I mean, I don't, I mean, this was literally
4 like three weekends ago.

5 MEMBER NELSON: Okay. So it's not
6 --

7 MEMBER EDIGER: Yes, no, the right
8 people --

9 MEMBER NELSON: -- fully
10 implemented.

11 MEMBER EDIGER: -- were at the
12 conference. So it was like, it was an all day
13 Friday, half the day Saturday. And like
14 literally on a Saturday, beautiful Colorado
15 day, we went an hour longer than we were
16 supposed to, because people were so engaged in
17 the solutions part of the conversation, which
18 I thought was fabulous.

19 MEMBER NELSON: It will be really
20 interesting if you can watch that over time,
21 and see if it changes --

22 MEMBER EDIGER: Yes.

1 MEMBER NELSON: -- the decisions
2 people would make.

3 MEMBER EDIGER: Yes, yes. And it
4 started much like this one did, with a parent
5 panel, with four parents who had, two had gone
6 for the surgery. Two had chosen not to. Of
7 the two that had chosen to do the surgery, one
8 of them the child died.

9 So, I mean, this is pretty, it was
10 intense. Like, everything was on the table.
11 And it was talking about the ethical decisions
12 around talking about affordability.

13 MEMBER NELSON: Interesting.

14 MR. AMIN: We'd welcome any other
15 reflections from yesterday, if anyone had any
16 other thoughts. And then, I'll just wait a
17 second on that. And then, Erin, maybe we can
18 talk through the agenda for today.

19 MS. O'ROURKE: Absolutely. So
20 seeing no other comments, I'll dive into the
21 agenda. After we're done here we'll go into
22 our breakout sessions, where we'll be

1 assigning everyone a case study to play out.

2 After that we'll have a report out
3 from the breakout sessions, take a break for
4 lunch, then have a conversation about, what
5 are the implications of affordability, and the
6 challenges to really getting this information
7 out to patients?

8 And do we have a -- what's our
9 path forward to getting them this information,
10 and starting to have these conversations
11 between consumers and their providers. Then
12 we'll have our final member and public
13 comment, and wrap up with our next steps.

14 MR. AMIN: I would just add, Erin,
15 to the group, the reason why we thought that
16 the case study approach would be a valuable
17 use of time, is to take the discussion that we
18 had yesterday around these various decisions,
19 and play them through an example, to see if,
20 you know, how these would really work in a,
21 you know, in a mock situation.

22 To understand if we can refine the

1 types of questions. Let me rephrase that. If
2 we can refine the type of -- the decisions
3 that we spoke about yesterday, through the
4 perspective of an actual case.

5 So, are there any questions about
6 what the objectives are? Because once we
7 break I'd like to just really be able to
8 quickly get started with the activity, once we
9 get into our small groups.

10 MS. WILBON: Just to add on a
11 little bit to that. So, when we get into the
12 break out groups, you'll have a facilitator.
13 And we'll also ask one person from each group
14 to kind of come back and share with the full
15 -- to represent their group and share with the
16 full group kind of what we came up with.

17 We'll have papers to kind of put
18 up, so you can kind of see if there's
19 anything, common themes across the groups, and
20 so forth. And then I think we'll have about
21 15 minutes, or about 20 minutes per group to
22 present and have any discussion about those

1 individual cases. So just so people are kind
2 of thinking about that.

3 MS. O'ROURKE: Thanks, Taroon and
4 Ashlie. So, we've developed these cases to
5 represent a number of conditions and consumer
6 types. And to demonstrate the ways that cost
7 and resource use information can really
8 support a consumer when they're facing
9 decisions about whether care will be
10 affordable for them.

11 So we're really looking for the
12 groups to explore, what are the decisions that
13 your case would, patient would need to make
14 with, as they move across these various
15 different phases of the episode of care?

16 And then what information about
17 cost and quality would that patient want to
18 support their decisions? And then finally,
19 what are the factors some of these other
20 things we talked about, like insurance status,
21 a person's income, their health literacy,
22 their health status, that might impact that

1 person's decisions? And what information they
2 want to make them? Are there any questions?
3 Or that we can give you your assignments?

4 (Off microphone comment)

5 MS. O'ROURKE: We've got groups
6 divided. We've got a slide.

7 (Off microphone comment)

8 MS. O'ROURKE: Yes, we're going a
9 couple of different place. So actually, we'll
10 be taking Group A, who will be doing the
11 first, Case 1 on the paper that we passed out
12 this morning. She'll be taking you to our
13 small conference room down the hallway.

14 Group B will be doing Case Number
15 2. And Liz and Taroon will be taking you to
16 our conference room on the eighth floor.
17 Group C will be staying here and doing Case 3,
18 with Melissa as their facilitator, and Lindsay
19 and myself as support. So I think, are we
20 ready to go? Any questions?

21 MR. AMIN: Yes, we're ready to go.
22 I would just ask Group B to just meet us right

1 here in the front of the hallway. And we'll
2 all walk down to the eighth floor together.

3 MS. WILBON: If Group A wants to
4 meet by the clock right here, we'll go off
5 over to the other room.

6 MR. AMIN: Also, if you could just
7 bring you name tags. Ron, if you'll bring
8 your name tag with you. Oh, no, sorry, the
9 table tents. If you could bring your table
10 tent with you.

11 (Whereupon, the meeting in the
12 above-entitled matter went off the record at
13 9:27 a.m. and back on the record at 11:07
14 a.m.)

15 MR. AMIN: So, maybe you guys can
16 get started with Group 1. I don't know who
17 your representative is.

18 MS. WILBON: Yes. So, we're Group
19 1, and we had Case Number 1 about Joe. And
20 Alyssa is going to be our spokesperson. I
21 wonder if we could get you a mic. Oh, you
22 have a mic. Great. Okay.

1 MEMBER KEEFE: Testing, testing.
2 So, apparently we had Corey's mom, but not
3 Joe. So this really resonated with Corey for
4 us. We had a really good group. Did you say
5 to read it, Ashlie?

6 MS. WILBON: Yes.

7 MEMBER KEEFE: Okay. So Joseph's
8 a retired 65 year old accountant. This is
9 key. Who's newly enrolled in Medicare this
10 month. Because he retired at 62 he's not had
11 full coverage for the last three years.

12 He currently lives with his wife
13 in a single home that they own in the suburbs
14 of Maryland, where he has three adult children
15 who often visit. Joe goes for long jogs with
16 his wife every week and is an active tennis
17 player.

18 Since he was uninsured and has
19 been feeling good, and seemingly healthy over
20 the last few years, Joe has held off getting
21 the screenings recommended for his age group,
22 and has not seen his primary care provider.

1 Two days ago during a family
2 dinner, he started to experience some
3 shortness of breath, chest discomfort and
4 lightheadedness. Since then the symptoms have
5 gotten worse. Joe's family physician is
6 currently out of town. And now Joe is waiting
7 in the ER at his neighborhood hospital.

8 It goes on to say that later Joe
9 is admitted to the hospital and is told that
10 he needs open heart bypass surgery. They'd
11 like to schedule surgery within a week. After
12 his surgery they anticipate he'll need to be
13 discharged to inpatient or outpatient cardiac
14 rehab.

15 So, we made a lot of assumptions
16 about Joe. So just go with it. And we made
17 it based on some key things within the study.
18 I'm sorry, within the case study. First and
19 foremost, he's newly enrolled in Medicare. We
20 did not make an assumption.

21 We talked about it, but we didn't
22 say he's, you know, Medicare Advantage or

1 fee-for-service. He is insured. And we
2 recognize that they will have different out of
3 pocket costs. So he's newly enrolled in
4 Medicare, but he is insured. But this is a
5 gentleman who has not necessarily accessed the
6 system.

7 He's an accountant. And we
8 believe he made some calculated risks about
9 not having full coverage prior to his
10 enrollment in Medicare. So at 62 it says he's
11 not had full coverage. So we assumed he had
12 some catastrophic coverage.

13 We assumed maybe his
14 socio-economic status was somewhat more
15 affluent, where he had this choice to not only
16 have the means for accessing health care.
17 That he only needed perhaps a backstop of
18 coverage. And that because he was otherwise
19 healthy, you know. This is a guy who runs and
20 plays tennis with his wife.

21 Again, it was at an income level
22 where he could retire early and still live in

1 the Maryland suburbs. And that's, you know,
2 not exactly a cheap place to live. Otherwise
3 healthy, he has adult children. It seems like
4 he has family support.

5 So when we're thinking about the
6 attributes, and the other parts about what
7 would go into some of his decision making,
8 these are the things that we thought about in
9 our head. We also noted that he was likely
10 probably pretty disciplined about his health.

11 As an accountant, and making these
12 calculated risks about types of coverage. He
13 also made time to do, you know, jogs and --
14 But at the same time, because he's had no
15 preventative care, he hasn't had any baseline,
16 you know, information about his health.

17 So this is a, you know, an
18 emergent issue that has happened to him. So,
19 anything else I forgot in our attributes? So
20 this is kind of like a what we've created Joe.

21 So we start with our first bubble
22 in staying healthy. This is an individual

1 who, he could have opted out of Medicare. He
2 did not. He enrolled. You know, we assume,
3 you know, obviously if you have resources it
4 may or may not be something that you choose.
5 Most people do.

6 But again, we assumed all choices.
7 And we talked about when he is in this staying
8 healthy, and he had to choose insurance, you
9 know. We talked all about his three years
10 prior. He chose more of a catastrophic plan.
11 Now he's in a Medicare plan.

12 He's thinking through, you know,
13 what are going to be his expenses under this
14 coverage, inpatient and outpatient. If you're
15 Medicare that's pretty set. And if you're in
16 a fee-for-service. The decisions that you
17 have to make about whether or not you have a
18 PCP.

19 Sometimes you're assigned a
20 Medicare PCP, depending on what plan, or what
21 you're in. He had to obviously, when he's in
22 this bubble, he's choosing to engage in a

1 healthy lifestyle, as we've talked about.

2 And then we got to the point where
3 there was the decision to go to the ED, during
4 the chest pains. And we talked about that a
5 lot yesterday. And I think that was
6 definitely a moment for many of us, thinking
7 through whether or not to go or not. And then
8 which ED to go to.

9 So those are some decisions that I
10 think he was thinking through. Now, when
11 you're having an emergent cardiac event,
12 you're not likely to get on Hospital Compare
13 to figure out, you know, you're ED wait times,
14 or any quality information that may or may not
15 be available there. But we did look.

16 In thinking through that decision
17 we were thinking about the information that
18 was available. And again, the same
19 information needed when picking his plan,
20 thinking about a premium versus out-of-pocket
21 deductibles and costs. Whether or not you
22 need supplemental insurance for the Medicare

1 beneficiary.

2 And there's a bunch of information
3 that's available, that is out there to go
4 through. I think many of you know Medicare
5 has open enrollment to choose plans. So we
6 were thinking it through, everything from him
7 choosing his Medicare plan, all the way
8 through his decision to go to the ED in this
9 section, in this bubble.

10 Any questions about that? Or
11 anything that I missed? Okay. So now we're
12 in the second bubble. This is the treatment
13 bubble. It says that he was admitted. Once
14 he's in the ED he was admitted.

15 But he has this window. There's a
16 week time where the ED physician, or whomever
17 he's seen, the admitting attending says, you
18 need open heart surgery. A lot of people,
19 we've decided, a lot of general consumers who
20 may not have access to the system, and they've
21 had an emergent event, will schedule that
22 surgery that day, and have it in that hospital

1 that day, with whomever the physician is that
2 they are recommended.

3 And that's Corey's mom's
4 experience. The rest of us were also
5 thinking, well, there's this window. A lot of
6 people don't have a window of time. And what
7 information would they like in making those
8 choices. So I appreciate the people in the
9 case study that gave us the window of time.

10 So, decisions about both cost and
11 quality in this window. And I think many of
12 us may have experienced this when you have a
13 window, and you're given a treatment option,
14 and you phone a friend.

15 But there's also whether or not
16 that friend provides either word of mouth
17 information about decisions you're making, or
18 if you're like me and you get on Hospital
19 Compare, and you look at where you were at,
20 and you look up health grades and the
21 information.

22 We thought that the decisions that

1 this particular, that Joe was going to make,
2 choosing a surgeon, perhaps getting a second
3 opinion on whether or not open heart surgery
4 is the most appropriate treatment plan.
5 Choosing the facility, which goes, has a lot
6 to do with when you're choosing your
7 physician. Choose whether or not to have that
8 surgery.

9 I think we all said that at
10 certain points some people may opt out. We're
11 not making a whole lot of assumptions about
12 his condition here. But we just wanted to
13 make sure that's always a decision that people
14 make. And decision to be compliant in that
15 period of time between when you've been
16 discharged, and you schedule that surgery.

17 Because I think oftentimes there's
18 prescriptions, and things you should or should
19 not do in anticipation of any treatment. So
20 in making those decisions, both about cost and
21 quality, information we wanted, or we thought
22 Joe would want, or outcomes for the surgeon

1 during the procedure.

2 As I mentioned, Google searching,
3 asking friends, position groups, looking at
4 Hospital Compare, whether or not there's any
5 information about heart procedures, mortality.
6 There's also Joint Commission Quality Check in
7 Maryland where this hospital, this patient is.
8 They have their own website. General
9 research.

10 Again, once you have a treatment
11 plan I think a lot of people think to go on
12 WebMD. And there's information that's there.
13 And we talked about what isn't there.

14 And I think what a lot of us felt
15 was the level of specificity for that specific
16 condition, and exactly being able to locate
17 that doctor timely and easily is, I think we
18 all recognize, a challenge with reliable
19 information, which is something we all strive
20 for. Wanting to know how long they'd be in
21 the hospital, because that will have a, again,
22 an affordability issue.

1 What it would be, your out of
2 pocket. Again, this is dependent on your plan
3 or if you're in fee-for-service. Oh, another
4 place to look, Consumer Reports and Leapfrog,
5 and other places that would go into a lot of
6 these decisions.

7 We were just listing off a list of
8 things and places people could go and find
9 information. And whether or not its
10 comprehensive enough to make your decisions,
11 you know, is obviously something that folks
12 have to take into account. But you get some
13 directional information.

14 Any questions? Or anything I left
15 out about Joe here? Okay. So then we debated
16 whether or not Joe had treatment. We talked
17 about how evasive his treatment is, and what
18 kind of cardiac rehab would he have? And, you
19 know, this is, where to get this cardiac rehab
20 is a question and a decision.

21 And again, when you think about
22 setting and treatment, you're thinking about

1 the cost of that treatment. And how do you
2 get information about that? I think you get
3 a list of resources obviously when you're
4 discharged, about where you can go and what
5 setting. But again, depending on the outcome.

6 We talked a lot about, well, did
7 Joe have a good outcome or not have a good
8 outcome? I mean, those are things that you
9 don't know. So regardless, you're thinking
10 through, what is the most appropriate setting
11 for this rehab that it says that he would
12 likely have? Whether or not to be, again,
13 compliant.

14 I mean, when you're covered you
15 have drug coverage under Medicare. Whether or
16 not you're compliant. How costly that is, is
17 still, depending on what plan you're in, was
18 information and questions that Joe might have,
19 again, going into his decisions about
20 affordability.

21 We thought about Joe choosing to
22 stay healthy. Is he going to join a gym and

1 continue his long jogs? And what is he doing
2 to contribute to lowering his risk for a bad
3 outcome? Will he be -- A recommendation may
4 be to see a dietician or a nutritionist.
5 Those also have likely out of pocket costs
6 that are associated. Decisions about
7 follow-up care.

8 This is an individual who we don't
9 believe had fully accessed the system. And
10 maybe he didn't like his provider in the
11 hospital. Maybe he wants to go find a new
12 one. But there's this whole decision that you
13 have to have about continued follow-up care.
14 And that has a cost associated, obviously.

15 And it just loops back to all the
16 same kind of decisions and questions, and
17 information, initially on onset of treatment.
18 It just repeats, I think is what we were
19 thinking.

20 Then we also just talked about
21 some of the other related issues for cardiac
22 patients, potential for depression, or other

1 behavioral health issues that may manifest.
2 That also may mean to seek treatment. And
3 then it becomes another set of questions and
4 decisions about finding a high quality, low
5 cost provider.

6 And so, again, the same issues
7 about information. There's a lot less
8 information. I think we would note about
9 what's the appropriate setting. And this all
10 goes to, well, did they really have, you know,
11 open heart surgery?

12 We kind of debated a lot of that.
13 The cost of the medications, as we talked
14 about. The side effects and risks of any such
15 medication, and what effect that would have
16 potentially on lifestyle. Full payment costs
17 for follow-up care. Again, an affordability
18 question.

19 And where to go to get info if
20 this happens, these other side effects or
21 unintended things that may manifest as an
22 outcome from his illness. That's where we

1 ended. Did I, anyone else? Thank you.

2 MR. AMIN: So, I think we're going
3 to have a great tag team with Paul and Adam on
4 the second group.

5 (Off microphone speaker)

6 MEMBER SIERZENSKI: Yes, that's
7 not uncommon that they'll stage -- The only
8 people who go emergently to the --

9 (Crosstalk)

10 FEMALE PARTICIPANT: It's okay.

11 FEMALE PARTICIPANT: So the
12 question was?

13 MEMBER SIERZENSKI: So, the
14 question was, is it normal for patients who
15 are admitted to the hospital with chest pain,
16 who are determined that they need cardiac
17 surgery, to be discharged home and have it
18 scheduled an outpatient? And the answer is,
19 it's not uncommon.

20 So generally, if someone comes in
21 with an acute myocardial infarction, many of
22 those patients will go immediately to the CAC

1 lab if they have certain criteria. It's
2 usually managed in that invasive approach.
3 But it's not uncommon that some people will
4 have --

5 It's actually rarer that people
6 come to the hospital and the ED, and go
7 emergently for CABG. That's the rarity.
8 Oftentimes folks may stay in the hospital to
9 get that done. Sometimes folks will be
10 discharged. Do you want to go first? Or do
11 you want me to go first? You want to pick a
12 transition point?

13 (Off microphone comments)

14 MEMBER SIERZENSKI: I could keep
15 talking all day.

16 (Off microphone comments)

17 MEMBER SIERZENSKI: Okay. Well,
18 good morning. I'm Paul Sierzenski. I'm
19 helping and tag teaming here with Adam to
20 discuss Case B, or 2. So Case 2 is, Lisa is
21 a 43 year old pharmaceutical sales manager,
22 living in New York City, the city that never

1 sleeps, with a history of multiple myeloma.

2 She has private insurance through
3 her employer, and visits her oncologist on a
4 regular basis for blood work and an annual
5 lumbar puncture to check for spinal fluid.
6 Her blood work and previous LPs have been
7 coming back normal, until recently, when her
8 oncologist told her that she will need another
9 bone marrow transplant. So she's had one in
10 the past.

11 She will need to be admitted to
12 the hospital for several weeks to receive
13 chemotherapy and the transplant. Her doctor
14 has privileges at several area hospitals. And
15 she will need to choose which to have her
16 treatment at.

17 Her doctor has mentioned that
18 there are several new chemotherapy drugs on
19 the market that she can consider to have with
20 her treatment. Each will have varying side
21 effects, costs and risks.

22 Following the transplant she will

1 need to remain on sick leave for several weeks
2 to regain her energy, and to assure her immune
3 system is sufficient for public interaction.
4 She may also need home health care for ongoing
5 care, by a nurse, to monitor blood cell
6 levels.

7 So in our initial assessment of
8 this we first decided what age group that we
9 thought Lisa was in. I mean, our first
10 thought that this is obviously a very
11 catastrophic diagnosis for her, given the fact
12 that she is in remission, but isn't
13 traditionally like a chronic disease state
14 patient, even though she has maintenance and
15 follow-up components to that that are
16 periodic.

17 So the concept is that she's
18 primarily in follow-up, and is experiencing a
19 relapse. Once again, the disease is myeloma.
20 That she has been in this state of probably
21 anxious watchful waiting while in remission
22 for this. So that she's in the surveillance

1 period, but is now ready to transition into an
2 acute episode, or an acute care period.

3 From the standpoint of the
4 decisions, the first, which Adam was keen to
5 initially, you know, key us in on was the fact
6 that she acknowledged this diagnosis. I mean,
7 once again, when people bring up cancer it is
8 one of the diagnoses that, generally if
9 someone's having chest pain and has cardiac
10 complaints, you say, you've got cardiac
11 disease.

12 I think generally the level of
13 acknowledgment and acceptance of that may be
14 a little more straightforward. This is a
15 young woman who's had this condition before.
16 Does she acknowledge the fact that she has
17 this diagnosis? And then the next big
18 decision question for her is whether to do
19 something about it.

20 Do you want us to go, and then do
21 the factors and back and forth, and stuff?
22 So, okay. So, why don't I take the first two

1 or three, and then we'll go from there. Okay.
2 So, whether to do something about it, and what
3 are her options?

4 So, if we move on initially to --
5 zero is, what is the disease, and overall? So
6 she's been diagnosed, or told that her
7 diagnosis is a relapse of her multiple
8 myeloma. So she's, this is a educated
9 individual who's been through this process
10 before.

11 So she's engaged in a health care
12 system in the past. But now she's got this
13 new potential devastating diagnosis. With
14 that, and with the concept of a remission, you
15 know, how are other people dealing with, or
16 how have other people dealt with this?

17 So really, what is her support
18 model that she has, that may have a
19 significant impact for her, given that this is
20 a recurrence of a disease? So those points of
21 information, overall whether to accept this,
22 we think will be important.

1 The factors that we think relate
2 to this are overall her knowledge of this
3 condition that she's had, and potentially what
4 factors play into this remission. The overall
5 sense of fear. This is a woman who's been
6 through this before, and now is getting, you
7 know, a potentially devastating life shock.

8 And obviously, educational culture
9 aspects and her beliefs, now that this is a
10 recurrence of this condition. From the
11 standpoint of whether to do something about
12 it, we found through our discussion that there
13 is almost a kind of key architecture of both
14 information, as well as factors, that relate
15 to almost every one of these decisions.

16 And so, as Adam will discuss,
17 we've kind of asterisked those. But from the
18 standpoint of whether to do something about
19 it, the first was the issue of cure potential,
20 which varies for disease, and certainly varies
21 for this disease. The side effects of the
22 treatment overall, you know, side effects.

1 We talked about risk benefit aspects,
2 but also the overall side effects, given the
3 fact that this is a healthy young person until
4 this recent diagnosis overall. How long off
5 of work she is. The lead-in tells us that
6 she's going to need several weeks of recovery.

7 And so there's an acute aspect to
8 this, as well as potentially a longitudinal
9 aspect to it. And it tells us that she's
10 employed, and that she has insurance. But
11 what about the employer's component? So we
12 dive into the issue of the insurance plan.

13 And we also didn't get into the
14 nuts and bolts of whether, you know, how much
15 she might have to pay. But we know that those
16 will likely be factors for her. And we define
17 that as kind of the generosity of her health
18 insurance. Specifically information for the
19 benefit and risk, given again that this is a
20 recurrence of a disease that she's had in the
21 past.

22 Is the overall cure the prognosis

1 of this? The side effects, the overall
2 mortality, is certainly something for her to
3 consider, and is information that she will
4 need. And the family effects. Obviously,
5 well, we'll talk about that in factors.

6 So that kind of backs up the
7 overall decision to do something at all. For
8 the factors that affect that, we talked about
9 her employment status. We know that she's
10 employed. Her social support network is going
11 to be key here, especially with this
12 recurrence of this disease, and the community
13 level of infrastructure.

14 Now, she lives in New York, which
15 has a multitude of institutions to potentially
16 go after for treatment. And I'll leave that
17 for Adam, as it talks about, you know, where
18 to get help potentially for her. The quality
19 of the medical care in that community we think
20 is going to be a key factor for her,
21 especially given the fact that this is a
22 recurrence of her disease.

1 Personal characteristics,
2 certainly are going to play into factors for
3 her. She's 43 years of age. She's a young
4 woman. She has an active, obviously
5 successful professional life as a
6 pharmaceutical sales manager. What is her
7 overall risk tolerance, as was discussed
8 before with this.

9 We did address issues such as her
10 religion, her values, and her overall culture.
11 We don't get a real sense of that with her
12 history here that's provided overall. Past
13 experience, such as her past experience with
14 a previous therapy treatment. Was that done
15 in New York, or was that done someplace else?

16 And then obviously, financial
17 status, which can't be ignored. I mean, she's
18 fully, she's got private insurance right now.
19 But we don't know about her debt burden. And
20 then we also brought up some other issues that
21 we think are fairly unique to this type of
22 disease, which is, what about legal aspects

1 for her?

2 I mean, this is a recurrence of
3 multiple myeloma, or is suspected to be. What
4 about her overall legal management of dealing
5 with her employer? If she's with potentially
6 a will or advance directives? That may seem
7 a little bit morbid. But for anyone who's had
8 cancer, they may have thought about that. And
9 they may certainly need to.

10 And we presume though, even though
11 we don't have input, her educational capacity
12 and literacy is, would certainly have an
13 impact in her ability to make the decisions,
14 and how to effect a decision. But she seems
15 like an educated consumer, and now entered in
16 again as patient. Adam?

17 MEMBER THOMPSON: So, after she's
18 decided to acknowledge the diagnosis or not,
19 and what to potentially do, the next decision
20 we felt she had to make was choosing a doctor.

21 And when looking at that, the
22 information we felt she needed were the

1 experience and results of that physician,
2 familiarity, physician's credentials, the
3 patient's experience with the provider, the
4 availability, whether it's in network in her
5 health care plan.

6 The practice characteristics, like
7 how it's structured, and how they actually
8 practice, not as a hospital or as a physician,
9 but their practice. Did that make sense? Did
10 I explain that right? Okay. As well as
11 access to clinical trials.

12 You know, thinking beyond the
13 treatment that's available, but what is novel
14 that might be coming down the road. And also
15 asking, can you work with my medical doctor?
16 So that was as it relates to that.

17 We kind of bridge doctor and
18 hospital together, because we had a very
19 difficult time trying to pull those two apart.
20 Even though we recognize they were two very
21 different environments.

22 So when we get to the factors, we

1 felt that a lot of these factors were both
2 provider and hospital factors. So that was
3 the availability of all of this information
4 that we said that she needed, as well as the
5 recognition of her role in health care, which
6 really speaks to patient activation and
7 patient engagement.

8 What is her prior experience?
9 What is the timing between when she can have
10 this surgery, so that she has time to make
11 this decision? What facilities are available
12 in her community to even have this done? Who
13 is the other person on the other end of the
14 phone?

15 We talked about people might
16 choose a hospital that was more kind to them,
17 which really has nothing to do with care. But
18 how quickly can I get a human on the phone
19 might impact my decision.

20 And then also for the hospitals,
21 we felt like their safety record, much like
22 the physicians, nursing quality, distance to

1 the person's home probably mattered. Whether
2 it was family-friendly? Like what is the
3 environment in relationship to their support
4 system? Is it a specialty hospital?

5 In particular, the issue was
6 raised that if someone had this condition they
7 would want an ICU in that hospital. So what
8 is available there? And again, what is the
9 reputation, and then the structural
10 characteristics, which was referenced, the
11 Leapfrog program again.

12 After looking at the doctor and
13 the hospital, the question then becomes when,
14 when to do this. And so when looking at that,
15 we felt the information she needed was, how
16 urgent is this? How long does she have? What
17 is the insurance process to do all the
18 paperwork to even pay for it?

19 And then looking at the
20 psychosocial aspects of her life, like what is
21 going on her family to even begin this
22 process? And do things need to be put in

1 place before this can happen?

2 Looking at pets, we had a big
3 discussion about pets. And people laugh. But
4 we had many examples in the room about how
5 people chose their pets over their care.

6 The length of the treatment and the
7 follow-up. So that when looking at scheduling
8 this, it's not just the surgery, but what's
9 going to come down the road as well. The
10 availability of providers, and then the
11 logistics on care coordination. How is this
12 all going to take place?

13 And the factors that we felt that
14 were appropriate here to when is, is she
15 ready? What is her readiness to actually do
16 this? What is her previous experience, as
17 well as emotional and mental health. You
18 know, is she emotionally ready to be engaged?

19 And then her other life factors,
20 what's going on legally, financially. And
21 then at the very end we had -- Oh, no, we had
22 two more, sorry.

1 Arrangements for her follow-up
2 care. And for this we felt that the
3 information that we needed are, what are the
4 clinical, social and medical needs going to be
5 in her follow-up care? As well as, what are
6 the other wellness options, that maybe aren't
7 prescribed, but that needed to be factored in,
8 such as yoga, exercise routine, healthy
9 eating.

10 We were looking at quality of
11 life, as well as, what is the projected
12 timeline? Not only for the treatment, but
13 through the follow-up care, and then back to
14 work.

15 And we talked a lot about getting
16 it as being back on the soccer field. Like
17 when can that happen? We talked about her
18 employment factors, really looking at this.

19 You know, will her employer even
20 let her leave to do this? And if not, does
21 she have to schedule that with her employer to
22 make it even possible.

1 As well as coverage after her
2 services. You know, what is actually going to
3 be paid for. And then we came to this last
4 decision, which was, then she has to decide
5 how to tell her employer what's happening.

6 And so we felt like, when looking
7 at how to tell the employer, we needed to know
8 coverage, what are her habits in the past?
9 Like how quickly is she going to recover? And
10 what is her emotional state? Is she exhausted
11 from the process?

12 So, like how is this all going to
13 take place? And what is going on at her
14 employer to be able to assess that, to know
15 how to tell them? Did I get all that? All
16 right.

17 MR. AMIN: Okay, Liz, if you want
18 to add?

19 CHAIR MORT: I just want to thank
20 Paul and Adam for doing an awesome job in
21 summarizing that. I was wondering how that
22 would go. You did a beautiful job. There

1 were just two things I wanted to add.

2 Remember, we got about two thirds
3 of the way through, and someone said, well,
4 this person is an employed pharmaceutical rep.
5 And so, you know, we had a mental model of who
6 she was. What if she was a 43 year old
7 immigrant from Laos, or Cambodia?

8 MEMBER THOMPSON: Yes. We talked
9 about cultural --

10 CHAIR MORT: Didn't speak English.
11 Didn't have a family. I mean, just think
12 about how difficult that was for some MBA in
13 New York City. What about if you were dealing
14 with someone with an entirely different
15 cultural framework?

16 The other point that we made at
17 the end was that this was a wish list. And,
18 you know, the gap is between how to get from
19 current state of no information, information
20 you know how to get to, how to assimilate it,
21 to something that would really help this 43
22 year old woman make a decision. So it was a

1 really, really good session. You guys did a
2 great job summarizing it.

3 MR. AMIN: Okay. A representative
4 from the third group?

5 CHAIR THOMASON: Yes. That's us.

6 CHAIR MORT: Raising the bar with
7 a Power Point.

8 MR. AMIN: Oh, wow.

9 CHAIR MORT: Wow. Good job.

10 CHAIR THOMASON: Do not be
11 impressed with Melissa. Melissa did not do
12 that power point. Okay. No, actually right
13 then Ron comes up. I mean, he's like, hey, I
14 have a Power Point. Do you want to use it?
15 I was like, that's why you make the big bucks,
16 baby. Okay. I feel weird talking to this
17 microphone.

18 Case Number 3. Christina is a 38
19 year old IT consultant, and mother of a 4 year
20 old boy named Jacob, with cerebral palsy, two
21 other children. When she selected her
22 insurance plan initially she thought she would

1 have adequate coverage for her and her
2 family's health care needs.

3 However, she is finding that she's
4 still paying a significant amount of out of
5 pocket costs for medications, equipment,
6 management and treatment of her son's
7 conditions.

8 In order to cover these costs, she
9 and her husband both needed to work full time,
10 and depending on Christina's mother to care
11 for Jacob during the day.

12 Her husband was recently laid off
13 from his job. Now Christina's the sole income
14 provider. The family recently had to move in
15 with Christina's mom. They lost their house.

16 Jacob is growing, and in need of a
17 new wheelchair and ongoing PT, both of which
18 will require Christina and her husband to pay
19 some portion out of pocket. And the family is
20 seeking to transfer Jacob's care to another
21 pediatric neurologist near her mother.

22 Is there a volume on this

1 microphone? Can we turn it down a little bit?
2 We can't? I feel overly dramatic. Okay.
3 Thank you. Okay. All right.

4 So we looked at these from really
5 the kinds of decisions she'd need to make. We
6 broke it down entirely different. I hope we
7 followed our assignment. Maybe not.

8 But we looked at, she really needs
9 to make, in essence three kinds of decisions,
10 insurance decisions, community resource
11 decisions, and the choosing a provider
12 decisions.

13 The first kinds of decisions, for
14 insurance, it came down to, really she's in a
15 unique place right now. Her husband just lost
16 his job.

17 And then with all the changes with
18 the Affordable Care Act, she needs to say,
19 hey, maybe there are other insurance options
20 out there right now. Maybe we need to start
21 looking at some of them.

22 So, first decision, would a change

1 in insurance really be beneficial to us in
2 this new market, at this time? As the husband
3 begins to look for a new job, he really needs
4 to be conscious of the insurance of that job.
5 We talked about, so what does he need to know
6 about that insurance?

7 Well, things like deductible,
8 annual max, out of pocket payments,
9 prescriptions, medical equipment's big for
10 them, their premiums per month, out of pocket,
11 what's this going to cost me? My co-pays, the
12 doctors that I already use, are those in this
13 network?

14 And we think, so we had this
15 conversation of, well, if you go to an
16 employer and you start asking those
17 conversations, they're going to red flag you
18 big time. And say, this person's going to
19 cost me a ton of money in the long run.

20 So I was like, well, because we
21 had Joe in our group. He had to leave early.
22 He had an appointment with his wife. But he

1 was saying that insurance companies, they have
2 all these indicators anyway of these quality
3 indicators. And then they have all of these
4 other things they look at, that they're
5 already measuring.

6 But none of that is available to,
7 on the consumer side. So if all these things
8 are already being measured, why can't we
9 translate them for the consumer? Even in
10 things like, if I'm going to go to an
11 employer, why don't they have to be completely
12 transparent?

13 Like, if it's a small employer,
14 they probably don't have a custom policy. So
15 if they say, well I use Blue Cross/Blue
16 Shield, I could go on line and look at things
17 like annual max and out of pocket, and
18 deductibles and co-pays. So that I can really
19 shop my company too, as well, as he looks for
20 a new job.

21 Can she get a case manager at her
22 insurance company? And of course, the

1 prescription limitations. So the second kind
2 of decision she would make would be community
3 resource decisions. And for a child with a
4 chronic illness that's a really big deal, as
5 Maureen was telling us.

6 So one of the biggest things
7 Maureen was saying was, she really needs to
8 find out if there are other resources out
9 there. And she needs a social worker. So,
10 does she already have a social worker? And
11 can she work with a social worker to see if
12 she's covered by any state sponsored programs
13 for Jacob?

14 She needs to know what is
15 available, what's out there. And she needs
16 someone to help her navigate the system. Can
17 her mom get paid for taking care of Jacob?

18 I have several friends through the
19 Loeys-Dietz Syndrome Foundation that actually,
20 one of my very good friends actually gets paid
21 for taking care of her chronically ill child.
22 So is that something her mom could do?

1 And what would the requirements be
2 for her mom to do that, to increase
3 affordability for them? What resources are
4 available through school already, for free?
5 And how can she use those?

6 Through early intervention
7 programs school has to provide OT/PT, speech
8 and social workers. So she needs to decide if
9 the PT and OT that is already available is
10 good enough for Jacob. If they're providing
11 enough of it. If it's just school centered
12 and she needs more of it.

13 If it's adequate, she's good. If
14 it's not, then she has to look into paying for
15 extra PT. And in that extra PT it is, what
16 does my insurance allow? What is the number
17 of sessions? What is my co-pay for those
18 sessions? And of course, she has to pick a PT
19 provider. So it will come down to out of
20 pocket expense when she's picking a provider.

21 And then are there community
22 organizations? Especially with durable

1 medical equipment, there are lots of community
2 organizations that can help sort of alleviate
3 the major cost of that.

4 Maureen was saying that there are
5 community programs that actually recycle
6 durable medical equipment. And making her
7 aware of those would be really advantageous to
8 her.

9 The last was, how does she pick
10 her provider? And, hold on, that's one of
11 these papers, guys. There we go. Oh, by the
12 way, we spent the first 20 minutes saying how
13 much we didn't like that bubble model. And
14 now we have a chronic care model provided by
15 Helen that we really like.

16 Okay. That was just us. Sorry.
17 And then the last one, so choosing a provider.
18 Of course she needs to know if this new
19 pediatric neurologist, when looking for one,
20 does he take my insurance? Is he going to be
21 part of a practice? Or is he an individual
22 provider?

1 If he is part of a practice, what
2 does the practice offer as a facility? Do
3 they have PT in house, social workers provided
4 to help me navigate the system, or anything
5 that she can do it all together?

6 And then one of the biggest
7 questions we had as consumers was, why is she
8 switching pediatric neurologists? And we know
9 that she needed a provider closer to her mom.
10 But once you get a place that really works for
11 you, it would be really rare for me just to
12 switch my care.

13 Because a pediatric neurologist, I
14 only see my neurologist about twice a year.
15 And I would drive several hours to see him if
16 he was already familiar with my case. So is
17 it even necessary for her to switch her care?
18 And then, if it is, of course she needs to ask
19 these other questions.

20 We think she should go to a CP
21 clinic. I switched my care particularly
22 because there was a specialty clinic for that.

1 And they seem to be much better with helping
2 you navigate all your options.

3 So, is there a CP clinic
4 reasonably close to her? Would this new
5 provider be willing to work with her other
6 providers? And to pull information from a
7 previous provider?

8 We talked about patient
9 centeredness. When you talk about patient
10 centered care, so you say, she should say, she
11 should evaluate if it's a patient centered
12 care facility. How do you do that? Like, do
13 you go to the doctor and say, are you guys
14 going to be nice to me? And I don't know.

15 So we talked about measures in
16 patient centered care, things like caps and
17 different things. But from a consumer
18 standpoint, it's really hard to evaluate if an
19 institution is patient family centered until
20 you go there. So I'm not sure if that's even
21 feasible.

22 And then of course, at the end of

1 the day, she's going to want to know her out
2 of pocket expense, and what's real world going
3 to come out of her pocket. And too, I think
4 it would be beneficial to know if they use
5 e-prescribing, so that her prescriptions would
6 be paid for.

7 Does anybody in my group have
8 anything to add? Okay. Oh, I lied. Sorry.
9 We have more. So one of the biggest things we
10 pointed out was, Maureen said, have you
11 noticed that when we all start talking about
12 affordability, it lasts for three seconds?
13 And then we're all talking about something
14 else like quality and different things.

15 So there really was just a common
16 theme. And again, reiteration of that
17 affordability can't be considered in
18 isolation. It's not in a vacuum. It is
19 always within the realm of these other
20 factors. That affordability to us meant
21 actual out of pocket costs.

22 And that we didn't know, unless

1 she has, I mean, an incredible health literacy
2 component to her life, that she could navigate
3 this without that social worker. That
4 navigator and finding it would be really
5 important.

6 MS. WILBON: So, any thoughts from
7 the groups about other groups that you were
8 not a part of? Or questions for other groups?
9 I think we're sitting here, kind of discussing
10 on the side. There are a lot of common themes
11 between the groups, which is great. Because
12 we were hoping that we would start to find
13 some commonalities.

14 And I think even something, a few
15 things we hadn't pulled out in the broader
16 discussion, which is great. So any feedback
17 from the group? We have about ten minutes
18 before we're scheduled to go to lunch, I
19 think.

20 MR. AMIN: No, we take public
21 comment.

22 MS. WILBON: Oh, public comment.

1 I'm sorry. So let's take a few comments.
2 We'll go to public comment and then break for
3 lunch. Yes, go ahead, Cynthia.

4 MEMBER ROLFE: I just wanted to
5 build on something Melissa was talking about
6 with patient centered. Because we spend a lot
7 of time, and we're spending a lot of time
8 right now, trying to understand how to talk
9 about all the different innovations we call
10 payment innovations, or care delivery
11 innovations behind the scenes. And helping
12 people understand what that means to them.

13 And I think patient centered is a
14 very interesting -- Patient centered medical
15 homes is a very interesting term. Because
16 when you say it, it's how we view it behind
17 the curtain, if you will. But patients have
18 a very different view of it. If it's patient
19 centered, it's pretty much what I want.

20 And I think we in this system need
21 to be really cognizant of what we say, and how
22 people are going to think it should feel,

1 based on how we describe it. It's a really
2 important call out that you made.

3 CHAIR THOMASON: One of the things
4 that we talked about. So, Joe was in our
5 group. And he would say -- I said, so if you
6 were going to pick a doctor, you, what would
7 you do? And he was like, oh, yes, I would
8 look at this. I would look at the quality
9 indicators.

10 I would, you know, I was like,
11 what are those quality indicators? How does
12 the insurance company decide if these guys are
13 going to make more money, because they met
14 certain quality indicators?

15 And if we could bridge the gap
16 between all the data that the insurance
17 companies are measuring anyway, and somehow
18 consumers and those people could come together
19 and say, well, this too. Because it's
20 consumer centered and this is important to me,
21 you know.

22 And then I would have access to

1 the basic easy-to-use translated version of
2 that, to have some sense of measurable
3 quality. You know, I don't, I would love,
4 ideally that would great.

5 MR. AMIN: Karen.

6 MS. ADAMS: One thing we discussed
7 in our group, and I know it's been part of our
8 conversation over the past two days, is
9 behavioral health. And we spoke to, you know,
10 what was your emotional state during this
11 time, impacts there.

12 And so, I think certainly it
13 applies across all three case studies. But I
14 think, Liz, as you said, it's kind of an
15 overlay for a lot of this work.

16 MS. WILBON: So, Lisa?

17 MEMBER LATTS: Yes. I just wanted
18 to re-emphasize something that Liz had said,
19 that we talked about in our groups, is how
20 quickly we put ourselves in that position, or
21 a family member in that position or, you know,
22 our experience in the position of these case

1 studies.

2 And we are all, even though we do
3 have patients here, you know, the frequent
4 fliers, we're still all, you know, born in the
5 U.S., relatively homogeneous. And so we just
6 need to be sure that when we're thinking about
7 this, the ability to apply other beliefs and
8 other backgrounds.

9 MS. WILBON: Thank you for that.
10 Go ahead, Liz.

11 CHAIR MORT: I'm just digesting
12 those last two comments you made, Melissa,
13 about -- They were on your Power Point that
14 you flipped by so quickly. But the first one
15 was affordability is out of pocket cost, to
16 me, to the consumer.

17 And I think that's a really
18 important -- We struggled with that yesterday.
19 But that is what we're talking about. It's
20 how much you have to pay out of pocket which
21 determines whether you can afford it. And
22 that is a really nice way of summarizing it.

1 I think we really circled around
2 cost, payment, price, all that other stuff.
3 But that's what we're talking about. So the
4 second comment, which was equally helpful for
5 me is, it doesn't exist in a vacuum.

6 You're trying to make decisions to
7 get the best value, and make it affordable.
8 And that's sort of, that's what all this is
9 about.

10 What are the other data points,
11 information types, measures, that need to be
12 available? And that consumers need to be able
13 to get access to and figure out how to
14 navigate and make the right decisions.

15 So I loved the way you summarized
16 that. Because I think that if we had started
17 that way -- Well, we couldn't have started
18 that way, because we weren't there. But I
19 think the next step would be, okay, if that's
20 how we're framing it, then how does the rest
21 of it fall out?

22 CHAIR THOMASON: I will add too,

1 when we first got together Helen said, you
2 know this morning, when you said that, well,
3 yes, and the cost matters to you, because you
4 have this much medical bills, but you only
5 have this much income. So relatively, yes, it
6 impacts you a great deal.

7 And she said, that's a measure.
8 And I was like, oh, really, you know. But
9 really, my out of pocket costs in ratio to my
10 income. And that really determines if
11 something is affordable to me. And so, if I
12 had to put it in very basic terms, to me, yes,
13 that's what affordability means to me.

14 MEMBER WILBORN: Out of pocket
15 costs meaning premiums and co-payments?

16 MR. AMIN: Deb, then Cynthia.

17 MEMBER DAHL: I also appreciate
18 your calling out social workers as a key
19 component in the work. Because sometimes we
20 think about out of pocket costs, and you're
21 making the choice between medication and food,
22 as an example. And that's not uncommon.

1 And the social workers, and other
2 community workers can help you access services
3 that will help you make those decisions.
4 Because food is available in other ways that
5 you don't know. So it's not medical care
6 isolated, it's the entire environment where
7 you are.

8 So if you live in a very small
9 rural facility, you may not have access to,
10 you know, Meals on Wheels, or some of those
11 other services, that in a larger community you
12 would.

13 So, you know, I'm not meaning to
14 take it back to a more complex idea, but
15 thinking about all the other things that area
16 available to a person.

17 CHAIR THOMASON: At the very
18 beginning, when we were doing the model
19 conversation, Marci pulled a model. And, you
20 know, she said that .0003, right, percent of
21 a person's life is actually spent in front of
22 a clinician. And then all of the rest of the

1 time, you know, we focus so heavily on that
2 time we spend in front of the clinician.

3 Well, honestly, if the person who
4 provides most of my care, if I wanted to call
5 them my primary care provider, that would be
6 me. I mean, I really have to coordinate it
7 all. And I have to live my whole life. And,
8 you know, and I live it in schools and
9 communities, and in the framework of all of
10 that.

11 So I really think access and
12 community resources is important for people to
13 make care more affordable. There's a lot more
14 out there I think than we realize.

15 MR. AMIN: Cynthia.

16 MEMBER ROLFE: Out of pocket cost
17 is such a wonderful, simple idea. I
18 completely agree, Liz, that you amplified
19 that. The thing that, only in collaboration
20 we can solve is, out of pocket cost varies so
21 much depending on the care given.

22 So we get back to kind of the

1 scenario discussion of yesterday, which is,
2 how do you help people when they're choosing
3 a plan that might be right for them,
4 especially if you're your care coordinator,
5 Melissa? So you're the only one that has all
6 the pieces, right?

7 And how do we help people estimate
8 their out of pocket costs? It is a
9 significant challenge for all of us. But it
10 requires collaboration.

11 MR. AMIN: Maureen.

12 MEMBER EDIGER: I was just going
13 to expand a little bit on the suggestion with
14 the social worker. Really, with a case like
15 Christina's that we were talking about, that's
16 really complex.

17 Getting her plugged into a
18 academic medical center, or something that
19 might have a clinic specifically for her, for
20 her child rather, for Jacob, is going to
21 include things like having a social worker
22 that specifically knows what programs and how

1 to access some of the services that are
2 available.

3 And how to find the durable
4 medical equipment recycling organization that
5 was started by two parents, ten years ago, and
6 is in a warehouse. Like, you know, there's
7 all these like little things.

8 And so I think getting over that
9 misconception that social workers are only for
10 a specific population. That really, that half
11 hour with a social worker during part of your
12 once a year annual clinic visit, can have huge
13 affordability outcomes for a family.

14 MR. AMIN: Melissa.

15 CHAIR THOMASON: I just wanted to
16 ask. So just like --

17 MR. AMIN: Melissa, the mic.

18 CHAIR THOMASON: Forgot it again.
19 Just like something Liz was saying when we
20 were talking about out of pocket costs. And
21 it really can vary between the patients and
22 the certain visits, and the insurance

1 companies, and all of that.

2 But when I have to consider was
3 that affordable, I will still always go back
4 to, what was my out of pocket cost in
5 relationship to my total income?

6 And if we consider it like that,
7 it also becomes about the reason that I have
8 medical insurance is because if I have it with
9 the cost of premiums, and what the cost of
10 what I have to pay for medical bills while
11 having it, I still have to pay less money out
12 of my pocket than if I didn't have it.

13 It is a more affordable option for
14 me to have insurance, than to not. And I
15 think if consumers at large thought about
16 affordability like that, in the long run
17 perhaps there would be better conversations
18 around it.

19 MR. AMIN: I think that's a great
20 vision statement. So, Corey, let's take this
21 last comment, then go public comment. Because
22 I'd like, after lunch there's a whole

1 discussion around some of the challenges of
2 being able to get to that future state.

3 MEMBER WILBORN: Well, I think she
4 summed it up really good. But I think we do
5 know what our maximum out of pocket amount
6 would be, based on our plan. So we just have
7 to choose the right plan. Am I correct with
8 that?

9 CHAIR THOMASON: Well, I think you
10 and I do. I think you and I know our annual
11 out of pocket, because we're hitting it every
12 year. But not everyone with insurance -- We
13 have a whole group of people that are not
14 frequent fliers.

15 MEMBER WILBORN: But just saying,
16 premium plus maximum co-pays, or whatever co-
17 pays you pay, we still have a ballpark of,
18 okay, I know I'm paying \$4,800 dollars a year
19 for health care.

20 CHAIR THOMASON: Right. And
21 that's how I determine affordability.

22 MEMBER LATTS: You have to know to

1 look. And unless you've used it before, you
2 have to know to look. And most people don't
3 even know to look.

4 MEMBER KEEFE: And I would say,
5 even if you have been traditionally insured,
6 and you just even moved to, like what I did,
7 which is a high deductible with an HSA. I had
8 no concept of how to figure that out. And I
9 am pretty educated at trying to like determine
10 some of that stuff.

11 It's kind of akin to when you're
12 trying to do your dependent care of your FSA.
13 Like when I was going to get Lasik, I knew
14 Lasik was going to be \$4,000 dollars, like I
15 knew. But that's elective. And it doesn't
16 help you do the risk stratification that you
17 need to do to assess your out of pocket.

18 MR. AMIN: Cynthia, and then Lisa.

19 MEMBER LATTS: And obviously we're
20 simplifying here when we're thinking about out
21 of pocket costs versus total income. But I
22 just want to make sure that we explicitly, you

1 know, as we're thinking about a schematic for
2 this, that there's some consideration for the
3 other financial constraints on a family.

4 So, you know the number of
5 dependents, both little and big, you know.
6 The taking care of the parents in the nursing
7 home, for the sandwich generation. So there
8 are so many demands on a family's income that
9 it's obviously much more complicated.

10 CHAIR THOMASON: And then, as a
11 frequent flier, that total indebtedness really
12 comes into play. So the out of pocket max the
13 first year was affordable. It was only \$6,000
14 dollars. Well then the next year it was six,
15 and the next year it was six.

16 And by your seven, or eight or
17 nine, that out of pocket max is no longer
18 affordable. That is very true. And thank you
19 for pointing it out.

20 MR. AMIN: So let's take a break
21 here and go to public comment. I actually
22 have one more question I would like to ask

1 before we break for lunch.

2 But let's see if there's anyone on
3 the phone who has any comments. Maureen, I
4 assume you're okay. I see your placard up.
5 But okay. Operator, can you open the lines
6 for public comment?

7 OPERATOR: Yes, sir. If you would
8 like to make a public comment, please press *,
9 then the number 1 on your telephone key pad.
10 At this time there are no public comments.

11 MR. AMIN: Are there any comments
12 in the room? No. I think we're okay. So, I
13 want to just explore one, just so I want to
14 make sure we're sort of crystal clear on this.
15 Because I think this is also really important
16 for how we're thinking about the concept of
17 affordability for the final paper.

18 And, Cynthia, I'm actually going
19 to ask you to help with this framing for me.
20 So, we had this conversation about the actual
21 patients that are not necessarily the frequent
22 fliers.

1 So this concept of how you would
2 assess the affordability. Because you may not
3 be hitting the annual max, right? So not
4 every patient would hit the annual max. And
5 we talked yesterday about the inability or the
6 challenge of being able to predict future
7 utilization, for the purposes of really
8 understanding what your future costs would be.

9 But it seemed for those patients
10 that are not your frequent fliers, that are
11 not hitting the annual max, that you would,
12 the big challenge that we have here in
13 essentially saying, a priori, you know, your
14 good faith estimate of what your costs, out of
15 pocket costs are going to be for the next, you
16 know, for the next year.

17 Can you help me articulate what
18 the challenge is in the current state, to be
19 able to a priori give consumers a sense of
20 what their out of pocket expenses would be,
21 given the challenge with the inability to sort
22 of predict utilization?

1 MEMBER ROLFE: I think, I can't
2 speak for every plan, every insurance company,
3 what challenge they might face. But I can
4 tell you conceptually some of the things that
5 are challenging.

6 I think the biggest, the first
7 one, is that both consumers, the people
8 consuming the information and the people
9 creating the information would have to agree
10 that these are scenarios. So someone would
11 have to feel comfortable going in and saying,
12 this person's scenario, fictional person, is
13 more like me than the other ones.

14 And that would only give them a
15 sense of relativity to the other scenarios.
16 And it might be completely different from what
17 they actually experience. And there is every
18 likelihood it would be.

19 So even if we did, you know, 100
20 scenarios for each product, which nobody would
21 ever look through, really they're going to
22 look through three or five, that's human

1 nature.

2 We wouldn't hit every possibility.
3 And that's why actuaries exist, right? So
4 that's one thing I just caution us on. I
5 think, you know, there's a lot of data out
6 there. We'd have to do quite a bit of work to
7 come up with scenarios for every product.
8 Some products would be new, so we wouldn't
9 have any history. So we have to do some
10 educated guesses.

11 You know, that would be another
12 thing that might be a vulnerability of the
13 scenarios really being helpful. So there's a
14 couple of things I could think of right off
15 the bat.

16 MR. AMIN: Lisa, then Liz.

17 MEMBER LATTS: So just to add to
18 that. I think the problem starts to get into
19 when you start to estimate these scenarios, is
20 managing expectations. You know, think when
21 you take your car into the mechanic, and they
22 give you an estimate.

1 They're always going to give you
2 the super high estimate, because if you they
3 come in under the estimate you're always
4 really happy, even if it's incredibly
5 expensive.

6 If they come in over the estimate,
7 you're always really pissed, even if they told
8 you it was just an average off the bat. And
9 there's just so much complexity in these
10 medical situations, that it's just, it's
11 really difficult.

12 CHAIR MORT: I agree it's complex.
13 And you could have disappointed people, angry
14 people. But I also think if perfection being
15 the enemy of good is our way of thinking about
16 it, we could go a long way towards beginning
17 the educational process.

18 Because I think now when you pick
19 a health plan on your annual benefit cycle,
20 what are you looking at? The paycheck
21 deduction. And I don't think people even
22 think about, oh, out of pocket co-pays, or

1 medications, or max, you know, annual maxes.

2 And even just having three, just
3 to help get people aware that there are these
4 other costs. I mean, you know, they're a
5 healthy 25 year old who may need one annual
6 exam, versus a 62 year old with medical
7 problems who needs a cabbage in the middle of
8 the year.

9 It would frame it for people. I
10 would really encourage more routine
11 development of those scenarios to help people
12 get it. What does affordability mean? What
13 am I going to have to pay?

14 MR. AMIN: So it certainly seems
15 like there's a lot more there for us to
16 explore, both in the paper, and potentially in
17 our afternoon discussion. So let's take a
18 break now. Since we're breaking a little bit
19 early, let's maybe come back at 12:30, after
20 lunch.

21 And let's get into this sort of
22 challenges, and the path forward on some of

1 these topics. But thank you all, for all that
2 individual group work and the report outs.

3 Thank you.

4 (Whereupon, the meeting in the
5 above-entitled matter went off the record at
6 12:07 p.m. and back on the record at 12:44
7 p.m.)

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

(12:44 p.m.)

MS. WILBON: Pardon our tardy. We were trying to, we had a session planned already, which is part of the discussion guide, to kind of go over some of the challenges in the path forward.

But we wanted to try to take some of the input we've heard over the last two days, and kind of reframe that for us in a way that might hopefully relate things together a little bit more in a way, context that we have discussed them over the last two days.

And there's, this was done quickly over lunch. So there's definitely some flexibility in this. We're looking for your input on kind of this very high level summary of where we kind of, we think we landed. But we'd like to kind of discuss, come to some agreement and discuss some of the overarching issues that we've come up with.

And then start thinking about how

1 some of these challenges might be addressed in
2 the future. And kind of what are some of the
3 next steps for doing that. Particularly with
4 some of these challenges. And maybe even more
5 broadly as a whole for --

6 I think the other aspect that we
7 are still juggling is kind of the audience for
8 this work. I think we had been kind of
9 thinking, going into this thinking more of a
10 White Paper. But we've heard a lot ideas
11 today about how we can have this be a piece
12 that is also kind of guidance for consumers,
13 potentially for providers on helping consumers
14 make decisions.

15 So any ideas that you have about
16 that, as we kind of go into this paper writing
17 stage, and thinking about which audience we're
18 writing for, and how to reflect your, you
19 know, amazing input over the last two days,
20 would be really great.

21 So what we've done again, is list
22 some of the high level issues, overarching

1 issues we've come up with. And a lot of these
2 were already in the discussion guide. But
3 we've kind of regrouped them and organized
4 them in a little different way.

5 The first of those is patient
6 empowerment, or consumer empowerment. And a
7 lot of that seems to be focused around patient
8 attributes, and their personal experiences,
9 you know, health literacy, just general
10 literacy for, you know, reading and writing,
11 understanding the health system. Yes.

12 MR. AMIN: Just on that particular
13 topic. That includes the consumer empowerment
14 discussions, Adam, that you brought up even
15 before this in person meeting, during our
16 call, around how do we even sort of get
17 consumers engaged or empowered.

18 And we've had a number of
19 different conversations with that particular
20 term. So the more that we can get some more
21 granularity around that, but then also sort of
22 set at least some sense of what the path

1 forward could be on, on those topics, that
2 would be great.

3 MS. WILBON: Yes. And I'll
4 summarize these. And we can kind of come back
5 and open it up for discussion, and see where
6 we go from there. The next of which is the
7 availability of information.

8 We've had some discussions about
9 kind of the information that health plans have
10 that they use internally to, you know, create
11 their plans and do tiering, both quality and
12 cost measures that oftentimes consumers don't
13 have access to.

14 We've talked about crowd sourcing
15 for some information. Because the
16 availability of information that consumers are
17 looking for when trying to find a clinician
18 for their particular condition is often hard
19 to find, in terms of, you know, getting
20 anecdotal information or sharing from other
21 people in the community.

22 And so also the lack of having

1 information kind of in one place that you need
2 to find on your particular condition. If
3 you're going in for a procedure you have to go
4 one place to find physician information,
5 another place to find hospital information,
6 another place potentially to get some
7 anecdotal information on that particular
8 clinician.

9 So there's information spread
10 everywhere. There's a lack of information.
11 There's gaps in information. So that bullet
12 point kind of encompasses all of that
13 discussion that we've had over the last few
14 days, couple of days.

15 The third bullet is around trust.
16 We've heard some discussions around like who
17 is the authoritative source? People want to
18 hear information, or have the discussion with
19 health care providers who are providing their
20 care. They want to have that discussion.

21 We heard from Maureen in her
22 experience in Colorado that, you know, the

1 parents want to hear this information from the
2 doctor. We've heard from Alyssa, whose
3 brother got the call from the health insurance
4 company about where to go for the MRI. And he
5 was suspicious of that.

6 So who is the authoritative source
7 for this information, to help consumers make
8 those informed decisions. So some discussion
9 about that and how, and what potentially some
10 next steps forward for that are.

11 Also, and then I think the other
12 kind of major thing that we've heard also was
13 around billing. And the idea that the system
14 is fragment even within a health system. You
15 may get very fragmented information around
16 what the cost of your care was.

17 How much is actually owed by the
18 patient, versus what's owed by the insurance
19 company. How much you potentially "saved".
20 And so that was another overarching issue that
21 we pulled out as well.

22 CHAIR MORT: Can I make two

1 comments on the overarching issues?

2 MS. WILBON: Sure.

3 CHAIR MORT: Where do you see --

4 Because there's two that I'm thinking about
5 that I don't see where they fit here.

6 MS. WILBON: Okay.

7 CHAIR MORT: Maybe you do, and can
8 help. One is the importance of insurance.

9 MS. WILBON: So, we have one more
10 slide.

11 CHAIR MORT: Oh.

12 MS. WILBON: Yes. So the other
13 two --

14 CHAIR MORT: Never mind.

15 MS. WILBON: Okay. That's fine.

16 CHAIR MORT: I thought that was
17 it.

18 MS. WILBON: No. These were some
19 of the overarching issues. The next slide,
20 Erin, if you go to. So there's other kind of
21 two big buckets around challenges that we
22 pulled out. And one was about kind of

1 navigating the insurance enrollment process.

2 And the other was just in general
3 navigating the system. And within the system
4 we're kind of grouping in engaging with the
5 clinician, you know, the whole decision about
6 do I go to the doctor? Do I not go to the
7 doctor? What doctor do I pick? Hospital
8 engagement, do I go to the hospital? Do I not
9 go to the hospital? All of those types.

10 And when you're in the hospital
11 system, how you get the information. Or
12 you're in a acute care setting, how you get
13 the information you need. And then the last
14 one that was really highlighted I think by the
15 last group that presented in the breakout
16 groups, around community resource engagement.

17 And, you know, accessing the
18 social workers and all the things in the
19 community that aren't necessarily related to
20 health care all the time. But, you know, the
21 food and all the other things that a consumer
22 or patient is balancing when they're trying to

1 decide whether or not something is affordable.

2 That there will be other resources
3 outside of the health care, the traditional
4 health care system. That there may be
5 resources outside in the community that will
6 help them make those decisions.

7 So that's kind of how we bucketed
8 things out, with the idea that some of the
9 things on the first slide kind of, there's
10 elements of that that run through the decision
11 making process in these two buckets around
12 insurance enrollment and navigating the
13 system. Does that make sense?

14 So thoughts in general about how
15 we've -- You guys have talked about a lot. It
16 seems like we've kind of summarized it in two
17 slides. But I think there's a lot within each
18 of those bullets as well. So any -- Sure,
19 just go back.

20 Any other thoughts you have on how
21 we've kind of grouped this together would be
22 great. And then we can start to kind of talk

1 about how we would address some of those
2 challenges and issues.

3 MEMBER ROLFE: Hi. So I just
4 wanted to think about empowerment from the
5 consumer's standpoint. Because when we are
6 talking about it here, we're describing them
7 again. So it's this, you know, this third
8 party object thing.

9 And so I try and always put it
10 into an I statement. So, just to try it on
11 for size, it's something I'm just pulling out
12 of some research we've done. To summarize
13 what empower me feels like, it's reduce my
14 effort, focus on my financial clarity, give me
15 control and choice. But help me when it's
16 hard.

17 And we kind of boiled down to
18 empowerment as, we always talk about it in the
19 first person from the consumer's standpoint,
20 so that we don't get into the, I call it the
21 objectifying mode.

22 CHAIR THOMASON: So, was your

1 first one, first part of that empowerment was
2 reduce my effort? See, that's, it's strange
3 to hear you say that. Because from a
4 consumer's perspective, I feel like when I'm
5 empowered I work more.

6 And I take on more responsibility
7 in my own care. And I'm asking the questions.
8 And I'm having to learn. And I'm seeking
9 information. And I'm, I've never thought of
10 empowerment as reducing my efforts.

11 MEMBER ROLFE: So to explain that.
12 Because it's a distillation after a long
13 research read out. So the context is around
14 the idea that, yes, you want to know more. We
15 should make easier for you to know more. It
16 should be, everything you want to do should be
17 easier to do.

18 CHAIR THOMASON: Okay. You'll
19 make it easier for me to do these things, make
20 the right --

21 MEMBER ROLFE: Or to do anything
22 you want to do.

1 (Off microphone comments)

2 CHAIR THOMASON: Make it easier to
3 accomplish my goals.

4 MEMBER ROLFE: Sure. Go ahead.

5 MS. WILBON: Lisa, Adam, and then
6 Liz.

7 MEMBER LATTS: So the other thing
8 that we may need as an overarching issue, or
9 I don't know, or put under billing or
10 something, is sort of the whole idea of
11 nomenclature, and how much words matter here.

12 And, you know, like a lot of the
13 discussions we had about price versus cost.
14 And what does something cost to whom? Because
15 it matters, you know. Is it what the doctor's
16 going to bill, what the insurance is going to
17 pay, what something really costs, which is a
18 fantasy in health care. We have no idea.

19 So I think those, the nomenclature
20 we use is very important. And the average
21 consumer, or even, frankly, the informed
22 consumer doesn't necessarily understand those

1 distinctions. And it becomes incredibly
2 complex very quickly.

3 So even asking the right question.
4 Like, one of the things that drives me crazy
5 is when someone asks, and this is
6 nomenclature, but it's different. You know,
7 and ask a doctor, do you accept my insurance?

8 Well of course they accept your
9 insurance. They accept anybody that's going
10 to pay them. But that's the wrong question.
11 The right question is, are you in my network?
12 Because that means something totally
13 different.

14 And so, a physician's office will
15 always say, yes, I accept that insurance.
16 I'll accept whatever. And you'll have to pay
17 the difference. Whereas, the right question
18 is, are you in my network?

19 MEMBER THOMPSON: So, I'm glad you
20 mentioned nomenclature. Because that's what
21 I'm going to touch on, which is the word
22 empowerment. I don't like it. I think it's

1 really hard to measure empowerment. It's also
2 really hard to tell someone how to do that.

3 Like, a provider, like, oh, build
4 empowered patients. Okay, how? So I think
5 really what that is is activation. Because I
6 think those are skills that you can talk
7 about, you can teach, you can frame. The
8 other one is around availability of
9 information.

10 I think it's not just
11 availability, but appropriateness too. And I
12 think, I heard us just say, make it easier to
13 read. And I actually, I hate that concept.
14 Because I think you should educate me to
15 understand. Because I just think learning is
16 a life long process.

17 And so, I get what you mean by
18 keeping things simple. But I think when we
19 put that frame on top of it, sometimes we take
20 things that people should understand, and we
21 dumb them down. And then they don't
22 understand the process further down the road.

1 So I think it's not just that the
2 information is available, but that it's the
3 appropriate information. And appropriateness
4 to me is also how the words are constructed.

5 MEMBER LATTS: Can I respond to
6 that directly? So, I actually am going to
7 take issue with you on activation versus
8 empowerment. I think empowerment is more
9 overarching than activation. We had this
10 conversation in the break outs.

11 Activation is the first part of
12 empowerment. But empowerment is actually,
13 because I've had a lot of difficulty
14 understanding the two. So my understanding of
15 the two is that activation is part of
16 empowerment.

17 But empowerment is more than
18 activation. You can have -- So I actually
19 like empowerment better, even though I know
20 it's incredibly hard to measure. Whereas, we
21 can measure activation through the PAM
22 measure.

1 CHAIR MORT: I'm going to add
2 another path. Does anybody want to do more on
3 empowerment?

4 (Off microphone comments)

5 CHAIR THOMASON: I just wanted to,
6 I think education under empowerment, or
7 whatever we're going to label that one. I
8 think we probably need to write the anonymous
9 first thing that we're talking about.

10 Somewhere in there I just want to
11 mention specifically education and -- So that
12 when we really think about really teaching our
13 patients to navigate this system.

14 And when I think about literacy it
15 almost seems more like, of a patient attribute
16 than -- I think it's more education and
17 patient attribute, instead of, and literacy is
18 an attribute.

19 (Off microphone comment)

20 CHAIR THOMASON: Right. Well,
21 there's literacy and health literacy.
22 Because, you know, they're still very

1 different.

2 CHAIR MORT: I had another
3 observation about the list, which is, at the
4 end of our last session we talked about this,
5 you know, concept of affordability being
6 related to your out of pocket costs.

7 And then there was this
8 interesting discussion about a possible
9 measure. But I don't see the, you know, an
10 overarching issue is, we need to make more
11 visible the concept of affordability.

12 So it's kind of a definitional
13 approach, or a clarification of what we mean
14 by affordability. And I think it's an
15 overarching issue, or a key outcome of the
16 work.

17 CHAIR THOMASON: So what is
18 affordability?

19 CHAIR MORT: Yes, yes. The
20 definition, the concept. People need to have
21 a better understanding of what we're talking
22 about.

1 MS. WILBON: Okay. Corey, and
2 then Tayler. Tayler and then Corey.

3 MEMBER LOFQUIST: I don't know if
4 this is taking things in a different
5 direction. But just talking about the
6 empowerment and education side, I think not
7 only should information be available, but it
8 should be discoverable.

9 And in order for you to discover
10 information you need to know the question to
11 ask first. Like, that's what we were talking
12 about. Like, I don't know what I don't know.
13 So how do I even know like the first question
14 to ask? And then seek information. Is that
15 information there

16 And then, can I continue moving.
17 I think you can have a great tool and a great
18 resource. But if I don't know the URL, or if
19 I don't know the pamphlet in your office that
20 contains it, how am I even going to get that
21 information?

22 CHAIR MORT: That's kind of an

1 education issue. And I wonder if education
2 should also be referenced under availability.
3 Because again, you don't even know that you
4 don't know it.

5 MEMBER LOFQUIST: Right. That's
6 my point.

7 CHAIR MORT: So, if you have this
8 need, this is what you should know, whatever
9 the need might be.

10 MEMBER WILBORN: I just want it to
11 be clear, under empowerment when we're talking
12 about patient attributes. Are we talking
13 about patients as in the frequent flier
14 people? Or are we speaking about the
15 population at risk?

16 MS. WILBON: Right. So that was
17 our bad. It should be consumer/patient.

18 MEMBER WILBORN: Okay. Thank you.

19 MS. WILBON: Thank you for
20 clarifying. This was done very, in like five
21 minutes over lunch though. Bear with us.
22 There may be a lot -- We're not trying to

1 wordsmith, we're just trying to capture the
2 general ideas. But you guys get the idea.

3 MEMBER ROLFE: Just quickly, to
4 follow up on Tayler's point. I think part of
5 the concept on availability is also awareness.
6 So it can be available. It can be very
7 appropriate. But people need to be aware.
8 And that does require special action to get
9 there.

10 MS. WILBON: So I was kind of
11 writing. Okay, so I've lost the order here.

12 MEMBER ROLFE: I think it's part
13 of availability and appropriateness of
14 information, and awareness on the part of the
15 consumer that it's there. Because unless
16 they're aware, it doesn't matter how good it
17 is.

18 MS. WILBON: Okay.

19 MEMBER LATTS: Can you elaborate
20 on that, Cynthia? Aware of?

21 MEMBER ROLFE: Aware of where, you
22 know, where do I find it? Who could I ask if

1 I was looking to find it?

2 MEMBER LATTS: The need for the
3 information?

4 MEMBER ROLFE: The need is part of
5 it, yes. I see that as part of the literacy
6 bundle. It's kind of like, what questions do
7 you ask? But then where do I go to get them
8 answered, is what I'm thinking about.

9 MEMBER LATTS: A lot of health
10 plans have transparency tools, but no one
11 knows to look for them.

12 (Off microphone comments)

13 MS. WILBON: So I'm going to go,
14 forgive me if I'm going out of order. You
15 guys already know. Tina, I'll just go back
16 and forth. Tina, Carrie, Maureen, and then
17 Kris.

18 MEMBER FRONTERA: So, I don't know
19 if this would go under availability of
20 information, or affordability needs to be more
21 visible. But the concept of perspective, and
22 looking, and being aware, or somehow having

1 access to information that allows for a larger
2 perspective. So that affordability will
3 eventually grow. So that individuals will
4 look at it from beyond just their world.

5 But understand that it is 17
6 percent of GDP, et cetera. And expand, have
7 our definitions in ways that we will be able
8 to expand the future, so we look at
9 affordability for society.

10 MS. WILBON: Carrie.

11 MEMBER NELSON: In the category of
12 consumer/patient attributes, I know we can't
13 be comprehensive enough. But I would say
14 we've got to add a few things like culture,
15 socioeconomic status, personal values perhaps.

16 MS. WILBON: Yes, we have the list
17 from the discussion.

18 MEMBER NELSON: Okay.

19 MS. WILBON: We're just trying to
20 make sure that we've captured the categories,
21 in terms of starting to discuss how to address
22 some of the challenges.

1 MEMBER NELSON: Sure. Okay.

2 MS. WILBON: So if you guys feel
3 like the overarching categories are there, I
4 don't want us to spend time kind of rehashing
5 what, we've got a lot of the detail.

6 But if you have like broad topic
7 areas that you think that we've missed in
8 terms of the overarching issues in terms of
9 the challenges that we've discussed over the
10 last two days, in the context of navigating
11 the system and navigating insurance, I think
12 that would be really helpful.

13 MEMBER NELSON: Thanks.

14 MS. WILBON: Kris. Let's go with
15 Kris. Oh, okay. Kris, and then Liz, and then
16 Adam.

17 MEMBER SOEGAARD: So what I wanted
18 to add I think is something that Melissa said
19 earlier. It's really important. The
20 information needs to be in context of
21 something.

22 So what Melissa talked about was,

1 she wanted cost information. But she needs it
2 to be in context with her benefit plan design,
3 and where she is, at a point in time in her
4 out of pocket maximums, her deductible, those
5 kinds of things.

6 CHAIR MORT: And in terms of a
7 overarching issue, we spent a lot time in the
8 last two days talking about the bubble
9 diagram, and how it didn't work. And I think
10 what that was there for was to try to frame
11 the different types of health care decisions
12 people have to make in their lifetime. So,
13 where do you see that?

14 MS. WILBON: It's actually more on
15 the next slide. So these, the idea is that
16 these overarching issues impact help people
17 make decisions about the next slide. About
18 navigating insurance enrollment, and
19 navigating the system.

20 And so if you look within that
21 navigating the system bullet, really the kind
22 of clinician engagement, you could kind of

1 think about, or kind of going to the doctor at
2 all, you can kind of think about that first
3 bubble of like staying healthy.

4 The hospital engagement, which is
5 generally like your acute care treatment
6 bubble, would be like the middle bubble. And
7 then the last one about community engagement,
8 you could kind of think about follow-up care.

9 You've been discharged from the
10 hospital. You're now in the community. You
11 have care coordination issues, and so forth.
12 So, it's there loosely. But we've, and I
13 think in some ways it's still relevant.

14 We were trying to not force you
15 guys back into the bubbles for this. But in
16 some ways it is still there in spirit, I
17 think.

18 CHAIR MORT: But I think on the
19 second page you're talking about navigating
20 the system, depending upon, you know, what
21 your clinical needs are at the time,
22 prevention, acute, da, da, da.

1 MS. WILBON: Right. Okay, right.

2 CHAIR MORT: Can we put navigating
3 insurance selection in enrollment?

4 MS. WILBON: Oh, yes.

5 CHAIR MORT: Maybe we've exhausted
6 overarching issues.

7 MS. WILBON: So, Adam, Kris, and
8 then Melissa. Oh, okay, Adam and then
9 Melissa.

10 MEMBER THOMPSON: I think the
11 other thing that we might need to add to this
12 is, we've talked a lot about where people get
13 information from. And we've really
14 highlighted that peers and other people, you
15 know, either suffering under the same
16 condition or have a family member. That
17 people go to them for information.

18 And I think you have to look at
19 inclusion of patients in the development
20 process, like tables like this. Because I
21 think that information cascades down.

22 For example, so I participated in

1 the infectious disease process. And then over
2 the past year I've been able to take that to
3 them that we have outcome measures now, and
4 how exciting that is. And what this means to
5 us as a piece of our care.

6 But that would not hit our
7 community if we don't come to tables like
8 this. And so I think it's really making sure
9 that inclusion happens. Not, oh, we designed
10 this perfect system. Now, here's the
11 information you need.

12 But that inclusion happens, oh,
13 we're thinking about our system. You're at
14 the table. Because otherwise, the communities
15 lose that sort of generational capacity that
16 just doesn't take place.

17 MS. WILBON: So I'm trying to
18 think out. So maybe in a separate issue,
19 another bullet would be engaging the consumer
20 in trying to think about what the like end --

21 MEMBER THOMPSON: I've heard terms
22 like inclusion. I've heard meaningful

1 involvement.

2 MS. WILBON: Okay.

3 MEMBER THOMPSON: And there's sort
4 of lots of different ways. But I think it's
5 less about sort of what the engagement is, and
6 more about when it happens.

7 MS. WILBON: Okay.

8 MEMBER THOMPSON: Because I think
9 people wait two or three steps down the road,
10 and then go, oh crap, we forgot the patients.
11 And so I think having us there from the
12 beginning, even when you're saying, what are
13 the questions we're going to ask? Because I
14 think we can help frame those questions in a
15 way that can move, you know, things forward a
16 little faster.

17 MS. WILBON: Right.

18 CHAIR THOMASON: Yes, I think
19 really it's about having all stakeholders at
20 the table from the very beginning, including
21 the patients. And really, to take it back to
22 consumer centered or patient centered.

1 We have the one part that talks
2 about -- Where's the one that says
3 nomenclature? Oh, consumer friendly
4 nomenclature. But really, and that's just
5 under trust.

6 But really, I want all of this,
7 the empowerment and all the information, the
8 billing, even the affordability definition to
9 all be consumer friendly.

10 MS. WILBON: Right.

11 CHAIR THOMASON: This all has to
12 happen in the context of a patient centered
13 environment. And I want people to understand
14 that.

15 MS. WILBON: Maureen, did you have
16 a comment?

17 MEMBER EDIGER: Yes. A follow-up
18 to what Adam said about having us at the table
19 to begin with. But I hope that one of the
20 outcomes -- I know you touched on this, that
21 the White Paper will be useful.

22 But I think if we can, any kind of

1 material or summary that we can get to take
2 back. Like, I've thought of, you know, three
3 different meetings, or places that I would
4 love to say, hey, I went to this great event.
5 And I'd like to share with you what we found
6 out.

7 So, I think bringing us to the
8 table in the first place is great. But then
9 also giving us something to take back to our
10 communities is also really helpful. So we're
11 working for you two ways.

12 MS. WILBON: Right. Thank you.
13 You're right, that is really important. And
14 we are thinking about that. So continue to do
15 that. I think the other thing we'd like to do
16 at this time is to start thinking.

17 So we've got all these issues.
18 We're really good at identifying problems. It
19 was really easy to do that, I know. But we'd
20 like to start thinking through kind of, what
21 are the next steps? So where do we go from
22 here?

1 We've got all these challenges.
2 We've identified how difficult it is to
3 navigate the system. There are burdens and
4 barriers. I think we talked about that at
5 dinner last night a little bit. Kind of the
6 difference between a barrier and a burden to
7 do some things, and to engage.

8 And so, you know, what are some
9 kind or realistic, or maybe even kind of
10 future state next steps that we might take to
11 start kind of addressing some of these
12 challenges and moving forward?

13 MEMBER LATTS: So, I think we
14 could start to think about a set of minimum
15 requirements. And I use requirements in the
16 loosest sense of the word. In fact I'm not,
17 it's actually not the right word, minimum --
18 maybe, maybe expectations. Because
19 requirements is too, it's not like a --

20 Yes, it's not the right word. So
21 minimum set of something. And then it's for
22 who. So, for example, for health plans it's

1 relatively easy.

2 I mean, you should have some sort
3 of a transparency tool. You should have a
4 cost estimator tool, you know, things like
5 tools to help individuals make informed
6 decisions, with the reasonable expectation
7 that there will be enough communication to
8 allow people to understand that these tools
9 exist.

10 But then there should also be, you
11 know, some expectations of providers, and some
12 expectations on patients. So instead of,
13 again, expectations is, I don't know. I don't
14 know what the right word is. But we could
15 start to map out who should be doing what, if
16 this is going to happen.

17 MS. WILBON: So, we're going to
18 try to pull up the list on the side screen.
19 So you can kind of look at the list. Then we
20 can maybe go one by one. So give us a second
21 while we're figuring that out.

22 But if I recall, the first one was

1 the consumer/patient empowerment/activation,
2 until we figure out the correct terminology
3 for that. But I know that, Adam, I'm going to
4 put you on the spot. You do a lot of work in
5 this area. So any kind of --

6 MEMBER THOMPSON: I completely
7 agree with you. I mean, activation is a step
8 towards empowerment, you know. The only
9 reason I said activation was because it's
10 easier, I think.

11 I mean, it's easier to go into a
12 place that's never done it and say, here are
13 the, you know, four steps in the decision
14 making process. This is how a patient is
15 activated.

16 Empowerment to me seems really
17 soft. You know, it's sort of like, I'm going
18 to a conference where we're going to talk
19 about clinician joy, you know. And like to
20 me, empowerment sort of falls in that category
21 of like, I get it. It's a meaningful
22 conversation. But it's hard to have.

1 Because at the end of the day
2 empowerment means very different things. And
3 to be honest, I know coming from the HIV
4 community, again, lots of barriers. But
5 that's a loaded word for a lot of people. And
6 empowerment is beyond their disease state.

7 And so we started saying
8 activation, because that was what we were
9 talking about in that patient room. But it
10 leads to empowerment, which takes place in all
11 aspects of my life. It's sort of how I kind
12 of frame it.

13 CHAIR THOMASON: Should we define
14 -- Oh, sorry. So when you make that point
15 though, that empowerment happens in all of
16 these areas of my life, should we say, should
17 we clarify empowerment in that arena then?

18 So, is it, I mean, do we really
19 want to leave it that broad? Or do we say,
20 health consumer empowerment, you know? Do you
21 clarify?

22 MEMBER THOMPSON: It's really

1 tough. Because people can be empowered in
2 pieces of their life, but not their whole life
3 as well.

4 CHAIR THOMASON: Right.

5 MEMBER THOMPSON: So, I mean, even
6 though that's where you want to move towards,
7 you know, you're talking about sort of, you
8 know, being self actualized, and kind of
9 getting to that place. An activation is the
10 health piece that moves you towards that.

11 CHAIR THOMASON: Yes. Activation

12 --

13 MEMBER THOMPSON: But I don't
14 think you can say, this person is empowered.

15 CHAIR THOMASON: Right.

16 MEMBER THOMPSON: You know what I
17 mean?

18 CHAIR THOMASON: Yes. Activation
19 implies activity, or some action, you know.
20 It seems more actionable. So I see the point
21 you're making.

22 MEMBER LATTIS: One of the,

1 something to this point that I've been sort of
2 struggling with for the past couple of years
3 now is, one of the, you know, one of the big
4 trends in health care is patient centeredness,
5 right?

6 I mean, everybody's talked about,
7 you know, Marci's not here anymore. But the
8 patient centered primary care, patient
9 centered medical home, and da, da, da.
10 Patient centered, it's all about patient
11 centered.

12 A concept that we have not fully
13 wrestled with yet is that if you're patient
14 centered it means you meet the patient where
15 they are. And not every patient wants to be
16 activated, or wants to be empowered.

17 And so we're imposing our, you
18 know, by virtue of us being here we're all
19 activated and we're all empowered. But not
20 every patient wants to be empowered.

21 And so we have to meet them where
22 they are, without imposing our value system,

1 which says, it's good for you to be activated
2 and empowered, because you'll get better
3 health care. So this is something I've been
4 struggling with for a couple of years now is,
5 thinking about these two concepts.

6 And then, you know, sort of the
7 third piece of the stool that I'm struggling
8 with, which is a little bit outside this
9 conversation is, what does that mean for the
10 physician, or the provider, or the health plan
11 who's being evaluated based on their
12 performance, when they have a patient who
13 doesn't particularly want to do what they're
14 recommending? And so that clash.

15 So there are a couple of sort of
16 inevitable clashes that I've been seeing in
17 the way these separate trends in health care
18 are proceeding.

19 MS. WILBON: Thank you.
20 Definitely food for thought. We'll have to
21 weigh that when we start talking the paper.
22 Ron, did you have a comment?

1 MEMBER WALTERS: So I think we've
2 spent a day and a half analyzing the
3 limitations, as every group does. We're very
4 good at the gap analysis. Done great gap
5 analysis the last day and a half.

6 But the name of the group, and we
7 talked about this earlier, was measuring
8 affordability. So with only an hour to go
9 left in the program, at some point in this
10 process, and it won't be today, we do have to
11 start to identify, are there measures out
12 there that measure affordability?

13 If not, here's the gaps. Here's
14 what's out there in the marketplace that
15 hasn't been, gone through any sort of
16 measurement endorsement process. And what can
17 we head towards?

18 So, I mean, again, we've pointed
19 out all the limitations, and all the
20 considerations of doing it. But there's a
21 very practical end result of this as far as
22 what are the measures involved in measuring

1 affordability.

2 MR. AMIN: So, if you don't mind,
3 Ashlie, let me, I don't want to pretend that
4 I can digest everything that's happened in the
5 last two days. But I want to suggest that
6 there are at least some concepts that I've
7 heard, that still need some refining.

8 So, the one is the concept of
9 percent of your income that is dedicated to
10 spend, that is out of pocket expenses, as a
11 percentage of your income, which Melissa laid
12 out.

13 There's also this second concept
14 that I haven't quite worked through yet, which
15 is the question I was asking Cynthia before,
16 which is having some concept of, as you're
17 getting set up with your health care.

18 And this might just be
19 information, it might not be a measure. But
20 some information that may need to be more
21 readily available about your expected costs
22 that you can expect a priori to actual

1 utilization. So, having that information much
2 more transparent in some way.

3 But then, those are two sort of
4 actual sort of cost components. But I think
5 what we've heard today and yesterday, but more
6 clearly today, that those decisions and those
7 measures, if you will, still need to be within
8 a context of larger number of issues, or a
9 larger number of concepts.

10 Quality being one of them, other
11 values, and things of that nature. And that,
12 I think, is going to be a whole series of
13 additional work that we're going to need to
14 work through.

15 Liz has pointed out before, I
16 think, there's a whole decision making
17 framework longitudinally that needs to be
18 understood about how you think about
19 affordability along the continuum. That needs
20 to be defined a little bit more.

21 But, so I wouldn't sell yourself
22 short, or the group short, in the sense that

1 I think we have come up with at least
2 information sources, or information needs that
3 consumers need. But we, I think, may have
4 even come pretty close to some measurement
5 ideas. Maybe not completely there yet.

6 CHAIR MORT: I have a comment
7 about that. If we're talking about measuring
8 affordability, you know, we had a concept
9 earlier that affordability from the
10 perspective of the consumer's percentage of
11 total income that goes to out of pocket health
12 care costs.

13 Okay. So that's one way of
14 thinking about it. But affordability is an
15 attribute of the health care system. So in
16 the same way the HEDIS measures attributes of
17 preventive care, chronic disease management of
18 a health plan, I think thinking about the
19 measurement framework is, what are the
20 attributes of affordability as measuring
21 different parts of the health care system?

22 So there could be, you know, to

1 what extent is a health insurance company
2 supporting affordability? You could have a
3 measurement tool to assess that in an
4 insurance plan.

5 You could have a concept that
6 looks at affordability attributes of a
7 physician's practice, all the things that are
8 bubbled up. Affordability in a health care
9 delivery network. Affordability of, you know,
10 you could measure the attributes of
11 affordability on different pieces of the
12 health care system.

13 There were calls to action here
14 for health plans, for doctors, for practices,
15 for communities. I mean, I think if you're
16 really trying to get to the measurement piece,
17 Ron, which is really what we came here to do,
18 I'm seeing more clarity around actually how
19 that could happen. Just in the same way you
20 measure attributes of -

21 I'm going to stick with this for a
22 second. Attributes of patient experience. So

1 patient experience. If we were 20 years ago
2 talking about this, you know, we'd have this
3 whole thing plastered with patient's point of
4 view about their experience.

5 And then we'd think about, and
6 then come up with domains and measurement
7 tools, and then measure the experience of a
8 patient in an emergency department, or peri-
9 operative care in a day care setting, or, or,
10 or, or. So, I kind of see that maybe that's
11 the direction you want to move out the
12 measurement framework. It's a MAP thing?

13 MS. ADAMS: I think this does
14 bring up a good opportunity, Liz, to think
15 about some synergies, in particular with this
16 group. We mentioned earlier the Measure
17 Application Partnership. I know some of you
18 have been involved with that work.

19 But just briefly, it's a
20 partnership here that provides input to health
21 and human services on measures to be put into
22 different public reporting or payment

1 programs. And very importantly, we're
2 thinking a lot about cost. And we want to
3 think about cost and affordability from the
4 consumer lens.

5 So this is why we felt that this
6 would be a perfect complement to that. And
7 the one thing that the MAP did is that, just
8 as you're describing here, Liz, we reached out
9 to those different stakeholder groups, which
10 of course are represented by NQF membership,
11 consumers, doctors, health plans, supplier and
12 industry, et cetera.

13 And we said to them, how do you
14 define affordability through your lens? And
15 what do you feel you're accountable for? And
16 what really matters most to you? Erin is also
17 working on this project. And it's, the one
18 common thread through all of that is that
19 there was a patient centered view.

20 And they defined it as ability to
21 pay. And so, I think that this group has
22 really -- We were anxious to bring back to

1 this group some of this work, to say, yes,
2 we're hearing out of pocket costs. Ability to
3 pay is very important.

4 But what they're looking at now
5 is, what measures do we have now? To Ron's
6 point. And what measures do we need for each
7 one of these stakeholders, that contribute to
8 affordability?

9 And we'd like to push a little
10 bit, about what people think are in their
11 control. But nonetheless, what's currently in
12 their control, and what should be a shared
13 accountability.

14 CHAIR MORT: A shared
15 accountability from the perspective of the
16 consumer trying to reduce the percentage of
17 their out of pocket costs?

18 MS. ADAMS: Right.

19 CHAIR MORT: So in the same way
20 that Melissa says, I want to hold you
21 accountable for the cost of my bill, that's
22 the voice we want to send back to the --

1 MS. ADAMS: Exactly.

2 CHAIR MORT: -- all the
3 constituents.

4 MS. ADAMS: And we've heard that
5 the -- For me, and I know that Erin has been
6 in this work. To hear what you're saying
7 really allows us to go back to this group and
8 say -

9 Because the takeaway message from
10 that group is that every person around the
11 table is accountable for affordability through
12 the consumer lens. And what can we do that
13 is, first, easily within our control?

14 But let's push a little further.
15 What can we do, and how can we measure that?
16 And what measures do we have now, but what
17 measures do we have to look for? Because we
18 do have some measures.

19 And when we looked at this in
20 regards to guidance that we provided through
21 the health insurance exchanges, Liz, you
22 talked to several structural attributes, you

1 know, from a health plan. And health plans
2 have to report, of course, on many things.
3 And, you know, the plan integrity.

4 But one thing they said, well,
5 would you look to a health plan that
6 participated in, around transparency,
7 providing that information to consumers around
8 cost and price. Some plans do, others don't.

9 So I think that we're getting a
10 lot of synergy here. And I think that when
11 the group goes back, we'll have to think about
12 how we can tie this together. So that when
13 you do go back, Maureen, you have the whole
14 picture.

15 Because NQF is doing work across
16 affordability in many different project areas.
17 And I think we want to be able to give this
18 group to be able to go back with one story.

19 CHAIR MORT: Well, that's helpful
20 that you can see how these would synergize.
21 But I think that's very helpful to know that
22 you can take it back, and start making those

1 connections.

2 MS. WILBON: Adam, did you have a
3 comment?

4 MEMBER THOMPSON: So, I was just
5 going to recommend that one way we might be
6 able to look at this is the same way we look
7 at quality, you know, where we have, we use
8 those two concentric circles, where they
9 overlap, not concentric, overlapping.

10 And one is provider lens, one is
11 patient lens, right? And we look for the
12 place where those two thing meet to do the
13 best quality work, right? Because both the
14 stakeholders are in it.

15 Well, I'm wondering if
16 affordability isn't the same way, where
17 there's affordability from the people sending
18 you a bill, and then there's affordability
19 from the person getting the bill.

20 And I wonder if it's that simple,
21 you know. If you're looking at what are the
22 places where they cross, and maybe those are

1 the really cool affordable measures. Because
2 it's meaningful to both the provider and the
3 patient. But just to think about it kind of
4 in that way. I don't know. Just a
5 suggestion.

6 MS. WILBON: Melissa.

7 CHAIR THOMASON: We threw around
8 the concept earlier of a Venn diagram, and
9 where it would overlap, and things like that.
10 But I think we could be here for several days
11 talking about a visual representation of what
12 we've covered.

13 I was just going to, I was really
14 moving forward. So if anyone has anything
15 else? But on next steps I would really love
16 to see us produce a list of questions for
17 consumers that they should ask around
18 affordability.

19 So a lot of times when we talk
20 about patient engagement it's, well, give me
21 the questions to ask. Because, as Tayler so
22 eloquently put it, I don't know what I don't

1 know. And you can give me the details that I
2 need to find out.

3 But then I have to translate those
4 details and come up with the questions I then
5 need to ask to figure out those details, when
6 really we could just give them the questions
7 to ask.

8 So if we could, and we do it in
9 patient engagement anyway. So it's, ask these
10 questions of your providers. Or ask these
11 questions of everyone. So if we could just
12 extend that to affordability, ask these
13 questions of your providers, of your insurance
14 companies, of your, and all that along the
15 entire continuum.

16 And this might not even speak to
17 affordability. Well, you know, it does. I
18 think there's such a huge need in this country
19 to increase our health literacy, as a
20 population. And things like health literacy
21 curriculums for young people, surrounding
22 affordability. I really hope we make progress

1 in those areas in the future.

2 MS. WILBON: I'm not sure who's
3 first. We'll go with Corey, and then Lisa.

4 MEMBER WILBORN: I think that,
5 Melissa, we, me and you, and the other
6 frequent fliers want that information. But I
7 think that maybe 90 percent, from what I'm
8 hearing, 90 percent of the population at risk
9 doesn't need any of that information, aren't
10 going to go look for it.

11 So it may be more costly to try to
12 research and provide that information for
13 people. And that's something that I think we
14 need to look at in going forward too.

15 CHAIR THOMASON: But when I got
16 sick, I mean, I haven't lived sick my whole
17 life. I went 28 years and thought I was
18 perfectly healthy. And then all of a sudden
19 was thrown very quickly and very dramatically
20 into this episode.

21 And I had all of these decisions
22 to make. And I want that information, you

1 know. Because, yes, it was really hard to
2 process it all when I was in the hospital bed.
3 But I was starting to have to make decisions
4 very early on.

5 And when I started looking for
6 information, there just wasn't a lot on
7 everything, on my disease, on who's better, on
8 money, on what I'm really going to pay, on any
9 of that.

10 I'm translating this huge
11 engagement, affordability, and all of that, to
12 my terms, you know. I didn't know where to
13 find information. So, yes, I'm not sure that,
14 maybe a lot of the population won't access it
15 yet. But I think they eventually will.

16 (Off microphone comment)

17 CHAIR THOMASON: But it's got to,
18 well, it's got to be there. But then, even if
19 you give frequently asked questions for say
20 insurance companies.

21 Now we're telling people who've
22 never had insurance that they need to get

1 insurance. So providing tools and questions
2 you should ask around insurance may be
3 helpful.

4 And maybe there, I think there are
5 people who have not been in the system before
6 who will now be interested in this system.
7 Not everyone, but I think there will be a lot
8 of people. What do you think?

9 MEMBER WILBORN: Well, I think
10 their interest is going to be that
11 affordability part, which is co-payments, and
12 again, their premium.

13 CHAIR THOMASON: I agree.

14 MEMBER WILBORN: And they're going
15 to --

16 CHAIR THOMASON: And I think we
17 need to teach --

18 MEMBER WILBORN: -- choose the
19 lowest possible thing. Because that's what,
20 in their mind, is affordable. The cheapest
21 isn't the most affordable.

22 CHAIR THOMASON: Right. And I

1 think so too. And if we, but if we teach
2 them, you know, if nothing happens to you this
3 year, then you're out, the money out of your
4 pocket, that is your co-pays and deductibles
5 and things.

6 And if something does happen to
7 you this year, this is going to be the money
8 out of your pocket. And they say, oh, yes, I
9 want the less money out of my pocket. So
10 teaching them how to make those decisions.

11 MS. WILBON: I think Lisa, and
12 then Liz, and then Tina, and then Ron.

13 MEMBER LATTS: I really love the
14 idea of the list of questions for consumers.
15 I think that's very sort of concrete,
16 actionable thing that we could do.

17 And then, what I would like to see
18 is a companion piece to that, that would be
19 information for those that the consumers would
20 be asking the questions to, the doctors, the
21 hospitals, the health plans, of information
22 that they should be prepared to provide.

1 Or providing, you know, even
2 before those questions are asked. But then,
3 you know, have companion pieces that are the
4 payer side of that, payer, payee.

5 CHAIR MORT: On adult learning, I
6 mean, I'm not an expert on education at all.
7 But I know that when you're trying to teach
8 something to adults, they learn best on a need
9 to know basis. So it's like, you can lead a
10 horse to water, but you can't -- It's along
11 those lines.

12 So if these modules of information
13 were available when consumers were at the
14 point of making important decisions, enrolling
15 in insurance, choosing among plans, that could
16 be a product that, you know, what are the
17 things you need to ask. And make those
18 available for a need to know basis, on a need
19 to know basis.

20 So that it could help facilitate
21 making the right decisions, thinking about
22 affordability. But if you just publish it and

1 put it out there, it's going to be, oh, yes,
2 that's interesting.

3 CHAIR THOMASON: I agree.

4 CHAIR MORT: You have to have a
5 need to know.

6 CHAIR THOMASON: I agree
7 completely. And I think having them out there
8 for when they come to that decision point, so
9 that they can use them and consider
10 affordability on the front end, and not when
11 they get the bill later, you know, like I did
12 it at first.

13 MS. WILBON: Tina, and then Ron.

14 MEMBER FRONTERA: Okay. I think
15 it's also important to think of the concept
16 when we think of next steps, what's impactful,
17 meaningful and useful.

18 Because I heard some folks talk
19 about too much information is way too much
20 information. And information can be costly.
21 Development of measures can be costly. And,
22 you know, we already have an issue of, some

1 folks don't even necessarily want to pay for
2 information.

3 So we have to be careful, and
4 choose whatever it is we're going to be
5 putting in front of folks in a wise fashion,
6 so that we've got a high cost benefit.

7 MS. WILBON: Ron.

8 MEMBER WALTERS: So I like the
9 analogy as mentioned earlier, if you think
10 back to the earlier days of CAHPS, you know,
11 the CAHPS surveys. What we've done today is,
12 if there were a tool that existed, what would
13 be the key elements of that tool. And we've
14 defined those all around the board here.

15 The second part then, to follow
16 Donabedian, I mean, the second thing,
17 structurally does that tool exist? Or is it
18 something that needs to be developed. And
19 then, I'm not quite sure who would develop it,
20 if it hasn't been developed. But that's a
21 different problem.

22 And then, the process measure is,

1 is it utilized? And we've talked a lot about
2 in here how it would be utilized, how it would
3 be applied, how it would be applied in
4 different situations, applicable to different
5 groups, different types of providers, et
6 cetera, et cetera.

7 And then finally, what is the
8 outcomes that we'd expect from that? And I
9 think we got, we haven't formalized the
10 outcomes we would expect, because we're way
11 far back in the process.

12 But certainly we've alluded to the
13 things that were on that first slide, would be
14 the kinds of outcomes we would expect from the
15 application of a tool, and application and
16 utilization of a tool that incorporates the
17 principles we've talked about in the last two
18 days.

19 So, when I said earlier, I mean,
20 we haven't done a full search. Although I
21 think the people in the room kind of have a
22 real good feel. Does such a tool exist?

1 Boy, I hope we can find a magic
2 tool out there that does everything we talked
3 about the last day and a half, that's
4 applicable to a lot of people.

5 But if not, then we've got to go
6 back to, all right, now how is the tool is
7 going to be developed? How are we going to
8 get this done? And then, how are we going to
9 get it utilized? And that's what I was trying
10 to say earlier is --

11 MS. WILBON: Can I ask, one of the
12 things we had on the overarching issues was
13 around trust, and who was the authoritative
14 source. So, future state, we have this tool.

15 Who, I guess I'm wondering, who is
16 the entity that would be the trusted source of
17 this information? We can talk about maybe who
18 we think, who should be the responsible
19 entity.

20 But I'm wondering, from a
21 consumer, you know, if a consumer was looking
22 for information about these different things,

1 who would be the person, or the entity that
2 they would want to give them that information?
3 Alyssa, and then Maureen.

4 MEMBER KEEFE: I think they want
5 the clinician who's telling them their
6 treatment options. However, a clinician and
7 a hospital have no idea where you are in your
8 out of pocket expense, and where you are in
9 your deductible and your max.

10 And while they can talk to you in
11 general terms, what I hear from some of our
12 colleagues around the table, and consumers is
13 the little bit more level of specificity,
14 which goes back to Cynthia's point about, you
15 know, you're giving your best effort, or good
16 faith estimate is how I think you put it. But
17 there's -

18 Physicians were not trained,
19 clinicians were not trained. They're trained
20 to treat your illness. They're not trained in
21 a mechanism for providing some of this
22 additional information, which is what I

1 believe is the perceived trusted place of
2 information.

3 And so I think that is something
4 that we could acknowledge in the paper, about
5 -- Because I wanted to talk a little bit about
6 the limitations of, you can have a list of
7 questions.

8 But I think, depending on who
9 they're directed to, whether or not in current
10 state versus future state, whether that
11 information is available at the place in which
12 you're directing.

13 And then the only other thing I
14 just want to make sure we incorporate. We
15 talked a lot about out of pocket as a
16 percentage of income.

17 But my percentage of income, of
18 where my threshold is, depends on how I value
19 other things within my life, and where I
20 prioritize health care versus other things.
21 You know, it's like the person who wants the
22 Range Rover versus a Hyundai. I mean, it

1 depends on how you perceive.

2 So I would want to make sure that
3 we incorporate some of the models in the value
4 structure, and the perceived context in which
5 we think about some of these measures.
6 Because I think this is not the standard
7 measure of a clinical practice of care, or an
8 outcome. It's just a little bit squishier for
9 me, anyway.

10 MS. WILBON: Maureen, Corey, and
11 I'm sure I'm out of order here, Melissa, Liz
12 and then Deb.

13 MEMBER EDIGER: The question was,
14 who should collect and present this data? And
15 I agree that patients and consumers would most
16 want it to come from their providers. But
17 exactly what you said. That's not what
18 they're trained to do.

19 So I think then the next, you
20 know, it's like, well, what about insurance
21 companies? And I think, no. As a consumer or
22 patient I don't think that is where we would

1 feel like we were getting good information
2 either. So it almost needs to be a third --

3 CHAIR THOMASON: I would say pp

4 MEMBER EDIGER: Yes, a patient
5 advocate, a consumer group that is working
6 with both providers and insurance companies.

7 MS. WILBON: Okay. I even forgot
8 what the last order was. So, I should be
9 writing this down. I apologize.

10 CHAIR MORT: It's hard to keep
11 track.

12 MS. WILBON: Liz, why don't you go
13 from here.

14 CHAIR MORT: Okay. The issue
15 about the physician. Of course, you know, we
16 hope that our physicians are objective. You
17 know, they've taken the Hippocratic Oath.
18 They have you in mind, et cetera, et cetera.

19 But as everyone has pointed out,
20 it's a complicated amount of information that
21 you're asking from one person. I'm going to
22 come back to the concept I've made a couple of

1 times, or the point I've made a couple of
2 times, which is, you really want to choose a
3 system or a practice.

4 So if you have cancer, and you
5 have an oncologist, I want to know if that
6 oncologist is in a cancer center where those
7 resources are available. So you come to me as
8 your oncologist. I say you have treatment A
9 or treatment B.

10 What I can tell you is how much
11 time you're going to have to spend, how many
12 sessions of treatment A and treatment B, what
13 the side effects are, how those may relate to
14 you given your particular clinical
15 circumstances. And then, you weigh that
16 information.

17 And then I send you to our
18 practice manager, who can then look up your
19 insurance and help you understand what's
20 covered. So that you need to have it done in
21 a patient centered way. And you want to have
22 it connected within your clinical care.

1 That's why the practice and the
2 systems of care are so important. There is
3 this wishful thinking that the doctor knows
4 everything. And doctors have done that, you
5 know. Because we've sort of presented
6 ourselves as autonomous and omnipotent, and
7 all that stuff.

8 Well, we have to undo that.
9 Because we know a certain set of activities,
10 a certain set of information. We can do a
11 certain set of things. But you need the
12 system. So, I think, I keep going back to
13 that.

14 And I couldn't emphasize it more
15 strongly. Because it's wishful thinking that
16 a physician will have access to all the
17 information a consumer or patient will need to
18 make the most affordable decision that's right
19 for them.

20 MS. WILBON: So, Melissa.

21 CHAIR THOMASON: Yes, I completely
22 agree. So, I guess I would want my physician,

1 because we already have an established
2 relationship of trust. It's not necessarily
3 that I need him to give me the information.
4 I just need him to be the one to direct me to
5 someone with the information, because I
6 already trust him.

7 And then if there is a financial
8 advisor or coordinator, or someone like that
9 in the practice that I can sit down and talk
10 to, I would be fine with it.

11 Just like when I first got
12 pregnant. One of the very first appointments
13 I had, the financial facilitator, or whatever
14 her name was, I went into her office. And she
15 said, this is the average cost of having a
16 baby.

17 These are all the appointments
18 you're going to have. This is what such and
19 such is going to cost. This is the total
20 cost. This is what I need you to pay per
21 month. Are you okay with that? Absolutely.
22 Thank you for this conversation. Then I wrote

1 my check every month.

2 And it was very, you know, a very
3 open discussion. And I felt well informed and
4 well prepared for what was to come. They
5 didn't calculate aortic dissection in there,
6 you know, by the way. But I was okay with
7 that.

8 As a consumer, later, I knew that
9 couldn't be. But, more than that too, I know
10 that -- So, like I said, out of pocket expense
11 versus my income. And like we were talking
12 about during the break.

13 Liz was saying, well, you'd almost
14 have to tier it where below the poverty line
15 there's a different percentage of income.
16 Because so much of what you make has to go to
17 living expense anyway. So could you rank it
18 in poverty levels, or things of that nature.

19 I know that much more goes into,
20 it's not as basic as what I'm paying out of
21 pocket this year against my income. Because
22 as my medical bills pile up, and my

1 indebtedness increases, then it changes things
2 too. But I think that's a starting point.

3 MS. WILBON: Okay. Corey, use
4 your microphone.

5 MEMBER WILBORN: We're getting
6 away from the part where you choose your plan
7 based on your income. You know, I would only
8 choose a plan that I knew that I could pay
9 every month. And then my co-pay, I would know
10 that I could afford this co-pay. That's
11 affordable to me.

12 MS. WILBON: Okay. Deb?

13 MEMBER DAHL: What I was thinking
14 in the trusted source was, it depends on which
15 of the bubbles you're in. So if I'm making a
16 decision on which insurance plan, I would
17 never think about going to my physician on
18 which insurance plan.

19 Consumer Reports, the Government,
20 and there are a whole lot of sources out there
21 that I would think would provide me good
22 information that I would use.

1 When it comes down to out of
2 pocket costs, I appreciate Liz's comment
3 about, if you're in a really large practice
4 with lots of resources, that might happen.
5 But there are still a huge number of physician
6 offices out there where it's a solo
7 practitioner that does not have all those
8 resources.

9 And do we want to add that to our
10 health care cost, to say every practice needs
11 to have the navigator? And if I have
12 contracted with Blue Cross/Blue Shield to be
13 my provider, isn't that where I should go for
14 the accurate information for my particular out
15 of pocket costs?

16 So, for me, where the physician
17 and that office comes in is in the shared
18 decision making. Somebody to help me say you
19 can go, you know, for chemotherapy you can do
20 this, this or this. These are the kinds of
21 risk and complications.

22 Maybe diabetes would have been a

1 better example. These meds will do this.
2 These are some of the potential weight issues.
3 These are some of those other things. Let's
4 walk through what the risks and costs are in
5 those areas.

6 Not absolute values for cost, but
7 conceptual, approximate values for costs, to
8 help me make a decision on the treatment plan
9 that is related to the out of pocket costs.

10 CHAIR MORT: Can I just respond to
11 that quick, Deb, because you mentioned a very
12 important point. There are still solo
13 practitioners. Although the percentage in
14 those is diminishing with change in health
15 care delivery systems.

16 But you certainly could get the
17 information about cost from your insurance
18 plan. And I think if Joe were here he would
19 say, oh, don't you know, we have an easy 1-800
20 number to get that.

21 They're probably, and my bias is
22 probably influenced by my historical

1 relationship with trying to get information
2 out of insurance companies. Because, in fact,
3 that's what the navigator, or the financial
4 person is doing in your office practice, is
5 accessing that information on behalf of the
6 consumer or patient.

7 But it is doable by, you know, the
8 consumer just calling up and saying, here's
9 the oncology regimen A, here's the oncology
10 regimen B. Can you tell me, Blue Cross, how
11 this affects my out of pocket?

12 MEMBER DAHL: Yes. And so the
13 person in your office is the translator for
14 complex cases. And that's appropriate.

15 CHAIR THOMASON: And I would be
16 okay, just to interject really quickly. I
17 would be okay with speaking to someone from
18 the insurance company. It's not like that's
19 bad, and I don't necessarily want to deal with
20 them. That's perfectly okay with me.

21 And even accessing that
22 information on line. As long as it is

1 consumer friendly and I can understand it, and
2 it's really easy for me to get.

3 Rob pulled up a site earlier
4 where, California's using it now, where he
5 typed in his age, some brief little medical
6 history things, and it said, here's your
7 insurance options listed. And he got to pick.
8 I'm not against using tools like that. I
9 think they're great.

10 MEMBER DAHL: And I can envision,
11 because they do have enormous amounts of data
12 now. And the processing ability to do that.
13 That I then type in my own name to say, these
14 are the options that my office is providing to
15 me for treatment X, you know, let's just get
16 the cost direct. And to help reduce the costs
17 of health care overall in the country by
18 everybody duplicating that middle man.

19 MS. WILBON: Carrie.

20 MEMBER NELSON: In terms of that
21 trusted partner, yes. I was feeling
22 uncomfortable with being the physician, to

1 have to have that conversation with patients.
2 And yet, I think what, as we've talked about
3 it further I think the issue is that patients
4 need to know that whoever the source of
5 information is, is trusted by their physician,
6 right.

7 So if your physician refers you to
8 a source, that implies trust. I really think
9 this partnership with Consumer Reports has
10 opportunity in this area. So you have a
11 relationship with Consumer Reports. They were
12 also a partner with the Choosing Wisely
13 campaign. So right there you see medical
14 societies embracing a Consumer Reports
15 relationship.

16 And I really think that, first of
17 all you do need to have a source that's
18 trusted by the medical community. Otherwise,
19 the medical community will undermine that
20 source.

21 And so incorporating it as a
22 component of shared decision making is

1 absolutely making sense to me. And
2 potentially this tool that we keep dreaming of
3 could be something that Consumer Reports could
4 sort of co-brand with this organization and
5 medical societies.

6 MS. WILBON: Tina, and then Adam.

7 MEMBER FRONTERA: Yes. With
8 regards to trusted source, maybe I'll tell you
9 a little bit of the Minnesota story for a
10 little bit. We did work with Consumer
11 Reports. So we're fortunate in that we have
12 a community collaborative where we norm storm
13 and conform, and argue.

14 And we have competing hospitals
15 and health plans together in the same room.
16 And we have come to consensus on, you know,
17 quality standards, and then how to measure
18 total cost of care. But, you know, it hasn't
19 been easy.

20 But the positive thing about it
21 is, because of that process, which is
22 sometimes very painful, we have a trusted

1 source for data. So Consumer Reports came to
2 us and said, you know, we'd like to put some
3 of your measures in Consumer Reports.

4 And that, in and of itself, was
5 another six month process, to have the
6 physicians feel comfortable. Now, taking it
7 to the next level with little Consumer Reports
8 bubbles. Because that was like rendering a
9 judgment now. It wasn't just scores that
10 could hide behind a screen.

11 So yes, it's I think a trusted
12 neutral source could be. If I were to draw a
13 product I'd kind of have a, you know, the big
14 bubble would be the trusted neutral source
15 that has those decision making, high level
16 cost and affordability concepts, and
17 information and data.

18 And then, as other folks were
19 talking about, you've got the payer and the
20 health plans, maybe even some employers that
21 get more granular with what the specific co-
22 pay is.

1 And then you may have something
2 else in the actual provider setting that may
3 get something more granular with regards to
4 real clinical kinds of things, or even care
5 coordination, if necessary. But trust is key,
6 I think, if we're going to get to the next
7 level.

8 MEMBER THOMPSON: Yes. I just
9 wanted to sort of jump off and echo what you
10 were saying, Carrie, which is, I think trust
11 is relative. And I think physicians speak
12 with authority. So I think physicians are in
13 a unique place to determine who gets to speak
14 these things.

15 But it does require that
16 physicians take on that advocacy role. And I
17 think when you look at patients, we're
18 uniquely experienced to guide people through
19 this. We've had to do it.

20 And I think earlier today we said
21 something about role models, and successful
22 role models, right? The problem with these

1 role models is we can't get them in the
2 hospitals to work with the patients. Because
3 unless they're hired, and covered under all
4 these different forms, people think,
5 volunteer, can't happen. And that's just not
6 true. It can totally happen.

7 But I think you have to have the
8 physician saying, we need these experienced
9 patients guiding our new patients around
10 affordability. Because I don't have the time.
11 Nor do I want to do it. But they do, and they
12 have this knowledge.

13 So I think it's not just gathering
14 patient experience, but starting to leverage
15 it, you know. Use it for something, instead
16 of just gathering it and going, crap, what do
17 we do with it now?

18 You know, take the patients and
19 take our activation, and give us life purpose,
20 which is one of the co-factors of getting
21 healthy, is having that purpose again. And
22 helping others get healthy is a beautiful

1 purpose.

2 CHAIR THOMASON: Our health system
3 has done a really good job of leveraging
4 advisors for lots of different things. And
5 like I was saying yesterday, I've done
6 everything from FMEAs to rounding in the
7 hospital, you know. So we do lots of
8 different things.

9 But it's almost exclusively with
10 staff. I help train staff. I help teach
11 staff about how to handle patients. And it's
12 all about, I talk about patients to staff a
13 lot of times. And one of the first things I
14 wanted to do as an advisor was, you know, we
15 talk all the time about, to staff about being
16 able to deal with patients.

17 But we don't get to talk a lot to
18 patients and help empower them. So I love
19 rounding, which I do get to do that in the
20 hospital. I get to do it with managers and
21 other leaders. But then I also get to do it
22 alone. So I get to go into patient rooms.

1 And I get to have these conversations.

2 So they do facilitate that
3 interaction. But not whole group setting. Or
4 say, we'll leverage our patient advisors to
5 teach on affordability and things of that
6 nature. I do think that many are
7 uncomfortable with that notion as of now.

8 MS. WILBON: So, we've got about
9 seven minutes before we were to move on to our
10 next agenda item. And I wanted to take some
11 time to talk a little bit about the billing
12 issue, which I know we, yesterday I think we
13 talked about it quite a bit.

14 But I wonder if there's any sort
15 of kind of next steps or path forward
16 recommendations we might have in that area.
17 Over the course of the two days I've heard
18 about, you know, consolidating billing. Is
19 there some way to make the, you know,
20 terminology on the bills more, you know,
21 consumer friendly?

22 But are there other kinds of

1 recommendations we have around that? And
2 then, I think we, unless we have any other
3 kind of parting words, we can probably move
4 on. But just, any discussion or thoughts on
5 that will be great. And then we'll move on to
6 the next agenda item to wrap up.

7 CHAIR MORT: I had two comments on
8 billing. Yesterday we talked a lot about
9 taking the billing process and making it more
10 transparent and simpler. So that's clear. If
11 simplifying formats, agreeing on formats that
12 patients, consumers could understand, and that
13 are useful.

14 The other piece though, that
15 Melissa kept emphasizing, was accountability
16 in that simple and transparent systematic
17 bill. So it's one thing to have a bill that
18 you can read and understand, and understand
19 what check you have to write. And that it's
20 really not a bill, it's just a summary, as
21 opposed to something you have to pay.

22 Another thing to propose, we're

1 asking providers to be accountable for how you
2 got to that bill of \$100 dollars. What was in
3 that bill for \$100 dollars?

4 Because you're going all the way,
5 Melissa, to say show me why you had to charge
6 \$12 dollars for that Tylenol. Or, I know that
7 the last time I was hospitalized in Hospital
8 X, that Tylenol was not \$12 dollars, it was \$6
9 dollars.

10 And you were talking about your
11 genetic testing being two entirely different
12 prices. Same exact test, same exact lab. So
13 you're asking for the bill, not only to be
14 easy to read and simple, and combined, but
15 accountable.

16 So there's, I wanted to just make
17 the point that that aspect is above and beyond
18 what I think part of conversation was about,
19 which is just simple.

20 MS. WILBON: Kris.

21 MEMBER SOEGAARD: I think there's
22 information that could be given to consumers

1 that could help them understand that if they
2 go into a hospital, you're not going to get
3 just a hospital bill. You're going to get
4 bills from ancillary providers too.

5 And I think that that's a big
6 surprise for a lot of people that go into the
7 hospital. They think, I'm going Hospital X,
8 and that's going to cover everything. They
9 don't realize that the anesthesiologist's bill
10 is going to be separate. The radiology bill
11 is going to be separate for reading it, those
12 kind of things.

13 So I think we can help consumers
14 understand that in the billing process they're
15 going to get multiple bills, potentially.
16 Especially if they go into a hospital. And I
17 think that's a big surprise for people.
18 Especially if you have had a first time
19 hospitalization.

20 MS. WILBON: Cynthia.

21 MEMBER ROLFE: I have a couple of
22 things. One more is just a voice of the

1 customer, having heard so many of them talk
2 about that particular thing. That one of the
3 things that really astounds people is when
4 they get bills from someone they've had almost
5 no contact with.

6 Because physician bills usually
7 come with a name on them. And low contact
8 physicians, like radiologists and
9 anesthesiologists, like I didn't even see
10 them. Why are they charging me, you know?

11 So that, just a voice of the
12 customer channeling through there. I think
13 one of the things I've also heard is, people
14 want to know when it's done. And then, you
15 know, the hospital stuff comes trickling in,
16 our EOBs come trickling in, explanation of
17 benefits come trickling in.

18 And they're like, when is this
19 going to be over, and all of that. And then
20 the third thing, one thing to say about those,
21 when is it done is, how do I factor this into
22 my life. People have varying degrees of

1 ability to plan for financial impact, and what
2 to do to deal with it

3 And we've talked to people who we
4 say, well, so where they tell us in their
5 stories they've had \$12,000 dollars in
6 hospital bills. And then we say, well, what
7 did you do with it? Because they're like, I
8 don't know what it's about. And we'll send a
9 drawer over there.

10 So people need some financial
11 support. They need budgeting support, planning
12 support, payment plan arrangement support.
13 And they don't always know they can call the
14 hospital.

15 Not all hospitals worked with them
16 that way. They don't even know they can call
17 their insurer. Because sometimes we can help
18 them work that way with the hospitals. So
19 there's a whole, you know, third piece around,
20 how do you actually pay it, even if you
21 understand it?

22 MS. WILBON: it almost sounds like

1 there need to be a set of questions around
2 billing as well. When you get a bill, this is
3 what you need to ask. I don't -- Yes.

4 (Off microphone comment)

5 MEMBER KEEFE: I would just point
6 you to a resource. There's a lot of resources
7 about patient friendly billing, and guidance
8 that's out there. And drawing on that in the
9 paper may be useful.

10 MS. WILBON: Great. So, Deb, and
11 then Liz.

12 MEMBER DAHL: I was thinking
13 about, for me, the conflict between a simple
14 bill. The frustration over the \$12 dollar
15 Tylenol. The independent bills that come
16 dragging for the next three years, that you
17 don't know what to expect.

18 And the opportunity to change the
19 entire billing system, as Melissa mentioned,
20 with the bundled bill. So, when I buy a
21 shirt, I don't expect to know what the cost of
22 the buttons were, and the thread, and the

1 cotton that went into it. I expect to know
2 what the price of the shirt was.

3 So I would hope that there would
4 be an opportunity, from a consumer
5 perspective, as well as the simplification of
6 the entire cost, to say, I'm going to have a
7 knee --

8 And yes, sometimes the cost will
9 be a little higher, sometimes the cost will be
10 a little lower. That's not my problem. My
11 problem is, the knee billed to me, or to the
12 insurance company, as the case may be,
13 including the anesthesiologist and the
14 physician, and the lab, and probably the first
15 three follow-up bills, will be \$15,000
16 dollars.

17 And to move to a model that makes
18 it less expensive to produce all the details
19 that go forward, and more understandable to
20 consumers. So, yes, the \$12 dollar Tylenol.
21 It's just a funky old leftover 1950s model of
22 how to collect cost.

1 MEMBER LATTIS: Can I ask you a
2 question on that though? You're remodeling
3 your house, you're putting in a new kitchen.
4 And, do you want the contractor just to give
5 you a bill for \$50,000 dollars and say, okay,
6 it's done?

7 Or do you want to know, this is
8 how much the refrigerator cost? And this is
9 what the stove cost. And this is how much
10 they spent for the floor. So I want to, I
11 sort of disagree with you on that last point.

12 MEMBER DAHL: Okay. And I'm going
13 to disagree even with your example. So, in a
14 house remodel, I'm not going to necessarily
15 ask, what did it cost for the contractor you
16 hired to take out the trash, off the property.

17 What I want to know is, what's it
18 going to cost to do my kitchen remodel with
19 these finishes? So, I'm asking for total
20 cost, not the individual subcontractor pieces
21 in between there. If I'm my own contractor,
22 that's a whole different model.

1 But I'm looking to buy a house in
2 this case, or I'm going to buy a knee. I want
3 to know what the whole pieces are. As a knee,
4 I don't get to choose necessarily which
5 implant, beyond a certain level. You know, I
6 might say, yes, I'm a sports person, and I
7 need running, and blah, blah, blah.

8 But I'm not going to be
9 knowledgeable enough about what suture to
10 select. So, I'm not going to make that level
11 of detail. I'm staying pretty high level.
12 I've chosen my physician. I've chosen the
13 implant that I want. And I've chosen the site
14 that I'm going to have it in. So, what's the
15 bundled cost?

16 MEMBER LATTS: Yes. See, and I
17 still want to know. I want to look, and I
18 look through my bills to say, yes, I got that,
19 yes, I got that, yes, I got that.

20 MEMBER DAHL: Yes. And you know
21 that the bills mean nothing.

22 MEMBER LATTS: The dollar amount -

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MEMBER DAHL: I'm just telling you
that the bill --

MEMBER LATTIS: -- means nothing.

MEMBER DAHL: -- means nothing.

MEMBER LATTIS: The dollar amount
associated with each item means nothing.

MEMBER DAHL: Yes.

MEMBER LATTIS: But the services --

MEMBER DAHL: But you've got the
tally of it all.

MEMBER LATTIS: -- listed, you
know.

MEMBER DAHL: Okay.

MEMBER LATTIS: And I actually
thought it was pretty interesting to say, wow,
that ICU day cost, you know, \$800 dollars.
And, you know.

MEMBER DAHL: Yes.

MEMBER LATTIS: So, I did want some
transparency into the services provided.

MEMBER DAHL: Okay. Services

1 provided I can probably go with. This fake
2 cost thing just makes me nuts.

3 MS. WILBON: So, we're going to go
4 Maureen, Melissa, and then Corey.

5 MEMBER EDIGER: Thank you, Deb and
6 Lisa, for making a great point for me. That
7 not everyone is going, we can't do this one
8 size fits all.

9 We're either going to have to
10 figure out enough about how to hit everybody's
11 preferences on communication. Or know enough
12 about patients to send them what we know they
13 want, which is impossible. So thank you.
14 That was beautifully illustrated.

15 Like, you're both correct, you
16 know. And patients and families are always
17 going to be the same way. Like, I am so
18 impressed with, I feel like I should outsource
19 some of my questions to Melissa. Like, she
20 can drill down to a level of detail that I
21 just can't, you know, for whatever reason.

22 So I think you're going to have

1 Melissa's, you're going to have Maureen's.
2 And you're going to have to figure out a
3 system that makes us both happy. So, good
4 luck.

5 MS. WILBON: Melissa.

6 CHAIR THOMASON: That should have
7 been the concluding comment of the entire day.

8 MS. WILBON: Yes.

9 CHAIR THOMASON: So, good luck. I
10 was going to say really quickly, so I can't
11 say necessarily that as a consumer I won't
12 bundle billing. I just, I want it considered.
13 And I want it considered from the consumer's
14 perspective.

15 So when I look more into bundled
16 billing, and the resources that I have
17 available to me as a consumer. And I want to
18 know, well, what is that going to mean to me?
19 There's not a lot out there from my
20 perspective. It's what it's going to do to my
21 providers, and everything like that.

22 Well, I want to know how it's

1 going to affect me, and my total cost in the
2 end to me. And I know that, yes, I go through
3 my hospital bills, and say, got that, got
4 that, what the heck is that? And then I'll
5 ask, what is that, to someone at the office
6 later.

7 So, yes, I like to check those
8 things off. But I think I like the idea of
9 bundled billing, in that when we wanted to
10 convey to providers that patient experience
11 was truly important, and not going away, we
12 linked their money to it.

13 Well, I'll tell you what's really,
14 really important to me, collaboration. And
15 they don't get that. And linking their money
16 to it would force them to work together, at
17 least on some plane. So that's why it's
18 important to me.

19 Because I have no idea how to
20 bridge the gap in collaboration among
21 providers. It affected my care. And it is
22 the biggest problem we deal with at the

1 medical center I volunteer with. And I don't
2 know that there are easy answers. But I think
3 we should have the conversation, and with
4 patients at the table.

5 MEMBER KEEFE: Can I just respond?
6 Because I think you've introduced a vernacular
7 to me from my consumer perspective, that I
8 don't think I've thought of. You said, I
9 think, two things. And I just want to make
10 sure there's anyone else hearing two things.

11 You want a bundled bill, right?
12 You don't want to receive multiple competing
13 priorities bills from your provider, and then
14 your insurance company, right? That to me is
15 administrative simplification, and making it
16 easier.

17 But you've also said bundled
18 payment, which is aligning incentives between,
19 you know, providers and physicians, you know,
20 hospitals and physicians, or whatever, in an
21 episode of care payment, which is very
22 difficult to get at. But are you talking

1 about both? Because I've heard both, I think.

2 CHAIR THOMASON: I want something
3 that facilitates collaboration, or well,
4 almost requires it among my physicians. I
5 want my bill to be easier for me to
6 understand, and to pay. I don't want to owe
7 19 people \$25 dollars a month, okay, with
8 minimum payments.

9 And whatever that entails, that's
10 what I want. Or at least to have a
11 transparent conversation about those things,
12 so that we can make an educated decision as
13 consumers about those things.

14 MEMBER LATTS: Well, and that's
15 really interesting in light of the whole ACO
16 movement. And I don't know how much the
17 consumers in the room are aware of sort of
18 ACOs, and the Accountable Care Organization,
19 and what that means.

20 But what that's trying to do is
21 just, as you said, Melissa, align incentives
22 around coordination. So it's forcing that

1 coordination by paying the organization, from
2 a payer perspective, paying the organization
3 one fee. And then the organization divvies
4 that up, and is responsible for the fee.

5 But, despite the fact that the
6 payer is paying the organization a fee for
7 your care, you are still getting billed by
8 each provider for your care. So that next
9 step of bundled billing is not happening.

10 So it's almost like, that's an
11 interesting challenge that should be sent out
12 to the ACOs of the world, that okay, it's time
13 to now push it out to the patient, the bundled
14 billing that we're paying you for the service.

15 CHAIR THOMASON: On the consumer
16 end, yes. Thank you for clarifying, Alyssa.
17 Then yes, I'm in favor of those.

18 MEMBER KEEFE: But again, an ACO
19 and a Medicare ACO is based on, as Kris was
20 just saying, on a fee for service system that
21 is not traditionally a capitated bundle given
22 to a, you know, a plan.

1 Or if you're a Kaiser, you know,
2 in California, you're going to get one, maybe
3 two bills, right? But if you're in Sutter or
4 Dignity or another, you're not. And that's
5 actually just an inherent horrible aspect
6 about our, you know, this terrible system.

7 I mean, hospitals actually have to
8 bill over 1,300 health insurance plans. I
9 mean, it's not just you. We feel the same
10 way. So I think, and this is the one time I'm
11 going to put my hospital hat on. But I think
12 we feel it in the same way as providers.

13 I mean, think about how a
14 physician -- I get errors on my bills all the
15 time. And it's because they're, I've switched
16 plans, you know. And they've resubmitted to
17 the wrong plan.

18 But keeping up with the churn of
19 me, and then the churns of the different
20 payment methodologies, et cetera, it is an
21 incredibly complex administrative system, that
22 I think we should note, because of how hard

1 that makes to assess affordability. It's just
2 something that we really need to make sure we
3 handle carefully, I think, in this paper.

4 CHAIR THOMASON: Can I be honest
5 with you? I don't want to imply that I
6 understand all the ins and outs, from a
7 consumer's perspective, of bundled billing.

8 I want to have the conversation.
9 I want access to the information. I want it
10 to be transparent. I want consumers at the
11 table. And how it influences us, and the care
12 we get, and how we pay for it on our end.

13 MS. WILBON: So, in the interest
14 of time, and making sure everyone gets out and
15 gets to their plane. I just want to thank
16 everyone for an awesome discussion. And I
17 think we're going to wrap this portion up.

18 And I think we've got some really
19 great notes, particularly for those
20 overarching issues, next step, path forward
21 section. And I'm going to, I think the next
22 session was around next steps and wrap up.

1 But Erin was going to take us through.

2 So, I'll turn it over to her. And
3 then we'll part with some final thoughts from
4 the chairs and staff. And then everyone will
5 be released to go. Oh, I'm sorry, public
6 comment. Is that now? Oh, that's after.
7 Okay. Yes, thank you.

8 MS. O'ROURKE: Thanks, Ashlie. So
9 just briefly, our next steps. We were
10 planning to distribute the draft of the white
11 paper to the expert panel on May 19th. We'd
12 started talking about lunch, or over lunch,
13 about lunch. You can see where my priorities
14 are.

15 If this committee would want to
16 have another web meeting to discuss the paper
17 before we release it for public comment, and
18 push some of these deadlines back. Taroon and
19 Ashlie, is that still what you're envisioning?

20 MS. WILBON: Yes. I mean, I think
21 what we may do is pull the committee, the
22 panel for some availability between May and

1 June. I know that's going to be summertime,
2 and a lot of people will be traveling.

3 But I think it would be really
4 useful and nice to have kind of, you know,
5 we've had two days of really rich discussion.
6 And we've kind of been around the world and
7 back again.

8 It would be nice to have some
9 feedback, again, when everything's kind of on
10 paper and written down. And kind of tweak
11 some things before it goes out for comment, to
12 make sure that the panel's in agreement that
13 the paper's kind of a reflection of the
14 sentiments, and what we wanted it to go.

15 So we'll probably, hopefully send
16 something out sooner than later, and let you
17 guys know where to do that. But I think
18 that's, over the last two days I think that
19 became increasingly clear to me that that's
20 something we probably should do. Alyssa, and
21 then Maureen. Sorry, I just have --

22 MEMBER KEEFE: I don't disagree

1 with any of that. If there's an opportunity
2 for, just a -- I know I'm having a hard time
3 distilling the tremendous, you know, feedback.
4 And you guys have done a good job in the
5 recaps.

6 But it might be helpful just to do
7 a detailed outline to shoot around. I don't
8 know if you guys -- Just to get initial
9 reactions, right direction, wrong direction.
10 How are you shaping and forming it.

11 Rather, before you get to a
12 complete draft, it may be helpful to you or
13 not. I don't want to sidetrack it. But I
14 think, you know, I often find that that's a
15 good place to start.

16 MS. WILBON: Yes. I think it's
17 part of the writing process. And I think
18 that's definitely a good recommendation.
19 Thank you. Maureen?

20 MEMBER EDIGER: I'm just curious
21 if you expect public comments. I mean, since
22 we've, when, you know, you've asked if there's

1 been questions on the phone. I'm just
2 curious. In other projects that you do, do
3 you often get public comments?

4 MS. WILBON: Yes, we get a lot.

5 MEMBER EDIGER: Okay. I'm just
6 curious about the -- Yes, okay.

7 MS. WILBON: It depends on the
8 topic area. But generally we get upwards of
9 100.

10 MEMBER EDIGER: Okay.

11 MEMBER KEEFE: But what we don't
12 get is this kind of public comment.

13 MS. WILBON: Yes.

14 MEMBER KEEFE: In my perspective.

15 MS. WILBON: Yes.

16 MEMBER KEEFE: We have a lot of
17 consumer groups at our table. No disrespect
18 to NQF. But having frequent fliers and, you
19 know, affectionately.

20 MS. WILBON: Yes.

21 MEMBER KEEFE: The, you know,
22 folks like Adam who are every day, and

1 Melissa, who are translating this to really
2 meet the objectives. I know that I would read
3 this very differently today. I mean, even
4 coming into this meeting.

5 Within 15 minutes, just as Liz, it
6 was a different meeting than what I had
7 anticipated. But I do think that having the
8 opportunity to maybe even shepherd this out to
9 some of your consumer, not necessarily, I
10 mean, a real push for actual consumers, not
11 just the groups that represent them.

12 MS. WILBON: Yes. I think that's
13 a great idea. We've had some -- John, we've
14 been working with John Santa. He had some
15 really great ideas on how to get other
16 external people involved, and get some
17 publicity to it. So it's not kind of just the
18 regular folks, you know, from the membership,
19 and so forth.

20 MR. AMIN: But we would also look
21 to you guys. If you have ideas, or if you
22 also have your networks. That's a very

1 important channel for how this information
2 ultimately gets commented on, and has impact.
3 So we'll certainly look to you for that as
4 well.

5 MS. WILBON: Yes. Any
6 recommendations you have would be really well
7 received.

8 MR. AMIN: So, Maureen --

9 MEMBER LATTS: Yes. I mean, this
10 is, if anything ever sort of cried for social
11 media sharing the opportunity to comment, it
12 would be this report. Yes. Tayler's in
13 charge of communicating, of gathering public
14 comment and the various websites, and blogs,
15 and et cetera, et cetera.

16 MR. AMIN: Maureen.

17 MEMBER EDIGER: Yes. I was just
18 going to say, we shall activate our networks.
19 Consider it done. I think, I'm excited about
20 this process. I don't feel like this is the
21 end. I feel like there's something really
22 great that could come out of this.

1 CHAIR THOMASON: I completely
2 agree. I have a really good friend that's
3 another advisor, who is working on NQF's
4 patient engagement panel. And then I'm doing
5 this one.

6 And she emailed me last night.
7 And she's like, I need your feedback on all of
8 this. And so, you know, I'll email her. But
9 really to leverage our other relationships,
10 partnership for patients. Even, I met with a
11 rep yesterday morning. And they have access
12 to incredible advisors all over the country.

13 MS. WILBON: That sounds really
14 awesome. So we would definitely -- And those
15 are networks that we oftentimes don't have
16 access to at NQF.

17 Like Alyssa mentioned, we have the
18 traditional kind of consumer advocate groups,
19 and so forth. So that's a new element that
20 we'd be very welcome to including,
21 particularly in this process. So, thank you.

22 MS. O'ROURKE: Okay. So, hearing

1 all that, it sounds like my next step slide is
2 woefully inadequate. So we'll be polling
3 everyone. We'll be polling everyone in the
4 next week or so, to get some availability for
5 a call or a web meeting, before we release the
6 paper for public comment.

7 And then rescheduling this July
8 date, so that we can have some more time with
9 getting the expert panel's feedback before we
10 have that final call to go through what we get
11 for public comment, and come up with our final
12 paper.

13 And it sounds like there's some
14 desire to provide feedback to us through the
15 writing process. So hopefully we can finally
16 get our malfunctioning SharePoint site up and
17 running, and post --

18 (Off microphone comment)

19 MS. O'ROURKE: Yes. Okay. The
20 discussion board is now up. So we can, that
21 will be open. We can post outlines and drafts
22 on SharePoint. And as people have the ability

1 and desire to continue providing us with
2 volunteer efforts, we would much appreciate
3 your feedback.

4 MS. WILBON: Operator, can you
5 open the line for anyone who wants to provide
6 a public comment?

7 OPERATOR: Yes, ma'am. At this
8 time if you'd like to provide a public
9 comment, please press *, then the number 1 on
10 your telephone keypad.

11 MS. WILBON: Is there anyone in
12 the room?

13 MR. AMIN: So, I'm the -- Just
14 another thought I guess. I didn't really
15 think to describe this at the beginning. But
16 just wanted to give people context in terms of
17 what the intent of this public comment period
18 is.

19 So, NQF is a membership
20 organization that tries to bring together
21 stakeholders across the, you know, across the
22 continuum. And when we, you know, we think of

1 this as sort of consensus building process.

2 Typically it's done in our
3 measures work, where we, you know, we
4 recommend measures, and they ultimately get,
5 you know, CMS ultimately looks to that
6 consensus process for decisions about
7 selecting them for payment or public recording
8 purposes.

9 But also looks to us for setting
10 agendas and important measurement areas. This
11 being one that's very important. So when the
12 recommendations of this panel are sort of
13 complete, they go to the membership in
14 particular.

15 But the broader public, you know,
16 obviously is a very important constituency.
17 But we have our members that are generally the
18 ones that are most interested in the work of
19 the panel. But then we also get public
20 comments about anything that happened.

21 That's why the transparency in the
22 meeting, having the stopping points during the

1 meeting for anyone in the public or the
2 membership that wants to have some input. So
3 everything that we're doing, this is certainly
4 as, Maureen, to your statement, this is really
5 only the first step in the process.

6 We certainly expect to get a
7 significant number of comments, that we will
8 ask you. And each comment is adjudicated. We
9 expect the committee to sort of be part of
10 that process, to review what we get in the
11 comments, to reflect on them, to make some
12 decisions about how they're ultimately
13 adjudicated.

14 So that's the intent of the work
15 here. I just want to kind of put that in
16 context for what we expect of this work. And
17 we also have our, you know, the work of this
18 panel then feeds to our governing structure
19 bodies, which are notably consumer weighted.

20 Our consensus standards approval
21 committee, which will get the final -- Or
22 well, not actually, not this probably. So

1 that's only for actual measures, actually.
2 But the recommendations will continue to go
3 to, you know, at least the membership. So
4 with that said, I don't think I have anything
5 else.

6 MS. WILBON: So, I think in
7 closing, I would just, I'd welcome the chairs
8 to provide any closing remarks. And then I
9 think we probably have some remarks as well.
10 But I'll invite you guys to go first.

11 CHAIR MORT: Well, I'll just close
12 by saying that when I started with this group
13 yesterday morning I was thinking about what it
14 was like when I was young, in terms of
15 affordability. It was pretty clear cut.
16 Service, write the check.

17 And over the last few days, so
18 much has changed in the last, you know, 30
19 years. The service aspect, and what we've
20 heard so much about is that consumers,
21 patients today are demanding and deserve a lot
22 more information about the pros and cons, and

1 the quality associated with the service.

2 So that's evolved immensely in
3 that time period. And the demand for that
4 information is now very, very high, as it
5 should be. And then the complexity of the
6 payment business has just gotten exponentially
7 larger.

8 Insurance, access to,
9 understanding which, what the different
10 payments are. That just creates a tremendous
11 opportunity challenge, two sides of the same
12 coin, to help make it, to make it clear to
13 patients what they need, or what's affordable.

14 I think the idea about
15 affordability being a measure potentially,
16 percentage of income, and that you could maybe
17 stratify it. And that you could have
18 attributes of affordability that you could
19 apply to certain aspects of your care
20 experience. I think this is tremendously
21 promising.

22 And there's so much more light

1 shed on the topic now, for me, than there was
2 two days ago. And I would imagine if you look
3 forward ten years from now, hopefully it won't
4 be 20 or 30 years.

5 But in ten years I would hope a
6 group was sitting here thinking back on today
7 as ancient history, and having something a lot
8 more valuable for patients and consumers. I'm
9 very optimistic that we'll be able to get
10 there.

11 CHAIR THOMASON: So, I knew that
12 I'd be working with a lot of really smart
13 people when I came to D.C. But I didn't know
14 you guys would rock so much. So thank you for
15 that.

16 You've been so open to having
17 consumers at your table, and so transparent
18 and candid about your own stories, and the
19 details you're willing to share. Many of you
20 already have consumers in your organization at
21 decision making tables.

22 If you do not, going back I hope

1 you remember how much it changed the
2 conversation to have consumers at these
3 tables. I hope you take that into your own
4 atmospheres when you return. And I understand
5 that we all seem like frequent fliers, and so
6 activated, and all of that. But, -- I'm
7 losing my voice.

8 I am a product of the health care
9 system. And don't forget that I didn't start
10 out like this. I became like this because I
11 had to become like this to be an advocate for
12 myself.

13 So, embrace those patients. Work
14 with those patients. And thank you so much
15 for all that you do to advance really
16 affordability and patient centeredness in our
17 country. I appreciate it.

18 MS. WILBON: I just want to echo
19 both Melissa and Liz's sentiments. And thank
20 the two of them for their leadership
21 throughout these two days. I think they've
22 done an awesome job of facilitating.

1 There's been a lot of -- And for
2 the panel for being so engaged in the
3 discussion. We haven't had any shortage at
4 any point of people providing their input.
5 And I think that's awesome. And that's going
6 to be reflected in hopefully the output that
7 comes out of this group.

8 I also want to provide, give a
9 special thank you to our consumers. I think
10 coming in, our frequent fliers, if you will.
11 I think, you know, I've talked with a few of
12 you off line about, you know, we didn't really
13 come to this meeting with a lot of
14 expectations.

15 Because our work, generally our
16 meetings are very structured. They're around
17 measures. We have criteria. We know how the
18 day is going to go. And so, I think we've all
19 been really, really happy with how things have
20 evolved and, you know, kind of allowing that
21 evolving kind of discussion to grow over the
22 last two days has been really interesting and

1 fascinating to sit through.

2 And I think I'm also sitting here
3 reflecting on the importance of having
4 consumers at the table. And we really
5 struggle a lot of times in our measurement
6 side to get consumers at the table.

7 But I think now it's just even
8 more apparent to me how important that is, and
9 how much it does change the discussion. So,
10 I'd like to thank everyone for, you know,
11 sharing and being open. And yes, it really,
12 I think it makes a big impact.

13 MR. AMIN: Yes. I think you said
14 it, said it very well. I think, I would just
15 provide maybe just some additional reflections
16 to say that, you know, our typical work that
17 we do in terms of measurement.

18 You know, we think that the work
19 that we're doing in terms of policy, in terms
20 of these value based purchasing initiatives,
21 and the way quality measures are being used,
22 and cost measures are going to be used for the

1 purposes of influencing consumer decision
2 making.

3 It's extremely challenging to
4 understand exactly how some of those efforts
5 are going to be successful, if we don't engage
6 patients in a way that really reflects some of
7 the discussions that we've had over the last
8 two days.

9 And what I mean specifically is
10 that this affordability framework, in terms of
11 the multitude of decisions that consumers are
12 making at various different points in time,
13 really requires a much deeper understanding
14 than we have now.

15 And I think that the work that
16 we've done here is a very small step, but an
17 important first step to trying to set in play
18 a real framework for addressing what very
19 clearly seems to be a moral imperative for how
20 to make transparency clear from the patients'
21 perspective when they're making important
22 decisions, not only about their health care,

1 but also putting financial decisions at a time
2 when they might least be able to make them, a
3 time when they're actually sick.

4 So the work here has been
5 tremendously important for us. We've
6 certainly, the structure of the meeting, the
7 conversation has been very helpful. And
8 you'll certainly, the way we certainly think
9 about this is a first step to, we hope, a much
10 more important framework for moving this whole
11 area forward, in terms of what's needed in the
12 field.

13 So thank you, particularly the
14 consumers, the panel that spent a lot of time
15 describing their own personal experiences with
16 the health care system. And we look forward
17 to engaging this conversation, and continue to
18 engage going forward. So, thank you again.

19 MS. WILBON: Yes. Thank you,
20 everyone. We will be in touch. Thank you.

21 (Whereupon, the meeting was
22 concluded at 2:23 p.m.)

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Before: NQF

Date: 03-28-14

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