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.
KRIS SOEGAARD, Minnesota Health Action Group
ADAM THOMPSON
RON WALTERS, University of Texas MD Anderson Cancer Center
COREY WILBORN, USPS Government Contractor

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ASHLIE WILBON

T-A-B-L-E O-F C-O-N-T-E-N-T-S

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

(9:05 a.m.)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

about measures hat.

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

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

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

to be done.

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

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

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

affordability.

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

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

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

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

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

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

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

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

volunteered full time after college.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

exercises.

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

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

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

But the question really came down

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

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

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

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

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

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

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

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

calling and saying, we wanted to talk to you.

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

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

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

conversation?

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

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

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

MEMBER NELSON: -- fully implemented.

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

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

MEMBER EDIGER: Yes.

MEMBER NELSON: -- the decisions people would make.

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

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

MEMBER NELSON: Interesting.

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

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

assigning everyone a case study to play out.

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

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

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

To understand if we can refine the

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

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

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

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

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

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

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

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

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

(Off microphone comment)

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

(Off microphone comment)

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

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

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

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

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

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

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

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

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

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

MS. WILBON: Yes.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

healthy lifestyle, as we've talked about.

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

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

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

beneficiary.

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

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

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

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

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

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

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

We thought that the decisions that

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

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

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

during the procedure.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

ended. Did I, anyone else? Thank you.

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

(Off microphone speaker)

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

(Crosstalk)

FEMALE PARTICIPANT: It's okay.

FEMALE PARTICIPANT: So the question was?

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

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

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

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

(Off microphone comments)

MEMBER SIERZENSKI: I could keep talking all day.

(Off microphone comments)

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

sleeps, with a history of multiple myeloma.

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

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

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

Following the transplant she will

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Is the overall cure the prognosis

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

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

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

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

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

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

for her?

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

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

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

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

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

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

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

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

So when we get to the factors, we

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

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

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

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

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

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

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

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

place before this can happen?

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

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

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

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

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

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

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

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

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

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

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

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

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

were just two things I wanted to add.

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

MEMBER THOMPSON: Yes. We talked about cultural --

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

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

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

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

CHAIR THOMASON: Yes. That's us.

CHAIR MORT: Raising the bar with a Power Point.

MR. AMIN: Oh, wow.

CHAIR MORT: Wow. Good job.

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

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

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

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

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

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

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

Is there a volume on this

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

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

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

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

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

So, first decision, would a change

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

And then are there community organizations? Especially with durable

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

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

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

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

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

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

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

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

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

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

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

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

And then of course, at the end of

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

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

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

And that we didn't know, unless

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

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

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

MR. AMIN: No, we take public comment.

MS. WILBON: Oh, public comment.

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

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

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

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

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

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

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

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

And then I would have access to

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

MR. AMIN: Karen.

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

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

MS. WILBON: So, Lisa?

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

studies.

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

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

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

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

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

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

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

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

CHAIR THOMASON: I will add too,

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

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

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

MR. AMIN: Deb, then Cynthia.

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

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

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

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

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

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

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

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

MR. AMIN: Cynthia.

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

So we get back to kind of the

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

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

MR. AMIN: Maureen.

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

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

to access some of the services that are available.

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

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

MR. AMIN: Melissa.

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

MR. AMIN: Melissa, the mic.

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

companies, and all of that.

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

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

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

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

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

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

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

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

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

MEMBER LATTS: You have to know to

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

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

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

MR. AMIN: Cynthia, and then Lisa.

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

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

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

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

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

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

before we break for lunch.

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

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

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

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

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

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

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

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

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

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

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

nature.

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

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

MR. AMIN: Lisa, them Liz.

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

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

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

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

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

medications, or max, you know, annual maxes.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

And so also the lack of having

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

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

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

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

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

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

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

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

CHAIR MORT: Can I make two

comments on the overarching issues?

MS. WILBON: Sure.

CHAIR MORT: Where do you see -- Because there's two that I'm thinking about that I don't see where they fit here.

MS. WILBON: Okay.

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

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

CHAIR MORT: Oh.

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

CHAIR MORT: Never mind.

MS. WILBON: Okay. That's fine.

CHAIR MORT: I thought that was it.

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

navigating the insurance enrollment process.

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

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

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

decide whether or not something is affordable.

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

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

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

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

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

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

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

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

CHAIR THOMASON: So, was your

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

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

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

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

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

(Off microphone comments)

CHAIR THOMASON: Make it easier to accomplish my goals.

MEMBER ROLFE: Sure. Go ahead.

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

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

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

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

distinctions. And it becomes incredibly complex very quickly.

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

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

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

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

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

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

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

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

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

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

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

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

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

(Off microphone comments)

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

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

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

(Off microphone comment)

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

different.

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

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

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

CHAIR THOMASON: So what is affordability?

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

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

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

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

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

CHAIR MORT: That's kind of an

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

MEMBER LOFQUIST: Right. That's my point.

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

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

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

MEMBER WILBORN: Okay. Thank you.

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

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

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

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

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

MS. WILBON: Okay.

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

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

I was looking to find it?

MEMBER LATTS: The need for the information?

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

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

(Off microphone comments)

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

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

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

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

MS. WILBON: Carrie.

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

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

MEMBER NELSON: Okay.

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

MEMBER NELSON: Sure. Okay.

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

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

MEMBER NELSON: Thanks.

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

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

So what Melissa talked about was,

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

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

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

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

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

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

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

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

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

MS. WILBON: Right. Okay, right.

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

MS. WILBON: Oh, yes.

CHAIR MORT: Maybe we've exhausted overarching issues.

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

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

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

For example, so I participated in

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

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

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

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

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

involvement.

MS. WILBON: Okay.

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

MS. WILBON: Okay.

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

MS. WILBON: Right.

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

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

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

MS. WILBON: Right.

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

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

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

But I think if we can, any kind of

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

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

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

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

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

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

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

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

relatively easy.

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

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

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

But if I recall, the first one was

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

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

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

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

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

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

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

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

MEMBER THOMPSON: It's really

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

CHAIR THOMASON: Right.

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

CHAIR THOMASON: Yes. Activation --

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

CHAIR THOMASON: Right.

MEMBER THOMPSON: You know what I mean?

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

MEMBER LATTS: One of the,

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

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

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

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

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

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

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

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

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

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

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

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

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

affordability.

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

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

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

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

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

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

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

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

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

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

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

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

So there could be, you know, to

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

MS. ADAMS: Right.

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

MS. ADAMS: Exactly.

CHAIR MORT: -- all the constituents.

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

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

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

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

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

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

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

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

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

connections.

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

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

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

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

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

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

MS. WILBON: Melissa.

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

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

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

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

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

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

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

in those areas in the future.

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

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

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

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

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

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

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

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

(Off microphone comment)

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

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

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

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

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

CHAIR THOMASON: I agree.

MEMBER WILBORN: And they're going to --

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

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

CHAIR THOMASON: Right. And I

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

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

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

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

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

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

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

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

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

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

CHAIR THOMASON: I agree.

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

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

MS. WILBON: Tina, and then Ron.

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

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

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

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

MS. WILBON: Ron.

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

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

And then, the process measure is,

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

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

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

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

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

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

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

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

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

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

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

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

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

believe is the perceived trusted place of information.

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

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

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

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

depends on how you perceive.

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

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

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

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

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

CHAIR THOMASON: I would say pp

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

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

CHAIR MORT: It's hard to keep track.

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

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

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

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

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

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

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

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

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

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

MS. WILBON: So, Melissa.

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

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

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

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

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

my check every month.

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

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

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

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

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

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

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

MS. WILBON: Okay. Deb?

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

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

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

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

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

Maybe diabetes would have been a

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

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

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

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

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

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

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

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

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

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

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

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

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

MS. WILBON: Carrie.

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

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

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

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

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

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

MS. WILBON: Tina, and then Adam.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

purpose.

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

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

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

And I get to have these conversations.

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

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

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

But are there other kinds of

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

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

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

Another thing to propose, we're

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

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

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

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

MS. WILBON: Kris.

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

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

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

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

MS. WILBON: Cynthia.

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

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

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

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

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

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

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

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

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

MS. WILBON: it almost sounds like

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

(Off microphone comment)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

MEMBER LATTS: The dollar amount -

-

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

MEMBER LATTS: -- means nothing.

MEMBER DAHL: -- means nothing.

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

MEMBER DAHL: Yes.

MEMBER LATTS: But the services --

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

MEMBER LATTS: -- listed, you know.

MEMBER DAHL: Okay.

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

MEMBER DAHL: Okay. Services

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

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

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

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

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

So I think you're going to have

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

MS. WILBON: Melissa.

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

MS. WILBON: Yes.

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

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

Well, I want to know how it's

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

But Erin was going to take us through.

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

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

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

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

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

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

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

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

MEMBER KEEFE: I don't disagree

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

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

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

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

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

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

MS. WILBON: Yes, we get a lot.

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

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

MEMBER EDIGER: Okay.

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

MS. WILBON: Yes.

MEMBER KEEFE: In my perspective.

MS. WILBON: Yes.

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

MS. WILBON: Yes.

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

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

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

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

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

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

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

MR. AMIN: So, Maureen --

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

MR. AMIN: Maureen.

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

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

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

MS. WILBON: That sounds really awesome. So we would definitely -- And those are networks that we oftentimes don't have access to at NQF.

Like Alyssa mentioned, we have the traditional kind of consumer advocate groups, and so forth. So that's a new element that we'd be very welcome to including, particularly in this process. So, thank you.

MS. O'ROURKE: Okay. So, hearing

all that, it sounds like my next step slide is woefully inadequate. So we'll be polling everyone. We'll be polling everyone in the next week or so, to get some availability for a call or a web meeting, before we release the paper for public comment.

And then rescheduling this July date, so that we can have some more time with getting the expert panel's feedback before we have that final call to go through what we get for public comment, and come up with our final paper.

And it sounds like there's some desire to provide feedback to us through the writing process. So hopefully we can finally get our malfunctioning SharePoint site up and running, and post --

(Off microphone comment)

MS. O'ROURKE: Yes. Okay. The discussion board is now up. So we can, that will be open. We can post outlines and drafts on SharePoint. And as people have the ability

and desire to continue providing us with volunteer efforts, we would much appreciate your feedback.

MS. WILBON: Operator, can you open the line for anyone who wants to provide a public comment?

OPERATOR: Yes, ma'am. At this time if you'd like to provide a public comment, please press *, then the number 1 on your telephone keypad.

MS. WILBON: Is there anyone in the room?

MR. AMIN: So, I'm the -- Just another thought I guess. I didn't really think to describe this at the beginning. But just wanted to give people context in terms of what the intent of this public comment period is.

So, NQF is a membership organization that tries to bring together stakeholders across the, you know, across the continuum. And when we, you know, we think of

this as sort of consensus building process.

Typically it's done in our measures work, where we, you know, we recommend measures, and they ultimately get, you know, CMS ultimately looks to that consensus process for decisions about selecting them for payment or public recording purposes.

But also looks to us for setting agendas and important measurement areas. This being one that's very important. So when the recommendations of this panel are sort of complete, they go to the membership in particular.

But the broader public, you know, obviously is a very important constituency. But we have our members that are generally the ones that are most interested in the work of the panel. But then we also get public comments about anything that happened.

That's why the transparency in the meeting, having the stopping points during the

meeting for anyone in the public or the membership that wants to have some input. So everything that we're doing, this is certainly as, Maureen, to your statement, this is really only the first step in the process.

We certainly expect to get a significant number of comments, that we will ask you. And each comment is adjudicated. We expect the committee to sort of be part of that process, to review what we get in the comments, to reflect on them, to make some decisions about how they're ultimately adjudicated.

So that's the intent of the work here. I just want to kind of put that in context for what we expect of this work. And we also have our, you know, the work of this panel then feeds to our governing structure bodies, which are notably consumer weighted.

Our consensus standards approval committee, which will get the final -- Or well, not actually, not this probably. So

that's only for actual measures, actually. But the recommendations will continue to go to, you know, at least the membership. So with that said, I don't think I have anything else.

MS. WILBON: So, I think in closing, I would just, I'd welcome the chairs to provide any closing remarks. And then I think we probably have some remarks as well. But I'll invite you guys to go first.

CHAIR MORT: Well, I'll just close by saying that when I started with this group yesterday morning I was thinking about what it was like when I was young, in terms of affordability. It was pretty clear cut. Service, write the check.

And over the last few days, so much has changed in the last, you know, 30 years. The service aspect, and what we've heard so much about is that consumers, patients today are demanding and deserve a lot more information about the pros and cons, and

the quality associated with the service.

So that's evolved immensely in that time period. And the demand for that information is now very, very high, as it should be. And then the complexity of the payment business has just gotten exponentially larger.

Insurance, access to, understanding which, what the different payments are. That just creates a tremendous opportunity challenge, two sides of the same coin, to help make it, to make it clear to patients what they need, or what's affordable.

I think the idea about affordability being a measure potentially, percentage of income, and that you could maybe stratify it. And that you could have attributes of affordability that you could apply to certain aspects of your care experience. I think this is tremendously promising.

And there's so much more light

shed on the topic now, for me, than there was two days ago. And I would imagine if you look forward ten years from now, hopefully it won't be 20 or 30 years.

But in ten years I would hope a group was sitting here thinking back on today as ancient history, and having something a lot more valuable for patients and consumers. I'm very optimistic that we'll be able to get there.

CHAIR THOMASON: So, I knew that I'd be working with a lot of really smart people when I came to D.C. But I didn't know you guys would rock so much. So thank you for that.

You've been so open to having consumers at your table, and so transparent and candid about your own stories, and the details you're willing to share. Many of you already have consumers in your organization at decision making tables.

If you do not, going back I hope

you remember how much it changed the conversation to have consumers at these tables. I hope you take that into your own atmospheres when you return. And I understand that we all seem like frequent fliers, and so activated, and all of that. But, -- I'm losing my voice.

I am a product of the health care system. And don't forget that I didn't start out like this. I became like this because I had to become like this to be an advocate for myself.

So, embrace those patients. Work with those patients. And thank you so much for all that you do to advance really affordability and patient centeredness in our country. I appreciate it.

MS. WILBON: I just want to echo both Melissa and Liz's sentiments. And thank the two of them for their leadership throughout these two days. I think they've done an awesome job of facilitating.

There's been a lot of -- And for the panel for being so engaged in the discussion. We haven't had any shortage at any point of people providing their input. And I think that's awesome. And that's going to be reflected in hopefully the output that comes out of this group.

I also want to provide, give a special thank you to our consumers. I think coming in, our frequent fliers, if you will. I think, you know, I've talked with a few of you off line about, you know, we didn't really come to this meeting with a lot of expectations.

Because our work, generally our meetings are very structured. They're around measures. We have criteria. We know how the day is going to go. And so, I think we've all been really, really happy with how things have evolved and, you know, kind of allowing that evolving kind of discussion to grow over the last two days has been really interesting and

fascinating to sit through.

And I think I'm also sitting here reflecting on the importance of having consumers at the table. And we really struggle a lot of times in our measurement side to get consumers at the table.

But I think now it's just even more apparent to me how important that is, and how much it does change the discussion. So, I'd like to thank everyone for, you know, sharing and being open. And yes, it really, I think it makes a big impact.

MR. AMIN: Yes. I think you said it, said it very well. I think, I would just provide maybe just some additional reflections to say that, you know, our typical work that we do in terms of measurement.

You know, we think that the work that we're doing in terms of policy, in terms of these value based purchasing initiatives, and the way quality measures are being used, and cost measures are going to be used for the

purposes of influencing consumer decision making.

It's extremely challenging to understand exactly how some of those efforts are going to be successful, if we don't engage patients in a way that really reflects some of the discussions that we've had over the last two days.

And what I mean specifically is that this affordability framework, in terms of the multitude of decisions that consumers are making at various different points in time, really requires a much deeper understanding than we have now.

And I think that the work that we've done here is a very small step, but an important first step to trying to set in play a real framework for addressing what very clearly seems to be a moral imperative for how to make transparency clear from the patients' perspective when they're making important decisions, not only about their health care,

but also putting financial decisions at a time when they might least be able to make them, a time when they're actually sick.

So the work here has been tremendously important for us. We've certainly, the structure of the meeting, the conversation has been very helpful. And you'll certainly, the way we certainly think about this is a first step to, we hope, a much more important framework for moving this whole area forward, in terms of what's needed in the field.

So thank you, particularly the consumers, the panel that spent a lot of time describing their own personal experiences with the health care system. And we look forward to engaging this conversation, and continue to engage going forward. So, thank you again.

MS. WILBON: Yes. Thank you, everyone. We will be in touch. Thank you.

(Whereupon, the meeting was concluded at 2:23 p.m.)

C E R T I F I C A T E

This is to certify that the foregoing transcript

In the matter of: Measuring Affordable Care

Before: NQF

Date: 03-28-14

Place: Washington, DC

was duly recorded and accurately transcribed under my direction; further, that said transcript is a true and accurate record of the proceedings.

Neal R. Gross

Court Reporter