NATIONAL QUALITY FORUM

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MEASURING AFFORDABLE CARE EXPERT PANEL

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THURSDAY, MARCH 27, 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
DEBORAH 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, BlueCross BlueShield Association
ALISON SHIPPY, National Partnership for Women & Families
PAUL SIERZENSKI, American College of Emergency Physicians
JOESEPH SINGER, HealthCore, Inc.
KRIS SOEGAARD, Minnesota Health Action Group
ADAM THOMPSON, National Quality Center
LINA WALKER, AARP
RONALD WALTERS, University of Texas MD Anderson Cancer Center
COREY WILBORN, USPS Government Contractor

NQF STAFF:

KAREN ADAMS

TAROON AMIN

HELEN BURSTIN

ANN HAMMERSMITH

VY LUONG

ERIN O'ROURKE

ROB SAUNDERS

LINDSEY TIGHE

ASHLIE WILBON

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(9:10 a.m.)

MR. AMIN: Good morning, everyone. Thank you all for getting here on time and we are ready to get started. We are very excited to get this two-day meeting on a very important topic both for NQF and for, I would say, broadly, the healthcare field in general, who is really interested in this topic of affordability. So, we are very excited to get this kicked off.

So, we will get started with our introductions and disclosures that we will do together. So, I will actually turn it over to our general counsel, Ann Hammersmith, that will walk us through the process of disclosures and introductions.

And we should introduce our staff first, as Ashlie pointed out. That's good. So maybe I will get started.

So, my name is Taroon Amin. I am senior director here at NQF, working on mainly

cost and resource use activities in addition to readmissions work.

So, maybe I will ask Vy to introduce herself and then we will go around the room.

MS. LUONG: Hi, everyone. My name is Vy Luong and I am the project analyst on this project. Welcome and we are excited to have you all onboard.

MS. O'ROURKE: Hi, everyone. I am Erin O'Rourke and I am the project manager.

CHAIR THOMASON: Hi, I'm Melissa Thomason, a patient and family advisor from eastern North Carolina.

MR. AMIN: Okay. We will come -- yes, so maybe I will just quickly introduce the staff we could just move quickly. And then we have Ashlie Wilbon here, who is our managing director; Ann Hammersmith, who is our general counsel; Lindsey Tighe, who is our senior project manager, who has been supporting our work here; Karen Adams, our VP

and our VP in our Strategic Partnerships group; and Helen Burstin, our senior vice president over multiple different areas.

(Laughter.)

MR. AMIN: So, Ann, take it away.

MS. HAMMERSMITH: Thank you, Taroon. As Taroon said, we will combine the introductions with the disclosures because it is a little bit quicker and easier for everybody. I am just going to walk you through what we are trying to get at with disclosures and then we can go around the table.

First of all, we are not looking for you to repeat your resume for us because then we will be here for a very long time you can actually start doing your work. You were given a rather long form, which we appreciate you filling out that asks you about professional activities, committee memberships and things of that nature. You are all sitting as individuals on this committee, so

you don't represent the interests of your employer or anybody who may have nominated you to serve on the committee.

So, we are particularly interested in your disclosure of consulting activities, any grants that you may have gotten, or research dollars that are directly related to the subject matter of the committee.

So, just because you disclose doesn't mean you have a conflict. A lot of this exercise is being open and transparent so that the public knows the committee's background and so that you know each other's background.

So, with that, why don't we get started with the chair? If you could all tell us your name, who you are with, and if you have anything you would like to disclose.

MR. AMIN: Liz, I would just point out that there is a speak button. Just for everybody in front of you, if you could press the speak button before you speak, that way it

helps with the transcription process as well. So, thanks.

CHAIR MORT: Good morning. My name is Elizabeth Mort and I am an internist at Mass General, currently the senior vice president for quality and safety and chief quality officer.

And I have no disclosures at this point. I am delighted to be here and I appreciate being asked to co-chair this important work.

CHAIR THOMASON: Hi. I am Melissa Thomason, a patient and family advisor in Eastern North Carolina. I am excited to be here and to see real patients with real stories and real experiences represented.

No disclosures at this time.

MEMBER LOFQUIST: Hi. My name is Tayler Lofquist. I live here in Washington, D.C. and I am an account coordinator at Beekeeper Group, which is a public affairs firm. I specialize in social media and online

technologies and I am really excited to talk about ways that can help everything that we are talking about here today. And I have no disclosures.

MEMBER WILBORN: Good morning. My name is Corey Wilborn, a patient, I guess, expert. I have had five open heart surgeries over the years. So, I have been through the healthcare system quite a bit and I am a government contractor for the United States Postal Service. And I have served in the Florida legislature as a legislative aide for three sessions.

MEMBER DAHL: Hi. I am Deb Dahl. I am the Vice President of Patient Care Innovation with Banner Health out of Phoenix, Arizona. I also do consulting with GLG Consulting on telehealth and accountable care organizations. And I am currently between grants.

MEMBER NELSON: I am Carrie Nelson. I am senior medical director for

advocate physician partners. We are a 13-hospital 4,000-physician organization that has a large accountable care organization really focused on delivering value. I have nothing to disclose.

MEMBER SHIPPY: Good morning. Alison Shippy with the national partnership for women and families. It is a consumer advocacy organization here in Washington, D.C., no disclosures.

MEMBER SOEGAARD: Hi. I am Kris Soegaard with the Minnesota Health Action Group. We represent employers at purchasers of healthcare. I have no disclosures.

MEMBER SIERZENSKI: Paul Sierzenski. I am an emergency physician at Christiana Care Health System in Delaware. I am the Clinical Medical Director for imaging there and I have served on TEP committees in the past 24 months with the Lewin Group related to imaging efficiency.

MEMBER KEEFE: Good morning. My

name is Alyssa Keefe. I am with the California Hospital Association. I have a background in hospital finance and quality measurement. I am based here in Washington, so I did not fly across the country this morning. We do have an office here and I am pleased to be here. Thank you.

MEMBER NIELSEN: Hi. I am Marci Nielsen. I am the CEO of the Patient-Centered Primary Care Collaborative here in Washington, D.C., a broad stakeholder group focused on patient-centered medical homes and primary care. My only disclosure is I am kind of chatty.

MEMBER SINGER: Hi. I am Joe Singer, Vice President of Clinical Affairs ta HealthCore, we are a health services research company that does contract research for many organizations within the federal government, NIH, CDC, FDA. We do contract research for biotech pharmaceutical companies, foundations, health plans. We are a wholly-owned

subsidiary of WellPoint. WellPoint owns 14 BlueCross/BlueShield plans across the country, as well as about two dozen Medicaid plans, 36 million lives, in total.

MEMBER ROLFE: Good morning. I am Cynthia Rolfe. I am the Vice President of Consumer Strategy and Research at the BlueCross and BlueShield Association. This is the blue end of the table, I guess.

I joined, actually, the insurance industry two years ago. So, I am relatively new to the industry from a consumer background. And the BlueCross and BlueShield Association is the national entity that supports and licenses to the 37 independent companies that run BlueCross and BlueShield plans across the country. And it is a 100 million lives. So, it is very important to use that those lives are improved and their interaction with healthcare is as great as it can be.

I have no disclosures at this

time.

MEMBER WALTERS: Ron Walters. I am a medical oncologist and the Vice President of M.D. Anderson in Houston.

Rather amazingly, despite that, I have avoided and still avoid all grants, research dollars and contracts. I am not sure how I succeed.

I am also, as many people in the room, a consumer of the healthcare system and care about this issue a lot.

MEMBER LATTS: Hi, good morning. Lisa Latts. I am currently a consultant and have been for the last year and a half. Prior to that I was with WellPoint. So yes, definitely blue end of the table.

I am an internist. In terms of consulting, I don't have any conflicts. I am the co-chair of the cost and resource use committee. So, I assume that is not a conflict but just for disclosure.

MEMBER FRONTERA: Hello. I am

Tina Frontera. I am the Chief Operating Officer with Minnesota Community Measurement. We measure cost quality and patient experience in Minnesota. Prior to that, I was an independent consultant and my area of expertise was cost transparency.

MEMBER THOMPSON: Good morning. My name is Adam Thompson. I am a coach with the National Quality Center, providing technical assistance to federally-funded HIV clinics. And I am here representing patients as a person living with HIV.

MEMBER EDIGER: Hi, many name is Maureen Ediger. I am on a quality and safety committee of the Board for Children's Hospital of Colorado in Denver and I am the mother of four children, two of which have special needs.

And I have nothing to disclose.

MS. HAMMERSMITH: Okay, thank you for those disclosures.

And the last thought I am going to

leave you with is if at any time during the meeting you feel that you might have a conflict of interest or have a concern about it, please speak up. You can do that openly in the meeting. You can approach your chair, who will go to NQF staff, or you can go directly to NQF staff.

You should also do the same thing if you feel that one of your fellow committee members has a conflict or is acting in a biased way. And we rely on you to help us preserve a healthy conflict-free environment in which to do the work.

So, based on that spirit, does anybody have any questions or anything you would like to discuss based on the disclosures, like Marci's chattiness or anything like that?

Okay, thank you. Have a good meeting.

MR. AMIN: Okay, so what we'll do to get started here is just we will do a quick

overview of the project and the project goals. And then I will sort of open it up to the chairs as well if they have any introductory comments to make just welcoming the committee, in general. And then I will turn it over to Erin to walk through a little bit of the, just some of the logistics about the meeting day and the agenda, if that is okay.

And Ashlie, please feel free to -- yes, I will shift over as well.

(Pause.)

MR. AMIN: Okay, so we are very excited again to get started with this work. As we will talk about later on this afternoon, or later on this morning, a lot of the work that we have been doing in cost and resource use has been informed by our overall conceptual framework of trying to get to our value and efficiency. And one of the big questions that we have been grappling with internally is really understanding the concept of affordability, particularly from various

different stakeholder's perspectives. This meeting is very unique in the nature of some of the meetings that we have at NQF and the fact that we have a number of consumers at the table. And we are very excited about that because this topic, the very question of affordability is very much rooted in individuals' perspectives of cost and the various different aspects of how one makes a decision about seeking healthcare behavior.

So, we see this work as very foundational in helping us put some context around how we think about the question of affordability and we, as a measurement organization, help to influence the type of data and the type of information that consumers need to be able to make decisions in healthcare, particularly, given the amount of changes that are happening in the healthcare system. We want to be sure that patients have the type of information they need to be able to be active consumers as will be required of

them as we continue to move forward with various different efforts around price transparency, increasing data that is going to be on websites, and exchanges.

So, the basic foundation of what we are trying to achieve with this project is fairly simple, simple but challenging at the same time, I should say. At the very core, there is obviously a number of different decisions that consumers need to make across the healthcare continuum at various different points in time. But basically what we are trying to understand is take an illustrative case of different decisions that consumers need to make and then really understand through those decisions what information is really available to them and the type of information that consumers really need. So, what is available and what do you really need?

And obviously, just as a precursor to this, there is no way can cover every decision for every point in time for every

condition. You know that would be nearly impossible to do during these two days. But what we have teed up during this session for today, tomorrow is to come up with an illustrative case of what are the decisions that various consumers need to make at different points in time, recognizing that there are different types of consumers and there are different condition types and there are different circumstances that face consumers but to really start to come up with a framework for how we can start to really think about the question of affordability and maybe what are the key elements of data that consumers really need to have in order to be able to be more active consumers in the healthcare market.

So, that is effectively what we are trying to achieve over the next two days. And so we will, obviously, walk through that in a little bit more detail. So, maybe I will just kind of go to the next slide, which is to

say we will go through some project goals, which essentially a little bit of what I described, which is the current state of what cost information is available to consumers and really how is this information accessed and what types of data are really available to consumers.

The other thing that we are really trying to understand is how this cost information really influences consumer decision-making. So, we will ask a series of sort of questions at the beginning, which are sort of, we will be using our voting, the vote SNAP to get a general sense of where people are, how they think about some of the main questions that consumers face, effectively how cost data may influence the way -- whether -- or how much cost information is actually available to you when you are actually trying to make decisions about healthcare.

And then we will lay out a conceptual model, which I described, which

gives us essentially three different points in time in which consumers make decisions about healthcare. And then basically through this process, we will really try to understand what information is needed and what information is currently available to consumers.

So, effectively, that is the structure of how the two days will go. And maybe I will turn it over to Ashlie or the co-chairs if they want to add anything about the structure of what we are trying to achieve.

MS. WILBON: Yes, I would just add that one of the primary outputs of this work will be a white paper. So, we will be taking the input -- the outline that we have put together is really kind of the foundation for how we have organized the meeting. So, we are looking to take the input and everything that we hear over these next two days to really build that white paper. And we will be sharing that back with you at the end in about a month or so after this meeting. And that

will really be kind of the output of this work and, hopefully, represent the sentiment of this group and any next steps that we will have going forward to, hopefully, get this information that consumers need to the consumers.

CHAIR MORT: I would just like to add that I think that this work is really, really important but also really, really challenging and complicated.

And I am looking around the room and there is probably a few people besides myself who remember the day when your mother took you to the pediatrician and you had a service and then she took out the checkbook. Right? A few of us remember that.

And back in the early '60s when I was a kid with my four siblings, my mother took us to the pediatrician, unloaded us from the station wagon, we all had our exams and she wrote the checkbook. Then you broke your thumb in soccer, you had a pneumonia and you

needed an x-ray. There was always the checkbook. So, services and payment just went together, much as the way we purchase everything else in our lives.

But since then, services have gotten really complicated. The whole idea of preventive medicine, chronic disease, and all those diagnostics and wonderful therapeutics but the payment piece has gotten completely disconnected and has a whole new administrative structure.

So, the work today, I think, today and tomorrow, is a really important first step at trying to unpack those components and figuring out at this point in time how do we get back to helping consumers understand what the payment is, how much they will have to pay in order to get the services, and you have to backtrack and divide it into these components.

So, I think the goals that are articulated are very practical and are really going to help us take a big step forward on a

very complicated but important journey.

MEMBER LATTS: I just had question maybe for Ashlie and then Taroon. I mean is the idea with the white paper we are just going to throw it on the water and hope somebody reads it and picks it up or is there sort of specific policy things that -- policy or something that is going to happen downstream with the white paper?

MS. ADAMS: Lisa, I think that is a really good question because certainly you don't want a deliverable to sit on the shelf. And many of us know that although the white paper is the deliverable from this, what is happening in this room is much more.

So, we have many receptor sites for this deliverable. One is the Robert Wood Johnson foundation who funds this work and is really trying to advance this. We have work that we are doing that is being funded by Health and Human Services looking at how you pay for care and what measures you use for

that. It will help inform that.

So, there are many policy implications for this because work across NQF is addressing affordability. Some of you, I know, Ron, Allison, are involved with our Measure Applications Partnership, where we provide input to HHS onto actual measures that go into our payment programs.

And so, this type of feedback that we get from you are: What are the right measures? What do you want to know? What are meaningful and useful to consumers, particularly as more choice is going to be coming your way and you are going to have to make these type of informed decisions?

So, although the white paper I would see as a vehicle, it has many policy receptor sites. And then I look to all of you around the table because each one of you have your sphere of influence. And where you work or where you live or what you do. And you are our champions. You are our clarions. And

actually, you bring a lot of validity to what we are doing. Because if it is just another Washington committee saying this is what should be measured and this is what matters, but coming from you, it just means so much.

So, we will work with you, of course, to try to -- I call them receptors sites, but different places where we can make sure that this gets disseminated and becomes part of the conversation. But certainly within NQF, we can use our levers with HHS as well as with our funder, Robert Wood Johnson.

MR. AMIN: Thanks, Karen. I would just -- the only other thing that I would add to that is since there are sort of newer members to the NQF table that are here, NQF also has a responsibility in our role to help advise HHS and the public in the private sector in how they should be investing the measurement development dollars toward future measure gaps. And we are very new in the area of cost and resource use measurement for the

sake of public sector programs. The private sector has been much more advanced in terms of the measures that they have been using.

But the goal here also is to have a first step toward understanding, as Karen described, the type of information that consumers really need to be able to make decisions. But at the same time, we also recognize that this may be an area where this might be a Hospital Compare type information source. It might be consumers may need information and they are already seeking information through other data types. Other social media applications or crowd sourced information that is out there.

So, the way that consumers may be seeking information may not be through our traditional measurement sources. And that would signal a whole series of other activities that NQF may take on.

So, as Liz described, this is certainly -- we see this as sort of a first

step into moving into this really important area, keeping the consumer's perspective at the forefront of the work, both from investing measurement dollars but also maybe thinking about different measurement vehicles or information vehicles that we may need to continue to expand in because that may be where the consumers are.

So, all of these things are within scope but, again, we are trying to keep it as structured as possible so that we can sort of wrap our hands around what the next few phases of this activity may end up becoming.

Does that answer your question, Lisa?

Melissa, did you have any opening just thoughts that you wanted to share with the group?

CHAIR THOMASON: I just wanted to welcome everyone. Like I said, I am very excited that we have real consumers and real patients sitting at the table but I wanted to

acknowledge, too, that I understand that most of you in this room, even as professionals, are also consumers of the healthcare system. So, I look forward to hearing your individual experiences as well.

MR. AMIN: Erin, do you mind just walking through some of the sort of logistics of the meeting for the next two days?

MS. O'ROURKE: Absolutely. So, just to start out with, how we will call on people. If you wanted to speak, turn your tent card up like this. And our co-chairs will be keeping a list of what order people raised their cards and we will be calling on you in turn.

Just to walk you through our agenda. This morning we will be spending some time talking about the consumer experience and what people are really going through out in the field trying to use to cost and quality data. Then, we will have some time to define affordability and really explore what it means

to consumers and how it relates to other concepts, including quality.

Then, we will take a break for lunch. After that, we will be introducing the patient-focused episode of care model. Staff has put together a draft conceptual framework for the committee to react to that is based off of this model. So, we will take some time to walk you through it.

And then after lunch, we will be really playing out the decisions that consumers need to make across each phase of this model when they are in the population at risk, once they have actually been diagnosed with a condition and what decisions they need and what information they need to make, once they are in the follow-up care phase.

After that, we will be breaking for the day. We will have an optional expert panel dinner. So, we will be polling you at lunch to see if you are interested in joining us.

On Day 2, we will come back and recap Day 1, then going into a brief breakout session exercise, where we will be giving everyone a case to play out across the model that we developed today, kind of as a pressure-testing mechanism to see when you actually try to apply it to a real patient, does it still hold up.

Then, we will be bringing the group back together to report out from your breakout sessions. And after lunch, having a conversation on the challenges, what is our path forward, how can we take some first steps to get this information to consumers so that they can make more informed healthcare choices.

A few logistical details. The restrooms, if you exit the main conference area, they are past the elevators on the right. We will have some breaks at 10:30, noon, and 1:45. Laptops and cell phones, you will see the access information for our

wireless network, if you would like to log on.

We have had some mentions of social media, so we will be tweeting about this meeting and we would encourage you guys to, if you are active on Twitter, or have thoughts you would like to share, to tweet using the hashtag #nqfaffordablecare and to copy NQF's twitter handle.

We will also be going through the discussion guide that is at your place as the guide to the meeting. It will have all the questions that we will be trying to get answers to. We know there is a lot of questions in that guide. So, we don't expect the committee to come to an answer to all of them. They are more food for thought, if you will, to start provoking the conversation.

Finally, I just wanted to mention privacy concerns. This meeting is being web streamed and is being transcribed with people's names. So, if you did want to share any personal health information, to please

keep that in mind. We don't want to put anyone on the spot to share anything they are not comfortable about. So, if you would prefer to say something like my friend had an experience or anything like that, just recognizing the importance of privacy in this area.

Taroon, anything else?

MR. AMIN: I think the only other things I would point out is our traditional kind of custom is to raise your table tent if you want to speak. And we certainly expect this to be sort of a conversation. So, it is not necessarily, this is not a presentation-style meeting. It is certainly a conversation among the committee. And just that as a caveat with the agenda, as Erin pointed out, I just want to reiterate a little bit of what I just said before, which is that the various three different points in time are, by themselves, they are illustrative. Obviously, they are sort of -- and we will walk through

it in a little more detail once we get to it, but they are intended to be illustrative. And the decisions that we sort of walk through are also intended to be illustrative. We don't expect it to be a fully comprehensive list of all the decisions at various different points in time that consumers would need to make. But once we are able to understand thematically what types of decisions and what type of information consumers would need to make, that is the type of information we will be extracting from the conversation at the end of this meeting.

So, staff will be talking all that information and then coming up with some thematic concepts from the group.

And I think that is all I wanted to cover in addition there.

MS. WILBON: So, our next agenda item is to kind of kick off the meeting sharing some consumer experiences. I think, as Taroon mentioned, this is somewhat unique

for us in that we do have a significant number of consumers around the table and that experience is really kind of core and the foundation of why we are doing this work. And so we would really just wanted to give some of the consumers around the table, and even open it up to others around the table who weren't necessarily invited specifically as consumer representatives or patient representatives but to share your experiences and some experiences you have had with dealing with healthcare costs and how, perhaps, your decisions or interaction or engagement with the healthcare system have been influenced by costs and perhaps quality information.

So, I want to welcome any of the consumers that were invited to participate to kind of share their experiences and then anyone else who wanted to join in, to do so.

Did you maybe want to start, Melissa, as the chair?

CHAIR THOMASON: So, I guess I

will start. Again, my name is Melissa Thomason and just like I was saying earlier, I invite you, even if you are not a frequent flyer in the healthcare system, as we like to say, I also sit on the North Carolina Institute of Medicine's Patient Engagement Committee and a lot of times I like to listen to the professionals at the table, their individual healthcare experiences, as much as I do our other advisors.

So, in 2008 I was 35 weeks' pregnant with my son, as I said on the first phone call, some of you may remember. And my aorta dissected. I was already hospitalized for preeclampsia. I got in the hospital shower that morning, my aorta dissected from just above the aortic root down the entire descending aorta. And I had an emergency C-section that morning and was airlifted for emergency open heart surgery that night. I was in, the first time, for about six weeks.

Six months' later, I was diagnosed

with a rare genetic disorder called Loeys-Dietz Syndrome. I had my second open heart within three months after that, and then my third three months after that. So, three in the year and a C-section; six procedures in 18 months, including an aortic stent and a Voice implant. There was a whole lot in there.

So, as far as the first thing, just like we talked about on the call, really my concept of affordability and do I need this care and all of that changed when I needed emergent care versus when it was my chronic care and maintenance.

The emergency that morning, it was all about staying alive and affordability probably didn't even enter my mind at that point. It was about staying alive and if they had told me it would cost me everything I would ever earn in my life, I would have said well, let's do it. When I got to the hospital, the physician said there is a 75 percent chance you won't make it through the

day if you don't have this surgery. And I said well, then, where do I sign? And I would have done the same thing, regardless of cost at that point.

So, but once I was alive and sitting in the hospital bed, I remember about two weeks' in, sitting in the hospital bed and I looked at my husband and I said, we will never pay this off. In our entire lives, we will never pay this off. And he sort of disregarded it. He said it doesn't matter. Whatever it costs, we can just take care of you.

And really, I think that was great but I also think that alluded to this culture we have that we don't want to talk about money. And it is not just on the physicians' side. I know that a lot of times it was almost before it seemed rude to bring up the conversation of money from a provider's perspective. But even I found my own family doing that. No one wanted to talk about the

cost. No one wanted to talk about the money because what costs can you put on a life? And Melissa's life is at stake here and how could we even measure that?

But when I came out of the hospital, I had to pay those bills. And it was real world then and it really affected my everyday life. At one point, I was paying more in medical bills than we do for our house. And there was -- well, people would say oh well, you can pay $25 a month, but you can pay $50 a month. Yes, well when you have 25 bills, $25 a month still adds up. And it is really the reality that I was living in.

For chronic care, I have to have a CT scan and MRI every year, no matter how healthy I am because the genetic disorder that I have can spring aneurisms up throughout my entire arterial tree. So, I have an entirely artificial aorta now but they always have to scan for brain aneurisms and the like. And every year when I make those decisions, I know

that I have to have those scans. But to me, a CT scan is a CT scan. So, I comparison shop. You know I call and I say well, how much will cost and they almost never know. So, I have had to do it more by experience.

Well, I had a CT at that hospital and it cost this, then my next CT was at that other hospital and that cost this but the results were the exacts same. So, why wouldn't I go have it at the cheaper place?

And things like insurance maxes and all of those things that I had no idea about when I first got sick, when I looked at my husband and said we will never pay this off in our lifetime. I was a public school teacher and could not imagine ever paying that off. I had no idea there was an insurance max and that I wouldn't be required to pay the $400,000 bill that came from the first stay.

Then I said, oh, there is a system to this. You have got to know how to work the system of it. Okay, I get it. So, I can have

my CT scan in April and I will already hit my insurance max because that joker, that is how I would say it, because that thing is $11,000 because they scan my abdomen, and chest, and pelvis, and all of that. So, I will hit my insurance max then. And then for the rest of the year, I won't continually have to have this conversation and stress of appropriateness of care. I will know if I feel bad, I can go to the doctor because then it is already covered because I have already reached my insurance max for the year.

So, I would have that conversation with my primary care provider, Dr. Mullins. And I would say, Dr. Mullins, I have already reached insurance max. If you want to test me for anything, now is the month to do it. And she was very candid about it and understood because she was having conversations like that much more frequently now than before.

And we had to balance it. Just Sunday night, I will add just Sunday night --

my brother is a police officer, very intelligent, very well adjusted to society. I mean he handles his life perfectly. And Sunday night he was having pain. He has no experience with the healthcare system. We expect people to be able to navigate this system, even the cost of it, and we do not teach them how.

And he calls me and says I am having a lot of pain in my abdomen. Should I got to the emergency room? And I was like, well what are your symptoms. By the way, you know I'm not a doctor, right? Yes, I know but I really can't afford it. I really can't afford it, so what do you think of -- and he said I think I really need to go.

So, then he comes and picks me up and I go to the emergency room with him because I am going to be there to help him navigate the system because he is really scared. And on the way there, he pulls out his insurance card and he is reading insurance

deductible. That is this. Oh, whoa. Okay, that is a lot of money. And he goes what if I have to have a CT scan, aren't those are really expensive? And I said well, honey, if something is really wrong with you and you need it, it is not really a matter of if it is really expensive. And he is like well maybe they can do an ultrasound instead, if it my gall bladder because then they could look at -- and I was like, I don't know that is how that works.

And I was like, but there is an insurance maximum and once you are charged over a certain amount, your part can't ever be more than this. Oh, okay, let's go to the emergency room. And he really had no idea. And it became such a question -- it is such a source of anxiety. And if you have ever been a consumer in the healthcare system, you understand it. This appropriateness of care and do I really need to go to the doctor, and there is the whole aspect of do I need to be

treated. Because I don't want to show up at the emergency room and then nothing is wrong with me and I will look terrible. You don't want to look stupid in front of the doctor. And then more than that, you don't want to look stupid in front of your family when you leave and you have this $5,000 medical bill and nothing was wrong.

So, we are walking into the emergency room and he goes something better be wrong with me. And I started laughing. That is the only place in the world that you really almost want to a little something to be wrong with you to justify the money you know you are getting ready to spend.

And throughout the entire emergency room procedure that night, I laughed and laughed. And he checked in and he said that just cost me $82. And then he sat down and was called back and he got an IV. And he goes that just cost me $270. And he was like throwing these numbers out.

But it is. It is really how we think. And then you get the bill and we will get into that later about your perception of value and things like that. So, it very much affected my decisions as a consumer.

Other frequent fliers in here? Corey, you want to go next?

PARTICIPANT: Well, what did the doctor say?

CHAIR THOMASON: Oh, thank you. So we got there and they did say that they thought it might be coming from the gall bladder but they did an ultrasound of the gall bladder and they said well, if there is anything wrong, it is not enough to show up on the test. And we ended up leaving and he said, "I just went to the emergency room for nothing." And it was really that he paid all that money for peace of mind but it is such a source of anxiety, that should I go. It really is.

MEMBER WILBORN: Again, my name is

Corey Wilborn. And the word frequent flier to me is a little difficult to accept, although I have had medical conditions my entire life, having my first heart surgery at two months' of age for -- they didn't know what was wrong with me. I had congestive heart failure. I cried a lot. My parents took me to the doctor to find out two months' later that I had -- I need a coarctation of the aorta. And subsequently, a mitral valve prolapse and I had to have a mitral valve replacement.

But other than that, I wouldn't really consider myself a frequent flier in the hospital, if you will. I go occasionally once or twice a year for just general checkups but for my life, as a heart patient, it has been relatively different from most people's experience as a heart patient.

I did spend six weeks in the hospital. I have had five open heart surgeries, one with several complications, which included a fasciotomy, which is the

worst thing that has ever happened to me. It is worse than five open heart surgeries. Having to learn how to walk again and things of that nature, for me, mentally and physically was the most debilitating experience that I have ever had.

With cost, just like she said, you know when you are in a hospital and you have emergency situations, cost is the furthest thing from your mind. It has always been the furthest thing from my mind. But now that I am an adult and I am paying for it myself, these are the questions that you want to know. I was uninsured for about three years due to pre-existing condition rules. And for me to go to the doctor, $300 or $400 to go see a doctor and then $25 for this test, $150 for that test.

I got to the doctor one day and I was having just a catheterization for a checkup and they told me when I got there that it would be $3,000. And being a person who

just graduated from school and you know I am like $3,000, I couldn't believe it. I had to go home that day and come back later to get the procedure actually. But that was my maximum. I hadn't gone to the doctor so I hadn't paid into my deductible or anything.

And $3,000 was a lot. And I thought that that was very unaffordable for a procedure that takes five, ten minutes for them to stick a camera down your throat or take a few pictures. And everybody sitting around the room is, in my mind, these people are getting paid. You know I am saying why does it cost $900 for anesthesia? Why does it cost $3,000 for this procedure?

So, in my mind I couldn't understand all of these costs. And then, which I guess we will talk about later, when the papers come in the mail and then you see that this is the price that the physician charged and this is the price that your health plan pays. And they have this column now that

says your savings.

(Laughter.)

MEMBER WILBORN: Which I am like, oh, man! I saved $8,000 today. Man, this is great!

(Laughter.)

MEMBER WILBORN: So for me, the whole health care insurance thing, you know is a little confusing to, I mean, the average consumer. Somebody like us frequent fliers, we understand it better than probably 90 percent of anybody else. People that never go to the doctor don't understand that.

And it really upsets me. I talk about healthcare a lot with younger people and my friends trying to get them to sign up for healthcare. And for them, this is something that they have never had to have as a line item. You know, most of them have been insured through their jobs or their parents or whatever. But when it is a real line item in your life, it becomes something that is worth

thinking about for sure.

I am paying a premium now of about $400 and I wouldn't have done that if I had read this Cost of Your Healthcare article that you guys posted on the thing. You know I would have done a little bit more research about it. And you know so now you pay $400 a month is a huge -- that is a nice chunk of money to an average consumer to be paying. And for somebody like me, I am going to go the doctor just to get my medicine refilled or just to make sure nothing is wrong. I haven't really had much that I have had to go to the doctor for, other than medicine and just a regular checkup just so I feel good about what is going on with my health.

That has kind of been my experience as a patient. That has kind of been my experience as a patient and I am excited to now have affordable care, if you will, because that time when I didn't have healthcare, I didn't go to the doctor because

it was really not affordable in my mind to go there to pay $900 for an office visit and to get my finger pricked so they could check my INR levels.

So, I am very excited that some things are changing and I am going to be more excited when like I read the Health Partners thing and I think that is great. That people have where they can see the value dollars and the cost related to quality of care.

So, I am really excited about things like that actually coming into the forefront of the healthcare industry.

CHAIR THOMASON: Thank you, Corey. I think we are going to have a really good conversation surrounding value in a little while; value from a consumer's perspective and when I start getting those bills, do I really consider that that was a good value or did I really just pay that much money to get my finger stuck and do you feel like that?

Tayler.

MEMBER LOFQUIST: Sure. Again, my name is Tayler Lofquist. I am here because in 2005 I was diagnosed with food allergies, based off of a blood test. And I lived for about six years of my life thinking I had 23 separate food allergies. And it was life-changing to cut those foods out of my diet. I went from not being able to stand up straight at school and at softball practice from stomach pain to being pretty functional, finding gluten-free food before it was cool. I found my way around the system.

But as time went on, I started developing more and more health issues and would continue to cut foods out of my diet, to the point where it was basically down to rice and chicken and some vegetables. And I wasn't really getting any guidance from doctors that I was going to. So, I decided to stop taking this allergy situation in my own hands and would start finding a doctor.

I ended up bouncing from a

holistic doctor, to a primary care physician, to GIs, to dermatologists, to allergists, until I finally found a neurologist who diagnosed me with food-triggered migraines and that has been life-changing.

But it took nine years to get to that point from being a 16-year-old girl with stomachaches to being a 25-year-old who finally was able to get to the actual root of the problem. And it took all of that time and all of those different doctors and being confused and scared and feeling kind of alone and helpless.

I think definitely cost is something that I still feel really blind going into the system. But when you are in pain and you are scared, you are kind of doing whatever you can to find a solution.

So, that is just a really brief overview of my experience. But I am really passionate, I guess, about just how can we give people the information that they need not

only to find the right doctor, but what is going to be involved cost-wise to get to that point.

CHAIR THOMASON: Thank you, Tayler. I do have a further question for you. But, Deb, if you want to go ahead.

MEMBER DAHL: Sure. I would like to just chat for a little bit about behavioral health folks as well. Because we have talked about the people with very complex medical conditions.

I have a sister who has agoraphobia and is now finally was diagnosed and put into the Medicaid program and is in a group home. But one of her suicide attempts left her with multiple fractures for a leg and many other complications. And trying to get care to deal with that and the issues associated with not being able to communicate what your problems are, having no income whatsoever, no way to pay for these services, and not knowing how to deal with any of those

complex issues.

You know with Melissa, she had a support group that was able to help her because you could think and communicate and deal with those issues.

So, something else to think about just to add to the complexity, in case this wasn't complex enough.

CHAIR THOMASON: Very good point.

Really quickly, Tayler, so what was it like to transition from almost minor to adult healthcare? You know, I am 16-years-old, I am having stomach pains, I am on my mom and dad's insurance, they are paying my medical bills to learning how to do that on your own?

MEMBER LOFQUIST: Yes, I would say it still a process for sure. You know, I think the main difference is just that I wasn't seeing the bills maybe before and now I am seeing them come in myself. And I just don't know, or at least I felt this way

before, I didn't know what was normal. Like I didn't know who even submits these things to insurance. Where can I see that on my bill? Some bills are really itemized and you get to see how much you saved. Other bills, it is just this number. Where did this number come from?

And I would get bills sometimes and they would be huge and I would call my dad crying, you know I got this huge bill. And he was like well, do you know if they submitted it to insurance? I can't see that on here but again, others you do.

So, I think just knowing different providers give you their bills even in different ways and how to navigate that has been part of the process. But also I think I do feel more empowered now as an adult to like do some research ahead of time. But that has also been a frustrating experience because no matter how online savvy you are, there isn't a lot out there, I don't think.

And so as empowered as I feel and as much experience as I have, I still feel powerless a lot of the time.

CHAIR THOMASON: Thank you. I love that, when you said I didn't even know what was normal. And I really think that is a lot of the problem as consumers, you don't know until you are there.

Lisa, if you would like to go ahead, and then we will have Ron, and then we will jump to our other frequent fliers, Maureen and Adam.

MEMBER LATTS: So, I wanted to actually comment on something that Corey brought up, which I think is a critical component of affordability discussion, which is that it is now not just -- in today's world, it is not just about the affordability of the care you receive, it is also about choosing your health insurance. And that is a whole new deal.

So, I am not your average health

insurance consumer. I am a physician. I have been a health insurance executive for a long, long time. I understand the system way better than probably 90 plus percent of the people out there. And now that I am an independent consultant, I was planning on buying my healthcare on the exchange.

And we have a very competitive marketplace in Colorado. So, one of the most -- a number of insurers across the country and each had eight zillion plans. And I looked through them for probably a couple of hours until I gave up. I called a broker. She sent me a bunch of plans, and I have got ongoing healthcare needs, so I knew that my healthcare costs would be significant and I can go into that, if we have time. Similar to Melissa, I had a sort of bad pregnancy outcome.

But finally, I just gave up and I am still COBRAing with WellPoint because it was just way, way, too complex to navigate the exchange. And if I can't do it, who can truly

make an informed decision?

CHAIR THOMASON: Great point. Ron?

MEMBER WALTERS: So, I am a physician and also should know better. But, I don't.

So, I spent most of my life health, too, other than an occasional sports injury, which was event-driven. I didn't have any problems again until two years ago when I had bigeminy and trigeminy and couplets and all these things, where I said hey, these are unusual.

So, my point is not that. I went in. I was not concerned. I agree with what Melissa said. At that point in time, it doesn't matter. You go in; you get it taken care of. You don't know who are seeing, other than reputation, basically, go to a good place and see anyone there because they must be good, because they are at a good place. All those sorts of thoughts went through my mind.

But in the middle of the night, at about two in the morning, you really don't care. And that got taken care of and so on.

The point I wanted to make was even as a physician, and I have heard it around the room and I am exactly an example of that, until I tied it to a condition and we spend so much time talking about conditions, I don't -- the linkage is broken in some way.

So, I knew the value of staying healthy. But what am I staying healthy for? I am staying healthy not to get colon cancer. I am staying healthy not to get diabetes. I am staying healthy not to get high blood pressure. I am staying healthy not to get this, that, and the other thing. But they are nebulous concepts in my mind until an event occurs and then the connection becomes very solid about what I am doing now, what I am spending now on my current condition and the benefit that I am getting out of it.

So, I think that is something we

will have to wrestle with, too, over the next couple days is how to solidify that linkage to an amorphous concept like health. Because again, when you have something going on in an emergent situation, it is easy. And yes, the costs and who you are saying, and identifying all of that is important. It becomes very real at that point. But right before that or the years before that, it is difficult.

And how do we measure that?

CHAIR THOMASON: Really good point. And you know, I had never even thought about looking at staying healthy, like from a consumer's perspective. And it is like oh, I am staying healthy so that I won't die but I never think about the amount of money I am saving and how it will affect my life and all those things, too. Very good point.

Maureen?

MEMBER EDIGER: Hi, my name is Maureen and it is interesting that the term frequent flier has come up because I am a

parent, one of two parents that serves on the Children's Hospital Colorado's Quality and Safety Committee. And as the two parents and other parents of other committees I am on, we always introduce ourselves as frequent fliers. And finally, one of the doctors said you know we are not allowed to use that term. And so I didn't realize it was sort of this taboo term.

But I think parents and certainly parents of kids, I mean that is how we identify ourselves. We feel like we know the hospital, we know were the -- it is sort of this strange little club that none of us ever wanted to belong to.

But anyway, so my son, Everett, is seven and a half and he was born with spina bifida. He is a twin. I said I have four children. We were aiming for three. The twins were a surprise.

And I thought nothing would ever make me get over the shock of having twins but

then he was diagnosed when I was 17 and a half weeks as having a neural tube defect, which is spina bifida. So, being diagnosed prenatally, I had 17 ultrasounds just while I was pregnant partly because it was a twin pregnancy and partly because we knew he was going to be born with this birth defect.

So, I started Googling right away, the second I got home from the ultrasound. I found out spina bifida is the most costly, lift-long medical condition, at least it was at that point eight years ago when I found out that I would be having this little boy. And let's see, he was also born with club feet. he developed hydrocephalus, had a shunt placed to drain the excess fluid out of the ventricles of his brain when he was two and a half weeks old. He has had 20 surgeries, sort of equally spread between urology, orthopedics, and neurosurgery.

And a cost that we incurred that hasn't come up is durable medical equipment.

He has braces on his feet and well, feet and the other leg has a longer brace. And they cost about somewhere between $2,500 and $3,000 every time he needs a new set of braces. He was going through those about every five to eight months when he was really little. Now we can stretch it out to about nine months. But every time he grows significantly, it is going in and getting a new set of braces. His wheelchair, we just ordered his third wheelchair. He got his first wheelchair when he was about, let's see, 14 months old because we wanted him to be able to be mobile. And since he is a twin, his poor twin sister, we call her the control child.

(Laughter.)

MEMBER EDIGER: But we wanted him to be keeping up with his twin sister and his peers and be mobile about the same time that other kids would be walking.

So, he got his first wheelchair when he was 14 months old, the second chair

about two and a half years later. And we just ordered his third chair. And they have run between $5,000 and $6,000 each time. I don't know about you guys, but I have spent a lot less on cars in my lifetime.

So, durable equipment is a huge piece of it. And my husband and I both work fulltime and we are really so relieved because we both have health insurance through our employers. And we felt so lucky that we had double insurance because we certainly weren't planning to have a child that would incur all of these medical expenses.

And Colorado does have some really good programs. And there is a Medicaid waiver for kids with disabilities. And the social worker talked to us about getting on the list when he was born and he said it is about a year-long wait at this point, if you put his name on the list to get Medicaid insurance for him as an individual. And we said oh, no, we're good. We are covered.

And then on his first birthday, when we were in the hospital, he had a kidney infection -- and it was quite the first 18 months, really, of being in and out of the hospital a lot. And as the bills had piled up, I thought, you know, I just really got struck with what happens if my husband or I lose or our job or we both lose our job? We would be so up a creek. So, we went ahead and did the paperwork and the process to get him on the Medicaid waiver. And it was a two and a half year wait list at that point. So, by the time he was three and a half he did. And that was quite the process.

So, it is our tertiary insurance and usually it is the durable medical equipment that Medicaid ends up paying for. But it is such a piece of mind to know that if anything happens to us, just because of how expensive his healthcare is.

So, that is Everett. He is seven and a half and he is amazing and doing really

well, just in case you were wondering.

So, then two years ago my middle child, Harper, my daughter, when she was eight and a half, nine years old, started to have some behavior issues. And I am really good that you brought up, because it turned into a six-month process of finding out that she was diagnosed with immune disorder. So, again, I keep asking, what could possibly happen to make twins not as big of a deal, oh, spina bifida. Oh, what could happen to make spina bifida not a big deal, well, a nine-year-old diagnosed bipolar sort of knocked me again into wow. And I have to say the mental healthcare system is a totally different ball game as far as the out-of-pocket expenses, the medications, the assessments, the doctors' appointments, very few pediatric psychiatrists are on our plan and have a wait list less than three months. And when you have a kid, that is hallucinating and having serious issues at home and at school, you can't wait three

months to find a psychiatrist that is on your plan.

So, the out-of-pocket expenses we have had have been nothing compared to the out-of-pocket expenses we have had with Everett with spina bifida.

So, as a parent, I have sort of walked both sides of that cost issue. And I have some other sort of stories or experiences to share, both from being a parent and being on the quality and safety committee for Children's Hospital.

But the one point that I make over and over as a parent advocate, and this obviously applies to adult consumers as well but when parents are making these decisions, we are so overwhelmed and we are not our best selves. And you made the point that as a physician, you think and knowing the healthcare system, I should be able to navigate this and you throw up your hands. And I constantly think I speak English, I have

an education, I am assertive, I am chatty.

(Laughter.)

MEMBER EDIGER: I don't have -- I will ask questions. And I always think, oh, my gosh, how do these kids ever get through the system with a parent who doesn't speak the language of their providers, that doesn't have an education to give them the right tools and the right language to ask questions. So, that is where I come from as an advocate from parents, families, and kids, is that we are already coming from a place where we are overwhelmed and not our best selves to be asking good questions about affordability or quality or anything with healthcare.

So, that is the piece that I would try to figure out is how do we work with patients and families so that they are empowered to make good decisions and ask good questions, which I think is a perfect segue to Adam, since I have talked to him a little bit about what he does. And then I think some of

the stuff he has done is really cool.

So, Adam.

MEMBER THOMPSON: Thank you. So, I think I am going to need a shield when I start talking about my healthcare.

So, as a person living with HIV, we have our healthcare paid for. So, I kind of have the opposite problem that everyone else is facing, which is we are in a system where how we are cared for and how it is paid for is invisible to us. In fact, when it became visible in the State of Virginia when I was a patient, it was a really big problem. And they made all of the hospitals sort of their billing and everything became visible to the patient, they made them hire quality managers to hide that all away again.

So, what is interesting is now we have the Affordable Care Act and they are allowed to pay for our premiums with that money but what they can't pay is our copays. So, you have a whole group of people who have

never paid for care, who have just been given health insurance, and they are now told, congratulations, you are getting bills. Only, they weren't told they were getting bills. So, they just started arriving and people didn't know what these were, so they threw them away because they thought this must be a mistake because we don't get bills. I have insurance.

And we have had to explain to people that Ryan White is not insurance. In fact, it is not even an entitlement program and when we run out of that money, we run out. And so I think people living with HIV, when we look at affordability, affordability is free, first of all, to us.

(Laughter.)

MEMBER THOMPSON: That's what we know. But we also have supportive services paid for. We could, in New York City, you can get massages and acupuncture. I mean there are all kinds of things that go into this.

And I think part of it is the guilt for America for AIDS in the '80s. But it is also the failure to look at a group of people and really explain to us how we are going to navigate this system.

What is interesting is that they are telling us to navigate it the way Melissa navigates it, which is schedule your visits in the first half of the year, spend as much money as you can. We will pay for your medication. And when you hit that limit, then you have healthcare the rest of the year.

But you are talking about a group of people who don't make their own medical visits, who don't pay their own bills. I mean, the capacity is not there because we have been cared for.

But when you look at how we are going to spend this money, I don't think patients living with HIV in Ryan White systems understand this at all. We didn't get to pick our insurance. It was picked for us through

the Affordable Care Act. They said you will have this plan. It covers this amount and we will pay the premium and that is the only premium we are going to pay.

So, as the rest of the country was sort of gearing up, I think, to understand healthcare and to really think it through as patients, we were not being sort of brought to the table again, sort of being told what to do and how to do it.

And when we go to look at how we are going to decide where to go for our care, I think that is another thing that we don't know how to do because we don't have a whole lot of providers. If you look at HIV care, we have to go to the clinic that is near us and that is it. And so we don't have choice. We don't understand quality. We have never paid for anything.

And so I think as patients we look at it ourselves and this new landscape is very scary. And to us, it just costs money, money

that we didn't have. And you are looking at a group of people who have high rates of homelessness, substance abuse, mental health. And the minute this goes away, you are talking about copays for all their mental health meds, which are currently paid for through the Ryan White program. Their HIV medication copays which are paid for through the Ryan White program. And I think people are going to stop getting their care is what is going to happen.

I think we have looked at four years looking at linkage and retention for HIV across the country and in a matter of months, I think it is going to be destroyed when people get a $20 bill that they don't expect. And it is not that I think people shouldn't have to pay that $20 but I think it is the communication. It is telling the patients what are happening and understanding why these bills are coming, explaining to us for the past 20 years that what we had was not insurance. You know, I think that was a big

mistake to not explain to patients how their care was being paid for because now we don't get it and we don't understand it.

And a little example, my partner, he has health insurance. He is not covered by Ryan White. And the other day he had like a tooth problem and we went to get his tooth looked at. And afterwards, I said, how did you make that decision? And he said, well, it was after hours, so I went online and I found the person that was open. I said, okay. He said, then I compared it against my insurance to make sure they took it. I said, okay. And I said, but you didn't go to the dentist. And he said well, no, they didn't call me back until the next morning. And I was like, well, why did you wait when there were other options? And he said, well that is the one I called and that is the one my insurance paid for.

And he went there and he got his tooth fixed, emergency root canal and

everything like that. But I looked at him and said there was not a moment in that decision where we looked at how much it cost, the quality of it, or even were there more than one person that took this insurance.

And so when we made our decisions, living with HIV and our care being paid for, our decision was made by a Google search that came out alphabetically and probably in some manner of being paid for by the people.

And then the second search was his insurance company and how many of these names matched that list. And then the decision was made.

And I said well, what if you had all of this other information? How would you do this? And he said, I wouldn't even begin to know what to do. He said because how much does an emergency root canal cost? And I was like I have no clue what to tell you.

And he and I sat down and the past week we are trying to figure out what

information would we need. And really, we had a really hard time coming up with this. So, when we look at this affordability, I think it is important to remember that some of us have the opposite problem, which is coming at it from being incredibly cared for through government programs that are really, really well done. But moving us into primary care now, it is a whole different world and we don't understand how to do it. And in fact we were told as patients, don't go to those care centers because they don't know how to take care of you. And now we are being told not only to go to these places not to go but now go and pay them money.

So, that is our experience. And anyone living with HIV across the country, I think is feeling this right now. The Affordable Care Act was supposed to be our blessing and I think it has been a curse to us but not because of the services, but because we don't understand it. We don't know how it

works.

CHAIR THOMASON: I think you make a really good point. And throughout the entire continuum of care when I do advisor rounds, it is one my favorite parts of being a patient advisor but I get to go into patient rooms and really talk to them.

And almost always, the patients who have had a realistic expectation set in advance are happier. I think they are more satisfied and then I think the same applies to affordability. If we don't set an expectation for what this will cost, I think it affects the perception of value, certainly on the back end.

Tina?

MEMBER FRONTERA: Okay, Carrie, I think, was first.

CHAIR THOMASON: Okay, that would be fine. That would be fine, Carrie.

MEMBER NELSON: I have a niece who has, for simplicity sake, I will just say she

has cerebral palsy. And I have watched, she is now 18 years old but diagnosed at age three months with hydrocephalus and helicoptered and the whole emergency fire drill and do whatever we can to help Emily.

But over the course of her life, I have watched a lot of healthcare services delivered to her that didn't add value. And in the time that we were looking at, watching this, we were worried about lifetime limits. We don't have that concern so much anymore. At the same time, much of what Ron, I think, referred to was, these are investments we are making? We want to make sure they are good investments. And if you don't know the level of appropriateness, then how do you know it is a good investment?

So, example, you know, I think the closest relationship my sister had, my sister is a nurse, but that all goes away when you have a child with medical problems. You just do what the people you trust are telling you

to do. And the closest relationship in a healthcare provider was the physical therapist. And the physical therapist was very focused on keeping her back straight. Years and years of many times a week physical therapy but with, ultimately, back surgery to keep her back straight. And the cost, too, to the family, my sister has two other children and they have lives. They are in sports. They want to have a regular life, as much as possible, but the needs of Emily, sometimes have stepped on that.

So, the back surgery was a major consequence and then she went on to have hand surgery because of contractures and she has contractures still.

So, a lot of investment in healthcare services that have taken a toll on the family have had out-of-pocket costs that at one time, prior to the Affordable Care Act, we would have contributed to a lifetime limit with little gain.

And so I don't know how much the concept of appropriateness is tangential to this topic but it is real. So, I just wanted to raise that.

MEMBER FRONTERA: Okay, I'll be speaking as a consumer as well. I am age 58 and my significant other is 61. So, we are both divorced and we are living together. And I told him before I would live with you I want you to get long-term care insurance.

(Laughter.)

MEMBER FRONTERA: And so he did. So, we both know too much about cost of care and so maybe we are almost a little paranoid. So, some folks get married for insurance. We are, I think, not getting married because of it.

So as I look around the room, some are in this age range and some of us have taken care of maybe some aging parents as well. But if you have ever dealt with the Medicaid spend-down issue with your parents,

one starts looking at well, who is going to be the survivor here in this particular relationship. And if you get into a Medicaid spend-down situation, how do you impact the other's quality of life? What if one is disabled for ten years and totally depletes your savings and the other person is left unable to travel, unable to do as they want to do.

So, that is a decision that I think we could be making but we could change our minds. I don't know.

I think that also leads to we are talking about healthcare. Usually those things that are kind of medically necessary, there is that whole other spectrum of the long-term care which is really custodial and maybe that really isn't in the scope of this. Maybe that is more of a social issue than affordability from healthcare. But I think so many folks seem to think that basic nursing care in the home -- not even nursing care --

excuse me -- custodial care, i.e., bathing, all of that, is a covered expense under Medicare. And I think people are quite surprised when they find out that those things are not and that there is more responsibility than what we thought.

CHAIR THOMASON: Thank you, Tina. I know that we are nearing our agenda wrap-up time but I did want to comment.

I do think that there are times, not necessarily in emergent care, when I know that I have to have something done, I want to get the best quality for the most affordable price. But then when I don't have to have it done, that is when it really becomes a question of should I even do this. And I think when you are not sure you need to have it but those are the people that won't go seek care, really, because of the price.

The rare genetic disorder that I have, I knew my son had to be tested for it. There was a 50 percent chance that he would

have it. And I got him tested for it. I was tested in eastern North Carolina and then I went to another hospital to have him tested. And my parents went and they were tested. By the way, all were negative. That was the best day of my life when I found out that my son doesn't have the same disorder that hurt me so much.

But my brothers and sisters, really until my mom and dad were tested, needed to be tested and wouldn't be because they knew the price and it just wasn't worth it to them. And they said well, if we have symptoms later, maybe we will find out. But it really affects long-term care. If were to find out they had this disorder, it would completely affect their lives. But because of the cost of the test, the first thing they asked when I said the doctor says you guys really need to tested, was, well how much does it cost. And well, I can't pay that. I don't have that.

And then on the back end of it, because my son was tested at another hospital, when I got his bill, it was twice as much as mine. And I called the hospital and formally challenged it. And I said how is this double the price when you did the exact same test with the exact same lab? How do you even justify that? And I won that and they reduced the bill.

So, I think having to challenge it on the back end is much worse than being transparent on the front end, being able to really comparison shop, which is why we are doing what we are doing today.

Thank you so much for adding your consumer stories.

MS. WILBON: If we can get the people who have comments left, we are a little bit over break but if people can just be brief, we will go ahead and wrap-up.

We will go with Corey, Maureen, and then Helen.

MEMBER WILBORN: I just wanted to follow-up on Adam with the Ryan care. I think that is all young people that have never paid an insurance bill themselves that are coming into this new Affordable Care Act and wondering why they are going to have to pay a premium and just having to deal with that.

And then following up on Tina, I am a 33-year-old, unmarried man and have thought about getting married just because I have a preexisting condition and needed medical care and I have dated people that, you know, nurses and doctors.

(Laughter.)

MEMBER WILBORN: And I was like this will be great! You know I would have healthcare. And so these are some of the decisions that people have to make about healthcare.

Thank you.

MEMBER EDIGER: I can actually wait. Some of it is in follow-up to what

Carrie said. Just a teaser. We had a conference about high-risk spinal surgery and how to make that decision. And it was organized by the Ethics Panel at Children's Hospital. And it was fascinating and a great follow-up to what you said but I will talk about that more later.

MS. BURSTIN: I just want to say thank you for sharing those stories. Those are really remarkable. We are often blessed by having one or two patients on each of our clinical panels and this is really just a gift. And I think it is a great framing.

I want to make just one personal comment. My parents, my mom, in particular, is functionally illiterate, having come to America in 1950. And she had a cardiac catheterization -- two out of three of her children are physicians -- and got one of those really long bills from the hospital after her cardiac catheterization for $12,000. And she was terrified because she couldn't

really read this and immediately called the hospital to set up a payment plan, when very clearly at the bottom of that it said, "This is not a bill."

But again, if you don't read English. And I just want to put the issue in about literacy and language and acculturation and actually, frankly, just working class parents who, for them, the idea of not paying a bill has such a huge implication for them in a way that we just kind of go yes, we will pay it. It is no big deal. But if you are really billed to bill, you have a very different orientation on that. Thank you.

CHAIR MORT: And I just want to applaud NQF for putting the consumers around the table. Coming from a provider world, where I am an administrator, and I think about costs, so a lot of what I am doing is well, why is this test costing what it does. And then we put the cost up there. But what is very, very clear to me is affordability from

the consumer's perspective has everything to do about, when you do have insurance, the insurance.

So, I think back when my mom wrote the checkbooks, there was no insurance between my mother, her child, and the doctor. And now between consumers and providers there is this massively complex infrastructure. So, that is really, really important for us to acknowledge and making this task even more challenging.

CHAIR THOMASON: Absolutely, and it really is the reality of my life. It is not necessarily about, even if we push forward price transparency and I can go online and I see oh, my open heart surgery, roughly is going to cost me $200,000, it really means nothing to me as someone with insurance. I have to know both. I have to know price transparency and then I need to know how that translates into my real life cost.

MS. WILBON: Thank you. Let's take a 12-minute break and come back at ten

of. And then we will hop into the next discussion to really kind of get into some definitions and start talking about affordability a little bit more. Thanks, everyone.

(Whereupon, the foregoing matter went off the record at 10:35 p.m. and went back on the record at 10:51 p.m.)

MS. WILBON: So, this next session that we are going to dive into is really trying to set the groundwork for some of the terminology we will be using going forward in terms of affordability. We will talk a little bit about some of the work that we have done here at NQF around affordable care and around some of the other concepts like value, costs, efficiency, and how quality of care and appropriateness plays into those concepts.

So, without further ado, we have given everyone at their seats a little clicker device. And what we have done, just to kind

of keep things a little interesting today is we have inserted a few questions for polling throughout the two days just to kind of get a sense of where people's sentiments lie along some of these concepts and issues. And so we are going to queue up the first few questions and then we will kind of dive into some discussion and presentation into the next topic areas.

So, the first question is about whether or not you believe that cost efficiency and value are integral to determining affordability. On your clickers, you will see the numbers and you can see on the slide that if you agree, you can click one, neutral or don't know, two, or disagree is three. And we will give you a minute to enter your vote and then we will click the button and it will show a bar graph and show how many people agree, disagree, and so forth.

So, whatever you hit last will show up. So, if you change your mind, it is

fine. Just hit your button and then we will go ahead and start. You don't have to hit send, just hit the number.

Actually also, Vy over here has the laptop with the dongle thing --

MR. AMIN: The receiver.

MS. WILBON: The receiver. Thank you. So, point to her so that it gets the --

MEMBER KEEFE: Can I ask a question?

In the question you used the words cost efficiency and value. And we had in our discussion guide some definitions of that.

MS. WILBON: We are going to dive into that next.

MEMBER KEEFE: So, are we answering it based on our definition or --

MS. WILBON: Yes, just based on what you think right now.

MEMBER KEEFE: Thank you.

MS. WILBON: We are just looking for kind of a baseline, what people are

thinking so far.

And I believe we have 21 people, 20.

MS. LUONG: Keep clicking and if you noticed your receiver or your little clicker flashing red, let us know and we will get you a new one.

MS. WILBON: Okay, so most people agree. Okay, that is good. We will dive in. I think there is maybe one more question for this one.

The next question is -- so the concept of affordability is dependent on the specific individual circumstances, including, or for example, income preferences, values towards healthcare.

(Pause.)

MS. WILBON: All right, so a little bit of dissension there. Okay. There is one more.

So the next question, sorry, there is one more. You need to think about

healthcare quality when you are deciding if care is affordable.

Okay, so we have 13 people that agreed, two that are neutral, and four that said it depends. Okay.

All of those questions are directly related to some of the concepts that we are going to discuss in this next section. So, I did want to ask really quickly did Marci or Alyssa have questions before we get started or were those -- oh, okay. All right.

MEMBER NIELSEN: Actually, I had sort of global comment in our chattiness that we started chatting about that does relate back to this concept. And it is not really included in the definitions. And that is, we have been talking about the perspective of largely patients for people who have been in the system and their stories are so compelling and important and eye-opening, particularly when health professionals hear it. But I am thinking about the consumers who are well and

don't understand what it means to be a patient and to be ill trying to navigate the system. And in this day and age, we hear so often pull yourself up by your bootstraps and I don't need this, and I can pay out-of-pocket and lots of focus on what the world looks like in terms of quality and value and affordability when you are not ill.

So, is part of how we are going to separate out the white paper also going to speak to the messages that patients can deliver to consumers? Because they have got to understand insurance only works to the extent that we have got a risk pool where everybody is in and understands I, too, am at risk. So, that was just sort of my global chatty comment.

MS. WILBON: Yes, I think that is a good comment and we will actually, when we get to kind of the conceptual model of how we will be kind of mapping out the decision-making process, the first step is actually

kind of the preventative or population at risk where you would kind of conceptualize those people who haven't yet been diagnosed with anything. You are potentially seeing a primary care provider and weighing whether or not you get certain preventative services done. So, we will definitely have that discussion coming forward. That's a good point, thanks.

Okay, so the next section, as I mentioned, is going to be kind of starting with some of the concepts that we have used to guide our work in the past and kind of the definitions and terms we will be using for this work as well, just to make sure we are all on the same page, what we have learned from our past work and convening experts from different walks of life and different backgrounds is that everyone comes to the table with their own conceptualization, their own definition of what they think cost means or value or efficiency. And so we just kind

of want to make sure we are all on the same page going forward.

And we will have some discussion at the end of that we will kind of give a brief presentation of some of the work we have done in the past and how we have gotten to this point and have a brief discussion about how some of those concepts relate to each other and how those particular concepts will carry forward in our work here over the next two days.

So, affordability, as you can read is a broad concept that has been interpreted in many ways. While we have done a lot of work around costs and efficiency and value here, I think affordability itself has been a new term for us. And so we have really been trying to think about how we define that and it often comes back to the consumer and it often may change, depending on what perspective we are looking from.

So, we definitely want to take

some time to allow the panel to discuss what affordability actually means. But we are going to kind of take a few steps back and talk a little bit about some of the other concepts that we have used to guide this work, including quality of care, where you might also put the appropriateness concept, cost efficiency, value, resource use, price, and charges.

And I will say that in your discussion guide that everyone has at your desk on page -- you can follow along -- page three. Okay, so page three. We will just kind of be talking through some of these definitions.

Okay, it starts on the bottom of two into page three.

MEMBER LATTS: Mine is not standing up anymore. I actually sort of have issue with something that you said. I don't think appropriateness should be bunched of quality of care and I think it actually should

be a separate bullet.

MS. WILBON: Okay.

MEMBER LATTS: I think it is actually fundamentally different. It might not be different from a consumer perspective but in terms of what in the industry we think of as quality of care, I think appropriateness wouldn't fit under that category but it, instead, should be its own separate bullet.

MS. WILBON: Okay, that is --

MS. BURSTIN: Actually, just to add to that, Paul and I were just talking during the break how in some ways so much of the conversation this morning was so interesting and I think there has been very little consumer input or patient input into the definitions of appropriateness in even the way we categories it and understanding risk.

So, I would like to see it broken up because I think it is actually going to be a really important part of this work.

MS. WILBON: Okay. And I actually

don't think that we had a separate definition for appropriateness. We had a short discussion about it but that can definitely be something that we can talk about more. Thank you, Lisa.

So, starting with the quality of care. We have generally been guided by the IOM definition, in terms of measurement, which focuses on measures of safety, timeliness. So, whether or not you got a particular service within the appropriate time, effectiveness, efficiency, equity, and patient-centeredness. So, that concept of quality of care would include all of those six domains, based on the IOM definition.

In terms of the cost of care definition, in terms of how we, particularly in the measurement space, view this as the total resource use by unit prices for healthcare service, that can be associated with the specific patient population, time period, and also units of accountability.

So, essentially, the total healthcare spending for a particular service, for a particular population and time period, hopefully that resonates with people.

The next concept is efficiency of care. And that one, and actually I am going to fast-forward to our diagram here, which is a little bit easier to see how we have conceptualized some of these concepts together. So, if you think about cost in the sense of that and you associate a specified level of quality that are within the concept of efficiency. So, what did you get in terms of quality of care for what you paid for it or what was spent for that particular service.

And then, what do you think about value, what you are integrating into that in addition to efficiency is a stakeholder preference. So, how did they weigh the quality of care that they received along with the cost to determine what was of value to them at that point in time.

MR. AMIN: Actually, can I jump in?

MS. WILBON: Sure.

MR. AMIN: I will just point out a few things to describe what some of these concepts are not. So, costs, and a lot of people think about that in the pure economic terms of the production costs, meaning how much does it cost to produce. Generally, we don't have that type of data in healthcare in terms of the actual sort of strict definition of cost, which is sort of an activities-based costing approach.

So, that term, I will just clarify that that is not really what we have in terms of measurement, although some people would want that, I think it is probably a good goal but certainly our data systems don't support that right now.

And it also generally does not also include opportunity costs which is when you are looking at it from the consumers

perspective is obviously really important. We heard that in the narratives this morning, which is the cost that you forego for other spending that you might want to make, other spending that you would want or time that you have spent and things of that nature, which is generally in the bucket of opportunity cost.

We don't generally have measures that include that type of information, although, again, that would be something that would be important from a consumer's perspective. And I just would reiterate what Ashlie described, which is that the current conceptualization of value is inherently dependent on the individual or the individual stakeholder. So, it is a variable idea. There is no two -- each individual person may look at the weighing of cost and quality differently.

And so the concept of value is really inherently an individual perspective, an individual's perspective.

So, I think maybe I will just leave it there, unless maybe I will take these other two concepts of price and charge and sort of separate that as well in terms of the resource use to say that when we think about price that is generally the sticker price, if you will, the sticker charge of what a -- let me be more nuanced.

The sticker price of what a provider might end up having on their charge master, if you will, and the charge is generally the maximum allowed amount for a particular service. So, just drawing some distinctions between price and charge and resource use, which is generally resource use is much more what we want to measure or that we generally measure price and charge is usually a little bit outside the scope of what we are usually measuring in our portfolio of measures.

CHAIR MORT: If you go back to the slide that had all your bullet points on it.

That one. So the proposal was to add appropriateness, which I think is really important also. But what I have been moved by from the first session this morning is that the affordability piece really needs to be defined as to affordability to whom. And that is not cost. That is not price. That is payment, payment from the patient's perspective.

So, it is really important to be very specific when you talk about costs and price because, depending upon if you are the State of Massachusetts, the United States of America, a mother, a patient, a doctor, it all -- so you have to be, if this is about patient affordability, I think we need to have something about patient payment. Something unambiguously that is speaking to what patients, consumers actually have to write a check for or pay for to get the service.

MEMBER DAHL: And are you including the cost of the insurance that they

also have to write a check for?

CHAIR MORT: Well, I think that is exactly the point. It is tied to the insurance and there is two types of payments. If you are employed, it is what they take out of your paycheck every month but then there is the copay or you spend to your limit and then you pay afterwards. So, that is the piece that is complicated because the insurance is variable. The architecture of the different plans is quite variable. We have an architect in the room who we can thank for that. And that is the piece that I think we need to pull out and be unambiguous about as we move forward, if that is what we are really here to do in this group.

MEMBER KEEFE: Can I just build on that? Because I think I was so struck by some of the same discussion early on. I think I, too, in many ways, default to some of these consensus-based definitions because that is what many of us in the room are very familiar

with. But when I heard the stories in the room, again, it makes us think in a different way from that patient perspective. And I think the words of cost, et cetera, in particular, depending on your perspective and where you sit have multiple definitions.

I am not disagreeing with the ones that are proposed here but I think we need to be very cognizant about what we are trying to achieve. Because a cost to a provider to provide a service; a cost for an employer to purchase a service; a cost to the patient who is consuming the service. Depending on the perspective, it can really generate a total different cogmentation and if you are insured or not insured.

And that is something we didn't talk about this morning. And I am not suggesting we broaden or narrow. I just think that the context for what I heard this morning and where I thought this group was sharing just a really important perspective different

from other settings needs to probably be teased out and thought through in some of the definitions.

MS. WILBON: So, those are all very good points. And I am weighing here because we often get into this discussion, like I said, with a lot of groups that we convene about changing definitions. And I do think for this particular work it may be warranted to get some input from the committee on -- we don't necessarily need to wordsmith but if you have input on particular definitions that should be tweaked in some way to make them more consumer-centric, we would welcome that input.

CHAIR MORT: What I am hearing is not any criticism of the specific definitions as they are laid out. Those are kind of standard, technical definitions. It is more there is two important concepts from a patient's perspective, affordability and how much you have to pay. But if this is about

consumer affordability, those two concepts are particularly important, particularly the payment piece, which is everybody talked -- to a person. Everybody spoke about the complexities of actually figuring out how much it costs to me, the patient, how much I have to pay.

So, I just think those are additional ones and not really -- I think the definitions as they are standing are fine.

MEMBER ROLFE: May I offer a though on how to think about them? Because my comment is they are actually not on the same list.

So, this appears to be a well-constructed list of inside baseball. It is what contributes to cost. But what we are thinking about here is what will it actually feel like to be on the receiving end of cost certainty. It is kind of the way I think about it.

So, these are contributors to what

we are trying to improve, the experience we are trying to improve. And the affordability, the perception of value, the perception of affordability is the experience. So, they are not the same list but they interact with one another.

MS. WILBON: So, it actually sounds like -- there is a lot of name tents up and I don't want to stifle discussion. And I think everyone kind of understand where we were going with this. So, I think we will just jump to the discussion questions because you guys are actually starting to answer some of the discussions we had already posed.

And I am going to hand it over to Liz. And I will walk through some of the questions to kind of get the party started.

So, what does affordable care mean to consumers? Oh, I'm sorry.

CHAIR THOMASON: When Taroon was talking about cost, you said it doesn't take into -- or we are not talking about what it

costs the provider to actually deliver the service?

MR. AMIN: So, I don't want to get too -- maybe I am over-complicating it. So, I apologize for that if I am.

In economics, generally like what we refer to as cost is the production cost, meaning the cost of the labor inputs, the supplies, each widget, if you will, that is produced in the actual production process.

In healthcare, it is very difficult. What we talk about is sort of activities-based costing just because the majority of the inputs are labor. And it is difficult to quantify all of the two minutes of anesthesiology, 12 minutes of surgery, the five nurses that interacted with you, and to micro-cost each individual input.

So, generally, it is very difficult to do that type of costing in healthcare. So, there is the concept of sort of activities-based costing, which is

essentially the production cost. And some people think about when the term comes up cost in a sort of a manufacturing context, that is really what people are referring to.

So, I just wanted to draw some distinction between sort of that production cost, which is very difficult, if not -- it is just generally not feasible. Whether it should be done or not, I think we can have that conversation but it is generally not there.

So what we are really talking about in terms of cost measures, what we have is sort of what is paid by the health plan for the services that were rendered is generally the type of cost measures that we have.

Is that helpful, Melissa?

CHAIR THOMASON: Yes, it was helpful to hear you describe it because actually from a consumer's perspective, my ideas of value and affordability are all wrapped up in what I think it cost the

hospital. And so when I get five minutes of their time, versus 15 minutes, versus I get one shot and a little bit of liquid, versus I get two bags full of liquid, I mean I have this traditional sense of cost and a traditional market, consumer market in my head. And I expect that to apply when I go into healthcare, too.

MR. AMIN: Yes, and that is totally appropriate. So, we can certainly have that discussion.

MS. WILBON: Yes, I would just clarify I think what Taroon is trying to say that our traditional measurement, where we have been so far in measurement has allowed us to get to activities-based costing. That does not mean that as we have this discussion that from the consumer perspective if that is what people want to see, that that would be something that would totally be on the table as a way of discussing how that could be brought to consumer. So, I think it was just

more of a kind of where we have been. That is kind of the data that we have access to now. A lot of hospitals don't have infrastructure in place to be able to track -- I mean obviously they know what a bag of fluid has cost them, things like that. But in terms of the time and all that stuff, it becomes very difficult to track. So but again, that doesn't mean that it is off the table. So, we appreciate that input.

CHAIR THOMASON: It was more about the data we have available to us at this time.

MS. WILBON: Right.

CHAIR THOMASON: Okay, thank you.

CHAIR MORT: Okay, so we are going to open up the floor then to discuss these questions on the slide. But before that, Marci, you had your name tag up from the previous discussion. Did you want to wrap up your comment and then we can go to these questions?

MEMBER NIELSEN: Yes, although,

again, I think it is related and I promise this will be the last time that I say it. But I will say it in a different way. And that is NQF has an opportunity here that is unique. And you guys started this meeting by telling us that very point.

We have all kinds of meetings all the time in Washington, D.C. where we run through these sorts of lists of definitions and help professionals talk about it. But we have such a rich set of experiences of patients and the focus is to be on consumers and patients, sort of as our target audience. And Karen talked about who the receptor sites are. And I think we need to keep that in mind because who do we want to influence with this? What is the end game?

So, I will come back just one sort of final time and say in my world of the patient-centered primary care collaborative with really broad stakeholders, consumers, health plans, pharma, employers, consumers,

patients, consumers and patients are not the same. One sort of infers dependency. I am ill. I am in an acute situation. I cannot make choices about my healthcare based on money because I am trying to live, as Melissa told us.

The other is consumer is in a chronic care situation who need cost information to make long-term decisions about the health of them and their families. And so I would just encourage us to not just mish-mash them together, because we lose something important. And the important thing is for people who are sick, the system does not work and it is opaque and it is hard to navigate. And that is, whether you are trying to get through the healthcare system or pay for it.

For people who are consumers, you don't have to really get through the healthcare system much. It is still really hard to navigate in terms of the cost. But a little definition and context up-front that

isn't the normal Washington economic speak, with all due respect. Right? It means nothing to consumers and patients. And I should have said I do have one more thing to disclose, which is I am from the labor movement by background, by family, by upbringing, working class. We can talk gobbledygook and this will be one more paper that sits on a shelf or we can try to speak the language that consumers and patients speak and try to have meaning and validate their experience but that will require us to go outside of our comfort zone.

And so that would be the last time that I -- and no it is not. But I will try it to make it the last time.

CHAIR MORT: Well, Marci, I want to thank you for your comments. I think we are separating patients and consumers based on need or acuity of illness, if you will. And I think the way the word consumer has been used here, if I understand correctly, is a

little bit broader.

But tomorrow, when we do our case studies, I think it will become clear that depending if you are perfectly healthy in making choices versus critically ill and making choices, the affordability issues is different and the information you need is different.

So, I think that is a really important distinction. The language here doesn't match your model of it, though. So, I think we are -- can you live with it for now? I mean the use of the word consumer, I think as we are talking here, encompasses your consumer and patient group together.

MEMBER NIELSEN: There is no "I" in team. I can absolutely live with it.

CHAIR MORT: Way to go. Joe, you had your card up. Did you want to make a comment before we go to the questions?

MEMBER SINGER: Sure. I wanted to speak to really the concept of affordability.

You know price elasticity is people's tolerance and willingness and ability to pay for a service. So, when we are talking about life-threatening, acute catastrophic situations, there is maximal elasticity because nobody really cares with what is going on.

When you are dealing with parents taking care of a child, there is more elasticity because they are going to be willing to do more for their children than potentially for themselves.

Talk about a woman has more price elasticity than a guy. A guy is the ultimate in cheapness and not wanting to pay money for healthcare.

So really when we are talking about acute versus chronic and then who the utilizer of services all impacts in what perceived affordability is.

So, that is something I think is really, really important to bring into the

concept. You know there is an absolute affordability when there is no money there. And when you are uninsured, you get a $36,000 bill from a hospital for a procedure my wife got last week is very, very different than if you have health insurance and you have maxed -- I play the game, too. When I have maxed my out-of-pocket costs, price is irrelevant. There is complete elasticity.

So it is really depending upon whether it is discretionary versus non-discretionary services. And then the downstream consequences of whether you are going to do the procedure or not.

CHAIR MORT: That is very helpful, Joe. And I think that is the perfect segue to the first question, if could bring our conversation now to the bullet points. And Adam is next.

So, what does affordable care mean to consumers is the point of discussion right now. We have been alluding to it and talking

about it. But let's get something concrete out for the purposes of the workshop.

And I am going to call on Adam first.

MEMBER THOMPSON: Thank you. So, regarding the question around cost and payment, I mean I think it comes up to affordable. Recently, my mother went through a diabetic moment where she went into a coma. She had parts of her bodies amputated. It was a really terrible experience.

But when you ask her what was affordable about that, she says everything was affordable up until the point she got the bills.

(Laughter.)

MEMBER THOMPSON: No, wait, wait. But it wasn't the bills, it was the fact that for a single care encounter she had seven different bills. And each bill had a minimum payment.

And so what she found was I could

pay this, if it all came as one bill. But because she is paying seven or eight different bills for that single care, plus follow-up care, that is another ten bills, plus she ended up having cancer, which is a whole other one. So suddenly, affordable is now overwhelming because she can't even make that decision because she has something like 25 medical bills, like Melissa was saying, due every month.

So, I think when you look at affordable, it is not just on the front-end. I think it is on the back end, too. Like how does it come to me? How do I understand it? And what are the requirements for me to have to pay it?

And also just before we jump off, I wanted to echo what -- I'm sorry, Carrie, right? Your name tag. Marci.

MEMBER NIELSEN: Troublemaker. You can just refer to me as troublemaker.

MEMBER THOMPSON: Chatty. So, I

just wanted to say there are some really good working definitions of consumer and patient out there and they are not what has just been discussed here. And they decide what you are by what you are doing.

And if you are making decisions about healthcare, regardless of whether you are sick or not, it is about decision-making, then you are a consumer. But if you are actually receiving the care, then they refer to you as a patient.

And I find this very helpful because you start thinking about when am I a consumer? When am I a patient? What decisions do I need to make? How do I need to make them? And specifically what is the time frame I have to make them? As a consumer, I should be planning and have more time. As a patient, you don't have that time, often because you are getting the care in the moment.

So, I think these definitions do

matter, especially because patients have to understand this. I spend my whole job is translating what happens at these tables to patients. And that is all it is. It is translation of a word. Where I say cost, they mean what the doctor pays. And suddenly the whole room goes, oh.

So, I do think you have to look at these words from the perspective of the patients because, at the end of the day, you can create them but then you are going to pay people like me a lot of money to go out and explain them. And that is money that does not have to be spent, I think, if you think about it at the front-end.

CHAIR MORT: Thank you, Adam. So, we have to be crystal clear about what we are talking about so we can avoid paying for consultants. Is that the idea?

MEMBER THOMPSON: I mean I like work. Don't get me wrong.

(Laughter.)

MEMBER THOMPSON: But I do think that patients and consumers, those words are loaded for people and people assuming they mean things.

And if you look recently at the Robert Wood Johnson Foundation did this engaging consumers framework where they broke and divided this out. And what they found was it was very confusing for people. And if I am trying to figure this out, you are putting me in the framework I have to know what I am doing. Is it cognitive? Is it behavioral? Are there skills? How does this all work? Or I don't care if I get a bill at the end of the day and it is affordable because I may not have ever sought the care in the first place.

CHAIR MORT: Than you. Lisa and then Carrie.

MEMBER LATTS: So, on a similar vein to Adam, I think in this topic more than some of the others that I have been involved in with NQF, the words matter increasingly.

So, I actually, this question I think is difficult for me for two reasons. One, I think implied in this question is the idea that you would change doctors because a doctor is too expensive and you would go to a less expensive doctor. And I think in healthcare behavior, we actually have often seen the opposite, where people have changed doctors and gone to a doctor that is more expensive because there is a perception of cost as a proxy for quality. So, if a doctor is more expensive, they must be a better doctor.

So, I want to go to the best doctor out there, so I want to find the most expensive doctor there is.

So, I just want to, this question, I think, if people answer the question, you may not be getting what you think you are getting, number one. Number two, I think we need to be exquisitely careful in how we are using words. And here you say price, whereas

what I think you actually mean is cost. Because what a doctor's price is, in terms of what they are billing is irrelevant to me because I have insurance. And so I am going to pay the same copay if that doctor is contracted with my health insurance regardless of their price. So, it is meaningless to me. Now, that is different potentially if I have a deductible but potentially not because, again, what their price is may be irrelevant. It is what their contracted with my health insurance for.

So, I think in this topic in particular, more than what we have talked about, the words are exquisitely important. So, I would probably say my cost. I would change doctors based on what it is going to cost me out of pocket versus those words.

CHAIR MORT: Thank you, Lisa. Carrie.

MEMBER NELSON: You know what just occurred to me in hearing Adam describe your

mom, you know, you are a patient when you are in that emergency but you are a consumer later when you get the bill.

And so, I don't think we can discount that maybe the price is very elastic at the time when you were scared. It shrinks. It becomes less elastic when you actually get the people because we all know people who went to the emergency room really scared, thinking they had something bad, had the million dollar work-up and they had an anxiety attack or something that was not life-threatening. And they are left then with a big bill.

So, I think we just need to be cautious about minimizing the true cost at a point of a medical crisis, because it comes home eventually.

CHAIR MORT: Thanks, Carrie. Corey?

MEMBER WILBORN: I just wanted to know where do you find cost to choose a doctor based on their price or because when I search

for a doctor, it is a Google search. And it is going to be based on where they went to school, what hospital they work at, how close they are to me. It is never for me and my decision-making process. It has never been a line item cost a worksheet because we don't see that until we receive the bill in the mail. And we won't know how to separate it from one doctor to the next doctor to say this is a value. This doctor cured my illness and it only cost me X number of dollars.

CHAIR MORT: I think we are moving into the second bullet point what information do you need, cost that really isn't very available. And I think the point you made, Lisa, was very important about the Neiman Marcus effect, so that the higher priced seems better just because it costs more. So, in addition to cost, you needed some quality, independent quality measure to weigh those two I think is a really important contribution.

MEMBER LATTS: Well, and it really

gets to that issue of value because you know it is high cost is better if it is perceived as being of better value.

CHAIR MORT: Dorothy.

MEMBER SIEMON: I wanted to make a comment or a response relating to the second bullet. So, is that appropriate at this time? I think we are moving to the second bullet.

CHAIR MORT: Go right ahead.

MEMBER SIEMON: So, I just wanted to pick up on some of the comments here. I work for AARP and what we hear from consumers consistently is this confusion and ability to figure it out and that is what I heard in other people's comments in terms of just there is too much complexity. And I think what consumers really struggle with that we hear from are just why can't this be simpler? Why can't I get less billing or more discernable billing, and the ability to say and why isn't there just a straightforward transparency to some of these costs?

So, when you talk about information that is needed, I think we are sort of one generation away from of course we can't have a simple price list because everyone has talked about the complexity that drives the inability to just have a price list. Is at whose price? Is at whose cost? All of that.

But somehow the efforts have to be made to streamline or create some greater simplicity in how things are built and how the stuff is done in a standard way because people just can't even get at the affordability because there is so much effort it takes to read all the bills and figure them out.

And I think we heard that from a physician here, who couldn't discern the difference between how to pick an insurance, which I completely identify with in terms of just too much complexity.

So, I am not sure if that is a first step to getting to people understanding

costs efficiently enough to work on affordability but I think we are just one step away from it, almost, until we streamline in some way.

CHAIR MORT: So standardized billing, simplification in billing, we have heard that multiple times, very important.

I believe, Melissa, you were next.

MEMBER NELSON: Sure. I have a friend, sort of just to speak to what Corey was saying about so how do I find this information. And she is actually employed by the hospital that I volunteer with and she needed to have a basic procedure done. So, she wanted to comparison shop because it was really basic. And to her, you didn't need a lot of expertise to do it.

So, she talked to the hospital that she is employed by and then she talked to an outside clinic. And when she called the clinic and she called the cashier's department there and said I need to know the basic cost

of if I have such and such done to my knee. And the lady said do you know the code for that? And I just kind of laughed because I am like, no.

And there really is this, we are not speaking the consumer's language. I think Marci makes a great point that if what we do is really going to be relevant to consumers at large, we need to speak consumer language. And I think words do matter in this.

And as far as affordability goes, I really won't -- I think monthly payments matter a lot. I think it is about what comes out of my pocket and how that affects my lifestyle. And I can't separate the concept of affordability and the money from the quality of it because I really want great care at an affordable price. So, I always look at those for sure.

CHAIR MORT: Thanks, Melissa. I believe Carrie was next again and then Cynthia.

MEMBER NELSON: You know what you just said, Melissa, is very refreshing because I will tell you that the healthcare colleagues that I am around really believe consumers predominately make their decisions based on cost and especially if you look at the choice of the bronze plans that are out there right now.

We believe, and maybe I am wrong, it would be great to have a deeper understanding of this on the provider side, we believe that people assume quality. And so, therefore, the only variable they need to address is cost. And increasingly, they will make a decision in favor of lower costs. So, that kind of goes in conflict with what you were saying, Lisa, in terms of the Nieman Marcus effect.

I would like some output of this work to help the healthcare, the provider side understand how that all plays out really in the minds of patients more so. If there is

truly a quality component, which I believe that to some degree there is, how do we help them understand that quality component? And then how do we help healthcare providers be able to communicate that balance of quality and cost.

CHAIR MORT: Melissa wanted to add to that.

CHAIR THOMASON: And I really think that comes back to an inexperienced consumer versus an experienced patient.

Because I have been in it, I don't have this view that increased cost is increased quality. You know I know that those two doctors, because I have seen them both before, are going to do about the same thing to me. One is just going to charge me more.

And then what was -- what were we -- go ahead.

MEMBER NELSON: In terms of helping consumers understand quality and put that together with cost.

CHAIR THOMASON: Right.

MEMBER NELSON: Another word we could use for frequent fliers is professional patients and that is who we have here. I mean, we have a lot of people out there who are not in that category.

CHAIR THOMASON: I was trying to remember exactly what you said. When you said do you feel like consumers assumed quality, I think that a lot of the inexperienced consumers I know, do. But once you are in the system and you recognize, you sort of learn to navigate the system. Now, I don't.

MEMBER NELSON: And we have to address the needs of both.

CHAIR THOMASON: Yes, I agree.

CHAIR MORT: If I could make a comment about the quality piece, Carrie, before we take the next set of comments. There aren't that many places where you can go and get good quality measures to compare choices. But in the State of Massachusetts,

mortality for open-heart surgery for CABG is published on the state website, by individual doctors. And I remember when this was first happening, the cardiac surgeons were disappointed because everybody -- there was no difference between everybody.

And I said, well, that is disappointing. If you wanted to be better than everybody else, but think about it from the consumer's perspective. Because if mortality is an important quality indicator and now you know that across the state, at that time, everything looked like it was about the same quality, then you could start to factor in other things, cost, convenience, and so forth. But there aren't that many places, unfortunately, where you can get that rich information for comparative purposes. But quality it seems is a piece of information that is important.

Okay, I think Cynthia was next.

MEMBER ROLFE: So, I will try and

cover all my comments. I have been making notes.

I spend my entire job for the past two and a half years has been trying to speak for the consumer to 37 BlueCross/BlueShield plans who insure 100 million people. And I don't do insurance speak. I do know what CABG means but I still make fun of it, and HEDIS and all that stuff.

(Laughter.)

MEMBER ROLFE: But the reality is, people are having these conversations in two different places. So, first of all, we have to talk like consumers. We have to get out of our own inside baseball speak. I agree with that completely.

But consumers have what they believe is the value conversation with their doctors. So, we talked to over 100,000 consumers every year and all different kinds of research. The value conversation for most people is what is the health outcome. Is it

going to fix the problem? If it doesn't fix the problem completely, how does it linger and then impact my life beyond that?

So, they have the value conversation with their doctor and then they go into decision-making mode either about location, rare, very rare, that people look at location because their doctor tells them where it is going to happen. And then treatment choice. But again, they have the treatment process conversation with their doctor and that often has an impact with their cost.

So, we have completely disconnected, I think Liz, you said early on, that conversation. So, when we say affordability, affordability to your point about elasticity is how much is it worth to me, that balance with how much does it cost me. And those two conversations happen differently and the second one happens after the fact. That is one thing I want us to think about.

I also think we need to think about the fact that an episode for a consumer is not the episode the way we describe an episode.

So, if my son breaks his arm playing soccer, that episode is not done until he is back on the field playing soccer. And that is not how we think of it inside our world.

So, I think that is something we really have to understand. And that includes he has a behavioral health issue. He will be really mad at me if this ever gets out because he is a teenager. But it also includes what kind of impact did it have on his emotional health, that he couldn't do something he loved and get his energy out every day?

So, all those things are in the episode. So, I think that is really important. So, I am not quite done. So, I keep mine pent up, Marci, and then I go, go, go.

I think the other thing that I want to reiterate is we have been talking a lot about emergent care, deeply complicated crisis situations. And that is a small majority of consumers, small group of consumers, majority of the emotional intensity for sure, when we do research. But there are 80 percent of people out there who should be engaging with the system and aren't. And the way it feels, they are actually not engaging because they have a perception they are either in or out. And we talk about people as being in or out. Everybody has got to be in somehow to be healthy and to avoid being really in.

So, I do think we do need to think about that 80 percent of consumers a little more.

CHAIR MORT: Thank you, Cynthia. Back to Deb.

MEMBER DAHL: I think also with the "Affordable Care" part that the ACA has made a difference in that. And so we might

want to think of what is affordable, meaning what is affordable from an insurance perspective, when you have got time to sit down and think and explore those options and know what you can personally afford and how your copays or your max limits or those kinds of things are going to work out.

And then what happens in the crisis moment and when it is not part of that covered insurance. So, those are very different measures of affordability as we go through.

CHAIR MORT: Thanks, Deb. I think we have gotten, I am trying to follow the order, but as I am reading the questions, we really have addressed many of these. How can measurement help? How does affordability relate to cost efficiency and value? How is it different from cost efficiency and value and what are the relationships between quality and affordability.

So, I think since we are coming to

the end of the 30 minutes, look at those bullet points and just bring any comments that you haven't had a chance to voice, people who haven't spoken yet so we can cover the full spectrum. But Maureen is ready.

MEMBER EDIGER: It was said earlier about that the insurance being the buffer between parents or patients or families making the decision about cost and that we really don't. That it is about the copay. I just don't think that can be stressed enough.

But the point I wanted to make, and it sort of around a lot of these questions but it is not as explicitly but where, I am going to use consumers, I think, consumers get their information.

As a mother of a child, nobody has talked yet about -- so, my child has a pretty rare specific set of conditions and the people that I go to to get advice, a lot of times is other parents. Because with HIPAA restrictions, I can't necessarily say to the

nurses in the spinal defects clinic or doctors like so what do other families do? Because they can't talk specifically about it. But parents are savvy. Patients are savvy. We know how to find each other and to get advice about where to go and which doctors have a good way to talk to parents or to talk to patients or which urologist has the best nursing staff that is actually going to answer the phone when we call with a question. You know, that is parent-to-parent conversations that I don't really see reflected in if we are asking the questions where do consumers get their info about where to go. I just think that that is a huge component.

And so, I live in Denver. There is really only two pediatric -- we are not in a market that has a lot of choices but I talk to parents in Colorado in the sort of Rocky Mountain Region but I am also, I am in conversations with parents in Ohio. I am in conversations with parents in Florida. I am

in conversations with a mom in Canada, a mom in Australia, asking questions what do you know about the latest AFO technology or what kind of wheelchairs are you -- you know.

Like so, parents and patients are savvy. We are looking for information in a lot of different places.

CHAIR MORT: Maureen, that is a great contribution. We haven't heard that. So, for the gaps in information about service quality and all the other things that matter to your health and the experience, you are going to peers or focus groups or a burgeoning number of websites and facilities to do that, connect with other patients.

MEMBER NELSON: If I could just tail on your experience. You have this professional patient persona. Too many people don't have that. So, how do we tie some of the less experienced into that kind of network?

MEMBER EDIGER: I touched on this

earlier that even professional patients or the frequent flier parents or whatever you want to call it is like yes, we have gotten really good at advocating and we know where everything is and we know how to ask questions but not everybody does.

But we didn't plan to do that. So, there has to be a way to engage other people. And I think someone showed us, just goes down to the communication and being able to develop relationships with the parents or the patients to help them plug into these networks.

And I get really frustrated with the -- and I get HIPAA. I know why it is there. But it really sets up a lot of barriers for parents and patients to be able to connect on the level that they need to, I think.

CHAIR MORT: Thank you. That is a very important contribution.

Now, the four cards that are up, I

must say I lost track of who was first. Do you know who was first?

Okay, we are down to three. Of the three of you, do you know who went first? Tina? Okay. I'm going to need some help. Tina.

MEMBER FRONTERA: Okay. So, I would like to address the how can measurement help inform consumers to make better healthcare decisions.

In 2007, in Minnesota we had an experience where we just ranked providers from high to low based on cost of certain procedures, so, sort of the elective procedures that people would shop for. So if you took a normal vaginal delivery one provider would be $2,500, this is the hospital now, and another provider would be $11,000. And just this showing that variability, kind of what you were talking about, really helped the community compare. So, it helped the consumer, I think, make some decisions. But

it is interesting how the providers almost shop that website more than the consumers, just to see what their competition was doing, et cetera.

So, then it really kind of spurred on a community. I think similarly with quality, too, ranking providers from high to low creates some dynamics. And if it is understandable, then the consumers with a chronic condition or whatever at least have some choices.

Along with that, then the community can also take those measures and turn it into something else and get to the next generation into like tools that can help the consumer. But until you have some measurement to start, I don't know if you can really get anywhere. And then year over year, those measurements can get a little more refined. They are not perfect yet. But that variation, I think is what we found to be the most eye-opening.

CHAIR MORT: Yes, many say transparency just drives provider improvement a great deal as well. Thank you, Tina.

So, we are going to go Tayler, Paul, Lisa and Carrie, and then we are going to open it up to the public. So, probably not any more time for this more cards up.

MEMBER LOFQUIST: Yes, just really quickly I want to follow-up on what Maureen said that I definitely just agree that a lot of the information that I feel like is available is from other people. I am not finding like official sources of cost information. I am not finding official measurements of quality.

But like I have found doctors on Yelp before and it has been great because on Yelp, I can get quality rankings, cost rankings, people's stories and then comparative measurements. I am not suggesting that we need to like come up with like a Yelp for doctors but I am already using it for

that. And people my age expect that type of information to be there. I have no idea how to translate that at all but that has been my experience. Yes, but I agree, you end up going to your friends and crowd sourcing the information more times than not because there is nowhere else to go sometimes.

CHAIR MORT: Thanks, Tayler. Very important. Paul?

MEMBER SIERZENSKI: Well, as an emergency physician, I was sitting back and watching the entire situation unfold before I made my comments here but I will go rapid fire, as usual.

I am a consumer. My youngest son is a severe allergic child. My oldest is a Type 1 diabetic. And I have experienced the issue, as a provider, of having what was believed to be the best care and then realizing that there was an added value. We purchased an insulin pump. We purchased a glucose monitoring system. We paid about

$20,000 in total out-of-pocket and now my son is doing extremely well on pens only and that is because, after a communication with other parents who said keep him active, do the right thing.

What I thought was very interesting here is this discussion of immediacy of care and really what it has to do with is risk-bearing. What I am understanding is the patient's perception of what is their risk of the disease. And that is something I think that is critical when you come to the issue of the affordability and the elasticity. And I think that is important to note.

In our world in emergency medicine, I work at a Level 1 trauma center tertiary care sees about 180,000 patients a year, we are actually having this conversation. Patients are asking us about the issue of cost and pricing. That is not difficult for me. What is difficult for me is translating risk. And that is absolutely

critical because when someone is having ripping, tearing chest pain, that is different than having the discussion with someone who probably shouldn't be in my emergency department because they are not taking their blood pressure medication and the long-term silent effects from that. So, I think it is important that the issue of risk as the provider sees it and as the patient sees it, is important in this conversation.

CHAIR MORT: Thank you, important contribution. Risk is critical.

Lisa and then Carrie. Tayler, did you have another comment? Okay, Lisa.

MEMBER LATTS: I wanted to comment on a couple of things. One is harking back to one of Corey's comments way, way back about what sort of information are available. And health plans are increasingly making some sort of price transparency information available, although it is incredibly nascent and, frankly, not very useful. But there are

sources out there.

But there is the added problem of health plans not being seen as a particularly trusted source, even though they have, frankly, the majority of the information on maybe not what things actually what the price is but at least what things actually cost from their perspective.

The other thing that I think is a growing trend in the industry that is going to force consumers to be more active purchasers of health plans is value-based pricing. And I don't think we have anybody from California here but there have been some very successful initiatives around the country but specifically in California where the health plan says I am going to pay, and this is often for things where there is a luxury of shopping, doctor shopping and hospital shopping, I am going to pay $20,000 for your knee replacement. And here is a list of the hospitals and here is how much it costs. If

you go to this hospital and it is going to cost $25,000, you are responsible for that added cost. If you go to this hospital where it costs $18,000, we will share with you the savings. So, it is going to force consumers to be more active purchasers of healthcare.

And incidentally, the side effect of that methodology is that the hospital that costs $25,000 doesn't really want to be in that higher tier and they typically will drop their price. So, it does save the system money.

CHAIR MORT: Thank you. Thank you, Lisa, that is very helpful.

Carrie, are you declining?

MEMBER NELSON: Am I want?

CHAIR MORT: I thought you were -- go right ahead.

MEMBER NELSON: And I am really taking the risk of being called the chattiest person in the room here, Marci. Step up here.

Looking at the BlueCross side of

the table, I learned recently of a BlueCross tool that was out there that was, I think it is an app, where they are identifying some value-sensitive conditions where it provides quality and cost data to their patient population.

And I think we, as healthcare consumers, need to start to learn how to be the trusted source of information, not to take that away from these consumer resources but to compliment it. You know my sister's major died in all of her experiences with her daughter was her physical therapist. Is that really the right and only good source? I don't think so. So, I would love to hear more about that.

CHAIR MORT: I am going to suggest, Joe, that we have Melissa and then we open it up to the public. There might be a million people out there waiting to ask questions and we are running late getting to them.

Melissa.

CHAIR THOMASON: I feel bad even commenting again because we are so close on time. But I feel like there is an entire conversation around value that we really didn't get to have yet as consumers. I have a lot to say about it, so I will just pull it down.

Really quickly, I was going to say when we talk about inexperienced consumers, I hope that as a healthcare system we start more of a push towards like at one of my last NC IOM meeting, a professional pulled me aside and said can you come speak. We are an organization that is basically health literacy for youth. So now, how do we teach youth how to navigate the healthcare system and pick insurance and things like that?

So, I hope as we do things like that, that we will have a population who can navigate our system better. And that is just an aside.

So on value, what I consider as a consumer when I think about value on the back-end, I want to know, I look at how much time a doctor spent with me and that factors into if I consider that this was a good investment. I look at my outcome. If I got a really great outcome, I consider it worth my money. And if nothing came from it, then I see no value in it.

I look at what the other docs charged me. So, when I got out of the hospital and I got separate bills from providers, the guy who did a cath, who saw me for five seconds, charged me the exact same thing as the guy who did my open heart surgery. And I looked at the provider bills and I was like no way! He didn't do as much as Dr. Kitson did. So, it was a comparison thing and, therefore, influenced how I perceived the value of it.

And then, too, value is closely linked to quality and one of the quality

standards is patient and family-centered care. And that affects my perception of value. If I go into an emergency room and I am treated badly, even though the care is effective and successful, I will think the value or it was less valuable care, just because I will see the bill and it will disgust me.

I pay all the bills but some I am okay with paying. Others, I hate to write the check.

And so, that all factors into value for me. Thank you.

CHAIR MORT: Melissa, that is very helpful. The value is sort of was it worth it.

CHAIR THOMASON: Exactly.

CHAIR MORT: So, let's go to the phone first. Ashlie, can I ask you to help with that?

MS. WILBON: Sure. Operator, can you open the lines to anyone who is on the line and would like to make a comment?

OPERATOR: Yes, ma'am. If you would like to comment at this time, you may press star then the number 1 on your telephone keypad.

Okay, at this time, there are no comments.

MS. WILBON: Okay. Is there anyone in the room who would like to make a comment?

It doesn't sound like there is any. We have three minutes before lunch, if anyone would like to make any final comments.

CHAIR MORT: We asked Joe to pause, so let's bring Joe back to the conversation.

MS. WILBON: Okay, Joe.

MEMBER SINGER: Sure. No, I was just responding to Carrie's comments. You know the health plans that I am working with at Anthem are very, very dedicated and interested in provider transparency issues and empowering members to make good decisions,

especially with some of the consumer-directed health plans.

So, they have put on their web where patients can pick a procedure or a diagnosis using real-world terms, not ICD-9 or CPT codes. So, they can put knee replacement up there and they can go in and see what the average cost, not guaranteed to be their cost, but the average cost for that condition, what the mortality rate is, what the length of stay is, what the morbidity, the infection rate and other things are. And they can create an index, so they can say well, price is less important on this procedure but I don't want to die and I will be more tolerant of an infection. So, they can move things around to, based upon their own value system, try to figure out what they can do. And it is not every procedure but it is the top 20, 30 procedures or conditions and it helps people when it is elective discretionary service, to try to anticipate where they want to go.

We find that it is not used anywhere near as frequently as we would like it to be used. But when people do use it, they feel really empowered. You know, they can go online and plug in the brands drug that they were given to find out if there are similar drugs, generics available, and what the cost savings would be. And this way, people in advance can figure out what is going on.

And the other issue just about affordability is ten people can go to a hospital, the same hospital, the same doctors, the same procedure because of the different insurance companies they have. And the products from the same insurance company, different products, they will get ten different out-of-pocket costs. And that is where people have really not taken the time to really understand what they are buying up front if they are going to the exchange.

You know people pick the bronze at

the lowest price but if they are high utilizers of services, if it the most expensive product they can buy because they are going to get hit with a lot of copays and deductibles.

You know people who are buying insurance for the first time need somebody to teach them how to make those decisions.

So, the information a lot of this actually is out there now but people just have to figure out how to find it and then how to use it.

CHAIR MORT: That is very helpful, Joe, and what I am hearing you say is that the insurance industry is so complex that we need a new industry, called the insurance navigation industry to help with people.

My parents live on Cape Cod and they have to do their Medicare signups every year. And they go to the library because there are a lot of retirees on Cape Cod and the library has a great service for the

retirees and there is someone there who navigates. And so my mother used to struggle and now she doesn't struggle.

Alyssa, I think you will have the last question or comment.

MEMBER KEEFE: Thanks. And I hadn't commented on some of the discussion questions and wanted to be cognizant of being an active participant.

You know it is funny that you raised the issue of some of the work that the health plans are doing. I am more of a consumer than a patient. But I am the navigator for my family. I am the one who does a lot of the translation, Adam, that you do on a daily basis. And every time I go home to Maine in the summer, the family barbeque becomes Alyssa, I have this issue. Where do I go and what do I do?

And recently, it helped me think through again what I perceive as affordable and information that I need to help guide them

versus what my brother or my mother thinks is important to them.

And it is really interesting because the levels of health literacy all come into play and consumer behavior, decision-making that I think answering these questions, and then in the framework of measurement, seemed very difficult for me because what I think of a measure is very different than what one of my family members thinks of a measure. So, I was struggling with that.

And just to bring that to an example, a family member recently needed a CT scan and he was debating between surgery or some sort of shot in his neck to help alleviate some pain and his doctor really wanted him to do the surgery. And he knew that that surgery would take six weeks for him to recover and four weeks would not be paid. And that was just unattainable.

And I am saying to him, I said you need to talk with your doctor about the

appropriate clinical treatment but he was very much struggling. And so he did a lot of shopping about what a shot would cost versus what surgery and then where to get the CT scan so they could appropriately place the shot. His health plan called him and said I know you need to have a CT. By the way, there are five other places than where you doctor told you can get it that are a lot cheaper. And it was -- he called me up. He goes, you wouldn't believe who just called me. He is like, is this true? And he didn't believe them. And I said yes, because the doctor had sent him to the hospital-based out-patient clinic where it is more expensive to get a CT than the regular clinic up the street that didn't have some of those overhead costs.

But when I think through that discussion of someone introduced him again to a world where I don't think he would have known to even ask the question is there a cheaper -- and then not to believe it. Just

the bar that we are raising and then what information do I need to give him to help him make not just the cost but the quality decision-making at the same time.

And so these questions are incredibly difficult to answer from where you sit. And I am just hopeful that the richness of this discussion is really kind of called out in the paper because I don't think it is as clear-cut to any of us. I don't know what you are paying your writer but you might need to increase it. It is quite challenging.

(Laughter.)

CHAIR MORT: Thank you, Alyssa. That was a great wrap-up, I think. Basically, this was an incredibly rich segment. And comments on affordability from the heart, from the ground, from the perspective of patients and consumers.

I am particularly intrigued by Tayler's comment about Yelp, is it. The younger generation really is getting

information in a different way than my mother. So, navigators, information about cost, quality, health plans helping, wonderful discussion.

I think we are about at lunchtime. I am look at Ashlie to direct the next step here.

MS. WILBON: So, we will break for lunch for 30 minutes. We will resume at, we can resume at 12:35. And we will get started with the next section, which will be actually looking at the episode of care model and really parsing through some of these discussions we have had about consumer when you are at risk, what are those decisions and things that our consumers are thinking about at the different stages of their health throughout the episode of care. And also what are the attributes of patients that they have to weigh in their decision-making.

So, we have touched on a lot of those things already today. So, I think it

will be a rich discussion.

So, thanks everyone and lunch is in the back of the room. Thank you.

(Whereupon, at 12:03 p.m., a lunch recess was taken.)

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

(12:41 p.m.)

MR. AMIN: So, as we described at the beginning of our session this morning, what we are really going to do is start to understand the various decisions that consumers make about healthcare, in particular the type of financial decisions they make, but recognizing two different factors. First, that consumers will face different decisions at various different points in time. So, the NQF has an endorsed framework that is the patient-focused episode of care, which is a framework that we use to conceptualize how we would want measurement, the future of measurement, essentially.

And this is a graphical depiction of the patient-centered episode of care framework that puts together three different components. The population at risk -- so it defines again, three different points in time: the population at risk, what we term

evaluation and initial management, and follow-up care.

And I just wanted to point out that this sort of reflects at least a few of the conversations that we have had this morning already and the fact that we talked a little bit about selecting primary care and making decisions about risk, essentially because when you are the Phase 1 you are really sort of underlying, trying to figure out how to stay healthy. You are trying to figure out your underlying potential risk for an actual acute episode. And the element of time we discussed a bit as well, in terms of when you are actually going to need care may not actually be clear to you at that point in time.

So, we have identified here where a clinical episode begins and that sort of triggers Phase 2, which is sort of your evaluation and management. At this point in time, generally you are already in an acute

phase of care and so your decisions, as we discussed earlier this morning may be slightly different than when you are potentially at a population of risk.

There is also the question of discretionary versus nondiscretionary care in this phase. Some might be discretionary. Others might be acute and you may have to select the nearest provider and the question of cost may not be as present.

And then finally, we have the follow-up care section which we also discussed some of the concerns, Tina you raised this as well, around sort of the long-term care issues that may be present, depending on the underlying condition that you have.

So, why we brought this conceptual model up was to reflect was to reflect the conversation that not every condition will have the same type of decisions and the type of information that you will need will vary, depending on where you fall along this

continuum.

So, I just recognize that I just want to point out that again, this describes a continuum of time and is, in some ways, reflective of that.

Go ahead, Ashlie.

MS. WILBON: So, I will just piggyback a little bit and add a little bit of colorful, maybe a few examples. When you are a population at risk, the point at which the evaluation management Phase 2 would begin, could be a diagnosis of a chronic condition, as well as you fall and break your arm. So, the initiation of an acute episode as well. So, the model does lend itself to both a chronic and acute episode.

I will also mention that this is not -- while it is showing here in a linear fashion, it really is more of a continuum. Let's say to Cynthia's point earlier that really the episode doesn't end until her son is back on the field playing soccer. So, you

know he is playing soccer. He is fine. He falls and breaks his arm. He is in the evaluation and initial management phase. He is healing. He has his cast on. He is going to get his cast off in Phase 3. And then he goes back to population at risk phase again, when he is back on the soccer field playing.

So, it really is kind of a continuum, if you will. And depending on, if you have a chronic condition, you may have an exacerbation and have to be admitted to the hospital.

You are released, you go back into the follow-up care phase. You are dealing with care coordination issues or medication management and some other issues. So, the model is really designed to be -- they flow with one another but also you can jump between bubbles, depending on what is going on, particularly with your care.

So, just to kind of highlight that it is not as linear as it appears that we do

recognize that in real-life, as a patient or a consumer, you may be moving around in different areas.

CHAIR THOMASON: Ashlie, may I ask a question?

MS. WILBON: Sure.

CHAIR THOMASON: Is it also correct to assume that in different areas of your life you would be in different stages? So forever, I will be in follow-up care for my genetic disorder but I am still a population at risk heart disease patient.

MS. WILBON: Yes, absolutely.

So, this model is really what we are going to be using kind of for the next few activities that we have in terms of framing our discussion around thinking for each of these bubbles. What are some of the decisions that a consumer or a patient might have at this phase? What are they thinking about? What types of things are they weighing? And then we will go through each of these phases

and kind of have a discussion about those different types of considerations and we have a set of questions, a really long set of questions, not that we have to answer all of them, but just to kind of help us think through what some of those decisions might be and what types of information might be useful to help make those decisions at that point in time, depending on where you are in the episode care and the type of acute versus chronic, patient versus consumer-type setting you are in.

Marci and then Cynthia.

MEMBER NIELSEN: Just a quick question whether -- and I am fine to use this framework for the time-being. But I wonder if it wouldn't be useful to try to convert this, too, into words that have more meaning for average patients. Because this -- wow, talk about what does that mean. Unless you were sitting here.

So, just a suggestion.

MR. AMIN: So we are open to recommendations. So, if these fit sort of other sort of descriptions as we go through each of them, even illustrative examples is actually what we started to do, that will help provide some color as we build out diagram.

MS. WILBON: And I think, too, our exercises tomorrow will be breaking you out into groups and giving you a case study to really kind of see how this really does work out in almost, I won't say a real world scenario, but a real world-like scenario. So, I think that exercise might also help us figure out some better words to try to help reflect what that really does look like.

MS. ADAMS: Ashlie, could I make a quick comment on the common language for the, we affectionately call them the bubbles?

MS. WILBON: Sure.

MS. ADAMS: Because the earlier group had worked on that, it might be helpful to the group. Thank you so much.

When we were originally doing the patient-focused episode of care work, you know, as you smartly point out, this is kind of using measurement-geek language, which I certainly appreciate.

One thing that we did when we were translating this, we built on what was called the fact framework. Some of you might know this in the room. But you can tell me or tell the team if these words resonate.

So, with the population at risk, when we worked with consumers on the fact framework, they said that is about staying healthy, whether you are getting your good preventive services or, if, after you have a diagnosis, you are getting your good secondary and tertiary prevention.

The orange bubble was about getting better. You have this emergency, this scary event and you are kind of there in the middle. But your goal, of course, is to get better. And then the third bubble was coping

with chronic illness. Or, as we spoke about with the long-term care, coping with end of life or coping with that, depending on where you were. This built on a lot of -- not that it shouldn't be refreshed, but it did build on some consumer, a lot of consumer feedback.

So, certainly maybe we could take a look at that language and this group can certainly make it relevant to you or refresh it. But I really appreciated you bringing that out. We used to sometimes have different versions of the bubbles and maybe that would be useful. Thank you.

MEMBER NIELSEN: I like your language, Karen. And I think converting, if it has already been tested and vetted with consumers, the extent to which we can use it now to talk about affordability only helps to underscore the work you have already done. So, it sounds great.

MEMBER ROLFE: I still have a clarifying question. On the first bubble, do

you mean, is that everyone who is not currently getting treatment or is that just at risk populations?

MS. WILBON: Well, I would say everyone is at risk for something. Okay, so if you are walking down the street, you are at risk for --

MEMBER ROLFE: Right, so that is what I wanted to make sure.

MS. WILBON: Yes.

MEMBER ROLFE: Because I do think -- it is just everybody.

MS. WILBON: Everyone.

MEMBER ROLFE: Okay.

MEMBER SOEGAARD: So, my question is, is at risk necessary in the bubble, if it is really applying to everybody?

MEMBER LATTS: Well, is it meant to be that not everyone is at risk for everything? So, pediatric pneumonia, I am not at risk for that. So, I wouldn't be in the bubble for a population at risk because it

depends what the episode is.

MEMBER SOEGAARD: So, will a consumer get that?

(Chorus of no.)

MEMBER SOEGAARD: Okay.

MS. WILBON: Go ahead, Adam.

MEMBER THOMPSON: Yes, I just have a question about how this framework would handle an individual with a chronic condition, who is in self-management and then drops out of care. Do they re-enter, like at evaluation or do they become population at risk because they are not in care anymore?

I mean in HIV, we focus on retention a lot. And part of it is the language about getting people to realize they have made a choice and they have moved forward and they have done all of these things, so that you can reaffirm the positive action they have moved. So, I am wondering where would they go in these bubbles.

MS. WILBON: Someone who has

dropped out of care. I will share my thoughts but I would welcome others. I would say they are back at risk for whatever diseases or exacerbation that may occur based on them not getting treated for their condition.

Go ahead, Maureen.

MEMBER EDIGER: It is just a different level of risk. It is what Paul was talking about earlier, the measurement of risk. So, maybe it should be shaded or something.

MR. AMIN: Yes, that certainly fits in the construct of how this is constructed.

MS. WILBON: Go ahead, Corrie.

MEMBER WILBORN: I am just a little confused about how these bubbles are connected because I thought it was a percentage at risk that go into evaluation and initial management and then a percentage of people that do follow-up care. Because I know there are some people that may go to the

doctor and then may not do follow-up care.

So, just like you said, where do you drop out and where do you come back in? And why are they connected the way that they are connected, or is that just the way the pretty picture looks?

MS. WILBON: I may defer to Karen on this. She helped develop it.

MS. ADAMS: No, this a great question. So, in the population at risk, one way to think about this and I think, Lisa, that was a helpful example with pediatrics, that when we looked at that larger bubble, within that bubble are smaller bubbles which would be sub-populations. It might be a pediatric example. It might be a frail elder example. It would be across the life span.

So, in a total kind of population health type of way, where we don't only think within our patient panels or things like that, it would be your community, et cetera. But within that, there would be certain

populations that would have need.

Let me give an example that might help connect the dots, Corrie. We worked extensively with acute myocardial infarction and other heart disease with this example to do some measurement. And so, if you, in the green bubble, you may be at risk for heart disease for various reasons. If you do have a heart attack, you start to go into that purple bubble there, where, of course, you would be treated.

However, there is follow-up care after that. Some of it might be rehab, elsewhere, but then it is continuous because there are healthy lifestyle behaviors and other things that you would want to continue.

So, if you think about the patient as being thread that goes through bubbles, so you are living your daily life but you are a sub-population who may be at risk for heart disease, you do have that event or that acute event of a heart attack, you go into the

orange, and then there is follow-up care.

But as has been pointed out, there is different points of entry along this and different trajectories we called it, but trajectory might not be a good word, but different paths. So, if you are someone who was relatively healthy and had your first heart attack and followed through and did your rehab and behavioral changes, good food, exercise, et cetera, you would have a different trajectory than someone who had multiple, maybe had more than one heart attack, congestive heart failure, multiple other diseases, diabetes, et cetera. Your path of follow-up care might be different.

So, I think the important thing is that this is customizable to the person and your situation. We worked a lot with the cancer community and, depending on your stage of cancer, this would be different.

So, does that help, at least, with that one example?

MEMBER WILBORN: I really want to know why they are connected in a sense because it is a linear model here. So, I thought that there was something about the connection on this model. So, looking at it as a layman, I didn't understand that connection. That is what I am getting at.

MS. ADAMS: Sure. One reason why we show them as being connected is that we know that many times when you go through transitions of care, whether it is from the hospital to the home, or the hospital to the long-term care facility or to other areas, we know that drops occur, that this is often where the best care doesn't occur or the best coordination doesn't occur.

So, we wanted to show that connectivity that it should be continuous and that when there are hand-offs from either different settings or different types of care, that there should be a connectiveness.

MEMBER SHIPPY: But it is not an

affirmation, Karen, that it is a segment of the population. There is no affirmative there, right?

MS. ADAMS: Right, it is a segment.

CHAIR MORT: Sorry, you may have addressed this. I apologize but I had to step out. If this is episodic care, how are we going to view patients who have a chronic illness who need continuous care, like diabetes? Is that addressed in this model or is it a different model?

MS. WILBON: Sure. They would be in the follow-up care phase for that particular -- for diabetes, for that particular condition, they would be in that follow-up phase for their ongoing management, medication management, diet, exercise, for that particular condition. They might be in population at risk for another condition but for that particular episode, they would --

CHAIR MORT: Okay.

MS. ADAMS: And Liz, when this was conceptualized initially, the time frame, it was arbitrary because we were just starting to think about this type of measurement. This framework needs your refreshment. It is about eight years old now. We also have a multiple chronic condition framework, which I would be happy to share with people offline that speaks to some of the things that you are asking, Liz.

But the one-year time frame sort of allowed us, at least from a measurement perspective, to look at that. But certainly with multiple chronic conditions, then with disease, it goes over a lifetime.

MR. AMIN: So, let me also just, as a point of clarification for the group, I just wanted to point, as Ashlie pointed out, I think one of the things that we struggle with is it does seem sort of linear and it stops. But the idea is just for yourself, it just would be easier to kind of think about it

as a continuous kind of looping. I think that helps a little bit.

But the other thing I will just point out is that the reason why we found this to be a compelling framework to guide our work, I mean the main function of this was to be a measurement framework for how we would want to develop measures across time periods, across settings, and to follow the patient across time, which is really why it is sort of interchanged because care should be sort of longitudinal.

But with that being said, what we are trying to do is say, at least characterize in some broad strokes that there are different time periods within a consumer or patient's experience about making healthcare decisions. And that is a little bit beyond the scope of what this was conceptualized to do. But we still thought it was helpful to at least say or at least acknowledge that there are different time periods in your health-seeking

behavior and that would justify different decisions, which would justify different information, particularly cost information.

And so, we are sort of extending it beyond what it was intended to do but it was sort of to give us a broad sense of the fact that at least we can agree that there are these three different time periods. They roughly relate to one another but they are, obviously interconnected but it gives us some framework to work from.

MS. WILBON: I know Paul has been waiting patiently.

MEMBER SIERZENSKI: So my question is, is this just here as a building block for us on other issues or this is not supposed to be a new rendition? Because I would agree this is not a patient-focused approach to how I would visualize. I have seen lots of people doing this life cycle stuff, which makes more sense.

As a provider and someone who does

measurement, this makes absolute sense to me but I can see from a consumer standpoint or a patient standpoint, it seems finite. But I would just, if the goal of this was just to be a stepping stone, then I wanted to confirm.

MR. AMIN: Well, what I will say is again, I won't try to summarize everybody's, the whole discussion for the day. But what I am hearing about this segment is more along the lines of basically just taking the idea of these three different phases using the patient-focused language that Karen described about staying healthy, getting well, and coping with chronic illness. And just phrasing it in that way, and maybe not even using a graphical display of that, just describing these three different time periods.

But what would be really important is that we want to at least have general agreement that we are okay with these three time periods broadly, because that is the foundation of our work later on today and

tomorrow. So, that is what I am hearing. We might step away a little bit from the actual framework but use the language that has been described here. So, that is kind of what I am hearing but if it is not, feel free to correct me.

Go ahead, Ron.

MEMBER WALTERS: I understand this diagram was created long before we brought affordability into play. So, it is no problem.

I think we have an opportunity, though, to link to the affordability work and measuring that affordability because clearly what is defined as affordability changes within this diagram, with the left-hand part being all those -- what affordability is defined as when you are healthy. And that is almost akin to getting, again, the young invincibles to sign up for exchange plans.

But you may have aspects of your family risk, social risk, et cetera, personal

health history risks that add aspects to that to make certain things more affordable in your definition to you.

Now, there is no question you have heard all day once you get something really serious, the whole world changes and how you look at affordability changes almost instantaneously. And then as you circle back into post-acute care, chronic care, whatever you want to call it, and secondary prevention and so on of other situations, there is other factors yet that come into play to your definition of affordability and, therefore, how you would measure that.

So, this is a useful framework. I think we have to do some work to tie it in, to relate it to what we are here today is how would you measure affordability under these different sorts of timeframes.

MR. AMIN: Right. So, Ron, I just wanted to articulate that is exactly the structure of what our afternoon session will

be and maybe even tomorrow morning. I don't know if we finish that today or tomorrow but that is exactly the task at hand.

We just wanted to set up the time periods now and then get into the deep dive about what does affordability mean in each of these phases but we can term them slightly differently and we have taken that feedback and we will make sure that that is reflected in a final work.

Melissa.

CHAIR THOMASON: I just wanted to -- I think it is important to clarify long-term disease management with follow-up care because so many of us are dealing with this long-term care like diabetes and different things.

So, like from a consumer's perspective, if I saw this in the white paper, I would want it to specify follow-up care and disease management but something that lets a consumer know, this is your long-term care

forever.

And when I look at it as a consumer, it is the people at risk, treatment, disease management. It is just when I am being treated after.

And the other consumers can weigh in on that. But when I first saw this, that was -- all that is treatment.

CHAIR MORT: That resonates with the provider here, too. I'm on the same page.

MR. AMIN: Marci?

MEMBER NIELSEN: And one thing that we could do is start with that framework. I like the words that Melissa used a lot and even consider drawing and adding on some symbols to make this have more meaning, linked back to affordability.

So for example, you could see if in fact all the people who are in need of, potentially in need of treatment, and in Arrow 2, what you think about what factors make up affordability and you could list out health

insurance premiums, deductibles, those sorts of things. You could see some arrows and some dollar signs connected to treatment. Now, there is a whole different set of factors and definitions that you think about.

But I would want to add some symbols. I would want to test this through the lens of health literacy. You know we need to minimize the number of long-syllabled words and jargon.

And then to Melissa's point about follow-up care and chronic care, you could draw circles and dashes to just make it clear that there is a difference between the two because I think that is incredibly important.

So, if you are open to building from this model, I would say let's use what is already worked in the model and some consumer language but let's be open to new bells and whistles.

MR. AMIN: Yes, that's great. And actually maybe we can move to the next section

because what we will do is -- so what we will do is exactly that. What we wanted to sort of weigh out was these three and then we can build from that, using the perspective of the question of affordability. What are decisions that you would need to make in that phase? What information would you want to have? What is available to you?

But before we move past this model, I just wanted to add another layer to this and say that we wanted to recognize that in each of these phases, there are consumer attributes that are going to weigh the decisions differently. And I think, Marci, you pointed out one which is around health literacy. But we wanted to point out a few others and just have a conversation about just broadly what they are, just so as we start in the process of each of these phases, we can keep all these, as you described them, lenses in the forefront to say what are the other components, what are the other consumer

attributes that one would need to think about, besides potentially the question of risk or the progression of illness? Health literacy would be one.

MS. WILBON: We have some others. We have insurance status -- let me just fast forward here.

CHAIR THOMASON: Age, I think, is a big thing, too.

MR. AMIN: Yes.

MS. WILBON: So, here is a few that we started to list. This is not, by any means an exhaustive list. We just wanted to kind of -- this is strictly meant to get the discussion going. But we have already, as Taroon mentioned, heard some really good ones today about literacy, health literacy -- I think literacy alone, language barriers, and then obviously health literacy.

So, there are some discussion questions in your guide, as well as here, I think, that we have, for some discussion

around -- so what are these factors that people are weighing when they are making decisions about costs related to healthcare and healthcare and engaging with the healthcare system? How do those attributes affect decisions? And then perhaps giving some examples of how those factors are weighed or when some of those factors might have outweighed seeking healthcare.

So, on that note, I will hand it over to Liz and open it up for discussion.

CHAIR MORT: And I am going to hand it over to Melissa, who facilitated this section. We haven't differentiated expert panel from consumer panel. We have just had one big discussion, which seems like it is very organic and going fine. You don't want us to tease that apart, do you? Okay.

Melissa.

CHAIR THOMASON: Okay, so one question, Taroon. We have the stages of care listed later and we are going to talk about

specific things I need to know during treatment versus long-term. So now, are we talking about broadly or a whole or do we need to specify stage or what?

MR. AMIN: Yes, so I apologize for that. Ashlie and I were just having a discussion before we started to say that maybe this would have been better if each individual -- so, we can take this discussion into each individual phase but, at this point, we would just consider what are the lenses that would need to be, that would weigh on the decisions across all three of the different phases. So, that is how I would characterize it.

So, socioeconomic factors would be, depending on your health literacy, I think that would probably be the better example, would play into account for all three of the different phases. But they may weigh differently and we can go into those discussions when we get into each of the phases.

So, in summary, what it is is to look at it overall.

CHAIR THOMASON: So, more discussion on consumer attributes and how that might affect the decisions we need to make as a whole? Okay.

I think a really important one that Tayler was talking about earlier is age. I definitely think it can influence your decisions and I think it also influences how you look for information and how we need to provide it.

Adam?

MEMBER THOMPSON: Yes, two things I would add to that. One is just being sure to mention to remember that numeracy is a part of health literacy as well. We talk a lot about the words of our care but I think some of the biggest barriers are the numbers, particularly when you are supposed to understand those numbers to self-manage, so really paying attention to numeracy.

The second piece is the perception of one's role in health and healthcare. And I think that this, it stretches between the first one and the last one. Because what it is looking at is what is my role in health and healthcare and how do I activate myself in that? And I think there are cultural points in there, where people don't see themselves as being active in their healthcare. And it is not something that is in their culture. But it is a cognitive that I think has to be looked at because some people may never engage or even make decisions about affordability because they don't see that as their role to do that.

CHAIR THOMASON: I think is a great point. We talk a lot in patient engagement circles about patient activation measures and how empowered an individual feels to even make those decisions. So, it is a very good point that some consumers may not even feel the responsibility to make those

decisions.

Liz and then Deb.

CHAIR MORT: It is a related issue to empowerment but it is sort of even if you are empowered to make decisions of some type, some patients just don't want to make the decisions for this type. So, it could be that they are an activated individual, not just a quiet person in general. So, there is a slight difference there.

But the other thing I was going to mention was family, a spouse or family members, because many of the things that we make decisions about in healthcare involve hospitalizations or procedures, someone to drive you home from your colonoscopy. So, I think these decisions often need to be made in the context of who you live with. That is an SES, socioeconomic status, but a very important one, I think, when you are making healthcare decision.

MEMBER DAHL: Just to expand a

little bit on the culture, there are a lot of cultures that the healthcare should not happen at all. So, we need to be aware of those issues.

And then just from the opposite end of that spectrum, where I am from we have a pretty large gypsy population. And so the expectation there is that everything that they want when they walk into their door belongs to them as well, and you should be freely giving them everything. So, the cost is whether it is the cafeteria or the Band-Aid, that is theirs to have at no charge. So, just thinking about the cultural opportunities.

CHAIR THOMASON: And that would definitely influence their perspective of affordability. Expectation is really important going in.

Cynthia?

MEMBER ROLFE: I had a question. I wanted to echo something that Liz said. So my question is -- the first question is, what

are consumers weighing? So, when you asked me that question, I am thinking about how they are thinking about it. But what we seem to be talking about is descriptions of them. So, I want to make sure we answer the first question explicitly.

And I think regarding the second, Liz, you make a really important point, age and all those things have a lot to do with the mode that people want to get their information. But then personalities dictate a lot of preference among that. So, you can get people who really are digitally oriented at all ages, within a certain reasonability, 85 you are probably not. But your personality about how you like to engage and how much help you want, it is across all age bands. So, I just want to make sure that we account for that.

But I think it is really important to think about from their perspective, not just describing them.

CHAIR THOMASON: Great point. Ron, if you want to go ahead, and then we will have Dorothy and Adam.

MEMBER WALTERS: How many times have we heard this one? I don't know how to roll it up to another feature, but it might be roll-upable.

I couldn't go in to take care of myself because someone else in my family was sick. And I wanted to make sure they got the right care, whether that be from a cost perspective, a time perspective, whatever perspective.

I think this is complicated also as far as a what else is going on around them in their own respective family or whatever you want to call it.

MEMBER SIEMON: I was just going to say that I think we are sort of mixing decisions here because I think cost and burden, if you are strictly talking about cost and what people think about can I afford this,

that is one analytical frame. But if you are thinking more broadly about how consumers look at should I have this procedure because my husband really needs me home to do X, or my mother is really sick and I am taking care of her so, I can't take care of myself right now, that is not a cost decision. That is a different decision.

So, I think maybe I am parsing the words a little more literally, but I think you have to be clear about, analytically, people are making risk and burden analyses that is broader than cost. And cost is a factor.

CHAIR THOMASON: So, Taroon, when we talk about cost to the consumer and things like that of missed work, and wages, and time, where do we factor all that in?

MR. AMIN: I think this conversation is actually helping us in some ways, too, because I am not sure that this nuance that Dorothy is describing was as clear to us when we laid this out. So, I think we

will take sort of both and we will have to sort of separate them out in the discussion. But I think we sort of intended for both of these conversations, both of these types of considerations, both the patient attributes and the other factors that are going on in the patient's life that would influence the way they consider making decisions about cost.

Is that fair, Ashlie? Yes.

CHAIR THOMASON: And Dorothy, did you mean to imply -- or this is how I heard you, so I just wanted to clarify. That just because I could afford it, doesn't mean I could have it done and the burden in my life --

MEMBER SIEMON: Yes, I mean I can give you a specific example. Part of my job at AARP, I staff the National Policy Council and we have older volunteers coming in. And I can't tell you how many times I have heard from several of, it is usually women, who say I have held off my own healthcare for so long,

I really need a knee replacement, I need this but they are the caregiver to other people. So, the decision about whether to do it, they didn't even get to the cost decision yet and many of them can afford it but these other considerations are there. And I am sure that is not the only one.

So, I just think you have to tease all that out and create a different frame in the beginning.

CHAIR THOMASON: Great point. Adam and then we will move over here to Paul and Carrie. Okay, Paul?

MEMBER SIERZENSKI: You had listed before socioeconomic factors and I think you really need to parse that out and drill that down. I think income, indebtedness, or disposable, which is disposable cash or revenues, I think those issues really do drive the issue of cost for some individuals. Obviously, that would change, depending on where you are on the episode of care, as we

have talked about, the immediacy of care. But I think, if it wasn't planned to, I think they should be specifically drilled down as independent factors.

MEMBER NELSON: I agree with what was said earlier, particularly consumer attributes that may be connected to how they take the information on cost and interpret that in their life. So, it may be cultural. It may be the socioeconomic, a variety of other things we have talked about. But I do think there are some common themes that consumers still weigh. The way they interpret that is very personal. How they interpret that against their own set of values is more personal.

And I do think that a lot of what we are talking about is reflective of that component, which is important but I heard Melissa, some of what you said in terms of the things you weigh are, you know, how urgent is this and do I have time to really think about

the money. What kind of value do I perceive that I got out of that?

And so, I think those are some themes that we could potentially address in here. What the consumer does with that information, though, is going to be very personal, based on a lot of the things that we have called out here.

CHAIR MORT: I have a couple other consumer characteristics, so not circumstances, but intrinsic characteristics. And one is tolerance for bad outcomes. And I can't think of -- I can think of so many patients whom I laid out an option or two options with certain risk and I have been very surprised at how they viewed the risk of CABG, to bring up the CABG again. You know for some a 30 percent risk of stroke is just terrifying, intolerable, but for others it was worth it, given their symptoms related to heart disease. So risk tolerance.

And then a related thing is called

utilities, patients' utilities, which basically means what matters to them. And I can give you an example of prostate cancer. You could have a treatment that is radiation therapy, for certain kinds of cancers, radiation therapy versus surgery. And if the risk of impotence and incontinence is higher in one than the other, for some men, they just as soon have the surgery and live with the incontinence or the impotence and for others, it is unthinkable.

So, I think when you are going through decisions, particularly when there is two options, there is always two options, to do or not to do. But if there is between treatment options, what matters to the patient? You have to ask them. Because as well as you think you know their own patients, you don't know their utilities.

CHAIR THOMASON: Great point. Carrie, is yours up?

MEMBER NELSON: Just another brief

comment based on what you have said. You know, this is very much in the realm of shared decision-making in my mind. And share decision-making does portray as objectively and in a health-literate sensitive manner, various options and the important components to weigh. The value part of it is also. And so a patient will interpret all that based on their values.

So I really think that is the right way to think about this is an important part of shared decision-making.

CHAIR THOMASON: I think that is a great point. I will add to that when I made my decisions, like I need to have this surgery and not necessarily right now but I know I need to have it, we always made that decision as a family. It wasn't just my decision. We looked at our income and indebtedness, as Paul spoke of, and what we already owed and all those things, of course.

But then more than that, I need

someone to take care of me during recovery. And my mom's got to be able to do that. And well, my dad doesn't have vacation time left this year and he really wants to be at the hospital. And well, my husband, and I had a newborn son. And it really was, we really made that decision as a family. And it was about how this would affect our family, even more than me as an individual. So, I think that is really a great point.

MR. AMIN: Melissa, we had a few questions for this section as well, just to maybe break it up a little bit. Since we go to quarter to two on this one.

So, I should also point out, and I was remiss to mention this at the beginning of our introductions but I just wanted to also send a thank you to John Santa at Consumer Reports, who has been sort of another voice that has been helping staff and the chairs here, in terms of designing some of the questions and the decision-making. And it was

very helpful in terms of kind of just thinking through some stimulating questions. So, that is where some of these came from as well. So, I just wanted to attribute that properly.

So, I think the first question here was, so if you want to get your clickers out, consumers want quality and cost information when making healthcare decisions; agree, neutral, disagree, and it depends.

(Pause.)

MR. AMIN: Wow! Okay, so that is an interesting one.

So, the next one is as a consumer, I would change hospitals based solely on their price or maybe select hospitals, select a hospital. Yes, that is a little bit weighted. All right, maybe not the best calibrated questions. I would change maybe a few words here for next time.

Wow, okay. So that was hospitals. As a consumer, I would change doctors based on their price.

(Pause.)

MR. AMIN: Interesting.

CHAIR THOMASON: Can I ask a question, there Taroon?

MR. AMIN: Sure.

CHAIR THOMASON: How many of you disagreed because it said solely on price and didn't take anything else into account?

(Show of hands.)

CHAIR THOMASON: Yes, I think that was --

MR. AMIN: A bit loaded, yes.

MS. WILBON: So, the next --

MEMBER SINGER: I'm sorry. It would be very interesting if you asked the question say, if you have been with a physician a long time and you find other physicians that have the same credentials and the same capabilities but you are out-of-pocket costs would be half of nothing, that is the concept behind tiered networks, a different type of benefit design, whereas, if

you are willing to restrict which physicians you go to, as long as they meet the quality minimum and everything, would you be willing to change physicians because of lower out-of-pocket costs.

Ten years' ago when I was president of a health plan and we put this out there, people were not willing to change physicians. Two years' ago, in a different scenario where economic stress is maybe a little bit more on people, they are more sensitive, they are willing to do that.

CHAIR THOMASON: I would have to have reassurance that the quality really was going to be the same. Because I have such a rare disorder, finding a specialized that even knew what Loey's-Dietz Syndrome was was a very big deal for me. So, I didn't feel like I had a big choice. But if I knew that they knew my disorder and it would cost me less, then I would probably consider switching. Yes, for sure.

Deb and then Tina and Lisa.

MEMBER DAHL: I will just mention we have some real world experience with asking patients to change physicians, not based on price but based on their complex chronic diseases and their primary care giving them a referral to a new program that would require them to leave that primary care physician and go to a new one. More than half of them would not move because they had a long-term relationship with the existing physician.

So, even though that doc recommended the program, recommended the new primary care physician, they say no, I have been with Dr. X for 20 years and I am not changing.

CHAIR THOMASON: Yes, I form a relationship with my physicians. Right. I trust him and that is a big deal with providers. It is about that trust mechanism. You know, I am literally putting my life in his hands. And I have this trust built with

this surgeon already. So, it would be a hard decision.

MEMBER DAHL: On the other hand, I have changed, personally, because the front office was just bad.

CHAIR THOMASON: I understand. I did that based on an admissions coordinator in one hospital. I quit going there because of one admissions coordinator.

Tina and then Lisa, and I didn't see Kris over here and then Adam.

MEMBER FRONTERA: I had a hard time answering the question and maybe I was over-thinking or a couple of the questions because I didn't know if it was cost or cost to me if I were a consumer. So, I would still say that I don't think the consumer cares what it costs. I think they care what it costs to them.

And so when I entered it inconsistently, I sometimes thought of cost in general and then I said I didn't care. And

then when I thought about cost to me, I cared. So, I am not sure if the others had that issue and how accurate our responses are, if we were all thinking in different ways.

MEMBER LATTS: So, I am going to apologize in advance to the NQF people here because I think this is a bit heresy.

But as a quality person, and I say this with all love and affection for the quality measurement specialty, I cringe every time someone says what Joe just said, which is that quality being equal, because the reality is we know so little about measuring quality in physicians or providers of any sort and we measure what we can measure. We don't measure what is important because we can't measure it objectively. And so, there are so many aspects that go into quality. And again, quality is in the eye of the beholder, just as much as cost is.

So, I don't know, frankly, how we can ever say quality is equal from a true

comprehensive sense. We do what we can do based on the state of the industry today. So, I just cringe a little bit.

MEMBER SOEGAARD: I was just going to add that for me, it would depend on the difference in cost, I think. And then it would also depend on what kind of care it was associated with. So, if I was going in for more like preventive care or something that was just going to be treated once or twice, that might have -- I might have a different feeling about that than I would if I was going for ongoing care.

MEMBER THOMPSON: I just wanted to also echo your sentiments and also say it is not just a relationship with the physician but a relationship with the institution. And I have seen patients who will change their doctors within the institution. But if you say leave this hospital and go to another one, then they won't do it. And so it is not just with your doctors. I think it can also be

with your care setting and I think that is where you are comfortable.

CHAIR MORT: Picking up on what Lisa said about quality, I think I could not agree with you more that we don't have a full complement of quality measures but we do have some measures that measure some things well. So, I think when you are talking about what else do patients need or consumers need, they need measure on available aspects of quality, which identifies the fact that there are just some aspects of quality that we know something about. And to find out the other aspects, you are going to have to talk to people or experience it yourself. So, you can measure things like structural attributes of a facility, whether there is a computerized provider order entry, along the lines of a Leapfrog Group's structural measures, and you can look at service, patient experience through the HCAHPs and the CG-CAHPs. And those are valid surveys. They measure

something, an aspect of quality.

And HEDIS measures, for what they are worth, I mean they measure some aspects of testing and chronic disease management.

So, when we are looking at what factors consumers and patients need, I would say all available measures of quality, so that they get as full a picture as possible, but also be clear that there are big gaps.

CHAIR THOMASON: Really good point. I was going to add, too, an example of when another factor is outweighed, the affordability decision for me, I am really -- I don't buy anything at all without checking an Amazon review, literally. Not a $30 toy for my child without checking an Amazon review. And if the reviews aren't good, I don't buy it.

And I think there is, just like Taroon was saying earlier, well, this is what cost is in every other area of society but this is what we think it is in healthcare.

And as a consumer, I don't distinguish between the two. I am just a consumer. And when I go into the healthcare arena, I expect the same thing from it, as I do from everywhere else. And my reviews in the healthcare arena, because we don't readily provide reviews like Tayler and I were talking earlier, are usually by word of mouth. So, I talked to, just like Maureen was saying, I talked to other patients. I talked to Loeys-Dietz Syndrome Foundation and say who is the best, what do you think. And so we are really comparing quality, word of mouth now. And I wish we had a better way. I wish we had reviews and things of that nature, more transparent information for patients.

Cynthia, I think yours was up first.

MEMBER ROLFE: A quick comment. I want to make sure everybody thinks about the fact, because we have learned this kind of the hard way, is that some of the quality measures

that are available, consumers really have never thought about those things before. And that is not to say we shouldn't make it very transparent but when they start to find out the reinfection rates and what really drives that, stuff like that, we have to be prepared to help them understand and put that in context. Because, honestly, they think we all do that well. So, that is one caution.

And then the other thing, I wrote down, Melissa, when you were saying earlier, you talked about how you established value and outcomes was one of them and the other was kind of how it made you feel, how people treated you. And I do think you have hit on an Amazon approach, which is people like me. People like me liked this. People with my issues like this. People with my personality or my preferences liked this. But the concept of how it feels is so important to consumers and that is one of the reasons they won't switch based on cost. So, we do have to

figure out a way to systemically make that available to them or make their ability to get a read on an institution or a doctor and how it would feel for them to work with that person.

CHAIR THOMASON: Exactly. Ideally, just like Liz was saying earlier, there is the ability of some sites where they will actually give you the review and the basic demographic of the reviewer. So you can say oh, this person lives in the same part of the country as me. Oh, this person is relatively my age. And when I am purchasing anything, that matters to me and even more so, something that is going to affect my life for sure.

Corrie and then Adam.

MEMBER WILBORN: I think when we are looking at reviews, we have to think about the motivation sometimes behind reviews. For instance, I bought a pair of headphones. And because my friend was one of the manufacturers

of the headphones, I gave it a good review, just based on my relationship with that particular person, even though the left ear of the headphone went out within three weeks.

And I think that just looking at, I was reading, this article and it say 88 measures, the health partners used 88 measures of quality. What are those 88 measures? It is not listed here. I don't know what they are.

But in choosing a doctor, I went to the hospital recently, and one doctor had 15 patients in the lobby. And those patients were complaining and I got to the doctor and was able to see my physician immediately. And I was wondering why these patients were still waiting on this particular doctor all day long. You know I had seen my doctor, leaving, and these people are still sitting in the lobby. And so I was saying oh, man. But these people are indebted to this doctor because they have been seeing him forever and

so they are willing to wait. So, we have to think about that. As a reviewer, they may say oh, this is the greatest doctor ever. And I would look at it and say man, you guys have been here for five hours of your day. Is this doctor really that great? And they are part of the same institution.

And then saying that, you know, as Adam said, you may want to choose a different doctor in that same institution. And that may be one of your quality measure for a particular doctor.

CHAIR THOMASON: I think you raised a good point in questioning the objectivity of reviews. I naturally weed those out, or think I do, on Amazon. So, I will read it and I will go, oh, well, she wrote the book, definitely. Like she wrote that book she is reviewing. And you sort of weed those out when you go through Amazon and different ones that don't seem like reliable reviews and things of that nature. So it was

a good point.

Adam.

MEMBER THOMPSON: Yes, the other thing I was going to add is we just have to make sure that when data comes out we can't overwhelm people with it. Like if we were to publish every piece of quality data that we have, I think people would get lost in it.

And so I think what we have to do -- when preparing for this, the question came out, what would we need as consumers. What information? And all I kept thinking is I want to sit across from my doctor and I want to ask him, as an HIV specialist, what three things would you ask a doctor? And then that is where I think the starting point for the conversation takes place. Because patients will make a decision with the information they have. And the information we generally have is what were the magazines in the waiting room; how long did I have to wait there? So, we do make decisions based on experience and

we will stay at a provider because of that experience but I don't think it is because experience is so important as it is we have no concept of what else to measure these providers on, nor would we have the information to do so.

So, I think when you look at that, you have to think about all of those things, as well as recognizing what is a general American's cultural touch point on a percentage.

When you think about it, it is school. Right? What percentages did you get on your grades? Well, if you tell me my hospital is a 75 percent rate treating syphilis or whatever, I am going to go, well that is a D and that is really crappy. Even though when comparatively, I go, wow, they are better than everybody else is doing. They are doing really well.

So, I think it is even looking at when providing this quality information, not

just factors the way people use decisions but are they even using the information in the way that gets them to the right decision or are they just using whatever they have around them because it is not there. But I don't think we should say experience drives choice because I think we can say it does now. But in a landscape where we have more information, I don't know if that will be the case.

CHAIR THOMASON: I think that is a really good point. More data is not necessarily always better. I think one of the things we don't always do well, even in beside care, we go to the doctor and we say oh, we need to educate patients.

So, we give them 20 pamphlets on diabetes and all 20 go in the trash when I get home because I don't know which is the most important to read and I am not reading 20 of them. And we don't funnel the information for patients. So, look at it at large and say what is the most meaningful, useful

information that they need, present that in an easy to use way. And then also help them know how to use that information to get the outcome they are looking for.

Cynthia? Corey.

MEMBER WILBORN: Another important thing about this quality thing. Me sitting in the waiting room for 15 minutes while other people sat there for hours, when I leave there, I may be upset with the doctor because he only spent five minutes with me, while this particular doctor spent an hour with his patients. So, that is another side that we may look at when we are talking about quality and affordability.

CHAIR THOMASON: And that will probably factor into your concept of value and things.

MEMBER WILBORN: Exactly.

CHAIR THOMASON: Tayler and then Marci down here.

MEMBER LOFQUIST: Yes, and I was

just going to add as well, I think that we are talking about a lot of different points of information that are really siloed from one another. Like you can have all this rating and experiences that people are going through and just their story versus the quantitative information about how a hospital is doing. But are you connecting that information? Do people see those connectivities? And can you streamline that information altogether to come up with one like ranking point. Like, is there a way to do that --

CHAIR THOMASON: Absolutely. Ideally --

MEMBER LOFQUIST: -- instead of keeping these points so disparate from one another.

CHAIR THOMASON: Ideally, there would be one place to go, one site where you go to it and I would be able to Google. I would type in my symptoms. It would tell me, these are the choices in what you have. I

would say oh, okay. I would look at the providers in my area. I would pull that up, I would see the reviews. I would see all the safety data. I would be able to make an informed decision.

And right now, you go to WebMD, you Google your symptoms. Oh, I might have that. Then you go to somewhere else and you are really jumping around these silos, even in the information provided. It's a good point.

Marci.

MEMBER NIELSEN: I am just wondering about the scope and the mission creep as we talk about affordability and now we talk about quality. That is a whole other set of literature and consideration. And for the purposes of this writer, who is now going to get a raise, thinking about how to characterize in a couple of paragraphs the importance of quality because without it you can't measure value, but then sort of saying we got to put that in the parking lot because

that is another conversation, recognize they are siloed from one another. I just don't know how within the scope of this project you tackle both fairly. And I think if you are not going to tackle all of the nuances, it is a little dangerous.

MEMBER KEEFE: Can I just jump in? Because I think I was feeling the same way and maybe if you guys could help us because I was feeling a little scope creep beyond affordability. I know there is a lot of other work going on at NQF around the MAP affordability group. There is another expert panel on linking cost and quality information. Can you help us figure out how we fit around this work as fitting, just, again, to give us a little bit more context for those of us that sit around those tables as well?

MS. WILBON: Yes, so, we do have several other groups that are convened right now that are also discussing cost issues, one of which is the group that Lisa mentioned

earlier that she co-chairs. And that is a consensus development process, where we have a Steering Committee convened that just evaluates cost of resource use measures against our evaluation criteria. So, that is specifically an endorsement effort where we basically give the measures a stamp of approval to be used for accountability and quality or performance improvement purposes.

So, that is a more, I would say, very specific measurement, measure evaluation, measure-specific effort that we have. And that is on-going. We are kind of always doing that kind of in the background.

The other piece that is somewhat, I would say, connected to this piece of work, which was also funded by the Robert Wood Johnson Foundation, is the piece that you mentioned, Alyssa, around the linking costs and quality. And that group is convened to explore -- so this whole issue around efficiency, particularly in the measurement

space, we have been talking for a long time that it is really important to not just look at costs in isolation but to link that with a quality signal to really understand what we mean by efficient. You know, for a lot of stakeholders it is very dangerous territory to start making judgments based solely on costs.

And so this effort is really focused on, from a measurement perspective, what do you we really mean by saying that costs and quality should be linked? Are we saying that the two measurement s--

MEMBER KEEFE: And you are using your traditional definition of cost, which is total cost of an episode of care versus what a patient sees as their costs.

MS. WILBON: Right.

MEMBER KEEFE: So, I think that is where I am --

MS. WILBON: Right. So, I was going to explain that and then -- so, let me just finish explaining kind of what they are

doing and then kind of circle back to the perspective. Because you are right. There are nuances in terms of the work that we are doing with this, which is somewhat out on its own in terms of focusing specifically on consumers.

But the linking costs and quality effort, which is around looking kind of psychometrically at like how do those measures actually link together, what are the different measurement approaches that we can take to really to do that going forward, in terms of the evaluation efforts that we do? How do we ask for that information? How should it be evaluated and so forth?

The nuance that I will pull out is that a lot of our measurement efforts, at this point, have been very, I would say probably more provider-centric. A lot of the information as described earlier with the cost measures is based on information that we have access to, which is administrative claims

data. So, a lot of times we don't have the ability to measure costs besides a copay or an out-of-pocket cost from the consumer perspective, because we haven't had access to the data and the different modes to do that.

And so, I will say like those efforts are looking at cost measurement. I wouldn't say they are consumer-focused but just kind of looking at the data that we have now, administrative claims, potentially some other data sources and how we kind of link costs and quality, which kind of dovetails into our measure evaluation processes where we are looking at how we would bring those measures into NQF, review them, endorse them.

So, the measurement perspective there, like I said, is much more I would say health plan or provider-focused because that is where we get the data from.

On the other side of that kind of linking cost and quality picture, is the quality piece of that, which there are

different types of quality measure, the patient experience. So that is one place that the consumer perspective does come in.

This piece of work is somewhat different because it is so consumer-centric. And while we have consumers at the table for our other piece of work, because they so measurement-focused and based on the data that we have for measurement at this time, consumers are able to provide input but it is kind of based on those types of measures. Whereas here, we are really trying to figure out what is it that consumers really need and how are those measures different. Is it even measuring the way that we think about it? Maybe it is not necessarily a performance measure but some other -- you know, what is the proportion of patients like me that picked this health plan or some other type of measure that consumers are looking for.

So, I don't know if Taroon --

MEMBER KEEFE: That helps because

I think listening to that and, again, using a framework of affordability as the lens, because they are all interconnected. And so we talk about cost and quality information together to make a shared decision with the lens of how do you define it being affordable and valuable. Right?

And so I was just having a really hard time as I listen to people talk about all that information that goes into making those decisions, juxtaposing it against the affordability equation that we discussed earlier. So, that helps. And I think the discussion questions, though, we are answering them sometimes, I think, in a little bit more the traditional kind of way of measurement. And some of the answers that I am hearing think through a lot of the other, rather than -- and I actually think I am hearing it sometimes from the consumers, which actually makes me feel kind of positive in a way. I think I am connecting some things across both

-- I don't want to make them silos but sometimes they are silos, about bringing a different perspective.

So, I think we just need to be cognizant of our conversation here. Because while they are very related, I think they are separate. And I know for me, sitting in that other compartment usually, I am trying to put this in a different box because I think it is important but I am seeing them blurred and crossing lines. So, I know I am struggling, and maybe I am the only one but, about where this is going to go.

MR. AMIN: Let's talk about that a little bit because I think it is really important for the framing of when we start with this work in the next three phases when we look at it.

You know when we talked about the affordability equation, we looked at sort of the stakeholder preferences as they are weighing sort of cost and quality together.

And I think when we first approached this work, the framework that we were using was it is really sort of the very traditional like approach, which was a percentage of out-of-pocket income and that would vary by individual. And that is how somebody is going to look at the question of affordability.

But as we started having the consumer calls and we had the first call, it became really clear that that was not really the framework that people were comfortable with and, in fact, it was much more that you had to bring in the question of quality into the question of affordability. And that changed our framing of it.

And I think we are, quite frankly, struggling with it a little bit, too, because each person will weigh those two things sort of differently as well. But that is why the quality question has come up very clearly in the discussion of how do you think about affordability. Because what we have heard so

far, and I am open to thinking about this differently if the group feels otherwise, but what we have heard so far is the question of affordability cannot be thought of independently of a question of quality.

Well, definitely cost but quality. And that is across each of the different phases.

So, as we get into each of them, we can have a discussion about how much quality is important. Because just like cost may not be as important in an emergent situation, quality may not be either. You are just going to the nearest provider.

But that was the history of how we got to that point, too. So, you are not alone in thinking about that. And we can still have that discussion. It is not set in stone either. But that is kind of how we got to where we are now. That is why we framed it this way in the work.

CHAIR THOMASON: I know we are

running short on time. Taroon, do you want to continue into the break?

MR. AMIN: I think we should probably take a break but maybe just get these questions and then we will take a break.

CHAIR THOMASON: Okay. And I will add really quickly, I can only, as a consumer, I will only choose the most affordable option of the good quality options. I don't want something cheap if it is not good. And it really became that for me. I never look at affordability absent of quality. And I don't think I am the only consumer either that had that viewpoint on our consumer call. I think we all kind of looked at it as the best affordable choice among the high quality options.

MEMBER SIEMON: I was reacting to someone saying these things were separate. So everyone has iterated back that they are not separate.

I think the mission creep that we

are concerned about is one of emphasis that what this group seems to be going after is affordability in solving that and making sure you don't go down the rabbit hole of all the open questions in the quality rabbit hole. And there apparently are a lot. So, if you could sort of box that and say we understand the limits of the quality data now but, given the limits, how do we use that in the affordability question that we are trying to answer here.

Because I think it is wrong to de-link them in any way. They are so inherently linked. But it is also not okay to not recognize the limits of what is there and what it can do.

CHAIR THOMASON: Good point. Great point. Carrie, and then we will get Tina, and then Marci at the end.

MEMBER NELSON: Yes, very much what was just said. I was getting uncomfortable de-linking them and I was also

getting uncomfortable going too far down the path of quality because that is just sort of distracting from what I think we are supposed to do here.

But ultimately, you know, a poor quality episode of care could be very affordable in that episode and ultimately, very costly.

So, I think letting people -- you know speaking to that in some way in this white paper is going to be important.

MEMBER FRONTERA: I am wondering, rather than quality, if it is cost benefit as one way to keep it in that affordability mind frame.

Cost benefit from an affordability perspective. So, do we keep Grandma in the ICU in her last ten days of care at $2 million or do we send the grandson to college? That is still within the frame of affordability.

MR. AMIN: Just quickly, I would just also add I think the conversation we had

earlier today was around also ensuring that it is appropriate. Because you could have a low-cost episode but it may not have been appropriate at all. But yes, so we can --

CHAIR THOMASON: And I will just add as a consumer, I just wanted to acknowledge that quality very much plays into my thoughts on affordability but then acknowledging that is enough for me and that I can move into the affordability pathway.

And I think we should but it was just the recognition in the paper and at-large that this factors into my decision.

MR. AMIN: And that is fair. So, I think let's keep that in mind. I mean I can't necessarily change the discussion guide at this point but let's keep that in mind as we move through the structure of the afternoon, in terms of the different phases. We will just sort of acknowledge the quality elements. And to the extent that they are unique, let's bring them up. That is fair.

But we can sort of, the thrust of the conversation could be around the more of the cost elements, as we get into each of the phases.

Marci, did you have another --

MEMBER NIELSEN: Yes. I don't know if you all have any rules about how many figures you can have in a paper but it may be helpful right at the front of this paper to have a whole different model than the bubbles that connects affordability and quality and some of these other aspects and say this paper is going to be primarily focused on affordability. We recognize that decisions are ultimately tied to, and we can fill in however many factors we want. But that might be a way to frame it up-front and have our cake and eat it too, which I am all about cake.

MR. AMIN: Okay, that sounds great. On that note, we can have a cake break or a dessert break. But do you want to come

back at 2:15 or 2:10?

MS. WILBON: Yes, we will do 2:15.

MR. AMIN: All right, we will come back at 2:15 and start with the discussion around the population at risk phase, although we have a better term for that now, the staying healthy phase.

And I will also ask maybe -- do you want to do quick hands? Is that how you do it?

MS. WILBON: Yes, show of hands.

MR. AMIN: We would like anyone who is available and would like to join us for dinner, today we are going to go to Siroc, it is right around the corner from here, at 6:00 p.m. If you wouldn't mind raising your hands, we will just take a quick note of who is joining us so that we can just make sure we have enough reservations.

(A show of hands.)

(Pause.)

MR. AMIN: Okay, thank you. Enjoy

your cake, cookies.

(Whereupon, the foregoing matter went off the record at 1:57 p.m. and went back on the record at 2:17 p.m.)

MS. WILBON: So, we'll reconvene. So the next session is really the next few sessions -- I will say is we have been talking really at a high level I think for the first half of today, generally about decisions, consumer patient attributes, the types of information needed. But really now we are going to go back to this model again that we kind of agreed would be a starting framework for us anyway to kind of think about the different points in time at which patients or individuals matriculate through in their different health status, points at different health status -- what is the word I am looking for? Stati. Okay, thank you. Statuses at a point in time.

So, you know, I had a discussion

during a break and I think some of the broader discussion seemed to kind of potentially have a little scope creep on that. But I think kind of bringing it back down now to these different phases in the episode will help us kind of refocus and think through really what we are looking for, which is to think through what are patients or consumers really thinking about in these different stages or phases, in terms of engaging with the healthcare system. What types of decisions are they looking to make? What types of information would they need to help them make that decisions? Is that information currently available? If it is not available or if it was available, what would be the easiest way for them to get to it?

And so we have several questions in your discussion guide listed out to help guide the discussion, I think on page eight. There is that big box at the top.

So really, again, this first

discussion and we will talk about an hour, roughly, about 45 minutes to an hour for each of these bubbles if you will, and kind of frame our discussion around the decisions, the availability of information, what type of information would be needed, the weighting of those different attributes on decision-making. And I guess I will leave it there. Is there anything you want to add, Taroon?

MR. AMIN: I just would point out that one of the things that we want to start with is a discussion around the high-level decisions that you would make in this phase.

And on page seven, we sort of provided some illustrative examples and they include sort of selecting a health plan, making a decision about selecting a health plan, selecting a primary care provider. And then preventing disease and then screening.

So you know, just to give a sense of what type of decisions one would make when they are at this first phase of staying

healthy. And then the logical next step would then be to ask the question around what information would you need and is it available.

So, I guess we can start with the decision and then the information.

MEMBER LATTS: Can I ask a quick clarifying question? So, these things in here, other than the selecting a health plan, are first dollar covered by the ACA for the majority. So you picked sort of the one area where there is no cost. So, there is no affordability issues with these.

So, I am just wondering if these are really the most appropriate.

MS. WILBON: I think that is fine. I think that if there are other decisions that you think should be added, I think that is fine. And maybe we could restructure these and kind of identify that these decisions aren't really the ones that most impact affordability. I think that is fine.

MR. AMIN: Yes, they are just intended to be a starting point. Feel free to disregard them or build on them.

MS. WILBON: Cynthia.

MEMBER ROLFE: I would venture that the first thing people are doing in this phase, most people is why. Why should I get care? Why should I see a doctor? Why should I get my screening? I'm fine.

PARTICIPANT: Because my mother told me to.

MEMBER ROLFE: Right, and yes, there is some parental pressure that comes into play and stuff like that. But for the most part, what we find is people are saying why.

If I am understanding the definition of what is no longer called population at risk, it is called the healthy, right? And so in the back of their mind, most people are thinking I should have health insurance. If I do, I should see the doctor.

But we all have shoulds in our lives. How often do we deliver on them every day? So, that is the reality for healthy people for whom healthcare is not yet a perceived need.

MEMBER WILBORN: Wow, I think that the word in there itself says risk. So, for me, I think everybody would be thinking risk and not why me. Why should I pay for this?

MEMBER ROLFE: Just to clarify, they really, that is one of the reasons I asked about the definition population at risk. Because if you were to say to a consumer if they read a paper like this if they were interested and they saw a population at risk, they would say that is not me. That's not me. I don't think of myself as a population. I think of myself as a person who has to take care of themselves and I may have different ways of taking care of myself and I would be maybe more willing to consider different ways but most people need to understand the what is in it for me, how does it connect to what I

care about and what I have a stake in in my life.

MEMBER NIELSEN: I would just like to point out he also was looking for a bride for health insurance.

(Laughter.)

MEMBER NIELSEN: And so there may be a correlation between -- I'm just saying, those could be correlated.

MEMBER SIEMON: I just want to quickly respond that I think that could break down differently in male/female. And I am not doing this based on my work but more my anecdotal experience. So, I confess, I have no data on this. But young women go to the doctor's and young men often don't. Because young women manage different things in their lives and often need to go to gynecologists and go for routine screenings and all of that.

I have girls. My sister has a boy. And all the girls go to the doctor and the boy does not.

CHAIR MORT: Okay, Carrie.

MEMBER NELSON: So, is this question we are answering? Are asking what they weigh in their decisions? This is when and what are the decisions that they are making during that phase.

So, some of it is preventive issues. You know you described them as the healthy but that could also be a person who has got very poorly controlled diabetes but no real consequences of that poorly controlled diabetes just yet and they are making some decisions about whether to go on a medication or something.

So, I am just trying to clarify what question we are trying to answer, the kind of things people or the types of decisions they are making.

MS. WILBON: So, this was kind of the first question. There is a whole set of questions that kind of follow this, including how they weigh. So, this was kind of the

preliminary question.

MEMBER NELSON: Okay, so it is more about what they are weighing in their decisions.

CHAIR MORT: But this one, specifically, is talking about the keep me healthy group.

MEMBER NELSON: Okay.

CHAIR MORT: The population at risk group.

MEMBER NELSON: Well but that is what I am trying to clarify. Is the population at risk also the person who has got diabetes who isn't proceeding with --

CHAIR MORT: That is not the -- the concept here is that this is a healthy population. They could use healthcare services to reduce their risk of further problems, but they are healthy.

MEMBER NELSON: So, the model doesn't hold up for me in that manner because there are people with well-controlled chronic

conditions or poorly controlled that don't have an episode of illness yet.

CHAIR THOMASON: I thought we talked about long-term chronic disease management. So, that would be at the end of the spectrum.

CHAIR MORT: And I think the concept was, we struggled over the picture. But this discussion is really about that population of people that don't have chronic disease and are healthy out there and that group. Right?

MEMBER NELSON: However, if that person with the diabetes is poorly controlled hasn't even entered into the -- they know they have it. They haven't actually entered into an episode of care yet because maybe somebody checked their blood sugar at home. You know what I mean? That happens. I mean you have like let's try my dad's blood sugar monitor and see what I got.

I don't know, it is just like a

gambit and maybe I am just being distracting.

MEMBER WILBORN: Being that the model since that population at risk is now healthy people, maybe we should just change the word to healthy population and not population at risk.

MEMBER EDIGER: So, the consumer interpretation of that bubble, if this helps, was staying healthy. That might help. And Liz, that speaks to your point that this bubble -- and I think I might be able to Carrie, I hope.

So, when you think of that bubble, if you think of it around what we call primary prevention, that is about staying healthy. So, perhaps people don't have enough information about the risk and that they should be getting these preventive screenings and they choose not to, or, as was brought up, that sometimes life gets in the way. You are busy taking care of another person or you just don't make time for it.

So, that early population bubble focuses on this primary type of prevention, colorectal screening, breast cancer screening, just to give some examples. However, as you spoke to Carrie, because it is not linear, it is really a circle, although it is very hard to show that on a screen, there may be secondary prevention. After you are diagnosed with heart disease you may come back into that. You are in a subpopulation of risk where you may be on certain medications. There are certainly behavioral things like diet, exercise, et cetera. But I think, Liz, as you are saying, in this case, if we could focus it on staying healthy, it is mainly around behaviors to get primary prevention.

CHAIR MORT: So does everybody know what we are trying to do with this section? Okay, then if we are talking about primary prevention, let's keep the conversation going. And I believe it was Ron, Joe, Tayler, Melissa and Maureen, I think.

Ron.

MEMBER WALTERS: So, that is the population that I am going to talk about, too. I think we know a lot about this group from the past two years or so. Probably more so than any other group, this is cost, cost, cost. And when I mean cost, cost, cost, I mean for the most part premium, premium, premium, and out-of-pocket expense, whether that be a deduction from your paycheck or direct purchase. I mean this group is exactly who is in the news so much the last year or two, the difficulty is getting them to -- apparently, they don't value the benefit that they are going to get. But getting this group to sign up has been one of the major difficulties.

Secondly, I think the one that we have heard about the most in this group and applies to a little bit a spillover into some of the populations we are talking about is, is the person that I have seen in the past or the

person that I want to see in network for even those screening and prevention type services. So, if they were seeing someone before, am I able to continue to see that person?

And then thirdly, mostly because this is a healthy group, I would say what other amenities are available? And it could be for that price, am I getting health club memberships, the healthy lifestyle kind of benefits that may not be necessarily written into the ACA but can be different add-ons that apply to me.

But I mean, this group is an easy group to understand.

CHAIR MORT: Taroon.

MR. AMIN: So, I just want to make sure I am clarifying a few things as we go through this.

So, the first level, it sounded like Ron the four that you noted, the premium, the out-of-pocket spending, the in and out of network and the amenities are all within the

umbrella of select -- the decision, the umbrella is the decision of selecting a health plan. Correct?

Okay, and then those are the components of what are elements within that decision or what drives those decisions. Okay.

CHAIR MORT: Okay, good. Oh, Joe.

MEMBER SINGER: To take it from that point, once they have selected a health plan, affordability becomes less of an issue with the direct acquisition of healthcare services because the preventative screening services are now fully covered with no deductible and no copays. So, it is really access and availability.

And the indirect cost, so to speak, of obtaining those services, if there are people that are hourly wage earners and then they have to take time off from work to get these services, if they have to travel, the cost of travel, the cost of childcare, the

other indirect costs will impact affordability of obtaining those healthcare services. But the actual acquisition of the services is not an issue.

CHAIR MORT: That is an excellent point. It certainly plays out in my patient population amongst the younger folks. I think it bounces back to what Cynthia was saying is we need to make the case for the services, so that they feel it is valuable enough to take time off, get the babysitter or whatever.

MR. AMIN: So, Liz, can I just ask another follow-up question then?

Then the decision there is whether to seek care or not. You know, but this is pre an actual event.

CHAIR MORT: So the consumer has a plan. They have enrolled. But whether they actually access the provider, the affordability issue entails time away from work, babysitters, et cetera, et cetera.

So, how much is it worth? We have

to make the case, presumably, or make the care more accessible.

Tayler.

MEMBER LOFQUIST: I mean I think we have touched on it but my main point was just going to be do I even need primary care. I think if you are feeling relatively healthy, kind of going about your day and maybe for me, I see specialists but do I need to go to that primary care if I am getting my main acute situations taken care of, or if I am just generally healthy, why do that appointment once a year. I have got to take sick time from work that I might need later on or that I just want to take as a vacation later on.

I think you kind of get to that point where you don't always see the value of that initial primary care.

CHAIR MORT: Terrific. Melissa?

CHAIR THOMASON: Thank you. I think that was one of the big decisions. It is still that appropriateness of care. Do I

even need care to begin with? And it is one of the conversations we were having earlier about this initial phase.

My husband is an at risk population. So, he is mid-30s with a really high-stress job, and could stand to lose 15 pounds. If you tell him I said that, I will lie.

(Laughter.)

CHAIR THOMASON: Just so we are clear. I know it is recorded. He will never find it.

Okay, so he really is an at risk population for heart disease but if you asked him, he would say he was healthy, completely healthy because he has never been diagnosed with anything.

So, in this bubble, he doesn't have a primary care physician because he doesn't think he needs one. He will jump -- at whatever time in his life his health becomes an issue, he will jump directly into

the treatment phase. He will never experience the first bubble. Something will happen. It will throw him into the second bubble for sure. And I think that is the reality that a lot of us live in.

Another thing, say my parents -- for me I almost always reach my insurance max. So, it is more of a playing of the system. But for my parents, especially, it is will this doctor let me make monthly payments? And they need to know that in advance. Do I have to pay up-front? And do they take my insurance? So that in and out of network thing also goes into their choice of primary care physician and not just of selecting a healthcare plan.

My mom needs treatment right now, ortho treatment, and her nearest in-network provider is miles and miles away. So, she is just saying well, I don't need it right now because it is not as convenient.

And then, too, I think the

preventive care we were talking about in this bubble is what screens do I really need? Do I really need to get those? And is it worth it in the long-run?

CHAIR MORT: Thanks, Melissa. Let's see, Kris, you are next.

MEMBER SOEGAARD: Ron was talking about cost, cost, cost, and I think premium. But it seems like here is also where they need to understand insurance and sort of -- so, I put that bucket into insurance literacy. So, they need to understand well, if I am focused on my premium, that is all I care about right now. But as they go into other parts of the bubble, they are going to care after the fact.

But let's get this up-front. What is my deductible? What does that mean? What are my copays? What is my coinsurance? What is my out-of-pocket maximum? So, it is the details associated with the various choices, so that they hopefully will make more informed choices for when they need healthcare down the

road.

CHAIR MORT: And that is great, Kris. So, it is really insurance coverage, the first decision. Go to the website. We know we have had trouble with the websites. Lisa was saying even as a doctor, it is hard to navigate the website. So that is the first step, isn't it?

Lisa. Oh, wait a minute. I think it was Maureen, then Lisa.

MEMBER EDIGER: So, I was going to say a lot of what has already been said but I think it is that there is really two different that you could ask this question for the once a year, when you are making that annual decision during the enrollment phase. And then the other 364 days a year when you are not sitting down looking at your choices for the year.

And maybe at that point in time of figuring out how to drive the affordability message into the communications about open

enrollment periods and making people think more about what are you really getting for this insurance premium and, I think, making it more transparent how much employers are paying into it. Maybe it is that value thing. If you are seeing how much it really costs to provide an insurance policy, maybe you will look more at what is in it for me and what options are there for prevention and sort of keeping you healthy.

CHAIR MORT: I think you are also making the important point about you need to make the case, so that people understand why it is worth it to go ahead and access the care.

Lisa.

MEMBER LATTS: So, in follow-up to a couple of the comments that have been made, especially, Liz, what you just said, I have been thinking about this paradigm, which, as we have talked about, I think doesn't fit into this affordability discussion as easily as

maybe some of the others. But I have been thinking about the selecting a health plan, the purchasing of insurance, that event. And I might suggest that that decision, that purchasing, selecting health plan, purchasing insurance, is, in itself, a bubble. You know, that whole continuum.

You know there is the population who is uninsured and who needs to purchase an insurance. The clinical episode is actually that decision to purchase insurance. So, that process is not a clinical event, but using that schema, translating it over, the purchasing of health insurance is an episode in and of itself.

CHAIR MORT: An important consideration. Maureen, do you still have yours up from last time?

MEMBER EDIGER: I'm sorry.

CHAIR MORT: Okay, Deb.

MEMBER DAHL: I was also thinking about the changes in the insurance plan with

the Affordable Care Act and I think there are a lot of folks out there that don't know that the screenings and those things are free at this point. Some people are still thinking there is going to be a copay and avoiding those.

And I am hoping that people are starting to think about the appropriateness of care, so the choosing wisely and those kinds of things will go into their decision-making, both from an affordability perspective, as well as the provider selection.

CHAIR MORT: Great point.

Melissa, do you have another comment on this one?

CHAIR THOMASON: Yes, ma'am.

CHAIR MORT: Okay, go right ahead.

CHAIR THOMASON: I do think it is really important to make the case so that people do understand why it is important to access the system.

My sister, for years, and years,

and years has not had medical insurance. And when I ask her why she doesn't have medical insurance she says because I don't need it because I am healthy. And then I say I thought I was until my heart ripped open. And you really think you are until. And it sort of throws you in. But I think that surrounds the culture of healthcare and that healthcare is about diagnosing disease and it is all about disease and not necessarily health. And I think that plays into people's viewpoint of accessing the system.

CHAIR MORT: I think you underscore the point that Lisa was making, which is getting into the insured population is a barrier for many and a challenge for us to help them make that leap.

Okay, so we have had a good discussion on the types of decisions that you have to make when you are in the left side of this chart. Now, amongst, when you make those decisions, the next set of questions, we are

still talking about the bubble on the left, is it possible to get the cost and quality information consumers need to make the decisions before being diagnosed with an illness? So, let's talk about that one.

Where do consumers get the information they need to support their decisions?

CHAIR THOMASON: Is this phase where -- I do have a question. So, is this the phase where when my husband is having chest pains but doesn't know where -- so no Google symptoms, no Googling symptoms? Because he hasn't went to get care.

CHAIR MORT: This is still the healthy person.

CHAIR THOMASON: This is just before any symptoms occur at all, right?

MEMBER KEEFE: I think also tough, too, I think some of us choose our health plans based on our providers and who are in those health plans, let alone cost. I mean

that goes to the network, which happens before you are in the plan and then the plan is, okay, treatment decisions sometimes with that provider or where that provider is.

So, I think there is both questions.

CHAIR MORT: Well, if we take this by each kind of question, if we think about the first question of getting insurance. Let's take that one first.

So, if you are talking about getting a health plan, picking a health plan, how do you get the cost and quality information that you need to make a wise choice of health plans? Tina.

MEMBER FRONTERA: I think there is general information and there is specific information. And I think we have mentioned various websites that might give an individual an idea that an x-ray would be $200 versus an MRI that could be $1,200. And so that is readily available. And there are some other

information sources that are public and community-wide.

But then when we get into really specifically what is it going to cost me today, almost all of that information is really out of date because those of us that do measurement, it is based on claims that I incurred two years' ago, or you are projecting something that may occur in the future. But it is not really what is it that is our negotiated rated for your particular network in your particular health plan, for your particular hysterectomy that you are going to have.

So, it seems that right now the most reliable source is still going back to either that health plan, but then you got to the health plan will still ask you to ask the provider what it is they are doing. You could go to the provider. And if the provider knows their negotiated rate with the health plan, the provider can tell you. But again, it is

still fragmented.

CHAIR MORT: Terrific. So, you are talking about once you have insurance and then you are deciding whether or not to have a hysterectomy, as an example. You really have to hunt and peck.

Okay, what about the question about getting insurance? Cynthia.

MEMBER ROLFE: We have done a lot of work around this. Obviously, there are so many people coming into insurance for the first time. That is the hope and that is the evidence that we are seeing.

So, one of the first things that they think about is what they can afford in premiums. That is the basic thing. It is part of their regular budgeting. Helping people figure out monthly budgeting is really valuable, especially young people. They are not really doing it yet. It took me a long time to do it, so I am not pointing fingers.

So, that is one of the first

things they think about is what can I afford on a monthly basis.

Then for them to actually think about what else might I need is really hard. Because in most cases, it is two large groups. One, I am healthy. I have not really incurred any medical costs. So, how do I know if that is a lot of deductible. I have never had to spend anything.

And then the other population are people who have been accessing public care. So, we have done a lot of weeks and weeks of ethnographies of people like going through them with their medical decisions and their purchase decisions and understanding all around buying health insurance.

And there was on particular consumer in Denver actually who had been accessing, I think it was Denver Health, one of the big public hospitals out there. Evidently it does a very nice job. And their perception, they had such good care and such

good follow-up care from that public entity, that their expectation is once they got insurance that it was going to be great. They would never have to make an appointment. They wouldn't have to wait in the waiting room. All their information would be on that card. They would never have to fill out another form.

So, you are really dealing with very different perspectives of what do I think I am going to get. But beyond the premium, if someone doesn't have a good sense of what the cost of healthcare has been, they can't make a decision. We can tell them all we want about how much is your maximum you will pay that year, and how much will you pay for every doctor visit but there is no context to know what they might really incur yet, until they are insured and we know more about them and then that is where we might be more helpful.

CHAIR MORT: Excellent. Lisa?

MEMBER LATTS: So, I can

complement that with the information on the quality side. So, from a quality side, historically, NCQA was the big player in this area. And they have done a good job over the years measuring health plans' quality, mostly on the HMO side with increasing spillover the PPSI.

In recent years, one of the nice things they have done is take the 40 measures that they use to evaluate health plans and roll them up into five different domains that were relatively easy for consumers to understand that are a mixture of the HEDIS measures, so the clinical quality measures, the CAHPS measures, so the experience measures, and the standards. So, it is a necessary roll-up.

So, that information is available. It is public. It is on their website for those plans that are NCQA accredited or are submitting data, which is a good chunk of plans nationwide.

Now, on the exchanges, there is an exchange accreditation. Exchange accreditation can be done by NCQA and URAC today. There are other folks that are getting in the game and will be likely approved as accreditors down the road. For the federal exchanges, there is no quality information available. Some of the private exchanges, especially California, we have done some stuff in Colorado, some of the coastal of stuff have done some stuff. There is information available but it -- well, first of all, it is not on the actual exchange population because there is no population. But it is the best that can be done early on.

The ACA will not develop quality standards until 2016, which, again, makes sense because you won't have a population to measure until this year data into next year, and then start measuring it in 2016.

So, on the exchanges from a quality perspective, almost 100 percent the

decision is going to be based on cost. There is very little information from a quality perspective, other than my mom has BlueCross/BlueShield and she has a really good experience with it, so that is who I am going to choose.

CHAIR MORT: Taroon.

MR. AMIN: So, I just have some clarifying questions here. So, I think one of the big decisions at this phase appears to be selecting a health plan. That was what Ron pointed out some of the components of that, which is the premium, the out-of-pocket spending, who is in-network and who is out, some of the other "amenities."

So, the question I have is that it seems that the majority of this information is currently available from the health plan or from your employer. I mean it certainly should be. Whether you are looking at it is another story.

So, why do we -- I guess given

that that is available, why isn't that sufficient? And I would then sort of add a second part to that question to say is that enough information or is it, to Cynthia's point, is it more that consumers are actually looking for what their experience is going to be, given all these other constraints, which is their overall spending caps or their deductibles or their copays. So, actually describing in some level of detail that, if you have this condition, you should expect to actually have this out-of-pocket expense, given all these criteria for what the health plan entails, which is out-of-pocket expenses, copays, maximums and whatnot. Maybe that information is actually not getting translated into what consumers need.

So, it is a two part question, which is essentially, if this information is already available, why isn't -- is it sufficient? And if it is not sufficient, why is it not sufficient?

CHAIR MORT: Well, what I heard was that the information is available. Consumers don't necessarily understand that. And through their employer, they might have two choices. So, they make expedient decisions based on what they can -- their paycheck deductions are.

But it sounds like there could be more robust conversations to help the consumer tailor their choices based on their healthcare risks.

And then the quality issue that Lisa is bringing up is that in some places you have got good quality to compare your health plans but in other places, you are simply relying on the coverage issue.

So, it sounds like it is an emerging market, if you will, or emerging field clearly now with universal mandate that there will be a lot of vehicles emerging that we can hopefully make better over time.

But does that help? Anybody else

want to common on that? Joe? Dorothy?

MEMBER SINGER: But people are not exclusively, based upon the experience that we have seen since enrollment started with ACA and the exchanges, people are not always choosing the least expensive plan.

You know everybody is not going to bronze. And even those who are doing the metals, bronze, silver, gold, and platinum, even within any one class, they are not going to the cheapest within each of those four buckets. So, we are seeing people going to gold plans and silver plans, not a lot of platinum. So the middle groups are willing to spend more than the minimally necessary but even within that group, the majority of people are not going for the cheapest block.

CHAIR MORT: Do you know anything about why those decisions are? I am thinking it might be the flip side of the Neiman Marcus. You know you don't want the cheapest because you think it might --

MEMBER SINGER: Right. I mean I know from the Anthem WellPoint perspective we are never the cheapest. Sometimes we are middle to where -- we are rarely the least expensive.

But people are picking that they like the brand. They ask their peers. They don't know maybe of the competitors. So, there are other issues, maybe better marketing but there are a lot of other factors that I am not an expert on. I can't tell you the difference but people are, you know, when they make the decision to purchase, clearly, there has to be other decisions, other than just the bottom line cost.

CHAIR MORT: Okay, Melissa has a comment related to that. Then, we will go to Dorothy.

CHAIR THOMASON: I think for me, when I look at healthcare plans, I may not pick the cheapest one per month but I am picking the cheapest for me in my assessment

of what will cost me less I the long-run.

So, it this one may be cheaper per month but in the long-run, the 80/20 split or the out-of-pocket max is higher, so it is worth it for me to pay a little more every month because on the back end of it, I am still saving money.

MEMBER SINGER: You are a very sophisticated consumer.

CHAIR MORT: Yes, I think we have all learned that today, Melissa.

MEMBER SINGER: When most people first timers or people who have been assigned through their employer to an insurance product, most people, and this is from my experience as a primary care physician, too, when people ask me what insurance to pick, they don't know how to anticipate deductibles, copays, utilization. That is really, really hard to do.

So that when people are first neophytes into getting insurance, it could be

aging in from college students, getting out of the college program, or it could be people newly coming into the exchange, they can see out-of-pocket maximum but I doubt that many of them really understand what that means.

And to look at copays and deductibles and when they see a column of 20 numbers, primary care office visits, specialist office visit, urgent care, emergency room, hospitalization, PT, DME. DME is not included in out-of-pocket maximum, all that kind of stuff. It is very, very hard for people to anticipate potential costs, if they are not experienced looking forward.

CHAIR MORT: Great points. Dorothy?

MEMBER SIEMON: I was just going to say I just think it is still too complicated. Just in my employee group, we still have people who are highly sophisticated in lots of areas of their lives but understanding and predicting their own risk is

still very difficult for them.

Just making the decision of whether they can go with the PPO or the HMO because they might have more in-network versus out-of-network costs, is a complicated decision for a lot of people. So, the information is still too complicated and the presentation of it is still too complex.

MEMBER KEEFE: Even if you had the information, I think sometimes making the decision is difficult.

I mean I just wanted to chime in because I think I am this population. I go to the doctor. My husband doesn't. We have a 15-year-old daughter and I had to make the choice. I am insured. We have a Cadillac plan in our employ and we went to the -- I have the choice of going to a high deductible.

Making the calculated risk about moving from my PPO with full benefits to that high deductible health plan, first I was like oh, my gosh, if me and all the colleagues that

are like me jump, then that other full Cadillac plan is not going to be available next year. So, I was worried about skewing the risk pool within my own little employment opportunity.

But not knowing -- when you said is the information sufficient, you know I mean I didn't know. I said well how am I going to know if I am even going to meet that deductible or if that HSA is going to cover that deductible? I didn't have enough information, as sophisticated as I am looking at all the health bills for my family, trying to figure that out going into this new plan.

And so, I took a chance. And I feel like that is what we are doing right now is experimenting and taking a chance. So, I have been in it now two years and have had a very different experience than in a previous plan and have a different, probably perception of affordability. But I am still nervous because you don't know. I mean I am healthy

and I have always been in a much more, very rich benefit plan but those are no longer going to be our options.

And so, what is the information I am going to need five years from now to make that calculated risk? And I don't know that I have the answer to that but I do know that I want to know that but you can't predict your health. I don't know if I am going to have a debilitating disease a year from now or not. It is so challenging. And so for us to get our arms around how you make those decisions, I think is incredibly challenging.

CHAIR MORT: Clearly. Corey, did you --

MEMBER WILBORN: I just wanted to add on to that. When you do make that calculated risk, what happens if the worst happens and you do have those bills that you have to see? Will that affect your future choosing of a plan? And would it be, at that point, because you had that experience that

you would choose a plan that was more benefit-rich?

CHAIR MORT: Great thoughts. Great questions.

Cynthia and then maybe we should take on the next question like prevention, preventive care.

MEMBER ROLFE: I just wanted to briefly respond. Taroon was asking is it possible to help people understand someone who has these kinds of conditions, might experience these kind of costs.

And as I talked about us as an industry getting more comfortable with reviews as a non-system, system, getting more comfortable with reviews, we also have to get more comfortable with lack of specificity and precision. So, the concept of a good-faith estimate. If you are a 50-year-old diabetic who has the following kinds of treatment, just a range of like five profiles of different consumers who might have bought this health

plan and what kind of out-of-pocket costs they experience. And that is a really hard for an industry that is built on precision.

So, we all have to wrap our heads around and then the consumer would have to understand that it is just an idea. It is just a picture. And that is probably the best we could do.

CHAIR MORT: That is a lot more than we have now. Those are great aspirations. Just, hopefully, they are not too far down the line.

So, why don't we -- Kris, did you have a comment on the health plan decision-making?

MEMBER SOEGAARD: Yes, it is just a follow-up on what Cindy was saying.

CHAIR MORT: Okay.

MEMBER SOEGAARD: There are employers that are doing that in their open enrollment material, where they are taking a single young male and they are giving a

scenario about he goes to the doctor once a year, whatever. So, there are employers that are doing that to try to help guide people to make the right kinds of decisions, based on somebody like them.

CHAIR MORT: Thank you. In the interest of time, maybe we should consider -- I think we have touched on many of the points on this slide. Why don't we think about that next decision that we talked about? So, once you are in an insurance plan, then you are in the yellow or the green population, the keeping healthy. And we talked about making decisions to go to the doctor or not to go to the doctor for screening, annual exams.

So, what kind of information will we need in terms of cost and quality to make those decisions? And is it available?

MR. AMIN: Yes, the way I heard it was how do you make the case? I guess that was sort of how it was framed. I think that was a good framing.

CHAIR MORT: Yes, so how do you convince someone? Now they have the benefit for an annual preventive exam and how do you make the case? Well, it is the cost-benefit, the lost opportunity. And a lot of plans now, they start pinging you. Some of them work with employers to tag onto the paycheck. So people look at their paycheck and there is "You are due for your." So, making the case, urging people to do it, making it easier.

Maybe we covered kind of enough on that already in our prelude.

MR. AMIN: Yes, and I think what I am hearing as well is that, given the changes in the ACA around making the cost benefit their first dollar coverage, it may direct affect the affordability question.

If there is more there, I am happy to hear it. We can just make sure we capture it.

CHAIR MORT: Melissa?

CHAIR THOMASON: When seeking

preventive care, I guess really the big thing is it is frameworking risk and how do I perceive myself to be at risk. And I am not sure we really graded that. I think that a lot of things like -- so even back when I am purchasing the health care plan, when I need to decide if I need to go have these tests done, it is am I really at risk. So, is it worth it to go have this done?

I wish we had more time to explore the factors that go into that but my age, my genetics, what is their history of in my family? Things like that really help me decide am I really at risk or not because I am constantly making that decision, as a consumer.

CHAIR MORT: Good point. Making the case but based on your individual risk factors.

Oh, boy. Three popped up. Who was first? Kris, go ahead.

MEMBER SOEGAARD: And maybe some

of the health plans could speak to this. I think people are starting to use incentives in certain ways within health plan coverage, either by the employer, by the health plan, whatever, to try to get people to do these preventive care services. So, that is another component.

CHAIR MORT: Good point. One of the pieces of information would be is there a deal here for me.

I think Carrie and then Lisa.

MEMBER NELSON: I think this is a really problematic area because health care providers have a lot of bias they bring to these conversations. So you know, when should a woman start getting a mammogram? Should you do a comprehensive blood test on every person, as a matter of routine? And there is costs associated with overutilization. And so I think that is the part that we probably fall down on the most is the costs associated with too much healthcare, too much screening,

perhaps. I think people are much more swayed, sometimes, by fear. The classic Pink Ribbon Campaign has really got people thinking that they should get mammograms earlier and more often, when in fact that has its own costs associated with it.

CHAIR MORT: Is another way of saying that is that you need more information on appropriateness?

MEMBER NELSON: I think that is absolutely right, yes.

CHAIR MORT: And you know, mammograms, 40 to 50, maybe there is some wiggle room; 50 and above, the data are pretty fair. But even with the data, you would want to have the patient or the consumer weigh in and understand what their risk tolerance is.

MEMBER NELSON: Right, in an objective way.

CHAIR MORT: Yes, excellent. Lisa.

MEMBER LATTS: So, I was going to

sort of move off of the sort of preventative topic to the first question from a chronic disease perspective. Is this the appropriate time to do that or do you want to not talk --

CHAIR MORT: Maybe not chronic disease but disease, as opposed to preventive.

MEMBER LATTS: Do you want me to hold that?

MS. WILBON: Yes, if you guys are ready to kind of move on to the next bubble, if you will, I think that might be the appropriate transition, if people feel that we have kind of gotten most of the issues on the table.

CHAIR MORT: I think we have had a really good discussion on the preventive and the fact that we added in the insurance plan. We got a lot of information there.

MR. AMIN: I would just ask as we move into this next phase, just keep in mind if we can frame it in the sense of what the decision is and if there is some overarching

context like emergent versus non-emergent and then what the decision is. That will help us understand how to take this -- what information we are looking for.

So, if that could be your starter, what decision you are making.

CHAIR MORT: Melissa is going to facilitate.

CHAIR THOMASON: Sure. Do you want to clarify emergent versus non-emergent?

MEMBER LATTS: Yes, that is one of the things I was going to bring up, yes.

CHAIR THOMASON: Okay, Lisa, if you want to go ahead.

MEMBER LATTS: Yes, so that is back to this first question, then. In terms of I think the question may be slightly incorrectly phrased, in terms of being diagnosed with an illness. And that may be different than experiencing an illness or a symptom.

So, I think that the information-

seeking has to happen when someone has a problem for which they are going to seek care. And that is differentiated by emergent, where there is very little time versus someone who has the luxury to do research. And then it is a matter of what sort of information is available and where do they find it.

And realistically, everyone's first source of information is Google. You come down with a symptom. You open Google or Bing or Yahoo and you do your search. And so that is where people are going to start, for the most part. Or you ask your parent if you are a teen.

MEMBER NIELSEN: Although rare, academia occasionally has something to offer us.

(Laughter.)

MEMBER NIELSEN: And as we are having this conversation, I had a flashback to entirely too many classes in social and behavioral science, which is what my Ph.D. is

in. And so, there are actually models that frame this entire discussion. And my personal favorite is the Health Belief Model. And so, I promise I am not going to walk you through the whole thing but there are words for this that we would need to convert into English for it to mean something to consumers. But when Melissa talks, I hear these concepts.

First, it is perceived susceptibility. So, your opinion of whether or not you are going to get the condition. Next, is perceived severity. Your opinion of how serious this condition is and what its consequences are.

Next, is perceived benefits, your belief in the efficacy of whatever the advised action is of your provider or your health plan to reduce risk or the seriousness of the impact. There is just three more.

Perceived barriers, which is huge. Barriers is a big piece of this. One's opinion of the tangible and psychological

costs of the action. Hues to action. So strategies for you to actually engage in whatever it is, the behavior. And that is when you need to give how-to information, promote awareness, et cetera. And then finally, is self-efficacy, your confidence in your ability to actually do something about it.

So again, I see all these things being related to affordability but I feel like we keep broadening the scope. And there are places that we can go that link back to this without us having to write up too much new stuff because this Health Belief Model is old, old, and old. I mean I was in school a super long time ago.

CHAIR THOMASON: I think that is a really great point. They said that so well. I was like, wow, they really got that! Yes, they did.

But my perception of all of these things and what is my risk and how can it help

me and all of those things. It is a very good point. Paul?

MEMBER SIERZENSKI: In the world of emergency medicine, we are kind of trying to, although we don't want to broaden too much here, we are trying to broaden away from just the concept of emergency. Because I think when we talk about emergency, everyone is thinking emergency department. But we are starting to use more frequently the issue of scheduled care versus unscheduled care, and acute unscheduled care, recognizing that the cost of acute unscheduled care in nearly all of its environments is greater than the cost, likely, of scheduled care.

And so although I like the term emergent because it is what I do, I think it kind of, it really does pigeonhole things a little too much.

CHAIR THOMASON: So then, Paul, where do you classify if I don't have a primary care physician but I just go to the

clinic, not necessarily scheduling an appointment, but I am going for strep throat? It is not scheduled but I don't consider it emergent care.

MEMBER SIERZENSKI: We would define that as acute unscheduled. And what you are using is you are using a facility that is designed for acute unscheduled care and there would probably be another 50 patients like you, who have those same symptoms who are actually using the emergency department. And so it allows an understanding of acute unscheduled care and utilization with acute unscheduled care. And I think the issue is, is does a patient or a consumer who is having a symptom-driven complaint, do they feel that they need to activate healthcare system now or can they wait? And that we are looking at that as a way of how are they triggering acute unscheduled care versus scheduled care?

CHAIR THOMASON: I think the reason that I couldn't, me, personally, that

I couldn't use the word emergent was because scheduled or not, if I have the choice of whether or not to have this, then I will look more at affordability than my life is at stake or something just happened to me and I have to have it treated.

So, when I say emergent, I mean my choice of appropriateness is taken away. I have to have something done. And that focuses -- my perception of affordability, I mean it really drastically changes there. When my life is at stake, I don't think a lot about money.

Ron?

MEMBER WALTERS: Yes, and I agree. I don't remember where I read the Health Belief Model but somewhere way back in the past century. But I think this literally -- the thing and we are kind of getting to it, what does come immediately into play here is, is this arthritis, or is this a heart attack, or is it a dissecting aneurysm, or is it

cancer. Which, I can tell you I mean cancer is a very scary word. It carries all the implication of a dissecting aneurysm, though many times it is not. It is just emotional aspects to it.

But I think it is the perception of I would say acuity or immediate threat to life that tempers the affordability aspect of it. And that happens pretty quickly.

So, if I tell you you have got arthritis, well, my back hurts. It is arthritis but it isn't going to kill me. And all of a sudden, my mind shifts into affordability mode of all right, what do I have to do? How do I have to feel better? Can I put it off, all those other things. But there are other conditions that you don't even go into that. Or you may go into that mode but you go into it for like a second or two. And then you quickly shift out of affordability mode right away.

And I think that is where this

comes into play is the perceived impact of the problem and the perceived ability of intervention to impact the outcome.

So, I don't know. I would say in this group there are, again, somewhere affordability comes right into play and other ones where affordability is not even a consideration.

CHAIR THOMASON: So then, I wonder how much time we actually need to spend talking about emergent care. Because if our charge is really on affordability, I never consider affordability in emergent care. It is always who is the closest.

I will say that quality factors in, though. Because I have told my family the hospital that is closest to my house, if I pass out in the parking lot, you better fly me somewhere else. And we laugh when we say that but I don't trust them with my disease. And so, quality did factor in but never affordability really into emergent care.

So, do we want to focus on --

MR. AMIN: No, I think it would probably make sense to move on. I think the first decision is probably -- well, maybe not decision, but the first question is, whether it is emergent or not. If it is emergent, the issues of affordability are retrospective, at best. Right?

So, let's move on to --

MEMBER WALTERS: Not emergent. I mean, I agree.

MR. AMIN: Okay, so what is the proper term, then? The perceived.

MEMBER WALTERS: Perceived. It is the words that we are using in the model. It is the perceived immediateness of the problem.

MR. AMIN: Okay, got it. All right.

CHAIR THOMASON: I would like to know if my fellow consumers, though, or my frequent fliers -- I know we are all consumers -- agree with that assessment of emergent care

and how that really, you don't take affordability into account so much.

MEMBER THOMPSON: We actually talked about this the other night with an example that Melissa had given us about her brother seeking emergent care and trying to figure out whether to go or not.

And one of the questions that came up was how would you even begin to think about emergency rooms as affordable. Like, how could you do that when I don't know what is going to happen when I go in there? But what I would want to know is how much does it cost for me to walk through the door? Like if nothing is wrong with me at all and you don't do an MRI, you don't do a CT scan, just for me to walk in the door and for the doctor, whoever, to say, there is nothing wrong with you, walk out. Like, how much does that base cost?

Because my partner, he screws up his body all the time. He is a construction

worker. He breaks things. It is constantly. And every time we go to the emergency room, it is always a debate. Do we go? Do we not go? How much is this going to cost? Can we wait until tomorrow?

And I think I could make that decision if I knew some sense. And I know it is really hard because what if he goes in and he has cancer? You know, I mean that is obviously going to be a lot more. But if it is just this basic thing, what does that cost me? Because I think that helps me make the decision between do I go now or do I wait 12 hours when something is open the next day when I can make an appointment?

CHAIR THOMASON: I think you bring up a real good point in that we can't -- it was easy for me to say well, there is no appropriateness of care issue because I had the CT. I had a dissection. I have to have the surgery.

But when you are trying to decide

should I go to the emergency room, it is a really big decision and that appropriateness of care really weighs into your decision.

Thank you, Adam, for bring us back to that.

Paul, and then Maureen and Joe.

MEMBER SIERZENSKI: Yes, just not to get too into the weeds. I think that making the recognition that emergent care, which is basically prudent layperson care, because we have got rolls that cover this, you think you are having something that is potentially a life-threatening issue. You should go. You should be covered. And issues such as other federal regulations, such as EMTALA, for the emergency provider really do restrict our ability to basically post on the door this is what it costs for you to walk in.

And so, it may be helpful, just from a paper standpoint, to say one of the things that is difficult to address with emergent care is the fact that, one, there is

clearly a patient consumer perception, which is their belief that they are having an emergent, life-threatening issue, because the vast majority of chest pain that we see is not cardiac.

And then after they get evaluated and discharged and they get a zinger bill, which, trust me, is not my fee. It is hospital-based fees. They feel their value and their affordability is less because everything was, essentially, checked out and appropriate or negative from the work-up standpoint. But it is very difficult for us to have that discussion because until we have the evaluation, we really are restricted by federal law to talk about dollars in the world of emergency medicine.

What we have to do is do a medical screening exam first and then there are only some states that allow you. So, just raising that issue for the writer, may be a way to try to address that to say we have got some work

to do.

Congress has twice tried to address issues of EMTALA. Both of those large panels came up with no conclusion on how to modulate the wording.

CHAIR THOMASON: Very helpful. Liz, do you want to comment on that?

CHAIR MORT: Just specifically -- excuse me, Maureen -- is that many health plans now are publishing on your little card what your copay is for the emergency room. Because of utilization management and so on, they are really upping it. It is $150 now instead of a $20. So that piece, the copay part is visible, more and more so.

MEMBER EDIGER: So, I think my son's condition, having hydrocephalus and being shunted for hydrocephalus, and I think about how Maureen, the mom, reacts now to a seven and a half year old versus how Maureen, the mom, at six months old and it is so much of it is about education and knowing what is

a shunt failure symptom, what I can let go for 12 hours and maybe in more of a wait and see mode. Because if I go to my primary care physician, the pediatrician and say, I don't know. Everett has been throwing up. His eyes look like they might be crossing a little bit. What should I do? They are going to send me to the emergency room every time because my pediatrician never wants to be responsible for not telling me to go.

So, I don't even call my pediatrician anymore when I am concerned about those things, other than to say hey, just so you know, we are on our way to Children's.

But honestly, the factors that I consider if I am worried about Everett and I have become quite the diagnostician about shunt failures and urinary tract infections and everything. But with him, I think about, okay, if I go now, where are the other three kids? How much time are we going to be in the hospital? Okay, this time of day it is going

to take me 45 minutes to get there. If I am stuck in the ER, this is a busy time of day. There are so many factors that go into me deciding do I go in and get the CAT scan. Because that is the first thing they are going to do, if I go in through the emergency room.

So, just it is really complicated when I decide what to do. And I do factor in like how expensive CAT scans are because nothing makes me feel worse than -- well, it makes me feel very bad to go in and know that I have got a very expensive procedure to find out, oh, no, it is just a stomach bug, 12 hours later.

CHAIR MORT: I just want to ask the group, you know we are talking a lot about the emergency room. But what about if you have a symptom that you have a sense that it is not serious enough to need the emergency room but you need to be checked out? So, I am just trying to think about something. You know a little bit of acid reflux or -- Maureen

is right there.

MEMBER EDIGER: Well, the other part of what I was going to say is having a relationship where I know this is where choosing the doctor's offices that I have so carefully. Because I know there are offices I can call and get a nurse to return my call within 30 minutes or I have the nurse has given me her cell phone number and I can just text her say, Carol, I am worried about blah, blah, blah, and they get back to me. And that can avoid a whole trip to the emergency room.

So, I think with patients who are frequent fliers and being able to have some of those relationships has kept me out of the emergency room so many times. Or like not emergency room but also like clinic visits or we need to be seen right away.

CHAIR THOMASON: Me, too. And affordability factors into my decision some when it comes to clinic visits but a lot when it comes to the emergency room. When I am

going to the emergency room, it is a whole debate in the car for 30 minutes on the way there. It really, really, appropriateness of care factors in so much into emergent decisions for me.

Marci, and then I think we probably need to move into non-emergent care and how we make those decisions.

MEMBER NIELSEN: Well, and this gets back to a conversation we started this morning about the difference between frequent fliers and all you have learned about the health system and your own condition or the condition of your child versus consumers who are generally healthy and don't interact with the health system much and that the factors that go into that decision-making process differ quite a bit. And that is where this Health Belief Model is helpful because it is about self-efficacy.

So, you have attained a level of self-efficacy about your health or your

child's health that empowers you a bit more. It doesn't mean you don't factor into affordability. And depending on your socioeconomic status or your health insurance status, that, too, plays in.

I just keep coming back to how you write this paper. And maybe I just need to let that go. And we just need to have the conversation and the brainstorming. But how you frame this in a way so that the person reading this says yes, this makes sense to me and I recognize that it is a scale. If I am really knowledgeable about the health system, I do things differently than if I am not. If I am loaded versus I am poor, I do things differently. If I have health insurance or I don't, I do things differently. Like, all of these things fall along a spectrum.

And again, I just keep thinking, how do you frame the paper, initially, so that the rest of this dialogue fits in neatly? And I don't necessarily have the answer. I would

just tell you one small anecdote from somebody who is healthy but very self-actualized when it comes to healthcare which is, I fell off my bike last year and I figured that something went wrong when I couldn't switch gears on my bike, as I was riding back up the hill. But my priorities were to get my nails done. And I went from many, many hours with a broken arm getting my nails done, which are Jayhawk colors for you KU fans out there.

So, the guy doing my nails was freaking out. You think your arm is broken? Yup, I am almost positive. I can't stand to touch your hands. I want my nails done! I am going to D.C. tomorrow. I am not going to futz around with this.

(Laughter.)

MEMBER NIELSEN: So, like how do you factor that in? Right? So, these are people's individual lives. And we could all think of our example.

So, there you have it.

CHAIR THOMASON: That was very helpful! Thank you, Marci.

MEMBER NIELSEN: I will say they all went together. They were all color-coordinated.

CHAIR THOMASON: I will say that I have never gotten my nails done with a broken arm, though. That is a unique perspective.

I will add to, before we move on, that when you were talking about differences in a patient versus a consumer, and frequent fliers, and all that stuff, I will add that I hope very soon we do a better job in healthcare of providing more information for general consumers on appropriateness because even if we don't provide expert information, these consumers that are inexperienced will find their own experts.

So like we were saying earlier, it might be your best friend, and in my family it is me, it doesn't matter if I am an expert or not, I am going to have to be one for my

brother or for my mother, and they are going to call their frequent fliers and say I really got to make a call. Do I go to the emergency room or not?

So whether we provide the information or not, whether they are real experts or not, they are using them, our key learners, for sure.

MEMBER NIELSEN: Well, and I will end by just saying you know I work for the PCPCC. And what we believe to be true and what the evidence supports is when you have a trusted health care provider, often your physician, but sometimes your nurse practitioner, that relationship, because they know you, they know your perceived benefits or excuse me, your perceived self-efficacy, they know what your barriers are, they know if you have insurance, that healing relationship is what is supposed to help us.

The struggle I think we have, and I don't know if we want to say this in the

paper is, we train doctors to not focus on affordability. They are about healing you. And so we are putting clinicians in this brand new set of social pressures and circumstances for which many have not been trained. And they are very uncomfortable with it and a lot of patients don't like it. They actually don't want to talk about the cost of care with their provider because it is supposed to be more pristine.

CHAIR THOMASON: Yes, go ahead, Lisa.

MEMBER LATTS: So, that is actually a great point, Marci. And I don't know if it is outside the scope of this discussion but traditionally, in medicine it was always your obligation is to the patient 100 percent. Do the best for that patient. Damn the cost, full speed ahead kind of thing. And it is only in the past, this decade, the past five years really, that the concept of stewardship of resources from a professional's

point of view, and somebody mentioned choosing wisely, and just the whole idea overall of health medicine and the healthcare system is actually a scarce resource. And as a physician, we have obligations to steward that wisely and to start thinking about how do we ration. And nobody ever wants to use the R word. But how do we ration these scarce resources in a way that is most appropriate. And that is a very new concept in medicine.

CHAIR THOMASON: The conversation has definitely changed just even since I have been sick. Absolutely, the conversation in my providers' offices has changed.

Taroon -- yes, go ahead.

MS. WILBON: I just actually wanted to piggyback on Marci's comment before we got too far away from that in terms of kind of putting --

MEMBER NIELSEN: Are you a Jayhawk?

MS. WILBON: No, sorry. I went to

Michigan. Go Blue! And I am wearing blue today.

(Laughter.)

MS. WILBON: My nails aren't blue.

But we have been talking, the staff, kind of in-between breaks and stuff about how to capture this information in a way that could be visually appealing and kind of walk people through the conversation that we have been having. And I think where we landed at is really the person is the measure and that there is no measure, per say, for affordability. But I think what we are hearing is that no matter how the individual weighs those different factors, that the decision point is still kind of the same. So, whether or not to go to the ER, weighing risk, and so there may be a few others. If that conversation, it would be nice to kind of hear some more discussion about what maybe some of those other decision points are, kind of recognizing that depending how experienced of

a consumer you are, what your health status is, what other resources you may have, that the decision still may be the same but that the factors that you are considering to make that decision are going to vary. So, I don't know if that helps the discussion at all. But what we are trying to kind of narrowing down is that the decision point is still the same for all those different people, depending on -- regardless of where you are coming from.

CHAIR MORT: If I could just add to that. What I am hearing consistently about whether it is a decision to go the ED, emergency room, or to an office visit, one of the key factors is do I need to go. And that had never occurred to me. I mean I understand what it means you need to go but I thought there would be other factors. And it is very enlightening to me to understand that if someone is going to have to pay copay, or take time off from work, or put their kids in the car and take them to the emergency room, all

of that disruption is big. So, you really want to know do I need to go. And where on earth are consumers going to get that information? If you have a good practice that you can have a text to the nurse or a good call line, but that is just really kind of it is an epiphany to me how important do I need to go is.

CHAIR THOMASON: I will add, too, from a consumer standpoint, almost everything in my life that I have purchased -- because I don't work right now. Everything I do for the hospital is volunteer. I was a teacher before and you know how they pay teachers. So everything in my life was based on do I need this and healthcare was the exact same way. And once I know I need it, oh, okay, now I can make an informed decision based on quality and price.

So, Lisa and then Joe. Joe?

MEMBER SINGER: I mean that is a huge decision for people, do they seek care or

not. There are mechanisms for people to help them with those decisions now that tend not to be utilized. I mean most health plans have a 24-hour nurse call line, where they can call a nurse and discuss with them. And the decision, the tendency is to move people up along the level of care and not to underestimate what is happening. And those nurses can issue preauthorizations and do everything they need to make sure things get done well. And I can tell you it is used single digit percentage of the time, when it is possible.

Some health plans have live health online, where people can go online and do a video conference, actually see the physician. The physician can write prescriptions if they meet certain criteria. And it is an office copay. So, it is access. They don't even need to leave their house to see a physician. And if they get referred to an emergency room or an urgent care center, there is no charge

for that encounter.

So, part of this is anticipatory intervention and educating people that it is a $20 copay for an office visit, a $30 copay for an urgent care center or retail in one of these nurse or pharmacy-based retail health clinics. And it is $150 if we go to the emergency room. So, if people really understand what their alternatives are, again, it is their perception of how urgent and life-threatening the situation is.

Access and availability now is becoming less of an issue. And it is an education of people to understand how they can best utilize resources.

CHAIR THOMASON: And I think, too, letting those people know what resources they have at their disposal to decide if care is appropriate.

On Sunday night, my brother was like should I go? Should I go? And I said do you have a nurse care line? I don't know. Do

I? I said pull out your card. I have one! And I said call them. And they said go. It sounds like a gall bladder. You want to make sure it is not an attack.

Deb and then I don't want us to run out of time before we really clarify and address some of the particulars of the selection of a physician, selection of a hospital, things like that and what really goes into our decision to choose that doctor or this hospital.

MEMBER DAHL: I just want to say that we have been talking about people making decisions as though this was an intellectual choice only and Marci's comment about the broken arm and I will get to that after I get my nails done.

Last time I was in D.C., I fell down the steps in the Washington Monument, which was our first monument. And so I just went through the whole next three days going, it is just sprained. It is just sprained. It

is just sprained. And then I am back at the hospital that I was working at and the orthopedic surgeon said, why are you limping? And I said it is just sprained. And he looked at it and said, no, it is really not.

And then the next week, I am at home and my husband broke his little toe. Oh, my God! I have to go to the ER right now, I have broken my toe.

(Laughter.)

MEMBER DAHL: I said, oh, my God, no, you don't. So, what does he do? He picks up the phone and calls his brother, who is an OB/GYN, like that is going to make any difference.

(Laughter.)

MEMBER DAHL: He just laughs hilariously, no, you don't need to go.

PARTICIPANT: He needs a PAP smear.

MEMBER DAHL: Yes. Are you in labor?

(Laughter.)

MEMBER DAHL: So, then he calls his nephew, who is an intensivist, critical care medicine who also just laughs hilariously.

And finally, he gave up with the my toe is broken and I don't need to go to the ER. But that emotional decision plays a huge role. And I don't care what kind of facts you throw at people. We will just make those decisions that are stupid either way. You don't need to go to the ER if your broke is broken. If your leg is broken, it would be good if you went ahead and got it taken care of.

CHAIR THOMASON: That is a really good point, really, really good point. Because I have family members that almost, no matter what is wrong, some will go and some will not. So, it really is, there are other factors besides the intellectual decisions.

So, I wanted, Taroon, can you

clarify, too? I know, as a consumer, when I look at selection of a physician or a hospital or we covered this morning a lot about quality. And when I look at which doctor I am going to choose or which hospital I am going to choose, so much of that is quality. Do we need to specify particular points, so not quality at large, but I want to know the number of days since a serious safety event. I want to know. Do we specify those quality things or do we stick to affordability at this point?

MR. AMIN: Well, I would maybe frame the answer as saying that we talked a lot about the emergent decisions at sort of this, your acute episode has begun. We also talked about at the population at risk phase the decision about whether you need something or not. I guess I would ask is there a nuance between sort of this elective decision of seeking care and does that elective decision, what is in that decision with an elective

procedure or condition? I mean these are some potential ideas about what are the alternatives, what are the -- how do you weigh the various alternatives? How much is cost in part of that decision? And maybe the physician and hospital, as you are selecting those, how are you considering cost in that decision?

So maybe I would just ask for a conversation around the elective procedures or conditions and how that decision-making process works and how much affordability plays into that, cost in particular.

CHAIR THOMASON: I know for me it is always perceived benefit versus cost. And like someone said earlier, is it worth it? And it all comes down to that for me. Is it really worth it?

Cynthia.

MEMBER ROLFE: What I would like to just contribute to that question is there are procedures where people seem to be very

willing, based on the evidence we have seen, to shop around for cost. And actually, Melissa was giving a great example, DME procedures, MRIs, that kind of thing. They are very willing to because it is not invasive. It is just kind of impersonal anyway. So, they don't mind.

When it comes to shopping for facilities in which to have a procedure, it is very uncommon because you choose your doctor and your doctor has affiliations and preferences and you want the doctor you have chosen to be at the facility where they have the relationship and the status and the staff they want.

And so I actually cannot recall a single consumer in the last two years we have heard talk about actually actively choosing a facility for a surgery.

CHAIR THOMASON: I can say that I have actively chosen a facility for a scan but that is because I have done it so many times.

For a long, long time, you made the initial decision of choosing your doctor and then everything else was chosen for you, based upon the physician you chose. So, that is a really good point, Cynthia.

Deb and then Lisa.

MEMBER DAHL: I do think people choose their health plans based on the facilities that are in those programs. So they may pre-choose so they don't have to choose later.

We were just talking about Corey chose one because he is near Mayo and that is his preference. I made sure my sisters chose one that had a Banner facility in it, so I had some influence.

MEMBER LATTS: I just -- we have been talking around it but I just want to introduce the concept of commodity.

So, the reality is CT Scans, labs, DME to some degree. Those things are commodities. So, you price shop and they are

very price sensitive. Whereas, the things that are not commodities, your physician, the procedure that your physician or a specialist physician is going to do are not commodities. So, things that are commodities, they are much more price-sensitive than things that are not.

MR. AMIN: Can I ask a follow-up on that question? So, this issue of commodities, how does that vary depending on the level of frequent flier of the customer? So, do all customers recognize the commodities? And in addition to that, how transparent is the information about cost or pricing, even for the commodities?

MEMBER LATTS: I think it depends on how sophisticated the consumer is and the availability of those resources.

So, I think it was Alyssa's brother where the health plan called -- I wonder if it was Anthem -- that called and said you can get the exact same scan at these five places for cheaper. And its insertion at

that point in care to educate people that this is a commodity and it can be provided cheaper here. Because reality is, even most physicians don't know. Most physicians have no idea in the variability of pricing for these various commodities because the physicians don't care. I mean as long as the quality is relatively equal and they have access to the films or to the results, they don't care where it gets done. But they don't have the information either. So, within the health system, the information on that is not any more readily available.

CHAIR THOMASON: I just remembered when Lisa said that when we were talking earlier about preventative measures, both of my parents are required by their insurance to have these preventive scans or they lose insurance entirely. So, it is a requirement. She has to have it done or she loses her insurance. So for them, it is not a choice. They absolutely have to have it.

And then when we are talking about choosing the hospital and things like that, I really just chose my doctor. And I really did just say okay, that guy is a specialist in Loeys-Dietz. I did switch physicians. The guy who did my first open heart surgery had never heard of Loeys-Dietz syndrome. And I found a specialist through the Loeys-Dietz Syndrome Foundation and switched my care to him.

But upon switching my care to him, I didn't decide much for a long time. He decided everything.

Carrie? Oh, Tayler.

MEMBER NELSON: I mean I was just going to follow-up on the conversation just about knowing what is a commodity and what isn't. I mean I like to think I am relatively well-educated but I have definitely been through the ringer of having a lot of elective procedures that didn't need to happen. I didn't know what was a commodity and what

wasn't. I didn't know to shop around. I didn't know where to find the price.

That is just my experience. And it is with things that the consequences if you don't find out could be huge. And that is scary as the consumer to not really know. And so I think that has been prevalent in my experience.

CHAIR THOMASON: And then how do you know on the back-end, once you realize oh, I didn't have to have that done, and you are paying that bill?

MEMBER NELSON: I think my experience has just been how little follow-up there is. That has kind of been a signal to me. Like, I will get my results back and they will be fine. I won't even get a call from the doctor. I will just a call from the facility. It was negative. And there is zero follow-up whatsoever.

It is like well, if this could have had consequences, like why aren't you

following up more with me? That is just how I have been deducing it, I guess.

And then again, you get that bill and that value really diminishes all of a sudden when you see a price tag.

MEMBER FRONTERA: I'm not sure if with more transparency, more time, and more communication if we will see more of this, but I have seen some instances where consumers are choosing other things. They are choosing their physician but they are choosing a facility differently.

So, my example of normal vaginal delivery was one. You might have an OB/GYN that delivers in three hospitals and the couple may choose to go to a better facility. I had once consumer tell me that my concept of value for a hospital for my wife when she delivers is yes, the cost, and also if they have Wi-Fi in the waiting room. So, that was their value.

(Laughter.)

MEMBER FRONTERA: And so other kinds of elective procedures, too, that hysterectomy example was on.

Plastic surgeons have been one to do this for a long time because those folks pay cash up-front for everything. So, the person picks their plastic surgeon and then the surgeon might recommend a couple of facilities and then that consumer would shop because that is 100 percent out of pocket.

There is a couple of plastic surgeons that I know of that take it one step further, in order to enamor their patients, since the savings is even greater by doing it, by having the facility in the Bahamas, they then fly their patient out there. They still get their full surgical fee and the patient comes back with a tan. And it costs the same, had they gone to a facility in Minnesota or whatever.

So, I think it depends on the sophistication of the community and how much

transparency there is.

CHAIR THOMASON: Who was next? Do you know? Okay, we will go Carrie, and then Adam, and then Paul.

MEMBER NELSON: Yes, this concept of I just chose my doctor, I went where my doctor told me to go. So, how do you choose your doctor?

CHAIR THOMASON: As I said before, a lot of that was quality and he was a specialist. And then for others, it was recommendations from peers and things of that nature.

MEMBER NELSON: Yes, and yet some people do it fairly randomly. And I had, actually I have two examples where one friend had a hip surgery. The other had a hip surgery a couple weeks' later. One had an anterior approach. One had a posterior approach. Clearly, the anterior approach is much better, you know shorter turn around, less missed work. But they just did what the

doctor did. So the guy who does the posterior approach, that is what he does. So, he didn't even offer the alternative.

So, there is a risk in just doing what your doctor tells you to do. So, therefore, the choice of the doctor has to be a much more deliberate choice.

CHAIR THOMASON: I know Tayler said earlier that she goes to Yelp and do you want to say that really quickly so that we can move on?

MEMBER LOFQUIST: Yes, just how I have chosen doctors since I moved to D.C.

Just since moving to D.C., I think it is different maybe for people maybe if you have grown up having the same doctor your whole life and you have lived in the same town. You could kind of have recommendations. But being in a city where I am kind of on my own healthcare-wise, how do you even begin choosing a doctor was a little bit overwhelming.

So, I just went to Yelp, had the top-rankings for different doctors, and just started going through each of them based on like who is ranked the highest. And the first one that would take my insurance, that is who I would go to, pretty much. And then I would kind of read the stories and make sure that it matched up with the experience I was hoping to have. But yes, just kind of like crowd-sourcing that information. But, having the affordability with your insurance.

MEMBER NELSON: And yet we all know really nice doctors with bedside manner that are crappy doctors.

CHAIR THOMASON: But you don't know it until you go to them and then you change.

I think Paul and then Helen. I'm sorry I didn't see your name tag earlier.

MEMBER SIERZENSKI: Yes, I was going to say that all of our colleagues here who are active patients are extremely highly

skilled at managing the system here. And I think the vast majority of those out in the country right now probably use access to that individual, its location overall, and their insurance alignment as probably three key drivers. And although I think we all believe that quality should be a key indicator, I think generally there is a lot that is just given to the practice of medicine and healthcare that the assumption is they are out, they are a shingle, they are probably pretty good. Or if they are affiliated with a reputable organization, they are probably pretty good.

So, I think those three, for the vast majority of people in the country, I know from my mother, who is a chronic cardiac patient, that was pretty much it. It was, did they take the insurance; can I get to them; and can I get in were pretty much it. And then the other things, whether she likes them, whether they will deal with her, kind of

Italian approach to life was really -- even though I am Sierzenski, it is Polish and Italian. My mother always says I want to fight somebody but I forget who.

(Laughter.)

MEMBER SIERZENSKI: I think those four factors are kind of key.

CHAIR THOMASON: So, there was the assumption of quality engrained, sort of.

Helen.

MS. BURSTIN: Just a quick comment. And in some ways, it is interesting. My husband does stats and polling and I am a physician. And he is always amazed how risk-averse I am. So actually in some ways -- because you either think as a doc it is absolutely the worst possible thing or it is absolutely nothing. And there is rarely anything in-between.

So, I have to tell you when we pick plans, for me it is actually all about what is the facility included for the worst

possible thing. So, it is really. I mean I think in some ways that will change because there has been a lot of articles as well about some of the narrow network plans, excluding some of those providers.

And if you are really risk-averse, and I guess my point is a lot of this really comes down to a personal sense of risk aversion, about how comfortable you are with risk. And that is a lot of what we have actually been talking about.

CHAIR THOMASON: Maureen, and then Adam, and Carrie.

MEMBER EDIGER: This is short. I was just going to say I have asked the nurses before on the floor if it was their kid, which neurosurgeon they would have do the surgery or which urologist they would trust with their kid, and who they see the lowest infection rates from. So, that is my highly scientific source.

MEMBER THOMPSON: One thing I just

wanted to mention because it seems like it keeps coming up but I don't know if we said it, which is I don't know if everybody perceives there are decisions to be made around healthcare.

And you were talking about the health -- oh, she is gone. I love the Health Belief Model because I think it does. I think what she was pointing at is really, really important, which is the idea that I can shop for providers or there are commodities in healthcare. Because when you think about it, I mean by a show of hands, how many people are from bi-coastal metropolitan cities here, like living in urban centers? Okay, so more choice. Right? Like I come from a rural area where the choice is you go to UVA and that is it.

So, even thinking about the possibility of making these decisions, when you look at the percentage of people in the United States who live in a rural environment

that won't even, with these giant facilities, potentially even have a choice of which facility they go to, unless they can physically get somewhere further. And they may carry that forward with them wherever they go. Which is even if I move into a big city, I may still have the same outcomes because I have carried with me this idea that there is no decision to be made.

So, I think we have to look at not only what information people need to make decisions but be very clear about what decisions need to be even made in the process.

CHAIR THOMASON: Great point. Where they live but then also, like you raised earlier, are they engaged enough to make this decision and all those things like that for sure.

I think it was Kris and then Carrie.

MEMBER SOEGAARD: This going back a little ways in the conversation but it was

again something Cindy said about cost doesn't come into play with the hospital selection. And I agree with what you said but that doesn't mean to me that there aren't cost decisions that consumers should be asking questions about related to the hospital where their physician may be sending them. Because I am not going to get in quality but there is a huge cost variation in having something done at different hospitals and I think that is an important component that consumers, patients should be talking and maybe challenging their doctor about. If their doctor is sending them to the highest cost for that particular procedure, that is something that they should maybe be talking to them about.

MR. AMIN: So, I have a question about that.

CHAIR THOMASON: Taroon?

MR. AMIN: So, I have a question about that, which is, and it is sort of similar to our conversation before, which is

that it seems that that information about selecting a facility is not transparent at the time of the selection or if the selection is even an option, it is generally a retrospective issue. And so I wonder is that information available or is it very similar to the situation that we were talking with Cynthia, the example Cynthia brought up, which is that maybe the best approach here would be sort of a good-faith estimate of what one could expect, given the variation in what would be reimbursed, depending on various different health plans, contracting rates, all the different providers that are involved in the hospital environment.

MEMBER SOEGAARD: I would say that you can get directional information. And you can get directional information from Hospital Compare. So, it is available.

CHAIR THOMASON: I was in the healthcare system for a long time before I realized I could make that hospital call. But

even then, my surgeon will only do -- if I want him, in my area, he will only do that surgery at a particular hospital. So, if I want that doctor, I don't have the benefit of being in the large urban area. If I want doctor, I have to go to that hospital. So, I still feel like I don't have as much of a choice when it comes to surgeries and inpatient stays, as I do like diagnostics and things like that.

Carrie?

MEMBER NELSON: You are kind of tailing on what Adam was saying and Kris. I think that there may be a series of suggested questions we want to put into this white paper that would help people tease out their options and where they can find out where a price may need to help them make a decision. Because I don't think we can -- we can't look at every scenario and say here is what you should know about that but there is some key general questions. Are there alternatives to this

surgery? Are there other places I can go for the same procedure? Those kinds of things.

CHAIR THOMASON: I love that idea.

CHAIR MORT: I wanted to go back to the question about how you choose a physician. And people mentioned, obviously, doctors in their plan. Maybe it is copays. But I did want to say a couple other things about affordability. When you choose a physician, you also choose a practice. And there is aspects of the practice that really relate to affordability, like when they are open. So, can you go there off hours? Can you see another provider if your provider isn't working that day? Do they have call lines? All those sorts of things. Patient portals.

So, it is not just the physician anymore. It is the physician and the practice. And attributes of the practice, really, I think affect affordability decisions.

On the quality side, it is very, very hard to get real quality data at the individual physician level. It just doesn't work very well unless you are cardiac surgeon, getting back to the CABG stuff I mentioned before. But you can get information on credentials, where they went to school, how long they have been in practice, often information about what kind of procedures they do. There are special interests. And then you can get quality information again about the practice oftentimes. So, that is helpful as well. Wait times. I think Debbie, you mentioned before you left one practice because of the front desk.

So, I think there is a lot of information that we could get direct consumers to that is available to help them make better decisions about doctors that also relate to the practice.

And I think that risk issue that Helen mentioned earlier is really important.

I don't think I could live in a rural, rural, rural area that wasn't near a big tertiary hospital because I have been in a tertiary hospital since 1986. And just the idea of not having one available just in case. I'm not sick. But just in case tomorrow I get sick, I would like to be near it.

And this was made very apparent to me, my risk level tolerance when I have been all my life in cities and suburbs until I got married about 12 years ago and I moved 48 miles out of Boston to a rural area. And about a week into the move, I realized there were no fire hydrants. It never occurred to me that people lived in places without fire hydrants. And what they do is they go to a pond and they pump the water into the fire truck. It took me a long time to get over that. Now, I am comfortable with the fire trucks.

But you know people's risk tolerance really, really is important. So,

choosing a doctor that has admitting privileges at a hospital that you are comfortable with is also -- so it is the doctor, it is the practice, and the admitting privileges that I think comes into the decision-making. And maybe people don't understand that those things are all connected. So, that is an important piece of information that I think consumers should have access to.

CHAIR THOMASON: And I think it is about letting our inexperienced consumers know that you need this information. Because I want to know all these things now that I have already chosen. You know, but I didn't know what to even ask for way back when I was making the decision.

I know we need to move on but Corey, go ahead.

MEMBER WILBORN: I think the more stuff we add to the average person's list of things to look at, the average patient, the

population at risk, I think it turns them off. I think it is too much information for someone that -- you know, it is overload.

CHAIR THOMASON: Alyssa.

MEMBER KEEFE: I was just reflecting on all that information. I am sure this has been said before in some other forums. But you know when you are in high school, they make you take life skills classes, how to do financial planning, balance your checkbook. They give you health education but it is more about keeping yourself healthy. No one teaches you how to navigate the health system.

And that actually is a tremendous life skill or a tremendous piece of education that we just don't do in this country. And it lends to wanting all this decision later in life. And so, it is just something that I think if we invested in that kind of work, it would give us a different perspective. And it lends to affordability as well.

CHAIR THOMASON: I hope that is changing. Like I said, just last week I read a proposal in North Carolina that will roll out health literacy in high schools in our state. So, I hope that we go that way.

Taroon, do you want to move on or do you want to take these last couple of comments and then move on to the next phase?

MR. AMIN: Yes, let's take the ones that we have remaining and then do a quick introduction for Jessica Greene and quick disclosure and then we will move on to our last section.

MEMBER NIELSEN: I totally agree with Alyssa's point about life skills. And where the United States is so different from other industrialized countries is most other countries, two-thirds, three-quarters of their providers are primary care providers. And people have long-term relationships with those providers and they serve as your navigator or your coordinator in ways that we don't in this

country. And we are far more like your husband, Melissa, who waits until the last minute and then circumvents the primary care system and lands in the world of specialists without somebody to help them navigate.

So, some of this is how our health system is constructed and that is not our charge to fix that. But it does relate back to affordability because primary care -- and 30 years' of research on this topic, primary care and strong investments in primary care not only help the patients navigate the system but improve health outcomes and cost less money.

Tell everyone at the PCPCC I said that, by the way.

MEMBER DAHL: I was just going to add what a shame that our system is so complex and so messy and so poorly designed that we need navigators to get us through the system.

CHAIR MORT: Shall we move on to the next?

MR. AMIN: Okay, that sounds good.

CHAIR MORT: Do you want to start with the intro?

MR. AMIN: Yes. Jessica, welcome. If you wouldn't mind just quickly introducing yourself to the group. And if you have any financial disclosures related to any of the topics that we are discussing, grants, anything else, grants, employment, things of that nature. I generally don't do that part. It is important. I don't mean to make light of it. But anything that you feel is relevant for the group.

MEMBER GREENE: So, my name is Jessica Greene. I am a faculty member at George Washington University and I am here because I have done a number of studies where we present different presentations of quality and cost information to consumers and find that the way information is presented can have a pretty substantial impact on how people understand the information.

And so this issue of how to present information simply, which just came up, is something that I spent some time thinking about, though I have not solved. But I have seen a lot of problems doing things in a complicated way.

I don't have any financial disclosures, but I do apologize for having to miss most of today's meeting. I had a little grant proposal deadline, major problem, happened last night. But we are together now.

MR. AMIN: Excellent. So yes, let's quickly sort of transition into our phase three, which is sort of the post-acute phase, also includes -- and we can sort of break it apart between the post-acute phase including the selection of post-acute providers and then also maybe have some discussion about sort of chronic disease management post-acute discussions.

And effectively, maybe I will turn it over to Ashlie to kind of walk us through

a little bit.

MS. WILBON: Yes, I mean I am hoping we are hopefully all on the same page with the follow-up care but we can kind of conceptualize this as you are discharged from the hospital for an inpatient stay or you now have your diagnosis and your patient education for what you need to do for your condition and then you are now in this -- what was the word we used -- coping?

MS. ADAMS: It is living with chronic illness and coping with end of life.

MS. WILBON: Yes. So, living with chronic and coping with end of life phase. And so again, this might be medication management, care coordination issues, I think, is also in there, long-term care, skilled nursing facilities, physical therapy, anything like that would all kind of fall into this, just to give some examples of what might be going on in this phase, all might be in this follow-up -- I keep saying follow-up care but

this purple bubble for what we are looking to kind of think through again in terms of decisions and the information.

So, with that, we will open it up for discussion. I think Maureen is first.

MEMBER EDIGER: I just want to make sure that we are remembering mental health issues as we move into the purple bubble because I think that it is complicated and different and we haven't been talking about mental health a lot. So, I just wanted to remind everybody that there is another kind of health out there.

MR. AMIN: So, on that note, Maureen, I guess I have a question as well, which is that the issue of sort of mental health and behavioral health is important both -- so the decision there is and the decision of selecting the provider and also, in some cases, it may be selecting a plan, since it is a carved-out arrangement, so that is what we are referring to when we are talking about

that population, in particular.

MEMBER NIELSEN: Clarification. Taroon, just so that we are all on the same page, 70 percent of all behavioral health decisions are made in a primary care provider's office. So it is actually not all carved out. As a matter of fact, most treatment of behavioral health issues happen in primary care.

So, integration is huge there and I just wouldn't want folks to think we are talking about two disparate systems.

MR. AMIN: So can you help me understand what is the decision that we are looking at then, from the patient's perspective? I don't mean to put you on the spot but in general, if you were thinking about seeking behavioral health treatment in the primary care setting, what decisions are we trying to understand here from an affordability standpoint?

MEMBER NIELSEN: We could run the

whole gambit. I mean, focused on affordability, regardless of the behavioral or mental health issue, you need to know if they can be -- your loved one or you can be treated in a primary care setting or if you need a referral out.

If you need a referral out, now you have affordability questions because there could be all kinds of question about whether insurance covers this, doesn't cover this, et cetera.

If you stay in your primary care setting, you are still thinking about the same sorts of issues, copays, deductibles, et cetera. That is a whole separate issue than the treatment decisions themselves. I am just referring to the affordability fees.

MEMBER EDIGER: This is just my experience but it seems that the costs of medications for addressing behavioral health, there seems to be a lot more fluctuation and trying to find plans that will cover -- and

again, I have very limited experience. I am not speaking for all parents. But just that it seems like it is much more of a moving target, finding the right plan that will cover the right medications and unbelievably expensive if you miss that decision annually.

MEMBER NIELSEN: That is absolutely true. I am just talking about that initial about where your treatment happens. It is pharmacy copays, it is your benefit package. Now, this is all supposed to improve as part of the ACA. But historically, terrible disparity between what your health insurance, regardless of whether it is within a primary care behavioral health setting, disparities between what they will cover physical health and mental behavioral health.

MR. AMIN: Right.

CHAIR THOMASON: I do have a quick question. So, who helps these patients make those decisions?

MEMBER NIELSEN: Their primary

care provider, initially. The problem is a lot of the primary care providers aren't well trained. So, they are overwhelmed. It is not their area of expertise. Fifty percent of the time when they make a recommendation to their patient about getting a referral and they say I can't manage this here, 50 percent of the time, the patient doesn't go on and get additional treatment.

So, the gaps around mental and behavioral health are huge. The goal is to better integrate mental and behavioral health into primary care but we are just figuring out how to do that.

I just wouldn't want you to think that they are like two totally separate worlds because they may seem that way but that is actually not how they begin.

MR. AMIN: Okay, that is good.

MEMBER EDIGER: But since we are in that purple bubble, we have moved on to follow-up care, right?

MR. AMIN: Yes, we are in follow-up care.

MEMBER EDIGER: So, I agree that that point where maybe it starts might be really somewhere. But I think by the time we get to the purple bubble, it starts getting to be a lot more complicated about the choices that you have for affordability and paying for it.

I think we are saying the same thing.

MEMBER NIELSEN: We are and some of it has to do with the severity of the illness. So, if it is something that can't be treated in a primary care office, now you are in a whole other world.

MR. AMIN: I guess that is what I am trying to get some nuance around, which is is it a difference in the benefit design between what is available or is it a difference that the providers, the difference in what is available? That is what I am

trying to just understand.

MEMBER NIELSEN: It is all of the above. I mean there is a shortage of mental health providers, for starters. So, finding a good referral, if you can't be managed in a primary care setting, is just one of the many problems that you will have. Then, getting on the right medication, which often changes for the patient because they don't always work long-term if you are talking about schizophrenia, et cetera.

I mean the levels of complication around behavioral and mental health are significant.

MR. AMIN: Okay. All right, Joe, Lisa, and Maureen. We will work around this way.

MEMBER SINGER: Taroon, I mean with the initiation years ago of the Mental Health Parody Act, there is more benefits that are defined and structured for people with behavioral health.

As Marci said, most treatment for common behavioral health substance abuse issues initiate in a primary care office. So, we are talking about simple depression. We are talking about anxiety, different types of insomnias. That type of thing is handled by most primary care physicians fairly well.

If there is not a response, a good response to initial therapy or if a more serious disorder is identified, if initially depression has been recognized being part of a bipolar disorder, people are then referred on to specialty care.

Once that happens, there is a huge ratcheting up of cost for a patient because they are going from a primary care copay now to a specialist copay.

A lot of the medications that are out there are Tier 2 and 3, Tier 3 medications for some of the more serious conditions. And those copays and deductibles get very, very expensive.

So you know, as things escalate as far as severity of illness, the intensity of care goes up, the frequency of care goes up and then compliance becomes an issue where people start to cut back on expenses because copays and everything build up and they become sicker and they end up getting hospitalized. It is a very challenging situation.

The same thing with cardiac patients. Some of them will have their bypass and they can do all their shopping and then when they find out it is $20 a visit for the 12 to 30 cardiac rehab encounters that they need, after the CABG, they may end paying more in copays for the cardiac rehab than they do for the surgery itself.

So, it is getting people to understand the ramifications downstream of all of these interventions that people don't know how to anticipate up-front. And quite often, physicians themselves don't understand what is happening. And you know when someone gets

admitted to the hospital, they get a bill from a radiologist that they never see for reading the x-ray, and a cardiologist that they never see for reading the EKG.

And a lot of these things are not readily transparent to the patient and they have no control over picking the anesthesiologist who is par or non-par with their insurance company. So, it is really very challenging for people to control. And they have to put themselves in the hands of either the primary treating physician, be it the surgeon or whatever. It is challenging.

Some of the payment innovation processes that are coming out with providers and bundled payments and things like that will offset some of these challenges to patients, where there will be one bill, where the copay structure and out-of-pocket costs for an individual patient may get dropped. But that is still a very complicated process for people to understand a priori because, typically, it

doesn't get presented to them. Typically, it doesn't get presented to them.

MEMBER NIELSEN: But think about how much we have been talking about self-efficacy today and whether you think you can manage this yourself. When you are depressed or anxious or have any of these behavioral or mental health issues, your ability to manage your health, and you are often sick with something else, so the complications -- it is a rare thing to just have depression or just have anxiety. The comorbidity between diabetes -- diabetes predisposes you to depression and depression can predispose you to diabetes.

So, when I say they are intertwined, then your ability to actually act on your doctor's recommendations to take this drug, to get your exercise when you are depressed, I mean the behavioral health issue often precludes your ability to manage your physical health symptoms, which then just

continues to get worse.

MR. AMIN: All right, Lisa, Maureen, Deb, Ron, and then Tina.

MEMBER LATTS: Just to add to the complexity of the mental healthcare system, in addition to a severe shortage of providers, there is an incredible fragmentation among providers. So, unlike in the medical side, where there is a lot of organization, a lot of physicians are organized into groups, those groups have infrastructure, most mental health providers are single practitioners. So, they don't have back office staff. They don't have people to do the billing. They don't have people to return your phone calls.

So, often they don't bill, they bill much later. So, from a health plan perspective, most medical claims come in within 30 days. You know you will get mental health claims six months' out. And so that makes everything much more complicated.

A lot of mental health providers

won't bill the insurance directly. So, they will leave it up to the patient to bill the insurance. So, they will want you to pay them and then they will bill.

Psychiatrists, typically, are mostly prescribers and they will prescribe drugs and then you have to see other professionals, psychologists, social workers, et cetera, for the cognitive therapies. So that is fragmented and divided up.

And again, add somebody who is impaired in their ability to manage and it becomes very, very difficult.

MR. AMIN: Maureen?

MEMBER EDIGER: Everything Lisa just said, she just went through every single one of my points.

The only one, whereas with other medical issues you might do the crowd sourcing, like I need help finding a good orthopedic surgeon to do my knee replacement, you are not as likely to post on Facebook my

kid is having a psychotic episode, do you know a good psychiatrist that can help. So, it is one more layer that you don't have. You don't have that support system to go to either.

MR. AMIN: Very good point. Deb? Oh, you got it? Ron.

MEMBER WALTERS: Yes, I like the concept of we have gone kind of from, in some respects, a simple situation to an intermediate situation with something you can at least adapt to. I call the purple bubble almost chaos. And I think you have heard some of that, especially from an affordability perspective in that not only is it much harder than either of the two previous bubbles to predict exactly what factors might influence the decisions that I make but also what my exposure might be downstream but the interplay between the different aspects of the system gets very complex and that is even from just one disease's perspective. Then, you have to factor in all the relationships between the

other diseases that could occur as either side issues or consequences of what you just went through in the middle bubble. And this gets to be extremely complicated very, very quickly, and that is without any behavioral health issues.

So, I mean I think affordability, in my mind, although we focus so much on that acute phase, whether it is emergent or not as far as the affordability risk taking an abrupt turn upwards, especially compared to what came before it.

In a way this is more of this type situation and it is indefinite. I mean really, you don't really know when that unpredictability is going to end. And that, in itself, introduces all sorts of questions about how you would assess that affordability, when you don't even know what one your five years', ten years' in the future might be like.

MR. AMIN: So, Tina, I will have

you go next. I just have one question just for the group as well, after your comment.

Which it seems like there are at least two decisions her that we have talked about. One is around sort of deciding -- it is not really a decision but it is a question of how to coordinate across multiple riders when you are in this post-acute environment and that sort of includes, depending on what your condition is, but it gets even more complicated in a behavioral health situation.

And so the question I have is how good is the information in that coordination process. And then the second is, looking at selection of actual providers in the post-acute environment, how transparent is the data about cost exposure, in terms of post-acute provider. So, I am interested in conversation around those topics. So, Tina?

MEMBER FRONTERA: I will try to address some of that. I think in some ways we are almost getting into a total cost of care

issue, too, and care coordination.

When we speak about the mental health issue, if you have a parent, that parent can be the case manager. Or if you have a chronic illness condition and the parent can be the case manager for that child. Or sometimes, the child can be the case manager for their parent.

But in the absence of the person having enough information, or enough tools, or enough resources is when we get into total cost of care that could be out of control because of the fragmentation.

Again, there are models now where we are just beginning to start to publish information on total cost of care. But that doesn't get to all of these other fragmentation issues. If you happen to be lucky enough to get into a system that manages itself very well, and has controlled total cost of care, then that patient gets lucky. But I don't think we have enough out there

yet. I think it is emerging but it is still piecemeal.

MR. AMIN: Yes, well I guess the question I would then ask also to the consumers, in particular, is if you are moving out of an inpatient environment into follow-up care, into post-acute providers, how easy is it to interpret a total cost of care number, even really, about what your post-acute exposure really is going to look like, not only from an uncertainty perspective that you have a number of different providers that you are interacting but what the cost exposure looks like from a post-acute environment, whether it is rehab or -- Joe?

MEMBER SINGER: It is really a few different issues. Unit cost tends not to be as much of an issue in post-acute care because for insured population, the copays, deductibles are going to handle the issue. You know hit maximum out-of-pocket costs. But it is full utilization that tends to be a

problem, too.

You know some children with cerebral palsy may get -- I have seen them getting annual CAT scans and EEGs odd infinitum, when there is absolutely evidence that it is medically necessary. So, appropriateness continues to be a big issue here and utilization trend, as much as unit cost trend, is an issue so that coordinative care, and potentially patient-centered medical homes and other initiatives can help deal with more evidence-based delivery of care.

You know a lot of our frequent fliers, and I'm sorry for using that term, they are very, very specific, fortunately, not common conditions. So, you know it has forced people to become experts to protect themselves and their loved ones.

But when we talk about the general population, as a geriatrician, I see people that are seeing -- not any more -- but I was seeing people seeing six, eight physicians, be

on 15 to 20 medications. And you know for Medicare, a third of all hospitalizations are drug-related problems; either too many or not enough.

So, coordination of care is a huge issue in looking at total affordability of care. Make sure the people are getting what they need but not excess therapy. And in the U.S., it tends to be people -- the institute of medicine says what, 30 to 40 percent of care is not evidence-based. And that drives a lot of the cost that rolls down to individuals in getting work done that maybe is not necessary.

MR. AMIN: Melissa, and then Maureen, and then I think we may end up wrapping up this section.

CHAIR THOMASON: As patient, it is really hard to coordinate your care among several providers, even from a quality perspective, even when you are inpatient and you see all these specialists and especially

afterward.

My cardiologist and then nephrologist, and then the OB team, and the this team and the that team, then everybody comes and sees you independently of each other. And then they asked me what the other guys said. And I was like, by the way, I didn't go to med school, just so you know. So it is really hard from a quality perspective.

Then, too, from an affordability perspective. So, just relating to affordability in this stage of the episode of care it was, again, do I really need this. Because I was thinking about it on the front-end of all these preventive tests and things like that. And I was thinking about it in the middle of I am having these symptoms, do I really need to be seen? And then even more so at this stage because I just came out of the second stage of treatment and that concept like Paul was talking about earlier of indebtedness. And I felt like I just spent

all this money on being treated and on that hospital stay.

And so how I made my decisions for follow-up care and cardiac rehab, I felt like I was already so indebted to the healthcare system that I was really careful about well, I don't really need that. Do I? Well, I don't really need that, do I? And so affordability really played in a lot to my decisions in the end.

And then, too, again, insurance is so big because cost info is great but it will not help me if it cannot translate my real out-of-pocket expense in the framework of my insurance for an everyday consumer.

MR. AMIN: Yes, that is a definite theme.

Maureen and then Liz.

MEMBER EDIGER: I was just going -- I think what you said about having a primary care physician or, in our case, our pediatrician who really understands and knows

like both of my kids with special needs, that she is -- I seek her advice on cost issues. I will ask her, how necessary do you think this is. And I think having that medical home, that one person that coordinates, that care is key on affordability issues for frequent fliers.

And I feel like Ev, my son with spina bifida has always lived mostly in the purple bubble. Sometimes in the orange bubble but I feel like he lives his whole life on the right side of this diagram. And I think that investing in a good primary care pediatrician, in our case, has huge payoffs for us, as far as where we are accessing and the appropriateness of different things that we are engaged in.

And I have definitely been in the situation where when he has been inpatient in the hospital, I feel like I am the one who is saying well, urology was just here and they said this. And neurosurgery was just here and

they said this. And infectious disease was here and they said this. And I finally get to the point where I say, but I don't speak your language. Like I don't know but I feel like I am the one that is conveying all the information back and forth to specialists. And that is a horrible place to have a patient or a family member be in.

CHAIR MORT: One thing that I feel would be an important piece of information, if you have a chronic disease, not so much the post-acute follow-up after a hospitalization but again, the affordability issue, an important aspect of your choice about where to get care would be the practice. Are you going to be in a situation where you can only see one doctor and it is going to be spotty or can you see a team in a patient-centered medical home? And if you have diabetes, do you have a good endocrine consult that you can go to on a periodic basis? Is that person convenient.

I have really been moved today by

the emphasis from the consumers on the important costs, the indirect cost of convenience away from work, family disruption.

So again, if you have a chronic illness, a disease management need, the practice, your access, your resources, are really, really important, both primary care, height, if you are a high risk, sort of a high utilizer, do you have a case manager.

So, all those things I think are really important in making decisions about where to seek care for patients who have chronic needs.

Paul, you made that comment earlier about was it your son or your daughter who had diabetes?

MEMBER SIERZENSKI: Yes. Actually, I was going to respond to that. As a matter of fact, for my son who is a Type 1 diabetic who was diagnosed right over the Christmas holidays, which was one of the most traumatic experiences, not only just having a

child that was ill but, after the fact, the gap in care after being discharged was insane. I mean our life saving at that point was the JDRF and the contact families who let us know what to expect, even as an emergency physician who treats this, but our day to day touch point.

I would say first the decision of the follow-up was really driven by the initial provider. So, I think that is key because whether it be a primary care physician from a patient-centered medical home, or even a specialist or subspecialist, the decision that goes into the selecting of that individual is going to have significant carryover impact in the follow-up care component. We see our endocrinologist or my son sees his endocrinologist as a consultant only at times. His primary caregiver is, himself, with us as support, and his secondary support caregiver are the diabetes nurse practitioners who do that management that he can text if there is

an issue, if you know he is ill and needs to adjust things.

So, I would say that although we are discussing a lot about some of the primary care components, that initial interaction in the acute phase has significant carryover in there for follow-up because our primary care physician for our son, our pediatrician, essentially acquiesces a lot of that to the endocrinologist, which we are blessed that they actually do communicate and things get faxed that day and there is data exchange.

But it was really that initial interaction that set the ball in motion for the longitudinal follow-up care.

CHAIR MORT: And the other piece of the practice that I would point out is important from an affordability perspective is whether the practice has systems, infrastructure, that also support affordability.

You mentioned, Maureen, all the

consults coming at you. Well, if your PCP or your primary care taker has an electronic medical record, turn the lights on all these conversations. You can actually read them and the primary care person with an electronic medical record can help reduce the cost of care and make it more affordable because that person can really help you integrate.

And the same would go for does the practice have electronic prescribing? Other kinds of IT decision support things that will make care safer and avoiding adverse events, it makes care more affordable.

So not just the composition of the practice like when it is open, who is in it, whether they have teams, but also some of these really important factors around structural aspects. I think those are things that consumers may not even know are important but gee, if they really are important, the Leapfrog survey, as I mentioned before, they point out the value of those structural

aspects. But those structural aspects can really affect affordability.

MR. AMIN: Corey?

MEMBER WILBORN: My experience has been very different. And the fact that when I go to a primary care physician because of my heart problem, they immediately send me to a specialist. They don't spend time on any other problem. If you have a cold, if you have allergies, you are going to see the cardiologist. And the cardiologist is going to -- my cardiologist and my hematologist, at the time, that is where they send you.

So, most of my care, my primary care and everything has been done by my cardiologist over the years. And I have been in three separate states and it has always been that way. I see the primary care doctor and he shoots me right over to a heart doctor.

MR. AMIN: Marci?

MEMBER NIELSEN: So, I would just want to underscore both the points that Liz

and Paul were making, although I also feel like I need to respond to your cardiologist or your endocrinologist. Folks are bickering about who your medical home is and is it a primary care provider. Now, you can't tell some people, I am about to say this, but the reality is, it is whoever you want your medical home to be, based on what your needs are and your comfort is. And sometimes that is not going to be a primary care provider.

Of course a pediatrician is a primary care provider. Usually it is primary care but in the circumstances when you have a serious illness or condition, often they don't. In the world of HIV, most primary care providers want you to have a specialist and you want one.

But --

MEMBER WILBORN: That is where the cost comes in, too, because it costs a lot more to go see that specialist every time than it does to see a primary care doctor that

could handle the cold that I have.

MEMBER NIELSEN: Right. Well, and this gets back to a point that Paul was making and that Liz underscored around self-management. We often don't think of ourselves as being "on the team." And yet in reality, if you think about it, you are going to learn the literature on your illness or condition anyway. And then when you are really empowered to manage it yourself, because you are given self-management tools and EHRs and patient portals.

What we find is there is a whole group of family physicians arguing that maybe we don't have a physician shortage after all, if we actually used team-based care, technology, and most importantly, the patient, as a care giver for themselves.

We could think about affordability of the healthcare system and the number of providers in a whole new light. And so, I would throw that into affordability if only to

say if you feel empowered to manage your diabetes, suddenly, you are not having to go in for a lot of doctors' visits that cost you $20 or $50.

So, the patient as -- see and now I am going to say patient -- the patient as the consumer here, in this case, allows you to save money but, most importantly, feel better and self-efficacious about being able to take care of your condition.

MR. AMIN: Adam.

MEMBER LATTS: And Marci, can I just give a caveat to that? Which is, that it is fine for the specialist to be the medical home, as long as the specialist then assumes the responsibility for the total care of that individual.

So, if Corey's cardiologist is not ready to make sure he has his flu shot, and quits smoking, and gets enough exercise, and does all his preventive screening, then he has no home.

MEMBER NIELSEN: That is exactly right. And treating Corey like a whole person. I mean this is more than just sort of a condition management. It is longitudinal. It is continuous. It is comprehensive. And you know, what about Corey's heartache? He is still looking for his wife. You know? Is his cardiologist helping him on his quest? Because I just think that is the funniest thing I have heard in a long time.

(Laughter.)

MEMBER NIELSEN: I get it. I get it. It ranks right up there with manicures and broken arms.

MR. AMIN: So that is excellent. That is a great place to kind of bring the conversation together.

So, I will just kind of summarize what we have done and I will ask the chairs to reflect some themes that they have heard from the day. Does that sound like a plan? Unless anyone has any sort of closing thoughts, and

I will certainly open it up for the group if there is any sort of closing thoughts that you have from the day.

So, we walked this morning through sort of different consumer experiences on the concept of affordability and different experiences that folks have had with the healthcare system, and particularly with the healthcare costs.

And then walking through various definitions of established consensus definitions and really batting back different ideas about what exactly affordability means from the consumer perspectives and getting some real clarity around those topics.

We really took a deep dive on the patient-centered episode of care framework and really described, at least at the very minimum, redefining the terms of what we are using within this graphic, this graphical framework but potentially considering other components to add.

MS. WILBON: I will just add I think one of the aha moments for me, I think in that we are going to definitely do some thinking about back to the definitions piece, is to really go back and rethink words, really doing some wordsmithing and really thinking about how we might be able to either add on to the existing definitions or kind of rethink how we frame those within the context of this paper, so that it is consumer facing or from the consumer lens. So, I think that was a takeaway from that discussion.

MR. AMIN: Absolutely. And then what we did was to take each of these phases and really walk through effectively what decisions we think occurred during those time periods and what information we think is needed. And I think -- I won't attempt to summarize everything that we have done today because that would be an amazing feat. But what I would say is a few aha moments from my perspective is the issue of appropriateness

was clearly in the forefront across all three of the phases, really thinking through and having an understanding of whether you needed the care to begin with. And that really is a forefront issue in terms of defining affordability.

The second is this idea that knowing sort of a priori at the beginning of your care what your expected costs would be. The information about your copays and your information about your total spend, your total max spend cap, that information is generally available but the information about what your particular condition or patients like you, what an expected cost would be, just even getting started in that area would be a huge contribution.

And third, and I think Liz pointed this out as well, the theme around understanding the indirect costs and how patients really weigh that in various different decision points, I think was

certainly a theme that resonated with me.

So, I will hand it over to the chairs or Ashlie, or any of my NQF colleagues if they have any other themes or reflections from the day and then I will open it up to you guys, if we have any other reflections for the day, before we move on to tomorrow's agenda, an overview of tomorrow's agenda.

CHAIR MORT: Well, Taroon, you did a great job summarizing. And I just want to emphasize that the discussion today really, to me, reinforced the importance of having had this discussion and having had this workshop. Because there are aspects of the whole affordability conversation that the consumers brought to life today. And I think that conversation that we started getting mixed up with all the definitions, cost, price, but the affordability issue for consumers really is what it means to me. My paycheck. And what about the deductibles and the copays and the indirect costs, leaving work, all those things

that I don't want to repeat ourselves. But that story is huge and it is pretty well hidden in the healthcare administrative kind of dialogue that I sit in on a day to day basis.

The quality discussion, I think what was most enlightening for me was how important it is for individuals to know, patients to know what it is like for other patients who have this condition. And that is pretty much non-existent except through this internet and websites and all of that. We don't provide that as providers. Huge gap in that.

And I guess the other thing was -- well, there were several things but I just want to say how important knowing whether or not you need to come to the hospital is.

And we talk about population health management until we are blue in the face at Mass General and Partners HealthCare and we talk about patient-centered medical

home. We talk about specialist engagement. And then we walk about patient engagement. And we need to get to that piece a lot faster because bringing patients more actively into the conversation, spending more time on education, making information available to patients will certainly address a huge piece of what I heard this afternoon.

So, I am really looking forward to tomorrow's exercise around the case studies.

CHAIR THOMASON: I think we have covered the vast majority of it, the appropriateness, what it really means to me as a consumer and the out-of-pocket expense. And I think, too, we raised the issue of empowering consumers to make these decisions, to let them know that these decisions even need to be made and then to help them navigate this system of making those decisions.

CHAIR MORT: May I just way one more thing I forgot? I am looking at Tayler and she reminded me that we need to plan for

the future. And our current systems are woefully inadequate for the needs that Tayler and her cohorts require.

MR. AMIN: So, we have a few minutes before we go to public comment. Are there any other reflections from the group?

And then we will turn it over to Erin to walk through the agenda and the structure of tomorrow's session, how it relates to what we have done today.

Any other comments from the group? All right, so Erin, take it away.

MS. O'ROURKE: All right, so Taroon and Liz were mentioning, tomorrow will be starting the morning with our case studies activities and this will really be a chance for -- we will give you the story of a fake patient and to play them out across this episode of care model, thinking about what decisions that person would need to make and what information they would want to have to support those decisions about their care.

After that, we will come back together to have a report out time to see what the results of these cases were and are there additional considerations we need to think about, now that we have tried to use this model with a real person?

After that, we will break for lunch and then come back to think about challenges and the path forward. What could we start to do to make this information available to consumers and empower them to use it?

CHAIR THOMASON: I have a quick question, Taroon. We had a lot of conversation today about the complex system and how it is so hard to navigate and then to understand the bills and things like that.

I don't know if we have a time tomorrow at all but we didn't get into bundled payments at all today and I wonder how fellow consumers feel about that.

MR. AMIN: You know what we can do

is we have sort of some broad challenges in path forward. We can certainly add it in in tomorrow's afternoon discussion. I wouldn't try to fit it in right now. Okay.

So, yes, I mean if there are other sort of related conversations that we don't feel like we covered, we can certainly add them in tomorrow during the afternoon.

CHAIR THOMASON: I just wanted to throw it in somewhere.

MR. AMIN: Absolutely.

CHAIR MORT: But Melissa, can you just say a word about the aspect of your concern?

CHAIR THOMASON: I think it was briefly mentioned one time. I know as a consumer, I want to be able to look at a bill and understand it. So, a lot of times I hear conversations around bundled payments and what is the average cost of this and can't we just do that. And I don't know how my fellow consumers feel about looking at a bill and

seeing and average cost versus an itemized, complex listing of everything they did to me and what it cost me.

I am only one consumer and I wonder if you want to see a bill with everything listed out. Is that too complex? Or does it make you feel robbed when you just see a number and you are like hey, wait a minute, where did you get that?

That was my question. Maybe we can throw it in the mix tomorrow.

MR. AMIN: Yes, that would be certainly an interesting conversation to have.

MEMBER SINGER: Just a quick response to that. When you see the itemized bills, it makes no difference because that is not how the health plans pay the hospitals. They pay them on case rates or per diems. So, when you see your $12 Tylenol tablet, it will rip your heart out. But that is a number that I don't want to call it a fictitious number. It is a bookkeeping number for the hospital

for them to track resource utilization. That probably has very, very little to do with what ends up coming out of your pocket.

CHAIR THOMASON: And as a consumer, I -- bundled payments, I want to be able to look and see the average cost and things like that. I think an average cost or a bundled payment will make price transparency a lot easier on the front-end. But then Corey made the statement today and I look at this number and I am like where did you get that from. And that made me wonder how that translates into other consumers' lives.

But, a conversation for another time.

MR. AMIN: Okay, should we open? Operator, can we open the lines for public comment, please?

OPERATOR: At this time, if you would like to ask a question or make a comment please press *1, again that is *1 to ask a question or leave a comment.

MR. AMIN: Are there any comments in the room? No. Okay.

OPERATOR: And there are no questions or comments, at this time.

MS. O'ROURKE: We have no web chats. I should mention if you are joining us for dinner, it is an Siroc at 915 15th Street and we will be meeting at six o'clock. It is right across from the park.

MS. WILBON: Yes, if you are going back to the hotel first, if you walk out of the hotel -- you are at the Capitol Hilton, correct? Okay, if you walk out of the front door, make a left. You will be on the corner of 15th and -- oh, sorry, 16th and K. Make a left onto K Street. Walk down about two blocks and then make a right on Vermont and it will be -- it is on the block of Vermont. You will see the park over to your right. And it is like on Vermont, on that block.

MR. AMIN: Yes, on that block.

MS. WILBON: So it is like a two-

block walk. Just make a left and a left, and a right.

MR. AMIN: Yes. And Karen just reminded me. Feel free to tweet about the meeting and keep the conversation going.

MS. ADAMS: Thank you, Tayler.

We have had quite a few tweets and people have been tweeting. So, thank you.

MR. AMIN: All right, thank you everybody for a great Day 1.

MS. WILBON: Yes, thank you.

(Whereupon, at 4:46 p.m., the foregoing matter was adjourned to reconvene at 9:00 a.m. on Friday, March 28, 2014.)

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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: 03-27-14

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