

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

TABLE OF CONTENTS

	Page
Welcome and Staff Introduction	
Taroon Amin.....	5
Committee Introductions and Disclosure of Interest	
Ann Hammersmith.....	7
Project Overview and Opening Comments Facilitators:	
Elizabeth Mort, Melissa Thomason, Taroon Amin, and Ashlie Wilbon.....	16
Consumer Experience	
Melissa Thomason.....	36
Definition of Affordability and Its Relationship to Other Concepts Including Quality	
Taroon Amin, Ashlie Wilbon, Elizabeth Mort and Melissa Thomason.....	91
Public and Member Comment.....	159
Introduction of the Patient-Focused Episode of Care Model	
Taroon Amin, Ashlie Wilbon Elizabeth Mort and Melissa Thomason.....	170
How Can Cost and Resource Use Measurement Support Consumer Decisions and Increase the Affordability of Care	
Taroon Amin, Ashlie Wilbon Elizabeth Mort and Melissa Thomason.....	196

TABLE OF CONTENTS

	Page
Decisions About Affordable Care in the Population at Risk Phase	
Taroon Amin, Ashlie Wilbon	
Elizabeth Mort and Melissa	
Thomason.....	251
Decisions About Affordable Care in the Evaluation and Initial Management Phase	
Taroon Amin, Ashlie Wilbon	
Elizabeth Mort and Melissa	
Thomason.....	301
Decisions About Affordable Care in the Follow-up Care Phase	
Taroon Amin, Ashlie Wilbon	
Elizabeth Mort and Melissa	
Thomason.....	364
Recap of Day 1	
Taroon Amin and Ashlie Wilbon....	398
Public and Member	
Comment.....	409
Adjourn	410

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

2 (9:10 a.m.)

3 MR. AMIN: Good morning, everyone.

4 Thank you all for getting here on time and we
5 are ready to get started. We are very excited
6 to get this two-day meeting on a very
7 important topic both for NQF and for, I would
8 say, broadly, the healthcare field in general,
9 who is really interested in this topic of
10 affordability. So, we are very excited to get
11 this kicked off.

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

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

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

1 cost and resource use activities in addition
2 to readmissions work.

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

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

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

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

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

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

4 (Laughter.)

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

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

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

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

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

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

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

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

1 helps with the transcription process as well.

2 So, thanks.

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

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

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

17 No disclosures at this time.

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

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

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

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

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

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

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

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

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

22 MEMBER KEEFE: Good morning. My

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

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

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

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

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

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

22 I have no disclosures at this

1 time.

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

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

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

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

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

22 MEMBER FRONTERA: Hello. I am

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

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

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

19 And I have nothing to disclose.

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

22 And the last thought I am going to

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

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

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

19 Okay, thank you. Have a good
20 meeting.

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

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

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

11 (Pause.)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1 very complicated but important journey.

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

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

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

1 that. It will help inform that.

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

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

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

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

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

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

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

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

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

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

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

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

14 Does that answer your question,
15 Lisa?

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

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

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

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

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

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

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

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

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

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

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

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

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

1 wireless network, if you would like to log on.

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

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

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

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

8 Taroon, anything else?

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

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

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

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

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

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

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

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

22 CHAIR THOMASON: So, I guess I

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

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

22 Six months' later, I was diagnosed

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

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

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

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

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

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

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

5 But when I came out of the
6 hospital, I had to pay those bills. And it
7 was real world then and it really affected my
8 everyday life. At one point, I was paying
9 more in medical bills than we do for our
10 house. And there was -- well, people would
11 say oh well, you can pay \$25 a month, but you
12 can pay \$50 a month. Yes, well when you have
13 25 bills, \$25 a month still adds up. And it
14 is really the reality that I was living in.

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

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

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

11 And things like insurance maxes
12 and all of those things that I had no idea
13 about when I first got sick, when I looked at
14 my husband and said we will never pay this off
15 in our lifetime. I was a public school
16 teacher and could not imagine ever paying that
17 off. I had no idea there was an insurance max
18 and that I wouldn't be required to pay the
19 \$400,000 bill that came from the first stay.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

8 PARTICIPANT: Well, what did the
9 doctor say?

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

22 MEMBER WILBORN: Again, my name is

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

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

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

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

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

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

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

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

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

1 says your savings.

2 (Laughter.)

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

6 (Laughter.)

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

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

1 thinking about for sure.

2 I am paying a premium now of about
3 \$400 and I wouldn't have done that if I had
4 read this Cost of Your Healthcare article that
5 you guys posted on the thing. You know I
6 would have done a little bit more research
7 about it. And you know so now you pay \$400 a
8 month is a huge -- that is a nice chunk of
9 money to an average consumer to be paying.
10 And for somebody like me, I am going to go the
11 doctor just to get my medicine refilled or
12 just to make sure nothing is wrong. I haven't
13 really had much that I have had to go to the
14 doctor for, other than medicine and just a
15 regular checkup just so I feel good about what
16 is going on with my health.

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

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

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

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

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

22 Tayler.

1 MEMBER LOFQUIST: Sure. Again, my
2 name is Tayler Lofquist. I am here because in
3 2005 I was diagnosed with food allergies,
4 based off of a blood test. And I lived for
5 about six years of my life thinking I had 23
6 separate food allergies. And it was life-
7 changing to cut those foods out of my diet.
8 I went from not being able to stand up
9 straight at school and at softball practice
10 from stomach pain to being pretty functional,
11 finding gluten-free food before it was cool.
12 I found my way around the system.

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

22 I ended up bouncing from a

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

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

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

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

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

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

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

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

1 complex issues.

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

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

9 CHAIR THOMASON: Very good point.

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

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

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

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

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

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

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

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

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

22 So, I am not your average health

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

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

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

1 make an informed decision?

2 CHAIR THOMASON: Great point.

3 Ron?

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

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

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

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

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

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

22 So, I think that is something we

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

10 And how do we measure that?

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

19 Maureen?

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

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

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

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

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

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

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

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

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

16 (Laughter.)

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

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

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

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

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

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

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

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

1 well, just in case you were wondering.

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

1 months to find a psychiatrist that is on your
2 plan.

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

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

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

1 an education, I am assertive, I am chatty.

2 (Laughter.)

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

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

1 the stuff he has done is really cool.

2 So, Adam.

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

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

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

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

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

17 (Laughter.)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1 works.

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

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

16 Tina?

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

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

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

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

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

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

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

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

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

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

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

11 (Laughter.)

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

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

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

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

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

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

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

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

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

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

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

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

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

15 Thank you so much for adding your
16 consumer stories.

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

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

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

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

14 (Laughter.)

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

20 Thank you.

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

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

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

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

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

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

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

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

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

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

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

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

6 (Whereupon, the foregoing matter
7 went off the record at 10:35 p.m.
8 and went back on the record at
9 10:51 p.m.)

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

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

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

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

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

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

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

6 MR. AMIN: The receiver.

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

9 MEMBER KEEFE: Can I ask a
10 question?

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

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

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

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

20 MEMBER KEEFE: Thank you.

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

1 thinking so far.

2 And I believe we have 21 people,
3 20.

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

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

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

17 (Pause.)

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

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

1 healthcare quality when you are deciding if
2 care is affordable.

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

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

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

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

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

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

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

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

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

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

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

22 So, we definitely want to take

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

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

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

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

1 be a separate bullet.

2 MS. WILBON: Okay.

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

10 MS. WILBON: Okay, that is --

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

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

22 MS. WILBON: Okay. And I actually

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

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

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

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

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

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

1 MR. AMIN: Actually, can I jump
2 in?

3 MS. WILBON: Sure.

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

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

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

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

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

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

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

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

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

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

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

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

1 also have to write a check for?

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

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

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

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

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

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

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

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

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

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

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

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

22 So, these are contributors to what

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

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

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

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

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

1 costs the provider to actually deliver the
2 service?

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

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

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

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

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

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

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

17 Is that helpful, Melissa?

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

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

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

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

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

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

13 MS. WILBON: Right.

14 CHAIR THOMASON: Okay, thank you.

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

22 MEMBER NIELSEN: Yes, although,

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

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

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

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

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

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

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

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

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

1 little bit broader.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

3 And I am going to call on Adam
4 first.

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

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

16 (Laughter.)

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

22 And so what she found was I could

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

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

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

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

22 MEMBER THOMPSON: Chatty. So, I

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

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

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

22 So, I think these definitions do

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

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

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

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

22 (Laughter.)

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

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

17 CHAIR MORT: Than you. Lisa and
18 then Carrie.

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

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

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

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

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

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

19 CHAIR MORT: Thank you, Lisa.
20 Carrie.

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

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

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

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

18 CHAIR MORT: Thanks, Carrie.
19 Corey?

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

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

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

22 MEMBER LATTS: Well, and it really

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

4 CHAIR MORT: Dorothy.

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

9 CHAIR MORT: Go right ahead.

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

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

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

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

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

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

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

8 I believe, Melissa, you were next.

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

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

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

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

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

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

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

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

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

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

7 CHAIR MORT: Melissa wanted to add
8 to that.

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

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

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

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

1 CHAIR THOMASON: Right.

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

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

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

16 CHAIR THOMASON: Yes, I agree.

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

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

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

21 Okay, I think Cynthia was next.

22 MEMBER ROLFE: So, I will try and

1 cover all my comments. I have been making
2 notes.

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

10 (Laughter.)

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

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

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

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

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

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

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

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

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

1 I think the other thing that I
2 want to reiterate is we have been talking a
3 lot about emergent care, deeply complicated
4 crisis situations. And that is a small
5 majority of consumers, small group of
6 consumers, majority of the emotional intensity
7 for sure, when we do research. But there are
8 80 percent of people out there who should be
9 engaging with the system and aren't. And the
10 way it feels, they are actually not engaging
11 because they have a perception they are either
12 in or out. And we talk about people as being
13 in or out. Everybody has got to be in somehow
14 to be healthy and to avoid being really in.

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

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

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

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

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

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

22 So, I think since we are coming to

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

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

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

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

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

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

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

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

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

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

22 MEMBER EDIGER: I touched on this

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

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

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

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

22 Now, the four cards that are up, I

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1 \$20,000 in total out-of-pocket and now my son
2 is doing extremely well on pens only and that
3 is because, after a communication with other
4 parents who said keep him active, do the right
5 thing.

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

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

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

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

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

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

1 sources out there.

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

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

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

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

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

15 Carrie, are you declining?

16 MEMBER NELSON: Am I want?

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

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

22 Looking at the BlueCross side of

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

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

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

1 Melissa.

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

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

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

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

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

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

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

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

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

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

16 CHAIR THOMASON: Exactly.

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

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

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

5 Okay, at this time, there are no
6 comments.

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

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

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

16 MS. WILBON: Okay, Joe.

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

1 especially with some of the consumer-directed
2 health plans.

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

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

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

22 You know people pick the bronze at

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

13 (Laughter.)

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

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

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

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

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

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

1 will be a rich discussion.

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

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

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(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

1 evaluation and initial management, and follow-
2 up care.

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

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

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

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

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

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

1 continuum.

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

6 Go ahead, Ashlie.

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

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

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

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

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

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

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

4 CHAIR THOMASON: Ashlie, may I ask
5 a question?

6 MS. WILBON: Sure.

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

13 MS. WILBON: Yes, absolutely.

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

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

13 Marci and then Cynthia.

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

22 So, just a suggestion.

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

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

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

19 MS. WILBON: Sure.

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

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

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

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

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

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

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

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

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

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

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

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

10 MS. WILBON: Yes.

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

13 MS. WILBON: Everyone.

14 MEMBER ROLFE: Okay.

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

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

1 depends what the episode is.

2 MEMBER SOEGAARD: So, will a
3 consumer get that?

4 (Chorus of no.)

5 MEMBER SOEGAARD: Okay.

6 MS. WILBON: Go ahead, Adam.

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

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

22 MS. WILBON: Someone who has

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

6 Go ahead, Maureen.

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

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

15 MS. WILBON: Go ahead, Corrie.

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

1 doctor and then may not do follow-up care.

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

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

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

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

1 populations that would have need.

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

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

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

1 orange, and then there is follow-up care.

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

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

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

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

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

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

22 MEMBER SHIPPY: But it is not an

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

4 MS. ADAMS: Right, it is a
5 segment.

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

13 MS. WILBON: Sure. They would be
14 in the follow-up care phase for that
15 particular -- for diabetes, for that
16 particular condition, they would be in that
17 follow-up phase for their ongoing management,
18 medication management, diet, exercise, for
19 that particular condition. They might be in
20 population at risk for another condition but
21 for that particular episode, they would --

22 CHAIR MORT: Okay.

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

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

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

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

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

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

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

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

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

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

22 As a provider and someone who does

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

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

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

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

7 Go ahead, Ron.

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

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

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

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

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

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

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

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

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

11 Melissa.

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

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

1 forever.

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

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

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

11 MR. AMIN: Marci?

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

18 So for example, you could see if
19 in fact all the people who are in need of,
20 potentially in need of treatment, and in Arrow
21 2, what you think about what factors make up
22 affordability and you could list out health

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

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

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

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

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

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

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

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

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

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

10 MR. AMIN: Yes.

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

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

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

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

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

19 Melissa.

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

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

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

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

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

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

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

13 Adam?

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

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

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

1 decisions.

2 Liz and then Deb.

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

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

22 MEMBER DAHL: Just to expand a

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

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

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

19 Cynthia?

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

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

7 And I think regarding the second,
8 Liz, you make a really important point, age
9 and all those things have a lot to do with the
10 mode that people want to get their
11 information. But then personalities dictate
12 a lot of preference among that. So, you can
13 get people who really are digitally oriented
14 at all ages, within a certain reasonability,
15 85 you are probably not. But your personality
16 about how you like to engage and how much help
17 you want, it is across all age bands. So, I
18 just want to make sure that we account for
19 that.

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

1 CHAIR THOMASON: Great point.

2 Ron, if you want to go ahead, and then we will
3 have Dorothy and Adam.

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

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

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

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

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

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

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

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

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

9 Is that fair, Ashlie? Yes.

10 CHAIR THOMASON: And Dorothy, did
11 you mean to imply -- or this is how I heard
12 you, so I just wanted to clarify. That just
13 because I could afford it, doesn't mean I
14 could have it done and the burden in my life
15 --

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

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

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

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

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

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

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

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

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

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

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

22 And then a related thing is called

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

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

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

22 MEMBER NELSON: Just another brief

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

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

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

22 But then more than that, I need

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

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

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

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

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

10 (Pause.)

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

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

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

1 (Pause.)

2 MR. AMIN: Interesting.

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

5 MR. AMIN: Sure.

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

9 (Show of hands.)

10 CHAIR THOMASON: Yes, I think that
11 was --

12 MR. AMIN: A bit loaded, yes.

13 MS. WILBON: So, the next --

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

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

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

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

1 Deb and then Tina and Lisa.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1 something, an aspect of quality.

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

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

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

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

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

17 Cynthia, I think yours was up
18 first.

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

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

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

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

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

17 Corrie and then Adam.

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

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

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

11 But in choosing a doctor, I went
12 to the hospital recently, and one doctor had
13 15 patients in the lobby. And those patients
14 were complaining and I got to the doctor and
15 was able to see my physician immediately. And
16 I was wondering why these patients were still
17 waiting on this particular doctor all day
18 long. You know I had seen my doctor, leaving,
19 and these people are still sitting in the
20 lobby. And so I was saying oh, man. But
21 these people are indebted to this doctor
22 because they have been seeing him forever and

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

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

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

1 a good point.

2 Adam.

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

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

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

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

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

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

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

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

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

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

5 Cynthia? Corey.

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

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

19 MEMBER WILBORN: Exactly.

20 CHAIR THOMASON: Tayler and then
21 Marci down here.

22 MEMBER LOFQUIST: Yes, and I was

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

13 CHAIR THOMASON: Absolutely.
14 Ideally --

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

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

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

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

11 Marci.

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

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

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

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

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

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

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

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

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

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

17 MS. WILBON: Right.

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

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

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

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

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

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

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

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

20 On the other side of that kind of
21 linking cost and quality picture, is the
22 quality piece of that, which there are

1 different types of quality measure, the
2 patient experience. So that is one place that
3 the consumer perspective does come in.

4 This piece of work is somewhat
5 different because it is so consumer-centric.
6 And while we have consumers at the table for
7 our other piece of work, because they so
8 measurement-focused and based on the data that
9 we have for measurement at this time,
10 consumers are able to provide input but it is
11 kind of based on those types of measures.
12 Whereas here, we are really trying to figure
13 out what is it that consumers really need and
14 how are those measures different. Is it even
15 measuring the way that we think about it?
16 Maybe it is not necessarily a performance
17 measure but some other -- you know, what is
18 the proportion of patients like me that picked
19 this health plan or some other type of measure
20 that consumers are looking for.

21 So, I don't know if Taroon --

22 MEMBER KEEFE: That helps because

1 I think listening to that and, again, using a
2 framework of affordability as the lens,
3 because they are all interconnected. And so
4 we talk about cost and quality information
5 together to make a shared decision with the
6 lens of how do you define it being affordable
7 and valuable. Right?

8 And so I was just having a really
9 hard time as I listen to people talk about all
10 that information that goes into making those
11 decisions, juxtaposing it against the
12 affordability equation that we discussed
13 earlier. So, that helps. And I think the
14 discussion questions, though, we are answering
15 them sometimes, I think, in a little bit more
16 the traditional kind of way of measurement.
17 And some of the answers that I am hearing
18 think through a lot of the other, rather than
19 -- and I actually think I am hearing it
20 sometimes from the consumers, which actually
21 makes me feel kind of positive in a way. I
22 think I am connecting some things across both

1 -- I don't want to make them silos but
2 sometimes they are silos, about bringing a
3 different perspective.

4 So, I think we just need to be
5 cognizant of our conversation here. Because
6 while they are very related, I think they are
7 separate. And I know for me, sitting in that
8 other compartment usually, I am trying to put
9 this in a different box because I think it is
10 important but I am seeing them blurred and
11 crossing lines. So, I know I am struggling,
12 and maybe I am the only one but, about where
13 this is going to go.

14 MR. AMIN: Let's talk about that a
15 little bit because I think it is really
16 important for the framing of when we start
17 with this work in the next three phases when
18 we look at it.

19 You know when we talked about the
20 affordability equation, we looked at sort of
21 the stakeholder preferences as they are
22 weighing sort of cost and quality together.

1 And I think when we first approached this
2 work, the framework that we were using was it
3 is really sort of the very traditional like
4 approach, which was a percentage of out-of-
5 pocket income and that would vary by
6 individual. And that is how somebody is going
7 to look at the question of affordability.

8 But as we started having the
9 consumer calls and we had the first call, it
10 became really clear that that was not really
11 the framework that people were comfortable
12 with and, in fact, it was much more that you
13 had to bring in the question of quality into
14 the question of affordability. And that
15 changed our framing of it.

16 And I think we are, quite frankly,
17 struggling with it a little bit, too, because
18 each person will weigh those two things sort
19 of differently as well. But that is why the
20 quality question has come up very clearly in
21 the discussion of how do you think about
22 affordability. Because what we have heard so

1 far, and I am open to thinking about this
2 differently if the group feels otherwise, but
3 what we have heard so far is the question of
4 affordability cannot be thought of
5 independently of a question of quality.

6 Well, definitely cost but quality.
7 And that is across each of the different
8 phases.

9 So, as we get into each of them,
10 we can have a discussion about how much
11 quality is important. Because just like cost
12 may not be as important in an emergent
13 situation, quality may not be either. You are
14 just going to the nearest provider.

15 But that was the history of how we
16 got to that point, too. So, you are not alone
17 in thinking about that. And we can still have
18 that discussion. It is not set in stone
19 either. But that is kind of how we got to
20 where we are now. That is why we framed it
21 this way in the work.

22 CHAIR THOMASON: I know we are

1 running short on time. Taroon, do you want to
2 continue into the break?

3 MR. AMIN: I think we should
4 probably take a break but maybe just get these
5 questions and then we will take a break.

6 CHAIR THOMASON: Okay. And I will
7 add really quickly, I can only, as a consumer,
8 I will only choose the most affordable option
9 of the good quality options. I don't want
10 something cheap if it is not good. And it
11 really became that for me. I never look at
12 affordability absent of quality. And I don't
13 think I am the only consumer either that had
14 that viewpoint on our consumer call. I think
15 we all kind of looked at it as the best
16 affordable choice among the high quality
17 options.

18 MEMBER SIEMON: I was reacting to
19 someone saying these things were separate. So
20 everyone has iterated back that they are not
21 separate.

22 I think the mission creep that we

1 are concerned about is one of emphasis that
2 what this group seems to be going after is
3 affordability in solving that and making sure
4 you don't go down the rabbit hole of all the
5 open questions in the quality rabbit hole.
6 And there apparently are a lot. So, if you
7 could sort of box that and say we understand
8 the limits of the quality data now but, given
9 the limits, how do we use that in the
10 affordability question that we are trying to
11 answer here.

12 Because I think it is wrong to de-
13 link them in any way. They are so inherently
14 linked. But it is also not okay to not
15 recognize the limits of what is there and what
16 it can do.

17 CHAIR THOMASON: Good point.
18 Great point. Carrie, and then we will get
19 Tina, and then Marci at the end.

20 MEMBER NELSON: Yes, very much
21 what was just said. I was getting
22 uncomfortable de-linking them and I was also

1 getting uncomfortable going too far down the
2 path of quality because that is just sort of
3 distracting from what I think we are supposed
4 to do here.

5 But ultimately, you know, a poor
6 quality episode of care could be very
7 affordable in that episode and ultimately,
8 very costly.

9 So, I think letting people -- you
10 know speaking to that in some way in this
11 white paper is going to be important.

12 MEMBER FRONTERA: I am wondering,
13 rather than quality, if it is cost benefit as
14 one way to keep it in that affordability mind
15 frame.

16 Cost benefit from an affordability
17 perspective. So, do we keep Grandma in the
18 ICU in her last ten days of care at \$2 million
19 or do we send the grandson to college? That
20 is still within the frame of affordability.

21 MR. AMIN: Just quickly, I would
22 just also add I think the conversation we had

1 earlier today was around also ensuring that it
2 is appropriate. Because you could have a low-
3 cost episode but it may not have been
4 appropriate at all. But yes, so we can --

5 CHAIR THOMASON: And I will just
6 add as a consumer, I just wanted to
7 acknowledge that quality very much plays into
8 my thoughts on affordability but then
9 acknowledging that is enough for me and that
10 I can move into the affordability pathway.

11 And I think we should but it was
12 just the recognition in the paper and at-large
13 that this factors into my decision.

14 MR. AMIN: And that is fair. So,
15 I think let's keep that in mind. I mean I
16 can't necessarily change the discussion guide
17 at this point but let's keep that in mind as
18 we move through the structure of the
19 afternoon, in terms of the different phases.
20 We will just sort of acknowledge the quality
21 elements. And to the extent that they are
22 unique, let's bring them up. That is fair.

1 But we can sort of, the thrust of the
2 conversation could be around the more of the
3 cost elements, as we get into each of the
4 phases.

5 Marci, did you have another --

6 MEMBER NIELSEN: Yes. I don't
7 know if you all have any rules about how many
8 figures you can have in a paper but it may be
9 helpful right at the front of this paper to
10 have a whole different model than the bubbles
11 that connects affordability and quality and
12 some of these other aspects and say this paper
13 is going to be primarily focused on
14 affordability. We recognize that decisions
15 are ultimately tied to, and we can fill in
16 however many factors we want. But that might
17 be a way to frame it up-front and have our
18 cake and eat it too, which I am all about
19 cake.

20 MR. AMIN: Okay, that sounds
21 great. On that note, we can have a cake break
22 or a dessert break. But do you want to come

1 back at 2:15 or 2:10?

2 MS. WILBON: Yes, we will do 2:15.

3 MR. AMIN: All right, we will come
4 back at 2:15 and start with the discussion
5 around the population at risk phase, although
6 we have a better term for that now, the
7 staying healthy phase.

8 And I will also ask maybe -- do
9 you want to do quick hands? Is that how you
10 do it?

11 MS. WILBON: Yes, show of hands.

12 MR. AMIN: We would like anyone
13 who is available and would like to join us for
14 dinner, today we are going to go to Siroc, it
15 is right around the corner from here, at 6:00
16 p.m. If you wouldn't mind raising your hands,
17 we will just take a quick note of who is
18 joining us so that we can just make sure we
19 have enough reservations.

20 (A show of hands.)

21 (Pause.)

22 MR. AMIN: Okay, thank you. Enjoy

1 your cake, cookies.

2 (Whereupon, the foregoing matter
3 went off the record at 1:57 p.m.
4 and went back on the record at
5 2:17 p.m.)

6 MS. WILBON: So, we'll reconvene.
7 So the next session is really the next few
8 sessions -- I will say is we have been talking
9 really at a high level I think for the first
10 half of today, generally about decisions,
11 consumer patient attributes, the types of
12 information needed. But really now we are
13 going to go back to this model again that we
14 kind of agreed would be a starting framework
15 for us anyway to kind of think about the
16 different points in time at which patients or
17 individuals matriculate through in their
18 different health status, points at different
19 health status -- what is the word I am looking
20 for? Stati. Okay, thank you. Statuses at a
21 point in time.

22 So, you know, I had a discussion

1 during a break and I think some of the broader
2 discussion seemed to kind of potentially have
3 a little scope creep on that. But I think
4 kind of bringing it back down now to these
5 different phases in the episode will help us
6 kind of refocus and think through really what
7 we are looking for, which is to think through
8 what are patients or consumers really thinking
9 about in these different stages or phases, in
10 terms of engaging with the healthcare system.
11 What types of decisions are they looking to
12 make? What types of information would they
13 need to help them make that decisions? Is
14 that information currently available? If it
15 is not available or if it was available, what
16 would be the easiest way for them to get to
17 it?

18 And so we have several questions
19 in your discussion guide listed out to help
20 guide the discussion, I think on page eight.
21 There is that big box at the top.

22 So really, again, this first

1 discussion and we will talk about an hour,
2 roughly, about 45 minutes to an hour for each
3 of these bubbles if you will, and kind of
4 frame our discussion around the decisions, the
5 availability of information, what type of
6 information would be needed, the weighting of
7 those different attributes on decision-making.
8 And I guess I will leave it there. Is there
9 anything you want to add, Taroon?

10 MR. AMIN: I just would point out
11 that one of the things that we want to start
12 with is a discussion around the high-level
13 decisions that you would make in this phase.

14 And on page seven, we sort of
15 provided some illustrative examples and they
16 include sort of selecting a health plan,
17 making a decision about selecting a health
18 plan, selecting a primary care provider. And
19 then preventing disease and then screening.

20 So you know, just to give a sense
21 of what type of decisions one would make when
22 they are at this first phase of staying

1 healthy. And then the logical next step would
2 then be to ask the question around what
3 information would you need and is it
4 available.

5 So, I guess we can start with the
6 decision and then the information.

7 MEMBER LATTIS: Can I ask a quick
8 clarifying question? So, these things in
9 here, other than the selecting a health plan,
10 are first dollar covered by the ACA for the
11 majority. So you picked sort of the one area
12 where there is no cost. So, there is no
13 affordability issues with these.

14 So, I am just wondering if these
15 are really the most appropriate.

16 MS. WILBON: I think that is fine.
17 I think that if there are other decisions that
18 you think should be added, I think that is
19 fine. And maybe we could restructure these
20 and kind of identify that these decisions
21 aren't really the ones that most impact
22 affordability. I think that is fine.

1 MR. AMIN: Yes, they are just
2 intended to be a starting point. Feel free to
3 disregard them or build on them.

4 MS. WILBON: Cynthia.

5 MEMBER ROLFE: I would venture
6 that the first thing people are doing in this
7 phase, most people is why. Why should I get
8 care? Why should I see a doctor? Why should
9 I get my screening? I'm fine.

10 PARTICIPANT: Because my mother
11 told me to.

12 MEMBER ROLFE: Right, and yes,
13 there is some parental pressure that comes
14 into play and stuff like that. But for the
15 most part, what we find is people are saying
16 why.

17 If I am understanding the
18 definition of what is no longer called
19 population at risk, it is called the healthy,
20 right? And so in the back of their mind, most
21 people are thinking I should have health
22 insurance. If I do, I should see the doctor.

1 But we all have shoulds in our lives. How
2 often do we deliver on them every day? So,
3 that is the reality for healthy people for
4 whom healthcare is not yet a perceived need.

5 MEMBER WILBORN: Wow, I think that
6 the word in there itself says risk. So, for
7 me, I think everybody would be thinking risk
8 and not why me. Why should I pay for this?

9 MEMBER ROLFE: Just to clarify,
10 they really, that is one of the reasons I
11 asked about the definition population at risk.
12 Because if you were to say to a consumer if
13 they read a paper like this if they were
14 interested and they saw a population at risk,
15 they would say that is not me. That's not me.
16 I don't think of myself as a population. I
17 think of myself as a person who has to take
18 care of themselves and I may have different
19 ways of taking care of myself and I would be
20 maybe more willing to consider different ways
21 but most people need to understand the what is
22 in it for me, how does it connect to what I

1 care about and what I have a stake in in my
2 life.

3 MEMBER NIELSEN: I would just
4 like to point out he also was looking for a
5 bride for health insurance.

6 (Laughter.)

7 MEMBER NIELSEN: And so there may
8 be a correlation between -- I'm just saying,
9 those could be correlated.

10 MEMBER SIEMON: I just want to
11 quickly respond that I think that could break
12 down differently in male/female. And I am not
13 doing this based on my work but more my
14 anecdotal experience. So, I confess, I have
15 no data on this. But young women go to the
16 doctor's and young men often don't. Because
17 young women manage different things in their
18 lives and often need to go to gynecologists
19 and go for routine screenings and all of that.

20 I have girls. My sister has a
21 boy. And all the girls go to the doctor and
22 the boy does not.

1 CHAIR MORT: Okay, Carrie.

2 MEMBER NELSON: So, is this
3 question we are answering? Are asking what
4 they weigh in their decisions? This is when
5 and what are the decisions that they are
6 making during that phase.

7 So, some of it is preventive
8 issues. You know you described them as the
9 healthy but that could also be a person who
10 has got very poorly controlled diabetes but no
11 real consequences of that poorly controlled
12 diabetes just yet and they are making some
13 decisions about whether to go on a medication
14 or something.

15 So, I am just trying to clarify
16 what question we are trying to answer, the
17 kind of things people or the types of
18 decisions they are making.

19 MS. WILBON: So, this was kind of
20 the first question. There is a whole set of
21 questions that kind of follow this, including
22 how they weigh. So, this was kind of the

1 preliminary question.

2 MEMBER NELSON: Okay, so it is
3 more about what they are weighing in their
4 decisions.

5 CHAIR MORT: But this one,
6 specifically, is talking about the keep me
7 healthy group.

8 MEMBER NELSON: Okay.

9 CHAIR MORT: The population at
10 risk group.

11 MEMBER NELSON: Well but that is
12 what I am trying to clarify. Is the
13 population at risk also the person who has got
14 diabetes who isn't proceeding with --

15 CHAIR MORT: That is not the --
16 the concept here is that this is a healthy
17 population. They could use healthcare
18 services to reduce their risk of further
19 problems, but they are healthy.

20 MEMBER NELSON: So, the model
21 doesn't hold up for me in that manner because
22 there are people with well-controlled chronic

1 conditions or poorly controlled that don't
2 have an episode of illness yet.

3 CHAIR THOMASON: I thought we
4 talked about long-term chronic disease
5 management. So, that would be at the end of
6 the spectrum.

7 CHAIR MORT: And I think the
8 concept was, we struggled over the picture.
9 But this discussion is really about that
10 population of people that don't have chronic
11 disease and are healthy out there and that
12 group. Right?

13 MEMBER NELSON: However, if that
14 person with the diabetes is poorly controlled
15 hasn't even entered into the -- they know they
16 have it. They haven't actually entered into
17 an episode of care yet because maybe somebody
18 checked their blood sugar at home. You know
19 what I mean? That happens. I mean you have
20 like let's try my dad's blood sugar monitor
21 and see what I got.

22 I don't know, it is just like a

1 gambit and maybe I am just being distracting.

2 MEMBER WILBORN: Being that the
3 model since that population at risk is now
4 healthy people, maybe we should just change
5 the word to healthy population and not
6 population at risk.

7 MEMBER EDIGER: So, the consumer
8 interpretation of that bubble, if this helps,
9 was staying healthy. That might help. And
10 Liz, that speaks to your point that this
11 bubble -- and I think I might be able to
12 Carrie, I hope.

13 So, when you think of that bubble,
14 if you think of it around what we call primary
15 prevention, that is about staying healthy.
16 So, perhaps people don't have enough
17 information about the risk and that they
18 should be getting these preventive screenings
19 and they choose not to, or, as was brought up,
20 that sometimes life gets in the way. You are
21 busy taking care of another person or you just
22 don't make time for it.

1 So, that early population bubble
2 focuses on this primary type of prevention,
3 colorectal screening, breast cancer screening,
4 just to give some examples. However, as you
5 spoke to Carrie, because it is not linear, it
6 is really a circle, although it is very hard
7 to show that on a screen, there may be
8 secondary prevention. After you are diagnosed
9 with heart disease you may come back into
10 that. You are in a subpopulation of risk
11 where you may be on certain medications.
12 There are certainly behavioral things like
13 diet, exercise, et cetera. But I think, Liz,
14 as you are saying, in this case, if we could
15 focus it on staying healthy, it is mainly
16 around behaviors to get primary prevention.

17 CHAIR MORT: So does everybody
18 know what we are trying to do with this
19 section? Okay, then if we are talking about
20 primary prevention, let's keep the
21 conversation going. And I believe it was Ron,
22 Joe, Tayler, Melissa and Maureen, I think.

1 Ron.

2 MEMBER WALTERS: So, that is the
3 population that I am going to talk about, too.
4 I think we know a lot about this group from
5 the past two years or so. Probably more so
6 than any other group, this is cost, cost,
7 cost. And when I mean cost, cost, cost, I
8 mean for the most part premium, premium,
9 premium, and out-of-pocket expense, whether
10 that be a deduction from your paycheck or
11 direct purchase. I mean this group is exactly
12 who is in the news so much the last year or
13 two, the difficulty is getting them to --
14 apparently, they don't value the benefit that
15 they are going to get. But getting this group
16 to sign up has been one of the major
17 difficulties.

18 Secondly, I think the one that we
19 have heard about the most in this group and
20 applies to a little bit a spillover into some
21 of the populations we are talking about is, is
22 the person that I have seen in the past or the

1 person that I want to see in network for even
 2 those screening and prevention type services.
 3 So, if they were seeing someone before, am I
 4 able to continue to see that person?

5 And then thirdly, mostly because
 6 this is a healthy group, I would say what
 7 other amenities are available? And it could
 8 be for that price, am I getting health club
 9 memberships, the healthy lifestyle kind of
 10 benefits that may not be necessarily written
 11 into the ACA but can be different add-ons that
 12 apply to me.

13 But I mean, this group is an easy
 14 group to understand.

15 CHAIR MORT: Taroon.

16 MR. AMIN: So, I just want to make
 17 sure I am clarifying a few things as we go
 18 through this.

19 So, the first level, it sounded
 20 like Ron the four that you noted, the premium,
 21 the out-of-pocket spending, the in and out of
 22 network and the amenities are all within the

1 umbrella of select -- the decision, the
2 umbrella is the decision of selecting a health
3 plan. Correct?

4 Okay, and then those are the
5 components of what are elements within that
6 decision or what drives those decisions.
7 Okay.

8 CHAIR MORT: Okay, good. Oh, Joe.

9 MEMBER SINGER: To take it from
10 that point, once they have selected a health
11 plan, affordability becomes less of an issue
12 with the direct acquisition of healthcare
13 services because the preventative screening
14 services are now fully covered with no
15 deductible and no copays. So, it is really
16 access and availability.

17 And the indirect cost, so to
18 speak, of obtaining those services, if there
19 are people that are hourly wage earners and
20 then they have to take time off from work to
21 get these services, if they have to travel,
22 the cost of travel, the cost of childcare, the

1 other indirect costs will impact affordability
2 of obtaining those healthcare services. But
3 the actual acquisition of the services is not
4 an issue.

5 CHAIR MORT: That is an excellent
6 point. It certainly plays out in my patient
7 population amongst the younger folks. I think
8 it bounces back to what Cynthia was saying is
9 we need to make the case for the services, so
10 that they feel it is valuable enough to take
11 time off, get the babysitter or whatever.

12 MR. AMIN: So, Liz, can I just ask
13 another follow-up question then?

14 Then the decision there is whether
15 to seek care or not. You know, but this is
16 pre an actual event.

17 CHAIR MORT: So the consumer has a
18 plan. They have enrolled. But whether they
19 actually access the provider, the
20 affordability issue entails time away from
21 work, babysitters, et cetera, et cetera.

22 So, how much is it worth? We have

1 to make the case, presumably, or make the care
2 more accessible.

3 Tayler.

4 MEMBER LOFQUIST: I mean I think
5 we have touched on it but my main point was
6 just going to be do I even need primary care.
7 I think if you are feeling relatively healthy,
8 kind of going about your day and maybe for me,
9 I see specialists but do I need to go to that
10 primary care if I am getting my main acute
11 situations taken care of, or if I am just
12 generally healthy, why do that appointment
13 once a year. I have got to take sick time
14 from work that I might need later on or that
15 I just want to take as a vacation later on.

16 I think you kind of get to that
17 point where you don't always see the value of
18 that initial primary care.

19 CHAIR MORT: Terrific. Melissa?

20 CHAIR THOMASON: Thank you. I
21 think that was one of the big decisions. It
22 is still that appropriateness of care. Do I

1 even need care to begin with? And it is one
2 of the conversations we were having earlier
3 about this initial phase.

4 My husband is an at risk
5 population. So, he is mid-30s with a really
6 high-stress job, and could stand to lose 15
7 pounds. If you tell him I said that, I will
8 lie.

9 (Laughter.)

10 CHAIR THOMASON: Just so we are
11 clear. I know it is recorded. He will never
12 find it.

13 Okay, so he really is an at risk
14 population for heart disease but if you asked
15 him, he would say he was healthy, completely
16 healthy because he has never been diagnosed
17 with anything.

18 So, in this bubble, he doesn't
19 have a primary care physician because he
20 doesn't think he needs one. He will jump --
21 at whatever time in his life his health
22 becomes an issue, he will jump directly into

1 the treatment phase. He will never experience
2 the first bubble. Something will happen. It
3 will throw him into the second bubble for
4 sure. And I think that is the reality that a
5 lot of us live in.

6 Another thing, say my parents --
7 for me I almost always reach my insurance max.
8 So, it is more of a playing of the system.
9 But for my parents, especially, it is will
10 this doctor let me make monthly payments? And
11 they need to know that in advance. Do I have
12 to pay up-front? And do they take my
13 insurance? So that in and out of network
14 thing also goes into their choice of primary
15 care physician and not just of selecting a
16 healthcare plan.

17 My mom needs treatment right now,
18 ortho treatment, and her nearest in-network
19 provider is miles and miles away. So, she is
20 just saying well, I don't need it right now
21 because it is not as convenient.

22 And then, too, I think the

1 preventive care we were talking about in this
2 bubble is what screens do I really need? Do
3 I really need to get those? And is it worth
4 it in the long-run?

5 CHAIR MORT: Thanks, Melissa.
6 Let's see, Kris, you are next.

7 MEMBER SOEGAARD: Ron was talking
8 about cost, cost, cost, and I think premium.
9 But it seems like here is also where they need
10 to understand insurance and sort of -- so, I
11 put that bucket into insurance literacy. So,
12 they need to understand well, if I am focused
13 on my premium, that is all I care about right
14 now. But as they go into other parts of the
15 bubble, they are going to care after the fact.

16 But let's get this up-front. What
17 is my deductible? What does that mean? What
18 are my copays? What is my coinsurance? What
19 is my out-of-pocket maximum? So, it is the
20 details associated with the various choices,
21 so that they hopefully will make more informed
22 choices for when they need healthcare down the

1 road.

2 CHAIR MORT: And that is great,
3 Kris. So, it is really insurance coverage,
4 the first decision. Go to the website. We
5 know we have had trouble with the websites.
6 Lisa was saying even as a doctor, it is hard
7 to navigate the website. So that is the first
8 step, isn't it?

9 Lisa. Oh, wait a minute. I think
10 it was Maureen, then Lisa.

11 MEMBER EDIGER: So, I was going to
12 say a lot of what has already been said but I
13 think it is that there is really two different
14 that you could ask this question for the once
15 a year, when you are making that annual
16 decision during the enrollment phase. And
17 then the other 364 days a year when you are
18 not sitting down looking at your choices for
19 the year.

20 And maybe at that point in time of
21 figuring out how to drive the affordability
22 message into the communications about open

1 enrollment periods and making people think
2 more about what are you really getting for
3 this insurance premium and, I think, making it
4 more transparent how much employers are paying
5 into it. Maybe it is that value thing. If
6 you are seeing how much it really costs to
7 provide an insurance policy, maybe you will
8 look more at what is in it for me and what
9 options are there for prevention and sort of
10 keeping you healthy.

11 CHAIR MORT: I think you are also
12 making the important point about you need to
13 make the case, so that people understand why
14 it is worth it to go ahead and access the
15 care.

16 Lisa.

17 MEMBER LATTS: So, in follow-up to
18 a couple of the comments that have been made,
19 especially, Liz, what you just said, I have
20 been thinking about this paradigm, which, as
21 we have talked about, I think doesn't fit into
22 this affordability discussion as easily as

1 maybe some of the others. But I have been
2 thinking about the selecting a health plan,
3 the purchasing of insurance, that event. And
4 I might suggest that that decision, that
5 purchasing, selecting health plan, purchasing
6 insurance, is, in itself, a bubble. You know,
7 that whole continuum.

8 You know there is the population
9 who is uninsured and who needs to purchase an
10 insurance. The clinical episode is actually
11 that decision to purchase insurance. So, that
12 process is not a clinical event, but using
13 that schema, translating it over, the
14 purchasing of health insurance is an episode
15 in and of itself.

16 CHAIR MORT: An important
17 consideration. Maureen, do you still have
18 yours up from last time?

19 MEMBER EDIGER: I'm sorry.

20 CHAIR MORT: Okay, Deb.

21 MEMBER DAHL: I was also thinking
22 about the changes in the insurance plan with

1 the Affordable Care Act and I think there are
2 a lot of folks out there that don't know that
3 the screenings and those things are free at
4 this point. Some people are still thinking
5 there is going to be a copay and avoiding
6 those.

7 And I am hoping that people are
8 starting to think about the appropriateness of
9 care, so the choosing wisely and those kinds
10 of things will go into their decision-making,
11 both from an affordability perspective, as
12 well as the provider selection.

13 CHAIR MORT: Great point.

14 Melissa, do you have another
15 comment on this one?

16 CHAIR THOMASON: Yes, ma'am.

17 CHAIR MORT: Okay, go right ahead.

18 CHAIR THOMASON: I do think it is
19 really important to make the case so that
20 people do understand why it is important to
21 access the system.

22 My sister, for years, and years,

1 and years has not had medical insurance. And
2 when I ask her why she doesn't have medical
3 insurance she says because I don't need it
4 because I am healthy. And then I say I
5 thought I was until my heart ripped open. And
6 you really think you are until. And it sort
7 of throws you in. But I think that surrounds
8 the culture of healthcare and that healthcare
9 is about diagnosing disease and it is all
10 about disease and not necessarily health. And
11 I think that plays into people's viewpoint of
12 accessing the system.

13 CHAIR MORT: I think you
14 underscore the point that Lisa was making,
15 which is getting into the insured population
16 is a barrier for many and a challenge for us
17 to help them make that leap.

18 Okay, so we have had a good
19 discussion on the types of decisions that you
20 have to make when you are in the left side of
21 this chart. Now, amongst, when you make those
22 decisions, the next set of questions, we are

1 still talking about the bubble on the left, is
2 it possible to get the cost and quality
3 information consumers need to make the
4 decisions before being diagnosed with an
5 illness? So, let's talk about that one.

6 Where do consumers get the
7 information they need to support their
8 decisions?

9 CHAIR THOMASON: Is this phase
10 where -- I do have a question. So, is this
11 the phase where when my husband is having
12 chest pains but doesn't know where -- so no
13 Google symptoms, no Googling symptoms?
14 Because he hasn't went to get care.

15 CHAIR MORT: This is still the
16 healthy person.

17 CHAIR THOMASON: This is just
18 before any symptoms occur at all, right?

19 MEMBER KEEFE: I think also tough,
20 too, I think some of us choose our health
21 plans based on our providers and who are in
22 those health plans, let alone cost. I mean

1 that goes to the network, which happens before
2 you are in the plan and then the plan is,
3 okay, treatment decisions sometimes with that
4 provider or where that provider is.

5 So, I think there is both
6 questions.

7 CHAIR MORT: Well, if we take this
8 by each kind of question, if we think about
9 the first question of getting insurance.
10 Let's take that one first.

11 So, if you are talking about
12 getting a health plan, picking a health plan,
13 how do you get the cost and quality
14 information that you need to make a wise
15 choice of health plans? Tina.

16 MEMBER FRONTERA: I think there is
17 general information and there is specific
18 information. And I think we have mentioned
19 various websites that might give an individual
20 an idea that an x-ray would be \$200 versus an
21 MRI that could be \$1,200. And so that is
22 readily available. And there are some other

1 information sources that are public and
2 community-wide.

3 But then when we get into really
4 specifically what is it going to cost me
5 today, almost all of that information is
6 really out of date because those of us that do
7 measurement, it is based on claims that I
8 incurred two years' ago, or you are projecting
9 something that may occur in the future. But
10 it is not really what is it that is our
11 negotiated rate for your particular network
12 in your particular health plan, for your
13 particular hysterectomy that you are going to
14 have.

15 So, it seems that right now the
16 most reliable source is still going back to
17 either that health plan, but then you got to
18 the health plan will still ask you to ask the
19 provider what it is they are doing. You could
20 go to the provider. And if the provider knows
21 their negotiated rate with the health plan,
22 the provider can tell you. But again, it is

1 still fragmented.

2 CHAIR MORT: Terrific. So, you
3 are talking about once you have insurance and
4 then you are deciding whether or not to have
5 a hysterectomy, as an example. You really
6 have to hunt and peck.

7 Okay, what about the question
8 about getting insurance? Cynthia.

9 MEMBER ROLFE: We have done a lot
10 of work around this. Obviously, there are so
11 many people coming into insurance for the
12 first time. That is the hope and that is the
13 evidence that we are seeing.

14 So, one of the first things that
15 they think about is what they can afford in
16 premiums. That is the basic thing. It is
17 part of their regular budgeting. Helping
18 people figure out monthly budgeting is really
19 valuable, especially young people. They are
20 not really doing it yet. It took me a long
21 time to do it, so I am not pointing fingers.

22 So, that is one of the first

1 things they think about is what can I afford
2 on a monthly basis.

3 Then for them to actually think
4 about what else might I need is really hard.
5 Because in most cases, it is two large groups.
6 One, I am healthy. I have not really incurred
7 any medical costs. So, how do I know if that
8 is a lot of deductible. I have never had to
9 spend anything.

10 And then the other population are
11 people who have been accessing public care.
12 So, we have done a lot of weeks and weeks of
13 ethnographies of people like going through
14 them with their medical decisions and their
15 purchase decisions and understanding all
16 around buying health insurance.

17 And there was on particular
18 consumer in Denver actually who had been
19 accessing, I think it was Denver Health, one
20 of the big public hospitals out there.
21 Evidently it does a very nice job. And their
22 perception, they had such good care and such

1 good follow-up care from that public entity,
2 that their expectation is once they got
3 insurance that it was going to be great. They
4 would never have to make an appointment. They
5 wouldn't have to wait in the waiting room.
6 All their information would be on that card.
7 They would never have to fill out another
8 form.

9 So, you are really dealing with
10 very different perspectives of what do I think
11 I am going to get. But beyond the premium, if
12 someone doesn't have a good sense of what the
13 cost of healthcare has been, they can't make
14 a decision. We can tell them all we want
15 about how much is your maximum you will pay
16 that year, and how much will you pay for every
17 doctor visit but there is no context to know
18 what they might really incur yet, until they
19 are insured and we know more about them and
20 then that is where we might be more helpful.

21 CHAIR MORT: Excellent. Lisa?

22 MEMBER LATTIS: So, I can

1 complement that with the information on the
2 quality side. So, from a quality side,
3 historically, NCQA was the big player in this
4 area. And they have done a good job over the
5 years measuring health plans' quality, mostly
6 on the HMO side with increasing spillover the
7 PPSI.

8 In recent years, one of the nice
9 things they have done is take the 40 measures
10 that they use to evaluate health plans and
11 roll them up into five different domains that
12 were relatively easy for consumers to
13 understand that are a mixture of the HEDIS
14 measures, so the clinical quality measures,
15 the CAHPS measures, so the experience
16 measures, and the standards. So, it is a
17 necessary roll-up.

18 So, that information is available.
19 It is public. It is on their website for
20 those plans that are NCQA accredited or are
21 submitting data, which is a good chunk of
22 plans nationwide.

1 Now, on the exchanges, there is an
2 exchange accreditation. Exchange
3 accreditation can be done by NCQA and URAC
4 today. There are other folks that are getting
5 in the game and will be likely approved as
6 accreditors down the road. For the federal
7 exchanges, there is no quality information
8 available. Some of the private exchanges,
9 especially California, we have done some stuff
10 in Colorado, some of the coastal of stuff have
11 done some stuff. There is information
12 available but it -- well, first of all, it is
13 not on the actual exchange population because
14 there is no population. But it is the best
15 that can be done early on.

16 The ACA will not develop quality
17 standards until 2016, which, again, makes
18 sense because you won't have a population to
19 measure until this year data into next year,
20 and then start measuring it in 2016.

21 So, on the exchanges from a
22 quality perspective, almost 100 percent the

1 decision is going to be based on cost. There
2 is very little information from a quality
3 perspective, other than my mom has
4 BlueCross/BlueShield and she has a really good
5 experience with it, so that is who I am going
6 to choose.

7 CHAIR MORT: Taroan.

8 MR. AMIN: So, I just have some
9 clarifying questions here. So, I think one of
10 the big decisions at this phase appears to be
11 selecting a health plan. That was what Ron
12 pointed out some of the components of that,
13 which is the premium, the out-of-pocket
14 spending, who is in-network and who is out,
15 some of the other "amenities."

16 So, the question I have is that it
17 seems that the majority of this information is
18 currently available from the health plan or
19 from your employer. I mean it certainly
20 should be. Whether you are looking at it is
21 another story.

22 So, why do we -- I guess given

1 that that is available, why isn't that
2 sufficient? And I would then sort of add a
3 second part to that question to say is that
4 enough information or is it, to Cynthia's
5 point, is it more that consumers are actually
6 looking for what their experience is going to
7 be, given all these other constraints, which
8 is their overall spending caps or their
9 deductibles or their copays. So, actually
10 describing in some level of detail that, if
11 you have this condition, you should expect to
12 actually have this out-of-pocket expense,
13 given all these criteria for what the health
14 plan entails, which is out-of-pocket expenses,
15 copays, maximums and whatnot. Maybe that
16 information is actually not getting translated
17 into what consumers need.

18 So, it is a two part question,
19 which is essentially, if this information is
20 already available, why isn't -- is it
21 sufficient? And if it is not sufficient, why
22 is it not sufficient?

1 CHAIR MORT: Well, what I heard
2 was that the information is available.
3 Consumers don't necessarily understand that.
4 And through their employer, they might have
5 two choices. So, they make expedient
6 decisions based on what they can -- their
7 paycheck deductions are.

8 But it sounds like there could be
9 more robust conversations to help the consumer
10 tailor their choices based on their healthcare
11 risks.

12 And then the quality issue that
13 Lisa is bringing up is that in some places you
14 have got good quality to compare your health
15 plans but in other places, you are simply
16 relying on the coverage issue.

17 So, it sounds like it is an
18 emerging market, if you will, or emerging
19 field clearly now with universal mandate that
20 there will be a lot of vehicles emerging that
21 we can hopefully make better over time.

22 But does that help? Anybody else

1 want to common on that? Joe? Dorothy?

2 MEMBER SINGER: But people are not
3 exclusively, based upon the experience that we
4 have seen since enrollment started with ACA
5 and the exchanges, people are not always
6 choosing the least expensive plan.

7 You know everybody is not going to
8 bronze. And even those who are doing the
9 metals, bronze, silver, gold, and platinum,
10 even within any one class, they are not going
11 to the cheapest within each of those four
12 buckets. So, we are seeing people going to
13 gold plans and silver plans, not a lot of
14 platinum. So the middle groups are willing to
15 spend more than the minimally necessary but
16 even within that group, the majority of people
17 are not going for the cheapest block.

18 CHAIR MORT: Do you know anything
19 about why those decisions are? I am thinking
20 it might be the flip side of the Neiman
21 Marcus. You know you don't want the cheapest
22 because you think it might --

1 MEMBER SINGER: Right. I mean I
2 know from the Anthem WellPoint perspective we
3 are never the cheapest. Sometimes we are
4 middle to where -- we are rarely the least
5 expensive.

6 But people are picking that they
7 like the brand. They ask their peers. They
8 don't know maybe of the competitors. So,
9 there are other issues, maybe better marketing
10 but there are a lot of other factors that I am
11 not an expert on. I can't tell you the
12 difference but people are, you know, when they
13 make the decision to purchase, clearly, there
14 has to be other decisions, other than just the
15 bottom line cost.

16 CHAIR MORT: Okay, Melissa has a
17 comment related to that. Then, we will go to
18 Dorothy.

19 CHAIR THOMASON: I think for me,
20 when I look at healthcare plans, I may not
21 pick the cheapest one per month but I am
22 picking the cheapest for me in my assessment

1 of what will cost me less I the long-run.

2 So, it this one may be cheaper per
3 month but in the long-run, the 80/20 split or
4 the out-of-pocket max is higher, so it is
5 worth it for me to pay a little more every
6 month because on the back end of it, I am
7 still saving money.

8 MEMBER SINGER: You are a very
9 sophisticated consumer.

10 CHAIR MORT: Yes, I think we have
11 all learned that today, Melissa.

12 MEMBER SINGER: When most people
13 first timers or people who have been assigned
14 through their employer to an insurance
15 product, most people, and this is from my
16 experience as a primary care physician, too,
17 when people ask me what insurance to pick,
18 they don't know how to anticipate deductibles,
19 copays, utilization. That is really, really
20 hard to do.

21 So that when people are first
22 neophytes into getting insurance, it could be

1 aging in from college students, getting out of
2 the college program, or it could be people
3 newly coming into the exchange, they can see
4 out-of-pocket maximum but I doubt that many of
5 them really understand what that means.

6 And to look at copays and
7 deductibles and when they see a column of 20
8 numbers, primary care office visits,
9 specialist office visit, urgent care,
10 emergency room, hospitalization, PT, DME. DME
11 is not included in out-of-pocket maximum, all
12 that kind of stuff. It is very, very hard for
13 people to anticipate potential costs, if they
14 are not experienced looking forward.

15 CHAIR MORT: Great points.
16 Dorothy?

17 MEMBER SIEMON: I was just going
18 to say I just think it is still too
19 complicated. Just in my employee group, we
20 still have people who are highly sophisticated
21 in lots of areas of their lives but
22 understanding and predicting their own risk is

1 still very difficult for them.

2 Just making the decision of
3 whether they can go with the PPO or the HMO
4 because they might have more in-network versus
5 out-of-network costs, is a complicated
6 decision for a lot of people. So, the
7 information is still too complicated and the
8 presentation of it is still too complex.

9 MEMBER KEEFE: Even if you had the
10 information, I think sometimes making the
11 decision is difficult.

12 I mean I just wanted to chime in
13 because I think I am this population. I go to
14 the doctor. My husband doesn't. We have a
15 15-year-old daughter and I had to make the
16 choice. I am insured. We have a Cadillac
17 plan in our employ and we went to the -- I
18 have the choice of going to a high deductible.

19 Making the calculated risk about
20 moving from my PPO with full benefits to that
21 high deductible health plan, first I was like
22 oh, my gosh, if me and all the colleagues that

1 are like me jump, then that other full
2 Cadillac plan is not going to be available
3 next year. So, I was worried about skewing
4 the risk pool within my own little employment
5 opportunity.

6 But not knowing -- when you said
7 is the information sufficient, you know I mean
8 I didn't know. I said well how am I going to
9 know if I am even going to meet that
10 deductible or if that HSA is going to cover
11 that deductible? I didn't have enough
12 information, as sophisticated as I am looking
13 at all the health bills for my family, trying
14 to figure that out going into this new plan.

15 And so, I took a chance. And I
16 feel like that is what we are doing right now
17 is experimenting and taking a chance. So, I
18 have been in it now two years and have had a
19 very different experience than in a previous
20 plan and have a different, probably perception
21 of affordability. But I am still nervous
22 because you don't know. I mean I am healthy

1 and I have always been in a much more, very
2 rich benefit plan but those are no longer
3 going to be our options.

4 And so, what is the information I
5 am going to need five years from now to make
6 that calculated risk? And I don't know that
7 I have the answer to that but I do know that
8 I want to know that but you can't predict your
9 health. I don't know if I am going to have a
10 debilitating disease a year from now or not.
11 It is so challenging. And so for us to get
12 our arms around how you make those decisions,
13 I think is incredibly challenging.

14 CHAIR MORT: Clearly. Corey, did
15 you --

16 MEMBER WILBORN: I just wanted to
17 add on to that. When you do make that
18 calculated risk, what happens if the worst
19 happens and you do have those bills that you
20 have to see? Will that affect your future
21 choosing of a plan? And would it be, at that
22 point, because you had that experience that

1 you would choose a plan that was more benefit-
2 rich?

3 CHAIR MORT: Great thoughts.
4 Great questions.

5 Cynthia and then maybe we should
6 take on the next question like prevention,
7 preventive care.

8 MEMBER ROLFE: I just wanted to
9 briefly respond. Taroon was asking is it
10 possible to help people understand someone who
11 has these kinds of conditions, might
12 experience these kind of costs.

13 And as I talked about us as an
14 industry getting more comfortable with reviews
15 as a non-system, system, getting more
16 comfortable with reviews, we also have to get
17 more comfortable with lack of specificity and
18 precision. So, the concept of a good-faith
19 estimate. If you are a 50-year-old diabetic
20 who has the following kinds of treatment, just
21 a range of like five profiles of different
22 consumers who might have bought this health

1 plan and what kind of out-of-pocket costs they
2 experience. And that is a really hard for an
3 industry that is built on precision.

4 So, we all have to wrap our heads
5 around and then the consumer would have to
6 understand that it is just an idea. It is
7 just a picture. And that is probably the best
8 we could do.

9 CHAIR MORT: That is a lot more
10 than we have now. Those are great
11 aspirations. Just, hopefully, they are not
12 too far down the line.

13 So, why don't we -- Kris, did you
14 have a comment on the health plan decision-
15 making?

16 MEMBER SOEGAARD: Yes, it is just
17 a follow-up on what Cindy was saying.

18 CHAIR MORT: Okay.

19 MEMBER SOEGAARD: There are
20 employers that are doing that in their open
21 enrollment material, where they are taking a
22 single young male and they are giving a

1 scenario about he goes to the doctor once a
2 year, whatever. So, there are employers that
3 are doing that to try to help guide people to
4 make the right kinds of decisions, based on
5 somebody like them.

6 CHAIR MORT: Thank you. In the
7 interest of time, maybe we should consider --
8 I think we have touched on many of the points
9 on this slide. Why don't we think about that
10 next decision that we talked about? So, once
11 you are in an insurance plan, then you are in
12 the yellow or the green population, the
13 keeping healthy. And we talked about making
14 decisions to go to the doctor or not to go to
15 the doctor for screening, annual exams.

16 So, what kind of information will
17 we need in terms of cost and quality to make
18 those decisions? And is it available?

19 MR. AMIN: Yes, the way I heard it
20 was how do you make the case? I guess that
21 was sort of how it was framed. I think that
22 was a good framing.

1 CHAIR MORT: Yes, so how do you
2 convince someone? Now they have the benefit
3 for an annual preventive exam and how do you
4 make the case? Well, it is the cost-benefit,
5 the lost opportunity. And a lot of plans now,
6 they start ping-pong you. Some of them work
7 with employers to tag onto the paycheck. So
8 people look at their paycheck and there is
9 "You are due for your." So, making the case,
10 urging people to do it, making it easier.

11 Maybe we covered kind of enough on
12 that already in our prelude.

13 MR. AMIN: Yes, and I think what I
14 am hearing as well is that, given the changes
15 in the ACA around making the cost benefit
16 their first dollar coverage, it may direct
17 affect the affordability question.

18 If there is more there, I am happy
19 to hear it. We can just make sure we capture
20 it.

21 CHAIR MORT: Melissa?

22 CHAIR THOMASON: When seeking

1 preventive care, I guess really the big thing
2 is it is frameworking risk and how do I
3 perceive myself to be at risk. And I am not
4 sure we really graded that. I think that a
5 lot of things like -- so even back when I am
6 purchasing the health care plan, when I need
7 to decide if I need to go have these tests
8 done, it is am I really at risk. So, is it
9 worth it to go have this done?

10 I wish we had more time to explore
11 the factors that go into that but my age, my
12 genetics, what is their history of in my
13 family? Things like that really help me
14 decide am I really at risk or not because I am
15 constantly making that decision, as a
16 consumer.

17 CHAIR MORT: Good point. Making
18 the case but based on your individual risk
19 factors.

20 Oh, boy. Three popped up. Who
21 was first? Kris, go ahead.

22 MEMBER SOEGAARD: And maybe some

1 of the health plans could speak to this. I
2 think people are starting to use incentives in
3 certain ways within health plan coverage,
4 either by the employer, by the health plan,
5 whatever, to try to get people to do these
6 preventive care services. So, that is another
7 component.

8 CHAIR MORT: Good point. One of
9 the pieces of information would be is there a
10 deal here for me.

11 I think Carrie and then Lisa.

12 MEMBER NELSON: I think this is a
13 really problematic area because health care
14 providers have a lot of bias they bring to
15 these conversations. So you know, when should
16 a woman start getting a mammogram? Should you
17 do a comprehensive blood test on every person,
18 as a matter of routine? And there is costs
19 associated with overutilization. And so I
20 think that is the part that we probably fall
21 down on the most is the costs associated with
22 too much healthcare, too much screening,

1 perhaps. I think people are much more swayed,
2 sometimes, by fear. The classic Pink Ribbon
3 Campaign has really got people thinking that
4 they should get mammograms earlier and more
5 often, when in fact that has its own costs
6 associated with it.

7 CHAIR MORT: Is another way of
8 saying that is that you need more information
9 on appropriateness?

10 MEMBER NELSON: I think that is
11 absolutely right, yes.

12 CHAIR MORT: And you know,
13 mammograms, 40 to 50, maybe there is some
14 wiggle room; 50 and above, the data are pretty
15 fair. But even with the data, you would want
16 to have the patient or the consumer weigh in
17 and understand what their risk tolerance is.

18 MEMBER NELSON: Right, in an
19 objective way.

20 CHAIR MORT: Yes, excellent.
21 Lisa.

22 MEMBER LATTS: So, I was going to

1 sort of move off of the sort of preventative
2 topic to the first question from a chronic
3 disease perspective. Is this the appropriate
4 time to do that or do you want to not talk --

5 CHAIR MORT: Maybe not chronic
6 disease but disease, as opposed to preventive.

7 MEMBER LATTS: Do you want me to
8 hold that?

9 MS. WILBON: Yes, if you guys are
10 ready to kind of move on to the next bubble,
11 if you will, I think that might be the
12 appropriate transition, if people feel that we
13 have kind of gotten most of the issues on the
14 table.

15 CHAIR MORT: I think we have had a
16 really good discussion on the preventive and
17 the fact that we added in the insurance plan.
18 We got a lot of information there.

19 MR. AMIN: I would just ask as we
20 move into this next phase, just keep in mind
21 if we can frame it in the sense of what the
22 decision is and if there is some overarching

1 context like emergent versus non-emergent and
 2 then what the decision is. That will help us
 3 understand how to take this -- what
 4 information we are looking for.

5 So, if that could be your starter,
 6 what decision you are making.

7 CHAIR MORT: Melissa is going to
 8 facilitate.

9 CHAIR THOMASON: Sure. Do you
 10 want to clarify emergent versus non-emergent?

11 MEMBER LATTS: Yes, that is one of
 12 the things I was going to bring up, yes.

13 CHAIR THOMASON: Okay, Lisa, if
 14 you want to go ahead.

15 MEMBER LATTS: Yes, so that is
 16 back to this first question, then. In terms
 17 of I think the question may be slightly
 18 incorrectly phrased, in terms of being
 19 diagnosed with an illness. And that may be
 20 different than experiencing an illness or a
 21 symptom.

22 So, I think that the information-

1 seeking has to happen when someone has a
2 problem for which they are going to seek care.
3 And that is differentiated by emergent, where
4 there is very little time versus someone who
5 has the luxury to do research. And then it is
6 a matter of what sort of information is
7 available and where do they find it.

8 And realistically, everyone's
9 first source of information is Google. You
10 come down with a symptom. You open Google or
11 Bing or Yahoo and you do your search. And so
12 that is where people are going to start, for
13 the most part. Or you ask your parent if you
14 are a teen.

15 MEMBER NIELSEN: Although rare,
16 academia occasionally has something to offer
17 us.

18 (Laughter.)

19 MEMBER NIELSEN: And as we are
20 having this conversation, I had a flashback to
21 entirely too many classes in social and
22 behavioral science, which is what my Ph.D. is

1 in. And so, there are actually models that
2 frame this entire discussion. And my personal
3 favorite is the Health Belief Model. And so,
4 I promise I am not going to walk you through
5 the whole thing but there are words for this
6 that we would need to convert into English for
7 it to mean something to consumers. But when
8 Melissa talks, I hear these concepts.

9 First, it is perceived
10 susceptibility. So, your opinion of whether
11 or not you are going to get the condition.
12 Next, is perceived severity. Your opinion of
13 how serious this condition is and what its
14 consequences are.

15 Next, is perceived benefits, your
16 belief in the efficacy of whatever the advised
17 action is of your provider or your health plan
18 to reduce risk or the seriousness of the
19 impact. There is just three more.

20 Perceived barriers, which is huge.
21 Barriers is a big piece of this. One's
22 opinion of the tangible and psychological

1 costs of the action. Hues to action. So
2 strategies for you to actually engage in
3 whatever it is, the behavior. And that is
4 when you need to give how-to information,
5 promote awareness, et cetera. And then
6 finally, is self-efficacy, your confidence in
7 your ability to actually do something about
8 it.

9 So again, I see all these things
10 being related to affordability but I feel like
11 we keep broadening the scope. And there are
12 places that we can go that link back to this
13 without us having to write up too much new
14 stuff because this Health Belief Model is old,
15 old, and old. I mean I was in school a super
16 long time ago.

17 CHAIR THOMASON: I think that is a
18 really great point. They said that so well.
19 I was like, wow, they really got that! Yes,
20 they did.

21 But my perception of all of these
22 things and what is my risk and how can it help

1 me and all of those things. It is a very good
2 point. Paul?

3 MEMBER SIERZENSKI: In the world
4 of emergency medicine, we are kind of trying
5 to, although we don't want to broaden too much
6 here, we are trying to broaden away from just
7 the concept of emergency. Because I think
8 when we talk about emergency, everyone is
9 thinking emergency department. But we are
10 starting to use more frequently the issue of
11 scheduled care versus unscheduled care, and
12 acute unscheduled care, recognizing that the
13 cost of acute unscheduled care in nearly all
14 of its environments is greater than the cost,
15 likely, of scheduled care.

16 And so although I like the term
17 emergent because it is what I do, I think it
18 kind of, it really does pigeonhole things a
19 little too much.

20 CHAIR THOMASON: So then, Paul,
21 where do you classify if I don't have a
22 primary care physician but I just go to the

1 clinic, not necessarily scheduling an
2 appointment, but I am going for strep throat?
3 It is not scheduled but I don't consider it
4 emergent care.

5 MEMBER SIERZENSKI: We would
6 define that as acute unscheduled. And what
7 you are using is you are using a facility that
8 is designed for acute unscheduled care and
9 there would probably be another 50 patients
10 like you, who have those same symptoms who are
11 actually using the emergency department. And
12 so it allows an understanding of acute
13 unscheduled care and utilization with acute
14 unscheduled care. And I think the issue is,
15 is does a patient or a consumer who is having
16 a symptom-driven complaint, do they feel that
17 they need to activate healthcare system now or
18 can they wait? And that we are looking at
19 that as a way of how are they triggering acute
20 unscheduled care versus scheduled care?

21 CHAIR THOMASON: I think the
22 reason that I couldn't, me, personally, that

1 I couldn't use the word emergent was because
2 scheduled or not, if I have the choice of
3 whether or not to have this, then I will look
4 more at affordability than my life is at stake
5 or something just happened to me and I have to
6 have it treated.

7 So, when I say emergent, I mean my
8 choice of appropriateness is taken away. I
9 have to have something done. And that focuses
10 -- my perception of affordability, I mean it
11 really drastically changes there. When my
12 life is at stake, I don't think a lot about
13 money.

14 Ron?

15 MEMBER WALTERS: Yes, and I agree.
16 I don't remember where I read the Health
17 Belief Model but somewhere way back in the
18 past century. But I think this literally --
19 the thing and we are kind of getting to it,
20 what does come immediately into play here is,
21 is this arthritis, or is this a heart attack,
22 or is it a dissecting aneurysm, or is it

1 cancer. Which, I can tell you I mean cancer
2 is a very scary word. It carries all the
3 implication of a dissecting aneurysm, though
4 many times it is not. It is just emotional
5 aspects to it.

6 But I think it is the perception
7 of I would say acuity or immediate threat to
8 life that tempers the affordability aspect of
9 it. And that happens pretty quickly.

10 So, if I tell you you have got
11 arthritis, well, my back hurts. It is
12 arthritis but it isn't going to kill me. And
13 all of a sudden, my mind shifts into
14 affordability mode of all right, what do I
15 have to do? How do I have to feel better?
16 Can I put it off, all those other things. But
17 there are other conditions that you don't even
18 go into that. Or you may go into that mode
19 but you go into it for like a second or two.
20 And then you quickly shift out of
21 affordability mode right away.

22 And I think that is where this

1 comes into play is the perceived impact of the
2 problem and the perceived ability of
3 intervention to impact the outcome.

4 So, I don't know. I would say in
5 this group there are, again, somewhere
6 affordability comes right into play and other
7 ones where affordability is not even a
8 consideration.

9 CHAIR THOMASON: So then, I wonder
10 how much time we actually need to spend
11 talking about emergent care. Because if our
12 charge is really on affordability, I never
13 consider affordability in emergent care. It
14 is always who is the closest.

15 I will say that quality factors
16 in, though. Because I have told my family the
17 hospital that is closest to my house, if I
18 pass out in the parking lot, you better fly me
19 somewhere else. And we laugh when we say that
20 but I don't trust them with my disease. And
21 so, quality did factor in but never
22 affordability really into emergent care.

1 So, do we want to focus on --

2 MR. AMIN: No, I think it would
3 probably make sense to move on. I think the
4 first decision is probably -- well, maybe not
5 decision, but the first question is, whether
6 it is emergent or not. If it is emergent, the
7 issues of affordability are retrospective, at
8 best. Right?

9 So, let's move on to --

10 MEMBER WALTERS: Not emergent. I
11 mean, I agree.

12 MR. AMIN: Okay, so what is the
13 proper term, then? The perceived.

14 MEMBER WALTERS: Perceived. It is
15 the words that we are using in the model. It
16 is the perceived immediateness of the problem.

17 MR. AMIN: Okay, got it. All
18 right.

19 CHAIR THOMASON: I would like to
20 know if my fellow consumers, though, or my
21 frequent fliers -- I know we are all consumers
22 -- agree with that assessment of emergent care

1 and how that really, you don't take
2 affordability into account so much.

3 MEMBER THOMPSON: We actually
4 talked about this the other night with an
5 example that Melissa had given us about her
6 brother seeking emergent care and trying to
7 figure out whether to go or not.

8 And one of the questions that came
9 up was how would you even begin to think about
10 emergency rooms as affordable. Like, how
11 could you do that when I don't know what is
12 going to happen when I go in there? But what
13 I would want to know is how much does it cost
14 for me to walk through the door? Like if
15 nothing is wrong with me at all and you don't
16 do an MRI, you don't do a CT scan, just for me
17 to walk in the door and for the doctor,
18 whoever, to say, there is nothing wrong with
19 you, walk out. Like, how much does that base
20 cost?

21 Because my partner, he screws up
22 his body all the time. He is a construction

1 worker. He breaks things. It is constantly.
2 And every time we go to the emergency room, it
3 is always a debate. Do we go? Do we not go?
4 How much is this going to cost? Can we wait
5 until tomorrow?

6 And I think I could make that
7 decision if I knew some sense. And I know it
8 is really hard because what if he goes in and
9 he has cancer? You know, I mean that is
10 obviously going to be a lot more. But if it
11 is just this basic thing, what does that cost
12 me? Because I think that helps me make the
13 decision between do I go now or do I wait 12
14 hours when something is open the next day when
15 I can make an appointment?

16 CHAIR THOMASON: I think you bring
17 up a real good point in that we can't -- it
18 was easy for me to say well, there is no
19 appropriateness of care issue because I had
20 the CT. I had a dissection. I have to have
21 the surgery.

22 But when you are trying to decide

1 should I go to the emergency room, it is a
2 really big decision and that appropriateness
3 of care really weighs into your decision.

4 Thank you, Adam, for bring us back
5 to that.

6 Paul, and then Maureen and Joe.

7 MEMBER SIERZENSKI: Yes, just not
8 to get too into the weeds. I think that
9 making the recognition that emergent care,
10 which is basically prudent layperson care,
11 because we have got rolls that cover this, you
12 think you are having something that is
13 potentially a life-threatening issue. You
14 should go. You should be covered. And issues
15 such as other federal regulations, such as
16 EMTALA, for the emergency provider really do
17 restrict our ability to basically post on the
18 door this is what it costs for you to walk in.

19 And so, it may be helpful, just
20 from a paper standpoint, to say one of the
21 things that is difficult to address with
22 emergent care is the fact that, one, there is

1 clearly a patient consumer perception, which
2 is their belief that they are having an
3 emergent, life-threatening issue, because the
4 vast majority of chest pain that we see is not
5 cardiac.

6 And then after they get evaluated
7 and discharged and they get a zinger bill,
8 which, trust me, is not my fee. It is
9 hospital-based fees. They feel their value
10 and their affordability is less because
11 everything was, essentially, checked out and
12 appropriate or negative from the work-up
13 standpoint. But it is very difficult for us
14 to have that discussion because until we have
15 the evaluation, we really are restricted by
16 federal law to talk about dollars in the world
17 of emergency medicine.

18 What we have to do is do a medical
19 screening exam first and then there are only
20 some states that allow you. So, just raising
21 that issue for the writer, may be a way to try
22 to address that to say we have got some work

1 to do.

2 Congress has twice tried to
3 address issues of EMTALA. Both of those large
4 panels came up with no conclusion on how to
5 modulate the wording.

6 CHAIR THOMASON: Very helpful.
7 Liz, do you want to comment on that?

8 CHAIR MORT: Just specifically --
9 excuse me, Maureen -- is that many health
10 plans now are publishing on your little card
11 what your copay is for the emergency room.
12 Because of utilization management and so on,
13 they are really upping it. It is \$150 now
14 instead of a \$20. So that piece, the copay
15 part is visible, more and more so.

16 MEMBER EDIGER: So, I think my
17 son's condition, having hydrocephalus and
18 being shunted for hydrocephalus, and I think
19 about how Maureen, the mom, reacts now to a
20 seven and a half year old versus how Maureen,
21 the mom, at six months old and it is so much
22 of it is about education and knowing what is

1 a shunt failure symptom, what I can let go for
2 12 hours and maybe in more of a wait and see
3 mode. Because if I go to my primary care
4 physician, the pediatrician and say, I don't
5 know. Everett has been throwing up. His eyes
6 look like they might be crossing a little bit.
7 What should I do? They are going to send me
8 to the emergency room every time because my
9 pediatrician never wants to be responsible for
10 not telling me to go.

11 So, I don't even call my
12 pediatrician anymore when I am concerned about
13 those things, other than to say hey, just so
14 you know, we are on our way to Children's.

15 But honestly, the factors that I
16 consider if I am worried about Everett and I
17 have become quite the diagnostician about
18 shunt failures and urinary tract infections
19 and everything. But with him, I think about,
20 okay, if I go now, where are the other three
21 kids? How much time are we going to be in the
22 hospital? Okay, this time of day it is going

1 to take me 45 minutes to get there. If I am
2 stuck in the ER, this is a busy time of day.
3 There are so many factors that go into me
4 deciding do I go in and get the CAT scan.
5 Because that is the first thing they are going
6 to do, if I go in through the emergency room.

7 So, just it is really complicated
8 when I decide what to do. And I do factor in
9 like how expensive CAT scans are because
10 nothing makes me feel worse than -- well, it
11 makes me feel very bad to go in and know that
12 I have got a very expensive procedure to find
13 out, oh, no, it is just a stomach bug, 12
14 hours later.

15 CHAIR MORT: I just want to ask
16 the group, you know we are talking a lot about
17 the emergency room. But what about if you
18 have a symptom that you have a sense that it
19 is not serious enough to need the emergency
20 room but you need to be checked out? So, I am
21 just trying to think about something. You
22 know a little bit of acid reflux or -- Maureen

1 is right there.

2 MEMBER EDIGER: Well, the other
3 part of what I was going to say is having a
4 relationship where I know this is where
5 choosing the doctor's offices that I have so
6 carefully. Because I know there are offices
7 I can call and get a nurse to return my call
8 within 30 minutes or I have the nurse has
9 given me her cell phone number and I can just
10 text her say, Carol, I am worried about blah,
11 blah, blah, and they get back to me. And that
12 can avoid a whole trip to the emergency room.

13 So, I think with patients who are
14 frequent fliers and being able to have some of
15 those relationships has kept me out of the
16 emergency room so many times. Or like not
17 emergency room but also like clinic visits or
18 we need to be seen right away.

19 CHAIR THOMASON: Me, too. And
20 affordability factors into my decision some
21 when it comes to clinic visits but a lot when
22 it comes to the emergency room. When I am

1 going to the emergency room, it is a whole
2 debate in the car for 30 minutes on the way
3 there. It really, really, appropriateness of
4 care factors in so much into emergent
5 decisions for me.

6 Marci, and then I think we
7 probably need to move into non-emergent care
8 and how we make those decisions.

9 MEMBER NIELSEN: Well, and this
10 gets back to a conversation we started this
11 morning about the difference between frequent
12 fliers and all you have learned about the
13 health system and your own condition or the
14 condition of your child versus consumers who
15 are generally healthy and don't interact with
16 the health system much and that the factors
17 that go into that decision-making process
18 differ quite a bit. And that is where this
19 Health Belief Model is helpful because it is
20 about self-efficacy.

21 So, you have attained a level of
22 self-efficacy about your health or your

1 child's health that empowers you a bit more.

2 It doesn't mean you don't factor into
3 affordability. And depending on your
4 socioeconomic status or your health insurance
5 status, that, too, plays in.

6 I just keep coming back to how you
7 write this paper. And maybe I just need to
8 let that go. And we just need to have the
9 conversation and the brainstorming. But how
10 you frame this in a way so that the person
11 reading this says yes, this makes sense to me
12 and I recognize that it is a scale. If I am
13 really knowledgeable about the health system,
14 I do things differently than if I am not. If
15 I am loaded versus I am poor, I do things
16 differently. If I have health insurance or I
17 don't, I do things differently. Like, all of
18 these things fall along a spectrum.

19 And again, I just keep thinking,
20 how do you frame the paper, initially, so that
21 the rest of this dialogue fits in neatly? And
22 I don't necessarily have the answer. I would

1 just tell you one small anecdote from somebody
2 who is healthy but very self-actualized when
3 it comes to healthcare which is, I fell off my
4 bike last year and I figured that something
5 went wrong when I couldn't switch gears on my
6 bike, as I was riding back up the hill. But
7 my priorities were to get my nails done. And
8 I went from many, many hours with a broken arm
9 getting my nails done, which are Jayhawk
10 colors for you KU fans out there.

11 So, the guy doing my nails was
12 freaking out. You think your arm is broken?
13 Yup, I am almost positive. I can't stand to
14 touch your hands. I want my nails done! I am
15 going to D.C. tomorrow. I am not going to
16 futz around with this.

17 (Laughter.)

18 MEMBER NIELSEN: So, like how do
19 you factor that in? Right? So, these are
20 people's individual lives. And we could all
21 think of our example.

22 So, there you have it.

1 CHAIR THOMASON: That was very
2 helpful! Thank you, Marci.

3 MEMBER NIELSEN: I will say they
4 all went together. They were all color-
5 coordinated.

6 CHAIR THOMASON: I will say that I
7 have never gotten my nails done with a broken
8 arm, though. That is a unique perspective.

9 I will add to, before we move on,
10 that when you were talking about differences
11 in a patient versus a consumer, and frequent
12 fliers, and all that stuff, I will add that I
13 hope very soon we do a better job in
14 healthcare of providing more information for
15 general consumers on appropriateness because
16 even if we don't provide expert information,
17 these consumers that are inexperienced will
18 find their own experts.

19 So like we were saying earlier, it
20 might be your best friend, and in my family it
21 is me, it doesn't matter if I am an expert or
22 not, I am going to have to be one for my

1 brother or for my mother, and they are going
2 to call their frequent fliers and say I really
3 got to make a call. Do I go to the emergency
4 room or not?

5 So whether we provide the
6 information or not, whether they are real
7 experts or not, they are using them, our key
8 learners, for sure.

9 MEMBER NIELSEN: Well, and I will
10 end by just saying you know I work for the
11 PCPCC. And what we believe to be true and
12 what the evidence supports is when you have a
13 trusted health care provider, often your
14 physician, but sometimes your nurse
15 practitioner, that relationship, because they
16 know you, they know your perceived benefits or
17 excuse me, your perceived self-efficacy, they
18 know what your barriers are, they know if you
19 have insurance, that healing relationship is
20 what is supposed to help us.

21 The struggle I think we have, and
22 I don't know if we want to say this in the

1 paper is, we train doctors to not focus on
2 affordability. They are about healing you.
3 And so we are putting clinicians in this brand
4 new set of social pressures and circumstances
5 for which many have not been trained. And
6 they are very uncomfortable with it and a lot
7 of patients don't like it. They actually
8 don't want to talk about the cost of care with
9 their provider because it is supposed to be
10 more pristine.

11 CHAIR THOMASON: Yes, go ahead,
12 Lisa.

13 MEMBER LATTS: So, that is
14 actually a great point, Marci. And I don't
15 know if it is outside the scope of this
16 discussion but traditionally, in medicine it
17 was always your obligation is to the patient
18 100 percent. Do the best for that patient.
19 Damn the cost, full speed ahead kind of thing.
20 And it is only in the past, this decade, the
21 past five years really, that the concept of
22 stewardship of resources from a professional's

1 point of view, and somebody mentioned choosing
2 wisely, and just the whole idea overall of
3 health medicine and the healthcare system is
4 actually a scarce resource. And as a
5 physician, we have obligations to steward that
6 wisely and to start thinking about how do we
7 ration. And nobody ever wants to use the R
8 word. But how do we ration these scarce
9 resources in a way that is most appropriate.
10 And that is a very new concept in medicine.

11 CHAIR THOMASON: The conversation
12 has definitely changed just even since I have
13 been sick. Absolutely, the conversation in my
14 providers' offices has changed.

15 Taroon -- yes, go ahead.

16 MS. WILBON: I just actually
17 wanted to piggyback on Marci's comment before
18 we got too far away from that in terms of kind
19 of putting --

20 MEMBER NIELSEN: Are you a
21 Jayhawk?

22 MS. WILBON: No, sorry. I went to

1 Michigan. Go Blue! And I am wearing blue
2 today.

3 (Laughter.)

4 MS. WILBON: My nails aren't blue.

5 But we have been talking, the
6 staff, kind of in-between breaks and stuff
7 about how to capture this information in a way
8 that could be visually appealing and kind of
9 walk people through the conversation that we
10 have been having. And I think where we landed
11 at is really the person is the measure and
12 that there is no measure, per say, for
13 affordability. But I think what we are
14 hearing is that no matter how the individual
15 weighs those different factors, that the
16 decision point is still kind of the same. So,
17 whether or not to go to the ER, weighing risk,
18 and so there may be a few others. If that
19 conversation, it would be nice to kind of hear
20 some more discussion about what maybe some of
21 those other decision points are, kind of
22 recognizing that depending how experienced of

1 a consumer you are, what your health status
2 is, what other resources you may have, that
3 the decision still may be the same but that
4 the factors that you are considering to make
5 that decision are going to vary. So, I don't
6 know if that helps the discussion at all. But
7 what we are trying to kind of narrowing down
8 is that the decision point is still the same
9 for all those different people, depending on
10 -- regardless of where you are coming from.

11 CHAIR MORT: If I could just add
12 to that. What I am hearing consistently about
13 whether it is a decision to go the ED,
14 emergency room, or to an office visit, one of
15 the key factors is do I need to go. And that
16 had never occurred to me. I mean I understand
17 what it means you need to go but I thought
18 there would be other factors. And it is very
19 enlightening to me to understand that if
20 someone is going to have to pay copay, or take
21 time off from work, or put their kids in the
22 car and take them to the emergency room, all

1 of that disruption is big. So, you really
2 want to know do I need to go. And where on
3 earth are consumers going to get that
4 information? If you have a good practice that
5 you can have a text to the nurse or a good
6 call line, but that is just really kind of it
7 is an epiphany to me how important do I need
8 to go is.

9 CHAIR THOMASON: I will add, too,
10 from a consumer standpoint, almost everything
11 in my life that I have purchased -- because I
12 don't work right now. Everything I do for the
13 hospital is volunteer. I was a teacher before
14 and you know how they pay teachers. So
15 everything in my life was based on do I need
16 this and healthcare was the exact same way.
17 And once I know I need it, oh, okay, now I can
18 make an informed decision based on quality and
19 price.

20 So, Lisa and then Joe. Joe?

21 MEMBER SINGER: I mean that is a
22 huge decision for people, do they seek care or

1 not. There are mechanisms for people to help
2 them with those decisions now that tend not to
3 be utilized. I mean most health plans have a
4 24-hour nurse call line, where they can call
5 a nurse and discuss with them. And the
6 decision, the tendency is to move people up
7 along the level of care and not to
8 underestimate what is happening. And those
9 nurses can issue preauthorizations and do
10 everything they need to make sure things get
11 done well. And I can tell you it is used
12 single digit percentage of the time, when it
13 is possible.

14 Some health plans have live health
15 online, where people can go online and do a
16 video conference, actually see the physician.
17 The physician can write prescriptions if they
18 meet certain criteria. And it is an office
19 copay. So, it is access. They don't even
20 need to leave their house to see a physician.
21 And if they get referred to an emergency room
22 or an urgent care center, there is no charge

1 for that encounter.

2 So, part of this is anticipatory
3 intervention and educating people that it is
4 a \$20 copay for an office visit, a \$30 copay
5 for an urgent care center or retail in one of
6 these nurse or pharmacy-based retail health
7 clinics. And it is \$150 if we go to the
8 emergency room. So, if people really
9 understand what their alternatives are, again,
10 it is their perception of how urgent and life-
11 threatening the situation is.

12 Access and availability now is
13 becoming less of an issue. And it is an
14 education of people to understand how they can
15 best utilize resources.

16 CHAIR THOMASON: And I think, too,
17 letting those people know what resources they
18 have at their disposal to decide if care is
19 appropriate.

20 On Sunday night, my brother was
21 like should I go? Should I go? And I said do
22 you have a nurse care line? I don't know. Do

1 I? I said pull out your card. I have one!
2 And I said call them. And they said go. It
3 sounds like a gall bladder. You want to make
4 sure it is not an attack.

5 Deb and then I don't want us to
6 run out of time before we really clarify and
7 address some of the particulars of the
8 selection of a physician, selection of a
9 hospital, things like that and what really
10 goes into our decision to choose that doctor
11 or this hospital.

12 MEMBER DAHL: I just want to say
13 that we have been talking about people making
14 decisions as though this was an intellectual
15 choice only and Marci's comment about the
16 broken arm and I will get to that after I get
17 my nails done.

18 Last time I was in D.C., I fell
19 down the steps in the Washington Monument,
20 which was our first monument. And so I just
21 went through the whole next three days going,
22 it is just sprained. It is just sprained. It

1 is just sprained. And then I am back at the
2 hospital that I was working at and the
3 orthopedic surgeon said, why are you limping?
4 And I said it is just sprained. And he looked
5 at it and said, no, it is really not.

6 And then the next week, I am at
7 home and my husband broke his little toe. Oh,
8 my God! I have to go to the ER right now, I
9 have broken my toe.

10 (Laughter.)

11 MEMBER DAHL: I said, oh, my God,
12 no, you don't. So, what does he do? He picks
13 up the phone and calls his brother, who is an
14 OB/GYN, like that is going to make any
15 difference.

16 (Laughter.)

17 MEMBER DAHL: He just laughs
18 hilariously, no, you don't need to go.

19 PARTICIPANT: He needs a PAP
20 smear.

21 MEMBER DAHL: Yes. Are you in
22 labor?

1 (Laughter.)

2 MEMBER DAHL: So, then he calls
3 his nephew, who is an intensivist, critical
4 care medicine who also just laughs
5 hilariously.

6 And finally, he gave up with the
7 my toe is broken and I don't need to go to the
8 ER. But that emotional decision plays a huge
9 role. And I don't care what kind of facts you
10 throw at people. We will just make those
11 decisions that are stupid either way. You
12 don't need to go to the ER if your broke is
13 broken. If your leg is broken, it would be
14 good if you went ahead and got it taken care
15 of.

16 CHAIR THOMASON: That is a really
17 good point, really, really good point.
18 Because I have family members that almost, no
19 matter what is wrong, some will go and some
20 will not. So, it really is, there are other
21 factors besides the intellectual decisions.

22 So, I wanted, Taroon, can you

1 clarify, too? I know, as a consumer, when I
2 look at selection of a physician or a hospital
3 or we covered this morning a lot about
4 quality. And when I look at which doctor I am
5 going to choose or which hospital I am going
6 to choose, so much of that is quality. Do we
7 need to specify particular points, so not
8 quality at large, but I want to know the
9 number of days since a serious safety event.
10 I want to know. Do we specify those quality
11 things or do we stick to affordability at this
12 point?

13 MR. AMIN: Well, I would maybe
14 frame the answer as saying that we talked a
15 lot about the emergent decisions at sort of
16 this, your acute episode has begun. We also
17 talked about at the population at risk phase
18 the decision about whether you need something
19 or not. I guess I would ask is there a nuance
20 between sort of this elective decision of
21 seeking care and does that elective decision,
22 what is in that decision with an elective

1 procedure or condition? I mean these are some
2 potential ideas about what are the
3 alternatives, what are the -- how do you weigh
4 the various alternatives? How much is cost in
5 part of that decision? And maybe the
6 physician and hospital, as you are selecting
7 those, how are you considering cost in that
8 decision?

9 So maybe I would just ask for a
10 conversation around the elective procedures or
11 conditions and how that decision-making
12 process works and how much affordability plays
13 into that, cost in particular.

14 CHAIR THOMASON: I know for me it
15 is always perceived benefit versus cost. And
16 like someone said earlier, is it worth it?
17 And it all comes down to that for me. Is it
18 really worth it?

19 Cynthia.

20 MEMBER ROLFE: What I would like
21 to just contribute to that question is there
22 are procedures where people seem to be very

1 willing, based on the evidence we have seen,
2 to shop around for cost. And actually,
3 Melissa was giving a great example, DME
4 procedures, MRIs, that kind of thing. They
5 are very willing to because it is not
6 invasive. It is just kind of impersonal
7 anyway. So, they don't mind.

8 When it comes to shopping for
9 facilities in which to have a procedure, it is
10 very uncommon because you choose your doctor
11 and your doctor has affiliations and
12 preferences and you want the doctor you have
13 chosen to be at the facility where they have
14 the relationship and the status and the staff
15 they want.

16 And so I actually cannot recall a
17 single consumer in the last two years we have
18 heard talk about actually actively choosing a
19 facility for a surgery.

20 CHAIR THOMASON: I can say that I
21 have actively chosen a facility for a scan but
22 that is because I have done it so many times.

1 For a long, long time, you made the initial
2 decision of choosing your doctor and then
3 everything else was chosen for you, based upon
4 the physician you chose. So, that is a really
5 good point, Cynthia.

6 Deb and then Lisa.

7 MEMBER DAHL: I do think people
8 choose their health plans based on the
9 facilities that are in those programs. So
10 they may pre-choose so they don't have to
11 choose later.

12 We were just talking about Corey
13 chose one because he is near Mayo and that is
14 his preference. I made sure my sisters chose
15 one that had a Banner facility in it, so I had
16 some influence.

17 MEMBER LATTIS: I just -- we have
18 been talking around it but I just want to
19 introduce the concept of commodity.

20 So, the reality is CT Scans, labs,
21 DME to some degree. Those things are
22 commodities. So, you price shop and they are

1 very price sensitive. Whereas, the things
2 that are not commodities, your physician, the
3 procedure that your physician or a specialist
4 physician is going to do are not commodities.
5 So, things that are commodities, they are much
6 more price-sensitive than things that are not.

7 MR. AMIN: Can I ask a follow-up
8 on that question? So, this issue of
9 commodities, how does that vary depending on
10 the level of frequent flier of the customer?
11 So, do all customers recognize the
12 commodities? And in addition to that, how
13 transparent is the information about cost or
14 pricing, even for the commodities?

15 MEMBER LATTS: I think it depends
16 on how sophisticated the consumer is and the
17 availability of those resources.

18 So, I think it was Alyssa's
19 brother where the health plan called -- I
20 wonder if it was Anthem -- that called and
21 said you can get the exact same scan at these
22 five places for cheaper. And its insertion at

1 that point in care to educate people that this
2 is a commodity and it can be provided cheaper
3 here. Because reality is, even most
4 physicians don't know. Most physicians have
5 no idea in the variability of pricing for
6 these various commodities because the
7 physicians don't care. I mean as long as the
8 quality is relatively equal and they have
9 access to the films or to the results, they
10 don't care where it gets done. But they don't
11 have the information either. So, within the
12 health system, the information on that is not
13 any more readily available.

14 CHAIR THOMASON: I just remembered
15 when Lisa said that when we were talking
16 earlier about preventative measures, both of
17 my parents are required by their insurance to
18 have these preventive scans or they lose
19 insurance entirely. So, it is a requirement.
20 She has to have it done or she loses her
21 insurance. So for them, it is not a choice.
22 They absolutely have to have it.

1 And then when we are talking about
2 choosing the hospital and things like that, I
3 really just chose my doctor. And I really did
4 just say okay, that guy is a specialist in
5 Loeys-Dietz. I did switch physicians. The
6 guy who did my first open heart surgery had
7 never heard of Loeys-Dietz syndrome. And I
8 found a specialist through the Loeys-Dietz
9 Syndrome Foundation and switched my care to
10 him.

11 But upon switching my care to him,
12 I didn't decide much for a long time. He
13 decided everything.

14 Carrie? Oh, Tayler.

15 MEMBER NELSON: I mean I was just
16 going to follow-up on the conversation just
17 about knowing what is a commodity and what
18 isn't. I mean I like to think I am relatively
19 well-educated but I have definitely been
20 through the ringer of having a lot of elective
21 procedures that didn't need to happen. I
22 didn't know what was a commodity and what

1 wasn't. I didn't know to shop around. I
2 didn't know where to find the price.

3 That is just my experience. And
4 it is with things that the consequences if you
5 don't find out could be huge. And that is
6 scary as the consumer to not really know. And
7 so I think that has been prevalent in my
8 experience.

9 CHAIR THOMASON: And then how do
10 you know on the back-end, once you realize oh,
11 I didn't have to have that done, and you are
12 paying that bill?

13 MEMBER NELSON: I think my
14 experience has just been how little follow-up
15 there is. That has kind of been a signal to
16 me. Like, I will get my results back and they
17 will be fine. I won't even get a call from
18 the doctor. I will just a call from the
19 facility. It was negative. And there is zero
20 follow-up whatsoever.

21 It is like well, if this could
22 have had consequences, like why aren't you

1 following up more with me? That is just how
2 I have been deducing it, I guess.

3 And then again, you get that bill
4 and that value really diminishes all of a
5 sudden when you see a price tag.

6 MEMBER FRONTERA: I'm not sure if
7 with more transparency, more time, and more
8 communication if we will see more of this, but
9 I have seen some instances where consumers are
10 choosing other things. They are choosing
11 their physician but they are choosing a
12 facility differently.

13 So, my example of normal vaginal
14 delivery was one. You might have an OB/GYN
15 that delivers in three hospitals and the
16 couple may choose to go to a better facility.
17 I had once consumer tell me that my concept of
18 value for a hospital for my wife when she
19 delivers is yes, the cost, and also if they
20 have Wi-Fi in the waiting room. So, that was
21 their value.

22 (Laughter.)

1 MEMBER FRONTERA: And so other
2 kinds of elective procedures, too, that
3 hysterectomy example was on.

4 Plastic surgeons have been one to
5 do this for a long time because those folks
6 pay cash up-front for everything. So, the
7 person picks their plastic surgeon and then
8 the surgeon might recommend a couple of
9 facilities and then that consumer would shop
10 because that is 100 percent out of pocket.

11 There is a couple of plastic
12 surgeons that I know of that take it one step
13 further, in order to enamor their patients,
14 since the savings is even greater by doing it,
15 by having the facility in the Bahamas, they
16 then fly their patient out there. They still
17 get their full surgical fee and the patient
18 comes back with a tan. And it costs the same,
19 had they gone to a facility in Minnesota or
20 whatever.

21 So, I think it depends on the
22 sophistication of the community and how much

1 transparency there is.

2 CHAIR THOMASON: Who was next? Do
3 you know? Okay, we will go Carrie, and then
4 Adam, and then Paul.

5 MEMBER NELSON: Yes, this concept
6 of I just chose my doctor, I went where my
7 doctor told me to go. So, how do you choose
8 your doctor?

9 CHAIR THOMASON: As I said before,
10 a lot of that was quality and he was a
11 specialist. And then for others, it was
12 recommendations from peers and things of that
13 nature.

14 MEMBER NELSON: Yes, and yet some
15 people do it fairly randomly. And I had,
16 actually I have two examples where one friend
17 had a hip surgery. The other had a hip
18 surgery a couple weeks' later. One had an
19 anterior approach. One had a posterior
20 approach. Clearly, the anterior approach is
21 much better, you know shorter turn around,
22 less missed work. But they just did what the

1 doctor did. So the guy who does the posterior
2 approach, that is what he does. So, he didn't
3 even offer the alternative.

4 So, there is a risk in just doing
5 what your doctor tells you to do. So,
6 therefore, the choice of the doctor has to be
7 a much more deliberate choice.

8 CHAIR THOMASON: I know Tayler
9 said earlier that she goes to Yelp and do you
10 want to say that really quickly so that we can
11 move on?

12 MEMBER LOFQUIST: Yes, just how I
13 have chosen doctors since I moved to D.C.

14 Just since moving to D.C., I think
15 it is different maybe for people maybe if you
16 have grown up having the same doctor your
17 whole life and you have lived in the same
18 town. You could kind of have recommendations.
19 But being in a city where I am kind of on my
20 own healthcare-wise, how do you even begin
21 choosing a doctor was a little bit
22 overwhelming.

1 So, I just went to Yelp, had the
2 top-rankings for different doctors, and just
3 started going through each of them based on
4 like who is ranked the highest. And the first
5 one that would take my insurance, that is who
6 I would go to, pretty much. And then I would
7 kind of read the stories and make sure that it
8 matched up with the experience I was hoping to
9 have. But yes, just kind of like crowd-
10 sourcing that information. But, having the
11 affordability with your insurance.

12 MEMBER NELSON: And yet we all
13 know really nice doctors with bedside manner
14 that are crappy doctors.

15 CHAIR THOMASON: But you don't
16 know it until you go to them and then you
17 change.

18 I think Paul and then Helen. I'm
19 sorry I didn't see your name tag earlier.

20 MEMBER SIERZENSKI: Yes, I was
21 going to say that all of our colleagues here
22 who are active patients are extremely highly

1 skilled at managing the system here. And I
2 think the vast majority of those out in the
3 country right now probably use access to that
4 individual, its location overall, and their
5 insurance alignment as probably three key
6 drivers. And although I think we all believe
7 that quality should be a key indicator, I
8 think generally there is a lot that is just
9 given to the practice of medicine and
10 healthcare that the assumption is they are
11 out, they are a shingle, they are probably
12 pretty good. Or if they are affiliated with
13 a reputable organization, they are probably
14 pretty good.

15 So, I think those three, for the
16 vast majority of people in the country, I know
17 from my mother, who is a chronic cardiac
18 patient, that was pretty much it. It was, did
19 they take the insurance; can I get to them;
20 and can I get in were pretty much it. And
21 then the other things, whether she likes them,
22 whether they will deal with her, kind of

1 Italian approach to life was really -- even
2 though I am Sierzenski, it is Polish and
3 Italian. My mother always says I want to
4 fight somebody but I forget who.

5 (Laughter.)

6 MEMBER SIERZENSKI: I think those
7 four factors are kind of key.

8 CHAIR THOMASON: So, there was the
9 assumption of quality engrained, sort of.

10 Helen.

11 MS. BURSTIN: Just a quick
12 comment. And in some ways, it is interesting.
13 My husband does stats and polling and I am a
14 physician. And he is always amazed how risk-
15 averse I am. So actually in some ways --
16 because you either think as a doc it is
17 absolutely the worst possible thing or it is
18 absolutely nothing. And there is rarely
19 anything in-between.

20 So, I have to tell you when we
21 pick plans, for me it is actually all about
22 what is the facility included for the worst

1 possible thing. So, it is really. I mean I
2 think in some ways that will change because
3 there has been a lot of articles as well about
4 some of the narrow network plans, excluding
5 some of those providers.

6 And if you are really risk-averse,
7 and I guess my point is a lot of this really
8 comes down to a personal sense of risk
9 aversion, about how comfortable you are with
10 risk. And that is a lot of what we have
11 actually been talking about.

12 CHAIR THOMASON: Maureen, and then
13 Adam, and Carrie.

14 MEMBER EDIGER: This is short. I
15 was just going to say I have asked the nurses
16 before on the floor if it was their kid, which
17 neurosurgeon they would have do the surgery or
18 which urologist they would trust with their
19 kid, and who they see the lowest infection
20 rates from. So, that is my highly scientific
21 source.

22 MEMBER THOMPSON: One thing I just

1 wanted to mention because it seems like it
2 keeps coming up but I don't know if we said
3 it, which is I don't know if everybody
4 perceives there are decisions to be made
5 around healthcare.

6 And you were talking about the
7 health -- oh, she is gone. I love the Health
8 Belief Model because I think it does. I think
9 what she was pointing at is really, really
10 important, which is the idea that I can shop
11 for providers or there are commodities in
12 healthcare. Because when you think about it,
13 I mean by a show of hands, how many people are
14 from bi-coastal metropolitan cities here, like
15 living in urban centers? Okay, so more
16 choice. Right? Like I come from a rural area
17 where the choice is you go to UVA and that is
18 it.

19 So, even thinking about the
20 possibility of making these decisions, when
21 you look at the percentage of people in the
22 United States who live in a rural environment

1 that won't even, with these giant facilities,
2 potentially even have a choice of which
3 facility they go to, unless they can
4 physically get somewhere further. And they
5 may carry that forward with them wherever they
6 go. Which is even if I move into a big city,
7 I may still have the same outcomes because I
8 have carried with me this idea that there is
9 no decision to be made.

10 So, I think we have to look at not
11 only what information people need to make
12 decisions but be very clear about what
13 decisions need to be even made in the process.

14 CHAIR THOMASON: Great point.
15 Where they live but then also, like you raised
16 earlier, are they engaged enough to make this
17 decision and all those things like that for
18 sure.

19 I think it was Kris and then
20 Carrie.

21 MEMBER SOEGAARD: This going back
22 a little ways in the conversation but it was

1 again something Cindy said about cost doesn't
2 come into play with the hospital selection.
3 And I agree with what you said but that
4 doesn't mean to me that there aren't cost
5 decisions that consumers should be asking
6 questions about related to the hospital where
7 their physician may be sending them. Because
8 I am not going to get in quality but there is
9 a huge cost variation in having something done
10 at different hospitals and I think that is an
11 important component that consumers, patients
12 should be talking and maybe challenging their
13 doctor about. If their doctor is sending them
14 to the highest cost for that particular
15 procedure, that is something that they should
16 maybe be talking to them about.

17 MR. AMIN: So, I have a question
18 about that.

19 CHAIR THOMASON: Taroon?

20 MR. AMIN: So, I have a question
21 about that, which is, and it is sort of
22 similar to our conversation before, which is

1 that it seems that that information about
2 selecting a facility is not transparent at the
3 time of the selection or if the selection is
4 even an option, it is generally a
5 retrospective issue. And so I wonder is that
6 information available or is it very similar to
7 the situation that we were talking with
8 Cynthia, the example Cynthia brought up, which
9 is that maybe the best approach here would be
10 sort of a good-faith estimate of what one
11 could expect, given the variation in what
12 would be reimbursed, depending on various
13 different health plans, contracting rates, all
14 the different providers that are involved in
15 the hospital environment.

16 MEMBER SOEGAARD: I would say that
17 you can get directional information. And you
18 can get directional information from Hospital
19 Compare. So, it is available.

20 CHAIR THOMASON: I was in the
21 healthcare system for a long time before I
22 realized I could make that hospital call. But

1 even then, my surgeon will only do -- if I
2 want him, in my area, he will only do that
3 surgery at a particular hospital. So, if I
4 want that doctor, I don't have the benefit of
5 being in the large urban area. If I want
6 doctor, I have to go to that hospital. So, I
7 still feel like I don't have as much of a
8 choice when it comes to surgeries and
9 inpatient stays, as I do like diagnostics and
10 things like that.

11 Carrie?

12 MEMBER NELSON: You are kind of
13 tailing on what Adam was saying and Kris. I
14 think that there may be a series of suggested
15 questions we want to put into this white paper
16 that would help people tease out their options
17 and where they can find out where a price may
18 need to help them make a decision. Because I
19 don't think we can -- we can't look at every
20 scenario and say here is what you should know
21 about that but there is some key general
22 questions. Are there alternatives to this

1 surgery? Are there other places I can go for
2 the same procedure? Those kinds of things.

3 CHAIR THOMASON: I love that idea.

4 CHAIR MORT: I wanted to go back
5 to the question about how you choose a
6 physician. And people mentioned, obviously,
7 doctors in their plan. Maybe it is copays.
8 But I did want to say a couple other things
9 about affordability. When you choose a
10 physician, you also choose a practice. And
11 there is aspects of the practice that really
12 relate to affordability, like when they are
13 open. So, can you go there off hours? Can
14 you see another provider if your provider
15 isn't working that day? Do they have call
16 lines? All those sorts of things. Patient
17 portals.

18 So, it is not just the physician
19 anymore. It is the physician and the
20 practice. And attributes of the practice,
21 really, I think affect affordability
22 decisions.

1 On the quality side, it is very,
2 very hard to get real quality data at the
3 individual physician level. It just doesn't
4 work very well unless you are cardiac surgeon,
5 getting back to the CABG stuff I mentioned
6 before. But you can get information on
7 credentials, where they went to school, how
8 long they have been in practice, often
9 information about what kind of procedures they
10 do. There are special interests. And then
11 you can get quality information again about
12 the practice oftentimes. So, that is helpful
13 as well. Wait times. I think Debbie, you
14 mentioned before you left one practice because
15 of the front desk.

16 So, I think there is a lot of
17 information that we could get direct consumers
18 to that is available to help them make better
19 decisions about doctors that also relate to
20 the practice.

21 And I think that risk issue that
22 Helen mentioned earlier is really important.

1 I don't think I could live in a rural, rural,
2 rural area that wasn't near a big tertiary
3 hospital because I have been in a tertiary
4 hospital since 1986. And just the idea of not
5 having one available just in case. I'm not
6 sick. But just in case tomorrow I get sick,
7 I would like to be near it.

8 And this was made very apparent to
9 me, my risk level tolerance when I have been
10 all my life in cities and suburbs until I got
11 married about 12 years ago and I moved 48
12 miles out of Boston to a rural area. And
13 about a week into the move, I realized there
14 were no fire hydrants. It never occurred to
15 me that people lived in places without fire
16 hydrants. And what they do is they go to a
17 pond and they pump the water into the fire
18 truck. It took me a long time to get over
19 that. Now, I am comfortable with the fire
20 trucks.

21 But you know people's risk
22 tolerance really, really is important. So,

1 choosing a doctor that has admitting
2 privileges at a hospital that you are
3 comfortable with is also -- so it is the
4 doctor, it is the practice, and the admitting
5 privileges that I think comes into the
6 decision-making. And maybe people don't
7 understand that those things are all
8 connected. So, that is an important piece of
9 information that I think consumers should have
10 access to.

11 CHAIR THOMASON: And I think it is
12 about letting our inexperienced consumers know
13 that you need this information. Because I
14 want to know all these things now that I have
15 already chosen. You know, but I didn't know
16 what to even ask for way back when I was
17 making the decision.

18 I know we need to move on but
19 Corey, go ahead.

20 MEMBER WILBORN: I think the more
21 stuff we add to the average person's list of
22 things to look at, the average patient, the

1 population at risk, I think it turns them off.
2 I think it is too much information for someone
3 that -- you know, it is overload.

4 CHAIR THOMASON: Alyssa.

5 MEMBER KEEFE: I was just
6 reflecting on all that information. I am sure
7 this has been said before in some other
8 forums. But you know when you are in high
9 school, they make you take life skills
10 classes, how to do financial planning, balance
11 your checkbook. They give you health
12 education but it is more about keeping
13 yourself healthy. No one teaches you how to
14 navigate the health system.

15 And that actually is a tremendous
16 life skill or a tremendous piece of education
17 that we just don't do in this country. And it
18 lends to wanting all this decision later in
19 life. And so, it is just something that I
20 think if we invested in that kind of work, it
21 would give us a different perspective. And it
22 lends to affordability as well.

1 CHAIR THOMASON: I hope that is
2 changing. Like I said, just last week I read
3 a proposal in North Carolina that will roll
4 out health literacy in high schools in our
5 state. So, I hope that we go that way.

6 Taroon, do you want to move on or
7 do you want to take these last couple of
8 comments and then move on to the next phase?

9 MR. AMIN: Yes, let's take the
10 ones that we have remaining and then do a
11 quick introduction for Jessica Greene and
12 quick disclosure and then we will move on to
13 our last section.

14 MEMBER NIELSEN: I totally agree
15 with Alyssa's point about life skills. And
16 where the United States is so different from
17 other industrialized countries is most other
18 countries, two-thirds, three-quarters of their
19 providers are primary care providers. And
20 people have long-term relationships with those
21 providers and they serve as your navigator or
22 your coordinator in ways that we don't in this

1 country. And we are far more like your
2 husband, Melissa, who waits until the last
3 minute and then circumvents the primary care
4 system and lands in the world of specialists
5 without somebody to help them navigate.

6 So, some of this is how our health
7 system is constructed and that is not our
8 charge to fix that. But it does relate back
9 to affordability because primary care -- and
10 30 years' of research on this topic, primary
11 care and strong investments in primary care
12 not only help the patients navigate the system
13 but improve health outcomes and cost less
14 money.

15 Tell everyone at the PCPCC I said
16 that, by the way.

17 MEMBER DAHL: I was just going to
18 add what a shame that our system is so complex
19 and so messy and so poorly designed that we
20 need navigators to get us through the system.

21 CHAIR MORT: Shall we move on to
22 the next?

1 MR. AMIN: Okay, that sounds good.

2 CHAIR MORT: Do you want to start
3 with the intro?

4 MR. AMIN: Yes. Jessica, welcome.
5 If you wouldn't mind just quickly introducing
6 yourself to the group. And if you have any
7 financial disclosures related to any of the
8 topics that we are discussing, grants,
9 anything else, grants, employment, things of
10 that nature. I generally don't do that part.
11 It is important. I don't mean to make light
12 of it. But anything that you feel is relevant
13 for the group.

14 MEMBER GREENE: So, my name is
15 Jessica Greene. I am a faculty member at
16 George Washington University and I am here
17 because I have done a number of studies where
18 we present different presentations of quality
19 and cost information to consumers and find
20 that the way information is presented can have
21 a pretty substantial impact on how people
22 understand the information.

1 And so this issue of how to
2 present information simply, which just came
3 up, is something that I spent some time
4 thinking about, though I have not solved. But
5 I have seen a lot of problems doing things in
6 a complicated way.

7 I don't have any financial
8 disclosures, but I do apologize for having to
9 miss most of today's meeting. I had a little
10 grant proposal deadline, major problem,
11 happened last night. But we are together now.

12 MR. AMIN: Excellent. So yes,
13 let's quickly sort of transition into our
14 phase three, which is sort of the post-acute
15 phase, also includes -- and we can sort of
16 break it apart between the post-acute phase
17 including the selection of post-acute
18 providers and then also maybe have some
19 discussion about sort of chronic disease
20 management post-acute discussions.

21 And effectively, maybe I will turn
22 it over to Ashlie to kind of walk us through

1 a little bit.

2 MS. WILBON: Yes, I mean I am
3 hoping we are hopefully all on the same page
4 with the follow-up care but we can kind of
5 conceptualize this as you are discharged from
6 the hospital for an inpatient stay or you now
7 have your diagnosis and your patient education
8 for what you need to do for your condition and
9 then you are now in this -- what was the word
10 we used -- coping?

11 MS. ADAMS: It is living with
12 chronic illness and coping with end of life.

13 MS. WILBON: Yes. So, living with
14 chronic and coping with end of life phase.
15 And so again, this might be medication
16 management, care coordination issues, I think,
17 is also in there, long-term care, skilled
18 nursing facilities, physical therapy, anything
19 like that would all kind of fall into this,
20 just to give some examples of what might be
21 going on in this phase, all might be in this
22 follow-up -- I keep saying follow-up care but

1 this purple bubble for what we are looking to
2 kind of think through again in terms of
3 decisions and the information.

4 So, with that, we will open it up
5 for discussion. I think Maureen is first.

6 MEMBER EDIGER: I just want to
7 make sure that we are remembering mental
8 health issues as we move into the purple
9 bubble because I think that it is complicated
10 and different and we haven't been talking
11 about mental health a lot. So, I just wanted
12 to remind everybody that there is another kind
13 of health out there.

14 MR. AMIN: So, on that note,
15 Maureen, I guess I have a question as well,
16 which is that the issue of sort of mental
17 health and behavioral health is important both
18 -- so the decision there is and the decision
19 of selecting the provider and also, in some
20 cases, it may be selecting a plan, since it is
21 a carved-out arrangement, so that is what we
22 are referring to when we are talking about

1 that population, in particular.

2 MEMBER NIELSEN: Clarification.
3 Taroon, just so that we are all on the same
4 page, 70 percent of all behavioral health
5 decisions are made in a primary care
6 provider's office. So it is actually not all
7 carved out. As a matter of fact, most
8 treatment of behavioral health issues happen
9 in primary care.

10 So, integration is huge there and
11 I just wouldn't want folks to think we are
12 talking about two disparate systems.

13 MR. AMIN: So can you help me
14 understand what is the decision that we are
15 looking at then, from the patient's
16 perspective? I don't mean to put you on the
17 spot but in general, if you were thinking
18 about seeking behavioral health treatment in
19 the primary care setting, what decisions are
20 we trying to understand here from an
21 affordability standpoint?

22 MEMBER NIELSEN: We could run the

1 whole gambit. I mean, focused on
2 affordability, regardless of the behavioral or
3 mental health issue, you need to know if they
4 can be -- your loved one or you can be treated
5 in a primary care setting or if you need a
6 referral out.

7 If you need a referral out, now
8 you have affordability questions because there
9 could be all kinds of question about whether
10 insurance covers this, doesn't cover this, et
11 cetera.

12 If you stay in your primary care
13 setting, you are still thinking about the same
14 sorts of issues, copays, deductibles, et
15 cetera. That is a whole separate issue than
16 the treatment decisions themselves. I am just
17 referring to the affordability fees.

18 MEMBER EDIGER: This is just my
19 experience but it seems that the costs of
20 medications for addressing behavioral health,
21 there seems to be a lot more fluctuation and
22 trying to find plans that will cover -- and

1 again, I have very limited experience. I am
2 not speaking for all parents. But just that
3 it seems like it is much more of a moving
4 target, finding the right plan that will cover
5 the right medications and unbelievably
6 expensive if you miss that decision annually.

7 MEMBER NIELSEN: That is
8 absolutely true. I am just talking about that
9 initial about where your treatment happens.
10 It is pharmacy copays, it is your benefit
11 package. Now, this is all supposed to improve
12 as part of the ACA. But historically,
13 terrible disparity between what your health
14 insurance, regardless of whether it is within
15 a primary care behavioral health setting,
16 disparities between what they will cover
17 physical health and mental behavioral health.

18 MR. AMIN: Right.

19 CHAIR THOMASON: I do have a quick
20 question. So, who helps these patients make
21 those decisions?

22 MEMBER NIELSEN: Their primary

1 care provider, initially. The problem is a
2 lot of the primary care providers aren't well
3 trained. So, they are overwhelmed. It is not
4 their area of expertise. Fifty percent of the
5 time when they make a recommendation to their
6 patient about getting a referral and they say
7 I can't manage this here, 50 percent of the
8 time, the patient doesn't go on and get
9 additional treatment.

10 So, the gaps around mental and
11 behavioral health are huge. The goal is to
12 better integrate mental and behavioral health
13 into primary care but we are just figuring out
14 how to do that.

15 I just wouldn't want you to think
16 that they are like two totally separate worlds
17 because they may seem that way but that is
18 actually not how they begin.

19 MR. AMIN: Okay, that is good.

20 MEMBER EDIGER: But since we are
21 in that purple bubble, we have moved on to
22 follow-up care, right?

1 MR. AMIN: Yes, we are in follow-
2 up care.

3 MEMBER EDIGER: So, I agree that
4 that point where maybe it starts might be
5 really somewhere. But I think by the time we
6 get to the purple bubble, it starts getting to
7 be a lot more complicated about the choices
8 that you have for affordability and paying for
9 it.

10 I think we are saying the same
11 thing.

12 MEMBER NIELSEN: We are and some
13 of it has to do with the severity of the
14 illness. So, if it is something that can't be
15 treated in a primary care office, now you are
16 in a whole other world.

17 MR. AMIN: I guess that is what I
18 am trying to get some nuance around, which is
19 is it a difference in the benefit design
20 between what is available or is it a
21 difference that the providers, the difference
22 in what is available? That is what I am

1 trying to just understand.

2 MEMBER NIELSEN: It is all of the
3 above. I mean there is a shortage of mental
4 health providers, for starters. So, finding
5 a good referral, if you can't be managed in a
6 primary care setting, is just one of the many
7 problems that you will have. Then, getting on
8 the right medication, which often changes for
9 the patient because they don't always work
10 long-term if you are talking about
11 schizophrenia, et cetera.

12 I mean the levels of complication
13 around behavioral and mental health are
14 significant.

15 MR. AMIN: Okay. All right, Joe,
16 Lisa, and Maureen. We will work around this
17 way.

18 MEMBER SINGER: Taroon, I mean
19 with the initiation years ago of the Mental
20 Health Parody Act, there is more benefits that
21 are defined and structured for people with
22 behavioral health.

1 As Marci said, most treatment for
2 common behavioral health substance abuse
3 issues initiate in a primary care office. So,
4 we are talking about simple depression. We
5 are talking about anxiety, different types of
6 insomnias. That type of thing is handled by
7 most primary care physicians fairly well.

8 If there is not a response, a good
9 response to initial therapy or if a more
10 serious disorder is identified, if initially
11 depression has been recognized being part of
12 a bipolar disorder, people are then referred
13 on to specialty care.

14 Once that happens, there is a huge
15 ratcheting up of cost for a patient because
16 they are going from a primary care copay now
17 to a specialist copay.

18 A lot of the medications that are
19 out there are Tier 2 and 3, Tier 3 medications
20 for some of the more serious conditions. And
21 those copays and deductibles get very, very
22 expensive.

1 So you know, as things escalate as
2 far as severity of illness, the intensity of
3 care goes up, the frequency of care goes up
4 and then compliance becomes an issue where
5 people start to cut back on expenses because
6 copays and everything build up and they become
7 sicker and they end up getting hospitalized.
8 It is a very challenging situation.

9 The same thing with cardiac
10 patients. Some of them will have their bypass
11 and they can do all their shopping and then
12 when they find out it is \$20 a visit for the
13 12 to 30 cardiac rehab encounters that they
14 need, after the CABG, they may end paying more
15 in copays for the cardiac rehab than they do
16 for the surgery itself.

17 So, it is getting people to
18 understand the ramifications downstream of all
19 of these interventions that people don't know
20 how to anticipate up-front. And quite often,
21 physicians themselves don't understand what is
22 happening. And you know when someone gets

1 admitted to the hospital, they get a bill from
2 a radiologist that they never see for reading
3 the x-ray, and a cardiologist that they never
4 see for reading the EKG.

5 And a lot of these things are not
6 readily transparent to the patient and they
7 have no control over picking the
8 anesthesiologist who is par or non-par with
9 their insurance company. So, it is really
10 very challenging for people to control. And
11 they have to put themselves in the hands of
12 either the primary treating physician, be it
13 the surgeon or whatever. It is challenging.

14 Some of the payment innovation
15 processes that are coming out with providers
16 and bundled payments and things like that will
17 offset some of these challenges to patients,
18 where there will be one bill, where the copay
19 structure and out-of-pocket costs for an
20 individual patient may get dropped. But that
21 is still a very complicated process for people
22 to understand a priori because, typically, it

1 doesn't get presented to them. Typically, it
2 doesn't get presented to them.

3 MEMBER NIELSEN: But think about
4 how much we have been talking about self-
5 efficacy today and whether you think you can
6 manage this yourself. When you are depressed
7 or anxious or have any of these behavioral or
8 mental health issues, your ability to manage
9 your health, and you are often sick with
10 something else, so the complications -- it is
11 a rare thing to just have depression or just
12 have anxiety. The comorbidity between
13 diabetes -- diabetes predisposes you to
14 depression and depression can predispose you
15 to diabetes.

16 So, when I say they are
17 intertwined, then your ability to actually act
18 on your doctor's recommendations to take this
19 drug, to get your exercise when you are
20 depressed, I mean the behavioral health issue
21 often precludes your ability to manage your
22 physical health symptoms, which then just

1 continues to get worse.

2 MR. AMIN: All right, Lisa,
3 Maureen, Deb, Ron, and then Tina.

4 MEMBER LATTIS: Just to add to the
5 complexity of the mental healthcare system, in
6 addition to a severe shortage of providers,
7 there is an incredible fragmentation among
8 providers. So, unlike in the medical side,
9 where there is a lot of organization, a lot of
10 physicians are organized into groups, those
11 groups have infrastructure, most mental health
12 providers are single practitioners. So, they
13 don't have back office staff. They don't have
14 people to do the billing. They don't have
15 people to return your phone calls.

16 So, often they don't bill, they
17 bill much later. So, from a health plan
18 perspective, most medical claims come in
19 within 30 days. You know you will get mental
20 health claims six months' out. And so that
21 makes everything much more complicated.

22 A lot of mental health providers

1 won't bill the insurance directly. So, they
2 will leave it up to the patient to bill the
3 insurance. So, they will want you to pay them
4 and then they will bill.

5 Psychiatrists, typically, are
6 mostly prescribers and they will prescribe
7 drugs and then you have to see other
8 professionals, psychologists, social workers,
9 et cetera, for the cognitive therapies. So
10 that is fragmented and divided up.

11 And again, add somebody who is
12 impaired in their ability to manage and it
13 becomes very, very difficult.

14 MR. AMIN: Maureen?

15 MEMBER EDIGER: Everything Lisa
16 just said, she just went through every single
17 one of my points.

18 The only one, whereas with other
19 medical issues you might do the crowd
20 sourcing, like I need help finding a good
21 orthopedic surgeon to do my knee replacement,
22 you are not as likely to post on Facebook my

1 kid is having a psychotic episode, do you know
2 a good psychiatrist that can help. So, it is
3 one more layer that you don't have. You don't
4 have that support system to go to either.

5 MR. AMIN: Very good point. Deb?
6 Oh, you got it? Ron.

7 MEMBER WALTERS: Yes, I like the
8 concept of we have gone kind of from, in some
9 respects, a simple situation to an
10 intermediate situation with something you can
11 at least adapt to. I call the purple bubble
12 almost chaos. And I think you have heard some
13 of that, especially from an affordability
14 perspective in that not only is it much harder
15 than either of the two previous bubbles to
16 predict exactly what factors might influence
17 the decisions that I make but also what my
18 exposure might be downstream but the interplay
19 between the different aspects of the system
20 gets very complex and that is even from just
21 one disease's perspective. Then, you have to
22 factor in all the relationships between the

1 other diseases that could occur as either side
2 issues or consequences of what you just went
3 through in the middle bubble. And this gets
4 to be extremely complicated very, very
5 quickly, and that is without any behavioral
6 health issues.

7 So, I mean I think affordability,
8 in my mind, although we focus so much on that
9 acute phase, whether it is emergent or not as
10 far as the affordability risk taking an abrupt
11 turn upwards, especially compared to what came
12 before it.

13 In a way this is more of this type
14 situation and it is indefinite. I mean
15 really, you don't really know when that
16 unpredictability is going to end. And that,
17 in itself, introduces all sorts of questions
18 about how you would assess that affordability,
19 when you don't even know what one your five
20 years', ten years' in the future might be
21 like.

22 MR. AMIN: So, Tina, I will have

1 you go next. I just have one question just
2 for the group as well, after your comment.

3 Which it seems like there are at
4 least two decisions here that we have talked
5 about. One is around sort of deciding -- it
6 is not really a decision but it is a question
7 of how to coordinate across multiple riders
8 when you are in this post-acute environment
9 and that sort of includes, depending on what
10 your condition is, but it gets even more
11 complicated in a behavioral health situation.

12 And so the question I have is how
13 good is the information in that coordination
14 process. And then the second is, looking at
15 selection of actual providers in the post-
16 acute environment, how transparent is the data
17 about cost exposure, in terms of post-acute
18 provider. So, I am interested in conversation
19 around those topics. So, Tina?

20 MEMBER FRONTERA: I will try to
21 address some of that. I think in some ways we
22 are almost getting into a total cost of care

1 issue, too, and care coordination.

2 When we speak about the mental
3 health issue, if you have a parent, that
4 parent can be the case manager. Or if you
5 have a chronic illness condition and the
6 parent can be the case manager for that child.
7 Or sometimes, the child can be the case
8 manager for their parent.

9 But in the absence of the person
10 having enough information, or enough tools, or
11 enough resources is when we get into total
12 cost of care that could be out of control
13 because of the fragmentation.

14 Again, there are models now where
15 we are just beginning to start to publish
16 information on total cost of care. But that
17 doesn't get to all of these other
18 fragmentation issues. If you happen to be
19 lucky enough to get into a system that manages
20 itself very well, and has controlled total
21 cost of care, then that patient gets lucky.
22 But I don't think we have enough out there

1 yet. I think it is emerging but it is still
2 piecemeal.

3 MR. AMIN: Yes, well I guess the
4 question I would then ask also to the
5 consumers, in particular, is if you are moving
6 out of an inpatient environment into follow-up
7 care, into post-acute providers, how easy is
8 it to interpret a total cost of care number,
9 even really, about what your post-acute
10 exposure really is going to look like, not
11 only from an uncertainty perspective that you
12 have a number of different providers that you
13 are interacting but what the cost exposure
14 looks like from a post-acute environment,
15 whether it is rehab or -- Joe?

16 MEMBER SINGER: It is really a few
17 different issues. Unit cost tends not to be
18 as much of an issue in post-acute care because
19 for insured population, the copays,
20 deductibles are going to handle the issue.
21 You know hit maximum out-of-pocket costs. But
22 it is full utilization that tends to be a

1 problem, too.

2 You know some children with
3 cerebral palsy may get -- I have seen them
4 getting annual CAT scans and EEGs odd
5 infinitum, when there is absolutely evidence
6 that it is medically necessary. So,
7 appropriateness continues to be a big issue
8 here and utilization trend, as much as unit
9 cost trend, is an issue so that coordinative
10 care, and potentially patient-centered medical
11 homes and other initiatives can help deal with
12 more evidence-based delivery of care.

13 You know a lot of our frequent
14 fliers, and I'm sorry for using that term,
15 they are very, very specific, fortunately, not
16 common conditions. So, you know it has forced
17 people to become experts to protect themselves
18 and their loved ones.

19 But when we talk about the general
20 population, as a geriatrician, I see people
21 that are seeing -- not any more -- but I was
22 seeing people seeing six, eight physicians, be

1 on 15 to 20 medications. And you know for
2 Medicare, a third of all hospitalizations are
3 drug-related problems; either too many or not
4 enough.

5 So, coordination of care is a huge
6 issue in looking at total affordability of
7 care. Make sure the people are getting what
8 they need but not excess therapy. And in the
9 U.S., it tends to be people -- the institute
10 of medicine says what, 30 to 40 percent of
11 care is not evidence-based. And that drives
12 a lot of the cost that rolls down to
13 individuals in getting work done that maybe is
14 not necessary.

15 MR. AMIN: Melissa, and then
16 Maureen, and then I think we may end up
17 wrapping up this section.

18 CHAIR THOMASON: As patient, it is
19 really hard to coordinate your care among
20 several providers, even from a quality
21 perspective, even when you are inpatient and
22 you see all these specialists and especially

1 afterward.

2 My cardiologist and then
3 nephrologist, and then the OB team, and the
4 this team and the that team, then everybody
5 comes and sees you independently of each
6 other. And then they asked me what the other
7 guys said. And I was like, by the way, I
8 didn't go to med school, just so you know. So
9 it is really hard from a quality perspective.

10 Then, too, from an affordability
11 perspective. So, just relating to
12 affordability in this stage of the episode of
13 care it was, again, do I really need this.
14 Because I was thinking about it on the front-
15 end of all these preventive tests and things
16 like that. And I was thinking about it in the
17 middle of I am having these symptoms, do I
18 really need to be seen? And then even more so
19 at this stage because I just came out of the
20 second stage of treatment and that concept
21 like Paul was talking about earlier of
22 indebtedness. And I felt like I just spent

1 all this money on being treated and on that
2 hospital stay.

3 And so how I made my decisions for
4 follow-up care and cardiac rehab, I felt like
5 I was already so indebted to the healthcare
6 system that I was really careful about well,
7 I don't really need that. Do I? Well, I
8 don't really need that, do I? And so
9 affordability really played in a lot to my
10 decisions in the end.

11 And then, too, again, insurance is
12 so big because cost info is great but it will
13 not help me if it cannot translate my real
14 out-of-pocket expense in the framework of my
15 insurance for an everyday consumer.

16 MR. AMIN: Yes, that is a definite
17 theme.

18 Maureen and then Liz.

19 MEMBER EDIGER: I was just going
20 -- I think what you said about having a
21 primary care physician or, in our case, our
22 pediatrician who really understands and knows

1 like both of my kids with special needs, that
2 she is -- I seek her advice on cost issues.
3 I will ask her, how necessary do you think
4 this is. And I think having that medical
5 home, that one person that coordinates, that
6 care is key on affordability issues for
7 frequent fliers.

8 And I feel like Ev, my son with
9 spina bifida has always lived mostly in the
10 purple bubble. Sometimes in the orange bubble
11 but I feel like he lives his whole life on the
12 right side of this diagram. And I think that
13 investing in a good primary care pediatrician,
14 in our case, has huge payoffs for us, as far
15 as where we are accessing and the
16 appropriateness of different things that we
17 are engaged in.

18 And I have definitely been in the
19 situation where when he has been inpatient in
20 the hospital, I feel like I am the one who is
21 saying well, urology was just here and they
22 said this. And neurosurgery was just here and

1 they said this. And infectious disease was
2 here and they said this. And I finally get to
3 the point where I say, but I don't speak your
4 language. Like I don't know but I feel like
5 I am the one that is conveying all the
6 information back and forth to specialists.
7 And that is a horrible place to have a patient
8 or a family member be in.

9 CHAIR MORT: One thing that I feel
10 would be an important piece of information, if
11 you have a chronic disease, not so much the
12 post-acute follow-up after a hospitalization
13 but again, the affordability issue, an
14 important aspect of your choice about where to
15 get care would be the practice. Are you going
16 to be in a situation where you can only see
17 one doctor and it is going to be spotty or can
18 you see a team in a patient-centered medical
19 home? And if you have diabetes, do you have
20 a good endocrine consult that you can go to on
21 a periodic basis? Is that person convenient.

22 I have really been moved today by

1 the emphasis from the consumers on the
2 important costs, the indirect cost of
3 convenience away from work, family disruption.

4 So again, if you have a chronic
5 illness, a disease management need, the
6 practice, your access, your resources, are
7 really, really important, both primary care,
8 height, if you are a high risk, sort of a high
9 utilizer, do you have a case manager.

10 So, all those things I think are
11 really important in making decisions about
12 where to seek care for patients who have
13 chronic needs.

14 Paul, you made that comment
15 earlier about was it your son or your daughter
16 who had diabetes?

17 MEMBER SIERZENSKI: Yes.
18 Actually, I was going to respond to that. As
19 a matter of fact, for my son who is a Type 1
20 diabetic who was diagnosed right over the
21 Christmas holidays, which was one of the most
22 traumatic experiences, not only just having a

1 child that was ill but, after the fact, the
2 gap in care after being discharged was insane.
3 I mean our life saving at that point was the
4 JDRC and the contact families who let us know
5 what to expect, even as an emergency physician
6 who treats this, but our day to day touch
7 point.

8 I would say first the decision of
9 the follow-up was really driven by the initial
10 provider. So, I think that is key because
11 whether it be a primary care physician from a
12 patient-centered medical home, or even a
13 specialist or subspecialist, the decision that
14 goes into the selecting of that individual is
15 going to have significant carryover impact in
16 the follow-up care component. We see our
17 endocrinologist or my son sees his
18 endocrinologist as a consultant only at times.
19 His primary caregiver is, himself, with us as
20 support, and his secondary support caregiver
21 are the diabetes nurse practitioners who do
22 that management that he can text if there is

1 an issue, if you know he is ill and needs to
2 adjust things.

3 So, I would say that although we
4 are discussing a lot about some of the primary
5 care components, that initial interaction in
6 the acute phase has significant carryover in
7 there for follow-up because our primary care
8 physician for our son, our pediatrician,
9 essentially acquiesces a lot of that to the
10 endocrinologist, which we are blessed that
11 they actually do communicate and things get
12 faxed that day and there is data exchange.

13 But it was really that initial
14 interaction that set the ball in motion for
15 the longitudinal follow-up care.

16 CHAIR MORT: And the other piece
17 of the practice that I would point out is
18 important from an affordability perspective is
19 whether the practice has systems,
20 infrastructure, that also support
21 affordability.

22 You mentioned, Maureen, all the

1 consults coming at you. Well, if your PCP or
2 your primary care taker has an electronic
3 medical record, turn the lights on all these
4 conversations. You can actually read them and
5 the primary care person with an electronic
6 medical record can help reduce the cost of
7 care and make it more affordable because that
8 person can really help you integrate.

9 And the same would go for does the
10 practice have electronic prescribing? Other
11 kinds of IT decision support things that will
12 make care safer and avoiding adverse events,
13 it makes care more affordable.

14 So not just the composition of the
15 practice like when it is open, who is in it,
16 whether they have teams, but also some of
17 these really important factors around
18 structural aspects. I think those are things
19 that consumers may not even know are important
20 but gee, if they really are important, the
21 Leapfrog survey, as I mentioned before, they
22 point out the value of those structural

1 aspects. But those structural aspects can
2 really affect affordability.

3 MR. AMIN: Corey?

4 MEMBER WILBORN: My experience has
5 been very different. And the fact that when
6 I go to a primary care physician because of my
7 heart problem, they immediately send me to a
8 specialist. They don't spend time on any
9 other problem. If you have a cold, if you
10 have allergies, you are going to see the
11 cardiologist. And the cardiologist is going
12 to -- my cardiologist and my hematologist, at
13 the time, that is where they send you.

14 So, most of my care, my primary
15 care and everything has been done by my
16 cardiologist over the years. And I have been
17 in three separate states and it has always
18 been that way. I see the primary care doctor
19 and he shoots me right over to a heart doctor.

20 MR. AMIN: Marci?

21 MEMBER NIELSEN: So, I would just
22 want to underscore both the points that Liz

1 and Paul were making, although I also feel
2 like I need to respond to your cardiologist or
3 your endocrinologist. Folks are bickering
4 about who your medical home is and is it a
5 primary care provider. Now, you can't tell
6 some people, I am about to say this, but the
7 reality is, it is whoever you want your
8 medical home to be, based on what your needs
9 are and your comfort is. And sometimes that
10 is not going to be a primary care provider.

11 Of course a pediatrician is a
12 primary care provider. Usually it is primary
13 care but in the circumstances when you have a
14 serious illness or condition, often they
15 don't. In the world of HIV, most primary care
16 providers want you to have a specialist and
17 you want one.

18 But --

19 MEMBER WILBORN: That is where the
20 cost comes in, too, because it costs a lot
21 more to go see that specialist every time than
22 it does to see a primary care doctor that

1 could handle the cold that I have.

2 MEMBER NIELSEN: Right. Well, and
3 this gets back to a point that Paul was making
4 and that Liz underscored around self-
5 management. We often don't think of ourselves
6 as being "on the team." And yet in reality,
7 if you think about it, you are going to learn
8 the literature on your illness or condition
9 anyway. And then when you are really
10 empowered to manage it yourself, because you
11 are given self-management tools and EHRs and
12 patient portals.

13 What we find is there is a whole
14 group of family physicians arguing that maybe
15 we don't have a physician shortage after all,
16 if we actually used team-based care,
17 technology, and most importantly, the patient,
18 as a care giver for themselves.

19 We could think about affordability
20 of the healthcare system and the number of
21 providers in a whole new light. And so, I
22 would throw that into affordability if only to

1 say if you feel empowered to manage your
2 diabetes, suddenly, you are not having to go
3 in for a lot of doctors' visits that cost you
4 \$20 or \$50.

5 So, the patient as -- see and now
6 I am going to say patient -- the patient as
7 the consumer here, in this case, allows you to
8 save money but, most importantly, feel better
9 and self-efficacious about being able to take
10 care of your condition.

11 MR. AMIN: Adam.

12 MEMBER LATTS: And Marci, can I
13 just give a caveat to that? Which is, that it
14 is fine for the specialist to be the medical
15 home, as long as the specialist then assumes
16 the responsibility for the total care of that
17 individual.

18 So, if Corey's cardiologist is not
19 ready to make sure he has his flu shot, and
20 quits smoking, and gets enough exercise, and
21 does all his preventive screening, then he has
22 no home.

1 MEMBER NIELSEN: That is exactly
2 right. And treating Corey like a whole
3 person. I mean this is more than just sort of
4 a condition management. It is longitudinal.
5 It is continuous. It is comprehensive. And
6 you know, what about Corey's heartache? He is
7 still looking for his wife. You know? Is his
8 cardiologist helping him on his quest?
9 Because I just think that is the funniest
10 thing I have heard in a long time.

11 (Laughter.)

12 MEMBER NIELSEN: I get it. I get
13 it. It ranks right up there with manicures
14 and broken arms.

15 MR. AMIN: So that is excellent.
16 That is a great place to kind of bring the
17 conversation together.

18 So, I will just kind of summarize
19 what we have done and I will ask the chairs to
20 reflect some themes that they have heard from
21 the day. Does that sound like a plan? Unless
22 anyone has any sort of closing thoughts, and

1 I will certainly open it up for the group if
2 there is any sort of closing thoughts that you
3 have from the day.

4 So, we walked this morning through
5 sort of different consumer experiences on the
6 concept of affordability and different
7 experiences that folks have had with the
8 healthcare system, and particularly with the
9 healthcare costs.

10 And then walking through various
11 definitions of established consensus
12 definitions and really batting back different
13 ideas about what exactly affordability means
14 from the consumer perspectives and getting
15 some real clarity around those topics.

16 We really took a deep dive on the
17 patient-centered episode of care framework and
18 really described, at least at the very
19 minimum, redefining the terms of what we are
20 using within this graphic, this graphical
21 framework but potentially considering other
22 components to add.

1 MS. WILBON: I will just add I
2 think one of the aha moments for me, I think
3 in that we are going to definitely do some
4 thinking about back to the definitions piece,
5 is to really go back and rethink words, really
6 doing some wordsmithing and really thinking
7 about how we might be able to either add on to
8 the existing definitions or kind of rethink
9 how we frame those within the context of this
10 paper, so that it is consumer facing or from
11 the consumer lens. So, I think that was a
12 takeaway from that discussion.

13 MR. AMIN: Absolutely. And then
14 what we did was to take each of these phases
15 and really walk through effectively what
16 decisions we think occurred during those time
17 periods and what information we think is
18 needed. And I think -- I won't attempt to
19 summarize everything that we have done today
20 because that would be an amazing feat. But
21 what I would say is a few aha moments from my
22 perspective is the issue of appropriateness

1 was clearly in the forefront across all three
2 of the phases, really thinking through and
3 having an understanding of whether you needed
4 the care to begin with. And that really is a
5 forefront issue in terms of defining
6 affordability.

7 The second is this idea that
8 knowing sort of a priori at the beginning of
9 your care what your expected costs would be.
10 The information about your copays and your
11 information about your total spend, your total
12 max spend cap, that information is generally
13 available but the information about what your
14 particular condition or patients like you,
15 what an expected cost would be, just even
16 getting started in that area would be a huge
17 contribution.

18 And third, and I think Liz pointed
19 this out as well, the theme around
20 understanding the indirect costs and how
21 patients really weigh that in various
22 different decision points, I think was

1 certainly a theme that resonated with me.

2 So, I will hand it over to the
3 chairs or Ashlie, or any of my NQF colleagues
4 if they have any other themes or reflections
5 from the day and then I will open it up to you
6 guys, if we have any other reflections for the
7 day, before we move on to tomorrow's agenda,
8 an overview of tomorrow's agenda.

9 CHAIR MORT: Well, Taroon, you did
10 a great job summarizing. And I just want to
11 emphasize that the discussion today really, to
12 me, reinforced the importance of having had
13 this discussion and having had this workshop.
14 Because there are aspects of the whole
15 affordability conversation that the consumers
16 brought to life today. And I think that
17 conversation that we started getting mixed up
18 with all the definitions, cost, price, but the
19 affordability issue for consumers really is
20 what it means to me. My paycheck. And what
21 about the deductibles and the copays and the
22 indirect costs, leaving work, all those things

1 that I don't want to repeat ourselves. But
2 that story is huge and it is pretty well
3 hidden in the healthcare administrative kind
4 of dialogue that I sit in on a day to day
5 basis.

6 The quality discussion, I think
7 what was most enlightening for me was how
8 important it is for individuals to know,
9 patients to know what it is like for other
10 patients who have this condition. And that is
11 pretty much non-existent except through this
12 internet and websites and all of that. We
13 don't provide that as providers. Huge gap in
14 that.

15 And I guess the other thing was --
16 well, there were several things but I just
17 want to say how important knowing whether or
18 not you need to come to the hospital is.

19 And we talk about population
20 health management until we are blue in the
21 face at Mass General and Partners HealthCare
22 and we talk about patient-centered medical

1 home. We talk about specialist engagement.
2 And then we walk about patient engagement.
3 And we need to get to that piece a lot faster
4 because bringing patients more actively into
5 the conversation, spending more time on
6 education, making information available to
7 patients will certainly address a huge piece
8 of what I heard this afternoon.

9 So, I am really looking forward to
10 tomorrow's exercise around the case studies.

11 CHAIR THOMASON: I think we have
12 covered the vast majority of it, the
13 appropriateness, what it really means to me as
14 a consumer and the out-of-pocket expense. And
15 I think, too, we raised the issue of
16 empowering consumers to make these decisions,
17 to let them know that these decisions even
18 need to be made and then to help them navigate
19 this system of making those decisions.

20 CHAIR MORT: May I just way one
21 more thing I forgot? I am looking at Tayler
22 and she reminded me that we need to plan for

1 the future. And our current systems are
2 woefully inadequate for the needs that Tayler
3 and her cohorts require.

4 MR. AMIN: So, we have a few
5 minutes before we go to public comment. Are
6 there any other reflections from the group?

7 And then we will turn it over to
8 Erin to walk through the agenda and the
9 structure of tomorrow's session, how it
10 relates to what we have done today.

11 Any other comments from the group?
12 All right, so Erin, take it away.

13 MS. O'ROURKE: All right, so
14 Taroon and Liz were mentioning, tomorrow will
15 be starting the morning with our case studies
16 activities and this will really be a chance
17 for -- we will give you the story of a fake
18 patient and to play them out across this
19 episode of care model, thinking about what
20 decisions that person would need to make and
21 what information they would want to have to
22 support those decisions about their care.

1 After that, we will come back
2 together to have a report out time to see what
3 the results of these cases were and are there
4 additional considerations we need to think
5 about, now that we have tried to use this
6 model with a real person?

7 After that, we will break for
8 lunch and then come back to think about
9 challenges and the path forward. What could
10 we start to do to make this information
11 available to consumers and empower them to use
12 it?

13 CHAIR THOMASON: I have a quick
14 question, Taroon. We had a lot of
15 conversation today about the complex system
16 and how it is so hard to navigate and then to
17 understand the bills and things like that.

18 I don't know if we have a time
19 tomorrow at all but we didn't get into bundled
20 payments at all today and I wonder how fellow
21 consumers feel about that.

22 MR. AMIN: You know what we can do

1 is we have sort of some broad challenges in
2 path forward. We can certainly add it in in
3 tomorrow's afternoon discussion. I wouldn't
4 try to fit it in right now. Okay.

5 So, yes, I mean if there are other
6 sort of related conversations that we don't
7 feel like we covered, we can certainly add
8 them in tomorrow during the afternoon.

9 CHAIR THOMASON: I just wanted to
10 throw it in somewhere.

11 MR. AMIN: Absolutely.

12 CHAIR MORT: But Melissa, can you
13 just say a word about the aspect of your
14 concern?

15 CHAIR THOMASON: I think it was
16 briefly mentioned one time. I know as a
17 consumer, I want to be able to look at a bill
18 and understand it. So, a lot of times I hear
19 conversations around bundled payments and what
20 is the average cost of this and can't we just
21 do that. And I don't know how my fellow
22 consumers feel about looking at a bill and

1 seeing and average cost versus an itemized,
2 complex listing of everything they did to me
3 and what it cost me.

4 I am only one consumer and I
5 wonder if you want to see a bill with
6 everything listed out. Is that too complex?
7 Or does it make you feel robbed when you just
8 see a number and you are like hey, wait a
9 minute, where did you get that?

10 That was my question. Maybe we
11 can throw it in the mix tomorrow.

12 MR. AMIN: Yes, that would be
13 certainly an interesting conversation to have.

14 MEMBER SINGER: Just a quick
15 response to that. When you see the itemized
16 bills, it makes no difference because that is
17 not how the health plans pay the hospitals.
18 They pay them on case rates or per diems. So,
19 when you see your \$12 Tylenol tablet, it will
20 rip your heart out. But that is a number that
21 I don't want to call it a fictitious number.
22 It is a bookkeeping number for the hospital

1 for them to track resource utilization. That
2 probably has very, very little to do with what
3 ends up coming out of your pocket.

4 CHAIR THOMASON: And as a
5 consumer, I -- bundled payments, I want to be
6 able to look and see the average cost and
7 things like that. I think an average cost or
8 a bundled payment will make price transparency
9 a lot easier on the front-end. But then Corey
10 made the statement today and I look at this
11 number and I am like where did you get that
12 from. And that made me wonder how that
13 translates into other consumers' lives.

14 But, a conversation for another
15 time.

16 MR. AMIN: Okay, should we open?
17 Operator, can we open the lines for public
18 comment, please?

19 OPERATOR: At this time, if you
20 would like to ask a question or make a comment
21 please press *1, again that is *1 to ask a
22 question or leave a comment.

1 MR. AMIN: Are there any comments
2 in the room? No. Okay.

3 OPERATOR: And there are no
4 questions or comments, at this time.

5 MS. O'ROURKE: We have no web
6 chats. I should mention if you are joining us
7 for dinner, it is an Siroc at 915 15th Street
8 and we will be meeting at six o'clock. It is
9 right across from the park.

10 MS. WILBON: Yes, if you are going
11 back to the hotel first, if you walk out of
12 the hotel -- you are at the Capitol Hilton,
13 correct? Okay, if you walk out of the front
14 door, make a left. You will be on the corner
15 of 15th and -- oh, sorry, 16th and K. Make a
16 left onto K Street. Walk down about two
17 blocks and then make a right on Vermont and it
18 will be -- it is on the block of Vermont. You
19 will see the park over to your right. And it
20 is like on Vermont, on that block.

21 MR. AMIN: Yes, on that block.

22 MS. WILBON: So it is like a two-

1 block walk. Just make a left and a left, and
2 a right.

3 MR. AMIN: Yes. And Karen just
4 reminded me. Feel free to tweet about the
5 meeting and keep the conversation going.

6 MS. ADAMS: Thank you, Tayler.
7 We have had quite a few tweets and
8 people have been tweeting. So, thank you.

9 MR. AMIN: All right, thank you
10 everybody for a great Day 1.

11 MS. WILBON: Yes, thank you.

12 (Whereupon, at 4:46 p.m., the
13 foregoing matter was adjourned to
14 reconvene at 9:00 a.m. on Friday,
15 March 28, 2014.)

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21
22

A	28:7 35:8 43:6 53:8 54:9 55:19 56:3 65:13 69:20 86:12 115:4 136:5 147:10,17 214:2 227:15 233:20 234:4 240:10 261:11 264:4 319:14 397:9 400:7 407:17 409:6	accountable 10:18 11:3 accreditation 283:2 283:3 accredited 282:20 accreditors 283:6 acculturation 89:7 accurate 220:3 achieve 19:6 20:19 22:11 108:10 acid 318:22 acknowledge 30:1 90:9 189:21 248:7 248:20 acknowledging 248:9 acquiesces 392:9 acquisition 265:12 266:3 act 71:19 74:1 78:19 81:20 87:5 274:1 372:20 376:17 acting 16:10 action 1:20 11:12 181:19 304:17 305:1,1 activate 202:6 307:17 activated 203:8 activation 202:18 active 18:22 20:16 33:5 152:4 154:11 155:6 164:9 202:9 347:22 actively 337:18,21 404:4 activities 6:1 7:20 8:5 28:20 175:16 405:16 activities-based 103:12 112:13,22 114:16 activity 29:13 actual 26:7 54:9 103:11 112:10 171:13 192:2	266:3,16 283:13 381:15 acuity 118:20 309:7 acupuncture 72:21 acute 117:3 120:4 120:18 171:13,22 172:8 173:14,16 176:10 184:4,21 267:10 306:12,13 307:6,8,12,13,19 335:16 380:9 381:16 392:6 Adam 1:20 15:8 58:12 70:21 71:2 87:2 121:19 122:3 125:16 126:20 128:22 164:15 181:6 201:13 206:3 209:12 219:11 226:17 228:9 229:2 314:4 345:4 350:13 355:13 397:11 Adams 2:10 6:22 25:10 177:16,20 183:9 186:8 187:4 188:1 365:11 411:6 adapt 379:11 add 22:10,12 23:8 27:14 42:22 56:7 80:8 100:12 106:1 136:7 173:8 193:1 196:6 197:10 201:15 213:14 221:5 223:11 229:4 233:1 245:7 247:22 248:6 253:9 285:2 293:17 323:9,12 328:11 329:9 359:21 362:18 377:4 378:11 399:22 400:1,7 407:2,7 add-ons 264:11	added 151:20 154:2 155:3 254:18 301:17 adding 86:15 195:15 addition 6:1 35:18 102:18 130:19 339:12 377:6 additional 110:9 370:9 406:4 address 135:14 137:15 148:8 211:4 314:21 315:22 316:3 332:7 381:21 404:7 addressed 143:16 187:7,11 addressing 26:4 368:20 adds 40:13 Adjourn 4:22 adjourned 411:13 adjust 392:2 adjusted 43:2 administrative 24:11 238:22 239:10 403:3 administrator 89:18 admissions 219:7,9 admitted 174:11 375:1 admitting 359:1,4 ado 91:20 adult 48:12 56:12 57:18 69:15 advance 25:19 79:10 162:9 220:6 269:11 advanced 28:2 adverse 393:12 advice 144:20 145:5 388:2 advise 27:18 advised 304:16 advisor 6:13 9:13
----------	---	--	--	---

79:4,6	223:13 232:15	404:8 407:3,8	allergic 151:16	193:20 195:11
advisors 37:10	234:14 235:11,13	afterward 386:1	allergies 53:3,6	196:21 198:10
advocacy 11:9	241:2,12 242:20	age 47:5 80:2 82:6	394:10	200:5 207:18
advocate 1:15 11:1	243:7,14,22 244:4	82:19 96:3 151:1	allergists 54:2	214:11 215:11
69:14 70:10	245:12 246:3,10	198:8 201:8 205:8	allergy 53:20	216:2,5,12 242:14
advocating 147:4	247:14,16,20	205:17 226:13	alleviate 165:16	245:3 247:21
affairs 9:21 12:16	248:8,10 249:11	298:11	Allison 26:5	248:14 249:20
affect 62:17 85:17	249:14 254:13,22	agenda 17:8 30:17	allow 99:1 315:20	250:3,12,22
199:6 201:5 214:8	265:11 266:1,20	34:17 35:19 84:8	allowed 63:7 71:20	253:10 255:1
226:15 293:20	271:21 272:22	402:7,8 405:8	105:12 114:15	264:16 266:12
297:17 356:21	274:11 292:21	ages 205:14	188:12	284:8 296:19
394:2	297:17 305:10	aging 82:20 290:1	allows 307:12	297:13 301:19
affection 220:9	308:4,10 309:8,14	ago 13:11 60:10	397:7	311:2,12,17
affectionately	309:21 310:6,7,12	64:12 68:2 217:6	alluded 39:15	335:13 339:7
177:18	310:13,22 311:7	217:9 278:8	alluding 121:22	353:17,20 361:9
affiliated 348:12	312:2 315:10	305:16 358:11	alphabetically 77:9	363:1,4 364:12
affiliations 337:11	319:20 321:3	372:19	alternative 346:3	366:14 367:13
affirmation 187:1	325:2 327:13	agoraphobia 55:13	alternatives 331:9	369:18 370:19
affirmative 187:2	335:11 336:12	agree 60:15 92:15	336:3,4 355:22	371:1,17 372:15
afford 43:14,15	347:11 356:9,12	92:20 94:9 137:16	altogether 233:10	377:2 378:14
143:5 206:22	356:21 360:22	139:15 150:10	Alyssa 1:13 12:1	379:5 380:22
208:13 209:5	362:9 367:21	151:4 190:7,17	95:10 164:4,18	383:3 385:15
279:15 280:1	368:2,8,17 371:8	210:5 215:9 222:5	167:14 236:19	387:16 394:3,20
affordability 3:11	379:13 380:7,10	308:15 311:11,22	360:4	397:11 398:15
3:20 5:10 17:22	380:18 385:6	353:3 361:14	Alyssa's 339:18	400:13 405:4
18:7,14 20:13	386:10,12 387:9	371:3	361:15	406:22 407:11
26:4 30:22 38:10	388:6 389:13	agreed 95:4 251:14	amazed 349:14	408:12 409:16
38:15 58:16,18	392:18,21 394:2	agreement 191:20	amazing 67:22	410:1,21 411:3,9
70:14 72:15,15	396:19,22 399:6	aha 400:2,21	400:20	amorphous 62:3
78:3 79:12 83:20	399:13 401:6	ahead 55:6 57:19	amazingly 14:5	amount 18:18
89:22 91:4,14	402:15,19	58:10 67:9 86:20	Amazon 223:15,16	44:14 62:16 74:2
92:13 94:13 96:7	affordable 1:3 4:3	93:2 131:9 136:19	225:16 228:16,20	105:12
98:12,16 99:2	4:6,10 51:20 52:1	155:18 173:6	amenities 264:7,22	amputated 122:10
106:5,6,16 109:21	71:19 74:1 78:19	181:6 182:6,15	284:15	analyses 207:12
110:1 111:2,4	81:20 84:13 87:5	192:7 206:2	America 73:2	analyst 6:7
113:21 119:6,22	91:16 95:2 111:18	272:14 274:17	88:17 106:14	analytical 207:1
120:20 121:2	121:20 122:8,13	298:21 302:14	American 1:18	analytically 207:11
132:13 133:2	122:14 123:6,12	325:11,19 326:15	American's 230:10	Anderson 1:22
134:11,16 140:16	126:15 134:18	334:14 359:19	Amin 2:11 3:3,8,12	14:4
140:16 143:11,17	142:21 143:1,2	aide 10:12	3:17,20 4:4,7,12	anecdotal 257:14
143:21 152:13	164:21 193:2	AIDS 73:2	4:17 5:3,21 6:15	anecdote 322:1
162:12 167:17	241:6 245:8,16	aiming 63:19	7:5 8:19 16:21	anesthesia 49:14
179:18 192:10,13	247:7 274:1	airlifted 37:19	17:12 27:13 30:6	anesthesiologist
192:14,15,17	312:10 393:7,13	akin 192:19	34:9 93:6 103:1,4	375:8
193:7,13,18 194:6	AFO 146:3	alignment 348:5	112:3 114:9 170:3	anesthesiology
195:17,22 197:5	afternoon 17:14	Alison 1:17 11:7	177:1 182:12	112:16
202:13 204:17	193:22 248:19	alive 38:15,17 39:5	188:16 191:6	aneurisms 40:18

40:21	364:8	320:3 323:15	177:16 188:18	at-large 248:12
aneurysm 308:22	app 156:3	384:7 388:16	200:6 208:9	attack 129:11
309:3	apparent 358:8	400:22 404:13	364:22 402:3	184:9,22 185:8,13
Ann 2:13 3:5 5:15	apparently 246:6	approval 236:8	aside 157:13,22	308:21 332:4
6:19 7:5	263:14	approved 283:5	asked 9:10 85:19	attained 320:21
annual 271:15	appealing 327:8	April 42:1	160:13 205:1	attempt 400:18
296:15 297:3	appears 110:15	arbitrary 188:3	216:15 256:11	attempts 55:15
384:4	174:22 284:10	architect 107:11	268:14 350:15	attention 201:22
annually 369:6	applaud 89:16	architecture	386:6	attribute 215:4
answer 29:14 33:15	applications 26:6	107:10	asking 68:9 70:14	attributes 168:19
111:13 127:18	28:14	area 15:5 27:21	145:13 146:2	197:13 198:1
145:9 167:6 176:4	applies 69:15 79:11	28:9 29:2 32:19	152:19 188:9	199:5 201:4 208:5
205:5 246:11	263:20	34:7 223:21 234:2	218:3 258:3 294:9	210:7 222:16
258:16 293:7	apply 32:7 114:7	254:11 282:4	353:5	251:11 253:7
321:22 335:14	264:12	299:13 351:16	asks 7:19	356:20
answering 93:17	applying 180:17	355:2,5 358:2,12	aspect 44:22 223:1	audience 116:13
165:6 219:13	appointment	370:4 401:16	309:8 389:14	Australia 146:2
241:14 258:3	267:12 281:4	areas 7:3 92:9	407:13	availability 253:5
answers 33:13	307:2 313:15	175:3,8 186:13	aspects 18:9 192:21	265:16 331:12
241:17	appointments	290:21	193:1 220:18	339:17
anterior 345:19,20	68:18	arena 224:3,5	222:10,12,13	available 19:17,19
Anthem 160:20	appreciate 7:18	arguing 396:14	223:3 249:12	21:4,6,19 22:6
288:2 339:20	9:10 115:10 178:5	Arizona 10:17	309:5 356:11	115:12 130:15
anticipate 161:22	appreciated 179:10	arm 141:5 173:13	379:19 393:18	150:12 153:18,20
289:18 290:13	approach 16:5	174:2 322:8,12	394:1,1 402:14	162:7 197:8
374:20	103:13 190:18	323:8 332:16	aspirations 295:11	222:10 223:7
anticipatory 331:2	225:16 243:4	arms 293:12	assertive 70:1	225:1 226:2
anxiety 44:18	345:19,20,20	398:14	assess 380:18	250:13 252:14,15
46:20 129:11	346:2 349:1 354:9	arrangement	assessment 288:22	252:15 254:4
373:5 376:12	approached 243:1	366:21	311:22	264:7 277:22
anxious 376:7	approaches 238:11	arriving 72:5	assessments 68:17	282:18 283:8,12
anybody 8:2 16:15	appropriate 101:11	Arrow 195:20	assigned 289:13	284:18 285:1,20
50:12 154:13	114:10 131:7	arrows 196:2	assistance 15:10	286:2 292:2
286:22	166:1 248:2,4	arterial 40:19	associate 102:11	296:18 303:7
anymore 80:11	254:15 301:3,12	arthritis 308:21	associated 55:19	340:13 354:6,19
99:19 181:13	315:12 326:9	309:11,12	101:20 221:8	357:18 358:5
317:12 356:19	331:19	article 51:4 227:6	270:20 299:19,21	371:20,22 401:13
anyway 63:16	appropriately	articles 350:3	300:6	404:6 406:11
251:15 337:7	166:5	articulate 193:21	Association 1:13	average 50:9 51:9
396:9	appropriateness	articulated 24:21	1:17 12:2 13:8,14	58:22 161:8,9
aorta 37:14,16,18	42:9 44:20 80:16	artificial 40:20	assume 14:20	176:19 359:21,22
40:20 47:9	82:2 91:19 99:7	Ashlie 2:18 3:8,12	135:12 175:8	407:20 408:1
aortic 37:17 38:6	99:21 100:7,17	3:17,20 4:4,7,12	assumed 137:9	409:6,7
apart 199:18	101:2 106:2	4:17 5:19 6:18	assumes 397:15	averse 349:15
364:16	267:22 274:8	17:9 22:9 25:3	assuming 126:3	aversion 350:9
apologize 112:5	300:9 308:8	104:13 159:18	assumption 348:10	avoid 14:6 125:18
187:7 200:5 220:6	313:19 314:2	168:6 173:6 175:4	349:9	142:14 319:12

avoided 14:6	backtrack 24:19	basic 19:5 83:21	135:4,9,12 136:1	bifida 63:18 64:3
avoiding 274:5	bad 42:10 59:18	133:14,16,22	139:18 166:11,12	64:10 68:11,12
393:12	129:10 157:2	226:10 279:16	166:22 262:21	69:6 388:9
aware 204:3	211:12 219:5	313:11	324:11 348:6	big 17:19 24:22
awareness 305:5	318:11	basically 19:12	believed 151:19	68:10,12 71:13
B	badly 159:4	22:3 53:16 60:19	bells 196:19	75:22 89:12
babysitter 266:11	bag 115:5	157:15 167:15	belong 63:15	129:13 198:9
babysitters 266:21	bags 114:4	191:10 212:2	belongs 204:9	199:16 217:18,19
back 22:21 23:17	Bahamas 344:15	236:7 314:10,17	benefit 61:21	218:19 223:9
24:16 32:1,10	balance 42:21	basis 164:16 280:2	216:22 247:13,16	252:21 267:21
45:20 49:3 76:15	136:5 140:18	389:21 403:5	263:14 293:2	280:20 282:3
79:14 81:4,6,7,13	360:10	bathing 84:1	294:1 297:2,15	284:10 298:1
86:1,11 90:4,22	ball 68:15 392:14	batting 399:12	336:15 355:4	304:21 314:2
91:8 95:15 98:19	Band-Aid 204:12	becoming 29:13	369:10 371:19	329:1 352:6 358:2
99:3 105:21	bands 205:17	331:13	benefits 264:10	384:7 387:12
116:18 123:13	Banner 1:11 10:16	bed 39:6,7	291:20 304:15	bigeminy 60:11
136:10 141:7	338:15	bedside 347:13	324:16 372:20	biggest 201:19
142:19 151:11	bar 92:19 167:1	Beekeeper 1:14	best 69:17 70:13	bike 322:4,6
153:16,17 158:2	barbeque 164:17	9:21	84:13 85:5 127:14	bill 41:19 45:7 46:2
160:14 169:3	barrier 275:16	beginning 21:12	145:8 151:19	57:3,10 75:15
173:22 174:6,7,13	barriers 147:17	170:4 209:10	186:15,15 215:17	86:3,9 87:4 89:4
182:3 183:3 193:8	198:18 201:19	214:16 382:15	224:11 245:15	89:10,13 121:4
195:17 238:1	304:20,21 324:18	401:8	283:14 295:7	122:20 123:1
245:20 250:1,4	base 312:19	begins 171:19	311:8 323:20	126:14 129:3,13
251:4,13 252:4	baseball 110:16	begun 335:16	325:18 331:15	130:7 159:7 315:7
255:20 262:9	139:15	behavior 18:10	354:9	342:12 343:3
266:8 278:16	based 12:4 16:14	68:5 127:7 165:5	better 45:10 50:11	375:1,18 377:16
289:6 298:5	16:16 31:7 53:4	190:1 305:3	59:3 60:5 127:12	377:17 378:1,2,4
302:16 305:12	93:17,18 101:15	behavioral 55:8	130:18 131:2,3	407:17,22 408:5
308:17 309:11	117:4 118:19	126:12 141:12	138:8 148:9	billed 89:13
314:4 319:11	128:17 129:22	185:9 262:12	157:21 177:14	billing 71:15 128:3
320:10 321:6	130:2 135:5	303:22 366:17	178:19,22 200:8	131:19,20 133:6,6
322:6 333:1	148:13 161:17	367:4,8,18 368:2	200:17 224:14	377:14
342:16 344:18	182:4 211:7 213:1	368:20 369:15,17	230:19 231:12	bills 40:6,9,13
352:21 356:4	213:8 215:14,21	370:11,12 372:13	250:6 286:21	52:18 56:15,20
357:5 359:16	218:4,5 219:7	372:22 373:2	288:9 309:15	57:4,5,8,15 67:5
362:8 374:5	221:2 225:22	376:7,20 380:5	310:18 323:13	72:3,4,8 73:15
377:13 389:6	227:2 229:22	381:11	343:16 345:21	75:20 88:20
396:3 399:12	237:7 238:21	behaviors 184:15	357:18 370:12	122:15,18,20
400:4,5 406:1,8	240:8,11 257:13	262:16	397:8	123:3,4,9 132:15
410:11	276:21 278:7	beholder 220:19	beyond 140:3	158:12,16 159:8
back-end 342:10	284:1 286:6,10	belief 304:3,16	189:18 190:5	292:13 293:19
background 8:13	287:3 296:4	305:14 308:17	235:10 281:11	406:17 408:16
8:14 12:3 13:13	298:18 329:15,18	315:2 320:19	bi-coastal 351:14	Bing 303:11
118:6 236:14	337:1 338:3,8	351:8	bias 299:14	biotech 12:21
backgrounds 97:19	347:3 395:8	believe 49:2 92:11	biased 16:11	bipolar 68:13
	baseline 93:22	94:2 133:8 134:21	bickering 395:3	373:12

birth 64:7	book 228:18,19	239:14 243:13	366:1,9 370:21	C
birthday 67:1	bookkeeping	248:22 299:14	371:6 379:11	C 37:18
bit 7:9 10:9 17:6	408:22	302:12 313:16	380:3 388:10,10	C-section 38:5
20:21 21:2 34:18	bootstraps 96:4	314:4 398:16	bubbles 174:19	CABG 138:1 139:7
51:6 55:8 70:21	born 63:17 64:6,14	bringing 32:9	175:18 177:18	211:16,17 357:5
86:19 91:4,15	66:18	179:10 242:2	179:12 181:21	374:14
94:19 99:4 102:8	Boston 358:12	252:4 286:13	182:17 183:14	Cadillac 291:16
105:18 114:3	bottom 89:3 99:16	404:4	184:18 249:10	292:2
119:1 171:7,14	288:15	broad 12:11 98:13	253:3 379:15	cafeteria 204:12
173:8,8 189:2,18	bought 226:21	116:21 189:15	bucket 104:7	CAHPS 282:15
192:2 204:1	294:22	190:6 407:1	270:11	cake 249:18,19,21
214:13 215:16	bounces 266:8	broaden 108:19	buckets 287:12	251:1
216:12 217:11	bouncing 53:22	306:5,6	budgeting 279:17	calculated 291:19
220:7 221:3	box 242:9 246:7	broadening 305:11	279:18	293:6,18
235:17 241:15	252:21	broader 119:1	buffer 144:8	calibrated 215:17
242:15 243:17	boy 64:13 257:21	207:13 252:1	bug 318:13	California 1:13
263:20 317:6	257:22 298:20	broadly 5:8 191:21	build 22:20 107:17	12:2 154:13,16
318:22 320:18	brace 65:2	197:18 200:3	177:6 179:5 197:4	283:9
321:1 346:21	braces 65:1,4,9	207:2	255:3 374:6	call 27:7 30:10
365:1	brain 40:21 64:17	broke 23:21 126:7	building 190:15	37:13 38:9 41:3
bladder 44:9 46:13	brainstorming	333:7 334:12	196:16	57:9 65:15 76:15
46:14 332:3	321:9	broken 61:9 100:19	built 132:11 178:7	122:3 145:10
blah 319:10,11,11	brand 288:7 325:3	322:8,12 323:7	179:4 218:22	147:3 177:18
blessed 88:10	brands 162:5	332:16 333:9	295:3	193:10 206:17
392:10	break 31:3 86:19	334:7,13,13	bullet 100:1,9	243:9 245:14
blessing 78:20	90:22 100:13	398:14	105:22 121:18	261:14 317:11
blind 54:15	168:8 173:13	broker 59:13	130:13 131:7,8	319:7,7 324:2,3
block 190:15	214:13 245:2,4,5	bronze 135:7	144:2	329:6 330:4,4
287:17 410:18,20	249:21,22 252:1	162:22 287:8,9	bunch 59:14	332:2 342:17,18
410:21 411:1	257:11 364:16	398:14	bunched 99:21	354:22 356:15
blocks 410:17	406:7	brother 43:1 165:1	bundled 375:16	379:11 408:21
blood 53:4 61:14	breaking 31:18	312:6 324:1	406:19 407:19	called 38:1 45:20
153:6 260:18,20	177:8	331:20 333:13	409:5,8	59:13 76:19 86:4
299:17	breakout 32:2,11	339:19	burden 206:21	89:1 133:20,21
blue 13:9 14:16	breaks 32:20 141:5	brothers 85:9	207:12 208:14	155:20 163:16
327:1,1,4 403:20	174:2 313:1 327:6	brought 58:15 68:6	burgeoning 146:13	166:6,10,11 167:8
BlueCross 1:16	breast 262:3	74:8 114:22	Burstin 2:12 7:2	178:7 185:4 211:8
13:8,13,16 155:22	bride 257:5	172:17 192:9	88:8 100:11	211:22 255:18,19
156:1	brief 32:2 54:19	261:19 354:8	349:11	339:19,20
BlueCross/BlueS...	86:20 98:5,7	402:16	busy 261:21 318:2	calling 30:14
13:2 139:5 284:4	212:22	bubble 178:18,22	button 8:20,22	calls 43:9 243:9
BlueShield 1:16	briefly 294:9	179:22 180:16,22	92:19 93:1	333:13 334:2
13:8,13,16	407:16	183:13,14 184:7	buy 163:3 223:14	377:15
blurred 242:10	bring 27:1 39:19	184:10 261:8,11	223:18	camera 49:10
Board 15:15	120:22 121:17	261:13 262:1	buying 59:6 162:20	Campaign 300:3
bodies 122:10	144:2 160:14	268:18 269:2,3	163:6 280:16	Canada 146:1
body 312:22	165:12 211:17	270:2,15 273:6	bypass 374:10	canal 76:22 77:19
		276:1 301:10		

cancer 1:22 61:12 123:5 185:19,20 212:3 262:3 309:1 309:1 313:9 cancers 212:5 candid 42:18 cap 401:12 capabilities 216:19 capacity 73:16 Cape 163:18,21 Capitol 410:12 caps 285:8 capture 297:19 327:7 car 320:2 328:22 card 30:12 43:22 119:19 281:6 316:10 332:1 cardiac 88:17,21 138:4 315:5 348:17 357:4 374:9,13,15 387:4 cardiologist 375:3 386:2 394:11,11 394:12,16 395:2 397:18 398:8 cards 30:14 147:22 150:7 care 1:3,15,15 3:16 3:20 4:3,6,10,11 10:15,18 11:3,17 12:10,13 14:11 25:22 31:5,17 38:11,12,13 39:12 40:15 42:9,14 44:20 50:8 51:20 52:10 54:1 55:18 58:19 60:18 61:2 61:3 71:19 72:1 74:1,12,15 75:10 76:2 77:7 78:8,11 78:13,19 79:4 81:20 82:10,13,20 83:17,22,22 84:1 84:11,19 85:15 87:2,5,12 91:16 91:18 95:2 97:5	99:6,22 100:7 101:7,14,16 102:6 102:14,20 111:18 116:20 117:8 120:9 121:20 122:19 123:3,4 124:10,20 126:14 126:16 134:17 142:3,21 151:19 152:8,17 159:1,4 159:6 168:12,18 170:13,18 171:2,7 171:15 172:1,6,12 172:14 174:14,15 174:20 175:10 176:10 178:2 179:2 181:11,13 182:1,21 183:1 184:12 185:1,15 186:11,13,15,20 187:8,10,14 189:11 193:9,9 194:14,16,20,22 196:12,12 199:21 201:18 206:8,11 207:5,6 209:22 210:1 214:1 218:6 218:8,14 219:18 219:22 221:7,9,13 222:1 231:14 237:15 247:6,18 253:18 255:8 256:18,19 257:1 260:17 261:21 266:15 267:1,6,10 267:11,18,22 268:1,19 269:15 270:1,13,15 272:15 274:1,9 276:14 280:11,22 281:1 289:16 290:8,9 294:7 298:1,6 299:6,13 303:2 306:11,11 306:12,13,15,22 307:4,8,13,14,20 307:20 310:11,13	310:22 311:22 312:6 313:19 314:3,9,10,22 317:3 320:4,7 324:13 325:8 329:22 330:7,22 331:5,18,22 334:4 334:9,14 335:21 340:1,7,10 341:9 341:11 361:19 362:3,9,11,11 365:4,16,17,22 367:5,9,19 368:5 368:12 369:15 370:1,2,13,22 371:2,15 372:6 373:3,7,13,16 374:3,3 381:22 382:1,12,16,21 383:7,8,18 384:10 384:12 385:5,7,11 385:19 386:13 387:4,21 388:6,13 389:15 390:7,12 391:2,11,16 392:5 392:7,15 393:2,5 393:7,12,13 394:6 394:14,15,18 395:5,10,12,13,15 395:22 396:16,18 397:10,16 399:17 401:4,9 405:19,22 cared 71:10 73:17 78:6 220:1 careful 127:21 387:6 carefully 319:6 caregiver 209:2 391:19,20 cares 120:6 219:17 Carol 319:10 Carolina 6:14 9:14 37:5 85:2 361:3 Carrie 1:15 10:21 79:17,20 88:1 123:18 126:18 128:20 129:18	134:21 137:18 150:5 153:13 155:15 209:13 212:21 246:18 258:1 261:12 262:5 299:11 341:14 345:3 350:13 352:20 355:11 Carrie's 160:18 carried 352:8 carries 309:2 carry 98:10 352:5 carryover 391:15 392:6 cars 66:5 carved 367:7 carved-out 366:21 case 19:14 20:5 32:4 56:7 68:1 119:2 177:9 231:9 262:14 266:9 267:1 272:13 274:19 296:20 297:4,9 298:18 358:5,6 382:4,6,7 387:21 388:14 390:9 397:7 404:10 405:15 408:18 cases 280:5 366:20 406:3 cash 209:18 344:6 cashier's 133:21 cast 174:4,5 CAT 318:4,9 384:4 catastrophic 120:4 categories 100:18 category 100:8 137:6 cath 158:13 catheterization 48:20 88:18,21 caution 225:9 cautious 129:15 caveat 34:17 397:13	CDC 12:20 cell 32:21 319:9 center 1:20,22 15:9 152:16 330:22 331:5 centers 78:12 351:15 century 308:18 CEO 12:9 cerebral 80:1 384:3 certain 44:14 97:6 148:13 183:22 193:2 205:14 211:15 212:5 262:11 299:3 330:18 certainly 25:11 27:10 28:22 34:12 34:15 63:10 66:11 79:14 103:18 114:10 178:5 179:7,9 182:12 188:13 262:12 266:6 284:19 399:1 402:1 404:7 407:2,7 408:13 certainty 110:20 cetera 108:4 149:4 183:21 185:10,14 192:22 262:13 266:21,21 305:5 368:11,15 372:11 378:9 CG-CAHPs 222:21 chair 1:10,10 6:12 8:16 9:3,12 16:5 23:7 29:19 36:21 36:22 46:10 52:14 55:4 56:9 58:4 60:2 62:11 65:22 66:2 79:2,19 84:7 89:15 90:11 105:21 107:2 109:16 111:20 113:18 115:11,14 115:15 118:17 119:18 121:15
--	--	--	---	---

125:16 126:17	300:7,12,20 301:5	221:18 248:16	checkbook 23:15	261:19 276:20
128:19 129:18	301:15 302:7,9,13	261:4 347:17	23:21 24:2 360:11	284:6 294:1
130:12 131:4,9	305:17 306:20	350:2	checkbooks 90:5	332:10 335:5,6
133:5 134:20	307:21 310:9	changed 38:11	checked 45:18	337:10 338:8,11
136:7,9 137:1,7	311:19 313:16	127:8 219:4	260:18 315:11	343:16 345:7
137:16,17 142:18	316:6,8 318:15	243:15 326:12,14	318:20	356:5,9,10
143:13 146:8	319:19 323:1,6	changes 18:19	checking 223:14,16	choosing 58:20
147:20 150:1	325:11 326:11	185:9 192:15	checkup 48:21	227:11 274:9
151:8 153:11	328:11 329:9	193:6,7 273:22	51:15	287:6 293:21
155:13,17 156:17	331:16 334:16	297:14 308:11	checkups 47:15	319:5 326:1
157:2 159:13,16	336:14 337:20	372:8	chest 42:4 153:2	337:18 338:2
159:17 160:13	340:14 342:9	changing 52:6 53:7	276:12 315:4	341:2 343:10,10
163:13 167:14	345:2,9 346:8	109:8 218:16	chicken 53:17	343:11 346:21
175:4,7 187:6,22	347:15 349:8	361:2	chief 9:6 15:1	359:1
194:12 195:9	350:12 352:14	chaos 379:12	child 65:15 66:12	Chorus 181:4
198:8 199:12,20	353:19 354:20	characteristics	68:3 80:21 90:6	chose 338:4,13,14
201:3 202:16	356:3,4 359:11	211:10,11	120:9 144:17,18	341:3 345:6
203:3 204:15	360:4 361:1	characterize	151:16 223:16	chosen 337:13,21
206:1 207:14	362:21 363:2	189:14 200:14	320:14 382:6,7	338:3 346:13
208:10 209:11	369:19 385:18	234:19	391:1	359:15
211:9 212:20	389:9 392:16	charge 105:3,7,10	child's 321:1	Christiana 11:17
213:13 216:3,6,10	402:9 404:11,20	105:11,14,17	childcare 265:22	Christmas 390:21
217:13 218:17	406:13 407:9,12	136:17 204:13	children 15:17	chronic 24:7 38:12
219:6 222:3	407:15 409:4	310:12 330:22	63:19 81:8 88:19	40:15 117:8
223:10 226:6	chairs 1:8 17:3	362:8	120:11 384:2	120:18 149:10
228:13 231:10	22:10 214:20	charged 44:13	Children's 1:11	173:12,16 174:10
232:16,20 233:13	398:19 402:3	49:21 158:11,14	15:15 63:2 69:12	176:11 179:1
233:18 244:22	challenge 86:10	charges 99:9	88:4 317:14	181:9 187:9 188:7
245:6 246:17	275:16	chart 275:21	chime 291:12	188:14 191:14
248:5 258:1 259:5	challenged 86:5	chat 55:8	choice 26:13 74:17	193:9 196:12
259:9,15 260:3,7	challenges 32:12	chats 410:6	135:6 140:10	218:5 223:4
262:17 264:15	375:17 406:9	chattiest 155:20	181:17 217:19	259:22 260:4,10
265:8 266:5,17	407:1	chattiness 16:17	231:6 245:16	301:2,5 348:17
267:19,20 268:10	challenging 19:7	95:13	269:14 277:15	364:19 365:12,14
270:5 271:2	23:10 90:10	chatting 95:14	291:16,18 308:2,8	382:5 389:11
272:11 273:16,20	167:12 293:11,13	chatty 12:14 70:1	332:15 340:21	390:4,13
274:13,16,17,18	353:12 374:8	96:17 123:22	346:6,7 351:16,17	chunk 51:8 282:21
275:13 276:9,15	375:10,13	cheap 245:10	352:2 355:8	Cindy 295:17
276:17 277:7	champions 26:22	cheaper 41:10	389:14	353:1
279:2 281:21	chance 38:22 84:22	166:9,22 289:2	choices 32:16 117:4	circle 193:8 238:1
284:7 286:1	144:3 292:15,17	339:22 340:2	119:5,6 137:22	262:6
287:18 288:16,19	405:16	cheapest 287:11,17	145:18 149:11	circles 196:13
289:10 290:15	change 83:11 92:22	287:21 288:3,21	233:22 270:20,22	202:18
293:14 294:3	98:20 127:4	288:22	271:18 286:5,10	circumstances
295:9,18 296:6	128:17 209:21	cheapness 120:15	371:7	20:10 94:14
297:1,21,22	215:14,18,21	check 52:3 106:20	choose 129:21	211:11 325:4
298:17 299:8	217:4,8 218:4	107:1 159:10	228:9 245:8	395:13

circumvents 362:3	clinical 11:18 12:16	145:19 283:10	208:19 279:11	340:2 341:17,22
cities 351:14	88:12 166:1	Colorado's 63:2	290:3 321:6	common 177:17
358:10	171:19 273:10,12	colorectal 262:3	328:10 351:2	210:12 287:1
city 72:20 346:19	282:14	colorful 173:9	375:15 393:1	373:2 384:16
352:6	clinicians 325:3	colors 322:10	409:3	communicate
claims 238:22	clinics 15:11 331:7	column 49:22	comment 3:15 4:20	55:19 56:4 136:5
239:10 278:7	close 130:3 157:3	290:7	58:14 84:9 88:15	392:11
377:18,20	closely 158:21	coma 122:9	95:13 96:17,19	communication
clarification	closest 80:19 81:1	combine 7:7	110:13 115:20	75:18 147:10
188:17 367:2	310:14,17	come 6:15 20:4,11	119:20 131:6	152:3 343:8
clarify 103:14	closing 398:22	32:1 33:15 49:3	137:18 153:14,15	communications
114:13 194:13	399:2	49:19 56:21 57:6	159:22 160:2,9	271:22
208:12 256:9	club 63:14 64:14	62:22 64:22 70:10	164:5 167:21	community 1:12
258:15 259:12	264:8	88:16 90:22	177:17 213:1	15:2 148:21 149:6
302:10 332:6	clue 77:20	116:18 123:14	224:19 274:15	149:13 183:21
335:1	co-chair 9:10 14:19	150:21 152:12	288:17 295:14	185:19 344:22
clarifying 179:22	co-chairs 30:12	157:14 165:4	316:7 326:17	community-wide
254:8 264:17	236:1	183:3 193:12	332:15 349:12	278:2
284:9	coach 15:8	233:10 240:3	381:2 390:14	comorbidity
clarions 26:22	coarctation 47:9	243:20 249:22	405:5 409:18,20	376:12
clarity 399:15	coastal 283:10	250:3 262:9	409:22	companies 12:21
class 89:8 118:7	COBRAing 59:20	303:10 308:20	commented 164:7	13:16 162:15
287:10	Cod 163:18,21	351:16 353:2	commenting 157:3	company 12:18
classes 303:21	code 134:2	377:18 403:18	comments 3:6 17:4	77:12 162:16
360:10	codes 161:6	406:1,8	86:18 118:18	375:9
classic 300:2	cogmentation	comes 43:17 97:19	131:11,15 137:19	comparative
classify 306:21	108:15	98:19 113:2 122:7	139:1 144:2	138:18 150:20
clear 89:22 119:3	cognitive 126:12	129:16 134:13	151:13 153:17	comparatively
125:17 171:16	202:11 378:9	136:10 229:5	160:6,12,18	230:18
196:13 207:11,21	cognizant 108:9	255:13 310:1,6	167:17 272:18	compare 28:10
223:9 243:10	164:8 242:5	319:21,22 322:3	361:8 405:11	137:21 148:21
268:11 352:12	cohorts 405:3	336:17 337:8	410:1,4	286:14 354:19
clear-cut 167:10	coinsurance 270:18	344:18 350:8	committee 3:4 7:20	compared 69:4
clearly 89:3 192:14	cold 394:9 396:1	355:8 359:5 386:5	7:22 8:3,8 14:20	76:12 380:11
243:20 286:19	collaborative 1:16	395:20	15:15 16:9 17:4	comparing 224:12
288:13 293:14	12:10 116:20	comfort 118:13	27:3 31:7 33:15	comparison 41:2
315:1 345:20	colleagues 135:3	395:9	34:16 37:7 63:3	86:13 133:15
401:1	291:22 347:21	comfortable 34:3	69:11 109:10	158:18
click 92:15,18	402:3	222:2 243:11	236:3	compartment
clicker 91:21 94:6	college 1:18 247:19	294:14,16,17	committee's 8:12	242:8
clickers 92:13	290:1,2	350:9 358:19	committees 11:19	compelling 95:19
215:6	colon 61:12	359:3	63:4	189:5
clicking 94:4	colonoscopy	coming 26:14 27:5	commodities	competition 149:3
clinic 74:16 133:20	203:16	35:15 46:12 52:12	338:22 339:2,4,5	competitive 59:8
133:21 145:1	color 177:6 323:4	70:12 75:20 78:2	339:9,12,14 340:6	competitors 288:8
166:14,16 307:1	Colorado 1:12	78:5 87:4 89:17	351:11	complaining
319:17,21	15:16 59:9 66:14	97:8 143:22	commodity 338:19	227:14

complaint 307:16	computerized 222:17	174:10 181:9	connectiveness 186:21	consults 393:1
complement 222:6	concept 17:21	182:5 187:16,19	connectivities 233:9	consumer 3:9,19
282:1	38:10 62:3 82:2	187:20 188:7	connectivity 186:18	11:8 13:7,12
complete 121:9	94:13 95:15 98:13	285:11 304:11,13	connects 249:11	14:10 21:10 30:18
completely 24:9	99:7 101:13 102:5	316:17 320:13,14	consensus 236:2	35:21 36:8 44:19
85:17 132:19	102:12 104:20	336:1 365:8	399:11	46:5 50:10 51:9
139:16 140:2,13	112:21 119:22	381:10 382:5	consensus-based 107:21	59:1 82:6 86:16
268:15	121:1 134:15	395:14 396:8	consequence 81:14	98:19 100:5,16
complex 55:10 56:1	216:21 225:19	397:10 398:4	consequences 121:13 258:11	110:1 114:6,18,22
56:8 59:21 90:8	230:4 232:17	401:14 403:10	304:14 342:4,22	117:7 118:21
163:15 218:5	259:16 260:8	conditions 47:3	380:2	119:13,15 124:2,9
291:8 362:18	294:18 306:7	55:11 61:8 144:19	consider 47:13	124:14,17 129:2
379:20 406:15	325:21 326:10	156:4 161:20	52:19 158:1,5,7	134:9 136:11
408:2,6	338:19 343:17	188:14 260:1	195:15 200:11	139:5 141:2
complexities 110:5	345:5 379:8	294:11 309:17	208:8 217:21	148:22 149:16
complexity 56:7	386:20 399:6	336:11 373:20	256:20 296:7	151:15 156:10
131:16 132:5,20	concepts 3:11 31:2	384:16	307:3 310:13	158:2 164:13
377:5	35:16 61:17 91:17	conference 1:6	317:16	165:5 168:14
compliance 374:4	91:19 92:5 95:7	32:18 88:2 330:16	consideration 234:16 273:17	175:2,19 179:6,6
complicated 23:10	97:12 98:8,9 99:5	confess 257:14	310:8	181:3 189:16
24:6 25:1 107:9	102:9 103:6 105:3	confidence 305:6	considerations 176:2 208:5 209:6	191:2 194:22
142:3 206:14	109:20 110:1	confirm 191:5	406:4	195:3 196:18
290:19 291:5,7	304:8	conflict 8:10 14:21	considering 328:4	197:12,22 199:15
318:7 364:6 366:9	conceptual 17:18	16:3,10 135:16	336:7 399:21	201:4 207:15
371:7 375:21	21:22 31:6 96:20	conflict-free 16:12	consistently 131:13	210:6 211:5,10
377:21 380:4	172:17	conflicts 14:18	328:12	214:18 215:13,21
381:11	conceptualization 97:20 104:14	confused 54:12	constant 69:22	219:16,17 224:1,2
complication 372:12	conceptualize 97:2	182:17	298:15 313:1	239:3 240:3 243:9
complications 47:21 55:17	170:14 365:5	confusing 50:9	constraints 285:7	245:7,13,14 248:6
376:10	conceptualized 102:9 188:2	126:9	construct 182:13	251:11 256:12
compliment 156:11	189:19	confusion 131:13	constructed 110:16	261:7 266:17
component 58:16	concern 16:3 80:11	congestive 47:6	182:14 362:7	280:18 286:9
136:1,3 145:15	407:14	185:13	construction 312:22	289:9 295:5
210:19 299:7	concerned 60:15	congratulations 72:3	consult 389:20	298:16 300:16
353:11 391:16	246:1 317:12	Congress 316:2	consultant 14:13	307:15 315:1
components 24:14	concerns 33:19	connect 146:15	15:5 59:6 391:18	323:11 328:1
24:19 170:20	172:13	147:18 184:3	consultants 125:19	329:10 335:1
197:22 213:6	conclusion 316:4	256:22	consulting 8:5	337:17 339:16
265:5 284:12	concrete 122:1	connected 182:18	10:17,18 14:18	342:6 343:17
392:5 399:22	condition 20:1,9	183:4,5 186:2,9		344:9 387:15
composition 393:14	31:15 48:15 61:7	196:3 210:7		397:7 399:5,14
comprehensive 35:5 221:1 299:17	61:20 64:11 87:11	236:16 359:8		400:10,11 404:14
398:5	149:10 161:9	connecting 233:8		407:17 408:4
	172:16,19 173:12	241:22		409:5
		connection 61:18		consumer's 29:2
		186:4,6		52:17 62:14 90:1
				104:11 113:20

134:6 138:10 194:18 consumer-centric 109:14 240:5 consumer-directed 161:1 consumer-focused 239:8 consumer-type 176:11 consumers 18:4,17 18:22 19:10,14,18 20:6,8,11,15,16 21:4,7,16 22:2,6 23:5,6 24:16 26:12 28:7,11,16 29:8,21 30:3 31:1 31:12 32:14 35:7 35:10 36:2,6,17 58:7 69:15 89:16 90:7 95:22 96:12 103:22 106:19 111:19 116:12,21 116:22 117:1,18 118:3,10,19 121:21 126:2,7 131:12,17 134:8 135:4 136:21 137:9,11 139:14 139:17,20 142:5,6 142:16 144:15,15 145:13 148:9 149:2,9 154:11 155:5 156:8 157:6 157:10 167:19 168:16 170:7,10 178:12 179:17 195:6 202:21 205:1 207:2 210:13 215:7 222:9 223:6 225:1 225:20 229:11 238:6 240:6,10,13 240:20 241:20 252:8 276:3,6 282:12 285:5,17 286:3 294:22	304:7 311:20,21 320:14 323:15,17 329:3 343:9 353:5 353:11 357:17 359:9,12 363:19 383:5 390:1 393:19 402:15,19 404:16 406:11,21 407:22 409:13 consuming 108:13 contact 391:4 CONTENTS 3:1 4:1 context 18:12 108:20 113:3 117:22 203:18 225:8 235:17 281:17 302:1 400:9 continually 42:7 continue 19:1 29:7 53:15 184:16 245:2 264:4 continues 377:1 384:7 continuous 184:14 186:18 187:10 189:1 398:5 continuum 19:11 79:4 173:1,4,19 174:9 273:7 contract 12:18,20 contracted 128:6 128:11 contracting 354:13 contractor 1:22 10:10 contracts 14:7 contractures 81:15 81:16 contribute 336:21 contributed 81:21 contributes 110:17 contribution 130:21 146:9 147:21 153:12 401:17	contributors 110:22 control 65:15 375:7 375:10 382:12 controlled 258:10 258:11 260:1,14 382:20 convene 109:8 convened 235:20 236:3,20 convenience 138:15 390:3 convenient 269:21 389:21 convening 97:17 conversation 27:10 32:12 33:17 34:13 34:15 35:12 39:20 42:8,13 52:16 100:14 113:10 121:18 139:18,21 140:5,11,15 152:19 153:10 157:5 160:15 172:19 197:17 207:19 229:17 235:1 242:5 247:22 249:2 262:21 303:20 320:10 321:9 326:11,13 327:9 327:19 336:10 341:16 352:22 353:22 381:18 398:17 402:15,17 404:5 406:15 408:13 409:14 411:5 conversations 42:19 139:12 140:19 145:11,21 145:22 146:1 171:5 208:4 268:2 286:9 299:15 393:4 407:6,19 convert 176:17 304:6	converting 179:15 conveying 389:5 convince 297:2 cookies 251:1 cool 53:11 71:1 coordinate 381:7 385:19 coordinated 323:5 coordinates 388:5 coordination 174:15 186:16 365:16 381:13 382:1 385:5 coordinative 384:9 coordinator 9:20 219:7,9 361:22 copay 107:7 128:5 144:10 239:2 274:5 316:11,14 328:20 330:19 331:4,4 373:16,17 375:18 copays 71:21 75:5 75:7 143:6 163:4 265:15 270:18 285:9,15 289:19 290:6 356:7 368:14 369:10 373:21 374:6,15 383:19 401:10 402:21 coping 178:22 179:2,3 191:14 365:10,12,14 copy 33:8 core 19:8 36:3 Corey 1:22 10:6 46:7 47:1 52:14 58:14 86:21 129:19 133:10 232:5 293:14 338:12 359:19 394:3 398:2 409:9 Corey's 153:17 397:18 398:6 corner 250:15 410:14	correct 175:8 192:5 265:3 410:13 correctly 118:22 correlated 257:9 correlation 257:8 Corrie 182:15 184:3 226:17 cost 3:19 6:1 14:19 15:3,6 17:16 18:8 21:4,9,17,18 27:22 30:20 38:18 39:3 40:1 41:4,7,8 43:7 45:19,21 48:7,9 49:14,15 51:4 52:10 54:14 64:21 65:3 69:8 77:3,19 79:13 81:7 82:13 85:18 85:21 89:21 90:16 90:20 92:11 93:12 97:21 99:7 101:16 102:10,21 103:9 103:12 104:3,7,18 106:7,22 108:4,10 108:11,12 110:17 110:19 111:21 112:7,7,8 113:1,2 113:7,13,16,22 114:5 115:6 117:8 117:21 122:6 125:5 127:11 128:1,16,18 129:15,21 130:6 130:11,14,19 131:2 132:7 133:22 135:6,14 136:6,13,22 138:15 140:12,18 143:18,19 144:9 148:13 150:13,18 152:20 154:7 155:2,3 156:5 161:8,8,9 162:8 166:3 167:3 168:2 172:10 190:3 204:11 206:11,20 206:21 207:7,13
---	--	---	--	---

207:13,15 208:8	106:11 110:6	coverage 271:3	cultural 202:7	218:2 219:3
209:4,20 210:8	112:1 121:8	286:16 297:16	204:14 210:9	273:21 332:12
215:7 217:20	130:18 131:22	299:3	230:10	333:11,17,21
219:15,15,21	133:1 135:15	covered 42:11	culture 39:15	334:2 338:7
220:1,20 221:6	154:22 155:4,9	66:22 76:5 84:2	202:10 204:1	362:17
223:21 225:22	162:18 166:17	143:10 254:10	275:8	daily 164:16
235:14,21 236:4	199:3 216:20	265:14 297:11	cultures 204:2	184:19
237:14,15 238:20	217:5 219:18,18	314:14 335:3	cured 130:10	Damn 325:19
239:3,7,21 241:4	236:19 237:3,7,11	404:12 407:7	current 21:3 61:20	dangerous 235:6
242:22 244:6,11	237:16 238:7	covers 74:2 368:10	104:13 405:1	237:6
247:13,16 248:3	239:2,12 266:1	CPT 161:6	currently 9:5 10:19	dashes 196:13
249:3 254:12	272:6 280:7	crappy 230:17	14:13 22:6 75:6	data 18:16 19:3
263:6,6,7,7,7,7	290:13 291:5	347:14	180:2 252:14	20:14 21:6,17
265:17,22,22	294:12 295:1	create 125:11	284:18	28:13 30:21
270:8,8,8 276:2	299:18,21 300:5	132:10 161:12	curse 78:20	103:10,18 115:2
276:22 277:13	305:1 314:18	209:9	custodial 83:17	115:12 156:5
278:4 281:13	344:18 368:19	created 192:9	84:1	229:5,7 231:11
284:1 288:15	375:19 383:21	creates 149:8	custom 34:11	234:4 239:1,5,9
289:1 296:17	390:2 395:20	credentials 216:18	customer 339:10	239:11,19 240:8
297:15 306:13,14	399:9 401:9,20	357:7	customers 339:11	246:8 257:15
312:13,20 313:4	402:22	creek 67:9	customizable	282:21 283:19
313:11 325:8,19	Council 208:18	creep 234:14	185:17	300:14,15 357:2
336:4,7,13,15	counsel 5:15 6:20	235:10 245:22	cut 53:7,15 374:5	381:16 392:12
337:2 339:13	countries 361:17	252:3	cycle 190:20	date 278:6
343:19 353:1,4,9	361:18	cried 47:7	Cynthia 1:16 13:6	dated 87:12
353:14 362:13	country 12:5 13:2	cringe 220:10	134:22 138:21	daughter 68:3
363:19 373:15	13:17 59:10 74:5	221:3	142:18 176:13	156:13 291:15
381:17,22 382:12	75:13 78:17	crisis 129:16 142:4	204:19 224:17	390:15
382:16,21 383:8	154:15 226:12	143:9	232:5 255:4 266:8	day 4:16 17:7 23:13
383:13,17 384:9	348:3,16 360:17	criteria 236:5	279:8 294:5	31:19 32:1,2 39:1
385:12 387:12	362:1	285:13 330:18	336:19 338:5	48:19 49:3 76:6
388:2 390:2 393:6	couple 59:12 62:2	critical 58:15	354:8,8	85:6 96:3 125:10
395:20 397:3	153:16 211:9	152:12 153:1,12	Cynthia's 173:20	126:15 141:17
401:15 402:18	219:14 234:19	334:3	285:4	191:8 193:5
407:20 408:1,3	272:18 343:16	critically 119:5		227:17 228:5
409:6,7	344:8,11 345:18	criticism 109:17		256:2 267:8
cost-benefit 297:4	356:8 361:7	crossing 242:11	D	313:14 317:22
cost-wise 55:2	couplets 60:11	317:6	D 230:17	318:2 356:15
costing 89:20	course 27:7 80:6	crowd 28:14 151:5	D.C 1:7 9:20 11:10	391:6,6 392:12
103:13 112:13,20	132:3 178:21	347:9 378:19	12:11 116:8	398:21 399:3
112:22 114:16	184:10 213:21	crying 57:10	322:15 332:18	402:5,7 403:4,4
costly 64:10 247:8	395:11	crystal 125:17	346:13,14	411:10
costs 36:12,14	cover 19:21 35:18	CT 40:16 41:2,2,6	dad 57:9 85:10	days 20:2,19 22:8
39:12 40:2 49:17	139:1 144:4	41:7 42:1 44:3	214:3	22:19 30:8 62:2
59:16 62:6 74:22	292:10 314:11	165:13 166:4,7,15	dad's 56:14 260:20	92:3 98:11 247:18
81:19 89:19 91:17	368:10,22 369:4	312:16 313:20	Dahl 1:11 10:14,14	271:17 332:21
98:15 103:6,8,21	369:16	338:20	55:7 106:21	335:9 377:19
			142:20 203:22	

de 246:12	273:4,11 281:14	215:8 229:22	define 30:21 98:18	145:16 280:18,19
de-linking 246:22	284:1 288:13	231:1 241:11	241:6 307:6	department 133:21
deadline 364:10	291:2,6,11 295:14	249:14 251:10	defined 106:6	153:5 306:9
deal 55:18,22 56:5	296:10 298:15	252:11,13 253:4	192:15,18 372:21	307:11
58:21 68:10,12	301:22 302:2,6	253:13,21 254:17	defines 170:21	depend 221:5,7
87:7 89:12 150:3	311:4,5 313:7,13	254:20 258:4,5,13	defining 401:5	dependency 117:2
217:18 218:19	314:2,3 319:20	258:18 259:4	definite 387:16	dependent 94:13
299:10 348:22	327:16,21 328:3,5	265:6 267:21	definitely 14:16	104:15
384:11	328:8,13 329:18	275:19,22 276:4,8	54:14 97:7 98:22	depending 98:20
dealing 36:11	329:22 330:6	277:3 280:14,15	101:3 150:10	106:12 108:5,13
120:8 174:14	332:10 334:8	284:10 286:6	201:9 204:16	119:4 121:10
194:15 281:9	335:18,20,21,22	287:19 288:14	228:18 244:6	172:15,22 174:9
dealt 82:21	336:5,8 338:2	293:12 296:4,14	326:12 341:19	174:19 176:9
Deb 10:14 55:6	352:9,17 355:18	296:18 320:5,8	388:18 400:3	179:3 185:19
142:19 143:13	359:17 360:18	330:2 332:14	definition 3:11	200:16 209:21
203:2 218:1	366:18,18 367:14	334:11,21 335:15	93:17 97:21 101:1	321:3 327:22
273:20 332:5	369:6 381:6 391:8	351:4,20 352:12	101:8,15,17	328:9 339:9
338:6 377:3 379:5	391:13 393:11	352:13 353:5	103:11 117:22	354:12 381:9
debate 313:3 320:2	401:22	356:22 357:19	193:3,13 237:14	depends 95:5 181:1
debating 165:14	decision-making	366:3 367:5,19	255:18 256:11	215:9 339:15
Debbie 357:13	21:11 124:8 130:5	368:16 369:21	definitions 91:3	344:21
debilitating 48:5	140:6 167:4	379:17 381:4	93:13 95:16 97:14	depiction 170:17
293:10	168:20 213:3,4,12	387:3,10 390:11	99:15 100:17	depletes 83:6
DEBORAH 1:11	214:22 253:7	400:16 404:16,17	107:21 108:6	depressed 376:6,20
decade 325:20	274:10 320:17	404:19 405:20,22	109:3,8,13,17,19	depression 373:4
decide 74:12 124:4	336:11 359:6	declining 155:15	110:10 116:9	373:11 376:11,14
298:7,14 313:22	decisions 3:19 4:3,6	dedicated 160:20	124:2,22 196:5	376:14
318:8 331:18	4:10 18:17 19:10	deducing 343:2	399:11,12 400:4,8	dermatologists
341:12	19:14,16 20:5	deductible 44:1	402:18	54:2
decided 53:19	21:20 22:2 26:15	49:6 128:9 265:15	degree 136:2	descending 37:18
341:13	28:8 31:11,15	270:17 280:8	338:21	describe 103:5
deciding 95:1	35:3,6,9 36:12	291:18,21 292:10	Delaware 11:17	113:19 128:22
279:4 318:4 381:5	40:22 46:5 69:16	292:11	deliberate 346:7	141:3
decision 18:10	70:19 77:6 87:18	deductibles 163:5	delighted 9:9	described 21:3,22
19:22 60:1 76:9	117:9 124:6,15	196:1 285:9	deliver 96:12 112:1	28:6,21 104:13
77:2,8,13 83:10	135:5 148:10,22	289:18 290:7	256:2	170:3 191:13
88:3 96:21 123:8	160:22 163:8	368:14 373:21	deliverable 25:12	192:4 197:20
135:15 144:9	168:15 170:6,8,10	383:20 402:21	25:14,17	238:20 258:8
165:5 203:21	171:8 172:1,20	deduction 263:10	delivered 80:8	399:18
207:7,8 209:3,4	175:18 176:6,8	deductions 286:7	delivering 11:4	describes 173:3
213:17,18 214:7	189:17 190:2	deep 194:5 399:16	delivers 343:15,19	describing 191:17
219:2 223:13	197:5,14 199:3,6	deeper 135:10	delivery 148:16	205:22 207:21
229:18 231:3	200:12 201:5,10	deeply 142:3	343:14 384:12	285:10
234:5 241:5	202:13,20 203:1,5	default 107:20	demographic	descriptions 177:3
248:13 253:17	203:7,14,17	defect 64:2,7	226:10	205:4
254:6 265:1,2,6	206:20 208:8	defects 145:1	dentist 76:14	design 216:22
266:14 271:4,16	212:13 213:15	defer 183:7	Denver 15:16	371:19

designed 174:17 307:8 362:19	355:9	193:19 194:16	direct 168:6 263:11 265:12 297:16 357:17	58:16 91:2 92:8 93:13 97:8 98:3,7 99:11 101:3
designing 214:21	diagram 102:7 177:6 192:9,16 388:12	196:4 200:13,19 207:8 209:9 216:22 217:9	directional 354:17 354:18	107:19 109:6 111:9,12 114:11
desk 99:12 357:15	dialogue 321:21 403:4	220:4 221:11 228:9,21 233:2 238:10 239:5	directly 8:7 16:7 95:7 268:22 378:1	114:17 115:19 121:21 152:7
despite 14:5	dictate 205:11	240:1,5,14 242:3 242:9 244:7	director 5:22 6:19 10:22 11:18	153:3 164:7 166:19 167:8
dessert 249:22	die 62:15 161:15	248:19 249:10 251:16,18,18 252:5,9 253:7	disabilities 66:16	168:4 169:1 175:17 176:1
destroyed 75:14	died 156:12	256:18,20 257:17 264:11 271:13 281:10 282:11	disabled 83:6	191:8 198:15,20 198:22 199:11,16
detail 20:21 35:1 285:10	diems 408:18	292:19,20 294:21 302:20 327:15 328:9 346:15	disagree 92:16,20 215:9	200:7,9 201:4 208:2 241:14
details 32:17 270:20	diet 53:7,15 187:18 262:13	347:2 353:10 354:13,14 360:21 361:16 363:18	disagreed 216:7	243:21 244:10,18 248:16 250:4
determine 102:21	Dietz 38:2	366:10 373:5 379:19 383:12,17 388:16 394:5 399:5,6,12 401:22	disagreeing 108:7	251:22 252:2,19 252:20 253:1,4,12
determining 92:13	differ 320:18	differentiated 199:14 303:3	disappointed 138:5	260:9 272:22 275:19 301:16
develop 147:11 183:8 189:8 283:16	difference 56:19 132:18 138:6 142:22 196:14 203:10 221:6 288:12 320:11 333:15 371:19,21 371:21 408:16	differently 104:19 140:20 194:8 197:14 200:20 243:19 244:2 257:12 321:14,16 321:17 343:12	disappointing 138:8	304:2 315:14 325:16 327:20 328:6 364:19
developed 32:5 64:15	differences 323:10	difficult 47:2 62:9 112:12,15,20 113:7 115:8 127:2 152:21,21 165:8 167:6 291:1,11 314:21 315:13 378:13	discern 132:17	366:5 400:12 402:11,13 403:6 407:3
development 27:20 236:2	different 7:3 18:1,9 19:2,9,11,14 20:7 20:8,9,10 22:1 27:8 29:5 34:20 35:6 47:17 54:11 57:14,16 68:15 78:9 89:13 97:18 97:18 100:4,5 107:10 108:2,15 108:22 116:3 119:7,8 121:5 122:20 123:2 128:8 139:13,20 143:11,19 146:7 153:2 162:14,17 162:18 165:9 168:1,17 170:9,10 170:11,19,21 172:3 175:3,8,9 176:2 179:11 182:8 185:3,4,6 185:11,15,20 186:20,20 187:12 189:15,22 190:1,2 190:8 191:11,17	discernable 131:19	disclose 8:9,18 11:5 15:19 118:5	260:9 272:22 275:19 301:16 304:2 315:14 325:16 327:20 328:6 364:19
device 91:22		difficulties 263:17	disclosure 3:4 8:5 12:13 14:21 361:12	366:5 400:12 402:11,13 403:6 407:3
diabetes 61:13 185:14 187:11,15 194:16 231:17 258:10,12 259:14 260:14 376:13,13 376:15 389:19 390:16 391:21 397:2		difficulty 263:13	disclosures 5:13,17 7:8,12 9:8,17 10:4 11:10,14 13:22 15:21 16:17 363:7 364:8	discussions 111:14 168:14 200:21 364:20
diabetic 122:9 151:17 294:19 390:20		digit 330:12	disconnected 24:10 140:14	disease 24:7 152:11 175:12 184:5,8,21 188:15 194:14,21 195:4 211:21 223:4 253:19 260:4,11 262:9 268:14 275:9,10 293:10 301:3,6,6 310:20 364:19 389:1,11 390:5
diagnosed 31:14 37:22 53:3 54:4 55:13 64:1,3 68:8 68:13 80:2 97:3 262:8 268:16 276:4 302:19 390:20		digitally 205:13	discount 129:5	disease's 379:21
diagnosing 275:9		diminishes 343:4	discretionary 121:11,12 161:21 172:6,7	diseases 182:3 185:14 218:6 380:1
diagnosis 161:5 173:12 178:16 365:7		dinner 31:20 250:14 410:7	discuss 16:16 95:8 99:1 115:16 330:5	disgust 159:7
diagnostician 317:17			discussed 124:4 171:14 172:2,12 241:12	disorder 38:1 40:17 68:8 84:20
diagnostics 24:8			discussing 114:21 235:21 363:8 392:4	
			discussion 33:10	

85:7,16 175:11 217:16,20 373:10 373:12 disparate 233:16 367:12 disparities 369:16 disparity 369:13 display 191:16 disposable 209:18 209:18 disposal 331:18 disregard 255:3 disregarded 39:11 disruption 329:1 390:3 dissected 37:14,16 dissecting 308:22 309:3 dissection 313:20 disseminated 27:9 dissension 94:19 distinction 113:6 119:10 distinctions 105:14 distinguish 224:1 distracting 247:3 261:1 dive 91:11 92:7 93:14 94:9 194:5 399:16 divide 24:19 divided 126:8 378:10 divorced 82:8 DME 290:10,10 337:3 338:21 doc 218:12 349:16 docs 158:10 doctor 42:10 43:13 44:21 45:4 46:9 47:7 48:16,17,19 49:5 50:13 51:11 51:14,22 53:21 54:1 55:1 85:19 90:6 106:14 125:6 127:5,6,9,11,13 127:15,16 128:5	129:21 130:1,9,9 130:10 140:5,8,11 154:19 158:4 165:16,22 166:8 166:13 183:1 226:3 227:11,12 227:14,17,18,21 228:3,6,10,12 229:13,15 231:14 232:10,12 255:8 255:22 257:21 269:10 271:6 281:17 291:14 296:1,14,15 312:17 332:10 335:4 337:10,11 337:12 338:2 341:3 342:18 345:6,7,8 346:1,5 346:6,16,21 353:13,13 355:4,6 359:1,4 389:17 394:18,19 395:22 doctor's 128:2 257:16 319:5 376:18 doctors 53:18 54:11 63:6 68:17 87:13 127:4,9 128:17 136:15 138:3 139:19 145:1,6 150:16,22 162:13 215:21 221:19,22 325:1 346:13 347:2,13 347:14 356:7 357:19 397:3 doing 7:17 17:16 25:20 27:2 36:4 39:22 54:17 61:19 67:22 86:14,14 89:19 124:5 126:12 149:3 152:2 164:12 178:1 190:20 230:19,20 233:7 236:13 238:1,4	255:6 257:13 278:19 279:20 287:8 292:16 295:20 296:3 322:11 344:14 346:4 364:5 400:6 dollar 129:10 196:3 254:10 297:16 dollars 8:7 14:7 27:20 29:4 52:9 130:11 315:16 domains 101:15 282:11 dongle 93:5 door 204:9 312:14 312:17 314:18 410:14 Dorothy 131:4 206:3 207:21 208:10 287:1 288:18 290:16 dots 184:3 double 66:11 86:5 doubt 290:4 dovetails 239:12 downstream 25:9 121:13 374:18 379:18 dozen 13:3 Dr 42:14,15 158:18 218:15 draft 31:6 drain 64:16 drastically 308:11 draw 113:5 196:13 drawing 105:13 195:15 drill 80:4 209:16 drilled 210:3 drive 203:16 209:19 271:21 driven 391:9 drivers 348:6 drives 132:6 150:2 225:5 231:6 265:6 385:11 drop 155:10 183:3	dropped 182:1 375:20 drops 181:10 186:14 drug 162:5 376:19 drug-related 385:3 drugs 162:7 378:7 due 48:14 118:2 123:9 297:9 durable 64:22 66:6 67:16 dynamics 149:8 <hr/> E <hr/> ear 227:3 earlier 37:2 144:7 147:1 172:2 173:20 177:20 182:9 201:8 210:6 223:20 224:7 225:11 226:7 236:1 238:20 241:13 248:1 268:2 300:4 323:19 336:16 340:16 346:9 347:19 352:16 357:22 386:21 390:15 early 23:17 107:19 140:14 262:1 283:15 earn 38:19 earners 265:19 earth 329:3 easier 7:9 102:8 188:22 297:10 409:9 easiest 252:16 easily 272:22 eastern 6:14 9:14 85:2 easy 62:5 232:2 264:13 282:12 313:18 383:7 eat 249:18 echo 123:18 204:21	221:15 economic 103:7 118:1 217:10 economics 112:6 ED 328:13 Ediger 1:11 15:13 15:14 62:20 65:17 70:3 87:21 144:6 146:22 182:7 261:7 271:11 273:19 316:16 319:2 350:14 366:6 368:18 370:20 371:3 378:15 387:19 educate 231:15 340:1 educating 331:3 education 70:1,8 316:22 331:14 360:12,16 365:7 404:6 EEGs 384:4 effect 130:17 135:18 155:7 effective 159:4 effectively 20:18 21:16 22:7 364:21 400:15 effectiveness 101:12 effects 153:7 efficacy 304:16 376:5 efficiency 11:21 17:19 91:18 92:12 93:12 97:22 98:15 99:8 101:12 102:5 102:13,18 143:18 143:19 236:22 efficient 237:5 efficiently 133:1 effort 132:14 236:6 236:12 237:8 238:8 efforts 19:2 132:9 238:13,17 239:7
---	--	---	---	---

EHRs 396:11	319:12,16,17,22	316:3	entire 37:17 39:9	380:11 385:22
eight 59:11 64:12	320:1 324:3	enamor 344:13	40:19 45:16 47:3	essentially 21:2
65:6 68:3 123:2	328:14,22 330:21	encompasses	79:4 139:3 151:12	22:1 102:1 113:1
188:6 252:20	331:8 391:5	119:14	157:4 304:2	170:16 171:8
384:22	emergent 38:12	encounter 122:19	entirely 40:19	285:19 315:11
either 140:6 142:11	62:5 84:11 142:3	331:1	303:21 340:19	392:9
186:19 244:13,19	244:12 302:1,10	encounters 374:13	entitlement 72:12	established 225:12
245:13 278:17	303:3 306:17	encourage 33:4	entity 13:14 281:1	399:11
299:4 334:11	307:4 308:1,7	117:11	entry 185:3 222:18	estimate 294:19
340:11 349:16	310:11,13,22	ended 46:16 53:22	environment 16:12	354:10
375:12 379:4,15	311:6,6,10,22	123:5	351:22 354:15	et 108:4 149:4
380:1 385:3 400:7	312:6 314:9,22	endocrine 389:20	381:8,16 383:6,14	183:21 185:10,14
EKG 375:4	315:3 320:4	endocrinologist	environments	192:22 262:13
elastic 129:5,7	335:15 380:9	391:17,18 392:10	306:14	266:21,21 305:5
elasticity 120:1,5	emerging 286:18	395:3	epiphany 329:7	368:10,14 372:11
120:10,14 121:9	286:18,20 383:1	endorse 239:15	episode 3:16 31:5	378:9
140:17 152:13	Emily 80:5 81:11	endorsed 170:12	141:2,3,4,6,19	Ethics 88:4
elder 183:16	emotional 141:15	endorsement 236:6	168:12,18 170:13	ethnographies
elective 148:14	142:6 309:4 334:8	ends 67:17 409:3	170:18 171:13,19	280:13
161:21 335:20,21	emphasis 246:1	energy 141:17	173:14,16,21	Ev 388:8
335:22 336:10	390:1	engage 147:8	176:10 178:2	evaluate 282:10
341:20 344:2	emphasize 402:11	202:12 205:16	181:1 187:21	evaluated 238:15
electronic 393:2,5	employ 291:17	305:2	209:22 237:15	315:6
393:10	employed 107:5	engaged 352:16	247:6,7 248:3	evaluates 236:4
element 171:13	133:12,19	388:17	252:5 260:2,17	evaluation 4:6
elements 20:14	employee 290:19	engagement 36:13	273:10,14 335:16	171:1,21 173:11
248:21 249:3	employer 8:2	37:6 202:18 404:1	379:1 386:12	174:3 181:11
265:5	108:11 284:19	404:2	399:17 405:19	182:19 236:5,11
elevators 32:19	286:4 289:14	engaging 126:7	episodic 187:8	238:13 239:13
Elizabeth 1:7,9 3:7	299:4	142:9,10 199:4	equal 220:12,22	315:15
3:13,17,21 4:4,8	employers 11:13	252:10	340:8	event 61:17 178:20
4:13 9:4	66:10 116:22	English 69:22 89:6	equally 64:19	184:21,22 266:16
emergency 1:18	272:4 295:20	304:6	equation 241:12	273:3,12 335:9
11:16 37:18,20	296:2 297:7	engrained 349:9	242:20	event-driven 60:9
38:14 43:11,18	employment 292:4	Enjoy 250:22	equipment 64:22	events 393:12
44:16 45:2,10,17	363:9	enlightening	66:6 67:17	eventually 129:17
46:17 48:9 76:22	empower 406:11	328:19 403:7	equity 101:12	Everett 63:16
77:19 80:4 129:2	empowered 57:18	enrolled 266:18	ER 318:2 327:17	67:21 69:6 317:5
129:9 151:11	58:1 70:19 162:4	enrollment 271:16	333:8 334:8,12	317:16
152:15 153:4	202:19 203:5	272:1 287:4	Erin 2:15 6:11 17:6	everybody 7:10
159:3 178:19	396:10 397:1	295:21	30:6 34:17 405:8	8:21 49:11 96:15
290:10 306:4,7,8	empowering	ensuring 248:1	405:12	110:3,4 138:5,6,9
306:9 307:11	160:22 404:16	entails 266:20	escalate 374:1	142:13 147:6
312:10 313:2	empowerment	285:14	especially 125:1	180:12,17 224:20
314:1,16 315:17	203:4	enter 38:16 92:18	135:6 161:1 269:9	230:19 256:7
316:11 317:8	empowers 321:1	entered 219:20	272:19 279:19	262:17 287:7
318:6,17,19	EMTALA 314:16	260:15,16	283:9 379:13	351:3 366:12

386:4 411:10	283:2,2,13 290:3	369:6 373:22	237:22	270:15 300:5
everybody's 191:8	392:12	experience 3:9 15:3	explicitly 144:14	301:17 314:22
everyday 40:8	exchanges 19:4	30:18 34:5 36:3	205:6	367:7 390:19
387:15	283:1,7,8,21	41:5 43:5 47:18	explore 30:22	391:1 394:5
everyone's 303:8	287:5	48:6 51:18,19	143:4 236:21	factor 138:15
evidence 279:13	excited 5:5,10 6:8	54:20 57:20 58:2	298:10	207:13,17 223:12
324:12 337:1	9:14 10:1 17:13	78:16 111:1,4	exposure 379:18	232:17 310:21
384:5	18:5 29:21 51:20	118:12 122:11	381:17 383:10,13	318:8 321:2
evidence-based	52:5,7,11	146:12,17 148:12	exquisitely 127:21	322:19 379:22
384:12 385:11	excluding 350:4	151:4 189:17	128:15	factors 158:4
Evidently 280:21	exclusively 287:3	218:3 222:15,20	extending 190:4	159:11 170:9
exacerbation	excuse 84:1 316:9	229:22 230:2,3	extensively 184:4	193:12 195:21
174:11 182:4	324:17	231:6 240:2	extent 96:14	196:4 199:1,7,8
exact 86:6,7 158:14	executive 59:2	257:14 269:1	179:17 248:21	200:15 208:6
329:16 339:21	exercise 8:11 32:3	282:15 284:5	extracting 35:12	209:15 210:4
exactly 61:6 107:3	177:13 185:10	285:6 287:3	extremely 152:2	223:6 231:1
137:8 159:16	187:18 262:13	289:16 292:19	347:22 380:4	248:13 249:16
193:21 194:3	376:19 397:20	293:22 294:12	eye 220:19	288:10 298:11,19
197:2 226:6	404:10	295:2 342:3,8,14	eye-opening 95:20	310:15 317:15
232:19 263:11	exercises 177:8	347:8 368:19	149:22	318:3 319:20
379:16 398:1	exhaustive 198:13	369:1 394:4	eyes 317:5	320:4,16 327:15
399:13	existing 218:11	experienced 136:11	<hr/> F <hr/>	328:4,15,18
exacts 41:9	400:8	146:20 151:17	face 20:10 21:16	334:21 349:7
exam 297:3 315:19	exit 32:18	290:14 327:22	170:10 403:21	379:16 393:17
example 61:6 76:4	expand 29:7	experiences 9:16	Facebook 378:22	facts 334:9
80:18 94:15	203:22	30:5 35:21 36:10	facilitate 302:8	faculty 363:15
165:13 183:12,16	expect 33:14 34:12	36:10,18 37:9	facilitated 199:13	failure 47:6 73:3
183:17 184:2,5	35:5 43:6 75:15	69:9 116:11	Facilitators 3:7	185:13 317:1
185:22 195:18	114:7 151:1 224:3	156:12 233:5	facilities 146:14	failures 317:18
200:17 208:17	285:11 354:11	390:22 399:5,7	337:9 338:9 344:9	fair 208:9 248:14
212:3 223:11	391:5	experiencing	352:1 365:18	248:22 300:15
279:5 312:5	expectation 79:9	302:20	facility 186:13	fairly 19:7 235:4
322:21 337:3	79:12 204:8,17	experimenting	222:17 307:7	345:15 373:7
343:13 344:3	281:2	292:17	337:13,19,21	fake 405:17
354:8	expected 401:9,15	expert 1:3 10:7	338:15 342:19	fall 172:22 173:13
examples 173:9	expedient 286:5	31:19 199:14	343:12,16 344:15	299:20 321:18
177:4 199:7	expense 84:2 263:9	235:13 288:11	344:19 349:22	365:19
253:15 262:4	285:12 387:14	323:16,21	352:3 354:2	falls 174:2
345:16 365:20	404:14	expertise 15:6	facing 71:9 400:10	familiar 107:22
exams 23:20	expenses 66:13	133:17 370:4	fact 18:4 71:11	families 1:18 11:8
296:15	68:16 69:3,5	experts 97:17	72:12 78:10	70:11,18 117:10
excellent 266:5	285:14 374:5	323:18 324:7	122:18 140:21	144:8 145:2 391:4
281:21 300:20	expensive 44:4,7	384:17	141:2 171:6 178:8	family 6:13 9:13
364:12 398:15	67:20 127:5,6,10	explain 72:10 73:4	178:12 190:7	39:21 45:6 81:8
excess 64:16 385:8	127:12,16 163:3	76:1 125:13	195:19 222:11	81:19 118:6
exchange 59:7,22	166:15 287:6	237:21	224:21 243:12	164:14,17 165:10
162:21 192:20	288:5 318:9,12	explaining 75:20		165:13 192:22

203:12,12 206:9	255:2 266:10	55:13 59:19 63:6	138:3 139:13	flip 287:20
206:16 213:18	292:16 301:12	172:11 305:6	148:1,2,4 159:18	floor 1:6 115:16
214:7,8 292:13	305:10 307:16	334:6 389:2	163:7 170:9	350:16
298:13 310:16	309:15 315:9	finance 12:3	179:22 185:7	Florida 10:12
323:20 334:18	318:10,11 355:7	financial 170:8	195:7 202:4	145:22
389:8 390:3	363:12 388:8,11	360:10 363:7	204:22 205:5	flow 174:17
396:14	388:20 389:4,9	364:7	215:5 224:18	flu 397:19
family-centered	395:1 397:1,8	find 47:8 54:18	243:1,9 251:9	fluctuation 368:21
159:1	406:21 407:7,22	55:1 69:1 84:4	252:22 253:22	fluid 64:16 115:5
fans 322:10	408:7 411:4	85:14,16 124:12	254:10 255:6	fly 12:5 310:18
far 38:8 68:16 94:1	feeling 54:12 78:18	127:15 129:21	258:20 264:19	344:16
114:15 134:11	221:12 235:8,10	133:11 145:5	269:2 271:4,7	flyer 37:4
206:15 244:1,3	267:7	162:1,6 163:11	277:9,10 279:12	focus 96:6 116:12
247:1 295:12	feels 142:10 202:19	216:17 222:13	279:14,22 283:12	146:13 181:14
326:18 362:1	225:20 244:2	225:4 255:15	289:13,21 291:21	262:15 311:1
374:2 380:10	fees 315:9 368:17	268:12 303:7	297:16 298:21	325:1 380:8
388:14	feet 64:14 65:1,1	318:12 323:18	301:2 302:16	focused 11:4 12:11
fascinating 88:5	fell 322:3 332:18	342:2,5 355:17	303:9 304:9 311:4	81:4 237:9 249:13
fasciotomy 47:22	fellow 16:9 311:20	363:19 368:22	311:5 315:19	270:12 368:1
fashion 173:19	406:20 407:21	374:12 396:13	318:5 332:20	focuses 101:9 262:2
fast 198:6	felt 56:22 66:10	finding 53:11,21	341:6 347:4 366:5	308:9
fast-forward 102:7	386:22 387:4	68:7 150:13,14	391:8 410:11	focusing 238:5
faster 404:3	fictitious 408:21	217:16 369:4	fit 100:8 177:2	folks 55:9 82:15
favor 135:15	field 5:8 30:20	372:4 378:20	235:15 272:21	83:21 266:7 274:2
favorite 79:5 304:3	141:7 173:22	fine 79:20,20 93:1	407:4	283:4 344:5
faxed 392:12	174:7 286:19	110:10 174:1	fits 182:13 321:21	367:11 395:3
FDA 12:20	Fifty 370:4	176:15 199:17	fitting 235:16	399:7
fear 300:2	fight 349:4	254:16,19,22	five 10:7 47:20 48:2	follow 99:12
feasible 113:8	figure 70:17 77:22	255:9 342:17	49:9 65:5 112:17	143:14 171:1
feat 400:20	126:10 131:14	397:14	114:1 158:14	189:9 258:21
feature 206:6	132:15 161:18	finger 52:3,21	166:7 228:5	371:1
federal 12:19 283:6	162:9 163:11	fingers 279:21	232:11 282:11	follow-up 4:11
314:15 315:16	171:10,12 177:14	finish 194:2 237:22	293:5 294:21	31:17 87:2,22
federally-funded	226:1 235:15	finite 191:3	325:21 339:22	88:6 123:3 150:9
15:10	240:12 279:18	fire 80:4 151:14	380:19	172:12 174:14
fee 315:8 344:17	292:14 312:7	358:14,15,17,19	fix 140:1,1 362:8	175:10 182:21
feedback 26:9	figured 322:4	firm 9:22	fixed 76:22	183:1 184:12
179:6 194:8	figures 249:8	first 5:19 7:14	flashback 303:20	185:1,15 187:14
feel 16:2,9 17:9	figuring 24:15	24:13 28:5,22	flashing 94:6	187:17 194:14,20
42:10 51:15 52:21	110:5 271:21	32:13 37:12,21	flier 47:1,13 62:22	196:12 266:13
54:15 57:18 58:1	370:13	38:8 41:13,19	147:2 339:10	272:17 281:1
58:2 63:12 110:19	fill 249:15 281:7	47:4 65:11,21	fliers 46:6 50:10	295:17 339:7
137:9 150:11	filling 7:19	67:1,3 72:16 73:9	58:11 63:5 137:3	341:16 342:14,20
157:2,4 162:4	films 340:9	79:18 85:18 92:6	311:21 319:14	365:4,22,22
192:5 202:22	final 116:19 160:12	92:10 96:22 106:4	320:12 323:12	370:22 383:6
217:18 225:14	194:10	121:17 122:4	324:2 384:14	387:4 389:12
226:4 241:21	finally 33:18 54:3,9	126:16 132:22	388:7	391:9,16 392:7,15

followed 185:8	foundational 18:12	frequent 37:3 46:6	funnel 231:20	genetic 38:1 40:17
following 87:8	foundations 12:21	47:1,13 50:10	funniest 398:9	84:20 175:11
294:20 343:1	four 15:17 23:18	58:11 62:22 63:5	funny 164:10	genetics 298:12
food 33:16 53:3,6	63:18 75:11 95:4	137:3 147:2	further 55:5 91:20	George 1:13
53:11 185:9	147:22 165:19	311:21 319:14	259:18 344:13	363:16
food-triggered	264:20 287:11	320:11 323:11	352:4	geriatrician 384:20
54:4	349:7	324:2 339:10	furthest 48:9,11	getting 5:4 45:15
foods 53:7,15	fractures 55:16	384:13 388:7	future 27:20	49:13 52:18 53:18
force 154:11 155:5	fragmentation	frequently 42:20	170:15 278:9	61:21 65:9 66:17
forced 384:16	377:7 382:13,18	162:2 306:10	293:20 380:20	72:3,4 75:10
forefront 29:3	fragmented 279:1	Friday 411:14	405:1	82:16 87:10
52:13 197:21	378:10	friend 34:4 133:10	futz 322:16	124:20 127:19,20
401:1,5	frail 183:16	226:22 323:20		132:22 156:21
forego 104:3	frame 124:17 188:2	345:16	G	167:22 178:14,16
foregoing 91:6	188:11 207:1	friends 50:16 151:5	gain 81:22	178:19 180:2
251:2 411:13	209:9 247:15,20	front 8:21 45:4,6	gall 44:9 46:12,13	181:16 182:5
forever 175:10	249:17 253:4	86:12 162:21	332:3	186:7 191:13
195:1 227:22	301:21 304:2	219:4 249:9	gambit 261:1 368:1	192:19 246:21
forget 349:4	321:10,20 335:14	357:15 386:14	game 68:16 116:17	247:1 261:18
forgot 404:21	400:9	410:13	121:7 283:5	263:13,15 264:8
form 7:18 218:17	framed 244:20	front-end 123:12	gap 391:2 403:13	267:10 272:2
281:8	296:21	125:15 409:9	gaps 27:21 146:10	275:15 277:9,12
formally 86:4	framework 17:18	Frontera 1:12	223:9 370:10	279:8 283:4
forth 92:20 138:16	20:12 31:6 126:7	14:22 15:1 79:17	gearing 74:6	285:16 289:22
238:15 389:6	126:11 165:7	82:5,12 148:7	gears 322:5	290:1 294:14,15
fortunately 384:15	170:12,14,19	219:12 247:12	gee 393:20	299:16 308:19
Forum 1:1,6	176:16 178:8,13	277:16 343:6	general 5:8,15 6:20	322:9 357:5 370:6
forums 360:8	181:8 188:5,7	344:1 381:20	9:5 17:5 21:14	371:6 372:7 374:7
forward 19:1 23:4	189:5,7 190:11	frustrated 147:14	47:15 191:19	374:17 381:22
24:22 30:4 32:13	192:3 193:15	frustrating 57:20	203:9 219:22	384:4 385:7,13
90:13 91:13 97:8	195:13 241:2	full 114:4 144:4	230:9 277:17	399:14 401:16
98:2,10 107:15	243:2,11 251:14	222:5 223:8	323:15 355:21	402:17
181:17 198:7	387:14 399:17,21	291:20 292:1	367:17 384:19	giant 352:1
238:12 290:14	frameworking	325:19 344:17	403:21	gift 88:13
352:5 404:9 406:9	298:2	383:22	generally 101:7	girl 54:7
407:2	framing 88:13	fulltime 66:8	103:9,20 104:7,8	girls 257:20,21
found 39:21 53:12	175:16 242:16	fully 35:5 265:14	105:6,12,15,17	GIs 54:2
54:3 64:10,12	243:15 296:22	fun 139:8	112:6,19 113:8,10	give 36:5 54:22
76:10 85:6 122:22	frankly 89:8	function 189:6	113:15 171:22	57:15 70:8 92:17
126:8 149:21	153:22 154:5	functional 53:10	229:19 251:10	98:4 167:2 184:2
150:16 189:4	220:21 243:16	functionally 88:16	267:12 320:15	190:6 208:17
341:8	freaking 322:12	fundamentally	348:8 354:4	212:3 226:9
foundation 19:5	free 17:9 72:15	100:4	363:10 401:12	231:16 235:16
22:16 25:18 36:4	192:5 255:2 274:3	funded 25:20	generate 108:14	236:7 253:20
126:6 191:22	411:4	236:17	generation 132:3	262:4 277:19
224:11 236:18	freely 204:10	funder 27:12	149:15 167:22	305:4 360:11,21
341:9	frequency 374:3	funds 25:18	generics 162:7	365:20 397:13

405:17	182:19,22 184:9	24:20	206:15,18 208:6	14:12 15:7 16:19
given 7:18 18:18	184:22 186:10	gobbledygook	211:6 212:12	25:11 51:15 52:15
72:1 91:21 162:6	192:7 200:20	118:8	217:15 219:8	52:19 56:9 60:19
211:20 246:8	206:2,8 214:13	God 333:8,11	220:5 221:4,8,10	60:21,21 62:11,18
284:22 285:7,13	217:2 218:9	goes 44:2 45:10,21	221:12 222:14	66:15,22 68:5
297:14 312:5	220:18 221:20	75:4 80:20 125:7	223:11 226:15	70:14,19,19 79:3
319:9 348:9	224:2 228:17,20	134:11 135:16	229:4 230:16	80:14,17 94:9
354:11 396:11	230:16,18 231:14	147:10 166:10	233:1,5 234:17	96:19 97:8 103:17
giver 396:18	231:17 233:19,20	174:6 184:18	235:5,12 237:21	109:5 124:1
gives 22:1 190:10	234:6,8 242:13	188:15 241:10	238:12 242:13	137:21 145:7
giving 32:3 177:9	246:4 250:14	269:14 277:1	243:6 244:14	147:4 156:14
199:6 204:10	251:13 257:15,18	296:1 313:8	246:2 247:1,11	158:5 160:22
218:6 295:22	257:19,21 258:13	332:10 346:9	249:13 250:14	178:14,16 185:5,9
337:3	264:17 267:9	374:3,3 391:14	251:13 262:21	198:16 202:21
GLG 10:17	270:14 271:4	going 7:10 15:22	263:3,15 267:6,8	223:10,17 227:1
global 95:13 96:16	272:14 274:10,17	19:3 23:4 24:22	270:15 271:11	228:14 229:1
glucose 151:22	278:20 288:17	25:5,8 26:13,14	274:5 278:4,13,16	231:11 234:10
gluten-free 53:11	291:3,13 296:14	30:19 32:2 33:9	280:13 281:3,11	245:9,10 246:17
go 6:4 7:12 16:6,6	296:14 298:7,9,11	43:19 51:10,16	284:1,5 285:6	265:8 275:18
20:22 21:1 22:8	298:21 302:14	52:6,15 53:19	287:7,10,12,17	280:22 281:1,12
26:8 41:10 42:10	305:12 306:22	54:15 55:2 62:4	290:17 291:18	282:4,21 284:4
43:16,18 44:15,21	309:18,18,19	64:6 65:5,9 71:4	292:2,8,9,10,14	286:14 296:22
46:7,20 47:14	312:7,12 313:2,3	73:4,19 74:4,12	293:3,5,9 300:22	298:17 299:8
48:16,16 49:3	313:3,13 314:1,14	75:9,10,14 83:1	302:7,12 303:2,12	301:16 306:1
50:12 51:10,13,22	317:1,3,10,20	87:6 90:16 91:11	304:4,11 307:2	313:17 329:4,5
52:1 55:6 58:9	318:3,4,6,11	91:13 92:6 93:14	309:12 312:12	334:14,17,17
59:16 60:17,19	320:17 321:8	95:8 96:9,10	313:4,10 317:7,21	338:5 348:12,14
72:22 74:11,12,16	324:3 325:11	97:11 98:2 99:3	317:22 318:5	363:1 370:19
76:14 78:11,14,14	326:15 327:1,17	100:20 102:6	319:3 320:1	372:5 373:8
78:15 79:6 84:18	328:13,15,17	111:11,15 115:15	322:15,15 323:22	378:20 379:2,5
86:20,21 89:11	329:2,8 330:15	120:6,10 121:14	324:1 328:5,20	381:13 388:13
90:14 93:2 105:21	331:7,21,21 332:2	122:3 125:11	329:3 332:21	389:20
114:7 115:20	333:8,18 334:7,12	128:4,17 130:2	333:14 335:5,5	good-faith 294:18
118:12 119:18,20	334:19 343:16	134:8 136:16,17	339:4 341:16	354:10
125:12 127:5,14	345:3,7 347:6,16	140:1,9 143:7	347:3,21 350:15	Google 77:8 130:1
131:9 136:19	351:17 352:3,6	144:15 145:9	352:21 353:8	233:20 234:7
137:20 140:6	355:6 356:1,4,13	146:13 148:5	362:17 365:21	276:13 303:9,10
141:21,21,22	358:16 359:19	150:4,5 151:5	373:16 380:16	Googling 64:8
143:11 144:20	361:5 370:8 379:4	154:10,17,20	383:10,20 387:19	276:13
145:6,14 150:4	381:1 386:8	155:1,5 156:17	389:15,17 390:18	gosh 70:5 291:22
151:7,13 155:1,3	389:20 393:9	157:9 162:9,21	391:15 394:10,11	gotten 8:6 24:6,9
155:18 159:3,17	394:6 395:21	163:4 170:5	395:10 396:7	98:6 143:14 147:3
161:7,22 162:5,12	397:2 400:5 405:5	171:15 174:4,19	397:6 400:3	301:13 323:7
163:20 164:16,19	goal 28:4 103:17	175:15 187:9	410:10 411:5	government 1:22
173:6 174:13	178:21 191:4	197:13 198:15	gold 287:9,13	10:10 12:19 78:7
175:22 177:3	370:11	199:12,17,22	good 5:3,19 9:3	graded 298:4
181:6,21 182:6,15	goals 17:1 21:1	203:11 204:18	10:5 11:6,22 13:5	grades 230:14

graduated 49:1	179:8 188:17	H	262:6 271:6 280:4	268:21 273:2,5,14
Grandma 247:17	235:13,22 236:20	half 14:14 63:17	289:20 290:12	275:10 276:20,22
grandson 247:19	244:2 246:2 259:7	64:1,18 66:1	295:2 313:8 357:2	277:12,12,15
grant 364:10	259:10 260:12	67:12,13,22 68:4	385:19 386:9	278:12,17,18,21
grants 8:6 10:20	263:4,6,11,15,19	73:9 139:4 216:20	406:16	280:16,19 282:5
14:6 363:8,9	264:6,13,14	218:9 251:10	harder 379:14	282:10 284:11,18
graph 92:19	287:16 290:19	316:20	harking 153:16	285:13 286:14
graphic 399:20	310:5 318:16	hallucinating 68:21	Harper 68:3	291:21 292:13
graphical 170:17	363:6,13 381:2	Hammersmith	hashtag 33:7	293:9 294:22
191:16 399:20	396:14 399:1	2:13 3:5 5:15	hate 159:9	295:14 298:6
grappling 17:20	405:6,11	6:19 7:6 15:20	HCAHPs 222:21	299:1,3,4,13
great 13:20 39:14	Group's 222:19	hand 81:14 111:15	head 114:7	304:3,17 305:14
50:5 52:8 60:2	groups 109:7	194:3 199:10,13	headphone 227:4	308:16 316:9
87:16 88:5,13	146:13 177:9	219:3 402:2	headphones 226:21	320:13,16,19,22
134:7,17 135:10	235:20 280:5	hand-offs 186:19	227:1	321:1,4,13,16
146:9 150:3,17	287:14 377:10,11	handle 33:8 181:9	heads 295:4	324:13 326:3
158:6 163:22	growing 154:10	383:20 396:1	healing 174:4	328:1 330:3,14,14
167:15 179:20	grown 346:16	handled 373:6	324:19 325:2	331:6 338:8
183:9 196:21	grows 65:8	handles 43:3	health 1:10,11,14	339:19 340:12
202:17 206:1	guaranteed 161:8	hands 29:12 53:20	1:15,20 10:16	351:7,7 354:13
209:11 212:20	guess 10:6 13:9	69:21 216:9	11:12,17 12:17,22	360:11,14 361:4
213:14 214:10	36:22 49:18 54:21	218:22 250:9,11	25:21 33:22 49:21	362:6,13 366:8,11
228:6 246:18	253:8 254:5	250:16,20 322:14	50:8 51:16 52:7	366:13,17,17
249:21 271:2	284:22 296:20	351:13 375:11	53:14 55:9 58:20	367:4,8,18 368:3
274:13 281:3	298:1 335:19	happen 25:8 68:9	58:22 59:2 60:8	368:20 369:13,15
290:15 294:3,4	343:2 350:7	68:11 75:10 140:9	62:3 66:9 72:2	369:17,17 370:11
295:10 305:18	366:15 371:17	140:19 204:2	75:3,5 76:5 95:21	370:12 372:4,13
325:14 337:3	383:3 403:15	269:2 303:1	113:14 116:22	372:20,22 373:2
352:14 387:12	guidance 53:18	312:12 341:21	117:10 121:6	376:8,9,20,22
398:16 402:10	guide 33:10,11,14	367:8 382:18	128:6,11 139:22	377:11,17,20,22
411:10	93:13 97:13 99:5	happened 48:1	141:12,16 146:12	380:6 381:11
greater 132:10	99:11 164:22	308:5 364:11	153:19 154:3,12	382:3 403:20
306:14 344:14	189:5 198:21	happening 18:19	154:16 157:15	408:17
greatest 228:3	248:16 252:19,20	25:15 75:19 138:4	160:19 161:2	health-literate
green 184:7 296:12	296:3	330:8 374:22	164:12 165:4	213:5
Greene 1:13	guided 101:7	happens 67:7,19	166:6 168:3,17	health-seeking
361:11 363:14,15	guilt 73:1	125:3 140:20	183:19 193:1	189:22
ground 167:18	guy 120:14,14	143:8 260:19	195:22 196:8	healthcare 1:9 5:8
groundwork 91:12	158:13,15 322:11	277:1 293:18,19	197:15 198:3,17	10:9 11:14 13:20
group 1:14,20 7:2	341:4,6 346:1	309:9 369:9	198:19 200:16	14:10 18:10,18,19
9:21 11:13,20	guys 33:4 51:5 66:4	373:14	201:17 202:2,5	19:11 20:17 21:20
12:11 23:3 29:18	85:19 111:13	happier 79:10	217:7 227:7	22:3 30:3 32:15
32:10 35:16 55:15	116:5 228:4 235:9	happy 188:8	239:18 240:19	36:11,13 37:4,9
56:3 71:22 73:3	301:9 386:7 402:6	297:18	251:18,19 253:16	43:5 44:19 50:15
73:13 75:2 107:16	gynecologists	hard 78:2 117:15	253:17 254:9	50:17 51:4,22
108:21 119:15	257:18	117:21 219:1,12	255:21 257:5	52:13 56:12 59:7
142:5 177:21,22	gypsy 204:7	224:22 241:9	264:8 265:2,10	59:15,15 67:20

68:15 69:20 70:15 71:5,7 73:12 74:7 80:7 81:2,18 83:14,20 87:17,19 94:16 95:1 101:20 102:2 103:10 112:11,21 114:8 117:4,17,20 120:16 124:7 127:7 135:3,20 136:4 148:10 155:6 156:7 157:11,17 170:7 189:17 199:3,4,5 199:9 202:2,6,9 203:14,21 204:2 208:22 215:8 223:22 224:3,5 252:10 256:4 259:17 265:12 266:2 269:16 270:22 275:8,8 281:13 286:10 288:20 299:22 307:17 322:3 323:14 326:3 329:16 348:10 351:5,12 354:21 377:5 387:5 396:20 399:8,9 403:3,21 healthcare-wise 346:20 HealthCore 1:19 12:17 healthy 16:12 40:17 61:11,11,12 61:13,14,15 62:13 62:15 119:4 142:14 171:11 178:14 184:15 185:7 191:13 192:18 250:7 254:1 255:19 256:3 258:9 259:7 259:16,19 260:11 261:4,5,9,15	262:15 264:6,9 267:7,12 268:15 268:16 272:10 275:4 276:16 280:6 292:22 296:13 320:15 322:2 360:13 hear 22:19 95:21 96:3 113:19 131:12,17 156:15 297:19 304:8 327:19 407:18 heard 61:5 104:2 108:1,20 131:14 132:16 133:7 146:9 193:5 198:16 206:5 208:11,20 210:19 243:22 244:3 263:19 286:1 296:19 337:18 341:7 379:12 398:10,20 404:8 hearing 30:4 109:16 128:22 163:14 191:9 192:1,5 241:17,19 297:14 327:14 328:12 heart 10:7 37:20 38:2 47:4,6,16,18 47:20 48:2 90:15 158:15 167:17 175:12 184:5,7,9 184:20,22 185:8 185:12,13 211:21 262:9 268:14 275:5 308:21 341:6 394:7,19 408:20 heartache 398:6 HEDIS 139:8 223:2 282:13 height 390:8 held 208:22 Helen 2:12 7:2 86:22 347:18	349:10 357:22 helicoptered 80:3 Hello 14:22 help 10:2 16:11 18:15 24:22 26:1 27:17 43:19 56:3 80:5 116:10 135:20 136:2,4 143:17 147:12 148:5,9 149:15 159:18 163:17 164:22 165:15 167:2 176:5,8 177:5,13,14 184:3 185:21 205:16 225:7 232:2 235:9 235:15 252:5,13 252:19 261:9 275:17 286:9,22 294:10 296:3 298:13 302:2 305:22 324:20 330:1 355:16,18 357:18 362:5,12 367:13 378:20 379:2 384:11 387:13 393:6,8 404:18 helped 148:20,21 164:20 183:8 helpful 113:17,19 121:15 124:12 155:14 159:14 163:13 177:21 183:12 189:20 215:1 249:9 281:20 314:19 316:6 320:19 323:2 357:12 helping 18:12 24:16 136:21 168:3 207:19 214:20 279:17 398:8 helpless 54:13 helps 9:1 161:20 179:18 189:2	240:22 241:13 261:8 313:12 328:6 369:20 hematologist 394:12 heresy 220:7 hey 60:12 317:13 408:8 HHS 26:7 27:11,18 Hi 6:6,10,12 9:12 9:18 10:14 11:11 12:8,15 14:12 15:13 62:20 hidden 403:3 hide 71:17 high 61:14 75:2 131:2 148:13 149:7 163:1 245:16 251:9 291:18,21 360:8 361:4 390:8,8 high-level 253:12 high-risk 88:2 high-stress 268:6 higher 130:17 155:10 212:7 289:4 highest 347:4 353:14 highlight 174:21 highly 290:20 347:22 350:20 hilariously 333:18 334:5 hill 322:6 Hilton 410:12 hip 345:17,17 HIPAA 144:21 147:15 hire 71:16 historically 282:3 369:12 history 193:1 244:15 298:12 hit 42:1,5 73:11 92:21 93:1,2,3 163:4 225:15	383:21 HIV 15:10,12 71:6 72:14 73:20 74:15 75:7,12 77:7 78:17 181:14 229:14 395:15 HMO 282:6 291:3 hold 32:8 259:21 301:8 hole 246:4,5 holidays 390:21 holistic 54:1 home 49:3 55:15 64:9 68:22 83:22 129:17 164:16 186:12 203:16 207:4 231:18 260:18 333:7 388:5 389:19 391:12 395:4,8 397:15,22 404:1 homelessness 75:3 homes 12:12 384:11 honestly 225:8 317:15 honey 44:4 hop 91:1 hope 25:5 157:11 157:19 261:12 279:12 323:13 361:1,5 hopeful 167:7 hopefully 23:2,4 102:4 270:21 286:21 295:11 365:3 hoping 274:7 347:8 365:3 horrible 389:7 hospital 1:11,13 11:2 12:2,3 15:15 28:10 37:15 38:21 39:6,7 40:6 41:6,8 47:14,20 48:8 63:2,13 67:2,5 69:12 85:3 86:2,4
---	---	--	--	--

88:5,20 89:2 114:1 121:4 130:3 133:13,18 148:17 154:19 155:1,3,8 158:12 162:13,13 174:12 186:12,12 214:5 215:16 219:8 221:20 227:12 230:15 233:7 310:17 317:22 329:13 332:9,11 333:2 335:2,5 336:6 341:2 343:18 353:2,6 354:15,18 354:22 355:3,6 358:3,4 359:2 365:6 375:1 387:2 388:20 403:18 408:22 hospital-based 166:14 315:9 hospitalization 290:10 389:12 hospitalizations 203:15 385:2 hospitalized 37:14 374:7 hospitals 71:14 115:3 154:22 215:14,15,20 280:20 343:15 353:10 408:17 hotel 410:11,12 hour 232:12 253:1 253:2 hourly 265:19 hours 59:12 76:10 228:5 232:9 313:14 317:2 318:14 322:8 356:13 house 40:10 310:17 330:20 Houston 14:4 how-to 305:4 HSA 292:10	Hues 305:1 huge 51:8 57:9,10 66:6 89:10 145:15 304:20 329:22 334:8 342:5 353:9 367:10 370:11 373:14 385:5 388:14 401:16 403:2,13 404:7 Human 25:21 hunt 279:6 hurt 85:7 hurts 309:11 husband 39:8 41:14 66:7 67:7 207:4 214:5 268:4 276:11 291:14 333:7 349:13 362:2 hydrants 358:14,16 hydrocephalus 64:15 80:3 316:17 316:18 hysterectomy 278:13 279:5 344:3 <hr/> I <hr/> i.e 84:1 ICD-9 161:5 ICU 247:18 idea 24:6 25:4 41:12,17 44:16 89:9 104:16 125:19 127:4 151:2 188:21 191:11 277:20 295:6 326:2 340:5 351:10 352:8 356:3 358:4 401:7 Ideally 226:7 233:14,18 ideas 113:21 336:2 399:13 identified 171:18 373:10 identifies 222:11	identify 63:12 132:19 254:20 identifying 62:6 156:3 ill 96:2,8 117:3 119:5 391:1 392:1 illiterate 88:16 illness 118:20 130:10 179:1 187:10 191:14 198:3 260:2 276:5 302:19,20 365:12 371:14 374:2 382:5 390:5 395:14 396:8 illustrative 19:13 20:5 34:21 35:2,4 177:4 253:15 imagine 41:16 imaging 11:18,21 immediacy 152:8 210:1 immediate 309:7 immediately 89:1 227:15 308:20 394:7 immediateness 311:16 immune 68:8 impact 83:4 140:3 140:12 141:15 254:21 266:1 304:19 310:1,3 363:21 391:15 impacts 120:19 impaired 378:12 impersonal 337:6 implant 38:7 implication 89:10 309:3 implications 26:3 implied 127:3 imply 208:11 importance 34:6 234:20 402:12 important 5:7 9:11 13:18 23:9 24:13	25:1 29:1 62:7 78:4 90:9 95:20 100:21 104:1,11 106:3,10 108:22 109:20 110:2 117:13,13 119:10 120:22 128:15 130:16,21 133:7 138:11,20 141:20 147:21 151:9 152:14 153:8,10 153:11 161:14 165:2 185:16 191:18 194:13 196:15 201:7 203:20 204:18 205:8,20 210:19 213:6,11 220:16 225:20 230:3 231:19 232:6 237:2 242:10,16 244:11,12 247:11 272:12 273:16 274:19,20 329:7 351:10 353:11 357:22 358:22 359:8 363:11 366:17 389:10,14 390:2,7,11 392:18 393:17,19,20 403:8,17 importantly 396:17 397:8 impossible 20:2 impotence 212:7 212:10 improve 111:1,2 362:13 369:11 improved 13:19 improvement 150:2 236:9 in-between 327:6 349:19 in-network 269:18 284:14 291:4 inability 132:6 inadequate 405:2	incentives 299:2 incidentally 155:7 include 101:14 103:21 104:9 253:16 included 47:22 95:16 290:11 349:22 includes 141:11,14 364:15 381:9 including 3:12 31:2 38:6 94:14 99:6 106:22 258:21 364:17 income 55:20 94:15 209:17 213:19 243:5 inconsistently 219:21 incontinence 212:7 212:10 incorrectly 302:18 increase 3:20 167:12 increased 136:13 136:14 increasing 19:3 282:6 increasingly 126:22 135:14 153:19 incredible 377:7 incredibly 78:6 153:21 167:6,16 196:15 293:13 incur 66:12 281:18 incurred 64:21 278:8 280:6 indebted 227:21 387:5 indebtedness 209:17 213:19 386:22 indefinite 380:14 independent 13:15 15:5 59:5 130:20 210:4
---	---	---	--	---

independently 244:5 386:5	338:16 379:16	301:18 302:4,22	115:10 240:10	348:5,19 368:10
index 161:13	influenced 36:14	303:6,9 305:4	inputs 112:8,14	369:14 375:9
indicator 138:11	158:19	323:14,16 324:6	INR 52:4	378:1,3 387:11,15
348:7	influences 21:10	327:7 329:4	insane 391:2	insure 139:6
indirect 265:17	201:10	339:13 340:11,12	inserted 92:2	insured 50:20
266:1 390:2	info 145:14 387:12	347:10 352:11	insertion 339:22	108:15,16 275:15
401:20 402:22	inform 26:1 148:9	354:1,6,17,18	inside 110:16	281:19 291:16
individual 30:4	information 18:16	357:6,9,11,17	139:15 141:8	383:19
37:9 66:21 94:14	18:21 19:16,18	359:9,13 360:2,6	insomnias 373:6	insurers 59:10
104:15,15,17,21	21:4,5,10,18 22:5	363:19,20,22	instance 226:21	integral 92:12
112:18 138:2	22:5 23:5 28:6,10	364:2 366:3	instances 343:9	integrate 370:12
181:9 200:8,10	28:12,13,15,17	381:13 382:10,16	instantaneously	393:8
202:19 203:8	29:6 31:16 32:14	389:6,10 400:17	193:8	integrating 102:17
214:9 243:6	32:22 33:22 35:10	401:10,11,12,13	institute 37:6 385:9	integration 367:10
277:19 298:18	35:11,15 36:15	404:6 405:21	institution 221:17	intellectual 332:14
322:20 327:14	54:22 77:16 78:1	406:10	221:19 226:3	334:21
348:4 357:3	104:9 117:9 119:7	informed 17:17	228:7,10	intelligent 43:2
375:20 391:14	130:13 132:2	26:15 32:15 60:1	insulin 151:21	intended 35:2,4
397:17	133:12 138:18,19	234:5 270:21	insurance 13:10	190:5 208:3 255:2
individual's 104:22	144:16 146:6,10	329:18	41:11,17 42:2,6	intensity 142:6
individuals 7:22	150:11,14 151:2,6	infrastructure 90:8	42:12,16 43:22,22	374:2
18:8 209:20	153:18,20 154:5	115:3 377:11	44:13 50:8 56:14	intensivist 334:3
251:17 385:13	156:9 163:9	392:20	57:3,12 58:20	interact 111:5
403:8	164:22 167:2	inherently 104:14	59:1,2 66:9,11,20	320:15
industrialized	168:1,2 172:21	104:21 246:13	67:15 72:2,9,11	interacted 112:17
361:17	176:7 190:3,3	initial 4:6 171:1	73:22 75:22 76:5	interacting 383:13
industry 13:11,12	197:7 201:11	174:3 182:20	76:12,19 77:5,12	interaction 13:20
52:13 100:6	205:11 210:8	267:18 268:3	82:10,15 87:4	36:13 392:5,14
154:10 163:15,16	211:6 215:8	338:1 369:9 373:9	90:2,3,5,17 96:13	interchanged
163:17 221:2	224:16 229:12,18	391:9 392:5,13	106:22 107:4,9	189:11
294:14 295:3	229:19 230:6,22	initially 188:2	121:6 128:4,6,12	interconnected
inexperienced	231:2,8,20 232:1	321:20 370:1	132:18 139:7	190:10 241:3
136:10 137:10	232:3 233:3,7,8	373:10	143:2,10 144:7	interest 3:5 16:3
157:10 323:17	233:10 234:10	initiate 373:3	157:18 162:15,16	296:7
359:12	235:14 238:14,20	initiation 173:14	163:7,15,16 196:1	interested 5:9 8:4
infarction 184:4	238:21 241:4,10	372:19	198:6 255:22	31:21 160:21
infection 67:3	251:12 252:12,14	initiatives 154:15	257:5 269:7,13	256:14 381:18
161:11,16 350:19	253:5,6 254:3,6	384:11	270:10,11 271:3	interesting 62:21
infections 317:18	261:17 276:3,7	injury 60:9	272:3,7 273:3,6	71:18 73:6 92:1
infectious 389:1	277:14,17,18	innovation 10:16	273:10,11,14,22	100:15 149:1
infers 117:2	278:1,5 281:6	375:14	275:1,3 277:9	152:7 165:3
infinitum 384:5	282:1,18 283:7,11	inpatient 355:9	279:3,8,11 280:16	215:12 216:2,15
influence 18:15	284:2,17 285:4,16	365:6 383:6	281:3 289:14,17	349:12 408:13
21:17 26:20	285:19 286:2	385:21 388:19	289:22 296:11	interests 8:1
116:16 201:9	291:7,10 292:7,12	input 22:15,18 26:7	301:17 321:4,16	357:10
204:16 208:7	293:4 296:16	100:16,16 109:10	324:19 340:17,19	intermediate
	299:9 300:8	109:12,15 112:18	340:21 347:5,11	379:10

internally 17:21	157:13	408:1,15	K 410:15,16	83:15 89:11 91:2
internet 403:12	irrelevant 121:8	iterated 245:20	Karen 2:10 6:22	91:22 92:3,7
internist 9:4 14:17	128:3,10	IV 45:20	27:13 28:5 116:14	93:22 96:20,21
interplay 379:18	isolation 237:3		179:15 183:7	97:1,2,11,13,22
interpret 210:8,13	issue 14:11 69:8	J	187:1 191:12	98:4 99:3,14
210:14 213:8	82:22 83:19 89:6	jargon 196:10	411:3	109:18 110:20
383:8	99:20 131:1	Jayhawk 322:9	Keefe 1:13 11:22	111:10,17 115:1,2
interpretation	141:12 151:18	326:21	12:1 93:9,16,20	134:3 135:16
261:8	152:13,20 153:8	JDRF 391:4	107:17 164:6	141:15 146:4,20
interpreted 98:13	162:11 164:11,18	Jessica 1:13 361:11	235:7 237:13,18	148:19 149:5
intertwined 376:17	203:3 209:20	363:4,15	240:22 276:19	167:8 174:8,21
intervention 310:3	220:2 236:21	job 67:8,8 125:2	291:9 360:5	175:15 176:1,5
331:3	265:11 266:4,20	139:3 208:17	keep 29:10 34:1	177:10 178:3,20
interventions	268:22 286:12,16	268:6 280:21	68:9 81:7 92:1	183:18 188:22
374:19	306:10 307:14	282:4 323:13	94:4 116:15	189:1 192:4
intolerable 211:19	313:19 314:13	402:10	141:21 152:4	198:14 211:1
intrigued 167:20	315:3,21 330:9	jobs 50:20	197:20 247:14,17	215:1 221:7
intrinsic 211:11	331:13 339:8	Joe 12:15 119:18	248:15,17 259:6	224:21 225:14
intro 363:3	354:5 357:21	121:16 156:18	262:20 301:20	236:13,14 237:22
introduce 5:18 6:4	364:1 366:16	160:13,14,16	305:11 321:6,19	238:1,8 239:9,11
6:16 63:5 338:19	368:3,15 374:4	163:14 220:11	365:22 411:5	239:12,20 240:11
introduced 166:19	376:20 382:1,3	262:22 265:8	keeping 29:2 30:13	241:16,21 244:19
introduces 380:17	383:18,20 384:7,9	287:1 314:6	65:18 81:4 233:16	245:15 251:14,15
introducing 31:4	385:6 389:13	329:20,20 372:15	272:10 296:13	252:2,4,6 253:3
363:5	392:1 400:22	383:15	360:12	254:20 258:17,19
introduction 3:3,16	401:5 402:19	JOSEPH 1:19	keeps 351:2	258:21,22 264:9
361:11	404:15	John 214:18	kept 229:12 319:15	267:8,16 277:8
introductions 3:4	issues 53:14 55:18	Johnson 25:18	key 20:14 324:7	290:12 294:12
5:13,17 7:8	56:1,5 68:5,21	27:12 126:6	328:15 348:5,7	295:1 296:16
214:17	92:5 119:6 160:21	236:18	349:7 355:21	297:11 301:10,13
introductory 17:3	172:14 174:15,16	join 36:19 250:13	388:6 391:10	306:4,18 308:19
invasive 337:6	190:16 204:4	joined 13:10	keypad 160:4	325:19 326:18
invested 360:20	209:19 225:18	joining 31:21	kick 35:20	327:6,8,16,19,21
investing 27:19	235:21 254:13	250:18 410:6	kicked 5:11	328:7 329:6 334:9
29:3 388:13	258:8 288:9	joker 42:2	kid 23:18 68:20	337:4,6 342:15
investment 80:17	301:13 311:7	journey 25:1	350:16,19 379:1	346:18,19 347:7,9
81:17 158:5	314:14 316:3	judgments 237:7	kidney 67:2	348:22 349:7
investments 80:13	365:16 366:8	jump 58:11 103:1	kids 63:11 65:20	355:12 357:9
80:15 362:11	367:8 368:14	111:12 123:17	66:16 70:5,11	360:20 364:22
invincibles 192:20	373:3 376:8	174:18 235:7	317:21 328:21	365:4,19 366:2,12
invisible 71:11	378:19 380:2,6	268:20,22 292:1	388:1	379:8 398:16,18
invite 37:3	382:18 383:17	jumping 234:9	kill 309:12	400:8 403:3
invited 36:8,17	388:2,6	justify 45:14 86:8	kind 12:13 20:22	kinds 72:22 116:7
involve 203:14	Italian 349:1,3	190:1,2	22:16 23:1 32:5	139:20 143:6
involved 26:5 55:2	item 35:20 50:19	juxtaposing 241:11	34:11 35:20 36:3	212:5 274:9
126:21 354:14	50:21 130:6		36:18 51:17,18	294:11,20 296:4
IOM 101:8,15	itemized 57:4	K	54:12,17 71:7	344:2 356:2 368:9

393:11	194:2,22 196:8	386:8 389:4 391:4	355:5	learning 56:15
Kitson 158:18	200:1 206:5	392:1 393:19	largely 95:18	leave 16:1 45:7
knee 134:1 154:21	210:21 211:17	398:6,7 403:8,9	larger 183:13	105:2 218:8
161:6 209:1	212:18,19 213:2	404:17 406:18,22	late 156:21	221:20 232:9
378:21	213:16 218:21	407:16,21	latest 146:3	253:8 330:20
knew 59:15 61:10	219:15 220:13,21	knowing 55:22	Latts 1:14 14:12,13	378:2 409:22
64:6 84:21 85:12	222:12 227:9,18	57:14 69:19 292:6	25:2 58:13 99:18	leaving 46:16
165:17 217:17,19	228:8 231:9,18	316:22 341:17	100:3 126:19	227:18 402:22
217:19 313:7	232:2 235:3,11	401:8 403:17	130:22 153:15	left 55:16 83:7
knocked 68:13	237:5 240:17,21	knowledgeable	180:18 220:5	86:18 129:13
know 8:13 20:1	242:7,11,19	321:13	254:7 272:17	214:3 227:3
25:13 26:5,11	244:22 247:5,10	known 166:21	281:22 300:22	275:20 276:1
33:13 39:18 40:22	249:7 251:22	knows 8:12 278:20	301:7 302:11,15	357:14 410:14,16
41:3,4,21 42:9	253:20 258:8	387:22	325:13 338:17	411:1,1
43:13,13 44:10	260:15,18,22	Kris 1:20 11:11	339:15 377:4	left-hand 192:16
45:14 47:5 48:8	262:18 263:4	219:11 270:6	397:12	leg 55:16 65:2
48:13 49:1,13	266:15 268:11	271:3 295:13	laugh 310:19	334:13
50:8,19 51:5,7	269:11 271:5	298:21 352:19	laughed 45:17,18	legislative 10:12
56:2,12,18,22	273:6,8 274:2	355:13	134:3	legislature 10:12
57:1,2,10,11 58:5	276:12 280:7	KU 322:10	laughing 45:11	lend 173:15
58:8 60:5,18	281:17,19 287:7		laughs 333:17	lends 360:18,22
62:12 63:6,12,13	287:18,21 288:2,8	L	334:4	length 161:10
66:4 67:6,18 72:6	288:12 289:18	lab 86:7	Laughter 7:4 50:2	lens 196:8 241:2,6
72:19 74:14 75:22	292:7,8,9,22	labor 112:8,14	50:6 65:16 70:2	400:11
77:18 78:12,22	293:6,7,8,9	118:5 333:22	72:17 82:11 87:14	lenses 197:20
80:15,16,18 82:1	299:15 300:12	labs 338:20	122:16 125:22	200:11
82:13 83:12 84:8	310:4 311:20,21	lack 294:17	139:10 167:13	let's 38:20 44:15
84:11 87:13,16	312:11,13 313:7,9	lady 134:2	257:6 268:9	64:14 65:12 90:21
90:18,18,19 92:16	317:5,14 318:11	laid 109:18 207:22	303:18 322:17	122:1 159:17
94:6 115:5 120:1	318:16,22 319:4,6	211:14	327:3 333:10,16	160:14 173:20
121:1 126:11	324:10,16,16,18	landed 327:10	334:1 343:22	196:17,19 242:14
128:21 129:1,8,21	324:18,22 325:15	lands 362:4	349:5 398:11	248:15,17,22
130:8 131:1	328:6 329:2,14,17	landscape 74:21	law 315:16	260:20 262:20
133:22 134:2	331:17,22 335:1,8	231:8	lay 21:21	270:6,16 276:5
135:1 136:14,14	335:10 336:14	language 70:7,9	layer 197:10 379:3	277:10 311:9
137:11 138:12	340:4 341:22	89:7 118:10	layman 186:5	361:9 364:13
139:7 143:5 145:5	342:1,2,6,10	119:10 134:6,9	layperson 314:10	letting 247:9
145:11 146:3,4	344:12 345:3,21	177:17 178:4	leads 83:13	331:17 359:12
147:4,5,15 148:2	346:8 347:13,16	179:8,15 181:16	leap 275:17	level 80:15 102:12
148:4 149:17	348:16 351:2,3	191:12 192:3	Leapfrog 222:19	147:18 152:16
156:11 158:3	355:20 358:21	196:19 198:18	393:21	182:8 251:9
160:19 162:4,22	359:12,14,15,15	389:4	learn 48:3 137:12	264:19 285:10
163:6 164:10	359:18 360:3,8	laptop 93:5	156:8 396:7	320:21 330:7
166:6 167:10	368:3 374:1,19,22	Laptops 32:21	learned 97:16	339:10 357:3
174:1 178:3,8	377:19 379:1	large 11:3 134:9	156:1 224:21	358:9
182:21 186:2,10	380:15,19 383:21	204:7 231:21	289:11 320:12	levels 52:4 165:4
186:14 190:12	384:2,13,16 385:1	280:5 316:3 335:8	learners 324:8	372:12

levers 27:11	159:22 288:15	252:19 408:6	145:16 163:18	logistical 32:17
Lewin 11:20	295:12 329:6	listen 37:7 241:9	203:18 212:9	logistics 17:7 30:7
library 163:20,22	330:4 331:22	listening 241:1	269:5 330:14	long 7:16,18 59:2,3
licenses 13:15	linear 173:18	listing 408:2	351:22 352:15	88:20 176:3 192:9
lie 92:4 268:8	174:22 186:3	lists 116:9	358:1	194:13 208:22
life 38:19 40:2,3,8	188:20 262:5	literacy 89:7	lived 53:4 346:17	216:17 217:2
43:3 47:3,16	lines 159:21 191:10	157:15 165:4	358:15 388:9	227:18 229:21
50:22 53:5,6 60:7	222:18 242:11	196:8 197:16	lives 13:4,18,19	237:1 279:20
62:17 80:6 81:10	356:16 409:17	198:3,17,17,18,19	24:4 39:9 81:9	305:16 338:1,1
83:5 85:6 90:12	linger 140:2	200:16 201:17	85:17 226:11	340:7 341:12
90:20 97:18 140:3	link 192:13 237:3	270:11 361:4	256:1 257:18	344:5 354:21
175:9 179:3	238:10 239:11	literally 207:10	290:21 322:20	357:8 358:18
183:17 184:19	246:13 305:12	218:21 223:15	388:11 409:13	397:15 398:10
190:20 208:7,14	linkage 61:9 62:2	308:18	living 15:12 40:14	long-run 270:4
210:9 218:21	75:12	literature 234:16	71:6 72:14 73:20	289:1,3
226:15 257:2	linked 158:22	396:8	77:7 78:17 82:8	long-syllabled
261:20 268:21	195:16 237:11	little 7:9 17:6 20:21	184:19 351:15	196:9
308:4,12 309:8	246:14	21:2 34:18 35:1	365:11,13	long-term 82:10
329:11,15 331:10	linking 235:14	45:13 47:2 50:9	Liz 8:19 28:21	83:17 85:15 117:9
346:17 349:1	236:19 238:7	51:6 52:16 55:8	111:16 140:14	153:6 172:14
358:10 360:9,16	239:21	63:14 64:13 65:6	188:1,10 199:11	179:2 186:13
360:19 361:15	liquid 114:3,4	70:21 76:4 81:22	203:2 204:21	194:16,22 200:2
365:12,14 388:11	Lisa 1:14 14:13	82:14 86:18 91:4	205:8 226:7	218:10 260:4
391:3 402:16	25:10 29:15 58:9	91:14,21 92:1	261:10 262:13	361:20 365:17
life-changing 54:5	101:5 126:17	94:5,19 99:4	266:12 272:19	372:10
life-threatening	128:19 130:16	100:16 102:8	316:7 387:18	longer 65:2 255:18
120:4 129:12	135:17 150:5	105:18 114:3	394:22 396:4	293:2
314:13 315:3	153:13,14 155:14	117:22 119:1	401:18 405:14	longitudinal
lifestyle 134:15	183:11 218:1	142:16 149:19	LLC 1:14	189:12 392:15
184:15 264:9	219:10 222:4	171:7 173:8,8	LML 1:14	398:4
lifetime 41:15 66:5	235:22 271:6,9,10	182:17 189:2,18	loaded 126:3	look 26:18 30:4
80:10 81:21	272:16 275:14	192:2 204:1	216:12 321:15	44:9 45:3,4,6
188:15	281:21 286:13	207:10 214:13	lobby 227:13,20	72:15 73:3,18
lift-long 64:11	299:11 300:21	215:16 217:11	location 140:7,8	74:11,15,20 78:3
light 363:11 396:21	302:13 325:12	220:13 221:3	348:4	82:18 104:18
lights 393:3	329:20 338:6	235:6,10,17	Loey's-Dietz	123:11 125:8
liked 225:17,19	340:15 372:16	241:15 242:15	217:17	126:5 134:18
likes 348:21	377:2 378:15	243:17 252:3	Loeys 38:1	135:6 140:7 144:1
limit 73:11 81:21	list 30:13 35:5	263:20 284:2	Loeys-Dietz 224:10	158:3,6,10 168:6
107:7	66:17,20 67:12	289:5 292:4 303:4	341:5,7,8	177:15 179:8
limited 369:1	68:19 77:13	306:19 316:10	Lofquist 1:14 9:18	188:13 193:7
limits 80:10 143:6	110:14,16 111:5	317:6 318:22	9:19 53:1,2 56:17	195:2 201:2,11
246:8,9,15	132:4,7 154:21	333:7 342:14	150:8 232:22	207:2 222:20
limping 333:3	195:22 198:12,13	346:21 352:22	233:15 267:4	228:4 230:7
LINA 1:21	359:21	364:9 365:1 409:2	346:12	231:21 232:14
Lindsey 2:17 6:20	listed 199:22	live 9:19 26:21 82:9	log 33:1	234:1 237:2
line 50:18,21 130:6	209:14 227:9	117:5 119:12,17	logical 254:1	242:18 243:7

245:11 272:8	74:15 80:7 81:17	low 148:13 149:8	253:17 258:6,12	226:22
288:20 290:6	89:19 98:14 103:6	248:2	258:18 271:15	manufacturing
297:8 308:3 317:6	109:7 111:8 115:3	lower 135:15 217:4	272:1,3,12 275:14	113:3
335:2,4 351:21	125:12 133:17	lowest 163:1	291:2,10,19	MAP 235:12
352:10 355:19	134:13 137:5,10	350:19	295:15 296:13	mapping 96:21
359:22 383:10	142:3 144:13,20	lucky 66:10 382:19	297:9,10,15	March 1:5 411:15
407:17 409:6,10	145:18 146:7	382:21	298:15,17 302:6	Marci 1:15 12:8
looked 39:8 41:13	147:16 150:10	lunch 31:4,10,21	314:9 332:13	95:9 115:18
59:11 75:11 76:8	157:7 163:4,9,21	32:11 160:11	351:20 359:17	118:17 123:19
77:1,3 138:13	164:15 166:2,9	168:9 169:2,4	390:11 395:1	134:7 141:21
158:16 183:13	168:21 179:4,6	406:8	396:3 404:6,19	155:21 176:13
202:12 213:19	181:15 185:18	lunchtime 168:5	male 295:22	195:11 197:14
242:20 245:15	195:14 201:17	Luong 2:14 6:6,7	male/female	232:21 234:11
333:4	202:17 204:1	94:4	257:12	246:19 249:5
looking 7:14 22:18	205:9,12 210:17	luxury 154:18	mammogram	320:6 323:2
23:11 25:21 62:13	211:7 233:2	303:5	299:16	325:14 373:1
75:1,12 80:9 83:1	234:22 235:11		mammograms	394:20 397:12
93:21 98:21	237:5 238:17,19	M	300:4,13	Marci's 16:17
103:22 146:6	239:1 241:18	M.D 14:4	man 50:4,4 87:9	326:17 332:15
155:22 168:12	246:6 263:4 269:5	ma'am 160:1	227:20 228:4	Marcus 130:17
186:5 202:5 223:5	271:12 274:2	274:16	manage 257:17	135:18 287:21
226:19 227:5	279:9 280:8,12	mad 141:13	370:7 376:6,8,21	market 20:17
230:21 232:4	286:20 287:13	magazines 229:20	378:12 396:10	114:6,6 145:18
238:8 239:7,9,14	288:10 291:6	mail 49:19 130:8	397:1	286:18
240:20 251:19	295:9 297:5 298:5	main 21:15 32:18	managed 372:5	marketing 288:9
252:7,11 257:4	299:14 301:18	56:19 189:6 267:5	management 4:6	marketplace 59:9
271:18 284:20	308:12 310:18	267:10	171:1,21 173:11	married 82:15,16
285:6 290:14	313:10 318:16	Maine 164:17	174:3,16 182:20	87:10 358:11
292:12 302:4	319:21 325:6	maintenance 38:13	187:17,18 194:14	mash 117:12
307:18 366:1	335:3,15 341:20	major 81:13	194:21 195:4	Mass 9:5 403:21
367:15 381:14	345:10 348:8	156:11 263:16	223:4 260:5	Massachusetts
385:6 398:7 404:9	350:3,7,10 357:16	364:10	316:12 364:20	106:13 137:22
404:21 407:22	364:5 366:11	majority 112:14	365:16 390:5	massages 72:21
looks 96:6 183:6	368:21 370:2	142:5,6 154:5	391:22 396:5	massively 90:8
383:14	371:7 373:18	254:11 284:17	398:4 403:20	master 105:11
looping 189:1	375:5 377:9,9,22	287:16 315:4	manager 6:11,21	match 119:11
lose 67:8,8 117:12	384:13 385:12	348:2,16 404:12	382:4,6,8 390:9	matched 77:13
268:6 340:18	387:9 392:4,9	making 69:16	managers 71:17	347:8
loses 340:20	395:20 397:3	80:14 83:11 90:10	manages 382:19	material 295:21
lost 148:1 229:8	404:3 406:14	96:22 119:5,6	managing 6:19	matriculate 251:17
297:5	407:18 409:9	124:6 139:1 144:9	348:1	matter 8:8 39:11
lot 8:10 14:11	lots 96:6 190:19	153:19 165:6	mandate 286:19	40:16 44:6 57:21
17:15 27:1 33:13	290:21	171:8 189:17	manicures 398:13	60:17 75:13 91:6
37:7 38:7 39:18	love 58:5 156:15	199:2 203:20	manner 77:10	125:1 126:22
43:10 44:2 47:7	220:9 351:7 356:3	207:12 208:8	213:5 259:21	134:10,13 146:11
49:7 50:15 57:22	loved 141:16 368:4	215:8 237:7	347:13	251:2 299:18
58:3,7 66:4 67:5	384:18	241:10 246:3	manufacturers	303:6 323:21

327:14 334:19 367:7 390:19 411:13 matters 27:4 212:2 212:16 226:14 Maureen 1:11 15:14 58:12 62:19 62:21 86:21 144:5 146:8 150:9 182:6 224:9 262:22 271:10 273:17 314:6 316:9,19,20 318:22 350:12 366:5,15 372:16 377:3 378:14 385:16 387:18 392:22 max 41:17 42:2,6 42:12,16 143:6 269:7 289:4 401:12 maxed 121:6,7 maxes 41:11 maximal 120:5 maximum 44:13 49:5 105:12 270:19 281:15 290:4,11 383:21 maximums 285:15 Mayo 338:13 MD 1:21 mean 8:10 25:3 43:3 50:9 63:11 72:21 73:16 111:18 114:4,17 115:4,9 119:13 121:20 122:7 125:6,20 126:4 128:1 137:5 176:20 180:1 181:14 189:6 194:6 208:11,13 208:16 223:3 237:5,10 248:15 260:19,19 263:7,8 263:11 264:13 267:4 270:17	276:22 284:19 288:1 291:12 292:7,22 304:7 305:15 308:7,10 309:1 311:11 313:9 321:2 328:16 329:21 330:3 336:1 340:7 341:15,18 350:1 351:13 353:4 363:11 365:2 367:16 368:1 372:3,12,18 376:20 380:7,14 391:3 398:3 407:5 meaning 103:8 112:8 118:11 143:1 176:18 195:16 meaningful 26:12 231:22 meaningless 128:7 means 27:5 30:22 90:16 96:1 97:21 99:2 118:2 139:8 198:13 212:2 290:5 328:17 399:13 402:20 404:13 meant 180:18 198:14 measure 15:3 26:6 27:21 40:4 62:10 105:16,17 130:20 165:9,10 193:14 193:18 220:15,15 220:15,16 222:7 222:10,15,22 223:3 228:11 230:4 234:21 236:11 239:2,13 240:1,17,19 283:19 327:11,12 measure-specific 236:12 measured 27:4 measurement 1:12	3:19 12:4 15:2 18:14 27:20,22 28:18 29:4,5 101:8,18 103:16 114:14,15 143:17 148:8 149:17 165:7 170:15,16 182:9 184:6 188:4 188:12 189:7 191:1 220:10 236:11,22 237:9 237:12 238:11,17 239:7,16 240:9 241:16 278:7 measurement-fo... 240:8 measurement-geek 178:4 measurements 149:19 150:15,20 measures 25:22 26:7,11 28:3 101:9 104:8 105:20 113:13,16 137:21 143:11 149:13 189:8 202:19 222:6,7,19 223:2,7 224:22 227:7,7,8 236:4,7 238:9,21 239:15 240:11,14 282:9 282:14,14,15,16 340:16 measuring 1:3 105:19 192:14 220:13 240:15 282:5 283:20 mechanism 32:6 218:20 mechanisms 330:1 med 386:8 media 9:22 28:14 33:3 Medicaid 13:3 55:14 66:15,20 67:11,17 82:22 83:3	medical 10:22 11:18 12:12 14:3 40:9 45:7 47:3 55:10 56:15 64:11 64:22 66:13 67:16 73:14 80:21 87:12 123:9 129:16 275:1,2 280:7,14 315:18 377:8,18 378:19 384:10 388:4 389:18 391:12 393:3,6 395:4,8 397:14 403:22 medically 83:15 384:6 Medicare 84:3 163:19 385:2 medication 73:11 75:7 153:6 174:15 187:18 258:13 365:15 372:8 medications 68:17 262:11 368:20 369:5 373:18,19 385:1 medicine 24:7 51:11,14 152:16 306:4 315:17 325:16 326:3,10 334:4 348:9 385:10 Medicine's 37:6 meds 75:5 meet 217:2 292:9 330:18 meeting 5:6 16:2,5 16:20 17:7 18:2 22:17,22 30:8 33:4,11,19 34:15 35:13,20 116:5 157:13 364:9 410:8 411:5 meetings 18:3 116:7 Melissa 1:7,10 3:7 3:10,13,17,21 4:4	4:8,13 6:12 9:12 29:16 36:21 37:1 56:2 59:17 60:16 73:7 113:17 117:5 123:9 133:8 134:20 135:2 136:7 156:18 157:1 159:13 194:11 195:14 199:13,19 210:20 214:11 225:11 262:22 267:19 270:5 274:14 288:16 289:11 297:21 302:7 304:8 312:5 337:3 362:2 385:15 407:12 Melissa's 40:3 196:11 member 3:14 4:19 9:18 10:5,14,21 11:6,11,15,22 12:8,15 13:5 14:2 14:12,22 15:7,13 25:2 46:22 50:3,7 53:1 55:7 56:17 58:13 60:4 62:20 65:17 70:3 71:3 72:18 79:17,21 82:5,12 87:1,15 87:21 93:9,16,20 95:12 99:18 100:3 106:21 107:17 110:11 115:22 119:16,21 122:5 122:17 123:20,22 125:20 126:1,19 128:21 129:20 130:22 131:5,10 133:9 135:1 136:20 137:2,14 138:22 139:11 142:20 144:6 146:16,22 148:7 150:8 151:10 153:15 155:16,19
--	---	---	---	---

160:17 164:6	336:20 338:7,17	mentioning 405:14	271:9 362:3 408:9	moments 400:2,21
165:13 176:14	339:15 341:15	mentions 33:2	minutes 49:9	money 39:17,20
179:14,21 180:8	342:13 343:6	message 271:22	112:15,16 114:1,2	40:1 44:2 45:14
180:11,14,15,18	344:1 345:5,14	messages 96:11	144:1 160:11	46:19 51:9 52:20
181:2,5,7 182:7	346:12 347:12,20	messy 362:19	168:9 232:8,11	62:16 71:21 72:13
182:16 186:1,22	349:6 350:14,22	met 1:6	253:2 318:1 319:8	73:10,19 74:22,22
190:14 192:8	352:21 354:16	metals 287:9	320:2 405:5	78:15 117:5
195:12 201:14	355:12 359:20	methodology 155:8	mish 117:11	120:15 121:2
203:22 204:20	360:5 361:14	metropolitan	missed 207:16	125:12,13 134:16
206:4,18 208:16	362:17 363:14,15	351:14	345:22	155:12 158:7
209:14 210:5	366:6 367:2,22	Michigan 327:1	mission 234:13	211:1 289:7
212:22 216:14	368:18 369:7,22	micro-cost 112:18	245:22	308:13 362:14
218:2 219:3,12	370:20 371:3,12	mid-30s 268:5	mistake 72:8 76:1	387:1 397:8
220:5 221:4,14	372:2,18 376:3	middle 61:1 68:2	mitral 47:10,11	monitor 260:20
224:19 226:18	377:4 378:15	178:21 287:14	mix 408:11	monitoring 151:22
229:3 232:6,19,22	379:7 381:20	288:4 380:3	mixed 402:17	month 22:22 40:11
233:15 234:12	383:16 387:19	386:17	mixing 206:19	40:12,13 42:17
235:7 237:13,18	389:8 390:17	migraines 54:4	mixture 282:13	51:8 107:6 123:10
240:22 245:18	394:4,21 395:19	miles 269:19,19	mobile 65:13,19	288:21 289:3,6
246:20 247:12	396:2 397:12	358:12	mode 140:6 205:10	monthly 134:12
249:6 254:7 255:5	398:1,12 408:14	million 13:4,18	309:14,18,21	269:10 279:18
255:12 256:5,9	members 16:10	129:10 139:6	317:3	280:2
257:3,7,10 258:2	27:16 160:22	156:20 247:18	model 3:16 21:22	months 11:20
259:2,8,11,20	165:10 203:13	mind 30:6 34:1	31:5,8,13 32:4	37:22 38:3,4,6
260:13 261:2,7	334:18	38:16 46:19 48:10	96:20 119:11	47:4,8 65:6,7,12
263:2 265:9 267:4	memberships 7:20	48:11 49:12,16	168:12 172:18	65:22 67:4 68:20
270:7 271:11	264:9	52:1 60:22 61:17	173:15 174:17	69:1 75:13 80:3
272:17 273:19,21	men 212:8 257:16	67:18 92:22	175:14 186:3,5	316:21 377:20
276:19 277:16	mental 68:14 75:3	116:15 213:3	187:11,12 196:17	monument 332:19
279:9 281:22	75:5 366:7,11,16	247:14 248:15,17	196:18 197:10	332:20
287:2 288:1 289:8	368:3 369:17	250:16 255:20	249:10 251:13	morbidity 161:11
289:12 290:17	370:10,12 372:3	301:20 309:13	259:20 261:3	morning 5:3 9:3
291:9 293:16	372:13,19 376:8	337:7 363:5 380:8	304:3 305:14	10:5 11:6,22 12:6
294:8 295:16,19	377:5,11,19,22	minds 83:12	308:17 311:15	13:5 14:12 15:7
298:22 299:12	382:2	135:22	320:19 351:8	17:15 30:17 37:16
300:10,18,22	mentally 48:4	mine 86:4 99:18	405:19 406:6	37:19 38:14 61:2
301:7 302:11,15	mention 33:18	141:21	models 304:1	76:16 100:14
303:15,19 306:3	173:17 201:16	minimally 287:15	382:14	104:2 106:4
307:5 308:15	203:12 214:16	minimize 196:9	modes 239:5	108:18,20 170:4
311:10,14 312:3	218:2 351:1 410:6	minimizing 129:15	modulate 316:5	171:6 172:2 194:1
314:7 316:16	mentioned 35:22	minimum 122:20	mom 56:13 85:10	320:11 335:3
319:2 320:9	97:11 198:16	217:3 399:19	88:15 90:4 129:1	399:4 405:15
322:18 323:3	235:22 236:19	Minnesota 1:12,20	146:1,1 269:17	Mort 1:7,9 3:7,13
324:9 325:13	277:18 326:1	11:12 15:2,4	284:3 316:19,21	3:17,21 4:4,8,13
326:20 329:21	356:6 357:5,14,22	148:11 344:19	mom's 214:2	9:3,4 23:7 89:15
332:12 333:11,17	392:22 393:21	minor 56:11	moment 77:2 122:9	105:21 107:2
333:21 334:2	407:16	minute 75:4 92:17	124:21 143:9	109:16 115:15

118:17 119:18	348:17 349:3	347:19 363:14	286:3 307:1	276:3,7 277:14
121:15 125:16	motion 392:14	names 33:21 77:12	321:22	280:4 285:17
126:17 128:19	motivation 226:20	narratives 104:2	necessary 83:15	293:5 296:17
129:18 130:12	Mountain 145:20	narrow 108:19	180:16 282:17	298:6,7 300:8
131:4,9 133:5	mouth 224:8,13	350:4	287:15 384:6	304:6 305:4
134:20 136:7	move 6:17 19:1	narrowing 328:7	385:14 388:3	307:17 310:10
137:17 142:18	107:14 161:16	nascent 153:21	neck 165:15	318:19,20 319:18
143:13 146:8	196:22 197:9	national 1:1,6,17	need 18:17,21	320:7 321:7,8
147:20 150:1	209:12 218:10	1:20 11:7 13:14	19:10,15,18,19	328:15,17 329:2,7
151:8 153:11	248:10,18 301:1	15:9 208:18	20:6,15 23:5 28:7	329:15,17 330:10
155:13,17 156:17	301:10,20 311:3,9	nationwide 282:22	28:11 29:6 31:12	330:20 333:18
159:13,17 160:13	320:7 323:9 330:6	naturally 228:15	31:15,16 35:7,10	334:7,12 335:7,18
163:13 167:14	346:11 352:6	nature 7:21 18:2	38:10 43:16 44:6	341:21 352:11,13
187:6,22 195:9	358:13 359:18	48:4 104:6 224:15	44:21,22 47:9	355:18 359:13,18
199:12 203:3	361:6,8,12 362:21	228:22 345:13	54:22 71:4 78:1	362:20 365:8
211:9 222:3 258:1	366:8 402:7	363:10	84:17 85:20 90:19	368:3,5,7 374:14
259:5,9,15 260:7	moved 106:3	navigate 43:6,20	94:22 96:5 106:16	378:20 385:8
262:17 264:15	181:17,20 346:13	57:16 59:21 69:21	107:13 108:8	386:13,18 387:7,8
265:8 266:5,17	358:11 370:21	73:5,7 96:2	109:11 116:15	390:5 395:2
267:19 270:5	389:22	117:15,21 137:13	117:8 118:20	403:18 404:3,18
271:2 272:11	movement 118:6	157:17,21 271:7	119:7 124:15,15	404:22 405:20
273:16,20 274:13	moving 29:1 78:8	360:14 362:5,12	127:21 129:14	406:4
274:17 275:13	130:12 131:8	404:18 406:16	130:14 133:16,22	needed 22:5 24:1
276:15 277:7	175:2 291:20	navigates 73:8	134:9 135:13	38:11 85:11 87:11
279:2 281:21	346:14 369:3	164:2	141:1 142:15	130:19 132:2
284:7 286:1	383:5	navigation 163:17	147:18 148:5	133:14 165:13
287:18 288:16	MRI 40:16 277:21	navigator 164:14	150:21 156:8	251:12 253:6
289:10 290:15	312:16	361:21	163:7,15 164:22	400:18 401:3
293:14 294:3	MRIs 337:4	navigators 168:2	165:22 166:7	needs 15:18 59:15
295:9,18 296:6	Mullins 42:14,15	362:20	167:2,11 171:15	65:4 81:11 106:5
297:1,21 298:17	multiple 7:3 55:16	NC 157:12	172:21 184:1	109:1 137:15
299:8 300:7,12,20	108:6 133:7	NCQA 282:3,20	187:10 195:19,20	188:5 207:4
301:5,15 302:7	185:12,13 188:6	283:3	196:8 197:6 198:1	268:20 269:17
316:8 318:15	188:14 381:7	near 74:16 162:2	200:1,3,12 201:5	273:9 333:19
328:11 356:4	myocardial 184:4	338:13 358:2,7	201:11 203:17	388:1 390:13
362:21 363:2		nearest 172:9	204:3 209:1,1,16	392:1 395:8 405:2
389:9 392:16	N	244:14 269:18	213:15,17,22	negative 85:5
402:9 404:20	N.W 1:7	nearing 84:8	222:9,9,10 223:6	315:12 342:19
407:12	nails 322:7,9,11,14	nearly 20:1 306:13	229:11 231:15	negotiated 278:11
mortality 138:1,11	323:7 327:4	neatly 321:21	232:1 240:13	278:21
161:10	332:17	nebulous 61:17	242:4 252:13	Neiman 130:16
mother 15:16	name 5:21 6:6 8:17	necessarily 34:14	254:3 256:4,21	287:20
23:13,18 90:6	9:4,18 10:6 12:1	36:8 84:11 90:13	257:18 266:9	Nelson 1:15 10:21
106:14 122:8	15:8,13 37:1	109:11 144:22	267:6,9,14 268:1	10:22 79:21
144:17 164:2	46:22 53:2 62:20	213:16 231:12	269:11,20 270:2,3	128:21 133:9
165:1 168:1 207:5	66:20 111:8	240:16 248:16	270:9,12,22	135:1 136:20
255:10 324:1	115:18 123:19	264:10 275:10	272:12 275:3	137:2,14 146:16

155:16,19 210:5 212:22 246:20 258:2 259:2,8,11 259:20 260:13 299:12 300:10,18 341:15 342:13 345:5,14 347:12 355:12 neophytes 289:22 nephew 334:3 nephrologist 386:3 nervous 292:21 network 33:1 146:21 264:1,22 269:13 277:1 278:11 350:4 networks 147:13 216:21 neural 64:2 neurologist 54:3 neurosurgeon 350:17 neurosurgery 64:20 388:22 neutral 92:16 95:4 215:9 never 39:9,10 41:4 41:14 50:12,18 62:12,16 72:1 74:18 87:3 130:4 130:5 202:12 225:2 245:11 268:11,16 269:1 280:8 281:4,7 288:3 310:12,21 317:9 323:7 328:16 341:7 358:14 375:2,3 new 13:12 24:10 27:21 58:21 65:4 65:9 72:20 74:21 87:5 94:7 98:17 163:16 190:17 196:19 218:7,9,13 292:14 305:13 325:4 326:10 396:21	newborn 214:6 newer 27:15 newly 290:3 news 263:12 nice 51:8 280:21 282:8 327:19 347:13 niece 79:21 Nielsen 1:15 12:8,9 95:12 115:22 119:16 123:20 176:14 179:14 195:12 234:12 249:6 257:3,7 303:15,19 320:9 322:18 323:3 324:9 326:20 361:14 367:2,22 369:7,22 371:12 372:2 376:3 394:21 396:2 398:1,12 Nieman 135:17 night 37:20 42:22 42:22 43:4 45:17 61:1 312:4 331:20 364:11 NIH 12:20 nine 54:6 65:7 68:4 nine-year-old 68:12 nominated 8:2 non 121:11 non-emergent 302:1,10 320:7 non-existent 403:11 non-par 375:8 non-system 294:15 nondiscretionary 172:6 noon 32:21 normal 57:1 58:6 118:1 148:16 343:13 North 6:14 9:14 37:5 85:2 361:3	note 152:14 199:10 249:21 250:17 366:14 noted 264:20 notes 139:2 noticed 94:5 NQF 2:8 5:7,22 16:6,7 18:3 26:3 27:11,16,16 28:20 89:16 91:16 116:4 126:22 170:12 220:6 235:12 239:15 402:3 NQF's 33:8 nqfaffordablecare 33:7 nuance 207:21 238:16 335:19 371:18 nuanced 105:8 nuances 235:5 238:3 number 18:4 19:9 36:1 57:6,6 59:10 93:3 127:20,20 130:11 146:14 160:3 196:9 319:9 335:9 363:17 383:8,12 396:20 408:8,20,21,22 409:11 numbers 45:22 92:14 201:19,21 290:8 numeracy 201:16 201:22 nurse 80:20 319:7 319:8 324:14 329:5 330:4,5 331:6,22 391:21 nurses 87:13 112:17 145:1 330:9 350:15 nursing 83:21,22 145:9 365:18	o'clock 410:8 O'Rourke 2:15 6:10,11 30:9 405:13 410:5 OB 386:3 OB/GYN 333:14 343:14 objective 300:19 objectively 213:4 220:17 objectivity 228:15 obligation 325:17 obligations 326:5 obtaining 265:18 266:2 obviously 19:9,20 20:20 34:21 69:15 104:1 115:5 190:10 198:19 209:21 279:10 313:10 356:6 occasional 60:8 occasionally 47:14 303:16 occur 182:4 186:14 186:15,16 276:18 278:9 380:1 occurred 128:22 328:16 358:14 400:16 occurs 61:18 odd 384:4 offer 110:11 303:16 346:3 office 12:6 52:2 219:5 290:8,9 328:14 330:18 331:4 367:6 371:15 373:3 377:13 officer 9:7 15:2 43:1 offices 319:5,6 326:14 official 150:13,14 offline 188:8 offset 375:17	oftentimes 357:12 oh 40:11 41:20 44:1 44:15 46:10 50:4 62:14 66:21 68:10 68:11 70:4 90:15 95:11 111:19 125:7 226:11,12 227:20 228:3,17 231:14 234:1,7 265:8 271:9 291:22 298:20 318:13 329:17 333:7,11 341:14 342:10 351:7 379:6 410:15 Ohio 145:21 okay 6:15 15:20 16:19,21 17:8,12 41:22 44:1,15 76:11,13 79:17,19 82:5 94:8,9,19 95:3,5,11 97:10 99:13,16 100:2,10 100:22 115:14,15 138:21 148:3,5,7 153:14 159:9 160:5,7,16 180:5 180:14 181:5 187:22 191:20 199:18,20 201:6 209:13 215:11,20 234:1 245:6 246:14 249:20 250:22 251:20 258:1 259:2,8 262:19 265:4,7,8 268:13 273:20 274:17 275:18 277:3 279:7 288:16 295:18 302:13 311:12,17 317:20,22 329:17 341:4 345:3 351:15 363:1 370:19 372:15 407:4 409:16 410:2,13
--	---	--	---	---

O

old 56:13 64:18 65:12,22 68:4 80:2 188:6 305:14 305:15,15 316:20 316:21 older 208:19 oldest 151:16 on-going 236:13 onboard 6:9 once 31:14,16 35:1 35:8 39:5 44:13 47:14 137:11 193:5 221:10 265:10 267:13 271:14 279:3 281:2 296:1,10 329:17 342:10 343:17 373:14 oncologist 14:3 one's 202:2 304:21 one-year 188:11 ones 108:7 110:9 198:16 228:21 254:21 310:7 361:10 384:18 ongoing 59:14 187:17 221:13 online 9:22 57:21 76:10 90:14 162:5 330:15,15 opaque 117:15 open 8:11 10:7 17:2 36:6 37:20 38:2 47:20 48:2 76:11 90:15 115:16 150:6 156:19 158:15 159:21 177:1 196:16,19 199:11 244:1 246:5 271:22 275:5 295:20 303:10 313:14 341:6 356:13 366:4 393:15 399:1 402:5 409:16,17 open-heart 138:1	opening 3:6 29:16 openly 16:4 Operating 15:1 Operator 159:20 160:1 409:17,19 410:3 opinion 304:10,12 304:22 opportunities 204:14 opportunity 103:21 104:7 116:4 192:12 292:5 297:5 opposed 301:6 opposite 71:8 78:5 127:8 204:5 option 211:14 245:8 354:4 optional 31:19 options 76:18 143:4 211:15 212:14,14,16 213:6 245:9,17 272:9 293:3 355:16 orange 178:18 185:1 388:10 order 20:15 24:18 30:13 143:15 222:18 344:13 ordered 65:10 66:2 organic 199:17 organization 11:2,3 11:9 18:15 157:15 348:13 377:9 organizations 10:19 12:19 organized 22:17 88:4 377:10 orientation 89:14 oriented 205:13 originally 178:1 ortho 269:18 orthopedic 333:3 378:21 orthopedics 64:20	other's 8:13 83:5 out-of 216:19 217:4 243:4 out-of-network 291:5 out-of-pocket 68:16 69:3,5 81:19 96:5 121:8 152:1 162:18 239:3 263:9 264:21 270:19 284:13 285:12,14 289:4 290:4,11 295:1 375:19 383:21 387:14 404:14 out-patient 166:14 outcome 59:18 139:22 158:6,7 232:3 310:3 outcomes 211:12 225:13 352:7 362:13 outline 22:15 output 23:1 135:19 outputs 22:13 outside 105:18 118:13 133:20 325:15 outweighed 199:9 223:12 over-complicating 112:4 over-thinking 219:14 overall 17:17 201:2 285:8 326:2 348:4 overarching 301:22 overhead 166:17 overload 360:3 overutilization 299:19 overview 3:6 17:1 54:20 402:8 overwhelm 229:6 overwhelmed	69:17 70:13 370:3 overwhelming 123:7 346:22 owed 213:20 owns 13:1 <hr/> P <hr/> P-R-O-C-E-E-D-... 5:1 p.m 91:7,9 169:4 170:2 250:16 251:3,5 411:12 package 369:11 page 3:2 4:2 97:16 98:2 99:12,12,13 99:17 195:10 252:20 253:14 365:3 367:4 paid 46:18 49:6,13 71:7,10 72:1,20 74:18 75:6,8 76:2 76:19 77:7,10 87:3 102:14 113:14 151:22 165:19 pain 43:4,10 53:10 54:16 153:2 165:16 315:4 pains 56:13 276:12 pair 226:21 palsy 80:1 384:3 pamphlets 231:16 panel 1:3,6 31:20 88:4 99:1 199:15 199:15 235:14 panels 88:12 183:20 316:4 PAP 333:19 paper 22:14,20 25:4,9,14 26:16 96:10 118:8 167:9 194:19 247:11 248:12 249:8,9,12 256:13 314:20 321:7,20 325:1 355:15 400:10 papers 49:19	paperwork 67:10 par 375:8 paradigm 272:20 paragraphs 234:19 paranoid 82:14 parent 63:1 69:7,10 69:14 70:6 303:13 382:3,4,6,8 parent-to-parent 145:11 parental 255:13 parents 47:7 50:20 63:1,3,4,10,11 69:16 70:11 82:20 82:22 85:4 88:15 89:9 120:8 144:8 144:21 145:4,7,19 145:21,22 146:5 147:2,11,17 152:4 163:18 269:6,9 340:17 369:2 park 410:9,19 parking 234:22 310:18 Parody 372:20 parse 209:16 parsing 168:13 207:9 part 27:10 44:14 57:17 73:1 96:9 100:21 142:21 143:9 181:15 192:16 201:16 208:17 213:7,12 226:11 228:6 255:15 263:8 279:17 285:3,18 299:20 303:13 316:15 319:3 331:2 336:5 363:10 369:12 373:11 participant 46:8 164:9 255:10 333:19 participate 36:17 particular 83:2
--	--	--	--	---

88:15 98:9 101:10 102:2,3,15 105:13 108:5 109:9,12 128:14 170:7 187:15,16,19,21 227:3,17 228:12 232:12 278:11,12 278:13 280:17 335:7 336:13 353:14 355:3 367:1 383:5 401:14 particularly 8:4 17:22 18:18 26:13 95:20 101:17 110:2,2 154:3 167:20 174:20 190:3 201:20 210:6 212:13 236:22 399:8 particulars 332:7 partly 64:5,6 partner 76:4 312:21 partners 1:9 11:1 52:7 227:7 403:21 partnership 1:17 11:7 26:6 Partnerships 7:1 parts 79:5 122:10 270:14 party 111:17 pass 310:18 passionate 54:21 path 32:13 185:15 247:2 406:9 407:2 paths 185:6 pathway 248:10 patient 6:13 9:13 10:6,15 15:3 32:7 36:9 37:6 47:16 47:18 51:18,19 71:13,16 79:6,6 96:1 100:16 101:21 106:14,15 106:17 108:3,12 110:6 119:15	124:2,11,14,19 129:1 136:11 146:18 153:9 156:5 159:1 164:13 175:1,12 175:19 176:11 183:20 184:17 189:9 191:3 202:17,18 208:5 212:17 213:8 222:20 237:16 240:2 251:11 266:6 300:16 307:15 315:1 323:11 325:17,18 344:16,17 348:18 356:16 359:22 365:7 370:6,8 372:9 373:15 375:6,20 378:2 382:21 385:18 389:7 396:12,17 397:5,6,6 404:2 405:18 patient's 106:8 109:21 152:10 189:16 208:7 367:15 patient-centered 1:15 12:9,12 116:20 170:18 384:10 389:18 391:12 399:17 403:22 patient-centered... 101:13 patient-focused 3:16 31:5 170:13 178:2 190:18 191:12 patiently 190:13 patients 9:15 15:11 18:20 29:22 70:18 73:20 74:8,20 75:18 76:1 78:11 79:8 88:11 95:18 96:11 106:19	116:12,13 117:1,1 118:3,10,19 125:1 125:4,10 126:2 135:22 137:4 144:8 145:4,8 146:5,15 147:1,12 147:17 152:17,19 161:4 167:18 168:19 176:19 187:9 203:6 211:14 212:1,18 218:4 221:18 222:9 223:6 224:10,16 227:13 227:13,16 229:17 231:15,21 232:13 240:18 251:16 252:8 307:9 319:13 325:7 344:13 347:22 353:11 362:12 369:20 374:10 375:17 390:12 401:14,21 403:9 403:10 404:4,7 Paul 1:18 11:15 100:12 150:5 151:9 182:8 190:12 209:12,13 213:19 306:2,20 314:6 345:4 347:18 386:21 390:14 395:1 396:3 pause 17:11 94:17 160:14 215:10 216:1 250:21 pay 24:17 25:22 39:9,10 40:6,11 40:12 41:14,18 51:7 52:2,20 55:21 71:20,21 73:10,15 74:3,4 75:17 78:15 85:21 87:6 89:11 96:5 106:20 107:8 109:22 110:7	117:17 120:2,15 123:1,16 125:11 128:5 154:17,20 159:8 256:8 269:12 281:15,16 289:5 328:20 329:14 344:6 378:3 408:17,18 paycheck 107:6 263:10 286:7 297:7,8 402:20 paying 40:8 41:16 48:12 51:2,9 56:14 67:17 89:9 123:2 125:18 159:9 167:11 201:22 272:4 342:12 371:8 374:14 payment 24:2,9,17 26:8 89:2 106:8,8 106:17 110:3 122:7,21 375:14 409:8 payments 107:4 134:12 269:10 375:16 406:20 407:19 409:5 payoffs 388:14 pays 49:22 125:6 PCP 393:1 PCPCC 324:11 362:15 peace 46:19 peck 279:6 pediatric 68:18 145:17 180:20 183:16 pediatrician 23:14 23:19 317:4,9,12 387:22 388:13 392:8 395:11 pediatrics 183:12 peers 65:19 146:13 288:7 345:12 pelvis 42:5 pens 152:2	pent 141:21 people 14:9 21:14 23:12 30:11,13,19 40:10 43:6 49:12 50:12,15 52:8 54:22 55:10 59:4 71:22 72:5,11,14 73:3,14 75:2,9,15 75:16 77:10 80:22 84:3,18 86:18,19 87:3,12,18 92:20 93:22 94:2,8 95:3 95:18 97:3 102:4 103:7,16 113:2,4 114:19 117:14,18 125:12 126:3,3,9 127:8,18 129:8,8 132:12,22 135:12 137:5 139:6,12,22 140:7 142:8,12 144:3,19 146:18 147:9 148:15 150:12 151:1 156:20 161:20 162:3,9,12,19,22 163:6,10,17 181:16 182:21,22 188:8 190:19 195:3,19 199:2 202:8,12 205:10 205:13 206:22 207:11 209:2 217:8,11 220:6 222:14 225:14,16 225:17,17,18 227:19,21 229:6,8 231:1 232:9 233:5 233:9 241:9 243:11 247:9 255:6,7,15,21 256:3,21 258:17 259:22 260:10 261:4,16 265:19 272:1,13 274:4,7 274:20 279:11,18 279:19 280:11,13 287:2,5,12,16
--	--	---	---	---

288:6,12 289:12	243:4 330:12	205:11	276:9,11 284:10	39:17 88:19
289:13,15,17,21	351:21	personality 205:15	301:20 335:17	216:18 217:1,4,9
290:2,13,20 291:6	percentages 230:13	225:18	361:8 364:14,15	218:4,18 220:14
294:10 296:3	perception 46:3	personally 143:5	364:16 365:14,21	340:4,4,7 341:5
297:8,10 299:2,5	79:14 111:3,3	219:4 307:22	380:9 392:6	373:7 374:21
300:1,3 301:12	127:10 142:11	perspective 29:2	phases 29:12	377:10 384:22
303:12 327:9	152:10 159:2	39:21 52:17 62:14	175:22 191:11	396:14
328:9 329:22	202:1 280:22	90:1 95:17 98:21	194:7 197:12,19	pick 73:21 131:11
330:1,6,15 331:3	292:20 305:21	100:5 104:1,12,21	200:13,19,22	132:18 157:17
331:8,14,17	308:10 309:6	104:22 106:9	242:17 244:8	161:4 162:22
332:13 334:10	315:1 331:10	108:3,5,14,22	248:19 249:4	288:21 289:17
336:22 338:7	perfect 70:20	109:21 113:20	252:5,9 400:14	349:21
340:1 345:15	121:16 149:20	114:18 125:9	401:2	picked 73:22
346:15 348:16	perfectly 43:3	138:10 143:3	Phoenix 10:16	240:18 254:11
351:13,21 352:11	119:4	154:8 167:18	phone 37:13	picking 222:3
355:16 356:6	performance 236:9	188:13 194:19	145:10 159:18	277:12 288:6,22
358:15 359:6	240:16	197:4 204:16	319:9 333:13	375:7
361:20 363:21	period 101:22	205:21 206:12,12	377:15	picks 25:6 43:17
372:21 373:12	102:3	206:13 237:9	phones 32:21	333:12 344:7
374:5,17,19	periodic 389:21	238:2 239:4,16	phrased 302:18	picture 183:6 223:8
375:10,21 377:14	periods 189:8,16	240:3 242:3	phrasing 191:15	239:21 260:8
377:15 384:17,20	189:22 190:8	247:17 274:11	physical 81:2,3,5	295:7
384:22 385:7,9	191:17,21 194:5	283:22 284:3	156:13 365:18	pictures 49:11
395:6 411:8	272:1 400:17	288:2 301:3 323:8	369:17 376:22	piece 24:9 66:7
people's 33:21	person 15:12 48:22	360:21 367:16	physically 48:5	67:18 70:16 106:5
47:17 92:4 120:1	71:6 76:11 77:5	377:18 379:14,21	352:4	107:8,13 110:3
131:15 150:19	83:7 104:17 110:4	383:11 385:21	physician 11:1,16	137:18 138:19
275:11 322:20	155:21 185:17	386:9,11 392:18	38:21 49:20 54:1	202:1 229:7
358:21	203:9 220:8 226:5	400:22	59:1 60:5 61:5	236:15,16,18
perceive 164:21	226:11,12 227:3	perspectives 18:1,8	69:19 132:17	239:22 240:4,7
211:1 298:3	243:18 256:17	281:10 399:14	151:11 216:17	304:21 316:14
perceived 120:20	258:9 259:13	Ph.D 303:22	218:8,11,14	359:8 360:16
131:2 158:20	260:14 261:21	pharma 116:22	221:16 227:15	389:10 392:16
256:4 304:9,12,15	263:22 264:1,4	pharmaceutical	268:19 269:15	400:4 404:3,7
304:20 310:1,2	276:16 299:17	12:21	289:16 306:22	piecemeal 383:2
311:13,14,16	321:10 327:11	pharmacy 369:10	317:4 324:14	pieces 299:9
324:16,17 336:15	344:7 382:9 388:5	pharmacy-based	326:5 330:16,17	pigeonhole 306:18
perceives 351:4	389:21 393:5,8	331:6	330:20 332:8	piggyback 173:8
percent 38:22	398:3 405:20	phase 4:3,7,11	335:2 336:6 338:4	326:17
50:12 59:4 84:22	406:6	31:12,17 171:9,20	339:2,3,4 343:11	piled 67:5
142:8,16 211:18	person's 359:21	172:1,7 173:11	349:14 353:7	pinging 297:6
230:15 283:22	persona 146:18	174:3,5,6,14	356:6,10,18,19	Pink 300:2
325:18 344:10	personal 33:22	175:20 187:14,17	357:3 375:12	place 33:10 41:10
367:4 370:4,7	88:14 192:22	197:6 200:10	387:21 391:5,11	45:12 60:19,21
385:10	210:14,16 211:7	250:5,7 253:13,22	392:8 394:6	70:12 115:4
percentage 182:19	304:2 350:8	255:7 258:6 268:3	396:15	126:16 166:5
182:20 230:11	personalities	269:1 271:16	physicians 1:19	229:17 233:19

240:2 389:7	316:10 330:3,14	171:21 173:3,10	394:22 401:22	81:11 223:8 276:2
398:16	338:8 349:21	173:20 176:8	police 43:1	294:10 330:13
placed 64:15	350:4 354:13	178:3 188:17,18	policy 25:7,7 26:2	349:17 350:1
places 27:8 78:14	368:22 408:17	189:4 196:11	26:17 208:18	possibly 68:9
137:20 138:16	plastic 344:4,7,11	197:16 200:10	272:7	post 314:17 378:22
139:13 146:7	platinum 287:9,14	202:17,21 205:8	Polish 349:2	381:15
166:8 286:13,15	play 32:4 121:7	206:1 209:11	polling 31:20 92:2	post-acute 193:9
305:12 339:22	165:5 192:10	212:20 213:14	349:13	364:14,16,17,20
356:1 358:15	193:12 200:18	214:10,15 223:11	pond 358:17	381:8,17 383:7,9
plan 49:22 68:19	255:14 308:20	228:14 229:1,16	pool 96:14 292:4	383:14,18 389:12
69:2 74:2 89:2	310:1,6 353:2	230:10 231:11	poor 65:14 247:5	Postal 10:11
113:14 147:7	405:18	233:11 234:10	321:15	posted 51:5
154:17 166:6	played 387:9	238:18 244:16	poorly 258:10,11	posterior 345:19
217:7 239:18	player 282:3	246:17,18 248:17	260:1,14 362:19	346:1
240:19 253:16,18	playing 31:11	251:21 253:10	popped 298:20	potential 171:12
254:9 265:3,11	141:6,7 173:22	255:2 257:4	population 4:3	290:13 336:2
266:18 269:16	174:1,7 269:8	261:10 265:10	31:13 97:1 101:21	potentially 97:4
273:2,5,22 277:2	plays 91:19 135:21	266:6 267:5,17	102:3 156:6	120:12 128:8,9
277:2,12,12	248:7 266:6	271:20 272:12	157:20 170:20,22	172:3 195:20
278:12,17,18,21	275:11 321:5	274:4,13 275:14	172:4 173:10	198:2 211:4
284:11,18 285:14	334:8 336:12	285:5 293:22	174:6 175:11	239:10 252:2
287:6 291:17,21	please 16:4 17:9	298:17 299:8	178:11 180:22	314:13 352:2
292:2,14,20 293:2	33:22 409:18,21	305:18 306:2	181:12 183:10,18	384:10 399:21
293:21 294:1	pleased 12:7	313:17 325:14	187:2,20 204:7	pounds 268:7
295:1,14 296:11	plug 147:12 162:5	326:1 327:16	250:5 255:19	powerless 58:3
298:6 299:3,4	plus 59:4 123:3,4	328:8 334:17,17	256:11,14,16	PPO 291:3,20
301:17 304:17	pneumonia 23:22	335:12 338:5	259:9,13,17	PPSI 282:7
339:19 356:7	180:20	340:1 350:7	260:10 261:3,5,6	practical 24:21
366:20 369:4	pocket 128:18	352:14 361:15	262:1 263:3 266:7	practice 53:9 329:4
377:17 398:21	134:14 216:20	371:4 379:5 389:3	268:5,14 273:8	348:9 356:10,11
404:22	217:5 243:5	391:3,7 392:17	275:15 280:10	356:20,20 357:8
planned 210:2	344:10 409:3	393:22 396:3	283:13,14,18	357:12,14,20
planning 59:6	point 8:19 9:9	pointed 5:19 34:17	291:13 296:12	359:4 389:15
66:12 124:18	19:22 24:15 34:10	185:2 188:18	335:17 360:1	390:6 392:17,19
360:10	38:17 39:4 40:8	197:15 284:12	367:1 383:19	393:10,15
plans 12:22 13:2,3	53:16 54:7 55:3	401:18	384:20 403:19	practitioner 324:15
13:17 59:11,14	56:9 60:2,14,16	pointing 279:21	populations 180:3	practitioners
107:11 116:22	61:4 62:8,12,18	351:9	184:1 263:21	377:12 391:21
135:7 139:6	64:12 66:19 67:12	points 19:12 20:7	portals 356:17	pre 266:16
153:19 154:3,12	69:13,18 79:3	22:1 34:20 35:6	396:12	pre-choose 338:10
160:19 161:2	93:8 97:9 98:7	105:22 109:5	portfolio 105:19	pre-existing 48:15
164:12 168:3	102:22 103:4	121:18 144:2	portray 213:4	preauthorizations
192:20 276:21,22	107:3 116:6	170:11,21 185:3	posed 111:14	330:9
277:15 282:5,10	121:21 122:14	202:7 233:2,16	positive 181:19	precision 294:18
282:20,22 286:15	129:16 130:13,15	251:16,18 290:15	241:21 322:13	295:3
287:13,13 288:20	134:7 140:16	296:8 327:21	possibility 351:20	precludes 376:21
297:5 299:1	144:12 171:3,16	335:7 378:17	possible 29:11	precursor 19:20

predict 293:8 379:16	president 7:3 9:6 10:15 12:16 13:6 14:3 217:7	161:13 163:1 215:15,22 216:7 218:5 264:8 329:19 338:22 339:1 342:2 343:5 355:17 402:18 409:8	probably 23:12 38:16 50:11 59:4 59:12 77:9 103:17 109:1 128:16 150:6 153:4 200:17 205:15 217:21 232:17 238:18 245:4 263:5 292:20 295:7 299:20 307:9 311:3,4 320:7 348:3,5,11 348:13 409:2	273:12 320:17 336:12 352:13 375:21 381:14
predicting 290:22	presiding 1:8			processes 239:13 375:15
predispose 376:14	press 8:21 160:3 409:21			produce 103:9
predisposes 376:13	pressure 61:15 153:6 255:13	price-sensitive 339:6		produced 112:10
predominately 135:5	pressure-testing 32:6	priced 130:17		product 163:3 289:15
preeclampsia 37:15	pressures 325:4	prices 101:19		production 103:8 112:7,10 113:1,6
preexisting 87:11	presumably 267:1	pricing 152:20 154:12 339:14 340:5		products 162:16,17
prefer 34:4	pretty 53:10 144:18 183:6 204:7 300:14 309:9 347:6 348:12,14,18,20 363:21 403:2,11	pricked 52:3	problem 54:10 58:7 71:8,13 76:7 78:5 140:1,2 154:2 192:11 303:2 310:2 311:16 364:10 370:1 384:1 394:7 394:9	professional 7:20 137:3 146:18 147:1 157:13
preference 102:19 205:12 338:14	prevalent 342:7	primarily 249:13		professional's 325:22
preferences 94:15 225:19 242:21 337:12	preventative 97:1,6 265:13 301:1 340:16	primary 1:15 12:10 12:12 22:13 42:14 54:1 78:8 97:5 116:20 171:7 218:6,8,14 253:18 261:14 262:2,16 262:20 267:6,10 267:18 268:19 269:14 289:16 290:8 306:22 317:3 361:19 362:3,9,10,11 367:5,9,19 368:5 368:12 369:15,22 370:2,13 371:15 372:6 373:3,7,16 375:12 387:21 388:13 390:7 391:11,19 392:4,7 393:2,5 394:6,14 394:18 395:5,10 395:12,12,15,22		professionals 30:2 37:8 95:21 116:10 378:8
pregnancy 59:18 64:5	prevention 178:17 193:10 261:15 262:2,8,16,20 264:2 272:9 294:6	prior 14:14 15:4 81:20	problematic 299:13	profiles 294:21
pregnant 37:12 64:4	preventive 24:7 178:15 221:9 258:7 261:18 270:1 294:7 297:3 298:1 299:6 301:6 301:16 340:18 386:15 397:21	priori 375:22 401:8	problems 55:20 60:10 80:21 259:19 364:5 372:7 385:3	program 55:14 72:12 75:7,9 218:7,13 290:2
preliminary 259:1	previous 115:19 292:19 379:15	priorities 322:7	procedure 45:17 49:4,9,15 121:4 121:14 133:14 161:4,14,19 162:14 207:3 318:12 336:1 337:9 339:3 353:15 356:2	programs 26:8 28:1 66:15 78:7 338:9
prelude 297:12	price 19:2 49:20,21 84:14,19 85:12 86:6 90:14,18 99:8 105:3,6,6,9 105:14,17 106:7 106:12 120:1,13 121:8 127:22 128:2,7,10 129:5 129:22 132:4,6,7 134:18 153:20 154:6 155:11	private 27:18 28:1 283:8	proceeding 259:14	progression 198:3
premium 51:2 74:3 74:4 87:7 263:8,8 263:9 264:20 270:8,13 272:3 281:11 284:13		privileges 359:2,5	process 5:16 9:1 22:4 56:18 57:17 67:10,14 68:7 96:22 112:10 130:5 140:11 197:19 236:2	project 3:6 6:7,8,11 6:21 17:1,1 19:6 21:1 235:3
premiums 71:20 196:1 279:16				projecting 278:8
prenatally 64:3				prolapse 47:10
prepared 225:6				promise 116:1 304:4
preparing 229:10				promote 305:5
prescribe 378:6				proper 311:13
prescribers 378:6				properly 215:4
prescribing 393:10				proportion 240:18
prescriptions 330:17				proposal 106:1 361:3 364:10
present 1:9 172:10 172:15 232:1 363:18 364:2				proposed 108:8
presentation 34:14 92:8 98:5 291:8				prostate 212:3
presentations 363:18				protect 384:17
presented 363:20 376:1,2				provide 26:7 108:11 177:6 201:12 224:6
preserve 16:12				

240:10 272:7 323:16 324:5 403:13 provided 234:10 253:15 340:2 provider 42:14 81:2 89:17 97:5 105:10 108:10 112:1 135:11,20 148:17,18 150:2 151:18 153:9 158:16 160:21 172:9 190:22 195:10 222:18 230:1 244:14 253:18 266:19 269:19 274:12 277:4,4 278:19,20 278:20,22 304:17 314:16 324:13 325:9 356:14,14 366:19 370:1 381:18 391:10 395:5,10,12 provider's 39:20 367:6 provider-centric 238:19 provider-focused 239:18 providers 57:15 70:7 74:15 90:7 136:4 148:12 149:1,7 158:13 218:20 220:14 230:5 234:2 276:21 299:14 326:14 350:5 351:11 354:14 361:19,19,21 364:18 370:2 371:21 372:4 375:15 377:6,8,12 377:22 381:15 383:7,12 385:20 395:16 396:21 403:13	provides 156:4 providing 15:9 230:22 323:14 provoking 33:17 proxy 127:11 prudent 314:10 psychiatrist 69:1 379:2 psychiatrists 68:18 378:5 psychological 304:22 psychologists 378:8 psychometrically 238:9 psychotic 379:1 PT 290:10 public 3:14 4:19 8:12 9:21 27:18 28:1 41:15 150:6 156:19 278:1 280:11,20 281:1 282:19 405:5 409:17 publish 229:7 382:15 published 138:2 publishing 316:10 pull 96:3 107:13 157:7 234:2 238:16 332:1 pulled 157:13 pulls 43:21 pump 151:21 358:17 purchase 24:3 108:12 263:11 273:9,11 280:15 288:13 purchased 151:21 151:21 329:11 purchasers 11:13 154:11 155:6 purchasing 226:13 273:3,5,5,14 298:6 pure 103:7	purple 184:10 366:1,8 370:21 371:6 379:11 388:10 purposes 122:2 138:18 234:17 236:9 push 90:13 157:12 put 18:12 22:15 31:6 34:1 40:2 55:14 66:19 89:6 89:21 99:7 136:21 161:3,6 217:7 225:7 234:22 242:8 270:11 309:16 328:21 355:15 367:16 375:11 puts 170:19 putting 89:16 126:10 218:21 325:3 326:19 <hr/> Q <hr/> quality 1:1,6,20 3:12 9:6,7 12:3 15:3,9,14 30:20 31:2 36:15 52:10 63:2 69:11 70:15 71:16 74:18 77:4 83:5 84:13 91:18 95:1 96:7 99:6,22 100:7 101:6,14 102:12,14,20 104:18 127:11 130:19,20 134:17 135:12 136:1,3,5 136:14,21 137:9 137:18,21 138:11 138:14,19 143:20 146:11 149:7 150:15,18 156:5 158:22,22 167:3 168:3 215:7 217:2 217:14 220:8,10 220:12,13,18,19 220:22 222:4,6,10	222:12 223:1,7 224:13,22 227:8 228:11 229:7 230:22 232:7,14 234:15,20 235:14 236:9,20 237:4,11 238:7 239:12,21 239:22 240:1 241:4 242:22 243:13,20 244:5,6 244:11,13 245:9 245:12,16 246:5,8 247:2,6,13 248:7 248:20 249:11 276:2 277:13 282:2,2,5,14 283:7,16,22 284:2 286:12,14 296:17 310:15,21 329:18 335:4,6,8,10 340:8 345:10 348:7 349:9 353:8 357:1,2,11 363:18 385:20 386:9 403:6 quantify 112:15 quantitative 233:6 quarter 214:14 quest 398:8 question 18:6,13 20:13 25:2,11 29:14 44:17 55:5 84:16 92:10 93:10 93:11 94:10,12,21 121:17 122:6 127:1,3,17,18 145:10 164:5 166:21 172:5,9 175:5 176:15 179:22 180:15 181:8 183:10 190:14 193:4 197:5 198:2 199:21 204:20,22 204:22 205:2,5 215:5 216:4,16 219:13 229:10	243:7,13,14,20 244:3,5 246:10 254:2,8 258:3,16 258:20 259:1 266:13 271:14 276:10 277:8,9 279:7 284:16 285:3,18 294:6 297:17 301:2 302:16,17 311:5 336:21 339:8 353:17,20 356:5 366:15 368:9 369:20 381:1,6,12 383:4 406:14 408:10 409:20,22 questioning 228:14 questions 16:15 17:20 21:12,16 33:12,14 48:13 70:4,9,14,20 92:2 92:6 95:6,10 111:12,17 115:17 115:21 119:20 143:15 144:13 145:13 146:2 147:5 156:21 164:8 165:6 167:5 176:3,4 198:21 214:12,22 215:2 215:18 219:14 241:14 245:5 246:5 252:18 258:21 275:22 277:6 284:9 294:4 312:8 353:6 355:15,22 368:8 380:17 410:4 queue 92:6 quick 16:22 176:14 177:17 224:19 250:9,17 254:7 349:11 361:11,12 369:19 406:13 408:14 quicker 7:9 quickly 6:16,17
---	---	---	--	---

56:10 95:9 150:9 157:9 245:7 247:21 257:11 309:9,20 346:10 363:5 364:13 380:5 quiet 203:9 quit 219:8 quite 10:9 67:3,14 84:3 107:11 141:20 167:12 243:16 317:17 320:18 374:20 411:7 quits 397:20	rate 161:10,11 230:15 278:21 rated 278:11 rates 75:2 225:5 350:20 354:13 408:18 rating 233:4 ration 326:7,8 re-enter 181:11 reach 269:7 reached 42:12,16 react 31:7 reacting 245:18 reacts 316:19 read 51:4 52:7 89:1 89:5 98:12 132:15 226:3 228:17 231:19 256:13 308:16 347:7 361:2 393:4 readily 224:6 277:22 340:13 375:6 reading 43:22 143:15 227:6 231:19 321:11 375:2,4 readmissions 6:2 reads 25:6 ready 5:5 45:15 144:5 301:10 397:19 reaffirm 181:19 real 9:15,15,16 29:21,21 32:7 40:7 50:21 62:8 82:3 90:20 177:11 177:12 218:3 258:11 313:17 324:6 357:2 387:13 399:15 406:6 real-life 175:1 real-world 161:5 realistic 79:9 realistically 303:8 reality 40:14 90:12	139:11 220:12 256:3 269:4 338:20 340:3 395:7 396:6 realize 63:8 181:16 342:10 realized 354:22 358:13 realizing 151:20 really 5:9 10:1 11:3 17:21 19:15,17,18 19:19 20:11,12,15 21:5,6,8,10 22:4 22:16,19 23:1,8,9 23:9,9 24:6,13,21 25:11,19 28:7 29:1 30:19,22 31:11 36:3,5 38:9 39:14 40:7,14 43:14,14,16,20 44:4,5,6,7,16,21 45:12 46:1,18,21 47:13 50:14 51:13 52:1,11,15,18,20 53:18 54:15,19,20 56:10 57:4 58:6 61:2 62:11 65:6 66:8,14 67:4,6,22 68:5 71:1,13 73:4 74:7 78:1,2,7,7 79:3,7 83:17,18 84:15,19 85:10,15 85:20 86:13 88:10 88:12,20 89:1,12 90:9,9,12,16 91:2 91:11 95:9,15 98:17 100:21 103:15 104:1,21 106:2,5,10 107:15 108:14,22 110:9 113:4,12 116:21 117:19,20 119:9 119:22 120:6,17 120:22,22 121:10 122:11 124:1 129:9 130:14,21 130:22 131:17	133:16 134:5,8,12 134:17 135:4,21 136:9 141:11,13 141:19 142:14 143:16 144:10 145:12,17 147:3 147:14,16 148:20 149:5,18 150:8 152:8 155:9,19 156:14 157:5,9 158:6 162:4,19,20 165:3,16 167:8,22 168:13 170:5 171:10 173:19,21 174:8,17 175:14 176:3 177:10,10 177:15 179:10 180:17 186:1 189:10 191:18 193:5 198:16 201:7,22 204:17 205:8,13,20 207:4 207:5 209:1,16,19 210:22 213:10 214:4,6,6,10 217:14 223:10,13 224:12 225:1,5 228:6 230:17,20 231:11 233:3 234:9 237:2,4,8 237:10 238:12 240:12,13 241:8 242:15 243:3,10 243:10 245:7,11 251:7,9,12 252:6 252:8,22 254:15 254:21 256:10 260:9 262:6 265:15 268:5,13 270:2,3 271:3,13 272:2,6 274:19 275:6 278:3,6,10 279:5,18,20 280:4 280:6 281:9,18 284:4 289:19,19 290:5 295:2 298:1 298:4,8,13,14	299:13 300:3 301:16 305:18,19 306:18 308:11 310:12,22 312:1 313:8 314:2,3,16 315:15 316:13 318:7 320:3,3 321:13 324:2 325:21 327:11 329:1,6 331:8 332:6,9 333:5 334:16,17,17,20 336:18 338:4 341:3,3 342:6 343:4 346:10 347:13 349:1 350:1,6,7 351:9,9 356:11,21 357:22 358:22,22 371:5 375:9 380:15,15 381:6 383:9,10,16 385:19 386:9,13 386:18 387:6,7,8 387:9,22 389:22 390:7,7,11 391:9 392:13 393:8,17 393:20 394:2 396:9 399:12,16 399:18 400:5,5,6 400:15 401:2,4,21 402:11,19 404:9 404:13 405:16 realm 213:2 reason 186:8 189:4 307:22 reasonability 205:14 reasons 127:2 184:8 225:21 256:10 reassurance 217:14 recall 337:16 recap 4:16 32:2 receive 58:19 130:7 received 102:20 receiver 93:6,7 94:5
--	---	---	--	--

receiving 110:19 124:10	refilled 51:11	relates 31:1 405:10	Reports 214:19	responses 220:3
receptor 25:16 26:18 116:14	refined 149:20	relating 131:6 386:11	represent 8:1 11:13 23:2	responsibility 27:17 84:5 202:22 397:16
receptors 27:7	reflect 172:18,18 177:15 398:20	relationship 3:11 80:19 81:1 83:3 218:11,18 221:16 221:17 227:2 319:4 324:15,19 337:14	representatives 36:9,9	responsible 155:2 317:9
recess 169:5	reflected 145:12 194:9	relationships 143:20 147:11 319:15 361:20 379:22	represented 9:16	rest 42:6 73:12 74:5 321:21
recognition 248:12 314:9	reflecting 360:6	relatively 13:11 47:17 185:7 226:13 267:7 282:12 340:8 341:18	representing 15:11	restrict 217:1 314:17
recognize 28:9 137:12 173:2 175:1 197:11 235:1 246:15 249:14 321:12 339:11	reflections 402:4,6 405:6	released 174:13	reputable 348:13	restricted 315:15
recognized 373:11	reflective 173:5 210:18	relevant 134:8 179:9 363:12	reputation 60:19	restrictions 144:22
recognizing 20:7 34:6 170:9 230:9 306:12 327:22	refocus 252:6	reliable 228:21 278:16	require 118:12 218:7 405:3	restrooms 32:18
recommend 344:8	refresh 179:9	relied 66:8	required 18:22 41:18 340:17	restructure 254:19
recommendation 370:5	refreshed 179:5	rely 16:11	requirements 123:15	results 41:9 340:9 342:16 406:3
recommendations 177:2 345:12 346:18 376:18	refreshing 135:2	relying 286:16	research 8:7 12:17 12:18,20 13:7 14:7 51:6 57:19 139:21 142:7 303:5 362:10	resume 7:15 168:9 168:10
recommended 218:13,13	refreshment 188:5	remaining 361:10	reservations 250:19	retail 331:5,6
reconvene 251:6 411:14	regarding 122:6 205:7	remarkable 88:10	resonate 178:10	retention 75:12 181:15
record 91:7,8 251:3 251:4 393:3,6	regardless 39:3 124:7 128:6 328:10 368:2 369:14	remember 23:13 23:16 37:13 39:6 78:4 137:8 138:3 201:16 308:16	resonated 402:1	rethink 400:5,8
recorded 268:11	Region 145:20	remembered 340:14	resonates 102:4 195:9	retirees 163:21 164:1
recover 165:19	regular 51:15 81:10 166:15 279:17	remembering 366:7	resource 3:19 6:1 14:19 17:16 27:22 99:8 101:19 105:5 105:15,15 236:4 326:4 409:1	retrospective 311:7 354:5
recovery 214:1	regulations 314:15	remind 366:12	resources 156:10 325:22 326:9 328:2 331:15,17 339:17 382:11 390:6	return 319:7 377:15
red 94:6	rehab 184:13 185:9 374:13,15 383:15 387:4	reminded 404:22 411:4	respect 118:2	revenues 209:19
redefining 399:19	reimbursed 354:12	remiss 214:16	respective 206:16	review 223:15,17 226:9 227:1 239:15
reduce 259:18 304:18 393:6	reinfection 225:5	rendered 113:15	respects 379:9	reviewer 226:10 228:2
reduced 86:8	reinforced 402:12	rendition 190:17	respond 257:11 294:9 390:18 395:2	reviewing 228:19
refer 112:7 123:21 124:10	reiterate 34:18 104:12 142:2	repeat 7:15 403:1	responding 160:18	reviews 223:17 224:5,6,14 226:19 226:20 228:15,22 234:3 294:14,16
referral 218:7 368:6,7 370:6 372:5	relate 95:14 98:8 143:18 190:9 193:17 356:12 357:19 362:8	replacement 47:11 154:21 161:6 209:1 378:21	response 131:6 373:8,9 408:15	Ribbon 300:2
referred 80:13 330:21 373:12	related 8:7 11:21 52:10 95:7 116:1 199:3 203:3 211:20,22 242:6 288:17 305:10 353:6 363:7 407:6	report 32:10 406:2		rice 53:16
referring 113:4 366:22 368:17				rich 116:11 138:17 167:16 169:1 293:2 294:2
				richness 167:7
				riders 381:7
				riding 322:6

right 23:16 26:10 32:20 43:13 55:1 62:8 64:8 70:8,9 78:18 93:19 94:18 95:11 103:19 115:13 118:2 121:21 123:19 131:9 135:7 137:1 152:4 155:18 156:14 180:8 187:3,4 193:20 206:11 207:6 213:11,16 215:17 218:18 230:13 231:3 234:6 235:20 237:17,20 238:2 241:7 249:9 250:3,15 255:12 255:20 260:12 269:17,20 270:13 274:17 276:18 278:15 288:1 292:16 296:4 300:11,18 309:14 309:21 310:6 311:8,18 319:1,18 322:19 329:12 333:8 348:3 351:16 369:4,5,18 370:22 372:8,15 377:2 388:12 390:20 394:19 396:2 398:2,13 405:12,13 407:4 410:9,17,19 411:2 411:9	175:12 178:11 180:3,5,7,16,19 180:21,22 181:12 182:3,8,10,19 183:10 184:7,20 187:20 192:22,22 195:3 198:2 207:12 211:15,16 211:18,21 212:7 250:5 255:19 256:6,7,11,14 259:10,13,18 261:3,6,17 262:10 268:4,13 290:22 291:19 292:4 293:6,18 298:2,3 298:8,14,18 300:17 304:18 305:22 327:17 335:17 346:4 349:14 350:8,10 357:21 358:9,21 360:1 380:10 390:8	roll-upable 206:7 rolls 314:11 385:12 Ron 14:2 26:5 58:10 60:3 80:12 192:7 193:20 206:2 262:21 263:1 264:20 270:7 284:11 308:14 377:3 379:6 RONALD 1:21 room 1:6 6:5 14:10 23:11 25:15 30:2 43:11,18 44:16 45:2,10,17 46:17 49:12 61:6 82:18 107:12,22 108:2 125:7 129:9 155:21 159:3 160:8 169:3 178:9 229:21 232:8 281:5 290:10 300:14 313:2 314:1 316:11 317:8 318:6,17,20 319:12,16,17,22 320:1 324:4 328:14,22 330:21 331:8 343:20 410:2 rooms 79:7 312:10 root 37:17 54:9 76:22 77:19 rooted 18:7 roughly 90:15 190:9 253:2 rounds 79:5 routine 257:19 299:18 rude 39:19 rules 48:15 249:7 run 13:16 66:2 72:13,13 116:8 332:6 367:22 running 156:21 245:1 rural 351:16,22	358:1,1,2,12 Ryan 72:11 73:20 75:6,8 76:6 87:2 <hr/> S <hr/> s 237:12 S-E-S-S-I-O-N 170:1 safer 393:12 safety 9:6 15:14 63:3 69:11 101:9 234:4 335:9 sake 28:1 79:22 Santa 214:18 sat 45:19 77:21 232:9 satisfied 79:11 SAUNDERS 2:16 save 155:11 397:8 saved 50:4 57:5 saving 62:17 289:7 391:3 savings 50:1 83:7 155:5 162:8 344:14 savvy 57:21 145:4 145:4 146:6 saw 158:13 194:19 195:7 256:14 saying 27:3 37:2 49:13 62:6 123:9 133:11 135:17 165:21 223:20 224:9 225:11 226:7 227:20 228:8 234:21 237:10,12 245:19 255:15 257:8 262:14 266:8 269:20 271:6 295:17 300:8 323:19 324:10 335:14 355:13 365:22 371:10 388:21 says 43:9 50:1 85:19 122:13	154:17 220:11 256:6 275:3 321:11 349:3 385:10 scale 321:12 scan 40:16,21 41:2 41:2 42:1,4 44:3 165:14 166:4 312:16 318:4 337:21 339:21 scans 41:1 318:9 338:20 340:18 384:4 scarce 326:4,8 scared 43:21 54:12 54:17 129:6,9 scary 74:22 178:20 309:2 342:6 scenario 177:12,12 217:10 296:1 355:20 schedule 73:8 scheduled 306:11 306:15 307:3,20 308:2 scheduling 307:1 schema 273:13 schizophrenia 372:11 school 41:15 49:1 53:9 68:22 130:3 230:13 305:15 357:7 360:9 386:8 schools 361:4 science 303:22 scientific 350:20 scope 29:10 83:18 105:18 189:18 234:13 235:3,10 252:3 305:11 325:15 screen 262:7 screening 253:19 255:9 262:3,3 264:2 265:13 296:15 299:22 315:19 397:21
--	---	--	--	--

screenings 257:19 261:18 274:3	330:16,20 343:5,8 347:19 350:19	selection 274:12 332:8,8 335:2	304:13 318:19 335:9 373:10,20	seven 63:17 67:21 122:19 123:2
screens 270:2	356:14 375:2,4	353:2 354:3,3	395:14	253:14 316:20
screws 312:21	378:7 384:20	364:17 381:15	seriousness 304:18	severe 151:16
search 77:8,11 129:22 130:1	385:22 389:16,18	self 376:4 396:4	serve 8:3 361:21	377:6
303:11	391:16 394:10,18	self-actualized 322:2	served 10:11 11:19	severity 304:12
seats 91:21	395:21,22 397:5	self-efficacious 397:9	serves 63:1	371:13 374:2
second 38:2 64:9 65:22 77:11	406:2 408:5,8,15	self-efficacy 305:6 320:20,22 324:17	service 10:11 23:15 101:11,20 102:2	shaded 182:10
130:13 131:6,8	408:19 409:6	self-manage 201:21	102:15 105:13	shame 362:18
140:20 202:1	seeing 56:20,21 60:18 97:4 227:22	self-management 181:10 396:11	106:20 108:11,12	share 29:17 33:6,21
205:7 269:3 285:3	242:10 264:3	self-management 181:10 396:11	108:13 112:2	34:2 36:10,18
309:19 381:14	272:6 279:13	selves 69:18 70:13	120:3 146:10	69:10 155:4 182:1
386:20 401:7	287:12 384:21,22	send 93:3 214:18	161:21 163:22	188:8 213:3
secondary 178:16	384:22 408:1	247:19 317:7	222:20	shared 213:2,12
193:10 262:8	seek 84:18 266:15	394:7,13	services 12:17 24:2	241:5
391:20	303:2 329:22	sending 353:7,13	24:5,18 25:21	sharing 22:21
Secondly 263:18	388:2 390:12	senior 5:22 6:21	55:21 72:19 78:21	35:21 88:9 108:21
seconds 158:14	seeking 18:10 28:12,17 199:9	7:2 9:5 10:22	80:7 81:18 97:6	shelf 25:12 118:9
section 37:19 95:8	297:22 303:1	sense 21:14 92:4	113:15 120:19	shield 71:4
97:10 168:11	312:6 335:21	102:11 114:5	121:12 163:2	shift 17:10 309:20
172:12 196:22	367:18	186:2 190:6,21	178:15 259:18	shifts 309:13
199:14 214:12	seen 127:8 136:15	191:1 221:1	264:2 265:13,14	shingle 348:11
262:19 361:13	154:3 190:19	253:20 281:12	265:18,21 266:2,3	Shippy 1:17 11:6,7
385:17	221:18 227:18	311:3 313:7	266:9 299:6	186:22
sector 27:19 28:1,2	263:22 287:4	318:18 321:11	SES 203:19	shock 63:22
see 9:15 18:11	319:18 337:1	350:8	session 20:3 32:3	shoots 394:19
26:17 28:22 31:21	343:9 364:5 384:3	sensitive 213:5	91:10 106:4 170:4	shop 41:3 86:13
32:6,22 48:16	386:18	217:12 339:1	193:22 251:7	133:15 148:15
49:19 52:9 57:3,5	sees 152:17 153:9,9	sent 59:13 166:13	405:9	149:2 337:2
57:12 60:20 64:14	237:16 386:5	sentiment 23:2	sessions 10:13	338:22 342:1
65:12 90:15 92:14	391:17	sentiments 92:4	32:11 251:8	344:9 351:10
92:14 100:19	segment 167:16	221:15	89:2 91:12 116:11	shopping 154:19
102:8 114:19	187:1,5 191:9	separate 53:6	137:19 144:19	154:19,20 166:3
130:7 145:12	segue 70:20 121:16	96:10 100:1,9	176:3,3 194:4	337:8 374:11
149:3 158:8 159:6	select 172:9 215:15	101:1 105:4 130:8	196:4 210:15	short 101:2 245:1
161:7 177:10	215:15 265:1	134:15 158:12	234:16 244:18	350:14
191:2 195:18	selected 265:10	208:2 242:7	258:20 275:22	shortage 372:3
196:2 202:8,14	selecting 171:7	245:19,21 368:15	325:4 392:14	377:6 396:15
219:11 227:15	253:16,17,18	370:16 394:17	sets 147:16	shorter 345:21
233:9 234:3,3	254:9 265:2	separating 118:19	setting 176:11	shot 114:3 165:15
255:8,22 260:21	269:15 273:2,5	series 21:11 28:19	222:1 367:19	166:3,5 397:19
264:1,4 267:9,17	284:11 336:6	355:14	368:5,13 369:15	shoulds 256:1
270:6 290:3,7	354:2 366:19,20	serious 68:21 193:6	372:6	show 45:1 46:15
293:20 305:9	391:14		settings 109:1	92:19,19,22 186:9
315:4 317:2			186:20 189:9	186:17 216:9
				250:11,20 262:7
				351:13

showed 147:9	similar 59:17	244:13 331:11	270:7 295:16,19	99:19 103:11,12
shower 37:16	126:19 162:7	354:7 374:8 379:9	298:22 352:21	105:4 112:12,21
showing 148:19	353:22 354:6	379:10 380:14	354:16	113:3,6,14 116:13
173:18	similarly 149:6	381:11 388:19	softball 53:9	116:18 117:2
shrinks 129:6	simple 19:7,7 132:4	389:16	solely 215:14 216:7	132:3 133:10
shunt 64:15 317:1	373:4 379:9	situations 48:9	237:7	137:12 144:13
317:18	simpler 131:18	120:5 142:4	solid 61:19	145:19 148:14
shunted 316:18	simplicity 79:22	193:11 267:11	solidify 62:2	153:18,19 159:14
siblings 23:18	132:11	six 37:21,22 38:5	solution 1:14 54:18	165:15 171:4,10
sick 41:13 117:14	simplification	47:19 53:5 101:14	solved 364:4	171:19,20 172:14
124:8 206:10	133:6	165:18 316:21	solving 246:3	177:2,3 188:11,20
207:5 267:13	simply 286:15	377:20 384:22	somebody 25:6	189:10,11 190:4,6
326:13 358:6,6	364:2	410:8	50:10 51:10 163:7	197:2 203:4
376:9	Singer 1:19 12:15	six-month 68:7	243:6 260:17	206:19 208:1,2,3
sicker 374:7	12:16 119:21	skewing 292:3	296:5 322:1 326:1	214:19 220:14
side 39:18 135:11	160:17 216:14	skill 360:16	349:4 362:5	228:19 234:21
135:20 155:7,22	265:9 287:2 288:1	skilled 348:1	378:11	242:20,22 243:3
232:13 239:20	289:8,12 329:21	365:17	somewhat 35:22	243:18 246:7
275:20 282:2,2,6	372:18 383:16	skills 126:13 360:9	236:15 238:4	247:2 248:20
287:20 357:1	408:14	361:15	240:4	249:1 253:14,16
377:8 380:1	single 122:19 123:3	slide 20:22 92:15	son 37:12 63:16	254:11 270:10
388:12	295:22 330:12	105:22 115:17	84:21 85:6 86:2	272:9 275:6 285:2
sides 69:8	337:17 377:12	296:9	141:5 151:15	296:21 301:1,1
SIEMON 131:5,10	378:16	slight 203:10	152:1 173:21	303:6 335:15,20
206:18 208:16	Siroc 250:14 410:7	slightly 172:2	214:6 388:8	349:9 353:21
245:18 257:10	sister 55:12 65:14	194:7 302:17	390:15,19 391:17	354:10 364:13,14
290:17	65:18 80:19,19	small 142:4,5 322:1	392:8	364:15,19 366:16
Sierzenski 1:18	81:8 257:20	smaller 183:14	son's 316:17	381:5,9 390:8
11:15,16 151:10	274:22	smartly 178:3	soon 212:9 323:13	398:3,22 399:2,5
190:14 209:14	sister's 156:11	smear 333:20	sophisticated 289:9	401:8 407:1,6
306:3 307:5 314:7	sisters 85:9 338:14	smoking 397:20	290:20 292:12	sorts 60:22 116:9
347:20 349:2,6	sit 25:12 37:5 108:6	SNAP 21:14	339:16	193:19 196:1
390:17	143:3 167:7	soccer 23:22 141:6	sophistication	356:16 368:14
sign 39:2 50:16	229:13 235:18	141:7 173:22	344:22	380:17
192:20 263:16	403:4	174:1,7	sorry 94:21 111:19	sought 126:16
signal 28:19 237:4	site 233:19	social 9:22 28:14	123:18 187:6	sound 160:10
342:15	sites 25:16 26:18	33:3 66:16 83:19	216:14 273:19	398:21
significant 36:1	27:8 116:14 226:8	192:22 303:21	326:22 347:19	sounded 264:19
59:16 82:7 372:14	sits 118:9	325:4 378:8	384:14 410:15	sounds 111:8
391:15 392:6	sitting 7:22 29:22	society 43:2 223:21	sort 17:2 21:12,13	179:20 249:20
significantly 65:8	39:6,7 49:11	socioeconomic	25:7 27:15 28:22	286:8,17 332:3
signs 196:3	151:11 176:21	200:15 203:19	29:11 30:7 34:13	363:1
signups 163:19	227:19 232:7	209:15 210:10	34:22 35:3 39:10	source 28:11 44:18
silent 153:7	242:7 271:18	321:4	59:18 63:8,13	46:20 154:4 156:9
siloed 233:3 235:2	situation 53:20	Soegaard 1:20	64:18 68:13 69:7	156:14 278:16
silos 234:9 242:1,2	62:5 83:4 117:3,8	11:11,12 180:15	69:9 71:14 74:6,8	303:9 350:21
silver 287:9,13	151:12 185:18	181:2,5 221:4	74:9 95:13 96:16	sourced 28:14

sources 28:18 150:13 154:1 239:11 278:1	specified 102:11 specify 194:20 200:4 335:7,10	6:17 16:6,7 31:5 35:14 145:9 208:18 214:20	started 5:5,12,20 8:16 16:22 17:13 45:11 53:13 64:8	stent 38:6 step 24:13,22 28:5
sourcing 151:5 347:10 378:20	spectrum 83:16 144:5 204:6 260:6	327:6 337:14 377:13	68:4 72:5 95:10 95:14 111:17 116:5 168:10	29:1 96:22 132:22 133:2 155:21 168:6 187:7 192:2
space 101:18 237:1	321:18	stage 185:19 200:4 386:12,19,20	177:5 198:12 200:7 243:8 287:4	254:1 271:8 344:12
span 183:17	speed 325:19	stages 168:17 175:9 199:21 252:9	320:10 347:3 401:16 402:17	stepped 81:12 stepping 191:5
speak 8:20,22,22 16:4 30:11 34:12	spend 45:15 47:19 61:8 73:9,19	stake 40:3 257:1 308:4,12	starter 302:5 starters 372:4	steps 23:3 32:13 99:3 332:19
69:22 70:6 96:11 118:1,9,10 119:22	107:7 125:2 139:3 280:9 287:15	stakeholder 12:11 102:18 104:16	starting 97:11 101:6 111:13	steward 326:5 stewardship
133:10 134:9 139:4,7,15 157:14	310:10 394:8 401:11,12	242:21	188:3 229:16 251:14 255:2	325:22
265:18 299:1 382:2 389:3	spend-down 82:22 83:4	stakeholder's 18:1 stakeholders	274:8 299:2 306:10 405:15	stick 49:10 335:11
speaking 82:6 106:18 134:6	spending 30:17 61:20 102:2 104:4	stamp 236:7 stand 53:8 268:6	starts 83:1 99:16 371:4,6	sticker 105:6,7,9
247:10 369:2	104:5 264:21 284:14 285:8	322:13	state 21:3 71:12 106:13 137:22	stifle 111:9
speaks 188:8 261:10	404:5	standard 109:19 132:12	138:2,12 221:2 361:5	stimulating 215:2
special 15:17 357:10 388:1	spent 60:7 66:4 102:15 104:6	standardized 133:5 standards 159:1	statement 409:10 states 10:10 106:13	stomach 53:10 56:13 318:13
specialist 229:14 290:9 339:3 341:4	125:14 158:4 232:11,12 364:3	282:16 283:17 standing 99:19	315:20 351:22 361:16 394:17	stomachaches 54:8
341:8 345:11 373:17 391:13	386:22	110:10	Stati 251:20 station 23:20	stone 191:5 244:18
394:8 395:16,21 397:14,15 404:1	sphere 26:20 spillover 263:20	standpoint 191:2,3 314:20 315:13	stats 349:13 status 198:6 203:19	stop 53:19 75:9
specialists 267:9 362:4 385:22	282:6 282:6	329:10 367:21	251:18,19 321:4,5 328:1 337:14	stops 188:21
389:6	spina 63:17 64:3,10 68:10,11 69:6	star 160:3 start 7:17 20:11,12	Statuses 251:20 stay 41:19 161:10	stories 9:16 69:9 86:16 88:9 95:19
specialize 9:22 specialized 217:16	388:9 spinal 88:2 145:1	30:10 33:17 36:20 37:1 52:18 53:21	171:11 230:1 365:6 368:12	108:1 150:19 347:7
specialty 220:10 373:13	spirit 16:14 split 289:3	71:5 91:3 93:2 124:13 138:14	387:2 staying 38:15,17	story 233:6 284:21
specific 25:7 94:14 101:21 106:11	spoke 110:4 179:1 213:20 262:5	149:17 156:8 157:11 170:5	61:10,11,12,13,14 61:15 62:13,15	403:2 405:17
109:17 144:19 200:1 208:17	spoken 144:4 sports 60:8 81:9	184:9 195:13 197:18 225:4	178:13 191:13 250:7 253:22	straight 53:9 81:4,7
236:11 277:17 384:15	spot 34:2 367:17 spotty 389:17	237:7 242:16 250:4 253:11	261:9,15 262:15 stays 355:9	straightforward
specifically 36:8 124:16 145:3	spouse 203:12 sprained 332:22,22	254:5 283:20 297:6 299:16	Steering 236:3	131:21
154:16 210:3 236:6 238:5 259:6	333:1,4 spread 64:19	303:12 326:6 363:2 374:5		strange 63:14
278:4 316:8	spring 40:18 spurred 149:5	382:15 406:10		Strategic 7:1
specificity 294:17	staff 2:8 3:3 5:18			strategies 305:2
				Strategy 13:7
				streamed 33:20
				streamline 132:10 133:3 233:10
				street 1:7 166:16 180:6 410:7,16
				strep 307:2
				stress 42:8 217:10
				stressed 144:11
				stretch 65:7
				stretches 202:3

strict 103:11	submitting 282:21	supposed 78:19	355:3 356:1	157:11,17,21
strictly 198:14	subpopulation	190:16 201:20	374:16	161:17 199:5
206:21	262:10	247:3 324:20	surgical 344:17	252:10 269:8
stroke 211:18	subsequently 47:10	325:9 369:11	surprise 63:20	274:21 275:12
strokes 189:15	subsidiary 13:1	sure 14:7 18:20	surprised 84:4	294:15 307:17
strong 362:11	subspecialist	27:9 51:1,12 53:1	211:16	320:13,16 321:13
struck 67:7 107:18	391:13	55:7 56:18 76:13	surrounding 52:16	326:3 340:12
structural 222:16	substance 75:3	80:14 84:17 97:15	surrounds 275:7	348:1 354:21
222:19 393:18,22	373:2	98:1 103:3 119:21	survey 393:21	360:14 362:4,7,12
394:1	substantial 363:21	132:21 133:9	surveys 222:22	362:18,20 377:5
structure 22:8,11	suburbs 358:10	134:19 142:7	survivor 83:2	379:4,19 382:19
24:11 193:22	succeed 14:8	159:20 160:17	susceptibility	387:6 396:20
248:18 375:19	successful 154:14	175:6 177:19	304:10	399:8 404:19
405:9	159:5	180:9 186:8	swayed 300:1	406:15
structured 29:11	sudden 309:13	187:13 194:9	switch 225:22	systemically 226:1
372:21	343:5	201:15 205:5,18	322:5 341:5	systems 73:20
struggle 131:17	suddenly 123:6	206:10 207:20	switched 341:9	103:18 367:12
164:2,3 188:19	125:6 397:2	209:6 216:5	switching 217:21	392:19 405:1
324:21	sufficient 285:2,21	217:22 220:2	341:11	
struggled 260:8	285:21,22 292:7	224:20 226:16	symbols 195:16	T
struggling 165:11	sugar 260:18,20	229:5 246:3	196:7	ta 12:16
166:2 242:11	suggest 156:18	250:18 264:17	symptom 302:21	table 3:1 4:1 7:13
243:17	273:4	269:4 297:19	303:10 317:1	13:9 14:16 18:5
stuck 52:21 318:2	suggested 355:14	298:4 302:9 324:8	318:18	26:19 27:16 29:22
students 290:1	suggesting 108:19	330:10 332:4	symptom-driven	34:11 36:2,6,7
studies 119:3	150:20	338:14 343:6	307:16	37:8 74:9 89:17
363:17 404:10	suggestion 176:22	347:7 352:18	symptoms 43:12	97:20 114:20
405:15	suicide 55:15	360:6 366:7 385:7	85:14 211:20	115:9 156:1 240:6
study 177:9	summarize 191:7	397:19	233:21 234:7	301:14
stuff 71:1 115:7	398:18 400:19	surgeon 219:1	276:13,13,18	tables 125:3 235:18
132:12 139:9	summarizing	333:3 344:7,8	307:10 376:22	tablet 408:19
190:20 225:6	402:10	355:1 357:4	386:17	taboo 63:8
255:14 283:9,10	summary 201:1	375:13 378:21	syndrome 38:2	tackle 235:4,5
283:11 290:12	summer 164:17	surgeons 138:4	217:17 224:10	tag 115:18 123:19
305:14 323:12	Sunday 42:22,22	344:4,12	341:7,9	297:7 343:5
327:6 357:5	43:4 331:20	surgeries 10:7	syphilis 230:16	347:19
359:21	super 305:15	47:21 48:2 64:18	system 1:9 10:9	tail 146:17
stupid 45:4,6	supplies 112:9	355:8	11:17 14:10 18:20	tailing 355:13
334:11	support 3:19 56:3	surgery 37:20 39:1	30:3 36:14 37:4	tailor 286:10
style 34:15	103:18 276:7	47:4 81:6,13,15	41:20,22 43:5,7	take 7:5 19:13
sub-population	379:4 391:20,20	88:2 90:15 112:16	43:20 44:19 53:12	22:18 24:22 28:20
184:20	392:20 393:11	138:1 158:16	54:16 59:3 68:15	31:3,8 32:13
sub-populations	405:22	165:14,17,18	69:20 70:6 71:9	39:12 49:11 78:12
183:15	supporting 6:22	166:4 212:6,9	73:5 95:19 96:2	90:22 98:22 99:3
subject 8:8	supportive 72:19	213:15 313:21	117:14,17,20	105:2 107:5
submits 57:2	supports 13:15	337:19 341:6	137:12,13 142:9	111:21 137:19
submitted 57:11	324:12	345:17,18 350:17	151:22 155:11	149:13 156:9

165:18 179:7	116:14 128:14	207:14 216:4	135:3 178:9,9	399:19 401:5
200:9 206:8 207:6	132:5 133:18,19	223:20 240:21	208:20 230:14	terrible 45:3
208:1 210:8 214:1	139:19 144:18	245:1 253:9	233:21 268:7	122:11 369:13
216:8 238:11	171:6 210:1,11	264:15 284:7	278:22 281:14	Terrific 267:19
245:4,5 250:17	224:8,9,10 225:12	294:9 326:15	288:11 309:1,10	279:2
256:17 265:9,20	242:19 260:4	334:22 353:19	322:1 330:11	terrified 88:22
266:10 267:13,15	272:21 294:13	361:6 367:3	343:17 349:20	terrifying 211:19
269:12 277:7,10	296:10,13 312:4	372:18 402:9	362:15 395:5	territory 237:6
282:9 294:6 302:3	335:14,17 381:4	405:14 406:14	telling 73:7 75:18	tertiary 67:15
312:1 318:1	talking 10:3 30:18	task 90:10 194:3	80:22 116:5	152:17 178:17
328:20,22 344:12	35:14 61:8 71:5	Taylor 1:14 9:19	317:10	358:2,3
347:5 348:19	73:13 75:4 83:14	52:22 53:2 55:5	tells 140:8 346:5	test 42:16 46:16
360:9 361:7,9	91:3 95:17 99:14	56:10 150:4 151:8	tempers 309:8	48:17,18 53:4
376:18 397:9	100:12 111:21,22	153:13 201:8	ten 49:9 83:6 90:22	85:18 86:6 89:20
400:14 405:12	113:12 119:14	224:7 232:20	123:4 162:12,17	196:7 299:17
takeaway 400:12	120:3,17 121:22	262:22 267:3	217:6 247:18	tested 84:21 85:1,2
taken 60:17 61:3	125:18 142:2	341:14 346:8	380:20	85:3,4,10,11,20
81:18 82:20	148:20 182:9	404:21 405:2	tend 330:2	86:2 179:16
162:19 169:5	200:3 201:8 205:4	411:6	tendency 330:6	testing 223:4
194:8 267:11	206:21 210:18	Taylor's 167:21	tends 383:17,22	tests 298:7 386:15
308:8 334:14	222:8 224:7	teach 43:8 157:16	385:9	Texas 1:21
taker 393:2	232:14 233:2	163:8	tent 30:12 34:11	text 319:10 329:5
takes 49:9 132:14	237:1 251:8 259:6	teacher 41:16	tents 111:8	391:22
229:17	262:19 263:21	329:13	TEP 11:19	thank 5:4 7:6 12:7
talk 10:1 17:14	270:1,7 276:1	teachers 329:14	term 62:21 63:7,9	15:20 16:19 46:10
39:16,22 40:1	277:11 279:3	teaches 360:13	98:17 103:14	52:14 55:4 58:4
49:18 50:14 79:7	310:11 318:16	team 119:17	113:2 170:22	71:3 84:7 86:15
88:6 91:14 99:4	323:10 327:5	178:10 386:3,4,4	194:7,14 250:6	87:20 88:9 89:14
101:4 106:11	332:13 338:12,18	389:18 396:6	306:16 311:13	90:21 93:7,20
108:18 112:12	340:15 341:1	team-based 396:16	384:14	101:4 107:12
116:10 118:7	350:11 351:6	teams 393:16	terminology 91:13	115:14 118:18
120:13 132:1	353:12,16 354:7	tearing 153:2	terms 14:17 28:2	122:5 125:16
139:14 142:12	366:10,22 367:12	tease 199:18 209:8	91:14 96:7 97:14	128:19 142:18
145:3,7,7,18	369:8 372:10	355:16	100:6 101:8,16,17	147:20 150:3
157:10 165:22	373:4,5 376:4	teased 109:2	102:13 103:8,11	153:11 155:13,13
176:19 179:18	386:21	teaser 88:1	103:15 105:4	159:12 167:14
199:22 201:17	talks 304:8	technical 15:10	113:13 115:6	169:3 177:22
202:17 207:15	tan 344:18	109:19	117:21 128:2	179:13 214:18
222:14 234:14,15	tangential 82:2	technologies 10:1	131:15 132:19	250:22 251:20
241:4,9 242:14	tangible 304:22	technology 146:3	135:17 136:20	267:20 296:6
253:1 263:3 276:5	target 116:13 369:4	396:17	161:5 171:14	314:4 323:2 411:6
301:4 306:8	Taroon 2:11 3:3,8	teed 20:3	175:16 210:20	411:8,9,11
315:16 325:8	3:12,17,20 4:4,7	teen 303:14	214:21 215:1	thanks 9:2 27:13
337:18 384:19	4:12,17 5:21 7:7,7	teenager 141:14	238:3,5,12 248:19	91:4 97:9 129:18
403:19,22 404:1	25:3 34:8 35:22	telehealth 10:18	252:10 296:17	134:20 143:13
talked 38:9 55:9	111:20 114:13	telephone 160:3	302:16,18 326:18	151:8 164:6 169:2
66:17 70:21 110:3	198:16 199:21	tell 8:16 77:20	366:2 381:17	270:5

theirs 204:13	126:4 132:11	35:17,21 39:14,15	144:11,15 145:14	247:3,9,22 248:11
thematic 35:16	138:15 141:18	43:15,16 46:2	147:9,19 148:22	248:15 251:9,15
thematically 35:9	143:7 146:11	52:8,15 54:14	149:6,21 152:12	252:1,3,6,7,20
theme 387:17	153:16 154:6,7,18	56:4,6,19 57:14	152:14 153:7	254:16,17,18,18
401:19 402:1	157:18,19 161:12	57:17,22 58:6,15	154:9,13 156:2,7	254:22 256:5,7,16
themes 210:12	161:16 168:16,22	61:22 62:16 63:10	156:15 158:2	256:17 257:11
211:4 398:20	175:21 181:18	69:19,22 70:4,20	159:5 164:4,20	260:7 261:11,13
402:4	183:20 184:16	70:22 71:4 72:14	165:6,9 166:18,20	261:14 262:13,22
therapeutics 24:8	188:9,19 193:2	73:1,19 74:6,7,13	167:9,15 168:5,22	263:4,18 266:7
therapies 378:9	194:17 196:2	74:20 75:9,11,14	176:5 177:7,13	267:4,7,16,21
therapist 81:3,3	200:1 201:14	75:16,17,22 78:3	179:15 180:11	268:20 269:4,22
156:13	203:13 205:9	78:18,20 79:2,10	183:11,11,19	270:8 271:9,13
therapy 81:6 212:5	207:15 210:11,21	79:11,13,18 80:12	184:17 185:16	272:1,3,11,21
212:6 365:18	211:7 213:21	80:18 82:16 83:11	188:4,19,22 189:1	274:1,8,18 275:6
373:9 385:8	222:7,16 224:15	83:13,20,21 84:3	192:12 193:16	275:7,11,13
thing 16:8 21:8	225:2 228:22	84:10,17 86:10	194:13 195:21	276:19,20 277:5,8
27:14 38:8 39:3	229:15 230:8	87:2 88:13 89:18	196:5,15 197:14	277:16,18 279:15
42:3 48:1,10,11	231:13 232:18	90:4 93:19 94:10	198:1,8,18,22	280:1,3,19 281:10
50:8 51:5 52:8	241:22 243:18	94:22 96:18 97:21	200:16 201:7,9,10	284:9 287:22
61:16 74:13 85:18	245:19 253:11	98:16,18 99:21,22	201:18 202:3,7,11	288:19 289:10
93:5 117:13 118:4	254:8 257:17	100:3,6,7,15,20	202:16 203:17,20	290:18 291:10,13
136:16 140:21	258:17 262:12	101:1 102:10,16	205:7,20,21	293:13 296:8,9,21
142:1 152:5 154:9	264:17 274:3,10	103:7,17 105:1,5	206:14,19,20,22	297:13 298:4
158:15,19 178:6	279:14 280:1	106:2,16 107:2,13	207:9,10,18,22	299:2,11,12,20
185:16 189:3	282:9 298:5,13	107:18,19 108:2,4	208:3 209:8,15,17	300:1,10 301:11
195:12 198:9	302:12 305:9,22	108:8,19 109:9	209:19 210:2,2,12	301:15 302:17,22
203:11 211:22	306:1,18 309:16	110:8,9,12,20	210:17,22 211:3	305:17 306:7,17
224:4 225:10	313:1 314:21	111:10,11 113:2,9	211:13,13 212:12	307:14,21 308:12
229:4 232:7,7	317:13 321:14,15	113:22 114:13,22	212:18 213:10,11	308:18 309:6,22
255:6 269:6,14	321:17,18 330:10	116:1,15 118:18	213:13 214:9	311:2,3 312:9
272:5 279:16	332:9 335:11	118:21 119:3,9,12	215:5 216:10	313:6,12,16 314:8
298:1 304:5	338:21 339:1,5,6	119:14 120:21	219:17,18 220:7	314:12 316:16,18
308:19 313:11	341:2 342:4	121:16 122:7	221:6,22 222:1,4	317:19 318:21
318:5 325:19	343:10 345:12	123:11,13 124:22	222:8 223:19,22	319:13 320:6
337:4 349:17	348:21 352:17	125:8,14,14 126:1	224:12,17 225:8	322:12,21 324:21
350:1,22 371:11	355:10 356:2,8,16	126:20 127:2,3,6	225:15 226:18,19	327:10,13 331:16
373:6 374:9	359:7,14,22 363:9	127:18,19,20	227:5 228:2,13,16	338:7 339:15,18
376:11 389:9	364:5 374:1 375:5	128:1,13 129:4,14	229:8,9,16 230:2	341:18 342:7,13
398:10 403:15	375:16 386:15	130:12,15,21	230:7,8,12,21	344:21 346:14
404:21	388:16 390:10	131:8,16 132:2,16	231:5,7,10,12	347:18 348:2,6,8
things 7:21 25:7	392:2,11 393:11	133:2 134:6,10,12	233:1 235:4,8	348:15 349:6,16
29:9 34:10 41:11	393:18 402:22	134:13 136:10	237:18 240:15	350:2 351:8,8,12
41:12 46:4 48:3	403:16 406:17	137:10 138:9,21	241:1,13,15,18,19	352:10,19 353:10
52:6,12 57:2	409:7	140:14,22 141:1,1	241:22 242:4,6,9	355:14,19 356:21
60:12 62:18 72:22	think 18:13 20:13	141:8,10,19 142:1	242:15 243:1,16	357:13,16,21
83:15 84:4 92:1	21:15 23:8 24:12	142:15,15,20	243:21 245:3,13	358:1 359:5,9,11
103:5 104:6 115:6	24:20 25:10 34:9	143:1,4,13,22	245:14,22 246:12	359:20 360:1,2,20

365:16 366:2,5,9 367:11 370:15 371:5,10 376:3,5 379:12 380:7 381:21 382:22 383:1 385:16 387:20 388:3,4,12 390:10 391:10 393:18 396:5,7,19 398:9 400:2,2,11 400:16,17,18 401:18,22 402:16 403:6 404:11,15 406:4,8 407:15 409:7 thinking 29:4 51:1 53:5 94:1 95:22 110:18 124:13 129:9 168:16 175:17,20 204:14 205:2,3 207:2 215:1 220:4 229:12 234:18 244:1,17 252:8 255:21 256:7 272:20 273:2,21 274:4 287:19 300:3 306:9 321:19 326:6 351:19 364:4 367:17 368:13 386:14,16 400:4,6 401:2 405:19 thinks 165:1,10 224:20 third 38:4 65:10 66:2 178:22 385:2 401:18 thirdly 264:5 Thomason 1:7,10 3:8,10,13,18,21 4:5,8,14 6:12,13 9:12,13 29:19 36:22 37:2 46:10 52:14 55:4 56:9 58:4 60:2 62:11 79:2,19 84:7	90:11 111:20 113:18 115:11,14 136:9 137:1,7,16 157:2 159:16 175:4,7 194:12 198:8 199:20 201:3 202:16 204:15 206:1 207:14 208:10 209:11 212:20 213:13 216:3,6,10 217:13 218:17 219:6 223:10 226:6 228:13 231:10 232:16,20 233:13,18 244:22 245:6 246:17 248:5 260:3 267:20 268:10 274:16,18 276:9 276:17 288:19 297:22 302:9,13 305:17 306:20 307:21 310:9 311:19 313:16 316:6 319:19 323:1,6 325:11 326:11 329:9 331:16 334:16 336:14 337:20 340:14 342:9 345:2,9 346:8 347:15 349:8 350:12 352:14 353:19 354:20 356:3 359:11 360:4 361:1 369:19 385:18 404:11 406:13 407:9,15 409:4 Thompson 1:20 15:7,8 71:3 72:18 122:5,17 123:22 125:20 126:1 181:7 201:14 221:14 229:3 312:3 350:22	thought 15:22 33:16 46:12 49:8 62:12 63:21 67:6 72:7 84:6 87:10 108:21 109:2 152:6 155:17 182:18 186:3 189:20 219:21 220:1 225:2 244:4 260:3 275:5 328:17 thoughts 29:17 33:6 60:22 182:1 248:8 294:3 398:22 399:2 thread 184:18 threat 309:7 threatening 331:11 three 10:13 22:1 34:20 38:3,4,4 48:14 63:19 67:13 68:20,22 80:2 88:18 92:17 99:13 99:13,17 148:3,4 160:11 170:19,21 190:8 191:11,17 191:20 197:3 200:13,18 227:4 229:14 242:17 298:20 304:19 317:20 332:21 343:15 348:5,15 364:14 394:17 401:1 three-quarters 361:18 threw 72:6 throat 49:10 307:2 throw 25:5 69:21 269:3 334:10 396:22 407:10 408:11 throwing 45:22 317:5 throws 275:7 thrust 249:1 thumb 23:22	THURSDAY 1:5 tie 146:19 193:16 tied 61:7 107:3 249:15 tier 155:10 373:19 373:19 tiered 216:21 Tighe 2:17 6:20 time 5:4 7:16 9:17 14:1 16:1 19:8,12 19:22 20:7 22:2 24:15 28:8 30:18 30:21 31:8 34:20 35:7 37:21 51:21 53:13 54:10 57:19 58:3 59:3,17 60:16 61:8 65:4,8 65:19 66:3 67:13 78:2 80:9,12 81:20 84:9 99:1 101:11,21 102:3 102:22 104:5 114:2 115:7,12 116:2,8,19 118:14 118:16 124:16,18 124:19 129:6 131:7 138:13 143:3 150:7 157:4 158:3 160:2,5 162:19 163:7 164:16 167:4 170:11,21 171:14 171:17,22 173:4 176:9 188:2,11 189:8,10,16,22 190:8 191:17,21 194:4 206:12 207:16 210:22 214:3 215:19 216:17 219:13 220:11 237:1 240:9 241:9 245:1 251:16,21 261:22 265:20 266:11,20 267:13 268:21 271:20 273:18 279:12,21 286:21	296:7 298:10 301:4 303:4 305:16 310:10 312:22 313:2 317:8,21,22 318:2 328:21 330:12 332:6,18 338:1 341:12 343:7 344:5 354:3,21 358:18 364:3 370:5,8 371:5 394:8,13 395:21 398:10 400:16 404:5 406:2,18 407:16 409:15,19 410:4 time-being 176:16 timeframes 193:19 timeliness 101:9 timers 289:13 times 37:7 39:18 81:5 84:10 133:7 144:20 151:6 186:10 206:4 208:20 239:1 309:4 319:16 337:22 357:13 391:18 407:18 Tina 1:12 15:1 79:16 84:7 87:8 148:5,6 150:3 172:13 218:1 219:10 246:19 277:15 377:3 380:22 381:19 today 10:3 20:4 24:12,12 32:5 50:4 86:14 92:1 168:22 191:22 193:17 194:2 198:17 221:2 248:1 250:14 251:10 278:5 283:4 289:11 327:2 376:5 389:22 400:19 402:11,16 405:10
---	---	---	---	--

406:15,20 409:10 today's 58:17 364:9 toe 333:7,9 334:7 told 38:18 48:21 72:2,4 74:9 78:11 78:13 82:9 117:6 166:8 255:11 310:16 345:7 tolerance 120:2 211:12,21 300:17 358:9,22 tolerant 161:15 toll 81:18 tomorrow 20:4 24:13 119:2 177:8 192:1 194:1,2 313:5 322:15 358:6 405:14 406:19 407:8 408:11 tomorrow's 402:7 402:8 404:10 405:9 407:3 tool 156:2 tools 70:8 149:15 382:10 396:11 tooth 76:7,7,22 top 161:19 252:21 top-rankings 347:2 topic 5:7,9 18:6 82:3 92:9 126:20 128:13 301:2 362:10 topics 363:8 381:19 399:15 total 13:4 101:19 102:1 108:14 152:1 183:18 237:15 381:22 382:11,16,20 383:8 385:6 397:16 401:11,11 totally 68:15 83:6 114:10,20 361:14 370:16 touch 230:10 322:14 391:6	touched 146:22 168:21 267:5 296:8 tough 276:19 town 346:18 toy 223:15 track 115:4,8 148:1 409:1 tract 317:18 traditional 28:18 34:10 114:5,6,14 237:14 241:16 243:3 traditionally 325:16 train 325:1 trained 325:5 370:3 trajectories 185:4 trajectory 185:5,11 transcribed 33:20 transcription 9:1 transition 56:11 301:12 364:13 transitions 186:11 translate 151:3 387:13 translated 285:16 translates 90:20 409:13 translating 125:3 152:22 178:7 273:13 translation 125:5 164:15 transparency 15:6 19:3 90:14,19 131:21 150:2 153:20 160:21 343:7 345:1 409:8 transparent 8:11 86:12 224:15 225:4 272:4 339:13 354:2 375:6 381:16 trash 231:17 trauma 152:16	traumatic 390:22 travel 83:8 265:21 265:22 treated 45:1 159:3 182:5 184:11 195:5 221:10 225:15 308:6 368:4 371:15 387:1 treating 230:15 375:12 398:2 treatment 140:9,10 166:1 180:2 195:3 195:8,20 196:3 200:2 212:4,16 269:1,17,18 277:3 294:20 367:8,18 368:16 369:9 370:9 373:1 386:20 treats 391:6 tree 40:19 tremendous 360:15 360:16 trend 154:10 384:8 384:9 tried 316:2 406:5 trigeminy 60:11 triggering 307:19 triggers 171:20 trip 319:12 trouble 271:5 troublemaker 123:20,21 truck 358:18 trucks 358:20 true 129:15 166:12 220:22 324:11 369:8 truly 59:22 136:1 trust 80:22 218:19 218:20,22 310:20 315:8 350:18 trusted 154:4 156:9 324:13 try 22:4 27:7 32:7 70:17 118:9,11,15	138:22 161:17,22 176:17 177:14 191:7 260:20 296:3 299:5 315:21 381:20 407:4 trying 7:11 17:18 19:6,13 20:19 21:9,19 22:11 24:14 25:19 29:10 30:20 33:12 50:16 55:17 77:22 91:12 96:2 98:18 108:9 111:1,2 114:13 117:5,16 126:10 137:7 139:4 143:14 171:10,11 189:14 240:12 242:8 246:10 258:15,16 259:12 262:18 292:13 306:4,6 312:6 313:22 318:21 328:7 367:20 368:22 371:18 372:1 tube 64:2 turn 5:14 17:5 22:9 30:11,15 149:14 345:21 364:21 380:11 393:3 405:7 turned 68:6 turns 360:1 tweaked 109:13 tweet 33:6 411:4 tweeting 33:3 411:8 tweets 411:7 twice 47:15 86:3 221:10 316:2 twin 63:18 64:5 65:14,14,18 twins 63:20,22 68:10 twitter 33:5,8 two 13:3,11 15:17	20:2,19 22:8,19 30:8 39:7 47:4,8 60:10 61:1 63:1,3 64:17 66:1 67:11 68:2 81:8 88:11 88:18 92:3,16 95:4 98:11 99:17 104:17 105:3 107:4 109:20 110:1 112:15 114:4 127:2,20 130:20 136:15 139:4,12 140:19 145:17 170:9 196:14 201:14 211:14 212:14,14 214:14 217:9 224:2 237:12 243:18 263:5,13 271:13 278:8 280:5 285:18 286:5 292:18 309:19 337:17 345:16 367:12 370:16 379:15 381:4 410:16,22 two-day 5:6 two-thirds 361:18 Tylenol 408:19 type 18:15,16,21 19:17 26:9,15 28:6,10 35:10,11 103:10 104:9 112:20 113:16 151:1,17 170:8 172:20,20 176:10 183:19 188:4 203:5,7 216:22 233:21 240:19 253:5,21 262:2 264:2 373:6 380:13 390:19 types 20:8,9 21:6 28:13 35:9 107:4 175:21 176:2,7 186:20 208:4 240:1,11 251:11
---	--	--	---	--

252:11,12 258:17 275:19 373:5 typically 155:10 375:22 376:1 378:5	170:6 186:6 192:8 201:21 219:6 225:7 237:4 246:7 256:21 264:14 270:10,12 272:13 274:20 282:13 286:3 290:5 294:10 295:6 300:17 302:3 328:16,19 331:9 331:14 359:7 363:22 367:14,20 372:1 374:18,21 375:22 406:17 407:18	unpredictability 380:16 unscheduled 306:11,12,13 307:6,8,13,14,20 unthinkable 212:11 unusual 60:13 up-front 117:22 249:17 269:12 270:16 344:6 374:20 upbringing 118:7 upping 316:13 upset 232:10 upsets 50:14 upwards 380:11 URAC 283:3 urban 351:15 355:5 urgent 210:21 290:9 330:22 331:5,10 urging 297:10 urinary 317:18 urologist 145:8 350:18 urology 64:19 388:21 use 3:19 6:1 13:19 14:19 17:17 25:22 27:11,22 30:20 63:7 99:8 101:19 105:5,15,15 119:13 137:3 144:15 162:3 163:12 170:14 176:15 179:17 192:3 196:17 231:1 232:2,3 236:4 246:9 259:17 282:10 299:2 306:10 308:1 326:7 348:3 406:5,11 useful 26:12 153:22 176:7,17 179:13	193:15 231:22 USPS 1:22 usual 151:14 usually 67:16 83:14 105:18,19 208:21 224:7 242:8 395:12 utilities 212:1,1,19 utilization 289:19 307:13 316:12 383:22 384:8 409:1 utilize 331:15 utilized 330:3 utilizer 120:19 390:9 utilizers 163:2 UVA 351:17	267:17 272:5 315:9 343:4,18,21 393:22 value-based 154:12 value-sensitive 156:4 values 94:15 210:15 213:9 valve 47:10,11 variability 148:19 340:5 variable 104:16 107:10,11 135:13 variation 149:21 353:9 354:11 variety 210:10 various 17:22 18:9 19:2,11 20:6 34:19 35:6 170:6 170:11 184:8 213:6 270:20 277:19 336:4 340:6 354:12 399:10 401:21 vary 172:21 243:5 328:5 339:9 vast 315:4 348:2,16 404:12 vegetables 53:17 vehicle 26:17 vehicles 29:5,6 286:20 vein 126:20 ventricles 64:17 venture 255:5 Vermont 410:17,18 410:20 versions 179:12 versus 38:12 114:2 114:2,3 119:5 120:18 121:11 128:18 136:11 165:1 166:3 172:6 176:10,11 200:2 212:6 233:6 237:15 277:20 291:4 302:1,10
<hr/> U <hr/> U.S 385:9 ultimate 120:14 ultimately 81:6 247:5,7 249:15 ultrasound 44:8 46:13 64:9 ultrasounds 64:4 umbrella 265:1,2 unable 83:8,8 unaffordable 49:8 unambiguous 107:14 unambiguously 106:18 unattainable 165:20 unbelievably 369:5 uncertainty 383:11 uncomfortable 246:22 247:1 325:6 uncommon 337:10 underestimate 330:8 underlying 171:10 171:12 172:16 underscore 179:19 275:14 394:22 underscored 396:4 understand 19:13 19:15 21:9 22:4 24:16 30:1 35:8 44:20 49:17 50:11 50:13 59:3 73:21 74:6,18 76:3 78:10,22 96:1,13 111:10 118:22 123:14 125:2 135:21 136:3,21 141:11 162:20	understandable 149:9 understanding 17:21 28:5 75:19 100:18 132:22 135:11 152:9 255:17 280:15 290:22 307:12 401:3,20 understands 96:15 387:22 understood 42:18 unfold 151:12 unfortunately 138:17 uninsured 48:14 121:3 273:9 unique 18:2 35:22 116:4 248:22 323:8 unit 101:19 383:17 384:8 United 10:10 106:13 351:22 361:16 units 101:22 universal 286:19 University 1:13,21 363:16 unloaded 23:19 unmarried 87:9 unpack 24:14	unpredictability 380:16 unscheduled 306:11,12,13 307:6,8,13,14,20 unthinkable 212:11 unusual 60:13 up-front 117:22 249:17 269:12 270:16 344:6 374:20 upbringing 118:7 upping 316:13 upset 232:10 upsets 50:14 upwards 380:11 URAC 283:3 urban 351:15 355:5 urgent 210:21 290:9 330:22 331:5,10 urging 297:10 urinary 317:18 urologist 145:8 350:18 urology 64:19 388:21 use 3:19 6:1 13:19 14:19 17:17 25:22 27:11,22 30:20 63:7 99:8 101:19 105:5,15,15 119:13 137:3 144:15 162:3 163:12 170:14 176:15 179:17 192:3 196:17 231:1 232:2,3 236:4 246:9 259:17 282:10 299:2 306:10 308:1 326:7 348:3 406:5,11 useful 26:12 153:22 176:7,17 179:13	<hr/> V <hr/> vacation 214:3 267:15 vaginal 148:16 343:13 valid 222:22 validate 118:11 validity 27:1 valuable 159:6 241:7 266:10 279:19 value 11:4 17:19 46:4 52:9,16,17 52:19 61:10 79:14 80:8 91:17 92:12 93:12 96:7 97:22 98:15 99:8 102:17 102:21 104:14,20 111:3 113:21 130:10 131:1,3 139:18,21 140:4 143:18,19 151:20 157:5 158:1,2,8 158:20,21 159:2,5 159:12,14 161:17 211:1 213:7 225:12 232:17 234:21 263:14	value-based 154:12 value-sensitive 156:4 values 94:15 210:15 213:9 valve 47:10,11 variability 148:19 340:5 variable 104:16 107:10,11 135:13 variation 149:21 353:9 354:11 variety 210:10 various 17:22 18:9 19:2,11 20:6 34:19 35:6 170:6 170:11 184:8 213:6 270:20 277:19 336:4 340:6 354:12 399:10 401:21 vary 172:21 243:5 328:5 339:9 vast 315:4 348:2,16 404:12 vegetables 53:17 vehicle 26:17 vehicles 29:5,6 286:20 vein 126:20 ventricles 64:17 venture 255:5 Vermont 410:17,18 410:20 versions 179:12 versus 38:12 114:2 114:2,3 119:5 120:18 121:11 128:18 136:11 165:1 166:3 172:6 176:10,11 200:2 212:6 233:6 237:15 277:20 291:4 302:1,10

303:4 306:11	waiting 156:20	173:3 184:16	186:17 188:18	191:15 208:7
307:20 316:20	190:13 227:17	186:1 189:8	191:5 193:21	210:13 213:11
320:14 321:15	229:20 232:8	191:19 193:10	194:4,12 197:2,10	224:14,22 226:1
323:11 336:15	281:5 343:20	194:20 196:6,7	197:11,16 198:13	231:1,2 232:2
408:1	waits 362:2	197:7 199:17	204:21 206:10	233:12 235:8
vetted 179:16	waiver 66:15 67:11	203:6 204:9 205:5	208:12 214:17	240:15 241:16,21
vice 7:2 9:5 10:15	walk 5:16 7:10 17:6	205:10,17,18	215:4 221:14	244:21 246:13
12:16 13:6 14:3	20:20 30:16 31:9	206:2,17 215:6,7	248:6 291:12	247:10,14 249:17
Vidant 1:10	34:22 35:3 48:3	224:20 228:9	293:16 294:8	252:16 261:20
video 330:16	111:16 204:9	229:13,13 242:1	326:17 334:22	296:19 300:7,19
view 101:18 136:13	304:4 312:14,17	245:1,9 249:16,22	351:1 356:4	307:19 308:17
187:9 326:1	312:19 314:18	250:9 253:9,11	366:11 407:9	315:21 317:14
viewed 211:16	327:9 364:22	257:10 264:1,16	wanting 120:15	320:2 321:10
viewpoint 245:14	400:15 404:2	267:15 281:14	360:18	326:9 327:7
275:11	405:8 410:11,13	287:1,21 293:8	wants 214:4 317:9	329:16 334:11
Virginia 71:12	410:16 411:1	300:15 301:4,7	326:7	359:16 361:5
visible 71:12,15	walked 69:8 399:4	302:10,14 306:5	warranted 109:10	362:16 363:20
316:15	WALKER 1:21	311:1 312:13	Washington 1:7,13	364:6 370:17
visit 52:2 281:17	walking 30:7 45:9	316:7 318:15	9:19 11:9 12:4,10	372:17 380:13
290:9 328:14	65:20 180:6	322:14 324:22	27:3 116:8 118:1	386:7 394:18
331:4 374:12	399:10	325:8 329:2 332:3	332:19 363:16	404:20
visits 73:8,15 290:8	walks 97:18	332:5,12 335:8,10	wasn't 53:17 56:8	ways 10:2 57:16
319:17,21 397:3	Walters 1:21 14:2	337:12,15 338:18	56:20 85:12	98:14 100:13
visualize 190:19	14:2 60:4 192:8	346:10 349:3	122:18 210:2	107:20 173:4
visually 327:8	206:4 263:2	355:2,4,5,15	213:18 342:1	207:20 220:4
voice 38:6 144:3	308:15 311:10,14	356:8 359:14	358:2	256:19,20 299:3
214:19	379:7	361:6,7 363:2	watched 80:1,7	349:12,15 350:2
volunteer 133:13	want 18:20 22:10	366:6 367:11	watching 80:9	352:22 361:22
329:13	25:12 26:11 33:21	370:15 378:3	151:12	381:21
volunteers 208:19	34:1,12,18 36:16	394:22 395:7,16	water 25:5 358:17	we'll 16:21 251:6
vote 21:13 92:18	36:20 39:16 42:16	395:17 402:10	way 8:22 16:11	we're 66:22
voting 21:13	45:1,4,5,13 46:7	403:1,17 405:21	19:21 21:17 24:3	wearing 327:1
VP 6:22 7:1	48:13 55:6 80:14	407:17 408:5,21	26:14 28:16 43:12	web 33:19 161:3
Vy 2:14 6:3,7 93:4	81:10 82:9 83:8	409:5	43:21 53:12 55:21	410:5
	84:9,12 88:8,14	wanted 29:17,19,22	56:22 59:3,21,21	WebMD 234:6
W	89:6,15 95:9 98:1	30:11 33:18 35:17	61:9 73:7 85:5	website 138:2
wage 265:19	98:22 103:17	36:5,19 39:22	89:11 100:18	149:2 271:4,7
wages 207:16	104:4,5 105:16	40:1 58:13 61:4	108:3 109:13	282:19
wagon 23:20	111:9 112:3	63:15 65:13,17	110:20 114:21	websites 19:4
wait 66:19 67:12	114:19 115:19	82:3 87:1 113:5	116:3 118:21	146:14 271:5
68:19,22 76:17	116:16 118:17	119:21 123:18	119:18 132:12	277:19 403:12
87:22 122:17,17	119:19 127:14,15	124:1 129:20	133:4 141:3	weed 228:15,20
228:1 229:21	127:17 134:17	131:5,10 133:15	142:10 145:7	weeds 314:8
271:9 281:5	140:21 142:2	136:7 138:8	147:8 153:17,17	week 77:22 81:5
307:18 313:4,13	143:1 147:2 150:9	144:12 153:15	158:17 162:8	121:5 333:6
317:2 357:13	155:9,16 158:3	164:8 165:17	166:7 168:1 183:4	358:13 361:2
408:8	161:14,22 170:15	171:3 180:9	183:5,11,19	weeks 37:11,21

39:7 47:19 64:2 64:18 165:18,19 227:4 280:12,12 345:18 weigh 102:19 130:20 168:20 195:6 197:3,13 200:12,19 210:13 210:21 213:7 243:18 258:4,22 300:16 336:3 401:21 weighed 199:7 weighing 97:5 104:18 109:5 175:21 199:2 205:1 242:22 259:3 327:17 weighs 314:3 327:15 weighted 215:16 weighting 253:6 welcome 3:3 6:8 29:20 36:16 109:15 182:2 363:4 welcoming 17:4 well-controlled 259:22 well-educated 341:19 WellPoint 13:1,1 14:15 59:20 288:2 went 24:2 46:17 53:8,13 60:14,22 67:9 76:7,10,21 81:14 85:3,4 91:7 91:8 122:8,9 129:8 130:2 148:4 227:4,11 251:3,4 276:14 291:17 322:5,8 323:4 326:22 332:21 334:14 345:6 347:1 357:7 378:16 380:2 weren't 36:7 66:11	72:4 whatnot 285:15 whatsoever 55:21 342:20 wheelchair 65:10 65:11,11,21 wheelchairs 146:4 whistles 196:20 white 22:14,20 25:4 25:9,13 26:16 72:11 73:20 75:7 75:8 76:6 96:10 194:19 247:11 355:15 whoa 44:1 wholly-owned 12:22 Wi-Fi 343:20 widget 112:9 wife 121:4 343:18 398:7 wiggle 300:14 Wilbon 2:18 3:8,12 3:17,20 4:4,7,12 4:17 6:18 22:12 35:19 86:17 90:21 91:10 93:7,14,18 93:21 94:8,18 96:18 100:2,10,22 103:3 109:4 111:7 114:12 115:13 159:20 160:7,16 168:8 173:7 175:6 175:13 177:7,19 180:4,10,13 181:6 181:22 182:15 183:7 187:13 190:12 198:5,11 216:13 235:19 237:17,20 250:2 250:11 251:6 254:16 255:4 258:19 301:9 326:16,22 327:4 365:2,13 400:1 410:10,22 411:11 Wilborn 1:22 10:5	10:6 46:22 47:1 50:3,7 87:1,15 129:20 182:16 186:1 226:18 232:6,19 256:5 261:2 293:16 359:20 394:4 395:19 willing 120:11 217:1,3,8,12 228:1 256:20 287:14 337:1,5 willingness 120:2 wireless 33:1 wise 277:14 wisely 274:9 326:2 326:6 wish 224:13,14 298:10 woefully 405:2 woman 120:13 299:16 women 1:17 11:8 208:21 257:15,17 won 86:8 wonder 176:16 310:9 339:20 354:5 406:20 408:5 409:12 wonderful 24:8 168:3 wondering 68:1 87:6 181:20 227:16 234:13 247:12 254:14 Wood 25:17 27:12 126:6 236:17 word 47:1 118:21 119:13 125:5 137:2 185:5 224:8 224:13 251:19 256:6 261:5 308:1 309:2 326:8 365:9 407:13 wording 316:5 words 93:11 108:4 125:9 126:2,22	127:22 128:15,18 134:10 176:18 177:14 178:10 195:14 196:9 201:18 207:10 215:18 304:5 311:15 400:5 wordsmith 109:11 wordsmithing 400:6 work 6:2,22 7:17 9:11 16:13 17:13 17:15 18:11 22:13 23:1,8 24:12 25:18,19 26:3,20 27:6 29:3 36:4 41:21 66:7 70:17 91:15 97:13,15,17 98:5,10,15 99:5 100:21 109:9 117:14 125:21 126:13 130:3 131:12 133:1 135:20 143:7 152:16 164:11 177:10 178:2 179:19 189:6 190:11 191:22 192:13 193:16 194:10 207:16 226:4 235:12,16 236:16 238:3 240:4,7 242:17 243:2 244:21 257:13 265:20 266:21 267:14 279:10 297:6 315:22 324:10 328:21 329:12 345:22 357:4 360:20 372:9,16 385:13 390:3 402:22 work-up 129:11 315:12 worked 177:21 178:12 184:3	185:18 196:18 worker 66:17 313:1 workers 378:8 working 5:22 89:8 118:7 124:2 160:19 333:2 356:15 works 44:11 79:1 96:13 336:12 worksheet 130:6 workshop 122:2 402:13 world 40:7 45:12 58:18 78:9 89:17 96:6 116:19 141:9 152:15 166:20 177:11 193:6 218:3 306:3 315:16 362:4 371:16 395:15 world-like 177:12 worlds 370:16 worried 80:10 292:3 317:16 319:10 worse 48:2 86:11 318:10 377:1 worst 48:1 293:18 349:17,22 worth 50:22 85:12 140:17 158:7 159:14 211:20 223:3 266:22 270:3 272:14 289:5 298:9 336:16,18 wouldn't 41:10,18 47:12 51:3 77:17 85:11 100:8 166:10 176:17 180:21 239:8 250:16 281:5 363:5 367:11 370:15 407:3 wow 68:14 176:19 215:11,20 230:18
--	--	---	--	---

256:5 305:19 wrap 29:12 115:19 295:4 wrap-up 84:8 86:20 167:15 wrapped 113:22 wrapping 385:17 wrestle 62:1 write 106:19 107:1 159:9 305:13 321:7 330:17 writer 167:11 234:17 315:21 written 264:10 wrong 44:5 45:2,8 45:11,13 46:15 47:5 51:12 125:21 135:9 246:12 312:15,18 322:5 334:19 wrote 23:21 90:4 225:10 228:18,18	66:1 68:2,4 75:12 75:21 80:2 81:5,5 83:6 139:4 188:6 217:6,9 218:15 263:5 274:22,22 275:1 278:8 282:5 282:8 292:18 293:5 325:21 337:17 358:11 362:10 372:19 380:20,20 394:16 yellow 296:12 Yelp 150:17,18,21 167:21 346:9 347:1 York 72:20 young 87:3 192:19 257:15,16,17 279:19 295:22 younger 50:15 167:22 266:7 youngest 151:15 youth 157:16,16 Yup 322:13	1030 1:6 12 112:16 313:13 317:2 318:13 358:11 374:13 12-minute 90:22 12:03 169:4 12:35 168:10 12:41 170:2 13 11:1 95:3 14 13:1 65:12,22 15 114:2 227:13 232:8 268:6 385:1 15-year-old 291:15 159 3:15 15th 1:7 410:7,15 16 3:8 16-year-old 54:7 16-years 56:12 16th 410:15 17 64:1,4 170 3:18 18 38:5 67:3 80:2 180,000 152:17 1950 88:17 196 3:21 1986 358:4	25 40:13 123:8 25-year-old 54:8 251 4:5 27 1:5 28 411:15	8 80 142:8,16 80/20 289:3 80s 73:2 85 205:15 88 227:6,7,8
X X 130:11 207:4 218:15 x-ray 24:1 277:20 375:3	Z zero 342:19 zillion 59:11 zinger 315:7 zone 118:13	2 2 32:1 171:20 173:11 195:21 373:19 2:10 250:1 2:15 250:1,2,4 2:17 251:5 20 64:18 75:21 94:3 161:19 218:15 231:16,17,19 290:7 385:1 2005 53:3 2007 148:11 2008 37:11 2014 1:5 411:15 2016 283:17,20 21 94:2 23 53:5 24 11:20 24-hour 330:4	3 3 174:5 373:19,19 30 144:1 161:19 168:9 211:18 319:8 320:2 362:10 374:13 377:19 385:10 301 4:8 33-year-old 87:9 35 37:11 36 3:10 13:3 364 4:14 271:17 37 13:15 139:5 398 4:17	9
Y Yahoo 303:11 year 14:14 38:5 40:16,22 42:7,12 47:15 67:12 73:9 73:12 139:20 149:18,18 152:18 163:20 214:4 263:12 267:13 271:15,17,19 281:16 283:19,19 292:3 293:10 296:2 316:20 322:4 year-long 66:19 years 10:8 13:11 48:14 53:5 54:6 60:10 62:9 64:12	0 1 1 4:16 32:2 151:17 152:16 160:3 171:9 390:19 409:21,21 411:10 1:45 32:21 1:57 251:3 10:30 32:20 10:35 91:7 10:51 91:9 100 13:17 139:6 283:22 325:18 344:10 100,000 139:19	4 4,000-physician 11:2 4:46 411:12 40 282:9 300:13 385:10 409 4:20 410 4:22 45 253:2 318:1 48 358:11	4 4,000-physician 11:2 4:46 411:12 40 282:9 300:13 385:10 409 4:20 410 4:22 45 253:2 318:1 48 358:11	
		5 5 3:3 50 84:22 300:13,14 307:9 370:7 50-year-old 294:19 58 82:6	5 5 3:3 50 84:22 300:13,14 307:9 370:7 50-year-old 294:19 58 82:6	
		6 6:00 250:15 60s 23:17 61 82:7	6 6:00 250:15 60s 23:17 61 82:7	
		7 7 3:5 70 367:4 75 38:21 230:15	7 7 3:5 70 367:4 75 38:21 230:15	

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This is to certify that the foregoing transcript

In the matter of: Measuring Affordable Care

Before: NQF

Date: 03-27-14

Place: Washington, DC

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