PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

TRANSFORMING PATIENT-CENTERED RESEARCH:
BUILDING PARTNERSHIPS AND PROMISING MODELS

Saturday,
October 27, 2012

Renaissance Hotel
1828 L Street, NW, Suite 900
Washington, DC 20036
AGENDA

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P R O C E E D I N G S

[8:30 AM]

DR. SELBY: [Webcast video begins at 00:04:40 but audio begins at 00:05:17] -- Research Institute. I've been here since July of 2011. I was the first PCORI employee at that time. But there is quite an interesting history of the Patient-Centered Outcomes Research Institute before I arrived and my job this morning is to give you just a brief history of how we got to be created and what’s happened up to today. From today on, you’re in it with us.

So, as many of you know, PCORI was authorized by the Affordable Care Act, now commonly called Obama Care. In 2009, early 2010 there was wide recognition that despite the fact in the US we spent approximately $150 billion a year on clinical and health care research, patients as often as naught and clinicians as often as naught, lacked the information that they needed. The practice decision, the health care decisions were being made with uncertainty in the absence of good
information. That led to poor outcomes. To outcomes other than those that patients preferred. It led to medical errors, as you know, in large numbers and it led to wasted resources as well.

The story goes that sponsors, Senate and House sponsors had a pretty good idea what they wanted this institute to do. But they had a heck of time figuring out a name for it. There was a lot of interest in the kind of research called comparative effectiveness research. And the idea there was, in fact, precisely that. We needed to do research that was practical. That compared treatment options that patients and clinicians faced considered a wide-range of outcomes that are important to patients and looked for differences among patients in the ways that treatments work. So the recognition was that treatments didn’t work the same for everybody. That people were individuals, that comparative effectiveness research was supposed to find out what works for whom.

But as most of you, I’m sure know, the
The notion of comparative effectiveness research got tied up with the notion of coverage decisions in that political climate around election time, the word rationing was raised.

And comparative effectiveness research was just not a name that you wanted to put on a new institute. Casting about for a name, someone hit upon the name Patient-Centered Outcomes Research Institute. Patient-centered care was just taking off at that time and that sounded good, and I think the rationale had to be, how could one argue with research that was patient-centered? And that’s how PCORI got its name.

As soon as the Affordable Care Act was enacted, the Government Accountability Office began putting the law into effect and they selected a board. They recruited a board of 21 members. A multi-stakeholder board from across the country and I am here to tell you today that the vision of PCORI is the responsibility primarily of PCORI’s Board of Governors and just to illustrate how remarkable that board is, two years later they are
still on the job, passionately and in a spirited fashion directing and working with staff to make the vision of PCORI a reality.

So I want to ask those Board members who are here, and I know there’s at least five here, if you wouldn’t mind standing and I would just like to point out not only who you are, but where you’re from. So I told a lady from Mississippi this morning that there was another person from Mississippi in the audience and this is Dr. Gray Norquist from the University of Mississippi. And standing right next to Gray is Dr. Debra Barksdale from the University of North Carolina. Let’s see. It’s dark out there. I see a shadow over there but I swear I can’t -- oh that’s our Vice Chair Mr. Steve Lipstein from BJC Hospitals in St. Louis, Missouri and I told a St. Louisan last night that Steve was on the Board. Welcome Steve. Hello. And I know Gail Hunt is out there somewhere. Although I don’t see her right now. Gail Hunt is from the National Caregiver Alliance based here in DC. And I know Dr. Harlan Weisman is here. And
I’m not sure that I see Harlan. Harlan is --
there’s Gail, just walked in. And Harlan Weisman
is from New Jersey and represented when he was
appointed Johnson and Johnson.

Anybody else? Have I missed -- Anne, do
you see anyone else?

Okay, so those are five Board members and
I just want to say again that it’s largely the
Board that took a look at the name, asked itself
what that might mean, and determined, in fact, that
if research is going to be done differently, we
have in fact, have to put patients at the center of
the research enterprise. And that means involving
patients and their family members and also, the
clinicians who care for these patients in every
aspect of the research enterprise.

So from identifying the questions in the
first place, to prioritizing those questions and
helping PCORI decide where is the most important
place to go with the limited resources we have, to
reviewing the applications when they come in. So
we need to review applications and make sure that
the applications that are coming in, really do address practical patient-centered questions. They really do consider the right outcomes, and they really have a strong likelihood, when answered, of changing practice.

To participating in the research. So we tell applicant researchers that if they don’t bring patients and other important stakeholders along with them when they apply for research, they will not get funded. And we’re not talking about bringing patients along as subjects in this case, we’re talking about bringing patients along as partners in the research endeavor.

We also aim and need to work with patients and these other stakeholder groups. If we want the research findings to be disseminated, so to spread the word, we get the findings and lament is always that they stood on the shelf for 17 years. The evidence doesn’t get into practice. We think we can change that if we have patients involved from the very beginning, helping to guide the research and then there to disseminate it at the end.
So that, in fact, is our plan and we’re glad that you’re here with us to help us begin to put this plan in place. I was speaking with a lady this morning from New Jersey who told me that no one she had talked to had yet heard of PCORI, and so, with your help we will change that.

That’s all I’ve got to say other than thank you so much for being here, for taking your weekend to come to DC to join us, to hear about this. We want to lay out the plan as far as we’ve taken it. Get your feedback and input and go forward together. And right now it is my pleasure to introduce the brains behind this meeting. Our Director of Patient Engagement, Ms. Sue Sheridan.

[Applause.]

MS. SHERIDAN: Thank you. Good morning. Gosh, what an honor to be here with all of you and this was actually a brain child of Dr. Anne Beal, who is sitting here in the front of the audience, and mine when we were sitting at a workshop in Palo Alto in July, when there was a lot of conversation about patient engagement and we looked at each
other and said workshop. And about two weeks later we were back in the office and I was in the hallway and I was talking about how a workshop with patients in research was my dream and Joe Selby said, “No, that was his dream.”

You know, being a researcher, so we saw were going to bring these worlds together. And just having the discussion within PCORI, you’re going to meet a lot of PCORI staff here, our researchers, our support, and just the dialogue that we have had within PCORI itself, and with our board. It has created energy within our own organization and so there has been a momentum building.

So when PCORI’s name, Joe mentioned our name. The Patient-Centered Outcomes Research Institute. Before I joined PCORI, when I saw that title, and I come from an advocacy background -- a patient activist background, I saw this title and I thought to myself, “Really?” You know, is an agency really going to look at this patient-centeredness in a real way? And we believe that
patient-centeredness is a transformation of doing things for the patients to doing research with the patients. So PCORI intends on modeling that patient-centeredness in everything that we do. I want to share with you that when I was with the WHO, we did a survey globally about patients getting involved in assuring their own good outcomes. And so, we sent out a big survey and we asked the patient population of the world if they wanted to be involved in assuring their own good outcomes. And, of course, the resounding response was yes. And then when we said, “How many of you actually do that or would do that?” The percentage went way down. And so, the researchers kind of said to the patient group, kind of, “See. Patients don’t want to get involved.” And so, we kind of pushed the researchers, nothing against researchers, and we really encouraged them to go back out and ask the patient population, “What do you need from the health care system to activate you and to engage you and to be more involved in sharing your own good outcomes?”
And the resounding response from 59 countries, of hundreds of patients was a simple answer. And that answer was, “An invitation.”

So, this is an invitation to you. To help us build us. I’m going to show you a little video that was created a PCORI. You’re going to see some of our board members and some of our patients.

[Video shown.]

MS. SHERIDAN: The first time that I showed that, it was at Yale, I got so excited that I told the audience that I wanted to get involved, and I realized that I already am involved.

[Laughter.]

MS. SHERIDAN: But it just -- this is an invitation from us to you. We welcome you. We’re excited about your energy and this is an opportunity that we have at our fingertips. We invite you today, we invite you tomorrow, and we invite you when you go home. Even most importantly to join us in all of these engagement opportunities, to touch points that Joe references, about how we’re bringing the patient and
stakeholder population in the whole research cycle. We invite you to create processes and principles in the next day and a half, to help guide us. We aspire to be the gold standard in the science of patient engagement and we need you to be our partners. We invite you to create partnerships never imagined before. To help improve outcomes for those of us in the audience, for those of us back in our communities. And we invite you to create with us research done differently.

So I am excited. Last night the discussion and the enthusiasm about what’s going to happen in the next day and a half is up to us. We have an opportunity at our fingertips to create how research is done in the future in partnership with patient, caregivers, and other stakeholders to make a difference in the lives of patients.

So with that I am going to pass the microphone and introduce two of our facilitators, Marty Hatlie and Jonathan Peck, both of whom I’ve worked with in the past. I have -- when we were dreaming about this workshop and envisioning this
workshop I know the two facilitators I wanted.  
They’ve worked with me in the past here in the  
United States making patient groups under the guise  
and auspices of HRQ. Jonathan and Marty joined me  
in a very courageous journey with the WHO, creating  
a network of patients throughout the world founded  
on best practices and principles and values and  
hope. So I will invite my friends Jonathan and  
Marty to take over.  

MR. PECK: Thank you Sue. Thank you.  

[Applause.]  

MR. PECK: Wow. This is just so wonderful  
and we’re really pleased to be able to work with  
you today.  

What Marty and I are going to be doing  
today is getting you oriented and beginning to get  
the engagement going. So we’ll start with “Why are  
we here?” What are the objectives for today and  
tomorrow and then we’ll take you through the  
agenda. So -- go ahead.  

MR. HATLIE: I’m Marty Hatlie and this is  
Jonathan, just so you know the difference between
the two of us. And our first objective is to build partnerships to make patient-centered outcomes research a reality. We’re really excited about having this group here help PCORI do that.

MR. PECK: And last night, I could see the partnerships already forming and maybe formed. Second objective, which is we’ll be spending a lot of the time, especially from 11 to the end of the day is to generate ideas and principles. So, you’re going to be generating these ideas with and for PCORI.

MR. HATLIE: And one of the things we noticed last night is that there were many people here who sort of knew each other, so the dissemination process to invite people here and invite you to apply went through a lot of different channels and it was really a tickle for us to see how many of you got here and knew each other and began sharing ideas right away.

Also, we got a phenomenal response to the pre-work we sent out and, you know, often you don’t. So we knew you were a really proactive
group with a lot of ideas who were eager to be here and eager to pick up the phone and connect to the people that we asked you to do that, so thank you for that and we’re really, really eager to get your ideas.

MR. PECK: Great.

MR. HATLIE: And capture them and kind of use them to help PCORI.

MR. PECK: Our third objective is to develop the most promising models in patient engagement in research. And it’s going to be something -- well, you’re going to hear about some models that will help stimulate your thinking. You’re going to create some models of your own.

MR. HATLIE: Jonathan, one of the things that I heard as I was talking to the audience, or not to the audience, but to the participants last night, is where do our ideas go from here? What happens after the workshop? And there is a phenomenal working group that helped put this together, that’s been very front and center for them. I know it’s really front and center for
PCORI staff as well. So, I think we’ll start with the models today. We’ll learn about the models. We’ll see some models here, but we’ll also be able to, you know, take this input and plug it in a longer process at PCORI. That includes more workshops for other stakeholder groups.

MR. PECK: And fourth, and in some way the most important is to form an enduring community. This is not a onetime event that ends. This is the opportunity, the beginning of research done differently and we’re going to need your engagement and that really comes because you form a community together, an intentional community.

MR. HATLIE: Jonathan, if I could share an anecdote about this because Sue talked a little bit when she was up on the stage about her work with the World Health Organization. And at one point in time when the World Health Organization was getting behind the Safe Surgery Saves Lives initiative, they asked us to send a survey out through the network of patients that Sue had built at WHO. And
we got more surveys back than we sent out.

[Laughter.]

MR. HATLIE: And WHO said how did you do that? We were expecting three to four percent response rate. That’s what we normally get. And you returned 150 percent. But it was the networking. People got the surveys and they sent it out through their own networks and it was a really, really exciting thing. So this notion of community we’re catching a wave here, I think there are a lot of people connecting in a lot of interesting and different ways and we hope that will happen here.

MR. PECK: So are these objectives clear to everyone? Anybody have any questions about what we’re here for and how we’re going to be spending — or what we’re going to be doing? Then Marty, why don’t you take us through the agenda today and I’ll pick up and do tomorrow.

MR. HATLIE: Okay.

MR. PECK: I’m a futurist so I got to do tomorrow.
MR. HATLIE: Okay. Well, today the first part of the morning is really -- it’s orientation. We’ve already started that. We’re going to move on from here to bring Sue back to the stage to bring the phenomenal working group that helped put this event together, guided PCORI at every step in the process.

We’re then going to show four models. We’ve invited researchers who’ve partnered with patients or patients who have partnered with researchers or patient groups that have partnered with researchers to come up and just kind of tee-off our thinking, our ideas by showing some examples. We’ve got a nice variety of people of where the research community reached out to patients or patient groups and some of where the patients or patient groups reached out to the research community.

So we’ll just kind of tee those up and then we move into a little bit of instruction of how the breakout sessions will work and then we
start our first breakout session before lunch. And the breakout sessions, I hope this is pretty clear from your materials, but every participant in this event is going to have a chance to weigh in on every topic that matters to PCORI. So the rotation is really to make sure that no matter what your first, second, third or fourth priority is, you get a chance to contribute your ideas and give the guidance you’ve got to give.

And it’s typically a pretty exciting process. It involves some movement, and so, for those of you who need help at any time from getting place to place, please ask. Jonathan or me or a couple other people that we want to introduce who are going to be our colleagues today in helping.

We go to lunch after the first breakout session, which is one where we kind of really set the stage for what will happen. So the first breakout group, whatever group you’re assigned to, is going to generate the initial ideas and then the other people that rotate into that topic or that theme, that session, will be building on those and
adding and refining and converging, clustering.

So that’s the way the day generally will work, but we’re going to take a break at lunch obviously, we’ve got to feed you. And during lunch we’re going to have a presentation by Rachael Fleurence, who is a researcher, about how to submit a research question. So you saw a piece that we sent out to you just not too long ago. PCORI started a process to invite anybody who has got an experience that they think leads to a research question to do that and we’re going to do a little exercise around lunch with Rachael, taking us through how that process works.

Come back from lunch and --

MR. PECK: Oo-Oo! Don't forget the computers are out there. So you can actually go out and submit a research question during the break. Don’t all run out now, but you can go ahead and you can go right into PCORI.

MR. HATLIE: Good, great. Yes, so please do that. And those are going to be up all weekend, right?
MR. PECK: Yes.

MR. HATLIE: So you don’t have to do it during lunch, you can enjoy your lunch, but you can do it at any time. And it’s web-based, there’s a portal so you can do it afterwards as well. This evening during the cocktail party, for example.

Then we do the remaining breakout sessions through this afternoon. It will feel like a long day. I mean, we’re really going to take advantage of your coming here and giving us your weekend to get the best we can out of all of the creative minds in this room. So it’s going to feel long and if you need to take a break at any point, and there’s not a lot of breaks, honestly throughout the day. So if you need to take a break for bio reasons or for personal care reasons or just to recharge your batteries. We understand that that will happen and we just invite you to do that as you can over the course of the day.

We do have a couple small breaks here and there but really not too much.

We break right around 5:00, before 5:00
and then we come back for a reception and dinner tonight and that is not required. It’s optional so if you need to rest you can miss that, but I’m not going to miss it. I think it’s going to be great. Especially based on the reception last night where you could just see the cylinders firing on multiple levels, so we hope you’ll come to dinner tonight.

We’ll do a little programming around dinner also or at the reception around affinity groups. Last night we kind of -- just to -- as an icebreaker, asked you to write down some places that you’ve lived or where you would like to live, you know, had your destination wedding at or had visited or had wanted to visit. But we’re going to ask you to do something similar tonight around your interests, so sort of your affinities. We have a process where if there is a group that wants to form a cluster to talk about something in particular they could actually write the topic on a little flag or a little card at a table and cluster around that table. So it will be exciting to see how that works out.
MR. PECK: Okay. It should be fun.

So tomorrow we’re going to start as we should with breakfast at 7:30, then we’ll sort of move into the welcome. It’s going to be a shorter day, so we’re going to actually report out from the work today. So you will have travelled through the breakouts, through these five topics and you’re going to be delighted because we have a wonderful visual report for us here and you can see Patricia [inaudible] already -- Hi Patricia -- giving us a visual recording of the meeting. And she’s going to help us, so you’re going to go contribute in all of these breakout topics. You will have a facilitator who will be synthesizing this and then reporting back the ideas on each topic, the principles that we’re recognized through this for patient engagement. And then you’re going to have a chance to make recommendations based on the learning in each topic.

And so, we’ll be going through these reports and recommendation and discussion throughout the morning. At the end we’re going to...
invite the PCORI Board and leadership to give feedback on the learning and then we’ll hear about the next steps. We’re going to conclude at 12:30. We’ll give you a boxed lunch and the weather report.

[Laughter.]

MR. PECK: So that’s the agenda. Any questions on the agenda?

[No response.]

MR. PECK: You will feel it. Let’s just speak to our rules then.

MR. HATLIE: Jonathan, one more thing I want to mention before we leave the agenda is, today after the opening presentations, before we start our first breakout. We’ll actually travel to another floor of the hotel and that is a floor up. Yes. It’s the floor right above us. So that half-break in the escalator as you came down. And then, all of the breakout sessions are in the same corridor. So it will actually be pretty easy to move from breakout room to breakout room when we do the rotations, but they’re all clustered up on the
next mezzanine level.

MR. PECK: Okay, so now in the next minute here’s our rules. Show mutual regard and support for each other. That’s a vital rule. Everybody on board for that one? Thank you.

[Applause.]

MR. PECK: Respect the limits on time. This is going to be fast-paced. It means don’t clutch the microphone too long; Marty.

[Laughter.]

MR. HATLIE: What are you talking about -- I don’t see you very often. So it’s nice to be here with you.

[Laughter.]

MR. PECK: Third, is silence your phones. If you have a call you have to make or take, step outside so it doesn’t disrupt any of the group discussions. Are we all on board for that?

[Chorus of yeses.]

MR. PECK: Put them on stun? All right. Thank you. Thank you. Quick on rules and then we can move.
MR. HATLIE: Okay. So the rules. I mean, this is the community that is coming together here. That’s gathering here with a huge emphasis on patients and caregivers. I mean, the vast majority of people in this audience are here because of an experience you have had as a patient and a caregiver. Seventy-five percent of you was kind of our goal. We are aware that many of you wear multiple hats, but that’s like a core group for this workshop. There are other workshops that will have different percentages of patients and other stakeholders in it.

You’re partners and you’re educators of all of us. [Inaudible] energized and are clustering because you want me to hurry. Other stakeholders, are here as your partners. Partners of the patients and caregivers today. PCORI staff is here en masse, they’ve been very excited to meet you and they are going to be our hosts and our facilitators. Presenters are going to be storytellers and modelers. Giving you examples of models. The working group, they obviously put this
together but they’re also going to be ambassadors today. We’ll introduce the working group if you need anything over the course of the day, find a working group member and they will help you get what you need. And certainly, they are partners as well.

And then PCORI leadership, Joe introduced many of the PCORI leadership and especially tomorrow, throughout today, but tomorrow on stage they will be listeners and reflectors on what they’re hearing coming out of the ideas and the work that we do in the breakout groups.

MR. PECK: Now probably the most important role for us is to get the microphones to you. And we have help, Eric Meade is in the back. Eric, thank you.

MR. HATLIE: Natasha Washington. We can’t see in the lights, but she is over here in this sector somewhere.

MS. WASHINGTON: Over here.

MR. HATLIE: Hi Natasha. There you are.

Okay.
MR. PECK: Thank you Marty.

MR. HATLIE: You’re welcome.

MR. PECK: Sue, back to you.

MS. SHERIDAN: Great, I’m back. Thank you Marty and Jonathan.

Marty and Jonathan referenced the working group. And something that PCORI committed to was being authentically patient-centered and which meant we were going to create this event not for the patients but with the patients. So, given that charge I reached out to four individual patients that knew were leaders, four considerably patient organizations, one of our Board members, and two of our Methodology Committee members from PCORI. And we ended up with 11 working group members, completely different perspectives, which brought this richness and this challenge to all of us to create an extraordinary event.

I mean, after my first few working group calls I’d hang up exhausted and wondering why I, you know, formed it in this way. But I did it in this way to drive to an extraordinary, excellent
event. And so, we’re going to take the chance and you’re going to meet all of the working group. And we’re going to all share what brought us here. So I’m going to share what brought me, Sue Sheridan, here.

What brings me here to PCORI and to this event is my son Cal. My son Cal suffered brain damage when he was six days old from his newborn jaundice and I saw how there were prevention and diagnosis and treatments that could have been implemented. So I saw areas in our health care system that could have been improved. What brings me here is Pat. My late husband who died at 45 years of age of a cancer that went untreated when his pathology got filed without neurosurgeons or physicians ever seeing it. So Pat and Cal bring me here because I believe that in partnership we can make a difference. What brings me here is Mackenzie [phonetic], my daughter, who wishes she could remember her dad but aspires to be a health care worker.

So what brings me here is PCORI. And what
brings me here mostly is hope. I have seen a
witnessed in part of relationships and partnerships
with researchers where we did make change and it
was powerful for me to witness that.

So what brings me here is opportunity. An
opportunity that we all have to build a sustainable
architecture for patient-centered outcomes
research. So that’s what brings me here. I’m
going to invite our working group members -- we’re
not going to go in any specific order, so I’m going
to invite Chuck Bell. Where’s Chuck Bell. Let’s
start with Chuck Bell. You can introduce yourself
and share what brings you here.

MR. BELL: So, I’m with Consumers Union,
the publisher of Consumer Reports Magazine in New
York. And we’re an organization that cares about
value for money and consumers and patients need
information that we can trust. And so, we’re very
interested in the outputs of PCORI, because we
think that will advance the welfare of consumers.
We want safe, affordable, and effective care for
every consumer that’s out there. And we’re also,
as a National Consumer Organization, interested in contributing the resources we have to build this community and to help it succeed. We operate a project called the Safe Patient Project. I think some of our folks are here today, people on the ground working for safer care. We have a big mailing list and we’re going to try to bring more consumers and patients to the table and build a really rich community. So we’re thrilled to be here and look forward to working with you.

MS. SHERIDAN: Okay, Perry. Where is Perry?

MR. COHEN: I have my speech all written out so I don’t go over time.

I was diagnosed with Parkinson’s more than 16 years ago, so I’ve had a long journey on the advocacy road. I first lobbied Congress for greater funding for scientific research at the NIH like a lot of advocates do. Then in 2000 I was selected a patient representative for Parkinson’s at the FDA. I organized the Parkinson’s Pipeline Project in 2002 to give a voice to patients
interested in the regulatory process.

Now we are lucky to have PCORI, who are rapidly becoming champions for activation and empowerment of patients as we learn together how to do truly patient-centered research and medical care. Thank you.

MS. SHERIDAN: Thank you Perry. And Sara van Geertruyden is right next to Perry.

MS. VAN GEERTRUYDEN: Thank you. My name is Sara van Geertruyden, I’m here on behalf of the Partnership to Improve Patient Care. The partnership was created back when Congress started rumbling about creating a comparative effectiveness institute, and so, our organizations that are part of our coalition are organizations that had an interest in advocating for the creation of an institute and they used the words patient-centered a lot and looked at doing research that focuses on what patients need and what patient preferences are. And so, you see those terms woven into the legislation that created PCORI in large part because of the activities of PIPC.
Tony Coelho who is the chairman of PIPC is an epilepsy patient, a former Congressman, and a disabilities advocate. And he stated in a writing that he did for Health Affairs awhile back, “If the health reform law is implemented correctly, the most important stakeholders in health care, patients, will have a key role in the effort to fill gaps in evidence and identify the most effective treatments. They will have an equal voice in determining what questions researchers will study and equal input into how research findings will be communicated to the public.”

So for us, and for PIPC, and from myself and Tony, we are very excited and appreciate, Sue, your efforts to put this together.

MS. SHERIDAN: Thank you. And we have Regina right there. Let’s hear from Regina.

MS. GREER-SMITH: Good morning. My name is Regina Greer-Smith. I started -- I learned about PCORI in July of this year, and I’m just so excited about being here. I think I’ve died and gone to heaven. Just to think that someone would
even consider having patients as peers with researchers.

Who do I represent? I think I represent my mom who has dementia. My nephew who died from a medical error, he was actually dumped. I think I also represent or try to bring a voice to underserved and diverse patients. I have had the honor to work at Cook County Hospital and some of my colleagues are here now. And I’ll just tell a real brief story.

I used to leave the parking lot, walk to my office, and you see an amazing mosaic of diverse patients whose families’ countries of origin are all over the world. So hopefully, it’s my hope that being here with all of you wonderful people, that we can recognize them as patients. Honor them and really represent the needs and hopes of their participation and research.


MS. HUNT: Good morning. I’m Gail Hunt. I’m the head of the National Alliance for
Caregiving. We’re the people that do most of the national research around family caregiving. You know, how many caregivers there are? What tasks they do? What’s the impact on work? What’s the impact on caregivers health? So we do all that sort of research that some of you may have used and if you haven’t, if you ever need it, if you just go to our website, there it is.

But the other role that I play, is being a Board member for PCORI and one of those Board members as Joe said, who was around from the beginning before there was a Joe, before there was a Sue, before any of those people. So we actually have been working really hard to get PCORI started and I think this meeting is one of the meeting that will put right on the right path and I’m very excited to see all of you here.

Thank you.

MS. SHERIDAN: Thank you Gail. Linda Kenney.

MR. PECK: I was wondering where you were.

MS. KENNEY: Thanks. Hi. I’m Linda.
Kenney and they asked me what brought me here and I was going to say Sue. She asked. I came. It’s that simple. You know you build relationships in this work that, you know, when people reach out you make yourself available. But I’m here because I almost died of a medical error in 1999.

Actually, it wasn’t really a medical error. I say that just to get at it quickly. But the bottom line is the impact that it had on my family, on myself, and the staff involved was devastating and there were no support mechanisms in place, so I vowed to change that. So that’s what I do. But recently I’ve been an add-on, you know, a check the box. They’ve already done the research project for a state-wide coalition and “Oh yeah, we need a patient.” So I get added on.

And then I have comments, and then they say, “Oh it’s already done.” So, this idea to me is brilliant and I’m hoping that even some of your ideas I can bring back at a state level to say, “You know, they’re starting to think about this differently” and hopefully that can help make
change in my state, too. So thanks for being here and I can’t wait to meet you all.

MS. SHERIDAN: Great. Thanks Linda.

Reggie James.

MR. JAMES: Hi, I'm Reggie James. I'm with Consumers Union, the policy arm of Consumer Reports. Chuck kind of described some of the work that we’re doing, but I wanted to describe just one little aspect. He mentioned our Patient Safety Project. That stems out of a change in our work. Of course, Consumer Reports, we have the laboratories. We test products and we report on them. But we were kind of doing a lot of what the [inaudible] system does. We were the experts. We did this. We reported on it. We lobbied as experts. The change was engaging consumers in the advocacy work that we were doing. We started doing that 10 years ago and it makes a phenomenal difference.

So, I know there are several people in the room here that have been doing work with us and the effectiveness of our work as increased multifold,
but it also changes how we think about what we do.
So, we really, really support the mission of PCORI.
It’s a really cool thing. I wish it happened in
every single policymaking arena that governs every
single consumer issue, not just health care. But
health care is a great place to start because it’s
so important.

I saw one of the quotes of a person here
who shared one of the reasons why they thought this
was so important and I really, really loved it and
wanted to read it. It says, “If designing health
care is like planning a party, professionals have
been treating it like a surprise party.”

[Laughter.]

MR. JAMES: “What is really needed is for
patients to be part of the party planning
committee.” I loved that.

[Applause.]

MS. SHERIDAN: Thank you Reggie. Angela,
I’m not sure where you are sitting. Angela Ostrom.

Oh, she’s not here. Well, we’ll thank Angela for
her participation in the working group. Kristen
Sloan. Is Kristen here? From the National Partnership for Women and Families.

MS. SLOAN: Hi, good morning. I’m Kirsten Sloan. I’m with the National Partnership for Women and Families and I’m delighted to be here today. The National Partnership has been through its campaign for better care incredibly active in building a deeper bench of very experienced consumers to serve on governing boards and patient advisory councils and making sure that we’re really getting -- building a much more enthusiastic effort towards patient collaboration and patient engagement. Thank you.

MS. SHERIDAN: Thank you Kristen. And we also have three members that couldn’t make it that I wanted to thank. Mary Tinetti and Ethan Basch who were on all of our conference calls, who helped create some of those questionnaire exercises that you participated in. Again, thank you for that energy. They are on the PCORI Methodology Committee.

And then Dave deBronkhart, who is known by
many "e-Patient Dave." And he did send me, he was on his way to Europe, he sent me a message to read to you. So I will do that. His message is, “Do good work. I wish I could be there. I’ve heard from several people who are attending. This is important. We are the advisors on behalf of all the other patients. We are bending history. Be wise and strong.”

So that is our working group. I thank and applauded the working group. It took all of their effort to create this. So, we’re going to move from recognizing the working group and what brought us here, and move into the four different models. I would like to welcome the presenters to the stage.

And we’re going to listen to what brought them here and four different models of patient-researcher partnership or how patients are getting involved in research, and they come from all over the United States. We’re very lucky to have all of them. And I am not going to read their bios, so I’m going to invite you to look at their bios in
your packet.

And it is my great pleasure to introduce the first researcher-patient partnership. Gosh, I believe I am starting with Vinny and Kris. Is that the first one?

MR. HARTLIE: It doesn’t matter.

MS. SHERIDAN: Okay. I am pleased to introduce Maret and Ned. They are from Northeastern Colorado. I am from Idaho so we connected when we were on the phone. You know, thinking about the mountains and the Wild West. And that we’re all headed to Washington, DC where we had to dress up like grownups. And I really appreciated their story. It was very human. It was community-based. A really nice model on how they’ve worked with researchers. I understand they’ve given presentations before and they’re considered rock stars.

So I welcome the rock stars from Northeastern Colorado.

MS. FELZIEN: So we’re not quite sure how to manage the technology here, so we’re going to
try this and see if it works.

Well, good morning everyone. My name is Maret Felzien and this is my husband Ned Norman. Can you hear me okay.

[Chorus of noes.]

MS. FELZIEN: I’ll move up. How about that? So we are really excited to be here, to be in DC. All of the presidential candidates are in Colorado, so this is great for us. And we’re really honored to be talking to such an interesting group. A little intimidated, and thanks Sue for that.

[Laughter.]

MS. FELZIEN: We just want to tell you our story about how we do research differently. So, Ned and I believe that we are experts. Thank you very much. We are experts at understanding our community. We know what people are concerned about. We know what they need and want in our small towns, in rural eastern Colorado. We learn these things because we’re at the schools, the coffee shops, the tractor and implement
dealerships, and the grocery stores and we’re listening and we’re talking and we’re one of the community members.

We also know how information moves through our rural community. We know who moves it. We know what drives it. We have the pulse on Northeastern Colorado. We are experts in our community, just like you are experts in your community. We have come to realize that this kind of culturally relevant knowledge coupled with just natural community enthusiasm and “go get ‘em” attitudes is what makes this an authentic and potent resource for research.

And when you pair our energy and our knowledge with the research, then the health of our community can be improved. So, we have seen it happen and we’re going to tell you that story.

MR. NORMAN: So as Maret mentioned, she and I are both members of the Community Advisory Council for the High Plains Research Network. And HPRN is a practice-based research network that encompasses all of eastern Colorado. It is a
geographically-based network that includes a 33,000 square mile area. Almost -- about three times the size of Maryland. And the network includes every clinic, every practice, every doctor, every nursing home, every public health department within that large area. And HPRN seeks as its mission to translate evidence-based knowledge into practice in a way that’s relevant to a rural setting.

And this research network had been established for about six years when Dr. Jack Westfall, the director, heard the call to action for community-based practice research and knowing very little how to do this, he jumped right in. And as we go through this talk, we’re going to be using the word “community” a lot and we use that interchangeably with the word “patient,” which seems to be commonly found here.

MS. FELZIEN: So how did we get recruited? How did Jack recruit us? Just as Sue mentioned or one of the working groups mentioned today, when someone calls and you’re part of their group, of course, you step up and say yes. And so, he did
the exact same thing. He’s like, “Hmm, I want to create -- I want to gather community members to help me guide the research. How am I going to do that?” Well, he picked up the phone and he started calling people that he knew. And it went something like this: “Hi. I’ve got this crazy idea. Something about guiding and influencing my research, I’m not sure what it’s going to look like, will you try it?” It was that hard.

But what we found is that when given this invitation, had we not heard that this morning already, that the curious will come. And in fact, they will even say yes and probably stick around for a really long time. Those who don’t get it, they’ll say no thank you, but they’ll also leave behind someone else’s name and say but I know somebody who will be interested and they will be your next round of people to ask.

So for us, our Community Advisory Council, we’re just made up of normal people. We’re not the stakeholders of our community. We’re not mayors and bank presidents. We don’t own businesses.
We’re not the shakers and the movers of our communities, we’re not researchers. We’re not involved in the world of health care except as consumers.

However, we are dental hygienists and hardware store managers, and high school students, and retirees and people involved in the education of rural Colorado. Ned, in fact, is a cattle rancher. A city-born cattle rancher, how about that? I’m a junior college instructor and fourth generation wheat farmer. But, as a group we speak together, we representatives of our large rural expanse of a community. We don’t speak for a specific town. We don’t’ speak for a specific clinic, we don’t speak for a specific health issue. We speak for the community-at-large and we try to tap into all of those needs and interests.

So coming together for our first meetings, whew, man. They were a feeling out process on both sides. Nobody knew what to expect of the other. The researchers thought, “Oh, we’ll give you structure. You must need to be organized. This is
how we do this kind of work. We need bylaws and we need memorandums of understanding and we need mission statements. And the community looked at them like they were absolutely crazy. This is not how we get stuff done. And in fact, one gruff dry land farmer who is a retired educator stood up, I mean he physically got himself out of his chair and he said, “Listen Jack. If we’re going to do something and it’s going to be about improving the health of our community, then I’ll stay. But if this is just going to be about talk and you’re going to waste my time. I’m gone.”

So that’s the only memorandum of understanding we’ve ever needed and it’s been nine years.

[Laughter.]

MS. FELZIEN: So, of course, those first meetings were really interesting. We didn’t know anything about research. There was this disconnect between the community about what we were supposed to do. And as a community, when we’re activated and we hear a good idea what’s the first thing we
want to do? We want to get to work and we want to
do it now. But research is different. The
timeline is really slow. This is a big machine and
it moves in a different way. So this caused a
natural tension, this is something that we’ve had
to learn over the years.

Additionally, this is nine years ago.
There was no clear model to follow. There was no
one out there who had taken a very large expanse of
a region and brought together people and tried to
say “we’re going to cover all of the interesting
areas for us to follow,” we had to figure it out on
our own.

But our relationship with the researchers
grew and now the research is truly a partnership
and we are not a focus group. We do not just give
our rubberstamp of approval on like “Yeah, that’s
a good idea. Please move forward.” Instead, we
are completely and integrally entwined with the
research that’s going on in Eastern Colorado.

MR. NORMAN: So the question now is what
do we do? You know, how is our research done
differently with our involvement and maybe the
other question is why do we keep coming back and
doing it?

Well, we’ve been at this for nine years
now and we’ve been involved in a number of
projects. Some of these projects were born of
ideas that came completely from the Community
Advisory group, that we suggested. In fact, there
is a master list that started early on in the
process. One of these is our Eye on Health
Project, which is a health awareness project using
PhotoVoice, to engage fourth graders using high
school mentors. Other ideas have come to us from
HPRN and were the result of them finding projects
that were fundable and bringing them back to us and
showing them that our community had a need and that
money was available.

And this was really important, it was one
of first crash courses in the world of research and
how that process works. Other ideas have come to
us from other researchers and hospitals who have
wanted to come to HPRN and do partners with us to
get access to our area. And there are times when
we won’t allow that to happen.

There was one example where National
Jewish Hospital had a health initiative that was
already put together. They had the materials.
They had a 1-800 number. And they came and
presented it to us and we turned them down. And we
looked up and the HPRN staff was sort shocked at
the table, shock and awe. And they were shocked
that we had refused them outright. And at the same
time they were awed at our ability to protect our
community and shepherd projects through it the way
we thought was appropriate.

And we’ve always respected the fact that
they didn’t argue with us. They accepted that.

So, our council is fully involved with the
projects that we do from designing and implementing
the research. We evaluate, explain data, we
present at conferences. We do everything. I’m
going to skip that story.

MS. FELZIEN: So there’s a lot of things
on the horizon for us and Marty is giving me your
time’s up, and you know, as community members and storytellers, we could talk all day. We have lots of things going on. Research started a long time ago, continues through. We’re seeing projects that we have done in Northeastern Colorado move to the Southeastern corner. We’re seeing a project that we’ve done in Eastern Colorado move into the urban community and being tried there. So the research that we’re finding is sustainable. It’s effective. It’s something that can be picked up and shared with other communities, allowing communities to be involved and patients to be involved.

And we are excited to share those with you as we move throughout the day, because we’ve got lots we can talk about. So the last thing I want to say, hold on a minute. So why do we keep coming back?

We keep coming back because the research is fun, this is a community member talking. It is fun. It’s challenging. It’s mentally stimulating. But it really does affect the health of our community-at-large and for these reasons we keep
coming back. So, thank you.

[Applause.]

MR. PECK: Yes, please. And you’ll get a chance later to talk a little bit. First I want you to talk to each other at your table. And just talk for a few minutes about what you really like about this model, because you are going to be sneaking your ideas into these breakouts. So share with each other what you heard that you really like that you’ll want to build on for patient engagement. We’ll give you a few minutes.

MR. HATLIE: And by a few, Jonathan means two.

[Table discussion.]

MR. HATLIE: Okay. Jonathan, I think it’s time for us to --

MR. PECK: So, when I went to Maret and I said, Maret, that’s so wonderful, and she said, but I have so much more to say. And I know all of you do too, but we’re going to ask you, stimulated by this first model, that you bring the noise level down, that you turn your attention forward, and I
know you’re engaged. That’s great.

You want to hear about another model, so Sue?

MS. SHERIDAN: Okay, thank you. I hope that the discussion was energizing. It is my honor to introduce Dr. Vinod Bhutani and Kris Schulze. I have journeyed with both of them for the past 12 years through the research partnership that Vinny and Kris are going to talk about, and so I’m very proud to be on stage with both of them, and thank you for coming.

MS. SCHULZE: Thank you, Sue. And, again, when Sue calls, we come.

So, I’m going to share our story of the power of partnership and collaboration with Parents of Infants and Children with Kernicterus, or PICK.

My piece in this story started a bit over 14 years ago with the birth of my son, a nine and a half pound, full term, very healthy newborn. And within that first day he had developed newborn jaundice. By the time he left the hospital two days later, his jaundice was worsening and we were
told to keep him in the sun and follow up with our doctor for a well-baby visit two weeks later.

When we arrived on day ten, he had a bilirubin test, which, of course, we had no idea even existed or that there was an objective measurement for how severe jaundice could be, and we found ourselves in the NICU for the weekend receiving phototherapy.

Four months later, we discovered that our son had kernicterus, which is brain damage caused by severe newborn jaundice. Kernicterus, for my son, means that he has severe athetoid cerebral palsy, he is unable to sit on his own, he is unable to walk, he is unable to feed himself, he is unable to get a drink of water on his own, he is dependent on others for all basic cares and will be for the rest of his life. Had he had a one dollar blood test before we left the hospital and had received the appropriate treatment, he would have been just fine, we would have had a different journey that we would be on today.

When Justin was two years old, or just
after he was two years old, a coworker spotted a USA Today feature story on a young boy that looked a lot like our son -- there’s Justin right there -- and as I read the story of Cal Sheridan, Sue’s son, I realized that we were not just an isolated case. We had already connected with two other families in the Minneapolis-St. Paul area whose kids had kernicterus, even though we kept repeatedly being told that kernicterus no longer happens in our country. By the end of the day that we saw the USA Today article featuring Cal Sheridan’s story, we had connected with Sue and we found out that there was going to be a symposium on newborn jaundice and kernicterus the following weekend in Chicago.

So, six of us moms showed up in Chicago that weekend, dropped everything and made it happen, and a seventh mom soon joined us whose newborn baby had just been diagnosed with kernicterus in the Chicago-area, and PICK was born.

We connected with amazing, courageous doctors, Dr. Bhutani being one of them, and never underestimate the powers of moms on a mission. We
realized at that point that a lot of babies were falling through the cracks of the medical system and developing very preventable disabilities and we needed to do what we could to work with the medical researchers and medical community to make it stop so that we would have healthy newborns.

And that was our main focus early on, is how do we prevent this from happening. By the time we left Chicago, we had plans in place for not only our nonprofit organization of Parents of Infants and Children with Kernicterus, or PICK, but we had plans in place to meet four months later at the University of Pennsylvania in Pennsylvania Children’s Hospital for our first system-wide, consumer-centered workshop to meet with our representatives from the CDC, from NIH, from the Health and Human Services, and from the Joint Commission on the Accreditation of Healthcare Organizations, and we moms mixed ourselves up around the table and were able to share our stories, and by the time we left that meeting and we asked who was going to do what by when, and
trust us, we moms had a very short timeframe in which action was going to happen, we had a plan going forward.

Within several months we had Sentinel Event Alert had been issued on the reemergence of kernicterus and kernicterus was also listed as a never event and then several years later the APP ended up changing their treatment guidelines and standards for the treatment of newborn jaundice.

So, in a very short time, a small group of moms came together with amazing researchers and started connecting those dots and connecting the stories along with the research to change how we treat newborn jaundice in our country.

With that, I’m going to have Vinny share.

DR. BHUTANI: Thank you. So, we met Kris and Sue in Chicago. We had been working on a video to put together to define some of the effects of newborn jaundice that affects almost all babies who are born in the U.S.

And I put the video together from the clips that the families had sent to us, I did not
know the families then, but one of the things that we did was as you put the clips together and made the video, we decided to invite the moms at the luncheon of this video for education.

At the front row of the audience sat seven moms, and I was sitting across the dais as this video played, and as I looked across, the tears were there, the pain was there, but what was most apparent was a silent rage the emanated from these moms, and that had a powerful impact on those of us who were at the dais, because we felt that here were lives that had been thoroughly changed because of an inability to detect or prevent something that had been eradicated many years ago.

This was a journey that began about 13 years ago and since then, as you heard, with the leadership and the support of the moms on a mission, that we embarked on an effort to gather evidence, bring about change, bring about change in the communities of physicians who are taking care of babies in the U.S. as well as abroad, and I’m happy to report that their effort on the CDC
website, if you click on newborn jaundice or the word kernicterus, you will see a portfolio of teaching materials in four different languages for moms or moms-to-be, prepared by us as a partnership.

And more importantly, in the chapters of the books that pediatricians read now, as well as in practices that they are governed through the guidelines of perinatal care, the screening for newborn jaundice now is the standard of care.

It took a while, it took a lot of effort, but it was driven by the engine that is the passion of the moms generated with that silent rage, and now we need to keep our promise.

MS. SCHULZE: Just to wrap up quickly, we wanted to talk a little bit about what our next steps are. Unfortunately, we still continue to see and get contacted by families who have kids who have fallen through the cracks of the medical system or find themselves with kernicterus. The wonderful thing about technology now is that we’re starting to connect with families from around the
world, so as we get families from Nigeria who’ve
discovered that they have a child with kernicterus,
we’re able to put them in touch with other families
in Nigeria or families from Brazil are connecting,
families from India, from Great Britain, there are
families from around the world who are not only
using the PICK resources that were developed along
with the Centers for Disease Control, but also are
coming together on our Facebook groups and our
listserv and through our website to be there for
one another, to have that support, and guidance,
and hopefully, figure out, as Vinny mentioned, we
had a three-pronged approach of partnership,
prevention, and promise.

Right now, our main area of focus is going
to be moving forward on how to do more research to
create the future these kids deserve and how do we
make their lives better and make sure that they
have full, happy lives, have the technology they
need, and all the supports they need to have full
lives.

And I think that’s about it. So, thank
you.

[Applause.]

MR. PECK: Okay. Kris, Vinny, thank you so much.

Take a few minutes and talk with each other about what in their model that you really like that you want to build upon as we go to the break.

[Table discussion.]

MR. HATLIE: Okay, Jonathan, I think we’ve got to move on. Do we have time for comments?

MR. PECK: Okay, it’s a good thing I’m from New York; I don’t think it’s rude to interrupt. If you can, this was wonderful, I can see you’re primed. Let’s hear another model.

MS. SHERIDAN: Thank you, and I must share that if Ned and Maret were rock stars, Vinny and Kris, I think, were the Olympians, and now I’m going to introduce a super hero now, Ben Heywood, who is going to share a really creative model and I’m excited that he’s going to expand our thinking about how patients can really get involved in
MR. HEYWOOD: It’s very easy to meet that expectation. Thank you guys for having me here. It’s really, truly, and honor.

So, I think I’m on the stage because 13 years ago my brother was diagnosed with Lou Gehrig’s Disease and -- sorry, it’s always -- unfortunately, he passed away six years ago, but I want to talk a little bit about our family’s journey and what we’ve done, because I think it sheds a lot of light on this topic, and what’s possible when you really let patients in and engage them deeply.

So, you know, I think this idea that when patients are diagnosed and when my brother got diagnosed, we don’t have research questions; we just have questions. We want to know, what will help me get better, what can I expect. I think particularly in spaces where, you know, like Lou Gehrig’s Disease or illnesses in children where there are not great answers, we quickly become -- the question is, well, we realize that there isn’t

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answers to these questions. And not only are there not definitive answers, there’s not data to actually make -- to guide even partial answers to this.

And so, you know, and this sense of urgency is really acute for someone like my brother who was diagnosed at age 29 and our family. So, what happened? So, we as a family did a few things. My brother Jamie -- Steven was my brother who passed away, but my brother Jamie and our family started a nonprofit biotech called the ALS Therapy Development Institute, and it’s running today. We actually have raised about $70 million for that, and I say that as a top line just to give a sense of the scale, but not because that’s what we want to do.

What they tried to do -- it’s a nonprofit biotech doing really hardcore in vivo drug discovery and they really tried to take apart this disease at scale using a preclinical mouse study model.

They’ve actually run 30,000 mice through
that lab in the last ten years, just to give you
the sense of scale.

Now, what’s interesting about what they
did in terms of this discussion is it’s not just
about clinical research that we can bring people
into the fold; you can bring it in at any stage of
the environment. They had a completely open
research model, all of the research in their
pipeline and their knowledge network that they’d
developed to do this task was on the web and
available for patients.

Their Laboratory Information System, their
real-time LIM System of the mouse studies, was put
live to the web, blinded, but live to the web in
real-time so patients could engage and understand
it and know about it.

So, you can really let people into the
process early.

So, the other thing we did is Jamie and I
started Patients Like Me, and what Patients Like Me
set out to do was to actually begin to bring
together patients to allow them to tell their
story, but actually tell it in a way that we can
begin to capture the data about what happens to
them because, you know, every patient has a story.
I think these stories are too often not heard, but
I think more importantly these stories aren’t
turned into meaningful information, because it’s
not just a story that every patient has, every
patient has a deep understanding of how their
illness is affecting their body, their mind, their
lives, and I think we need to begin to capture
that.

And there is no system today to capture
that in a comprehensive sort of global patient
view. So, what we did is we started Patients Like
Me. It’s a community of patients coming to the
web. They come primarily to find answers, to share
their experiences, and to learn from the experience
of others, but what we help them do is we take
those stories and we turn that into qualitative
data, so we take their experiences and we give them
patient reported outcomes and we give them
structured Q&A to allow them to actually begin to
track and tell their story and paint the picture of the longitudinal course of their illness in their disease.

The scientific jargon around that is we try and help them create what we call a phenotype engine on our inside, which we want to understand fully the phenotype of that disease and our illnesses.

So, where are we at today? I mean, we started this about eight years ago. Again, you know, we have about 160,000 patients in this network across 1,000 different diseases. We’re definitely much stronger in a few communities, you know, you talked about your community. We started in ALS. One of our next early communities is MS. Those are some of our strongest ones. We actually have about 5 percent of the U.S. MS population on the site.

You know, just from the scientific side of this, it is a clinical research platform. We have published 25 papers in peer-reviewed journals over the last four years, so we are engaging in the
scientific research. We have an amazing science research team, but actually I think more importantly, and again, about letting patients into a transparent research process, we publish all of our data in real time, live, so we have data on over 10,000 treatments in our system. 

Now, that’s not just pharmaceuticals, that is prayer, that is nutraceuticals, that is, you know, pets, that’s the whole range, but actually all of that data is reflected back live. We have actually over 8,000 symptoms in side effects reports, again, reflected back live, and patients can slice and dice that data to make it meaningful for a patient like you, and that goes back to the evidence problem, right, so obviously in traditional research we want to get to the perfect standard of randomized placebo controlled trials, but the reality is, patients with these illnesses are making decisions, and I would rather them make them with some data than no data.

And we can learn which of that data, as long as we cycle back the learning into the system,
we can continue to improve and understand and ultimately get to the right answers for a patient like you.

I think there’s a few headwinds that I think this group can make a big difference on. I talked about patient reported outcomes, that’s a big part of what we do on our side. I think there are a few interesting headwinds there and I’m excited to see -- we’ve been doing this a long time at Patients Like Me. I’m excited to see this group and I’m excited to see the energy around this in other arenas too of both policy research and patients.

One is that there’s still a skepticism about the validity of the patient’s experience in research. There just fundamentally is, and obviously I’m saying this to this crowd, they don’t believe that, but when you get out there, you will find it, and that’s a headwind that we, as a group, can really make a difference on.

Two, I think, as we begin to design measures in research, I think it’s important that -
and this is something we focused on in the beginning is, those outcomes, those measures, those understanding should help a patient drive their own individual care, and then we can aggregate that up and learn how that affects the system. Let’s not measure patients to figure out how to change the system, let’s help them change the system through their understanding of their own illness and their own experience.

So, I think this group is really well positioned.

So, you know, we’re supposed to talk about what’s distinctly different about what we do -- I’m sorry, talk about how we incorporate patient engagement in the process. Well, we’re a website where patients come and participate. Engagement is our research process. We don’t have anything to do if our patients aren’t engaged and aren’t participating and so, you know, it’s funny, one of the things -- highlights that was exciting, I was just talking yesterday with our head of product and he said, we just ran the experiment where we said -
- when patients join, we ran -- we put them into
the sort of the charts that show the data as
opposed to the sort of stream of what updates in
what the community is doing and we found that
patients much more rapidly engage both in the site
ultimately in giving and tracking their data when
we give them the access to the community as their
first step.

And so, that’s amazing for us because it
means we’re going to get more engaged patients,
more ability to work with them to answer tremendous
questions. That’s not a research question, per se,
as we might think about it in this room, but
actually when engagement is the center of the
research, that’s a very, very important thing for
us.

Just a couple of great, quick anecdotes,
early on, this relates to the PRO story -- topic I
was talking about, we had a patient, Kathy Wolf,
who was an ALS patient, and the PRO we used on the
side, the patient reported outcome we use on the
site is called the ALS Functional Rating Scale. It
sort of goes from -- it’s a progressive disease and the end point of it, because it was designed for trials, was ventilations or death.

And so this patient was on a vent and she was like, well, I want to continue to understand how my progress and share that experience, she doesn’t want the line to flatten out an event that’s still meaning to where she is and how she is engaging in life. And so we actually worked with her to design an extension to that rating scale called the FRC extension, you know, we did the traditional PRO development process with our research team, but working directly with her we got it down to four questions, and now she can actually track and engage with that data and that meaning and actually convey her experiences after ventilation, because the PRO is designed for endpoints in trials, which the pharmaceutical company only cared about that endpoint, but then, you know, understanding it past that is something a patient cares about.

I think it’s a really powerful way to
think about engaging researchers.

I’m getting down to 28 seconds here, so -- what am I excited about? I think, you know, one of the things we’re trying to do is figure out how to make this -- we are a for-profit company, because we believe to scale this we really need to actually align the patient’s interest with the financial interest of the system, so we are trying to bring together patients, industry -- primarily pharmaceutical companies today -- and nonprofits -- I swear only 30 more seconds -- and we also are working on a project we’re not announcing yet, but I think a very exciting project where we’re going to be able to help with the rapid, I think, development and deployment of patient reported outcomes in the next year, and I think -- the other thing is I think we’re embarking on a really, I think, interesting dialogue about the dissemination of results to patients and where they can get them in the process, because patients want answers sooner. You talked about that tension, and the question is, what happens if you allow them in
sooner and how does that affect the research fundamentally.

And I think you’ll see over the next few weeks here a very interesting dialogue starting around that and I’m excited to have everyone participate.

Thank you.

[Applause.]

MR. PECK: Thank you. Before you process this, I have an announcement. The hotel is opening Internet access to everyone at the workshop and the access code is internet, all lower case.

Okay. Take a few minutes and talk about what in this model that you’ve just heard you really like that you’re going to bring into the other groups.

MR. HATLIE: And Ben, I think, has one more thing to say --

MR. HEYWOOD: Real quick, I apologize, I have to run home for a family event that was already preplanned, but I do have a colleague here, Sally Oaken, who is an amazing clinical nurse, who
works on our research team, so she is here for the whole conference, so if you have questions about Patients Like Me or my story, she is a wonderful colleague over here.

MR. PECK: Thanks, Ben.

[Applause.]

MR. PECK: Okay, take a few minutes and we’ll interrupt.

[Table discussion.]

MR. HATLIE: Okay, I think we’re going to -- we have one more presentation that we’re going to share with you if I could have your attention, please.

MR. PECK: Okay, he’s asking politely.

MR. HATLIE: I’m going to get up in a chair. Okay, we have one more presentation and then we will have 15 minutes for a little bit of Q&A or a little bit of comment on the presentations you’ve heard, so we’ll get that interaction going, but right now we’re going to ask Sue Sheridan to come back up to the stage and introduce our last presenter.
MS. SHERIDAN: Thank you, Ben, that was fabulous. Our last presenter is Janice Bowie, and I’m going to introduce her as the Saint in that when we connected on the phone to talk about her passion and her dedication to improving healthcare in disparate populations, it was really moving and I can’t remember how long we spoke, but it was a powerful story that she shared when a community actually came to the researcher, so it was a little different model than what Ted and Maret shared.

And so this is a community recognizing and confused why their county suffered from some of the worst outcomes and they approached Janice and so I’m going to introduce Janice Bowie, and hear her story.

MS. BOWIE: I’m going to apologize in advance for my voice. I don’t usually sound like this and I have not been on the presidential campaign trail, although I think I might, could do as good a job as some of them. Maybe that’s not so true.

Before I get started with my portion of
the presentation, we have a short video from my community partner who could not be here today because the National Association of Colored People, the NAACP, is having its meeting this weekend as well and so in lieu of Childlene Brooks being able to be here, we have a short video clip.

I understand it doesn’t come through very clearly, so I’ll do my best to try and fill in the gaps.

[Video shown.]

QUESTION: Childlene, why would you reach out to the Hopkins Center for Health Disparities Solutions? Also, what motivated you to do so?

MS. BROOKS: Dr. John Ryan, the former health policy director for the Talbot County Health Department approached me to [inaudible] and the fact that Talbot County ranked number one [inaudible] breast cancer and colorectal cancer. We began looking at ways to disseminate information into the community and to [inaudible] issues. The initial presentation was to the Talbot County NAACP.
Dr. Ryan knew about [inaudible] and he’s tied to the Eastern Shore, because he attended the University of Maryland Eastern Shore, he also knew about [inaudible] work with health disparities and he gave me his contact information and asked me if I would call him and I called him and spoke to him in 2008. And at that time he suggested several approaches to include professional [inaudible] assessment to clarify and define the problems in the county and he [inaudible] to identify and catalog [inaudible] stakeholder to the community.

[Inaudible.]  
[End of video.]

MS. BOWIE: Thank you. So, what I’d like to first do is to acknowledge my colleagues, the NAACP and the Talbot County Health Department, which is on the eastern shore of Maryland, as you can see in the slide. I also want to acknowledge that our work is collaboration through the Hopkins Center for Health Disparity Solutions, which is led by Dr. Thomas LaVeist and other colleagues, and one of my colleagues here who has been working with
some of the PCORI team is Cheri Wilson, and it was
through Cheri’s efforts with PCORI that we were
asked to share our story.

So, Talbot County is a very interesting
case because they contacted us. The Maryland State
Health Department issues a report annually on the
state of the health of Marylanders and Talbot
County, located on the eastern shore of Maryland,
there are other neighboring counties and the
neighboring county to it is Caroline County, and
they couldn’t understand why having similar
demographic characteristics in terms of population
size, in terms of socioeconomic status, and even in
terms of racial and ethnic mix, why did they have
very serious health outcomes that were not apparent
in the Caroline County.

So, they contacted us. The NAACP placed a
call, as you could maybe not hear in Childene’s
comments, was that Dr. LaVeist had trained at the
University of Maryland Eastern Shore and people
knew of his work and knew of the center at Hopkins,
and that is how this occurred.
So, we, during the conference call with them, began to look at the demographics in the counties. We met with them over the phone, and what we learned was that, yes, they have similar demographic characteristics, they even have a similar age distribution, but you will see in this next slide -- you can see -- hopefully you can see -- yes, that you can see the different -- the similar age distributions across each of the cohorts from 18 to 34 and 65 years of age and older.

And then in this next slide you’ll notice in the educational levels that the Talbot County group, which is -- and this is broken up by Talbot County whites and blacks because the county is largely white and black even though there is an emerging and growing population, like in many other places, of Latino residents.

And then the third bars represent Maryland, and what you can see from these bars is that the Talbot County population fares a little bit better than Caroline County for both income and
education level, so you can see the education levels here, slightly fewer more high school graduates and slightly more college graduates in Talbot County. Similarly in terms of higher incomes being represented in the Talbot County, and this is among the African-American populations.

So, what was most striking for us is that when looking at excess mortality, we could see that the blacks in the county compared to the whites, had a greater excess death rate, so the mortality was 64.5 percent compared to that mortality in terms of 20 percent in Caroline County and 30 percent at the state, so you can see it’s a huge excess mortality and excess mortality represents mortality that’s over and above what you would expect to see in terms of similar or comparative population groups.

Similarly, we could see that there was also excess in terms of all-cause mortality ratio, meaning that, when that ratio is above one, that you would see, again, that the Talbot County residents -- black residents in Talbot County were
faring worse than all others.

So, what happened is that as a result of this -- and then this bar also sees -- if you notice where -- and the read is the African-American group and then the yellow are the whites, and if you look at Talbot County, which is marked at the bottom highlighted in yellow, you can see this disparity in terms of mortality.

Similarly, you can see these are all the counties in Maryland followed by the whole state, which is in red, and the U.S., which is in the blue or white marked bars, and you see where Talbot County fares.

So, of all the counties, compared to the State of Maryland and compared to the U.S., that there’s a 60, almost 65 percent excess mortality.

So, of course, if you were a member of this county, you would be somewhat concerned about what’s going on. And so, again, when we met with the county, we thought, well, maybe must be something wrong with the data. And so, what that led us to do was to go back and try to rerun the
numbers, and in fact, we did see that these numbers were actually accurate. And when you think about the behavior of medical conditions, we could see that there were large rates of all of these conditions going on in the county, that there was greater smokers, that there was disparity in terms of cancer screening rates, that people -- fewer people were having their cholesterol checked and when you really looked at hypertension, it was really off the charts.

So, as it typically is, when researchers go to a county, they take our pictures, as opposed to taking everybody’s pictures, but this is Dr. LaVeist in our first community meeting, and as you can see, Hopkins looks at racial health disparities in Talbot. I would have had a different lead story, but -- and we had 35 community attendees from the Chamber of Commerce to clergy to the school of nursing, the head of the hospital association, average citizens, just an entire group -- just a very mixed and diverse group of people who met.
We went back again, we had another community meeting. This time, I’m in the paper and I try very hard not to be in that picture, but as it is.

So, what I want to really say about this, because it fits very nicely with what all of my other co-presenters have said in terms of their own personal stories, what’s most important in the work that I do, I’ve been involved for a long, long time in community-based participatory research, and we go from patients to consumers to communities, all of us are representing patients at an individual unit and we represent each other collectively as communities and as populations.

And what I think is important in the work that we try to do is to understand that that process has to involve communities in defining their own problems and expressing their own concerns versus how professionals, being the experts in deciding what those problems are. The work takes a long, long time, as has been pointed out by many of the other presenters, and that
decision making rests collectively. It’s not the decision of any one entity.

And finally, that our goal is not only in terms of changing health outcomes, but changing the capacity of people who are making those decisions, because if we are not building capacity, then at the end of the day, we really have not moved the agenda forward in the ways that we think we should.

I’m out of time and you will have these slides. We are still working. We have applications that are pending to continue our work, and I want to thank each and every one of you for putting up with my voice, and I really appreciate the work that you do.

MR. PECK: Thank you.

[Applause.]

MR. PECK: Okay, thank you. Should we take a few minutes to let them say what it is on this model at the tables and then we’re going to have a group conversation between you at the tables and our wonderful panel.

So, go ahead and take a few minutes just
to talk about what you like about the Talbot County work.

[Table discussion.]

MR. PECK: If we can now, we want to see -
- Marty and I have mics, will travel. So, if you’ve got something that you’d like to share with the panel that came out of your discussions at the table, it could be something that you want to share that you like or a question that you have about how they did it. You know, each of these speakers had a half hour presentation they condensed into ten minutes for us, so if I can end this conversation at the table, if I can just get you to forward it here, we want to center it up to the front. We only have them for a few minutes.

MR. VAN LEEUWEN: Oh, I’m Danny van Leeuwen. I really -- when I came to this conference, I was thinking, you know, there’s something wrong with the model of research itself that, you know, as my neurologist says to me, I know a lot about populations, none of it relates to you. You know, we still have to make decisions.
So, to hear you say, from the Patients Like Me angle, you know, that we as patients need information to make decisions right now, and research is like this really long process that’s about populations and it gets so narrow to qualify as a research project and gets really specific, and so it doesn’t necessarily help me make treatment or lifestyle decisions.

So, what is it, you know, in your experience with what you were describing in your work with Patients Like Me, so how does -- I guess it’s both, how do we move it forward so that people can use information to make decisions, but also so that it’s more accepted? I guess.

MR. HEYWOOD: You know, the definition today of clinical care of medical evidence is the randomized placebo controlled trial, right, which is the gold standard and is a very, you know, useful piece of medical evidence, but it doesn’t always relate to a patient like you and it’s not always available, right, about 15 percent of medicine is practiced on that kind of evidence,
right.

So, the question is, how do we begin to allow evidence on the spectrum of quality to drive decision-making? We make decisions in our lives every day with imperfect information, except specifically in medicine, right, but the reality is people do make those decisions on imperfect evidence, so what we need to do is begin to talk about what’s the quality evidence, why am I making it, and how does the quality of the evidence relate to the decision-making at that time.

And I think — but the other thing that’s really important, and this is what our system is not set up to do, is we need to then capture that experience and that experiment that happens with that physician and that doctor in real time and feed it back into the learning network so that we can — that model can get better and better.

I mean, there’s a great article in the BMJ about parachutes and no one’s ever decided that, you know, double blind placebo controlled trials —— people should use parachutes, but when you jump out
of an airplane, you know you should use one, and when we first started jumping out of airplanes with parachutes they had a nasty adverse event rate of about 1 percent, right? Today, there’s zero or almost zero adverse event of jumping out -- I mean, near zero, and we didn’t do that through this type of research that we traditionally talk about. We just looked at it, learned, learned and learned, and the system got better and knocked that out.

So, I think we really do need to rethink it and I don’t think any of the clinical infrastructure or informatics infrastructure we have today is designed to do that, and we’re trying to -- I mean, that’s what we’re trying to build outside the system.

MR. HATLIE: So, Ben, you talked about the headwind, and that’s Danny’s question too. What piece of advice would you have? I mean, how did you fight that headwind? Did you stand up and scream? Did you go to media? I mean, I know what the kernicterus moms did, they basically got a meeting, did an action plan, and said, we’re out of
time, let’s go.

I don’t know what your strategy was.

MR. HEYWOOD: Well, so one strategy -- I mean, I mentioned, our family both started a nonprofit and this for-profit, is I actually do fully think that you need to think about the financial incentives and aligning them to this cause, right? I mean, if this cause about putting patients in the center of healthcare is not incented in the system directly, then it’s not going to -- I mean, we live in a capitalist society, and so we really need to really align it, and so, you know, the questions need to flow through the patients, what we’re talking about, getting it to flow, but actually, ultimately, on some level, the money needs to flow through the patient directly in a very different way than it does today.

MR. HATLIE: Okay, great. Thanks. I hope that’s helpful.

[Applause.]

MR. FARBSTEIN: I’m Ken Farbstein and we
have some really smart people at our table, but we’re unclear, still, on the specific way that the partnership research model worked for several of the speakers.

So, Ben, for Ben, you know, patients like me, we get that, but for the others, like specifically, what were the steps of the research and, you know, what’s the recipe, like, you know, first we did this and then we did that and then we did that, and so forth? I’m sorry, but we’re kind of unclear on that.

MS. FELZIEN: is there specifically someone you want to have answer that or just jump in?

PARTICIPANT: [Off microphone.]

MS. FELZIEN: So, we have steps and a method and we stumbled upon it, and it looks like this. Either the community brings an idea forward or the researchers bring an idea forward, and then of course you need money, and so you have to go, you have to dance this dance about, well, where’s the money, what’s fundable?
When money is available and there is a research project that we are able to move down the path with, then the process works like this for us: the idea is pitched, long before the money arrives, the community says, wow, we like that, we see the need for that, or the community says, I’m not so sure, but talk to us more, or something. And eventually there’s buy in.

Then the community has to go through a pretty rigorous education process when we are going to embark on some sort of research program, and we call it a boot camp of sorts where we bring in someone who’s an expert in whatever it is the field that we are learning about, so next week we are going to have a boot camp on behavioral mental health. We have been working on hypertension, we’ve worked on asthma, we’ve worked on colon cancer.

So, each one of those topics we’ve had a two to three hour CME level, so, where a professional could go and get credit for attending this seminar, that’s the level seminar that we
receive as the community. Then that allows us to process this information. Now we understand, we have the language, we can talk fluently with the research community, and we can work shoulder to shoulder, but we can also continue to keep this information and make it relevant for our community.

That then starts us on this path of, okay, so now we understand, what are the salient points? Who are we trying to target? What are the research questions? And the community is involved in each one of those steps.

Then depending on what the research project is, there may be a lot of effort in creating some messaging and some materials and, you know, how do we get this information out, how do we put out an implementation process, how do we put out an intervention, how do we disseminate -- you know, get this out there, and able to collect the data.

Once that is going, then it’s the research team that collects the data. That’s their job; that’s not ours. But that data always comes back
and we help evaluate it, we help to explain it, and then ultimately in the end we help to present it and author papers and then bring it right back to the community and say, this is what we learned and this is what we can do with it now.

Does that help?

PARTICIPANT: Thank you, Maret, that’s terrific.

MR. HATLIE: We’ve got only time for a few more questions, so -- we’ve got --

DR. GOESCHEL: Very quick question here.

Chris Goeschel from Johns Hopkins. I’m a nurse and I’m a health services researcher and very quickly would like to say, two years ago I sat at a research conference with the NIH for two days where there were qualitative and quantitative researchers and at the end of the conference one of the quantitative researchers really said, I still don’t know why I’m here because you’re not a researcher, you don’t do randomized control trials.

I’m having déjà vu all over again because what’s happening here is the missing piece, that we
need to have the session where people understand that without patients as the center of this, we aren’t really doing research, so I applaud the efforts.

But my question is, we had four wonderful models, but there are no doubt thousands of them out there, so the planning that went into this, and I don’t know if it’s a question for you, Sue, or for throughout the day, how are we going to share what’s happening so that the people who are thirsty for this -- I mean, I’m taking notes as fast as I can -- but the people who are thirsty for this, my research colleagues, who want to know how to connect with patients and families because they’ve never done it need to know how. And you need to teach us, and so that’s kind of where the ask is.

MR. HATLIE: Chris, if I can just respond to that. I mean, the answer is in this room, so there’s going to be a lot of people here -- and we’re going to spend most of the rest of the conference just generating those ideas from you and then trying to harvest them and feed them back much
in the way that Maret mentioned, so you can refine them and help us put together the strategies to make it happen.

MR. PECK: And remember, this is just the beginning. Question here or comment.

MS. WISE: Hi, my name is Leslie Wise and I actually work for Biomet, which is an orthopedic medical device company, so I kind of have a different hat, and as I’m listening to the conversation, all these thoughts are flying through my head because obviously industry does most of the research or at least funds most of the research, and as we talk about the random control trial, which is what is required of us to get FDA approval, so, while that model, even to me, seems not to be relevant, it’s required of us.

But we do have new tools, we have registries, we have real world data, we have claims evidence, we have lots of evidence that -- and we’re now beginning to understand that some of that evidence needs to include the patient’s voice, but I do think it’s important for patients, clinicians,
and industry to partner and collaborate around how we can change the paradigm of research so that the questions that get asked, the ways they get asked, and even the ways that intervention -- because as he stated earlier, it’s 17 years between the knowledge to where it’s applicable in the clinical environment. That’s way too long.

You know, some of our loved ones won’t be here 17 years later, so how do we shorten that time? And that’s about us all collaborating to make that process, that regulatory process more user friendly because even though the evidence is there, it doesn’t mean that we could always use the intervention sort of legally or, I don’t know if that’s the right term, but you guys know what I’m saying.

I think that that’s going to take everyone’s mindset to shorten that time and make that information available in a real way so that we change the lives of real people.

MS. BOWIE: So, if I might respond to that, Marty. Thank you for your question and
comments and what I think is also important is to understand that there has to be a value shift. I think in this room we’re probably preaching to the choir, but I think that as part of that choir our responsibility is to go back in to share with others. We are those mechanisms for dissemination. I am involved in a research study that is trying, for the first time, to use a participatory approach and it’s a study on Duchenne, which is a form of muscular dystrophy for boys, and their life expectancy is relatively short. And my role on the study is to make sure that there is fidelity to the partnership process, so there is industry, because most of those studies are done by pharmaceutical companies, there are bioethicists, there are clinicians, there are researchers, there’s the March of Dimes and other advocacy groups.

And when we had our first meeting I said, well, where are the parents? Where are the patients? And so now our research team includes parents and patients and none of us are experts. What’s required is that we each listen to each
other and that the decision-making process is a collaborative one and so I think it’s the beginnings, but we have a ways to go, but I think that there has to be a value shift. Industry has to be willing to be at the table and to listen as much as we, as researchers, have to be at the table and be willing to relinquish control and to think about different kinds of research study designs.

Yes, absolutely, we know that that’s the gold standard for, you know, for getting drugs approved and getting interventions approved in many cases, but it’s not the be all and end all.

MR. PECK: So, we have one more, and we may have time for one more, but if we can keep questions and comments -- answers --

MR. HATLIE: Jonathan, I’m going to take a moment, though, and highlight something about Kris and Vinny’s tour that they didn’t highlight. Vinny talked about the silent rage of the moms that were just outraged that this could happen to their kids. One of the ways they channeled that was in a timeline. They went into meetings with researchers
with a timeline, and it was short. It’s here’s what we expect, here’s when we’d like you to have it done, and the researchers responded really, really fast.

So, think about things that you could do as people. I mean, you could bring a timeline to the mix. And it can be faster than 17 years.

Thanks.

MS. PRICE: My name is Carol Price and I think Ben touched on something talking about economics, but I think there’s still a piece that has not been talked about that needs to be brought up, and that is the whole paradigm that’s within this country of how universities operate and how research is done and that deals with researchers doing research to maintain their labs, to get tenure within universities. How are we going to change that paradigm so that when I do research grant reviews, I stop seeing research one on one side of the country, the same research being done on the other side of the country, and the researchers not talking together?
[Applause.]

DR. BHUTANI: So, if I may just add to that and to the other previous comments, I think the story that families bring to us, which is what they brought to us, and have researchers understand the value of the quality of the data, not the quantity of the data, is key. That’s a lesson I learned from PICK, and it happened with having to deal then and translating the stories to the headwinds that I was dealing with from the establishment.

I mean, we had to challenge the American Academy of Pediatrics, JCAHO, AHRQ, CDC, I mean, all the experts were versed in the traditional model of research of randomized control trials. These families did not fit into randomized control trials, there were not enough patients, they were not on the radar screen.

So, the element here was to bring this into a dialogue, into a national dialogue, and unfortunately, part of the national dialogue takes in the medical/legal arena, which is not the right
arena.

The arena is an open, transparent system and it is for the universities and for the families to demand it. We need to do it together and I hope we can find a mechanism to do so, but I think it can be done.

MR. PECK: I’m going to experiment. We’ve got three mics and what we’re going to do is ask you to just put your question out -- put your question out, put your question out, no comments, speeches, and we’ll give the panel a minute to -- or a couple minutes to respond, and then we’re going to move so we can prep you for the next session, which is where you’ll all really get to put your ideas out.

So, you’re on first, sir.

MR. BIGGERS: Hi. My question is quick. I’m Greg Biggers. I’m a patient caregiver and I’m associated with three organizations Invoke Health, Genetic Alliance, and Genomera. I appreciate the humility that you all brought with your stories in just telling us your stories rather than trying to
give us advice or preach to us, but you do have
experiences, and sue this morning talked about
needing to create a sustainable architecture in
what we’re doing.

And so, I want to ask most or each of you
to give us just one or two sentence advice about
how can we scale this level of participation in
research.

MR. PECK: Thank you. Next question, sir.

PARTICIPANT: There have been a number of
comments on working with industry and financial
incentives and I think it is evident that what is
cost effective to the institution is not
necessarily cost effective to the patient, and the
question would be is the role and the value of
value based purchasing in realigning those
incentives through financial incentives so that
cost effectiveness is now tilted in the favor of
the patient, and we have -- our organization has
written a study on this which was recently
published in the Journal of Nursing Scholarship,
and it’s something I think is just imperative for
an area of research. Thank you.

MS. WILLIAMS: Hello. I’m Pamela Williams
and I’m at the Medical University of South
Carolina, and for those of us that have -- are
already in the path of engaging the community in
ture partnerships and empowerment, my question is,
to all of you, but especially the PICK group, what
are the social media features that you’ve found to
be the most successful in channeling the rage and
creating the sustainable architecture? What social
media has worked the best for you?

MS. SCHULZE: For PICK, we have used a
listserv, which we started probably about 10 or 11
years ago. It would be a wealth of material for
researchers to go through and see all of our
discussions on what medications might be working,
what kind of therapies might be working, is
auditory neuropathy, which is one of the features
of kernicterus, you know, does it work to have
cochlear implants or are hearing aids going to work
or FM systems? There’s just so much material
there.
I think the sustainability part is really difficult for organizations like PICK. We are a parent, volunteer organization. We have very little funding, almost none existent. I mean, whatever time we have, is spent caring for kids who have severe disabilities. Some of us are working full time on top of that, and in our spare time we do what we can to keep our nonprofit going.

So, there are a lot of pieces there for engaging patients in how do we support patients to be able to come to the table. It takes time. It takes having other people care for your kids while you’re off doing this. It’s a lot of pieces there that we need to think about and truly engaging people with that financial piece of it also.

And also with the social media piece, you know, it’s our listserv. Right now we have an Effected by Kernicterus Facebook group that’s specifically for parents, along with our Facebook page for the broader public, and our website.

So, those are key pieces. We use Survey Monkey a lot to get quick feedback from parents.
MR. PECK: Thanks. In just a couple minutes, let’s pass the mic down, you’ve heard questions, and give a response to whatever you think you can add.

MR. HEYWOOD: Well, I would just touch on the question about granting -- and I think you emphasized, but even going a little bit more, sort of aggressively. I mean, I think those who hold the dollars can enforce change in the system and I think an important part is having sunshine is huge, having the grants be public, having the data be public, in positive and negative versions of it. Don’t let research be funded that people can’t learn from. Just flat out and stop.

MS. BOWIE: I want to say similarly that the most important way to get your efforts sustained, one, is to make sure that they do get published and not published just in the peer review literature, but it has to be published in places and ways in which it gets to the intended beneficiaries.
The second thing that I wanted to also say is that I think when you build the capacity, you know, whether you’re coming in as a parent, as a volunteer, as a community member, as a patient, as a caregiver, as a researcher, when you’re building that capacity from within, that helps lead to sustainability.

When we don’t do that, when we’re not coming together and doing this collaboratively, then, you know, we really can’t take -- it seems to me that then when things go wrong, then we’re responsible for that.

I feel that we have to work collectively. Resources are thin everywhere and the best way to do this work is to bring all of those limited resources together and try and work through this. And yes, it does take time, but, you know, we can’t get weary in well doing.

DR. BHUTANI: So, if I may add, is as an academician what I’ve learned from my working relationship with PICK is, number one, do the right thing, number two is in form the society, and
number three, really make an effort to change lives. Now, that is something we can ask all of ourselves to be able to do through the final medium that is of a value to a researcher, and that is a peer review publication.

How many parents or families or patient representatives are there on the editorial board of national journals? Is there anybody on the New England Journal of Medicine or Lancet? All right? We want to be able to know if the research that has been reported has actually changed lives and does it inform society?

I think if we can set that standard, then the granting will come and the money will flow. It’s not the flow of money, it’s the flow of knowledge. Knowledge flows from our patients to our providers, not the other way around.

[Applause.]

MR. NORMAN: A simple thought from a fairly simple person. You know, I started this project just trying to help my small rural community, very simple. And then through the work
that we’ve done, we’ve gained a little bit of access into this world, which amazes me, and now I’ve learned enough to know that we can’t just stop people from being -- from going farther than here, people like us. Through Maret’s involvement in some other committees that have come off of our group work, she’s getting to the point where she is able to review proposals and help bring the community voice to the granting portion of this so that hopefully that way we can change how money can flow more towards patient oriented ideas.

So, we just need to keep bringing people up, somehow, and get them farther and farther up and higher up, like you were saying, in the journals.

MS. FELZIEN: And I want to address -- and that actually leads in nicely -- I want to address your question about the paradigm shift of changing how the university research machine works. And, you know, money is there to change this paradigm and through the clinical and translational science awards, the universities are seeking really, really
large money -- what’s it, in its 10th year -- and part of that involves community engagement. There has to be a community engagement piece to this.

PCORI has caused, you know, this amazing ripple effect throughout the states, but the -- so there’s this momentum and this buzz, however, what we find is it’s not the community side that’s on the -- we know we’re in the dark and we’ll rise to the challenge and we’ll learn, but really the issue is the research side, and all of the sudden the pressure is out there. You need to do research, you need to have community engagement, you need to have patients involved also, and they really don’t know how.

And the guide needs to be there. In Colorado we’ve done a few things and I can share that later, but that’s where the education needs to start. If we can get researchers immersed in community, think about that, then the community can become immersed in the research.

MR. HATLIE: And we have a breakout group on matchmaking, so perfect timing. One more
comment. I guess you’re up again. But should we
give a round of thanks?

[Applause.]

MS. SHERIDAN: Thank you. I was just
going to comment before I leave the stage. What a
remarkable demonstration of passion, of courage, of
the power of partnership, like Kris said. You have
all -- you’re identifying opportunities that we
want to define and make recommendations to PCORI
over the next few days, so, thank you, panel, and
you will be, I think, asked lots of questions while
you’re here.

Meanwhile, I’d like to -- you can go join
the gang. Let’s give them another applause.

[Applause.]

MS. SHERIDAN: This storytelling that we
heard this morning and the importance of bringing
patients and researchers together, I want to
announce that PCORI is capturing your stories at
this event. We have a videographer here. I’ve
been asked to -- many of you know this already, but
in your breakout area session, in room eight and
nine, we’ll be right around the corner from where you’re breaking out, we will be pulling you aside and asking you to share your story so PCORI can capture your stories and share this out there and continue this momentum.

And so, moving on to the breakout sessions, it’s my pleasure to introduce my boss, Dr. Anne Beal, who is the Deputy Executive Director. She and Joe, talking of passion and courage, had the courage to hire me and they have the passion to see this vision through that we’ve been developing.

So, Anne is going to share with you our breakout sessions and the various touch points of engagement, that we call it, so we can all really dig in this afternoon and develop those to make recommendations tomorrow.

So, Anne?

DR. BEAL: Thanks, Sue.

So, good morning. I have to say, as I’ve been walking around, it’s just been thrilling to see the energy in the room and to actually hear an
idea, that as you heard Sue and I talked about last July, really coming to fruition.

One of the other things that I noticed as I was watching the webcast is that as a lot of people were getting up, behind them I saw a number of PCORI staff, so all scattered throughout the audience and listening to the conversation is our PCORI staff, so I’m very thrilled to see them.

So, as Sue mentioned, this is an idea that really started as we’ve been trying to ask ourselves, how do really meaningfully engage patients in the work of PCORI? One of the things we like to say is that we take the P in PCORI very seriously, that this is just not a name, but it is really part of what it is that we want to do.

And so as we start to look at other experiences, one of the things that we discovered is that there’s been a lot of work on patient-centered care, and what we’re hearing a lot today is that there’s actually a lot of experience in terms of patient advocacy, but we really started to ask ourselves, what is the paradigm, then, for
patient-centered research and how is that different, how is it the same, how does it build on the experience that already exists in terms of patient-centered care.

One of the things I often remember, because I am a health services researcher, is that I once was at a conference where someone said that, you know, the data that we see are really the story of peoples’ lives with the tears removed, and what that means to me is what we’re seeing here are not just these esoteric numbers, what we’re seeing here is the actual impact on peoples’ lives from the work that we’re trying to do, and the data is really telling the story of people, and so when we talk about a patient-centered paradigm, it really is understanding that these are not just numbers on a wall, but each number, each observation represents a person.

And so really understanding that and the outcomes that are really relevant to patients is something that’s very important to us. And so as we were starting to think about, okay, so what is
it that we want to do at PCORI and how can we
really be patient-centered, we said, well, let’s
ask the patients, let’s ask them how we can do our
job best.

And so that’s really one of the major
outcomes that we’re looking for today is guidance
from you all and guidance from folks who are
watching us as we’re webcasting, to really help us
be patient-centered in our approach.

So, as we think about it, as a research
institute, there are essentially four activities
that we engage in. So, first is asking research
questions. Are we asking the right questions that
are really meaningful to you and that are really
going to impact care? And so, one of the breakout
sessions is focused just on that area.

The second thing that we do as researchers
or as a research institute is engage in actual
conduct and review of research, and so the other
breakout session is really going to be focused on
this engagement of patients in a meaningful way,
which is something that we’ve heard about quite
frequently in terms of really partnering with
patients in research.

The fourth area, and the fourth activity
that we have as PCORI is on dissemination. So,
we’ve heard a lot of discussion about we can no
longer tolerate the 17-year gap between getting new
information and then getting it into practice. And
so, as we’re thinking about then, what are going to
be the activities that PCORI is going to engage in
in terms of trying to reduce that gap, then how do
we do that in a way that really engages patients in
a meaningful way.

And then, lastly, one of the things that
PCORI is holding -- we’re holding ourselves
accountable for, is that we don’t want to do
research for research’s sake. We don’t want to do
research that’s just going to help someone get
promoted or get tenured. We want to do research
that is having an impact, and at the end of the
day, only the patient community is really going to
be able to tell us if we are having that desired
impact.
So, part of our assessment in terms of whether we’re having the desired outcomes will come from the patient community and what we want to hear is what are the best practices. What are the things that we should be putting into place now to be able to collect those data and collect that information as it comes out?

So, there are four breakout sessions that really tie to what we call our four touch points in terms of what it is that we do, but the fifth area is also related to the fact that we’re interested in thinking about how can we bring researchers together with patients, and not patients as subjects, but patients as partners.

And so we’re thinking about what are some of the promising practices that we could potentially develop around matchmaking and bringing people together so that if you are a researcher on the East Coast and are interested in working on a project with someone on the West Coast, then we’re able to do that, and fortunately we now have capability through virtual organizations and
through virtual capability to be able to do that.  
  
    So, this is one of the ideas that we’re exploring, but we want to hear from you what are some of the promising practices around that.  

    So, when you go out, you’re going to see that there will be instructions to go up to the five different breakout rooms, and if everyone looks at their card, you’re going to see that you have been assigned to a group, and so this is really very straightforward. Go out of these doors and then go to the left, and what you’ll see is then there’s the escalators that we all had to come down in order to get down here, all the breakout rooms are upstairs.  

    And so what we’re going to be doing is asking people to provide time within each of the breakout areas to be able to provide us with feedback on those five areas, and then there will be time in between to move to the different rooms, then to be able to make sure that we have an opportunity to hear from you on all five areas.  

    So, look at your numbers, follow the
instructions that are outside, and then we’ll be looking forward to hear from you.

Is there anything else that we need to tell them right now? All right, so be upstairs --

[Whereupon, the PCORI workshop concluded.]