

Aortic Dissection Collaborative
Report to the Community
May 15, 2021
Presentation Transcript



Sherene Shalhub (00:00):

All right. Well, we're excited that you are all here. Good morning everybody and good afternoon, wherever you are. For those of us who are just waking up, hopefully you have your coffee in hand and enjoying your Saturday morning. So thank you for spending the next couple of hours with us. A couple announcements, all lines are muted. We will mute the lines as we are going through the talk, but we will have the chat open for questions and discussion, so feel free to use that. And Sarah Lawrence will help monitor this.

Sherene Shalhub (00:29):

And I guess I should start with introductions. I'm presuming that everybody knows that this is Sherene Shalhub, I'm a vascular surgeon at the University of Washington, and I'm also the lead on this Aortic Dissection Collaborative engagement work that we're doing through PCORI. So stay tuned for the discussion. So what we'll do is we'll go through the materials in the slides in the first part of the hour and we will plan intentionally on finishing a little early, give everybody a bio break, refresh your coffee, stretch out your legs, and then come back at the top of the hour, so that'll be at 9:00 AM Pacific or noon Eastern, at that time, and then we will have the room open and available for discussion, and we look forward to that.

Sherene Shalhub (01:10):

We will also plan on transcribing the presentation. During our prior community session discussion people had asked to have the transcript made available, but also the live transcription. We've discussed this in our group and decided that we're not going to do the live transcription because frequently the voice recognition is not quite there yet, but we will transcribe it for those who need it.

Sherene Shalhub (01:37):

So we'll talk about briefly about the collaborative background. There are some new faces here and there are some folks that have been involved in this since the beginning, so it is a mixed group of people. So just to bring everybody to the same knowledge state, we'll just briefly talk about the background. And I'll introduce the stakeholders and then I'll talk about the survey. We presented to the community before the results of the survey during COVID time, but this is the original survey that we had deployed when we started this engagement work and it started prior to COVID, and then went through the COVID slump, and then continued after COVID. So it took quite a bit longer to really collect all that information. I'll give you an idea of how we developed the survey and then we'll go through the results. And then we'll talk about the next steps for the collaborative. And like I said, I'm looking forward to the Q&A session which I think would be the most robust discussion, hopefully, in the hour after this.

Sherene Shalhub (02:32):

Again, just to refresh everybody on terminology, aortic dissection is the tear in the aorta, and it can start in any part of the aorta. I always say the aorta looks like a candy cane, and the tear in the liner of aorta can occur at any location. From a surgeon's perspective or from a physician's perspective, we classify them into type A and type B. So if you look on the right hand side, in the salmon color and the purple color, this is the current classification of aortic dissections as Type A and type B. And this is relevant because we learn from this survey actually, that people may not know what dissection they have or don't think of it in terms of the anatomy that we think of, so that was one of the early lessons that we've learned.

Sherene Shalhub (03:21):

And I'm just going to move this screen because I can't see my slide anymore. Give me a second. All right. So the main issue is that engaging patients in research, I would say, is the new movement now in how we think about research, and that's predominantly because you are the folks living with this experience and we have to understand your experience in order for us to shape our research questions and how we focus our efforts to help the community living with aortic dissection. And certainly, we do know that you are living with sometimes a lot of options and there may not be solid data for why these options may be good options or not so great options. And so in order to achieve that knowledge and to move the science forward, it's very important that we understand this experience. And so we have to bridge the gap between what we do in a research basis and between what your lived experience looks like.

Sherene Shalhub (04:16):

And a word of thanks to our funding organization, which is the Patient Centered Outcomes Research Institute, and that's precisely what they were developed to do is to focus the research dollars, federal research dollars, towards research projects that put the patients at the center.

Sherene Shalhub (04:34):

And we started this process in August of 2019. So you can see we launched less than a year prior to COVID and with the goal of engaging patients. And historically, when we started, we said we wanted to only focus on people living with Type B aortic dissection, and then quickly, like I said, we learned that people don't think of their dissection that way and that we should actually be more inclusive.

Sherene Shalhub (05:00):

What we are trying to do, and this is our goal at the end of the three years of this work, is that we create this collaborative network of stakeholders that include you and our researchers, and we want to understand the patient's needs, like I mentioned, and then not only that, but we also have to ask the questions in a way that we can think about them in a way that we can answer the questions from a research perspective. Let me paraphrase, in a way that is amenable to study design. Meaning, the way I think about research is that there are questions that could be answered with simple research methodology, but there are questions that require complex research methodology, and part of this work together is to figure that out as well, not only what's important, but how can we answer the questions. And we're doing this by building these partnerships. And every time we have these meetings, we're practicing this co-education and co-learning together, we are learning from each other, and meanwhile, we continue to build this infrastructure and we keep these collaborative relationships.

Sherene Shalhub (05:58):

And this is how our governance structure looks, we have an advisory group, and I'll introduce them, and we have a stakeholder group, which I'll also introduced, and then we have the virtual research network. So what that means is the advisory group, and this is actually before the advisory group, this is our main group. So the co-leads are Peter Byers and myself, and here's our team members, Sarah, Jenney, and Courtney. And then here is our advisory group. So this is the advisory group which our patients or family members of patients living with aortic dissections, they were involved in writing the original grant application for the engagement award, and they direct a lot of the nuanced day to day decisions that we have to take when it comes to how we're proceeding with this project.

Sherene Shalhub (06:42):

And then we have the stakeholder group, and we don't have everybody pictured here, but we have the majority of people. So these are different people who've come in from different backgrounds and different perspectives, and they are our sounding board. So whenever we have projects, we run this by them, we have similar to this report to the community, we have reports to the stakeholder groups where we ask questions and then help get advice on directions, and with their counsel continue this work together. And then on top of that, part of the stakeholder group are all these patient facing organizations or research collaborative, that are also involved and form also the foundation of the

stakeholder group. So again, they help us with their outreach to the patient community, we run, again, ideas by them and this interaction of co-learning back and forth with the community.

Sherene Shalhub (07:33):

So what are we trying to achieve by May of 2022? I would say, we are now in this middle of this project here. This is the middle end of the project. What is in gray is the end product that we want to achieve moving forward. So to start, we worked on identifying the key research topics amenable to pragmatic trials and comparative effectiveness research. And this started with this survey that I'm going to tell you about today. And then the next process that's going to happen over the next year is this research prioritization, and I will talk about that at the end in terms of how we're moving forward with that. But ultimately, in 2022, we really want to gear up for putting in a lot of research applications that are focused on what is relevant to you as a community.

Sherene Shalhub (08:21):

So here's the original survey, which I am presenting today, this is how we developed it. This is an example of this co-learning experience and this back and forth that happens between us and the stakeholders. So we start brainstorming the topic, we talk about different topics that are of interest to the stakeholders, patients, clinicians, advocates, researchers, and talk about everything, just be as comprehensive as possible.

Sherene Shalhub (08:46):

Then we worked on developing the questions under each of the topics. And that went back and forth, and it's an iterative process in which the stakeholders look at the questions and we start saying, are we asking the question in a way that is understandable? Is it easy enough to read? Does it make sense? Is it congruent with your experience? So that goes back and forth and it's an iterative process. And then you can see that, again, that happens through a bunch of meetings, and this is, again, pre-COVID time, so we had actually Zoom meetings as well anyways because people are all over the country and as well as within Seattle, it's sometimes more convenient to meet this way. We also launched a bunch of these community seminars at the time and those are also available if you wanted to see the beginnings. But that was part of that developing of that survey.

Sherene Shalhub (09:37):

And then ultimately, the stakeholders tested the survey, made sure it was fine. And once it was ready to launch, we launched the survey. So the survey went live, like I said, before COVID and we had advertisers at the time and it was initially focused on people with Type B aortic dissection. And then COVID happened and we had to slow down and reevaluate where we were, and this is when we realized that, again, we want to open this to everybody with aortic dissection. So here we are.

Sherene Shalhub (10:10):

We had 459 respondents and 390 made it through the entire survey. So the survey took about 20 minutes to fill out, but you can tell me more because you filled out the survey, so that would be interesting to hear your perspective as well. And but 390, thankfully, finished the whole survey and then 459 gave us quite a bit of data. So even if people left the survey in the middle of the survey, we still collected that data and included in the results that I will show you.

Sherene Shalhub (10:42):

So who answered the survey? So you can see here that 36% of the respondents had a Type A aortic dissection and 44% had a Type B aortic dissection. But you can see also that there is a group of people who said that they had A and B, or they weren't sure what the type was. And from a surgeons perspective, this made sense after the fact that I've learned this now from the community, is frequently people are told they have a Type A and Type B dissection, but from a technical translation component or research aspect, that really means that they have a Type A that went all the way down the aorta.

Sherene Shalhub (11:22):

And so when we think of, like I said, the diagnosis we think of Type A as anything starting in the ascending aorta, Type B, anything starting in this rest of this aorta, as you can see here in purple. But the extent of the dissection is not really captured when we say A and B. So it makes sense that people will say, I have A and B because the aorta is dissected from the beginning to the abdomen, and so that makes sense in terms of why people answered that question. And then the unknown type was also interesting because that tells me that perhaps it wasn't even brought up in discussions during the healing time or after recovery. So obviously, there's an opportunity here that we want people to understand their anatomy and to what extent the aortic dissection affects their aorta.

Sherene Shalhub (12:10):

Where did people come from, the ones who answered the survey? So here's a map of the United States, and this is the predominantly, about two thirds of the respondents came from the United States. So the darker color shows the higher number of respondents and the lighter colors, so we have no response from Wyoming or Indiana, for example, or West Virginia, or Louisiana. So that tells you that we have no penetrance in these areas. And in terms of where else from around the world, we can see that 35 respondents came from Canada and then 67 respondents from Europe. So that's the predominant, and there was a smaller numbers from around the world, we appreciate those responses as well. But that matches what we thought we would see predominantly because we're using social media, right. This survey went out on social media, and went out on Twitter, and LinkedIn, and Facebook, and I'll show you some interesting data on the social media aspect of things. But this is where you came from, most of the respondents.

Sherene Shalhub (13:12):

We also asked if you knew that you were at risk for aortic dissection. And you can see here's the percentage is on the left hand side. So that's 26% of the people. So one in four knew that they had a risk factor for aortic dissection, which also means that three out of four people, who had aortic dissection, did not know they were at risk. We also asked folks, if after the dissection, were you told that you have a condition that would have contributed to the aortic dissection? And over half the people who responded to the survey said, "Yes, somebody told us we had a risk factor."

Sherene Shalhub (13:54):

We asked people if they've had genetic testing. This is something, just to give you some historical perspective, we have known, we being the research community has known that aortic dissection, about 20% of people with aortic dissection have a family history of aortic dissection, meaning it runs in families. And so we were wondering if folks who answered the survey have had genetic testing. And so you can see that 50, over half have had genetic testing in this circumstance, and you can see that two thirds had a positive genetic testing, it identified one of the known gene variants that cause aortic dissections. And then you can see that about less than a quarter had negative genetic testing. And similarly, there was people who had variants of unknown significance.

Sherene Shalhub (14:47):

And this is actually important for a couple of reasons. One, it tells us that you the community who are engaged with us and who are answering the surveys, a high proportion of you who have had Genetic testing. So that means, compared to what we would expect in the world of aortic dissections, we don't think half the people are getting genetic testing at the moment and for a lot of reasons. One is that insurance has been slow to approve genetic testing as something that is part of the clinical care pathway, but that also changing over time. So that was an interesting thing to know.

Sherene Shalhub (15:27):

The other thing is this negative genetic testing is also important because even now, in our contemporary era, when we do genetic testing for people who have a family history, the majority of them, about 60%, will have negative testing. And that also just shows us that the limits of where we are, that there's absolutely more room for novel gene discovery and there's a lot of researchers working on that. And particularly, Diana Miller with this lab in Houston is doing a lot of this novel gene discovery in families.

Sherene Shalhub (16:00):

In terms of people who know what conditions they have, or were told they have a certain condition, you can see that the most common condition was Marfan syndrome. And this is 141 people have replied saying they have Marfan syndrome, and that accounted for about 30% of our respondents. Again, Marfan syndrome, in and of itself, is a known risk factor for aortic dissection, but when we look at the literature and say, what is the percentage of people with dissections who have Marfan syndrome? Those percentages are low, they're less than 5%. So that tells us, again, that we through our survey because of the nature of who we are collaborating with, in our stakeholder group, for example, the Marfan Foundation has a strong reach and strong presence on social media that help us reach the community of people who have Marfan syndrome, but perhaps not so much the community of people who have aortic dissections without a known cause.

Sherene Shalhub (17:00):

Well what about the other genetic condition? So you can see about 15% said they had a family history, Loeys-Dietz syndrome was also represented, so it was around 7%. And compared to Marfan syndrome, that was not unexpected. If we look at the numbers, we do have smaller numbers of people living with Loeys-Dietz compared to Marfan syndrome, so that at least made sense. And same thing with Vascular Ehlers-Danlos syndrome, the numbers were, again, smaller. And we had some people, ACTA2 was not on the list of options, it was more to say, yes, I have another condition. And we said, well, what is the other condition? So some people typed in that they had ACTA2. So that also taught us that maybe in the future, when we reach out, we want to be maybe more specific about what we're asking and what people think. But that was actually also informative to know that people knew what their genetic condition was.

Sherene Shalhub (17:51):

So based on this, and Timo actually made this observation and said, "Well half our respondents have heritable aortic disease and the rest of the group don't, so is the experience different, is the lived experience different just based on knowing a diagnosis?" And so you can see we divided the groups into two cohorts, one group that has the heritable aortic aortopathy and then the rest of the group, and we said, let's compare those experiences.

Sherene Shalhub (18:23):

So here's one comparison. And this is, it's a busy slide but this is the question that says, how far, on average, do you travel to get your medical care? And we showed it in miles and in kilometers, just because we had a broad respondents group. And so on the bottom you'll see this is less than 10 miles of travel, and all the way in the top people who traveled 50 to 100 miles to get to their health care providers.

Sherene Shalhub (18:50):

So let's start with the top. Sorry. Here is the number of participants, this is the number of participants or percentages, actually, this is percentages. So one in five, so 20% of people travel over 50 miles to get to their health care providers. And that's very, very important to know because that is quite a burden of travel, and time, and arrangements to be able to seek medical care. In comparison, what about the people that lived close to health care? So less than 10 miles. So you can see in this group that the majority of people who don't have a heritable aortopathy, live close to a health care center that can give them some care. But once people have a diagnosis of heritable aortopathy, there's less of them that live close to centers that have that specialized care, so that's about less than half.

Sherene Shalhub (19:45):

So you can see that, again, in the reddish color, in the salmon color, this is the responses of people with heritable aortopathy, and then in gray are the people who don't have a heritable aortopathy. So again, most people with heritable aortic disease have to travel longer distances to seek the care that is appropriate for them, compared to folks who have a generic diagnosis of aortic dissection. And this will be interesting again, when we discuss later on, open up for questions.

Sherene Shalhub (20:18):

We also asked, what is the most frustrating aspects of the aortic dissection diagnosis? In this case, it wasn't a ranking question, it was mostly, here are the things that our advisors and stakeholders said, these are frustrations, let's ask the rest of the community if they are also frustrated by these components of the diagnosis, and we said, check everything that applies. And we'll spend some time on this. I'm going to read all the questions that are here just to refresh people's memories, and then we'll go through what percentage of people said this is important to them.

Sherene Shalhub (20:53):

So fear of death due to another aortic dissection or rupture, fear of needing another surgery or the possibility of needing other interventions. There was a question about mental health, just dealing in general with fear, depression, and anxiety. Other questions we asked were being frustrated that care providers are not knowledgeable about aortic dissections or being frustrated in the decision making process, having to make decisions that may impact their their life. Having frustration with maybe emergency rooms being unfamiliar with aortic dissections. There was frustrations with work relationship or lifestyle strains as a result of the diagnosis. Frustrations with not having a cure or treatment available. Financial strain was also a frustration. Initially, things that scored lower in terms of frustration scales was, just not enough research about the condition, access to ongoing support, inability to get information quickly, and no in-person supports in my area.

Sherene Shalhub (21:59):

So the top three that had the most responses were related to fear, anxiety, and depression. This was really educational for us as a community, from a research perspective, to say this is something that is not well addressed by the professional community dealing with patients who have aortic dissections. That this component about worry about the consequences of the dissection, or worry about surgery, or just being generally dealing with depression and anxiety. So those scored the highest or had the most number of responses.

Sherene Shalhub (22:38):

The corollary to that, which was also interesting, is that not having an in person support group in my area scored the lowest, only one in five people or less than one in five people said this is a source of frustration. So that was also interesting to compare and contrast the source of frustration, the fear, and the anxiety, and the depression, but also that there's just no support group. Now one explanation could be, and this is going to be good to discuss how you interpret this, but one explanation could be that maybe in person support groups are not as important because there's an online community perhaps that takes the place of the in person support group, but that would be something that we should discuss a little bit more deeply.

Sherene Shalhub (23:27):

In terms of knowledge about aortic dissections, you can see that not quite half the people felt, about 40%, 45% felt that the care providers were not particularly knowledgeable about aortic dissection. Certainly, this is an item that we can work harder on to make sure that this is not the case for everybody. The decision making was also about 45% of the people had struggles or frustrations with the decision making process. And then you would expect, as we expected to see, that there's frustrations with the impact on lifestyle or financial strains, so that's also important.

Sherene Shalhub (24:05):

The last point I'm going to make on this particular slide has to do with information. Access to ongoing support and information, so one in three people felt that, that was a frustration, that they didn't have enough access to support and information, and one in five people felt that they couldn't get information fast enough in the way that, for them, that was appropriate and in an expeditious manner. So that's also another point for discussion. We did ask you though, where do you get information about your aortic dissection that is most useful for you? And again, we did the comparison here between people who have a named condition, meaning a heritable aortopathy versus people who had dissection. And again, in the reddish color, are the people with heritable aortopathies and in the grayish color the people who have aortic dissections. So again I'll go through that again.

Sherene Shalhub (25:01):

So internet searches were very common in terms of how people get their information. So 50%, half the people with heritable aortopathies said they use internet searches to get information about aortic dissections. And two thirds of the people with aortic dissections in general, not heritable aortopathies, also use the internet. So the internet is a very powerful medium by which people get information about aortic dissection that is useful for them. So that means the question not only said, are you just getting information there, but is it the most useful information that you're getting? So the internet searches are very important. Social media is also an important tool to get useful information. Half the people with aortic dissection said, yes, this is what they said was most useful to them in social media, about a third of the people said social media was useful.

Sherene Shalhub (25:54):

Now let's look at the other side, well, what about the physicians? And I highlighted two here because they scored relatively highest than anybody else. But people get information from their cardiologist, and people get information from their vascular surgeons. So the cardiologist group, about two thirds of the folks with a heritable aortopathy, clearly have a cardiologist and they get their most useful information from the cardiologist. Whereas a third of the people who had aortic dissection that is not a heritable condition, found their experience with their cardiologist to give them useful information. Vascular surgeons fared about equally for both groups. And then primary care physicians scored very low compared to internet searches or specialty care. So only 11% of people with heritable aortopathies and about one in five people with aortic dissection said their primary care physician gave them the most useful information.

Sherene Shalhub (26:58):

And then here is the social media part, we said, what social media do you use to connect with people with aortic dissection? Facebook is the winner in this one, 70% of people with aortic dissections use Facebook as a platform to connect with other people with aortic dissections. And in fact, quite a few of our stakeholders in this group run active Facebook support groups. And it makes sense that the people who responded to this survey saw the survey there, were more likely to engage with us via that avenue. So it makes sense that Facebook is one of those mediums or scored the highest in that. Twitter was less common, Instagram, Pinterest, but you can also see that a third of the people who respond to our survey, they don't use social media to connect with the aortic dissection community. But still there's a third of the community does not use social media.

Sherene Shalhub (28:03):

This is now the crux of all this work that we're doing, meaning, we're leading up to the research questions that are important to people, where we said, which of these questions about aortic dissection are important to you? Now please check all that apply. So this was not a prioritization question. This is more just trying to explore with you what is important to you. And the answers to this question is really the foundation for the work that we're doing over the next year.

Sherene Shalhub (28:32):

So we divided the questions into bins that have to do with the type of questions that they are into genetics, surgery, and just general overall management. And again, I will read those questions out for those who are listening in. So under management, things like knowing what my blood pressure goal should be, almost half the people said this was important to them. Knowing how often I need screening, this is again very relevant because we know this is a condition that requires lifelong follow up and screening or surveillance with CT scans, or Echoes, or MRIs depending on where the dissection location is. So knowing how often I need this, that's over half the folks said that this was important.

Sherene Shalhub (29:20):

Also, knowing the most effective medicines to take. And this is actually a very important topic because certainly people are on multiple medications, and there are side effects to medications, and so the end of the day you want to know, what is the most effective medication to take? And that's almost 60%. And then lastly, just globally, 70% of the people

said, it's really important to understand just the best way to manage my condition. What is the best way to manage my condition?

Sherene Shalhub (29:46):

In terms of surgery questions, the one that got a lot of likes, if you will, was effectiveness of new surgical techniques like stent procedures. This is a hot topic actually in the vascular surgery and the cardiac surgery world in terms of we also want to know how effective are stent procedures. And this matched, in a way, the community mirrored the same concern to say, are these things effective? And we need to know more about that. Also, similarly, what is the best type of surgery for my aorta? And knowing when I need surgery. So not just when do I need surgery, but what's the best way to fix my aorta if I need it?

Sherene Shalhub (30:28):

Genetics on the other hand didn't seem to get a lot of strong responses or strong favors, if you will, but knowing of genetic testing would help manage my manage my condition, that was a third of the people who responded. And you can see, similarly, follow up and knowing what follow up my family members need. And again, this is an important gap, I think, in the knowledge because again, it's very important that we highlight that this condition can be genetic and therefore, it not only affects the person affected with aortic dissection, but we have an opportunity to perhaps prevent dissections in the family members and we should screen for family members, at least we counsel people on that. But you can see that for some people they felt that, from a research perspective, maybe that's not so important. But that was an interesting point that we had a lot of discussions about as a group. And we'll leave that for, again, our discussion about where this factors in.

Sherene Shalhub (31:34):

So here's where we are now, we divided the topics that were identified. We expected surgery to be an important topic, we expected medications to be an important topic. We are driven to also answer the question about pregnancy, we didn't have a lot of pregnancy response women who have had pregnancies and had aortic dissection, there were not a lot of those respondents in the group, but we thought this is an important population that we need to address because they're historically understudied and there's not just a lot of research dedicated to them, so we put that on there.

Sherene Shalhub (32:08):

The two components that were not necessarily, from a researcher side of stakeholders, we're not expecting to see that, has to do with education and mental health. I showed you earlier that mental health came out to be a very strong topic of interest and a topic of concern by people living with aortic dissection, so now it has its own box of something that we have to pay attention to. And then education, and you are all familiar with a lot of the stakeholders in the group and you are yourself on this call, many of you are very actively involved in increasing education. Not only education for people living with aortic dissections, but education for other providers in the healthcare specialties who are trying to improve their education so they understand the experience or how to take care of people with aortic dissection.

Sherene Shalhub (32:57):

So we divided now into six groups or six working groups that are a mixed group of stakeholders, meaning, each of these groups will have surgeons, physicians, patients, perhaps we're trying to increase also family members in each of these groups, and we've included also medical students because we thought getting the new generation of minds early on, getting them engaged and interested in aortic dissections will help us with addressing a lot of this education component as well, so we included them on the team. And so this is our working groups at the moment.

Sherene Shalhub (33:34):

So where we are now going, back to the next steps. We have identified the key topics, so those were the six key topic areas that we thought are important. And this was generated not only from this survey, but also we had interviews, there are a lot of you who have interviewed with Jenny Lee, and based on that information as well, we were able to identify those topics. And now we are in the process of this research prioritization component of things. So going back to

these groups. And actually what's missing in this group is telehealth because we also added a telehealth component to this.

Sherene Shalhub (34:11):

Each of these groups are going to review the current body of literature where we know and identify the areas in which there are gaps. And specifically, from the lens of looking at the results of this survey that you have filled out to say, here are the gaps in what we currently know. And because these are the gaps, within that task, we have to also say, how can we address these gaps? What research or what efforts need to be made in order to start addressing these areas of gaps? So for example, in the education group, and Timo is in this group as well and he feels very strongly about this, so definitely we'll have room during the Q&A to talk about this.

Sherene Shalhub (34:53):

But in the education group, we need to develop better materials for people so that they can find this information in a reliable manner, whether they're searching the internet, but also that their own physicians will have access to similar materials that they can also give their patients, because again, not everybody who is living with an aortic dissection uses the internet as a form of access to educational material, and certainly, we want physicians and hospitals to also have that. So that's one example of that task for this group.

Sherene Shalhub (35:23):

So like I said, in these groups, people will conduct these landscape reviews. And we want to know what research or initiatives have been conducted. And if there's active research, where's that research, currently, where does it stand? And can we highlight, can we shine the light on these efforts that are happening? So for example, Siddharth Prakash at UT Houston, is doing work with exercise and ambulatory blood pressure monitoring during exercise, because that has always been an area of concern, well, how much should I exercise? How do I control my blood pressure during exercise? So we already know that this work is happening, so we want to shine the light on that and say, look, there's this effort that is happening, can we help him enroll patients to answer that question and so on? So that's one part of this work that we're doing is to highlight those researchers.

Sherene Shalhub (36:19):

And then also, again, identify the gaps and opportunities, perhaps there are not specific initiatives to answer those questions, so what's left? What hasn't been answered? What needs to be answered? And then within those, can we answer some of those quickly with the current resources that we have? There are datasets across the country where researchers have been reporting what we call single center experiences, where they report the results on people with aortic dissections presenting at a university system. But perhaps is there a way and an opportunity to harmonize that data, meaning, bring all these datasets together into one giant data set that can have more power to answer some of the questions.

Sherene Shalhub (37:02):

And then which of the questions lend themselves into comparative effectiveness research? Comparative effectiveness research, this is what PCORI specifically wants to fund or one of the aspects of what PCORI finds. But this is to say, here's treatment A and here's treatment B, or here's management A and here's management B, people have a choice or physicians and patients discuss these choices and say, there's not strong data for A or B, so let's talk about how we're going to approach A or B, but we really don't know if A is better than B or vice versa. So the in a comparative effectiveness research, we say, here's what happens on a day to day basis in every doctor's office, and can we compare those two approaches and see which one is better? So we have to identify what those questions are because those are the things that we now can turn back and submit for applications for larger grants to answer those questions.

Sherene Shalhub (37:59):

Now, you as a community who are engaged with us and who are watching this, part of our co-learning experience is to understand how research works. So just like we, as a research community, are wanting to understand your experience,

we also want you to understand how we see research and how we do research. So PCORI has rolled out this program of virtual web based free seminars, if you will, that are focused on research fundamentals. And the goal of the PCORI like I said, is to empower you as a community who are not necessarily living in the research world, to understand how research is done and how to be allies and collaborators in this research space.

Sherene Shalhub (38:42):

So I do encourage you to spend some time, particularly if you are working in our working groups, or interested in volunteering to be part of the working groups, or even if you just are curious, right, even if you say, you know what, I don't have the bandwidth and I'm not interested in necessarily being in a working group because I just can't afford the time to do that, but I am interested in being part of the bigger virtual research network, and I'm going to answer these surveys that you're going to send out to me in the future. So if you are interested in any way in research, this is a thing that you can easily access, it is free, and here are the topics. There are five modules, and these are also on my list of things to watch because this is, again, a recent program, but here's the link and this is on PCORI.

Sherene Shalhub (39:30):

So module one is developing research questions. And module two is designing the research study. This is very relevant, again, the work that we're doing over the next three months. Planning patient centered consent and study protocols, that's another module. And then sampling, recruiting, and retaining study participants, this is important to all of us in the research world. And lastly, understanding and sharing research findings. We have used this model of again, coming back to you as a community and sharing what we found as a way to reach you, but perhaps maybe this is not the best way to get the data to you. And again, we want to work with you to say, what is the best way to share that information? From a scientific perspective, our lingo is to present at meetings, and get posters or podium talk, and then publish the research in journals, so that's the currency of people living in the research world. But that is different than what is important to you. And so part of, again, our learning is to understand, how do we get the information to you? So I encourage you to check that out.

Sherene Shalhub (40:33):

And then in terms of what we're doing next, so in May, this is we're halfway through May now, we are making the working group assignments, adding people to the groups, and again, this is an opportunity that any of you who are watching who are interested, please, contact us and let us know that you're interested, if you want to participate in that way. It's going to be an intense time between now and October. In June, we are going to start having groups present, these working groups are going to present their findings to the stakeholder group, so we will have a series of these meetings.

Sherene Shalhub (41:08):

When we had applied for this grant, our intent was to have a one day, in person meeting. That was part of what we had proposed and we were hoping to have a meeting where in which patients, and stakeholders, and family members, and researchers can all come together into one real space where we had these findings in these projects. Unfortunately, things are still in flux and there's really not an in person meeting on the horizon. So what we decided to do is because again, our capacity watchers, you've been listening to me now for 45 minutes and if you've dozed off, that's okay. So it's hard, right? It's hard to do this virtually. And so we divided the product, if you will, of each of these working groups into different virtual meeting sessions, and those combined will be the equivalent of that in person day meeting.

Sherene Shalhub (41:56):

So the surgery group, because we feel like we know a lot about what's happening in the surgery literature, we decided that we would start with this group in June as the first meeting, but then we will continue throughout July, and August, and September for people to present and draft that information.

Sherene Shalhub (42:12):

By October, the product of this work, we will also because again, remember the currency is manuscripts in the world of the researcher world or the clinician world, so all this work will be, each of these groups will have their manuscripts and then we will put all that together to a journal basically called, seminars of vascular surgery, the editor has kindly agreed to have an issue dedicated to aortic dissection engagement and in this work that we are doing, and we will publish that. And I think this is a good model in terms of giving back the information to the research community. Other groups in PCORI have done similar things.

Sherene Shalhub (42:51):

And in fact, I was on the rare disease advisory panel yesterday, and the necrotizing enterocolitis, which is a condition very rare and it affects young children at birth, they have done similar engagement work, and that's exactly how they publish their findings is through a special issue of a journal. So it was interesting because part of this discussion in the rare disease advisory panel is that many groups that are focused on different disease conditions are performing similar methodology in terms of how to get there and get the information. So not only do we have an opportunity to learn from each other in this group and craft our way through this, but also we can look at other groups that have done similar work and see what else they have done to reach out to their communities.

Sherene Shalhub (43:38):

The other thing that I don't have a slide for but that is on the agenda is we are having also a meeting with industry, representation from industry. We for the last couple years have talked a lot about, how do we engage folks in industry to help align what they are doing with the interest of patients? Now we do know that industry spends a significant amount of money on campaigning or advertising and outreach to the community and developing educational materials, so can we find a mutually agreeable space that addresses the concerns for patients and is driven by what patients need not, again, what industry think is important for patients? So the whole bottom line is you have to be at the center of anything that is happening, whether it's industry, research, or educational materials. So that is what we're trying to do.

Sherene Shalhub (44:29):

So at this point, this is the perfect time for a bio break, you will have 12 minutes. I am going to unmute and go off camera, but we will leave the room open and people if they want to hang out and chat, that's fine. And then we'll come back at the top of the hour and we'll start addressing ... I see that there's 30 comments in the chat boxes, and I'm looking forward to having a robust discussion. I really appreciate your time this morning. I know it's early for some folks, it's late for some folks, and it's on a Saturday, but thank you for being here and I'll see you in 12 minutes.

Sarah Lawrence (45:00):

Everyone is muted but you should have the ability to unmute yourself if people wanted to chat. Feel free to do that.