**2018 Online KT Conference:**

**Engaging Ways to Engage Stakeholders**

How Do You Know Stakeholders Have an Impact on Research?

Thomas Concannon

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>> STEVEN BOYDSTON: Our first presenter for today is Thomas Concannon who is a senior policy researcher at The Rand Corporation. He is also an assistant professor of medicine at Tufts University, School of Medicine, and associate director of comparative effectiveness research programs at Tufts Clinical Translational Science Institute. His presentation: “How Do You Know Stakeholders Have an Impact on Research?” will offer practical guidance for designing a multi-stakeholder engagement approach for a given project or study. If you have any questions during the presentation, please ask them in the chat box and after the presentation Donna Mitrani will lead the interactive discussion with reactors and conference participants. Thomas, are you ready to begin?

>> THOMAS CONCANNON: Thanks. Thank you for the handoff on the introduction. I would like to start off the presentation today with just a little more background on me and why this material matters to me. Prior to my career in research I spent about ten years as a patient advocate working with people living with HIV and AIDS at a time when medicines were not great, and folks were facing the end of life and much of what I'm presenting here today rose out of knowledge and experience I had during that part of my career. And what I have been doing for the past ten years is my best attempt in partnerships to translate those experiences in the research world in to practical guidance that researchers can now use to engage with and involve stakeholders in their work.   
 My talk today starts off with two motivations. One, a positive motivation from 1987. It is a case study of engagement by patients in research and health care. Followed by a negative motivation, a sort of cautionary tale about whatnot to do from 2009, whatnot to do when considering engagement activities. I want to then follow up with some of the work I and my colleagues including both researchers and stakeholders are developed around how to plan engagement. And then I want to conclude with developing work that again am working on with colleagues both researchers and stakeholders on how measuring how we will know if engagement works.   
 So, motivation No. 1 from 1987, this is a picture of a young man being arrested. He is actually being arrested at ‑‑ after having chained himself to the balcony of the New York Stock Exchange. After the arrest he said this is only round 1. Lower the price or we'll escalate. When I am giving this talk to a room full of students I often ask who this person might be and what he was protesting. And I will invite folks to make comments in the chat window as I speak. And feel free to call that out if you know what this is about. But I will move on to tell you the answer right now. This is Peter Staley in 1989 being arrested for a demonstration protesting the price of ACT, the first anti‑retroviral drug that was released for people living with HIV in that same year. It was released at a price of $10,000 a year which nowadays seems quite low relative to other expensive medication, but at that time was, if not the most expensive, quite an expensive intervention. People with living with HIV and AIDS were concerned that they would not be able to afford this potentially life‑saving medication. So, they formed a demonstration. At this particular demonstration they had chained themselves successfully to the New York Stock Exchange balcony and disrupted the opening bell and four days after the demonstration buckled and lowered the price by 20%, they being the manufacturer at the time of this medication. From then on, the industry said it is probably smarter to try to talk to activists and placate them as much as we can. This is a quote by Peter Staley speaking years later on in his demonstration. Six months the FDA reduced it in half and brought the cost in to a much more affordable range.   
 So back to 1987 when ACT UP. In which people living with HIV had faced devastating illnesses, a high risk of mortality at 31 deaths in 1981 and a cumulative 18,500 deaths in 1990. They recognized the inaction of most policymakers. It was widely known that the President of the United States had not uttered the word HIV in public until that year. Perceived ‑‑ they also faced a perceived grindingly low pace of research in a time when care was urgently needed. So, ACT UP formed to "take direct action" to end the AIDS crisis. Imagine now 30 years later, this is a really profound change in the relationship of patients to the health care system. This was a group of patients who did not have a model of other activists to follow that was ‑‑ that would help them form their strategy. So, they went everywhere. No corner of health care was off limits. Members of ACT UP engaged with health care makers as partners and they trained themselves. They became self‑taught experts in drug development and immunology and biostatistics and in regulatory affairs. Through the work that they took on they achieved dramatic change. I described the demonstration against bureaus welcome and the propheteering from AIDS related drugs. And they worked with NIH and FDA to facilitate drug development. And they worked with NIH and FDA to establish alternatives to strict placebo control in randomized control trials.

They helped form community research initiatives which took research out of academic medical centers and enabled enrollment in to trials in community‑based organizations. And this was a joint effort of stakeholders and NIH and AHCPR now known as ARC. They worked on health care delivery, working with Health and Human Services leadership on the implementation of the Ryan White Care Act which became a multi‑billion-dollar program to support people living with HIV. And they worked with the CDC and NIH on creating an updated definition of AIDS in 1993. Making the condition more consonant in the experience of people living with ‑‑ injection drug users. HIV treatment today is now known as one of the great home runs for drug therapy. And really ACT UP became part of the success story that culminated in this discovery for millions of people in the United States across the globe. The real upshot is that ACT UP became part of the success story and activism by people living with HIV and AIDS really encourage waves of new patients-initiated engagement in health care and research. But it is interesting, I made the transition in to research around 2001. Finished my Ph.D. in 2006 and as I did that, I became ‑‑ began to understand that research academic research in particular was mostly shielded from patient activism. But that was changing at the time.

At the time there was new funding for this thing called comparative effectiveness research, a style or an approach to research. Funded by the American recovery and re investment act and the Affordable Care Act that introduced new requirements for patient and other stakeholder engagement and the foundation of an organization called the patient centered outcomes research institute or PCORI that developed detailed guidance on engagement in the work of research. And then PCORI guidance since 2009 has influenced funding from AHRQ, the agency for health care research and quality, from the National Institutes of Health and from other health and human service agencies. As this transaction happened I heard from a colleague, I don't know if this is worth it. This is trying to involve patients in the work of research. Training. It is hard to do. And I don't know if my effort here will be worth it and I ‑‑ it made me think of an experience I had as a patient advocate when talking with other patient advocates I heard someone say this job would be great if there were no patients. It was meant as a joke in part because, you know, it was ‑‑ it was a patient bringing personal concerns time after time after time about the way that programs were run and delivered. Made jobs that much harder. And so, what I did at that time, when I heard this from a researcher many years later I began to think why not take the experience I had of learning about how to engage with patients back as an advocate. And translate this to researchers? I partnered with at the time about 25 stakeholders and other researchers to begin writing guidance to other researchers. And now it is grown to MUs and it involves researchers and stakeholders from the United States, from Canada, Australia and the UK and has nearly 100 members.

And we ask ourselves if researchers engage patients and other stakeholders will there be other success stories like ACT UP. This is a person speaking on Larry King Live CNN who was talking about a failure in recent research in 2009 in which she said please ask about the recommendations made by this research. Makes it clear that we need to have better messages. And knowing this is 2009, if you want to weigh in the chat window of what you think this might be about. This is Diana Petti speaking on the widespread opposition that emerged to a new release of guidelines of mammography screening published by Federal Government includes experts and engaging with some stakeholders. There are 16 volunteer members who are experts in prevention, evidence‑based medicine and primary care and they engage with partner organizations outside of the task force such as medical societies, insurers and consumer organizations in activities before their work gets under way doing guideline development.

They engage with those folks to talk identification and nomination and prioritization of the topics that come forward and then once guidelines are completed, they work with these external partners on dissemination of the new guideline. But the task force does not engage with all stakeholders during guideline development. They exclude stakeholders who do not have methodological expertise and that principally includes patients and excludes certain stakeholders that they have a perceived conflict of interest. And this includes stakeholders like the for‑profit stakeholders in industry, insurance employers and some subspecialties of medicine.

A little back on the guideline that was released. It was re ‑‑ it was reissued or had been existing guideline. And this review found that mammography was successful at reducing breast cancer mortality by 15% in women ages 39 to 49. 14% in women ages 50 to 59 and 32% in women ages 60 to 69. They found that the younger group 39 to 49 was more likely to have false diagnosis than the other two groups. The recommendations were for routine biennial, that means every other year screening for women ages 50 to 74 I'll scroll back to the next ‑‑ to the last screen. 50 to 74 is the last two groups of their study. They said that mammography for women younger than 50 was recommended only after considering individual factors. And that it should be available and not routine. Women of all ages, any age should talk with their doctors about their risk for breast cancer and this is really important. The guideline said women should talk to their doctors about their preferences for screening. This screening should be available and if women have strong preferences for screening by all means they should get it. This part of the guideline was really seen as contentious. Mammography of women was the most contentious. It was recommended for women only younger than 50, only after considering individual factors and patient preferences. You would have thought from the response after the release of this guideline that this was the only part of the guideline. And that's what Diana Petti was saying that they had not messaged the full set of recommendations well enough. The release of this guideline, released from radiologists, oncologists and patients and advocacy groups. And I would have to ask if you want to weigh in on the chat window again who are these individuals. In the context of what I have been talking about. These are the groups that have been excluded from guideline development. They said that new guidelines "would turn back the clock" on the war on breast cancer and they got bipartisan legislation.

Many physicians and institutions revised these guidelines. In the end guidelines did not alter screening practices. To issue the guidelines in the way that they did. My message is that this wasn't a problem of just messaging. That this was a problem of exclusion of stakeholders. That in this case exclusions backfired on the developer of these guidelines. I am the ‑‑ the consortium I work with recommended that researchers use a structured process to identify and recruit all stakeholders, what is a stakeholder. A stakeholder is a person who ‑‑ a stakeholder of research is a person who uses research to make decisions or is affected by the decisions that are made on the basis of research and all stakeholders are experts in their own views including patients that conflict of interest can be managed and not an excuse to exclude industry and subspecialists.   
 We also recommend that researchers understand how we engage is an important factor. We really need to start by preparing everyone. All of the nonresearchers come to the table to work with us, should get some preparation and understand the basis of what we are doing and the methods that we do and how we plan to inform new decisions after the research is completed. Stakeholders ultimately need to meet each other at the same place in the same time. And the reason for this is that we need as researchers to see how stakeholders view a problem that we are trying to study. Anticipate where areas of disagreement are and agreement. That it is important for us as researchers to create and sustain relationships with nonresearchers. That sometimes meetings with between researchers and nonresearchers should be led by experts. And that we should choose the modes and methods by which we interact, when I say nonresearchers by the way I want to point out that almost no person fits cleaning in to a researcher or nonresearcher designation. It is where the principle identification is. It is important to choose modes and methods of involvement very carefully and get advice. Get advice from the many emerging experts on engagement. We advise that engagement is like any other activity and research. You can do it right and though resources at it and spend time on it and you can still fail. There is no guarantee of success. Nor in the approach you take for stakeholder engagement. It is like any other activity.

It does require tradeoffs with other goals of research and they include personnel time and resources. So on to the nuts and bolts here, how to plan engagement activities. We recommend four considerations before you begin as a researcher engaging with stakeholders. Think first about why you are working with stakeholders. It is important to think about the intrinsic reason. Intrinsic reasons are the reasons you would choose just because it is the right thing to do. In other words, we recognize that patients and policymakers and insurers are usually actually people who have dignity autonomy and have an interest in the way our ‑‑ that our share of the federal budget is spent. It is just intrinsically the right thing to do. Be accountable to those people. We also recommend that you ‑‑ that you think through in answering this question, how would engagement potentially improve your research. How can these individuals help you do a better job? And then ultimately how can engagement approve health care or health outcomes which is ultimately the goal of all of our space here. We suggest that you ask yourselves as a researcher with whom will I partner. I talked about models for identifying stakeholders. I am going to show you a few models and we recommend that you choose a model to systematically identify the individuals who are ‑‑ who have a stake in the work that you do.

We ask to think about what the research is for, what decisions is research meant to inform, which communities make those decisions and which communities are affected by those decisions. We recommend that you go through and talk to these communities about how they wish to be engaged. Don't assume that you know. So, these are three frameworks. I apologize for the small font on this screen, but I want to point out that you can look at this handout in the handout that Steven Boydston pointed to you at the beginning of the presentation.   
 What I want to say about this is that this presents three models for identifying stakeholders. On the left most column of this table, patients of the public, providers, payers, purchasers, policymakers, product makers and principal investigators. Across the rows you see two additional and I should say these are seven Ps and a definition of the P. And then across the three major rows you see two additional frameworks for identifying exactly the same groups. The PCORI model and something called the centers for medical technology policy model. And the point of showing this is that these three frameworks developed at about the same time independently of each other identified the same communities. This is important. If researchers in looking at our work across several organizations identify the same communities, what I can say is that if we scan appropriately across our environment through each of these groupings it is unlikely that we will fail to find a person with a stake in the work that we do. So, it is important to start with a framework for identifying stakeholders. This again small font, apologies. The seven Ps are arranged on the left most column of this table. And this is a worksheet for researchers. We recommend that researchers not start by identifying the names of patients and the names of providers, but rather what decisions do patients make that we seek to inform by the research that we do. What decisions to providers, health systems, clinician, nurses, other providers make that we seek to inform. And then to ask how are these communities affected by those decisions. And together these two middle columns represent the rationale or the reasons these folks could be involved in the work.   
 We then recommend that you move to the next right most column and identify a target number for each group and this allows you to think through what the appropriate balance will be among these communities. Do we want to overweight patient groups and make sure that patient voices are heard strongly in the engagement work that we do. And then once your target number for each community is identified, that you then begin identifying the names of the individuals who can fill those roles and the reason for this, this will help us as researchers come up with reasons and a plan before we start thinking through the who, who will do the work. And who will contact. The third consideration we recommend before you begin is to think through how extensively will the stakeholders be engaged. And think about this in three phases of research before research and during research and after research or in preparing for research and conducting research and in using the research using being disseminated and implementing the findings. And then think through how intensively can stakeholders be involved in each of the activities in these three stages and resources and time will you devote to supporting those engagement activities.   
 A fourth consideration, what are the appropriate roles and the modes by which stakeholders might be engaged in all the activities that you identified before, during and after research. What about the roles will stakeholders have control over the project? Will they help the research team carry out the research and will they provide input conduct or help with the research directly. About modes, will activities be conducted in person or remotely by the web, in telephone, in meetings by e‑mail. Will activities be conducted with individuals or with groups. Will stakeholder communities, the seven Ps be mixed in multi‑stakeholder activities. And what conflict of interest procedures can we implement now and conflict management resources can we implement now that will be needed to manage the discussion. And this again is practical guidance. This is just a reign in the before, during and after research stages preparing for research and conducting research and using research. And then arranging the seven Ps across columns and enables researchers to think through what is going to happen in each one of these cells. Not that something needs to happen in every single one of these cells. Sometimes these cells might be blended together and activities will be blended across stakeholder communities. Sometimes the cells might be left blank because there aren't enough resources to actually carry out that activity. As you can see if researchers went about filling every single cell it could become a daunting and expensive and not efficient approach. So, this is really a way to get a handle over the entire range of your activity as you carry out research, plan for and carry out research and plan accordingly.   
 If you have done both of those things, you have identified stakeholder systematically and you have done a careful job of planning the activities of engagement and how will you know if engagement works? This is developing work and I am working with the MUS consortium. All have the possibility of participating in ‑‑ in this work, in one way or another. And I would invite audience members to contact me after this presentation if you have interest in participating in MUS. We have begun to think about three dimensions of impact. We need to have good inventories of engaged research. We spend 35 million dollars annually on doing research activities at NIH and other HHS agencies. How much of that 35 billion dollars is engaged with outside communities? With stakeholder communities? I would say probably currently not terribly a lot. But then by condition or patient group how much of the work that's being done in research is involving those patient groups? We need really good inventors. We need to know better what we are doing and how we are doing it. We also need to assess whether the work of engagement involving outside groups adheres to principles that we have set forth in recent work for patient centeredness, for engagement, the material I am talking about today, and for something called translation or how research moves on in a life cycle of evidence. And it is used by others. And then finally and this is really the target, this is really why we are all here, we ought to think about how stakeholder engagement itself, not research but stakeholder engagement itself has an impact on health care and on health outcomes. Does it? It doesn't have an impact. If it doesn't, that will tell us quite a lot about how much time, effort, and resources we ought to be spending and whether we ought to change our course of action, whether we ought to alter the way we do engagement activity.   
 Again, small font. This is the chart I showed you earlier. This chart can also be helpful in creating a research plan that could be written in to study registrations. Many of you may be familiar with the NIH reporter system which is a registry of all randomized control trials funded by the NIH or with PROSPERO. These are meant to lay out the plan for research before it is carried out. We recommend that the material developed by ‑‑ through working on this form and summarized in very brief paragraphs perhaps be included in study registrations. So that in the future we can do better inventories of the kinds of engagement that is happening out there. And this diagram is just our startup working model for what we are thinking about measuring the impact of engagement. I'm going to try to walk through carefully. There is a lot here. In green the left most, box and the top most box of this diagram are the left most box, the stakeholder type, the seven Ps I described before who move in to this circle in the middle of the red circle, in the middle of the diagram as partners. In the top box are the modes and methods by which they are engaged in that work. Before research and during research and after research. In the red oval really about the back ‑‑ set of activities of research in red and written around the borders of the oval are five words. These are what we think are the key intrinsic reasons for engaging with stakeholders. By doing this we might improve trust between researchers and the public. We might show respect for persons. We recognize the autonomy of decision makers that relationships are important between researchers and these communities. And ultimately that justice is served by the use of public dollars that we are actually doing the ‑‑ doing the work that we do transparency and openly.   
 And then I want to point to the three boxes at the bottom of this diagram and they read the relevance of research questions which really corresponds to the earliest stages of research. Before you get started you define research questions. How relevant are they to stakeholder communities. The middle box says transparency of research activities. Carrying out research, how well do stakeholder communities folks not trained in research methods, folks who have a conflict of interest, how well do they understand the activities. How well can they articulate what happened during the research in the right most and lower most box, this is our goal when we involve stakeholders we would like to see them use the work that we produced. The evidence that we produce. We would like to see them use it in the decision making. And this is what we ‑‑ this is the work of research around dissemination of the findings of research. And so, we want to see that translate in to adoption in to actual decision making. The red oval and these three red boxes you can see they are connected by arrows and the research activities in the center of the oval are connected by arrows. If we do this well, the theory is that these activities could point to better health, better health care, and lower cost. We ought to be testing this. This is a matter of evaluation and further research. But this is the hypothesis on which we have embarked. And we think that this is a potential model by which we might plan out an evaluation activity. Aside from writing and inventory and adhering to principles, the procedures of stakeholder involvement described on the previous two slides, we ought to ask stakeholders a series of questions about the impact of engagement. Specifically, we should ask is the research question that was just undertaken relevant to decisions you make. If not, were you involved? Were your community members involved? Were other communities involved and community members? We should be asking can you describe what the research was about. If communities can't describe what the research was about how are they going to use the research in decision making. How will they defend the research in other communities that trash it and that does happen in public debates. And then ultimately, we should be asking stakeholders how will evidence be used in your decisions and these are questions that we can ask in routine surveys about the research work we do. They clearly need more wordsmithing and more development. These might be apparent questions with a series of subparent questions underneath. But we ought to be moving in this direction. And that's the end of my presentation. Thank you very much. Back to Steven Boydston.

>> STEVEN BOYDSTON: Thank you very much, Thomas. Very much appreciate it. Now we are going to go over to Donna Mitrani who will lead the interactive discussion. Donna.

>> DONNA MITRANI: Thank you, Steven. And thank you, Thomas, for a great presentation today. Before I introduce our reactors for the day I wanted to remind everyone and encourage you to do ‑‑ should you have any questions or comments that you would like Thomas or any reactors to address during this discussion today, feel free to utilize the chat pod to the left of your screen and we will make sure to get these answered as best as possible. And with that I would like to introduce our three reactors today. First up is Jennifer Weaver, George Washington University; Dr. Eileen Brennan, research professor of association work and investigator at the Research and Training Center at Portland State University and Lorraine Johnson. She serves on a steering committee, society to improve diagnosis in medicine and has been extensively involved with PCORI and the core net as a patient representative. Thank you to our three reactors for participating today. Before we turn over to our reactors with some questions that we had developed for them ahead of time I do want to address some of the questions that have come up from our participants today.

Thomas, our first question for you, does stakeholder engagement equate to integrated to knowledge translation. This is referring to the process of integrating knowledge translation at the front end of a project as opposed to waiting for the end of a project to incorporate knowledge translation strategies.

>> THOMAS CONCANNON: My response to that would be that certainly that strategy is exactly the same strategy that the ‑‑ that we recommend. That it is really very, very important to integrate the voices of stakeholder communities even as we are nominating topics for research and then forming research questions and then planning research protocols but I wouldn't say it equates exactly. Engagement may involve other activities that are tangential to or maybe not pointing directly to knowledge translation. I am going to caveat that by saying that I would have to think more about the word equates. But I think they are clearly closely related.

>> DONNA MITRANI: Thank you. Our next question comes from Laura and she says excellent comments on health care. Interested in your recommendations about the following. There are many barriers to getting new innovative products to market. How do you suggest that research agencies align and collaborate with our policymakers and payers to help them amass the evidence they need, but at the same time ensure there is a balance and achievable standard to develop evidence to practice and implementation to intervention. This is especially true for small heterogenous trials.

>> THOMAS CONCANNON: That's a lot.

>> DONNA MITRANI: It is a lot. If it would be helpful, Laura's comment and question can be seen on the chat pod on the left if it would be helpful to read it as well.

>> THOMAS CONCANNON: If you could reread the very beginning.

There are many barriers to getting new innovative products to market due to coding, coverage and payment barriers. How do you suggest that research agencies align and collaborate with our policymakers and payers to help them amass the evidence they need, but at the same time ensure there is a balance and achievable standard to develop evidence and timely transfer of knowledge to practice innovation.

>> How should they partner with policymakers? It is absolutely critical if research funding agencies wish to see the products of our research, do more than collect dust on book shelves. That we ought to see it moving from our laboratories and from our institutes in to the policy field, in to the development of payment policy in to the acceleration of drug development. The implementation planning for a new intervention. If that's the goal of funding agencies and I would venture to guess that for all 35 billion dollars in the United States spent in this way that it is in fact, the goal. So, I think funding agencies need to seriously bring policymakers in to the process of nominating topics for research, at least being present and witnessing the prioritization of research within institutes and centers of the NIH and within the other research funding agencies in HHS. That would be a really good start is ‑‑ is involvement in the process of nomination, prioritization in some way or another.

>> DONNA MITRANI: Thank you, Thomas. And so now I am going to move us in to the discussion with our reactors today and the first question is for Eileen Brennan. As Thomas mentioned many times stakeholders are experts on their own views. Consider the situation where a stakeholders' view may be inflexibility or in direct contrast to what research has shown. What would be the most effective way to work collaboratively with that person or group of people?

>> EILEEN BRENNAN: That's a great question. And exactly why I love this material. It really brings me back to the beginnings of the Ryan White Care Act when I was managing a small community clinic. And we were suddenly presented with the need to involve 25 ‑‑ to assess our board of directors with 25% comprised, a brand-new requirement and took the board of directors by surprise but this was a ‑‑ this was a contingency of the funding we took. In doing that, we do bring individuals on with rigid opinion. Sometimes those opinions are not well informed by past evidence. And so, a couple of things, no person is the sole representative of their community. It is super important that we not put patients in that spot. That we not make patients out to be the token representative. We need to support patients by bringing in a diversity of voices. And ‑‑ just a second. I had a call coming in that interrupted my line of thinking.

And then secondly, we need to stick to it, we need ‑‑ we need to persist and sustain relationships over time. I want to bring attention to a current controversy in stakeholder engagement. The anti‑vac movement. This is challenging to think about what went wrong there. But that represented ‑‑ right or wrong it represented a movement by members of the public to challenge evidence that was being produced by the research community. That is the gist of this challenge. And I would venture to say that all evolved in the wrong way because these communities were not meeting at the same time place in the same time. And over ten years a parallel track of opponents of vaccines and proponents of vaccines was developing that ultimately collided and is now an epicenter in LA that some of these preventable conditions are coming back. The problem here is that we need long‑term, sustained engagement where we persist as stakeholders with these relationships that we ‑‑ that we tolerate this agreement. That we not take this agreement to be the sole voice representing the community and we expose individual voices, diverse views within their own community.   
 Back to you.

>> DONNA MITRANI: Thank you, Thomas. And Eileen, curious if you have anything to add there in terms of what would be the most effective way to work collaborative with that person or group of people. We are talking about stakeholders specifically.

>> EILEEN BRENNAN: Yes, absolutely. I'm part of the Research and Training Center on Pathways to Positive Futures and we work to design and improve services to young people who are ages 14 through 29 who are experiencing mental health challenges. And what our project involved was designing training for ‑‑ for service providers including pure support providers who were working with these young people, usually in the community. And we brought together a training collaborative and that involved service providers, program administrators, researchers from different disciplines, young people with systems experienced who were part of a national organization called Youth Move with 60 affiliated chapters in 35 states and also family members who were raising young people with mental health disorders and who had joined family support organizations. There was a wide range of opinion there.

And we had a program that was were working on to design graduate level training and they were saying to us you have got to have this at below graduate level training. That you really need to look at who is providing services and get training prepared for a much wider group. And the thing that was important there was we did do what Thomas suggested, we really did listen and we learned to be flexible. And they kept moving us in different directions, directions that we weren't expecting given the literature review that we had done. And that was really very exciting because they helped us to implement the training and helped us to evaluate the training. So, we had this group of collaborators with us for an entire four‑year, five‑year period during which we designed, developed and implemented and evaluated. So, we certainly learned a lot from them. I will say one more thing and it has to do with the fact that we were planning to do a segment on culture and they convinced us that we had to do much more because we were not preparing people to work with Hispanic or Latino families, African American families. A general thing on culture would not do. We brought in specific content about Native American families and tested that later. And maybe I'll talk about the test later on. Thanks.

>> DONNA MITRANI: Thank you. Our next question is for Lorraine Johnson. As we have seen researchers have taken deliberate steps of trying to include stakeholders and research. Within our communities or larger social networks are there ways we should work to position ourselves to better work with researchers and/or practitioners?

>> LORRAINE JOHNSON: I think that's a great question. We at LymeDisease.org. We have launched a patient registry. We have 11,000 people who are registered in our registry for my line data. And what we receive, so we believe that patients need to be building research capacity of patients directly and they need to be doing that and reaching out to researchers at the same time. There was a question that was asked earlier which was if the researchers engage more patients, and I would sort of flip that question on its head and say if the patients engage more researchers and have the capacity to do that, because that really starts to become a conversation changer. And then the last point that I would make is that I think that patients and patient activists need to become part of rule makers.

So, I was fortunate enough to serve with PCORI and beyond their patient engagement advisory panel to serve on their executive steering committee with PCORI net. And in that role, I was able to influence the rules that were made. So, when we look at, you know, the grid that Thomas was showing with PCORI's engagement rules I was actually involved in creating those. And that's the type of role that I think patients need to be stepping in to and becoming empowered to take on. It is a new role.

>> DONNA MITRANI: Thank you. Thomas, I am curious if you had anything to add there from your perspective on how you feel consumers and stakeholders should work, position themselves better to work with researchers and practitioners? Sort of flipping it like Lorraine said.

>> THOMAS CONCANNON: It is a great question. So, consumers really with a ‑‑ with a high motivation to learn about research methods ought to maybe become ‑‑ come to the research table as best prepared they can be understanding in general terms, you know, what kind of research is being conducted and in general terms what the approaches are. And, you know, in the first link that I have just shared in the discussion window is a model for that ‑‑ the types of evidence that is being produced and how they might prepare ‑‑ how you might prepare for engagement in that type of evidence.

>> DONNA MITRANI: Thank you. Our next question is for Jennifer Weaver. Many times, practitioners are well positioned to be an intermediary between researchers and consumers and stakeholders. What are some of the challenges that you faced when working with researchers or finding relevant research for practical application?

>> JENNIFER WEAVER: Great question. It is a little bit of a two‑prong question. I am going to talk about the challenges that I faced with working with researchers. And I don't think this will come as a surprise to many of you, but I think kind of a forefront of it is communication. And I really focus on the communication piece because when we create these research teams with multiple stakeholders we all come with our own individual expertise. And so, we don't always speak the same language. And to kind of overcome these challenges and some of the work that I have done we have used some of the principles from the team science literature to create common ground about the research project. So just like Thomas was talking about and having the patients know in general terms about the research methods and methodology it can lay the common ground.

Another aspect that I think is really important when creating these teams with stakeholder engagement is to have that psychological safe space. And we see that more in the organizational literature, but I think this is really important because we want those new ideas to be contributed no matter who the person is and no matter what level of knowledge they have about the research process.

As a practitioner I have worked with patients with traumatic brain injury for many years. In terms of thinking about the challenges that I have faced when finding relevant research for practical application, any time I am reading a research article and thinking about the implications that might have for practice and, of course, how it might be adopted in to practice, however oftentimes when I am reading new knowledge about interventions or assessments for cognition in traumatic brain injuries we are challenged to adopt some in to practice. Then we are thinking about introducing that intervention in a more complex environment being the health care system.

And I think a few other challenges that exist when considering adoption in to practice is thinking about if it can fit within the context of where I work. Right. Is it feasible for the setting in which I work. So, these are all some of the questions that I ask myself when I am reading the literature and thinking about implementing some new knowledge. And I think that really goes back to what Thomas was talking about. But identifying the end user in selecting those stakeholders to engage in the research process is critical then for the later steps when we are trying to disseminate and implement these new interventions and new applications.

>> DONNA MITRANI: Thank you, Jennifer. And Thomas, Eileen, Lorraine, curious if you had anything to add to this question.

>> LORRAINE JOHNSON: I would just add that when you are ‑‑ I think it is really important when you are dealing with patients to empower them to understand what the role is on whatever committee that they are sitting on. And a lot of times if patients are not empowered in terms of understanding their role and what it is that they should be doing there in terms of representation of patient interest they may believe that they should be there to represent their personal viewpoints and their personal interest when actually their role there is much greater. And the personal interest matters, but also the community having a broader understanding of what the community interests are is really important to bring to the table. I think that would be an important training step.

>> DONNA MITRANI: Thank you. And Thomas, I believe you had ‑‑ you had wanted to chime in as well.

>> THOMAS CONCANNON: Just to say nothing to add.

>> DONNA MITRANI: Fair enough then. Okay. So, we are coming to a ‑‑ sorry, go ahead.

>> EILEEN BRENNAN: One of the things that has been valuable for our project is having people with mental health, what we can do that's more effective in training. And that has involved helping young people who are not familiar with research to understand what kinds of things that we are hoping to learn about their experience that we can translate to research. So, doing some preparation has been really important before they have gotten involved in our research efforts.

>> DONNA MITRANI: Thank you. So, we are coming towards the end of our discussion for Thomas' presentation. Before we move forward I wanted to open it up to Thomas and to any of our ‑‑ to all three of our reactors with any closing thoughts before we move to the next presentation. And so, Thomas, we will start with you.

>> THOMAS CONCANNON: No closing thoughts. I would like to underscore that this work is really at the stage of hypothesis generation. We are trying to figure out, you know, as a group of researchers what in collaboration with stakeholders what will work. Lots has to be done to find out if we are right. And I would really welcome individuals with a strong interest in this to contact me for involvement in multi‑stakeholder engagement.

>> DONNA MITRANI: Thank you. Eileen, Lorraine and Jennifer, any closing thoughts?

>> LORRAINE JOHNSON: One of the things that we are trying to do here is talking about doing the right thing. Doing things because it is the right things to do. And that is that we are really talking about this messy intersection of democracy and science. So, navigating the path through that I think is inherently very difficult. I am not sure that it has been tried before and we will always have its challenges.

>> DONNA MITRANI: Eileen and Jennifer, any closing thoughts on your end? Okay. Thank you so much to our participants for the great questions and to our reactors, Eileen, Lorraine and Jennifer, for the great discussion. And to Thomas for a fantastic presentation. And with that I will turn it back over to Steven. Thank you.