**2018 Online KT Conference:**

**Engaging Ways to Engage Stakeholders**

Lost in Translation:

How to Manage Multiple Stakeholders and Communicate Research Effectively in an Era of Competing Facts

Mark Bayer

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 >> JOANN STARKS: Now we are going to move ahead to our next presentation, who will be Mark Bayer, founder of Bayer Strategic Consulting, a Washington, DC, based firm that focuses on helping scientists, engineers, and technical professionals master the keys for successfully interacting with policymakers and other influential stakeholders.

 This presentation: Lost in Translation: How to manage multiple stakeholders and communicate research effectively in an era of competing facts, will highlight proven and actionable stakeholder management techniques, including how to segment stakeholders into similar categories, surface interest of each segment, and develop suitable, productive engagement approaches.

 Mark, are you ready to go?

 >> MARK BAYER: I am ready to go, Joann. How are you?

 >> JOANN STARKS: Good.

 >> MARK BAYER: Can everybody hear me okay?

 I just wanted to respond first just very briefly to a comment that Dr. Bowen made in response to the last question she was asked relating to relationships with policymakers and just wholeheartedly agree with Dr. Bowen's response. As somebody who was sort of born and bred in the policymaking world, the emphasis on relationships really cannot be emphasized, or I should say cannot be mentioned and reinforced too much. That's exactly what I would say if asked about how to craft messages and interact with policy-makers. I tell people not to just make requests of policy-makers but to build relationships with them. So exactly the right tone for policymakers specifically.

 So strategic international -- so strategic and intentional, I should say, involvement of stakeholders is a vital activity within the research enterprise. Everyone listening could appreciate that and be tuned into that, otherwise they probably would have skipped this. But understanding and accepting that fact is only the beginning, of course, because the varied interests and perspectives and degrees of influence of entities and individuals, all who sort of can have a say in accelerating or supporting or thwarting or delaying research, can really create a challenging landscape that can be difficult to navigate. So, what I want to focus on are what are the critical success factors for effectively communicating and interacting with key stakeholders, and which pitfalls should be avoided?

How can select stakeholders among the individuals who can influence your research or your work, how can they be enlisted to combat misperceptions that could undermine support for the work that you are doing?

 As Joann noted, the aim of my presentation is to show you proven and actionable stakeholder management techniques, how to segment stakeholders into similar categories, basically try to figure out what's motivating, what are the interests of each of the segments that you have that you've created, and then how can you develop suitable, productive engagement approaches that are tailored towards these specific categories?

 So, we have a lot of interesting, I would suggest, topics to cover, and I want to make sure that we leave time for plenty -- for questions, but this is the roadmap. This is where we are going, sort of what are the particular ingredients that you should be thinking about. If you say I accept the premise that engagement is important, what are the ingredients to actually create effective engagement? Why you should do it with a very specific example from my own experience, and we'll get to who I am in a moment. How you make your way through that landscape, avoiding problems, land mines, this could derail you. And taking channels and routes that are most productive. And what are sort of some of the -- boiling it down, what are some of the successful stakeholder kind of keys to engagement? And then what are some of the major problems that I have seen throughout my career? And we are also going to include a case study which, appropriately enough, builds on one of the last comments that one of our reactors made at the end of Dr. Bowen's presentation with respect to cancer patients.

 So, I spent 20 years on Capitol Hill in two different actually tours, right out of college and then later in my career, all told about five years. You can see I worked, I was chief of staff in the Senate and House of Representatives. And then as well as that, did other work in the private sector and in the nonprofit sector, and then since leaving the Hill, I have been focusing on helping scientists navigate this challenging environment, I would say, with respect to facts and a denigration of expertise, which I am sure many of you have experienced firsthand. This is just a small sample of some of the work that I have been doing.

 When I sort of teach, what I try to do is bring together my experience in the government, corporate, and nonprofit world, and there are distinct features obviously in each of these sectors, but I have seen, after spending time in each of them, that there absolutely are similarities across sectors, and there are really touchstones that you bump up against or notice within each sector. So, the skills I am wanting to share with you today are certainly portable, regardless of your professional environment. So, you know, from the bench to the boardroom and beyond, the skills and abilities that I want to talk about today are really designed to boost your effectiveness, whichever specific career path that you happen to be in.

 Okay. So, some of the things to keep in mind to really focus on when you are talking about how to be a powerful person engaging in this kind of, you know, within stakeholders and within your environment, where you have various interests all with different motivations and perspectives and points of view. So, you know, I want to just start with productive engagement I submit looks like in general before we move on to why it's an important part of the research process. You know, engagement is really not an appendage. It's not a bolt-on. At least not in the IT world. It's something that should be done by design. It should be baked in, we used to say in the policy realm. It's not an afterthought. Actually, it's an asset and not a liability. I think oftentimes when you think about changing practices or altering processes and you start to get to the root of -- you want to get to the root of why things are done the way they are, many times it begins with a mind-set. You know, it's attitudes that have been built up over time based on experience or based on values, based on an interpretation of what worked or didn't work in the past. So, I like to sort of start talking about kind of like a mind-set shift as we explore really what it means to engage. And part of that begins with the shift of this understanding that engagement is an asset and not a liability. In Dr. Bowen's presentation talking about many times this is a requirement now for funding. Of course, there are ways of complying and doing the minimum with requirements, and there are ways of doing a bona fide embrace of the requirement.

I would submit that the second, the latter, is the one that is much, much more productive.

 I have a question also, sort of the first question that will be asked -- I will be asking a few questions throughout the presentation -- you know, if engagement is so beneficial -- I've sort of laid this out, and I expect that the audience believes that engagement is important and is an asset. If it's so beneficial, why do you find that some scientists, colleagues, researchers, you know, fall into the nonproductive behaviors on the right side of the graphic? You know, why do you think it can be a challenge for researchers and others to be unproductive, to approach this as kind of a requirement and try to get around it in a sense, not necessarily as an opportunity but more as a liability? What are the causes of that?

 If you want to type in the Chat, I would be interested in getting your take on, you know, why that is.

 You know, it's funny, I was part of a panel in June over the summer up at Cornell, which is where I went to undergrad, was a panel put together to talk about SciComm, science communication, and one of the scientists there said she was hesitant to engage because she was afraid that advocates -- patients, for example, in this situation -- the patients would ask her a question about her work and she would not know the answer. And they would be very angry with her. So, she sort of retreated in general when she was talking with patients or to lay audiences into more of a technical, very cautious, dense way of speaking and vocabulary to, in many ways, kind of frustrate that interaction was she was afraid that, you know, she would get a question that she wouldn't know the answer to. I asked her if that had ever happened, and she sort of laughed and said no, but it could. Which is theoretically someone's going to ask you a question you might not know the answer, but that can be the beginning of a dialogue and not a comment on expertise. If you did experience that, by the way, if you were in a situation where you got asked a question by a patient, for example, you know, you didn't know the answer, how did you deal with it? How did you respond to a question or a comment that you really didn't know the answer to? I would be interested in knowing that as well.

 So, looking at beginning sort of this mind-set shift that thinking it's an opportunity and not an obligation per se, and it's not just a "nice to have," but it's actually a "need to have."  These were talked about previously as well, and I think that you are pretty -- you are familiar with sort of some of these benefits that have been talked about before. And I guess one other sort of -- another question that I would like to ask in this situation that kind of goes towards another benefit of incorporating patients, advocates as a part of an effective engagement strategy: Has anyone been confronted by the falsehoods, total inaccuracies about their research? And you know, how did you respond to them if you did? I am curious about that, and I think the reason will become clear as we move a little bit further into the presentation. But I am very curious, you talked about sort of competing facts as within the scope of this presentation, sort of like have any of you been in a situation where, you know, you are putting forward information and you were getting pushback from others who weren't basing their statements on evidence or fact or any sort of either reliable or verifiable source? And if you had that situation, how did you deal with it?

 This goes to another point on why it's so important to have patients or lay individuals as part of your coalition, as part of your -- you know, why should you engage with these sort of populations is it really helps identify what I call research champions, and this is so important when you are talking about advocacy with policymakers. Again, coming at it from my perspective, how I have seen -- you know, worked very closely with scientists, both throughout the State of Massachusetts, which is my home state, and then all across the country as part of my work, both on the Hill and then with AAAS and March for Science and others, I have seen how having champions who were actually -- you know, they are experiencing the condition or they've been affected by circumstances that your research is intended to either analyze or ameliorate, the action that either policymakers, whether that's members of Congress, staff members, regulators, that sort of reaction, those comments are very powerful, and in many I with as they can be more powerful than a graph or data, you know, based on a double-blind study, something like that. It's that element of engagement that I think advocates who are actually experiencing the circumstance that you are working on, that that's really an important role for those advocates who are so situated. Really telling personal stories about the importance of the research funding is sort of hitting a different, I would say, you know, dimension of persuasion in discussions with stakeholders. That is extremely powerful. In many ways it can be more powerful than the data, depending on the audience.

 Why is this engagement with stakeholders so critical? It really helps you test and hone your messages with lay audiences. I mean, you kind of can move out of the echo chamber that is your colleagues and -- I don't mean echo chamber as they are going to agree with you on everything, but I me echo chamber in the sense that you are sort of all broadcasting on the same frequency, have the same set of norms and understandings and relative education, so forth. And there are sort of just certain norms that everybody understands. But when you take your message on the road and you get out of your own circle and you start to make the case about the importance of your research with funders or with policymakers, people who aren't familiar with the technical details, it really would be great to have had sort of what I would call a focus group, you know, a focus group before you show your research. I mean, you know, the studios do this all the time with their movies. They have screenings, and they have questionnaires, and they are trying to get feedback from a subset of consumer who may see their movie before they finalize it. And if you can sort of look for opportunities to do that with lay audiences, if you are going to be going out, you know, and making the case of the importance of funding, continued funding, for example, new funding for your research, if you can do that, you are at a tremendous advantage if you can do that before you actually take your show on the road, as it were. And you know, you can respond accordingly. Right? This goes to this relationship building, meaning, you know, to have a group kind of or various groups that you have preexisting relationships with where you have sort of a dual -- a dialogue and not just broadcast.

Right? Where people are feeling that you do incorporate and respond to feedback as well as provide information. You kind of have that at the ready, and so you build sort of a community and start putting together your focus group that you have so you can consult with those folks before you expand your message to those outside of your immediate professional circle. And as a result, you can get -- you know, you get tips. You know, don't say that -- don't put it this way. Express it that way. Or you forgot this or that was misrepresented, so forth. Advocates can review posters, they can give feedback and so forth.

 So, this sort of takes us to a case study that comes from my work on the Hill. So, the Communications Act, when it was first put on the books, when radio, TV, it's been updated obviously many, many times over the years. But the Communications Act was still sort of operating in a very much sort of like in a manner that was not providing the degree of accessibility to people who are blind or people who are deaf. So, you know, the iPhone, satellite TV, you know, wireless, set-top boxes, in many cases those interfaces were just not required to be accessible to people who are blind or who are deaf. And I worked very closely in 2010 on an overhaul of the sections of the Communications Act that dealt with accessibility. And our idea, essentially, was to do an ADA, an Americans with Disabilities Act, for the electronic world, for the communication space. So, we talked a lot about on-ramps to the Internet. You know, we have taken care of ramps into buildings and so forth. We need to take care of ramps to the Internet. We need to make sure that communication devices and services and the whole universe of things that we take for granted, we need to make sure that they are accessible to people who are blind or people who are deaf because they are essentially utilities. They are kind of required equipment in today's world for purposes of work and social and entertainment and so forth.

 So, one of the things that we were very careful to do -- I should say taking a quick step back that this is an extremely -- as you would imagine -- extremely technical engineering focused area. I mean, every interest group that you could think of from Netflix to the Motion Picture Association of America to Apple, Samsung, all the handset makers, you know, the Consumer Electronics Association of America, you know, everybody was concerned that mandates put into this update would affect them and require them to, you know, do certain things with respect to engineering that were counter to either what they wanted to do or what their engineers told them was the best way to deliver a product or service. And so, there was a legion of folks from an alphabet soup of industry -- electronic industries, including various associations of companies and then the companies themselves -- who were intensely interested in what was going on. Which is all to the good, but I am sort of just describing what the general environment looked like. And so, we would make cases, you know, on policy grounds, and we could talk about the need for this, but it was much more credible and much more powerful when individuals who were actually affected would speak up and talk about what this would mean for them. Clearly, they were part of the constellation of stakeholders. We talked about worked very closely with the American federation of the blind, the National Federation of the Blind, the National Association for the Deaf, the Perkins School, which coincidentally happens to be in Watertown, Massachusetts, which was in my then boss's congressional district, now state as he is a U.S. Senator.

 It was much more compelling to hear from individuals who were enabled every day to live without technology being a hindrance than to have us explain exactly why this was so important. You know, there's a good bit from Dr. Jo Hanson that I love to use, which is that your data is not your story; it's a character in your story. It's necessary but not sufficient. I have my own Ecclesiastes of effective communication, and that is every message has a messenger. You should figure that out. Maybe it's not you. Maybe it's a patient advocate, kitchen cabinets when talking in the political realm.

 The other thing I just wanted to touch on there is why such a benefit is because those individuals, not only do they have a personal stake and can talk in a personal way about it, but they also can talk in an emotional manner, because it is an emotional topic, what this means for them, what it would mean if these changes were frustrated or not implemented. And that can be a challenging and difficult space for searchers. Emotional terrain. It's not fact based. It's touching upon another chord.

 So that -- you can in some ways sort of deputize advocates to deliver those sorts of emotional appeals. You know, I talk about who are the CEOs? Who are the chief emotion officers in your engagement strategy? And it's probably not you. It might be, but it doesn't have to be, and particularly it's not just because it may be difficult, but it's much more credible if you, yourself, don't have experience with an issue, to include a coalition member, a stakeholder who does as you talk to audiences where his or her views or experiences would be very relevant.

 Okay. This is essentially what I consider to be a stakeholder assessment. You know, an example of a stakeholder assessment. Trying to understand, okay, who are my -- who has the power or authority to influence my work? Kind of a beginning point to ask yourself before you set off to do this engagement. Who are the groups? Who are the individuals who could influence the work that I am doing? And you know, I sometimes call this, you know, painting the wall, the wall, painting the wall. And I mean that meaning that there's a lot of prep work that goes into painting a wall. As somebody who did that when I was in high school, you know, when there was wallpaper on the wall, when there wasn't, the amount of work just to get the wall ready for painting, you know, scraping off the glue if there had been wallpaper, patching the holes, sanding, all of that sort of stuff. Then you get that, it's about 90% of your work, and then once you've got your color and you paint it, people look at the wall and say oh, yeah, that looks great. That color is fantastic. The whole thing looks really great. What they don't see is all the prep work that you did to get to that point. And that's really what I urge you to think about is to do this sort of strong research and really come up with exhaustive list of who could influence the work that you want to do as a starting point.

 And the good news to tell scientists is that you are very good at research. You just need to know sort of where to look and what to research, where really to dig for this information. And that's something that is not too complicated once you are exposed to it.

 So, the next question sort of is all right, great, I did my assessment, and now how do -- how do I go about actually, you know, making my way through it. I know the groups, I know the individuals, and now I have to sort of decide what am I going to do to make the most out of this understanding? I guess what I am essentially saying is you've got -- you really have the map because you looked at it, you understand sort of where all the landmarks are. I guess it kind of -- stay within the same metaphor. The stakeholders are really the landmark that you want to visit, whether that's virtually or in person, as you decide, you know, what's my goal, how do I get from here to there? Well, I want to make sure that I check in with and engage with these individual stakeholders who are sort of like your landmarks along the way.

 You know, you'll find as you come up with this assessment, you know, you can categorize groups. Some groups have similar interests and influence so that you want to kind of put them in one bucket, so to speak, and they would receive sort of similar messages if they have similar interests and similar goals. Sometimes people forget kind of about the sequencing. Like, I was always very tuned in to sort of who do we want to talk to first? Maybe we should talk to this group first and make our case with this group because we know that the next group really takes its cues from or influenced strongly by the previous group. Well, when you have the second meeting, it's like, well, we did talk to the American Federation of the Blind about this, and they had some good comments which we are incorporating, and their feedback was very positive. So, you are kind of setting the scene with your follow-on group, and you are giving them a cue that, okay, you know, we understand where your interests might lie. We are citing a group that are engaged in what matters to you. So that Good Housekeeping Seal of Approval is important.

 Then you have a validation. Talked a little bit about this before, having your own focus group. So before even doing the message delivery, you want to think about trying to validate the message that you have with individuals who, you know, carry influence. Like you know, for example, just to stay within the case study, you know, we worked very closely with the American Federation of the Blind and the National Federation of the Blind, as I pointed out. And you know, but there were certain terminology. You know, we always were referred to people who were blind, people who are deaf. We would never say "the blind" or "the deaf."  That was mainly because, you know, those groups used the terminology, want to use the correct terminology, and that was done to emphasize that these were people. These were people who happened to be blind or people who happened to be deaf. And you know, not using that terminology would have been a big mistake. And it would have been seen as anywhere from insensitive to offensive. And maybe we wouldn't have picked that up if we hadn't been sort of working with and kind of running some of our material by these groups. So that's really important to have on your side, groups that carry influence with other groups that you want to influence. You know, it's not guilt by association, but I like to say it's gilded by association with a trusted stakeholder group.

 This is -- I sort of organize it as the double A. These are the features, these are the traits. Before you even set out your engagement journey, you want to know what your goals are, you know, where do you want to go. These are just key things you want to pack along with you on your journey. You know, these are really -- really important. They are not just, you know, nice things, but actually, they are in the self-interest of the researcher, of the scientist, of their proponent, of the policy. They can also be two-way streets. Active listening shows respect, but it also is an opportunity for to you get information that you might otherwise not pick up that can be incorporated into what you are talking about, into your message. You can refine your message accordingly as you sort of engage actively and actively listen to what people are telling you as you make your journey.

 This is also something that came up earlier, making sure everyone is on the same page and doesn't feel like you are a box checker and you don't really want to have what you say, but there is a requirement of the funding that you have a patient advocate as a part of your team, so you will do that, but it's really not bona fide. That's obviously a big mistake.

 Okay. As we sort of get to the end of the presentation here, I just wanted to mention another sort of case study. So many of you may have heard of the Cancer Research Center in the Finger Lakes. It does receive some funding from Cornell, which I think I mentioned it's my undergrad institution. I just thought this was a really great fit. It wasn't really about favoritism, mentioning the alma mater, but really, in meeting -- or talking with Bob and learning more about the Cancer Research Center.

>> That's obviously a big mistake.

Okay. So, as we sort of get to the end of the presentation here, I wanted to mention another sort of case study. So, many of you may have heard of a cancer resource center in the Lakes. It does receive some funding from Cornell which I think I mentioned is my undergrad achievement. Favoritism mentioning the Alma matter, but really in meet ‑ in talking with Bob Wright are and learning more about the cancer resource center and how they incorporate into real partners. I think there's a science article in October 27‑th ‑ I'm sorry. October 2017 issue where the article from patients to partners is included and that link‑ we can get that you link if that's of interest to you. There's article and materials that cancer resource center makes available. Just a couple of quotes that I pulled out that I thought were particularly relevant and, you know, those were quotes from researchers and students. One said we spent all our time in the lab developing an arsenal of experimental technique; however, in our daily work with petri dishes and microscopes, we felt that something was missing. We ‑was missing. We learned about the human dimensions of cancer. Even though our research is far from the clinic, we believe that interacting with patients and survivors would improve our understanding of cancer and the quality of our science. And, um, you know, I think it ‑really‑ the‑ reason I mention that is because it really reinforces this notion that active, effective bona feed stakeholder engagement is really an asset. It can also produce benefits that you may not have anticipated and but there are also sort of trip wires. There are trip wires you want to be aware of too before you set out on your engagement journey. I tried to cover some of the important ones there.

If you have questions or you want to follow up with me on the topics we've discussed. I'll leave this slide up. But now I'm interested to hear your reactions and your questions, if you have any.

>> Well, thank you very much, Mark. Now I'm going to hand it over to Donna for the discussion period.

>> DONNA MITRANI: Thank you so much for a fantastic certification. I encourage you if you have any questions or comments, please go in the chat box and we'll have Mark address them.

I wanted to reintroduce our reactors for the day. Dr. John Kramer, Dr. Deb Rose and Dr. Sandra Finestone. I wanted to ask Dr. Finestone. Can you describe experiences of effectiveness of an ingredient engagement?

>> SANDRA FINESTONE: Yes. I think the cancer community has been very effective and integrating the patient experience with at least cancer researchers. And I would say all researchers. But, um, I could give you an example of individual experiences I've had in the larger kind of real world experience. I had been doing reviews for the department of advanced for breast cancer research and was on the shuttle back to the airport and a researcher who was not in my particular review section sat next to me on the bus. And he said he was one of those lonely researchers that fits over his petri dish but had never met a patient before. He said that he was actually thinking of changing his area of research because he felt so disconnected from it, but that just meeting a patient and seeing the possible effect that his research could make in my experience or other cancer patients experiences was so phenomenal to him that he went back to his lab and was energized. And he and I have continued to exchange e‑mails every once in a while.

The other is a partnership with the triple ADV. And Mark is probably aware of this organization. It's accelerating in drug validation. It's a partnership between academia, PHARMA, and patient advocates and industry. So, it's wonderful. The interaction there is so encouraging. From a patient perspective, we had thought that industry was sort of the enemy that they're the ones who keep, you know, don't make or unable to make treatments available to patients or that the cost ‑‑ anyways, and then because of this interaction, because of this partnership involving patients and talking with academia and how drugs are developed and how they work together, when the FDA is there as well, I'm sorry. I some have mentioned that, it became clear us to as patients how important these partnerships are. The importance that the ‑‑ what we could add to the process and it's been very enhancing. I will share one more thing with you and then I will give it to my other colleagues. I just attended a meeting and one of the presenters is a woman with metastatic breast cancer. And she is on an oral medication. Most of us think that this is a huge advancement in the cancer world transitioning from intravenous treatment to oral treatment and how much better it is to be able to take a tablet every day as oppose said to going every day or every week for an infusion. It turns out because the way our system is, she's on Medicare, by the way. How our system is that all medications are not paid for. If she office intravenous drugs, the treatment would be paid for. The fact that it was an oral medication, she and her husband had to sit down and have a discussion on how they were going to pay for this. It is quite expensive. So, when herb time comes, hey ‑‑ when her time comes, they will use her insurance policy to pay off the credit cards. That is unacceptable that. Shouldn't be happening, but in this meeting, PHARMA was there, Medicare was there. But the realization is sometimes what we think are have advancements in science have huge impact on patients, things that we have not considered in the past. And so, I feel very, very strongly that patients and researchers and administrators and PHARMA and all of it and, of course, legislative because it has now become a legislative issue these discussions are extremely important and extremely impactful.

>> DONNA MITRANI: Thank you so much, Dr. Finestone. This question comes from Annette. And she's asking did you work with groups to communicate with patients or did you reach out to patients directly? How did you get your patient engagement?

>> MARK BAYER: That's a great question and the answer is both ways. Sometimes what happens is these groups would bring in patients and sometimes we would then follow up and communicate directly with the patients. If you're thinking about policy makers and an audience you really need to address, then you would think who would have impact with that particular policymaker. Let's take a cancer issue. We have been talking about cancer. So, if you're looking to increase funding at MIA for a particular type of cancer, you know, you could look to members of the committee, which would be the commerce committee and the appropriations committee and the house of representatives and say I should talk to some of those members. And then if you have a chance to sit down with those members and staff, each member of the house represents about 720,000 constituents. Say those constituents are the VIPs in that members mind because they decide whether the congressman or congresswoman comes back to congress in the next two years. If you can have a parent from that district or state of the U.S. Senator, then that would be doubly powerful from an advocate's perspective. That's what I would recommend. When I was on the other side of the table and a patient would, you know, make a point and that patient was from our district, that carries a lot of weight. Sometimes you need to reach out to individual patients to find ones that give the profile of who you are trying to influence, and it is not difficult to do that.

>> DONNA MITRANI: This question just in comment came in from the audience from Kerria. They're asking: Can we discuss compensation for patients? Any sort of thoughts you have on whether or not we should be compensating patients when engaging them in research?

>> MARK BAYER: Frankly, don't have any direct experience with that. With that being said, I can‑ I am familiar with a couple of different scenarios. You can imagine a situation where a drug company would be advocating for a particular type of drug‑ they manufacture. And they may man looking for patients that can been fit from it. The company can make a direct appeal to congress and the drug company can also hire a lobbyist who a lobby firm that has experience and that or may have relationships with members of congress that the drug company wants to influence. So, if the‑ as part of that coalition, the lobby firm sometimes reaches out to patients. It would sort of make complete sense and I think it would be reasonable. If a parent is basically going to ‑be‑ if‑ a patient is going to be supporting the lobbyist efforts through the process, then why shouldn't the patient be compensated? The person hitting to his or her right is probably the lobbyist, right? Not necessarily those, but if you are putting forward in helping or assisting lobbyists make the points, then you have a reasonable case to say I should be compensated as Lat least expenses at a minimum.

>> DONNA MITRANI: Thank you so much, Mark.

>> SANDRA FINESTONE: I didn't mean to interject. I will tell you that this is a struggle for patients exactly because of what Mark said. We want our voice to be heard. We want our position to be heard. But we don't want to appear to be influenced in any way by PHARMA. Some of the way we have gone around this is exactly what he said and that reimbursed for our expenses. If we go to our lab meeting at least or travel there, we'll be reimbursed. Or perhaps the researcher can include us when he or she is getting a presentation at a research meeting or sim podium so that we can be part of that. It's kind of ‑and‑ I will share with you there are other advocates that feel very, very strongly they should be compensated because it gives them value unfortunately. Dollars and value are very much together. But I did want to share with you that it is something that patients struggle with.

>> DONNA MITRANI: Thank you, Sandy. Even in my work, I've seen the patient population if they're not compensated, they feel taken advantage of and they're unveiled in the way they should be. Moving on.

Mark, this is for you. When trying to understand the ideal strategy for engaging decision makers, what is the method of strategy validation? Focus groups are unlikely to be appropriate. So, any thoughts on this?

>> MARK BAYER: Um, let's see. There are a lot of different ways to go about it. I guess the first way to be clear. When I said focus group, I didn't mean like a formal focus group that has kind of maybe vetted according to the pollsters’ definition of what a focus group should look like. I mean people who have the credibility to speak authoritatively about their own experience. Right? Who kind of understand what the audience you're trying to influence kind of is looking for. So, I can give you ‑so it ‑can ‑ it's‑ simple as, you know, calling on the phone and talking to some people who find them who understand the audience better than you do is really what it boils down to. And that audience could be, you know, anywhere. I will give you an example. I did a workshop at the optimal society of America and I had never worked with the Optical Society of America before, but I had a professor who was a member of the Optical Society of America. And I called him and had a chat with him about the norms. I don't want to tell him things they already know, but I don't want to leave out things that can be helpful. It all sort of goes back to this notion of relationship building and networking. So, if you don't know the person to call or whose feedback would be helpful, perhaps you know somebody who does, and it wouldn’t be an out of the blue request. Just a way for you to kind of road test your message. That's the overall point here.

>> DONNA MITRANI: Thank you, Mark.

Moving on to our next question. I will put this one to Dr. Rose. You can share any real-life examples of successful stakeholder interaction in a research project?

>> DEB ROSE: I would be happy to share some examples. I think in our school base practice working in the public-school system, we're supporting a lot of stakeholders who aren't familiar with knowledge use or using base practice. So, transferring that knowledge, for example, recommending an evidence-based on a new intervention for a child in that classroom, there can be a real mismatch of expectations. Teachers have their perspective on the child's goals from an educational standpoint and parents may have a very different goal or objective in what they want their child to do as far as participation. Well, initially it might seen that both their goals are kind of exclusive of each other, I think it's really important to help develop the commonality and shared expectations and help align those goals together. And I think one of the key things that we have used successfully are those key success factors. And one of those being is acknowledging every stakeholder that they're the expert in their area. The teachers the experts in education in the classroom. The parents are experts on their child and we need that along with all that knowledge that we have from the research to be able to make the intervention appropriate and successful for the child and that's what we have done several times especially when teachers are looking at educational goals, patients are looking at very functional goals and we marry those two together so that the child is successful across all the areas.

>> DONNA MITRANI: Thank you so much, Dr. Rose.

And our next question is for Dr. Kramer. What do you think the concept is considering stakeholders as customers?

>> JOHN KRAMER: I think that it's kind of an interesting idea. I think going back to I think it was the organizing the categories research address, research and calibrate messaging according to the specifics of stakeholder engagement. I think we do with the RTR, I think we do those not quite packaged quite in the way that we have talked about here today. But certainly, we do those pretty regularly particularly around calibrates the messaging fees. The findings that we produce around engagement employments are complex and they mean different things. They have different implications for different stakeholder statements. So which pieces do you emphasize with different groups, you know, obviously you might not engage with individuals with intellectual disabilities and family members the same way around policy as you would, you know, policy leaders. You would still engage with them, but you think about how to talk about it maybe not quite as jargony as, you know, using more, um, more common language, accessible language.

I think ‑ the one thing as I reflected on this question I thought was interesting is the idea of keeping them as customers. I feel like when you're really doing a good job in engaging a lot of different stakeholders and engaged in effective research, the ‑customers‑ the idea of a customer puts them at a different power level that I'm not ‑sure ‑ it's kind of interesting. In one sense they put in the time and they want to be satisfied with the outcome of the research and the implications. They want to have it be helpful, but also if they're really effectively‑ engaged, they're colleagues. They're cocreators of that research. They're co‑-interpreters‑ of the findings both for their own stakeholder group, but other stakeholder groups as well. I think it's an interesting kind of approach and I certainly agree with it from an accountability standpoint.

>> DONNA MITRANI: Thank you so much, Dr. Kramer. There's been a lot of very interesting commentary going on in the chat box. I want to take a few more questions from there and this one is for you, Mark, from Ana lease. And she is asking ‑she's asking how do‑ you convince researchers to really par take in stakeholder engagement when you're not in a position of power to do so?

>> MARK BAYER: I talk about what does that mean and I'm not talking about powers and politics. I'm basically talking about power relationships and the ability of certain people to influence outcomes and patterns and so forth. I always go back to interests. What's in it for me? I know that we just talked a little bit about the notion of customers or whatever and jargon like that. I really appreciate Dr. Kramer's comments on that.

I guess I would say it's a mindset shift. Why should I do this? Sort of demonstrate to me why it's important and why it's in my interest to do it. And I think you need to start there and really in most interactions when you're talking to stakeholders, you are figuring out what do they value and how you can address those values and sort of those points. So, I think that people do things for a whole host of reasons. But in many cases what's in common is that it has to be sort of a presentation and an acceptance of the benefit that the researcher could to gain from that sort of ‑‑ from engagement. And it does take a mindset shift and you can begin to influence that shift by demonstrating why it's a benefit.

>> DONNA MITRANI: Thank you so much.

And then our next question, I will put out there to Mark, you as well as our reactor to comment on. This comes from Carra. I'm wondering whether you can comment to the degree of which you have in person common for less personal strategies or less face-to-face contact.

>> MARK BAYER: Well, just to take the first cut at that, I think both is acceptable. If I was in an ideal situation, what I would recommend if it's not costly or if feasible completely, I would like to start with in person. And perhaps that can even be done on Zoom or Skype or whatever it is. A face-to-face is the best to begin a relationship. From there, email and phone can be fine. But I always like to begin a relationship with whatever you are trying to make something happen and move something by getting people together and getting a face to face.

>> DONNA MITRANI: Thank you, Mark. Again, the benefit of doing face-to-face stakeholder engagement versus nonfit face-to-face.

>> SANDRA FINESTONE: This is Sandy. Obviously, I always have something to say. I think face-to-face add to that relationship building. It isn't always necessary. I know Zoom or what have you is better than just verbal communication. For another reason not just the relationship building, but very, very often, it can be misinterpreted if it's written. If it's broken, it seems you get the body movement. You get the tone of what is being said. I think it's extremely valuable, even if it can just before the initial engagement at least there is relationship building and you know you're talking to a person. I would highly recommend it somehow for that to happen.

>> DONNA MITRANI: Thank you. They say face-to-face is generally preferable. Dr. Kramer, I don't know if you wanted to say anything more about that.

>> JOHN KRAMER: Yeah. I think there's an element to it that is being responsive to what the person kind of desires. In our work, face-to-face isn't ‑always‑ isn't‑ always preferable for a lot of reasons related to kind of personal preference, access issues and things like that. I think being really receptive to what the stakeholders, your colleagues are wanting, what they need to have an effective relationship is really the question. At least from our perspective, but yeah. Face to face, there is hard to kind of qualify the non‑linear kind of interactions that you get. It can't be kind of transferred and over the internet. I would agree with that.

>> DONNA MITRANI: Thank you so much. And thank you so much for all of the questions from our participants and for the great discussion from everyone. Thank you again, Mark.

>> MARK BAYER: You're welcome. Thank you.