**2018 Online KT Conference:**

**Engaging Ways to Engage Stakeholders**

Engaging with Health System Leaders: Strategies for Effective Research Partnerships

Sarah Bowen

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>> JOANN STARKS: We are going to move on now to our first presentation from Dr. Sarah Bowen. An applied research consultant in Nova Scotia. Founding Director of the Winnipeg regional health authority research and evaluation unit and also an associate professor at the School of Public Health University of Alberta. Her presentation, engaging with health system leaders: Strategies for effective research partnerships, will address approaches to health research partnerships, benefits, challenges, and cost of partnering, and strategies for determining appropriate knowledge users for specific research activity.

If you have any questions, please ask them in the Chat box, and we'll address them as we can. After the presentation, Kathleen Murphy will lead the interactive discussion.

Sarah, are you ready to begin?

>> SARAH BOWEN: I certainly am. Can you hear me clearly?

>> JOANN STARKS: We can hear you. Thanks so much. Take it away.

>> SARAH BOWEN: Well, thank you for that introduction, and thank you to the organizers for the honor of asking me to participate in this conference here today. And to all of the participants, thank you for your interest in the topic of engaging with health system leaders.

I should say before I go any further that while my focus will be on the work that I have been doing with the health system, really what I am going to talk about I think has applicability if we are talking about promoting change through knowledge translation in any large system.

One of the major changes, I think, over the last few years is the increasing attention to the importance of research that is conducted in partnership, but one area that's received much less attention is that of engaging with health system leadership.

So, this afternoon, I hope to cover two major topics. First, the 5 Ws, the why, the what, who the, the when, and the where of doing partnership research. And secondly, evidence on what we know about engaging effectively in developing health system academic research partnerships.

Before I do that, however -- oh. I think I must have skipped a slide here. I am wondering if I -- I was going to ask people if they could very quickly use their interactive screen to tell me a little bit about you, wondering if you would describe yourself primarily a researcher, a health service manager/decision maker, a clinician, a care provider, maybe in a hybrid role such as a manager with research responsibility, a patient, a client, a service user, a research funder, or any other role.

While I can't see you, it would just be really helpful if I could get a bit more information about who I am talking to. So, if you could just select the category that best describes your role, that would be absolutely wonderful.

I know that many of us wear many hats, so it may be a bit difficult to actually choose one that seems to be the priority for you. And I notice with the responses coming in that quite a few people, about a quarter, are sort of saying that they have another kind of role. I am a bit curious about what that is.

All right, now. Oh, numbers are coming up again. I think that's giving me a sense of participants. It seems that we've got a good number of researchers. A lot of people in the other category. That's helpful.

>> JOANN STARKS: Sarah, I am not sure if you can see all the comments that people are putting in the Chat box. We have a KT specialist, an educator, program development; funder/researcher/patient. So, we do have, let's see, grant manager, academia, education. We do have quite a few people responding in the Chat box as well. Sorry to interrupt you. Go ahead.

>> SARAH BOWEN: Oh, that's wonderful. This isn't unusual that we have all these roles, and it's wonderful to hear from people who are really playing a KT role specifically.

So perhaps we'll just move on now. Thank you.

Now, I've found out a little bit about some of you. But perhaps, just so you know where I am coming from, like many of you, I bring many perspectives to the topic that I am going to talk about. In my early career, I was responsible for community development and creating and managing health programs, particularly for underserved communities, and yes, in that role, I did refer to the research, and it was actually this experience that led me to return to graduate school because what I found was not only was there little research on topics that I or the communities I was working with were interested in, but also that when that research was conducted, it often got really important things wrong. Sometimes completely wrong.

Through my graduate education, I was exposed to what was then an emerging field of knowledge translation and undertook research with a number of health regions to try to determine what worked in promoting research use. And after that, I went on to be the founder of the Winnipeg regional health authority in Manitoba, Canada. This was an eye-opening experience for me use in that role I was allowed to build a team to actually respond to the research needs of the health region, and in doing Shah, I really gained some startling insights into how research was viewed by many decision-makers, and it also exposed me to what I call the dark side of university health system research partnerships because sitting in my desk, if anything didn't go well with research that was conducted in or with the region, I was the person on the end of the phone. So, when I was offered a position at the University of Alberto to design and teach a course and engage scholarship, I was delighted and took this on with a goal to better prepare young researchers to work in collaboration with clients, community, clinicians, managers, and policymakers.

There's been a much greater emphasis on partnerships in research over the past many years, and there seem to be a few reasons for this. First, questions facing the health system and, indeed, facing society are increasingly complex. They're questions that cannot be adequately addressed by one or two researchers or one discipline working alone. So, this trend towards team science can be found in all the countries and across all health-related disciplines. But we must also acknowledge the contribution of patients and of communities who insist that their rights be respected and that their voices heard and that their priorities are recognized in the research conducted. Nothing about us without us. And of course, many researchers are exploring partnership research, whether or not they are convinced of its value, because having a community partnership is a requirement of many health research funders. In fact, in Canada, in particular, funding requirements are a major driver promoting this kind of collaboration.

And at the same time, authors from diverse approaches to partnering are promoting potential benefits and values of research that's co-created. This broad umbrella of research includes things like participatory reaction research and converges on many important principles.

In recent research, I've been working with a team where we've found that while researchers and health leaders believe in the many potential benefits of partnered research, many problems were experienced in trying to establish and lead effective partnerships. We found a lack of guidance for how to initiate and develop as well as maintain these in the literature.

So, based on that preliminary work, I've been involved with a team that has been digging deeper into the issue. This is the -- the PI on this is Ingrid Botting, and it's part of a larger Canadian Institutes of Health Research Foundation grant, led by Dr. Ian Graham, who I am sure many of you may be familiar with. So as part of that project, we've just concluded a review of the gray literature, and I will be including some of these preliminary results in my presentation. So, to start off, I would like to present for your consideration some ideas of how we might approach this question of research partnership. I have organized the first part of my discussion as the 5 Ws of partnership research. What is it? Why do it? With whom should I partner? When should partnership occur? And why?

First let's look a bit more closely at the concept of partnership in health research. What do we mean by this exactly? We know that there are many differences between types of research and differences that have important implications for partnership. Bench science is very different than health services research or community-based research, for example. Also, when partnering with a health system, it's important to consider what exactly is considered research. The interviews that we have been conducting with health leaders across Canada have found that leaders in the system articulate very different understandings of what research is, and this ranges from what one person called the white coat working in the lab to very insightful and complete definitions recognizing the whole scope of knowledge-generating activities.

And we also found that attitudes to how useful research is logically connected to what individuals think it is and isn't. So, if, for example, people think that it's academic work detached from what we are doing, the perceived usefulness of research to looking at questions of organizing health service design or system change was pretty low.

An even trickier concept might be that of research partnership. So first of all, who are the partners? Much of team science is conducted with academic researchers from different disciplines, and we call that interdisciplinary or transdisciplinary research.

In this presentation, though, I am going to be focusing on partnerships between academics and those of other sectors. Although some partnerships, of course, involve both interdisciplinary and intersectoral teams.

These partnerships occur at different levels within the health system. They may be with patients, with providers, with managers, whether from front-line or executive management, or with policymakers.

And another important consideration is whether the partnership is with an individual within the system or with an understanding with a sponsoring organization. What our interviews are telling us is that too often an individual researcher makes contact with someone they know and works with them. This may or may not be the most appropriate person. And what happens when the person you are working with moves on to another job?

And of course, the important question: What do we mean by partnership? By collaboration? There's many different levels of collaboration. This can range from simply signing off on a research project or writing a letter of support -- and this is a situation that's still far too common -- to what I call managed participation, where the decisions are made by the research team and health personnel consulted in token ways, to true partnership. And by this, I mean that partners are involved in meaningful ways at all stages of the research. Decision making is shared.

And there's many different traditions of such partnership. As I mentioned before, engaged scholarship, ITT, KR. The important thing I want to stress for this discussion is that it really is partnership.

And perhaps the most important question of all is this: Who is driving the train? Is it the researchers? Is it the needs of the system? And what kind of train is it? Where is it going? And are we being realistic about the trip?

Which gets us to the next consideration: Why bother with partnership research at all? Is it worth it? Many researchers enter the world of partnership research because it's a funder requirement. They may or may not have an interest or the skills needed for this work. And they may not even be convinced of the benefit. But as one interview participant said to me: Researchers are small people. They know how to play the game. If partnerships are required, they will go out and find a partner. It may not be what we consider a real partnership, but they will find somebody to sign off.

But let's look for a moment at the potential benefits of partnership research. It certainly has its challenges. Is the aggravation worth it? Well, research suggests that it can be, though not, of course, in every case. Which, of course, is the argument for learning how to engage effectively. There's not time to go over these benefits in detail, but benefits of authentic engagement are not simply that research is more likely to be used, which is often the motivation for researcher and funder interest. But that it is more likely to be of higher quality. And this is because by engaging with diverse partners, you have many different perspectives and many different knowledge sets. And there's other often side benefits, such as building capacity within organizations and individuals. And -- and this is my favorite reason -- it actually protects the researcher.

Just to give an example of this, several years ago I was called in to help diffuse tension between a university research unit and a health region. The unit had -- with funding from government -- undertaken an analysis of patient safety using indicators from administrative databases. This research, along with other similar studies, suggested that hospitals in the region had poorer outcomes on patient safety than equivalent hospitals across the country. Not surprisingly, clinicians were upset. The response of the researchers was that the region didn't want to hear the truth. I was involved in some pretty intense meetings that actually went back and pulled the files of the patients that actually triggered these indicators. What we found out is there were a lot of errors made in the research. These errors, it turns out, could have been fairly easily prevented. We figured out in the end that if the research team had spent a couple of hours with the Director of Health Services management, they could have actually had a better understanding of what was in those databases, what the indicators meant.

The results of this very high-profile within the organization conflict went on for a few years. It was really a breakdown in trust. The report was delayed for I think over a year and cost a lot of money. And I learned a lot from that about how important it was not only to get good results, not only to get results used, but to actually promote confidence and trust among partners and not to end up being the one that's looking a little bit stupid.

But while I want to emphasize the potential benefits, I think it's also important to recognize that there is not solid research evidence on the benefits. Most reports are qualitative and retrospective. There's a gap here, and I think we all need to work on filling it.

This example leads quite nicely, I think, to another key question: Who exactly should I partner with? Whose door do I knock on? And working on issues of system change or of health service organization, this isn't really an easy question. It takes an investment of time, not only to determine the most appropriate person, but all too often, the demands of time force a rushed response, and sometimes even token involvement.

One of the challenges, I think, is that we often think only of stakeholders. And on questions of healthcare, there's often very many of them. And I'd like to suggest that we think about this more critically and differentiate between interested and affected parties -- that means those people who are affected by the issue the research addresses -- and knowledge users, who are those who we expect, or hope will act on the research findings. And that will help us narrow down the question of who exactly we should be working with.

We need to ensure that the question of the research is of concern to those who can act, and these people may not be the ones who care the most or who are the most affected by the question. Generally, those people are the clients of health services or the family of those clients. But those clients are not the ones who are in a position to adopt many changes. It is the managers, it's the policymakers, and so those are the people we need to engage with. Often, it’s not as easy or as satisfying as engaging with clients, however. We all hope that we will be working in a supportive team with our research partners. Not all relationships are of the warm and fuzzy kind. We need to be prepared for some variations of the Odd Couple, and even some relationships that are downright difficult.

So, the question of when to partner is an easy one. You want to do it before any slips are made. Ideally, that means before you even have a research idea, certainly before you have a proposal. What is needed? What are the interests and concerns of health services? It's not a matter of providing results at the end. If there's partnership, there's involvement and decision-making throughout the project. And a side benefit of that is there can be learning and implementation of that learning as the research progresses.

And where does partnership take place? The key principle here is to meet people where they live. In my role with the Winnipeg region, I was aware in many cases that research team meetings were scheduled for the convenience of researchers, and that often prevented meaningful engagement of managers and other decision-makers. Just important to fit into the schedule of all those you want to truly engage.

I remember one evaluation research project, really strong program team. We decided that we needed to have a VP buy-in to all of this. The approach there, I asked for ten minutes of the person's time, showed them the research plan, they had wonderful input, and ten minutes was actually all that was needed. So, there can be quite a bit of flexibility in how that's done.

Now perhaps we could look a bit at the specifics of how best to engage with health leaders around questions of health service organization. As I mentioned, the team that I am working with did a thorough review of the literature a few years ago, and while we found good coverage and good consensus on the benefits and challenges of research partnerships, and the factors associated with success -- though I must say there's much more out there on challenges than there are on strategies to address those challenges -- but there was very little operationalization of those general principles into concrete guidance what we found was that principles were extrapolated from the community collaboration literature, and there was often as well a common assumption that the purpose of partnership was simply to promote research use. And that is important, but I'd like to suggest that it's more than that.

We also found that there was a failure to differentiate between researcher-driven research and that that responded to the needs and the priorities of the health system. And on the whole, the voice of nonacademic partners was missing. So, the experience of researchers in partnership research was strong, not so much that the other partners.

And of course, when we are looking at health system research, there are additional challenges. A few years ago, I had the opportunity to do a stent with Academics Without Borders in Nepal. Electricity there was really limited a few hours a day. Every so often you would see people expressing some concern about one of the lines, but as you might guess from this photo, the whole system was so shaky, it was often difficult to see exactly where the problem lay. And it reminded me how often we approach problems in healthcare this way. We deal with the broken line we can see. But the system is completely interconnected. Thus, very hard to address the really big questions.

So, going back to the research project I mentioned earlier, we set out to determine how effective research projects, particularly those focused on health system design and organization of health services, could best be developed and supported. But as we got into the literature and further into it, we realized we needed to take a step back and actually ask what are the issues? What's really going on? Knowing that there was little guidance in the peer-reviewed literature, we decided to explore other sources that might be providing such guidance, and we did this through two separate Web reviews. The results of the first are the most relevant to what I am discussing today, so I will go through those findings very briefly.

So, this Web review focused on sites that address health system organization and functioning, and that's because these sites might be consulted by health leaders as they attempt to improve health system functioning and organization.

Sites that promote knowledge translation or evidence used in healthcare. And that's because current KT research emphasizes the importance of early and meaningful relationships, so we thought we might find something there. And we also looked at sites of Canadian health research funders because in Canada, much research collaboration is driven by funder requirements, and of course, we found other sites through a bit of a snowball effect.

Any resources we found on the site were assessed for two inclusion criteria -- that they addressed health system change or health service organization; and that they also dealt with the practical issues of how actually to do research partnership. As well as the inclusion criteria, we had these exclusion criteria. We didn't look at resources that were limited to clinical research focused on relationships with communities or individuals rather than the health system that focused on end-of-project or knowledge transfer activities only. We really wanted to look at resources that promoted actual partnerships. And we also didn't review those that addressed capacity building within the healthcare system or relationships just between researchers themselves.

We used a standardized template, and this included such items as intended audience, recognition in the stages and diversity of partnerships, recognition of identified challenges, along with other factors.

And from 46 sites, we found only 12 resources that met criteria for full review. None were written specifically for health system leaders, and only one directly addressed the topic of our research.

Of those 12 resources, only 10 gave specific guidance, and that guidance was really quite limited. Two were short blog posts. Four were written specifically for the international development context. Nine gave more than only a few suggestions for establishing partnerships.

Another finding of interest to those who are working in the field of knowledge translation is the approach to knowledge translation found in these resources. What I call knowledge transfer, promoting awareness and use of research findings on research already completed, this was dominant, and the integrated knowledge translation approach which focused on co-creation or coproduction of research, was not that common.

So, resources intended for knowledge users tended to focus on how to use research. Those intended for researchers focused on how to communicate research. So, in other words, researchers communicate the findings, and hopefully health leaders listen.

While there's certainly a need for researchers to learn how to communicate around research, the model of simple knowledge transfer, while it was really helpful early, I think, in the whole development of the field of knowledge translation, I'd suggest that it now needs to be replaced with some more up-to-date models that reflect current research. As one of the interview participants said, that approach, that knowledge transfer approach is so last year.

We also noticed an interesting contrast with information and specific guidance that was given on health system research partnerships in contrast with information given on other forms of partnerships. So, for example, patient engagement, community participation, even interprofessional care or north-south research relationships. There was much more practical guidance that we found on those specific topics.

It would be interesting to explore reasons for this difference, and two come to mind for me that I would really like to look into more. One is that in spite of the fact that many in the healthcare system state that they feel a bit that they are being used by researchers, unlike research with patients, with indigenous communities, or in developing countries, partnership and inclusion don't seem to be viewed by healthcare leaders as sovereignty kinds of issues. And secondly, a theme coming from the interviews we are now undertaking is that all too often research isn't really seen as relevant or useful to those managing the system.

I'd like to end up with some practical guidance that's been emerging from the work we've been doing. First of all, for researchers who are interested in true partnership, many of us may feel that we are not well prepared for this, and it may feel like we are taking a bit of a flying leap into the unknown.

Like many of other of life's activities that might bring risk, like collecting mushrooms, something I have recently learned to do, many researchers don't have the practical preparation on how to do this. It's not something we just -- we can just assume we know how to do any more than we would recommend that somebody go out and harvest chanterelles for dinner without some basic preparation.

So, the first step is to prepare yourself. Like mushroom hunting, one of the most sensible things to do might be to go out with somebody who knows what they are doing the first few times.

The other recommendation is to develop skills in researching real-life questions. One of the things that we are learning from interview participants is there seems to be a bit of a mismatch with how we often train researchers, the emphasis on focus, focus, don't get distracted from your own interests, preparing researchers to be very good in certain methods but not necessarily very flexible in others. So there really seems to be a need for more practical application of research skills.

Also, important to really learn about the organization and its priorities and to take time to identify those within the organization, not only those who are working in your area, but also providing research leadership. And through all of this, it's important to focus on relationships first, not the task. You want to respond to needs and not just think about your own agenda.

The preparatory stage can be challenging because not only are health organizations busy places, but they are complex and can be difficult to maneuver. So, make yourself useful. Start with an orientation of how you can help rather than how you can get the organization to buy into your plan, and look for opportunities to hang out, to participate and find small ways you can contribute. For example, are there planning grants that might fund a get-together of health leaders and researchers? And remember how busy those working in the healthcare system are. Position yourself as a potential solution rather than another set of demands. And be aware of the different timeframes that system leaders and researchers have. As one of the interview participants said, by the time researchers get back to us, operations has left the building. We need a timely response.

And most of all, show respect. I am sure that most researchers hearing this will say, well, of course I show respect. What I have found, though, from both my work within a large health region and the entries we are conducting right now, actually, I see all too often there is, however unintended, lack of respect, especially to those on the front line. I have had nurses in tears who feel they have been abused on the phone because the data that the researcher needed was not provided quickly enough. Within the first half dozen interviews we conducted over the last few months, we identified few cases where HR complaints had been laid for disrespectful workplace behavior, another where a patient went public about research behavior, and these needed legal input.

And as one interviewee stated, it seems like there's a hierarchy, and we are treated like gophers.

What about guidance for those in the healthcare system? So often health leaders feel that they are really doing a difficult balancing act on the edge of disaster. And in a crisis-prone culture, it may be easy to fall into being reactive, but I would argue that time is saved by being proactive. What we are learning is that those who have proactively developed clear guidelines and criteria for partnerships and communicate these and communicate their priorities to researchers, ideally through forums that they, themselves, initiate, have far more effective relationships.

One of the other findings from -- well, the interviews might have been the strongest finding is the importance of leadership within the health system and how quickly an effective leader -- whether that's of a program or of a whole organization -- can move an organization ahead in terms of use of evidence or how quickly, as one person said, things can crumble.

Being clear about what the organization expects out of the partnership also allows one to be pleasantly firm when there's inappropriate or unimportant demands. So be firm. Communicate that your criteria are met. Don't feel obliged to go along with something that's not a priority for your organization. And simply say no to signing off on a proposal you have not had a part in.

Be realistic. Partnership does take time, and the people who are chosen by the organization as the contact points must not only be chosen carefully, they must have a voice in planning as well.

In the research that I cited earlier, we came to the conclusion that what was more important about thinking about knowledge brokering was thinking about relationship brokering, that finding an individual who could bring those two different worlds together was really important.

Anticipate difficulties. Don't be afraid to have a frank discussion of how you need to have things go. Document expectations and agreements. Establish processes for monitoring, for problem identification and conflict management. And be clear about whether you are dealing with one researcher or if there's a larger departmental commitment. Deal with any concerns early.

And of course, it's impossible to overstate the importance of communication. It's not simply because health leaders and academics work in different worlds. That can be addressed by mutual orientation and a respectful attitude. But think about providing opportunities for social interactions. Eat together. Ask questions and don't take anything for granted. Make sure you update the research team on organizational activities. And require regular reporting. And provide feedback to the academic center where that's appropriate.

There's also a need for funders to move beyond requiring partnerships or collaborations to actively facilitating it. This can be done through funding initiatives. In my experience, it's not only that we need to fund opportunities for partnership development, but also support the development of partnership guidelines and criteria aimed at increasing skills and collaborative research. Funders can support research into the impacts of partnered research because, as I mentioned earlier, very little is known of this. Sand we need to urge funders to review requirements so that we can facilitate genuine participation because sometimes a requirement of the funding proposal actually makes that very difficult.

>> JOANN STARKS: Hi, Sarah. This is Joann. I want to let you know we are getting close to the end of your time. I know you are close to the end of your slides, with you wanted to make sure we have time for our discussion. Thank you.

>> SARAH BOWEN: Thank you.

Well, from my experience with review panels in Canada, not much progress has been made in enhancing the process. more work is needed, and I have made some suggestions here.

Before I close, I'd also like to mention that it's important to look at changes that need to be made within academia. I mentioned earlier the lack of preparation for partnership work. A lot of that is considered soft skills education and practice, how to listen, partner, build teams. And also look at the values that we are promoting on the openness to alternate methods and ways of doing things.

There's also been a lot of attention, of course, to addressing internal reward systems.

One of the themes coming out of the interviews that I have just mentioned is really an urge coming from the system that we need to reimagine research. We need to move away from thinking about specific research projects, you know, that come in from the outside and may take a few years and think about more as using sort of research thinking and research skills that get brought to daily problem solving.

Before I go, I'd like to acknowledge the larger team that has been working on the work that some of this presentation has referenced.

And now I'd like to close this part of the presentation and pass over to the discussion section. I believe that's Kathleen. So, thank you very much for your attention.

>> Thank you so much, Sarah. That was a great amount of information that you shared with us, and Kathleen Murphy will be facilitating our discussion session. Kathleen?

>> KATHLEEN MURPHY: Sure. Hi, everyone. This is Kathleen back. I think people have been making great use of the audience chat, and we are going to try to address some of those questions now, Sarah, before we turn it our formal reactors' questions. So, this is really great. It's been a very active chat, and we will get to as many of them as we can. I am not promising to get to all of them, though, because we do want to have time for everybody who has prepared their reactions as well.

So, Sarah, I don't know if you, yourself, have you been looking at all at the chat? Were there some questions that you wanted to prioritize, or would you like me to pull one out for you?

>> SARAH BOWEN: There's been a lot of recall interesting comments in Chat, but I haven't been able to monitor it as closely as I would have liked, so please kick off for me.

>> KATHLEEN MURPHY: Sure thing. I am pulling out one first because I think it will benefit everybody. Is your lit review on partnerships available somewhere?

>> SARAH BOWEN: It was not a formal literature review partly because we couldn't find very much at all of what we were looking for. The article that I flashed up earlier in the presentation -- and it is referenced -- we did summarize what we found in that. So that's a partial answer.

>> KATHLEEN MURPHY: Okay. So, there's no citation we can post in the Chat for people yet?

>> SARAH BOWEN: No. I would suggest the article that I referred to earlier on -- and the reference is on the slide there. Because that is a bit of a summary of what we found, but we haven't published the results of this last round of research. That is correct.

>> KATHLEEN MURPHY: Okay. And a few of the questions talk about examples. Laura Cohen asked do criteria and guidelines for partnerships exist today, or are there examples of early adopters that we can learn from?

>> SARAH BOWEN: That's an excellent question. We have been gathering information across Canada. We have not been looking broadly internationally except for the websites that I mentioned earlier. So, some of these are the organizations that seem to be the early or more advanced adopters in a we've been talking to. Some of these criteria are very basic. Does it fit in with our organizational strategic priorities? Has the researcher already been in touch to determine what we are working on? Some people that I've been interviewing have said, quite frankly, if they just approach us about something that they haven't talked to us about before, sometimes we just automatically say no. Having costs covered. And there's a lot of in-kind expectations for organizations around research, so there's often quite a bit of tension of is this important enough that we should try and help out the researcher, or is this really important to us as an organization? And should the funding be -- that the researcher is getting to do this research also be directed towards covering some of the costs of the organization, either backfilling or supplementing in another way? Those are some of the very simple things that can be done.

>> KATHLEEN MURPHY: And are any of those examples or guidelines, do you have any suggestions specific to engaging policymakers and insurers?

The question was absolutely like to engage policymakers and insurers. Any suggestions for being more successful in this?

>> SARAH BOWEN: Okay. Some of the principles, I think, are very much the same. It's such a huge topic, it's very hard to come off with a summary. One of the key approaches that I would suggest is really understanding the world view and what's important to policymakers and insurers. Within the policymaking context, there's always priorities and dynamics that are leading to some things getting more attention than others. Trying to hook your issues onto that is a really good strategy, but even more important is to have an ongoing relationship with people who are setting policy in your area of interest and expertise and taking a lead from trying -- finding out early, right, which direction are we going in? Are we trying to respond to what system needs are? Are we trying to inform things that are important to us?

>> KATHLEEN MURPHY: So, I know we didn't get to everybody's questions. Some of the questions were more comments oriented. I think Shaun Best pointed out a publication that others might find. We are incorporating all of these. If they can be worked into another Q&A, we will do that. If not, we will follow up with you after the conference and post on our conference website a Q&A o so that everybody can benefit from the answer to your awesome questions.

Go ahead.

>> SARAH BOWEN: I certainly welcome any questions individually on my presentation. My contact information is there as well, so I am certainly -- would be more than happy to engage in sort of more specific conversations with people.

>> KATHLEEN MURPHY: Thanks so much, Sarah.

So, I do want to introduce our three reactors today. Dr. John Kramer is with us from the Institute for Community Inclusion at the University of Massachusetts Boston. He is a knowledge translation manager and research associate there.

Dr. Deb Rose is a physical therapist who is Board certified pediatric clinical specialist, currently a school-based practice consultant. She is also vice chair of capacity development for Knowledge Translation Committee of the Academy of Pediatric Physical Therapy, APTA.

And last but by no means least, Dr. Sandra Finestone is Executive Director of The Association of Cancer Patient Educators.

So, one of the questions that we had you three think about is this one here. Can you identify any specific benefits from stakeholder partnerships that you have experienced in your research projects or could see taking place in the future? Maybe John, do you want to?

Go ahead.

>> SANDRA FINESTONE: This is Sandy Finestone. Did you want to speak with John first, or did you want me to jump in?

>> KATHLEEN MURPHY: Go for it, Sandy.

>> SANDRA FINESTONE: Okay. All right. Well, my area is a little bit different than what the discussion has shown so far, of course, in that my interaction with researchers are clinical researchers or bench scientists. But Sarah said something that I think needs to be reinforced. In any kind of stakeholder partnership, whether it's researchers or administrators or patients or communities, I think what needs to be identified before the conversation takes place is what's important to whom. Because with administrators, they are looking at bottom line. Researchers are looking at either research advancement or perhaps advancement of their own research or place in the research community. And patients come from a very different place, of course. But if there can be that respect about what is important to whom, then I think the conversation can start. And without that, I don't think it's going to go anywhere. It's -- you know, the question about who should partner with whom, I -- my position, of course, is that a patient needs to be part of every discussion. I am not sure that administrators can see the benefit of that. I know that in my community, in the cancer community, cancer researchers have -- mostly because they are required to. Their research is not going to be funded unless there's a patient perspective involved.

Now, we as patients had to fight very hard and long for that to happen, but I think we've been successful. And more than that, researchers are now wanting us to participate because we've brought something to the table that's not been brought to the table before.

>> Yes, absolutely.

>> SANDRA FINESTONE: My experience has been a little different with health administrators.

>> KATHLEEN MURPHY: Thank you for sharing that.

Did anyone else have any comment on this question about specific benefits?

Okay. What about any situations where you've collaborated successfully with researchers and/or practitioners?

John or Deb, any comments on that?

You might want to check if you are muted or not.

Hello?

>> JOHN KRAMER: My phone auto-muted, so I am sorry. I was trying to chime in. Sorry, it was a technical problem on my part. I can respond to this one since it's still up on the screen.

You know, I think there's two ways to think about benefits of stakeholders. One really relates to the quality of the research. I mean, ideally, in our work, we know we focus on competitive integrated employment, and that's a topic that has a lot of different stakeholder groups that we are accountable to and that kind of guide the research process. We know that, you know, we couldn't pull off this research without authentic relationships.

One of the things we try to look at from our perspective is the rigor of the research that we do, how accurate is it, are we hitting the right thing that matters to the different stakeholders that we are engaged with?

Also, And I know Dr. Bowen mentioned this and I want to underscore this -- we are in a position where we can start to see how our research is actually used in different ways. One of the things that we have noticed -- you know, I just got an email back from somebody who was really excited about one of the recent research publications that we had. He provided me some really, from a knowledge translation professional perspective, great feedback. He walked through like how he was using some of the themes that were in the research article to implement in a survey that he was implementing for employment specialists in kind of his professional sphere.

So not necessarily stakeholders we had engaged with directly, but certainly from the same class of stakeholders in a we had engaged in directly, and so we were hitting -- we felt like we couldn't really hit those kinds of targets if we didn't have that kind of authentic kind of engagement.

>> Yeah, it's interesting, there's been so many comments about the authenticity of relationship and emphasis on relationship building.

We do have a couple more minutes before we go to our next presentation. We have Mark Bayer waiting in the wings.

Deb, did you have any kind of thoughts to close us out?

>> DEB ROSE: Yes. I would definitely like to share especially what I found really relevant were the five Ws of partnership research. Working in the public school system and really our partnership involves transferring knowledge for a child in their occupation as a student to use in their educational program. And using those five Ws, I really see kind of forms a platform to respond to the educational needs of the student. It can really help us in reflecting on those to minimize the impact of barriers, maximize the effect of the benefits, and really foster shared expectations across a large group of stakeholders. So, I think those are really effective considerations that we can use in our work and would be applicable to continue using.

>> KATHLEEN MURPHY: Okay. Thanks so much, Deb.

I think we are at time as far as the Q&A for Sarah's presentation. Thanks so much, Sarah. I have Joann here with me, and she's going to kick us off for the next one.

>> JOANN STARKS: Thank you so much, Sarah, and thank you, Kathleen and reactors.