**Show Notes**

Description: Dr. Amy Valent engages in a compelling conversation with Dr. Amanda Bruegl of the Oneida and Stockbridge-Munsee Nations. Dr. Bruegl is an Associate Professor specializing in Gynecologic Oncology, Vice Chair of Diversity, Equity, and Inclusion, and deeply involved in community outreach. In this episode, they discuss the methods and strategies for effective community engagement research in the realm of obstetrics, gynecology, and reproductive health. Discover the importance of partnership models, ethical consideration, and building trust within the community. Tune in to explore how community engagement can drive meaningful research and improve patient outcomes.

Speakers

(AV) Amy Valent, MD

(AB) Amanda Bruegl, MD

Transcript:

AV: Hello and welcome back to the SMFM Race and Research podcast series. I am Amy Valent, a maternal-fetal medicine at Oregon Health and Science University and during this podcast series, we have been interviewing experts around the country about approaches to conducting and consuming research in maternal-fetal medicine and the areas of reproductive health with an anti-racist and equity promoting framework. Today I have the honor and privilege of speaking with Doctor Amanda Bruegl of the Oneida and Stockbridge-Munsee Nations, who is an associate professor in the division of Gynecologic Oncology at Oregon Health and Science University, in addition to Vice Chair of Diversity, Equity, and Inclusion; Clinical Assistant Director of Community Outreach and Engagement in the OHSU Knight Cancer Institute; and Associate Director of the Education Cor within the Northwest Native American Center of Excellence. Today we will be engaging about methods and strategies for effectively using community engagement research in our areas of obstetrics, gynecology, and reproductive health. Welcome Doctor Bruegl. It is such a pleasure.

AB: Thank you so much for having me, Doctor Valent.

AV: Well, I think I would love to just take a moment to briefly have you simply define what is community.

AB: I think it's difficult to just provide a finite definition for something that's so non-tangible, right? There are many layers of what community is and we just think about our own identity. So, for myself, for example, I'm a native woman. I am a professional. I am an educator. And these are all different communities. I think when we're thinking about research and communities, it's a grouping or it's a constellation of people with similar values along certain minds or a continuum.

AV: I think that's great and certainly everybody may have their own definitions of community as well. And I guess you know, when we think about using community engagement in a research framework, how would you define that, whether it's within your own work or how you like to be reading about it in the literature?

AB: I think there's been a lot of popularity and momentum behind engagement with community. And so, I think it's good that we're having this discussion of like what does this actually mean? And I think about my own experiences. I'm a, you know, indigenous person and I work with tribal nations to do my research. And so, there's very clear sort of expectations of how you engage with the tribe because tribes as you may or may not be familiar with, are considered sovereign nations, and so engagement has both subtle connectivity to it, as well as a formality. You're engaging with somebody like you would with someone from Canada or from the UK, or from Colombia. You know, it's formal, but when you really think about engagement, it's how do you include, invite, and create space for that community to be a part of and inform how research goes.

AV: I think that's really great, and you know, certainly when we think about different populations there may be ways how they themselves define how engagement looks. And so, in your view, as you're looking at your patient population or you're looking at your literature. What impact do you think community has on patient outcomes and inequities?

AB: I think community engagement and participation is central. I think the sort of old school way of looking at research is like we as researchers come in with a question and we go in and we get an answer, and we extract it. Historical research has been extracted and I think the voice and the need is in participatory, right? I hate to overuse the word engagement, but really, like how are we partners in this? And I think the sort of respectful exchange of culture and communication is what allows the results of research and intervention to actually be adopted, heard and assimilated. It's really not a great word in this day and age, but sort of like brought into the communities ongoing value system.

AV: I think that's great, and I guess you know when we think about a traditional, quote-on-quote research process, where we do we go and we gather information, that this is just a different way of gathering information and I guess just from that perspective, how much more time do you think that people would need to think about of incorporating within the research process to be able to engage in such satisfactory aspects of this research?

AB: I think you have to really blow up the time map when you are doing true engaged participatory research. I think of my own journey here at OHSU, and doing native based community informed research. I was recruited here in 2015 and it took years before my first grant and publication because it required that amount of time to build trust with the community. To show that I was here and not just showing up to complete my Masters's degree or to get a grant and really establishing true street cred. And then as I have received some grants, it's taken a long time to like publish and to create projects that the communities on board with. So, for most of the things I do, it requires multiple IRBs for example. So I go through the tribes, for example, Health and Welfare Committee, and so a concept will be presented to Health and Welfare, and then they take it to the Tribal Council, who will say yes or no to proceeding. And then I do the Regional Tribal Indian Health Service IRB. And then, because I'm an academician, I need my institution to sign off. And you have the cultural disconnect between two different IRB's. And that's just logistical paperwork, not to mention making sure the players are in agreement on both sides of that. And then there's also the back end. So, as you have completed are you sharing that information with community stakeholders? So, every time I sort of finish a project, I need to get approval from the community about what I am hoping to publish. You get extra points if you have a community member who is actually on your manuscript. But then I also present to the tribes in the region so that the tribes get the information first not the feather in my cap of having some peer-reviewed journal. And so, it's really shifting the hierarchy of the value, right? It's not manuscript first, it's like serving community first and that can't just be a box you check when you say, oh, I'm going to do a community-based project like you must always think about it as this community, this agreement that I have with this population needs to always supersede like your own individual self-advancement.

AV: Well, and certainly as clinicians, we can relate that our patients want us to be improving the way we care for them in ways that are certainly evidence-based, but you know this is truly a translation in active form, so that's really wonderful, and you know, certainly very beneficial for the people that you collaborate with as well. I guess you know when we think about methods of community-engaged research, can you provide examples of how we can incorporate that just within the scientific and research process? When should we start thinking about it and what methods can we use to try to even get started?

AB: I think one thing that's really important to remember is there's like my goal and the community goal. And so, I have a personal goal of GYN cancer prevention among native women. And that might not be every tribes primary focus or goal. Right? And so, when I first, you know, arrived here in the Pacific Northwest, rather than being like, hey, I want to solve cancer, you know? You know, people would say kind of like, pack your bags on me. It's sort of like, hey I have this skill set, I'm very interested in this, is there any way that we could align our goals, right? So, coming in on a very equal footing in terms of like, hey, I have this, is there any value and for me very fortunately many of the tribes in the region have their own goals of HPV vaccination and cervical cancer prevention. And so, it worked out very well that, as I said, hey, do you have any unheard needs, we aligned. And so, I think making sure that there's a shared goal thing. It's not uncommon for tribes to be like, hey, that's great, but actually we have some issues with rheumatology disorders here. What do you have? And I'm like, I personally can't do this, and can I connect you with the rheumatology outreach folks from my institution, right? So, like good faith assistance, even if it doesn't advance your own personal mission, really important. And then I think getting to know who are the stakeholders or the voices within the community. Sort of in common lingo, right, who are the influencers for who you're working with? Because reaching out and saying, like, hey, can you get a cup of coffee, can we talk, that can be really important. I worked at one of the tribal clinics here in Oregon and here I'm trying to be this professional GYN oncologist doing a GYN clinic for the tribe and you know, trying to be my best professional self. And then I saw a patient and they looked down at my socks and I was like, oh man, I'm wearing mismatched socks today haha, how funny. And I didn't think anything of it and moved on with the visit and then later that day, through the moccasin telegraph, things got out in the community that like, oh, they wore mismatched socks, but just like oh, this person's real, you know, and so like you might be advertising for yourself in ways you aren't aware of and just knowing that things can happen through an indirect route and be very, very positive.

AV: I think that's so nice to know, that yes, probably community engagement research truly allows the community to realize that we are not there to, you know, be scientific, but we're also real people, so I think that's a really reassuring message to be able to share with each other. You know, when we think about some of the ethical and methodological considerations and conducting this type of research, what do you think of some strategies or things that we need to be thinking about before we start engaging in this type of research? Certainly, with all of your expertise and experience in this you've probably learned a lot along the way, but what do you think are some tips that we need to be considering?

AB: I think really do your homework in terms of who's the community, whether, you know for me, it's the indigenous community, but if you're working with the black community, the LGBTQ community, you know? Know what the history is in your region. Know what your institution's history is because you may be a great person and maybe your department has a great reputation, but like, let's say another department went and there was something that didn't go well. We all reflect the same institution academically and so whatever eggs on the face or whatever sun shines on the face, you're bringing that in with you. So just knowing, you know, am I starting behind or am I starting with good footing and knowing some of that stuff. Also knowing some of the customs and practices around certain things, for example, there are traditional ceremonies that are very classic of certain times a year and so you know, scheduling a meeting for you know the middle of berry picking season or the middle of you know green corn or you know whatever community event you have like don't be tone deaf and it's hard. How do we know all of these things like, google is powerful, your resources at your institution are powerful, you know, friends and colleagues from, you know, certain communities can help guide you. But being aware of those things before you even get started, it's super helpful. And I think the other thing is as a physician we all interrupt a ton. I like start each day trying not to interrupt my husband, but usually like 3 sips into the first cup of coffee, I’m like, oh yeah, and then this thing or vice versa and it's like we have to stop interrupting people and just allow our community stakeholders to tell their story in their own way. Because once you start being that interrupted, you start silencing people with your degree and I think that can be a real roadblock.

AV: That's great. And I guess you know along those similar lines as you are able to engage with the community and you're able to get, you know, your research aims and objectives hopefully in that meaningful way done. How do you incorporate them within the rest of the process, whether it's in manuscript writing or what have you and dissemination like how is all of those parts of the research process associated with within that context?

AB: I think it's very helpful to have all members of the community part of an Advisory Board so you can sort of regularly give updates on what's going on, you know whether it's quarterly or twice a year, kind of whatever fits the needs of your project. Asking the community how do I get these results back to you? You know, many communities have their own Facebook pages. Like, OK do I make a poster and put it on. Is there a radio station locally or program that they can interview you for, you know, really saying like, hey, I want to share this information, what is the best way? And then doing that, whatever it is, I think that's an incredibly powerful thing, and then in the middle having a community member, either as an author or, you know, able to sort of edit, particularly if things come back with like sort of negative results, letting the community decide, OK, this I don't like how this is phrased or what level of anonymity will the community like. So, you know, here in the Pacific Northwest tribes are small. And if you say, oh, I was at this tribe, you can lose anonymity really quickly or a tribe could get a label. And so sometimes, you know, you will be given instructions, we would like you to use the word land-based reservation or coastal. So that you really still protect that community. And it's particularly negative things because you know labels can be so damning for a long time. And so just getting that information before you actually go public with things. And I think ensuring communities that they're the owners of the data. You know this is helpful for me because we have sovereign nations and I don't have any pushback from the NIH when I say, I will not be giving you my data set because this belongs to the tribes, but allowing people to have that power and typically you know, if you've done your relationship building correctly with the community, you are able to share your scientific information and they don't hold you back from saying, hey, don't share this information. And then that allows you to sort of do the next phase, right? With every good research, you spur more questions for interventions and so if you lay the foundation, things may get quicker as you go forward and you may find that you would have taken one angle, but the community is like no, actually, I see this is the issue and we'd like to go with this and you find yourself on a better journey than you would have been had you just taken the reins and gone where you wanted to go.

AV: Yeah. No, that sounds like a much more gratifying process of being able to publish the research, so that's great. I guess you know in your experience and maybe others that you know that do community engagement type of research, can you provide some examples of some research partnership models that help bridge and share knowledge building within community members?

AB: I think if you’re looking to do this kind of work and find a framework, I think a starting point is community-based participatory research and you can find tons of publications in a lot of the health sciences on the health services research and literature, and when you're in sort of the planning phase you know, meeting or connecting with somebody at your institution who does this work. And you don't have to do the full, community-based participatory research. It's a very heavy lift, but I continue to do sort of like community-based participatory research light. I guess I would say community-informed research, where there's partnerships, but I'm still sort of the guiding force of the science. And so, I think identifying people in your department or your institution is the best way to do it and then talking to stakeholders or other people who have worked with that community to help you tailor that approach to fit the community needs and wants and expectations.

AV: Great, perfect those are great suggestions and I guess you know lastly, do you have any recommendations for anyone who wants to do research in this space?

AB: I think the biggest lesson that I would tell myself from when I was beginning is, slow down and have some patience. You know, we're all some specialist and we are all so driven and organized and bullet point and like this is the way and I have to often slow down my little surgeon brain and be like OK this is this is actually not how it's done. This is not going to be done in two years or three years and so take your timeline and throw it out. After you do that, repeat it back to yourself, because I can't tell you how many times, I'm like I want it done now. You know, it's like a very Veruca Salt, Charlie and the Chocolate Factory kind of moment. But I want it now. And just really let yourself be sort of moved by the process. You're constantly code-switching between like NIH timeline, deliverables, products of your grant, with what does the community want and it is like this war that you're always fighting and I myself have to tell myself all the time you know, slow your role and try to find other ways to be product that sort of build into this, you know. Is it a review article, is it what not. If you want to serve a community, identify stakeholders. Really, really important. Like who are the voices, who are the influencers in the community that will amplify your voice and get to know them so that they can influence in a good way. And I think, you know another thing that's really powerful and helpful is how can you be of service to this community? Do the healthcare workers need CME talk? Do they need opportunities for the youth in the community to come and chat. Do they need someone to talk at their health fair like, how can you give without stings to the community and demonstrate overtime? It can't be like, OK, I'm going to give a CME and then I'm going to do this and then I'm going to give a grant, like just half of the battle. And it’s not even a battle, just half of the collaboration is demonstrating a sustainable commitment overtime. And I can tell you that anytime you spend advocating and representing this community in the way that they say they need, we'll come back in dividends later and it actually really creates this altruistic process with research that can help you pull out of the NIH mindset and I'm not bashing the NIH, it's just, I think it needs to evolve to understand this community centric based approach and I think always reevaluating, you know, as you get stressed about, have I had enough publications, am I doing enough things. Evaluating like, am I serving this community? Because at the end of the day, if you are serving the community and representing their needs, the rest is going to come, it’s just going to take longer.

AV: Definitely, and probably even just us, as academicians for sure, like making sure that we're able to continue with being able to be promoted and all of those things. So, all of that gets a little bit tricky, but it sounds as though, and definitely through the community engagement research that you're doing as well as others, that you know, that's why we're clinicians anyway because we want to be able to help people. And so, this is a really good way for us to be able to help people, but at the same time be able to, you know, identify discoveries and hopefully innovations that are going to help the same community, so that's great. Well, thank you so much for your time, Doctor Bruegl. This has been so wonderful, and you know, I wish you the best of luck with all of your research. And as we know, research takes time. So, this is just another example of how we need to be able to be patient and give us ourselves some grace. But I'd also like to thank our listeners for taking time today to listen to this important conversation and you can find tips that Doctor Bruegl mentioned in our podcast notes. Please join us for future podcasts on equity, race and racism in research and application of these concepts and clinical medicine within our amazing fields of maternal-fetal medicine and in the broader context of reproductive health. Thank you so much.