

Beyond the Manuscript: Values and Practices to Strengthen Genetic Research Partnerships with Indigenous Communities

Julie Beans, Erica Woodahl, and Hal Strelnick

Welcome to Progress in Community Health Partnerships' latest episode of our Beyond the Manuscript podcast. In each volume of the Journal, the editors select one article for our Beyond the Manuscript post-study interview with the authors. Beyond the Manuscript provides the authors the opportunity to tell listeners what they would want to know about the project beyond what went into the final manuscript.

In this episode of Beyond the Manuscript, Co-Editor-in-Chief, Hal Strelnick interviews Julie Beans and Erica Woodahl, authors, *Values and Practices to Strengthen Genetic Research Partnerships with Indigenous Communities*.

Hal Strelnick: Hello. I'm Hal Strelnick, and I am the co-editor-in-chief of *Progress in Community Health Partnerships*. This is our issue-by-issue podcast, Beyond the Manuscript. We're asking authors of one of our articles in this issue, "Values and Practices to Strengthen Genetic Research Partnerships with Indigenous Communities," and we have two of the co-authors of that manuscript with us today, Julie Beans and Erica Woodahl. I'm going to ask them to introduce themselves. Julie?

Julie Beans: Yeah, thank you, Hal, for having us. I really appreciate it. My name is Julie Beans. My father is from St. Mary's, Alaska, which is a small village on the lower Yukon River in Western Alaska, and my mother is from the Oneida Nation of Wisconsin, so I am Yup'ik on my father's side and Oneida on my mother's side. I grew up fairly split between the two communities throughout my life, so after getting my master's degree in public health, I applied to work as a researcher with Southcentral Foundation. I have been with Southcentral Foundation, which is a tribally-owned and operated healthcare organization in Anchorage, Alaska, for about the last nine years. There, I work on several projects that address the health priorities that have been identified by the Alaska Native and American Indian community served by Southcentral Foundation.

Hal Strelnick: Thank you, and you are speaking today from Anchorage, Alaska, is that correct?

Julie Beans: I am, yes, I'm in Anchorage, Alaska.

Hal Strelnick: I'm in the Bronx in New York, and Erica, you are in?

Erica Woodahl: Thank you. I am in Missoula, Montana, and thanks, Hal. Thanks for having us. I'm excited to talk about this paper a little bit. I am a professor in the School of Pharmacy at the University of Montana, and I have been here for 15 years. I'm actually originally from Montana, so I grew up here. I left to do my undergrad and graduate work, and was fortunate enough to be able to come back to this position. My research area that is part of the focus of this paper is I've been working with the Confederated Salish and Kootenai Tribes on the Flathead Reservation in Northwestern Montana for the past 15 years, and we have conducted a variety of research studies focused on pharmacogenetics, so how we

can use an individual's genetic information to tailor medicines to, hopefully, improve drug response and decrease adverse events.

Hal Strelnick:

Well, thank you. Your paper, and the title is, “Values and Practices to Strengthen Genetic Research Partnerships with Indigenous Communities,” is a rigorous summary of an all-day meeting that was held on August 19, 2019, pre-pandemic, with 40 face-to-face participants. It has 11 authors, and why don't each of you tell me what drew you to the meeting in the first place. Erica?

Erica Woodahl:

Sure. This meeting was actually part of a grant that we have at both Southcentral Foundation and the University of Montana, as well as other collaborators at Oregon Health Science and University and University of Washington. We have been working together for about a dozen years now in a center called the Northwest-Alaska Pharmacogenomics Research Network. Every year, prior to the pandemic, we would have a yearly all-investigators meeting, where we talked about progress of the different aims of the grant, and kind of bringing everybody together in a more hands-on, one-on-one way. But, for our annual meeting in 2019, we added on an additional day to the meeting where we brought in our partners across Montana and Alaska to talk about their perspectives in pharmacogenetic research, as well as brining in some other partners who were also co-authors on the study. It was a meeting that we probably organized for about a year, or close to, before we actually held the meeting.

Julie Beans:

Yeah, so as Erica was saying, I've also been a part of the Northwest-Alaska Pharmacogenomic Network since I started with the Southcentral Foundation. At that time it was about six years, and, throughout that time, I had been a part of the Center for the Ethics of Indigenous Genomic Research, which is a center that is out of the University of Oklahoma. This was funded in 2016. Being a part of these two different groups, there were a lot of the same type of considerations that we were thinking through and talking through as a group. This kind of a conversation that was planned for this particular meeting was very relevant to the work that was happening in both of those centers, and then there were two other collaborator groups that also joined the meeting, so that's kind of how I came to be part of this group.

Hal Strelnick:

If you can think back to the date of that meeting, what were your thoughts and feelings while you were at the meeting?

Julie Beans:

Let's see. I'm always very excited to hear perspectives from different individuals on the conduct of genetic research, what are perspectives on the conduct of genetic research with tribal communities, and just the promotional of dialogue, not just between researchers but also in dialogue with communities. So, listening to those conversations, and then also being part of it, it's very exciting. I think learning different ways to phrase what we mean, just because it can be—genetics is a very complex area, so being able to put that into language that everyone understands is always a challenge. I think having groups coming together like this really helps to get better practice, especially including community members so they can be like, “Oh, when you say X, Y, Z, I'm not really understanding what you're saying.” Just getting that clarity really helps to kind of push us out of that comfortable space and learn how to expand our language so that it's all-encompassing so that it's open for all audiences.

Hal Strelnick:

Erica, can you remember your thoughts and feelings at the meeting?

Erica Woodahl:

It was all pre-pandemic so it's kind of a blur. But, yeah, I would just echo what Julie said. It was really nice because we brought tribal community members from Montana, from Alaska, from Oklahoma,

South Dakota and others, and it was really interesting to hear different communities' perspectives on pharmacogenetics and genetic research more broadly. I think it was interesting to hear how in some ways communities, there was a lot of alignment with thoughts on how research could be done appropriately in tribal communities, but then there were some differences, too. It was really interesting to hear, and I really think, at least the community I work with, they really valued that, too, being able to hear how other tribal communities are thinking about approaching genetic research.

Hal Strelnick:

How did you get involved with writing?

Erica Woodahl:

Well, as you mentioned, it's a big to-do, so there were 11 of us but we also asked for input from the 40-some meeting attendees in the form of an evaluation survey. Julie mentioned that we had four main groups coming together—the Northwest-Alaska Pharmacogenetics Research Network, the Center for the Ethics of Indigenous Genomic Research, the Stanford Precision Health for Ethnic and Racial Equality, and the Native BioData Consortium—so a lot of stakeholders. It was fun writing a paper like that, but challenging, too. We started writing this paper right near the beginning of COVID, so that was also its own challenge. We were all starting to work from home, and just figuring out what our new reality was.

Hal Strelnick:

You, Julie?

Julie Beans:

Yeah, it was a very collaborative paper that everyone was—it's always interesting in these because everyone kind of contributes their own area of specialty, and so it just really strengthens and that voice comes through of the group, so that's kind of where I fit in in that paper.

Hal Strelnick:

Well, then, you'll be able to share what you think is the takeaway that readers should get from the paper since they weren't able to be at the meeting.

Julie Beans:

I think one of the takeaways is that this partnership is this evolving process, it is definitely not static, and that we are continuing to learn as a group. No matter how long we've been working together, we revisit that, and do these checks with one another and with community members to make sure that we're all meeting the goals of the group, and just remembering that revisiting part. This was one of the meetings rechecking where everyone is to make sure we're all on the same page, and making sure those lines of communication are open.

Hal Strelnick:

Your thoughts, Erica? What is the takeaway?

Erica Woodahl:

Sure. I think one of the big takeaways was that we did ask the people who attended the meeting, both the academic researchers as well as the community members, to prioritize some of what they thought would be the most important things when approaching genetic research with tribal communities. Really, one of the things that came out that was the most important is developing these trusting relationships, that you can't move forward, really in any kind of genetics, or sorry, any type of research but a particularly genetic research, without having the trust built between the community and the researchers. We talked a lot about respecting the sovereignty of the tribal communities and the community authority, and that is obviously something really essential to moving forward with genetic research, and making sure that the work that researchers pursue is something that is of value to the community and, ideally, hopefully has a future potential benefit to improve health.

Hal Strelnick:

Thank you. What surprised you at the meeting that you remember being something that you did not expect?

- Erica Woodahl:* That meeting was held in Seattle, and it was a really beautiful August day in Seattle. If you've never been in the Pacific Northwest at that time of year, it's really nice. We had a reception afterwards, and I think that was something that just was really fun. We had been sitting and having these conversations all day, and those days can get long, and then, afterwards, we just all kind of celebrated together, and had some food and chatted and joked. I think that was the nicest part of the meeting for me.
- Julie Beans:* I mean, it wasn't a surprise, but I think just the engagement by everyone. It was just something that you always hope for, and I wasn't necessarily surprised by it but it's just something that kind of sticks out to me and always feels like you had a great, successful meeting. Everybody was engaged and spoke, and that's why we left the room for the large groups and the small groups so that all the various comfort levels would be able to put in their thoughts on the different topic areas. That was just kind of one of the things that stuck out to me.
- Erica Woodahl:* Yeah, that's a good point, Julie. I should not say that I was surprised that we had such a nice evening, kind of social, but just something that was just really nice to see.
- Julie Beans:* Yeah.
- Hal Strelnick:* How was it organized that it had that really positive outcome? Is there something, some special recipe for a meeting that is productive in both kind of the emotional level and the energy, as well as the content?
- Julie Beans:* I think just creating that safe space for conversation, and everybody just being open to hearing what one another has to say, and, like I said before, just kind of going outside of your comfort zone of, "This is my area of expertise." But, really, trying to understand what the other is saying, I think that was very clear at the meeting. Then, our different sessions that we had as far as speakers, they really brought up some great points to consider as far as some of the considerations with genetic research with tribal communities.
- Hal Strelnick:* Were there any surprises in the writing process, or the results of your survey?
- Erica Woodahl:* Not really that I can think of. No, I don't think so.
- Julie Beans:* Yeah, I think one of the points that was kind of brought up in the paper and brought up in the discussion was that on the researchers side, I think transparency was prioritized higher, where that wasn't necessarily true on the non-researcher side. Although that was brought up a couple times, I don't think it was necessarily a surprise just because of the training that researchers go through, and I don't think it is to say that it's not a priority or expectation on the non-researcher side. But, that was kind of one of the things that was a point of discussion.
- Hal Strelnick:* That certainly is an interesting finding and an important difference that the paper highlights. Since that meeting, and you alluded to writing the paper during COVID, has the two years of the pandemic changed any of your perspectives about what is important in working with indigenous communities?
- Erica Woodahl:* Yeah, so in Montana, we have a community advisory board with the Confederated Salish and Kootenai Tribes that we've been having monthly meetings with since 2010. Of course, at the start of the pandemic, that all had to stop, and it was about six months before we kind of thought, "Well, maybe people would be interested in re-joining but in Zoom," and it was great. About, as I said, six months after our last

meeting, our last in-person meeting, we had our first virtual meeting with our community advisory board. We had probably more participation at that meeting than we did sometimes in person, because to come to an in-person meeting meant people had to drive great distances. The Flathead Reservation is quite large, and, in the winter, it's maybe not the best kind of time to be driving all around.

But, virtually, people could come and we had a great conversation. I think it just really meant a lot to me that the community I work with was still willing to put in time and think about, "How do we move forward with genetic research even in the midst of all the challenges everybody has been facing?" Yeah, that was really great, and so we carried on virtual meetings for about a year, and then just, let's see, a few months ago, we started in-person meetings again, so we've had three in-person meetings with the community advisory board, which is awesome.

Julie Beans:

I think for me, one of the things that the COVID-19 pandemic kind of has altered in my perspective is just how important it is that we do cater to these relationships, and that we have had these research relationships established pre-pandemic. The pandemic really highlighted some of the grave disparities that are within American Indian and Alaska Native communities, and having these strong relationships, community and academic relationships with tribal communities on health research projects is really important to be able to address some of these very highlighted disparities among communities across the country. I think that's one of the things that the pandemic has altered for me, is just it highlighted the importance.

Hal Strelnick:

I think it was just this past week that *The New York Times* had an article on the disparities among tribal groups in the U.S. around COVID and the COVID-19 morbidity and mortality that was quite striking. I think the importance of that pre-pandemic relationship is certainly important, as you have remarked, Julie. This is a question that comes out of the blue, but my introduction to this issue of genetic research with indigenous communities was on the front page of *The New York Times* probably more than a decade ago from the Havasupai people. Is that something you're familiar with, and how do you view that? It was important enough to be on the front page of *The New York Times*. Was that an important part of your education or your experience?

Erica Woodahl:

Yeah, Julie, do you want to go first?

Julie Beans:

Yeah, so I mean it's a very important event in general, and then specific to American Indian, Alaska Native communities with health research, with genetic research. This is a topic that is brought up in my research world all the time, but I find it very surprising when I kind of go outside of my research bubble. There are a lot of health researchers who are not aware of what had happened with the Arizona State University research project. Yeah, so this is a topic that comes up often, and we definitely don't forget it. We definitely try to learn from it, and this is one of the many reasons that prompts us to come together for meetings like we had to discuss the importance of strengthening these relationships, and moving forward in a good way that everyone can be comfortable with and letting everyone know what does that communication look like.

Erica Woodahl:

Yeah, Julie, I would just like to echo a lot of what you said. It's something that we talk about all the time. It was actually brought up in a meeting I was at earlier today, the Havasupai case. It's definitely something that was well known within the tribal community where I work, and, when we started our partnership, it was kind of at the forefront of people's thoughts like, "Oh, there is a lot that could go

wrong in embarking on this project,” and, unfortunately, recent examples that they could point to. It’s something that’s been in the back of our mind and really trying to work towards conducting the research in an appropriate way and within the safeguards set by the community.

Hal Strelnick:

Anything that I didn’t ask about that you think is important to share?

Julie Beans:

I would just like to say that I think it really can’t be emphasized enough the importance and the length that we have worked on these partnerships and the relationships between the community and the university researchers for this work to take place. It has been a long time, almost going on two decades, and we’re still evolving as a relationship. We’re still learning from one another and making those checks, so I think that process can’t be overemphasized. It’s really hard to kind of communicate what that is and what that’s like, but it’s been really great, and I think the community is in a good place in the partnership, at least from my perspective. It’s because I think on both sides we’re willing to have that open dialogue.

Erica Woodahl:

Yeah, and I would maybe add, too, from the researcher academic perspective is that this type of work takes time, takes more time perhaps than traditional clinical research, or certainly more bench-based research, taking the time to have the conversations, taking the time to maybe have some uncomfortable conversations about the Havasupai tribes, for instance. But, being willing to listen and, importantly, come back, that you don’t just come to the community once and then never return, really taking that long-term approach to building these relationships. I think that has been something that I’ve learned and something that I think is really important for researchers who are considering working with underserved communities.

Hal Strelnick:

Well, I would like to thank you both for taking time to talk with us, and to share more about the work that you’ve done together, and the important work that still lies ahead. And, the guidance that the paper that you’re publishing with us provides in highlighting the importance of trust and of the ongoing relationships and the communication needed for the successful and mutual learning that is always there to be had. I thank you for your time and your thoughts, and your work.

Erica Woodahl:

Thank you, Hal.

Julie Beans:

Thanks for having us.