

In each volume of the Journal the editors select one article for our Beyond the Manuscript podcast with the authors. Beyond the Manuscript provides the authors the opportunity to tell listeners more about their project beyond what went into the final manuscript. The associated editors who handled the article conducted our Beyond the Manuscript interview.

This edition of Beyond the Manuscript features Sarah Kastelic and Bonnie Duran, authors of *Evaluating Community Based Participatory Research to Improve Community Partnered Science and Community Health*. They are interviewed by special guest editor Michelle Proser.

Michelle Proser:

Hello. And on behalf of the guest editors of this particular issue, I just want to say we're pleased to have organized a special issue of Progress in Community Health Partnerships on the science of community engagement. This special issue will stand as a compendium of the latest concepts for developing and assessing the impact of community engagement, provide exemplars of rigorous empirical studies and provide several practical methodological and practical strategies for initiating and strengthening community partnerships. In it, readers will find articles representing different types and states of community academic partnerships illustrating the varieties of current research, priority conditions and priority populations, as well as the diversity of partnerships.

We are pleased to have two authors from one of the articles in this issue. Let's start with a very brief orientation to your research, including its purpose and the current phase of your research progress.

Sarah Kasteltic:

Our project is a four-year mixed methods study funded by the Native American Research Centers for Health Funding Stream, a partnership between the National Institutes of Health and the Indian Health Service. Our work is an in-depth investigation of factors that contribute to and detract from meaningful and effective community/academic partnerships in American Indian and Alaska Native communities, other communities of color and other communities that face health disparities. So our study was funded in 2009. And we are finishing up the third year of work right now.

Proser:

It sounds like there are quite a few partners involved. Can you tell us who the partners are and how that partnership began?

Bonnie Duran:

There are three partners involved. The lead partner is the National Congress of American Indians Policy Research Center of which Sarah is one of the founders. And the Center for Participatory Research at the University of New Mexico, headed by Nina Wallerstein. And then at the University of Washington, we have the Indigenous Wellness Research Institute, Center for Indigenous Health Research headed by me, Bonnie Duran.

Proser:

Going to back to some of the history of the partnership, how did that partnership move from a pilot that you describe in your article to being led by the community entity?

Duran:

Well, I'll take that question. We, Nina Wallerstein and I, I was actually at the University of New Mexico. I started my career there. And Nina Wallerstein was one of my most cherished mentors and dearest friends and research partners. We had gotten – Nina, as PI, had gotten some National Institute – actually, at the time it was a National Center for Minority Health and Healthy Disparities. She got some leftover end of year money for three years in a row to really start this investigation. And we, and our wonderful team of predominately American Indian and Latina researchers and other researchers of color at University of New Mexico started this. And we brought in some of the most wonderful advisory board members. You know people like Barbara Israel, and Eugenia Eng and Amy Shultz. Just wonderful CBPR scholars from around the country.

And then this opportunity came up from HIS and NIH for this Native American Research Centers for Health Initiative. We, Nina and I had done NARCH research projects before, but we really wanted to go national in scope to look at the science of CBPR. And we actually got advice from Cheryl Crazybull, who was the president of Northwest Indian College at the time. She was on the board of the PRC, National Congress of American Indians Policy Research Center. And she recommended that we take this idea to Sarah. And we did. And she was so welcoming and enthusiastic and had a huge amount to offer as far as understanding equitable partnerships, from the very beginning. So that's how it started. I don't know, Sarah, if you have anything else to add to that.

Kastelic:

Yeah, Bonnie. I think I would just add, you know as a native institution, that at the time we talked with Bonnie and Nina we were about 2 ½ years old. So pretty fledgling new research center. Working to build our own capacity. And to be approached by scholars of this caliber, really leaders in the field of community based participatory research. Nina Wallerstein and Bonnie Duran coming to us to say, "We'd really like to work with your center. We'd like to work with American Indian and Alaska Native tribal governments. We recognize that because tribes are sovereign governmental entities that they are really at the forefront of community regulation of research." It was a wonderful opportunity for us to be engaged in this kind of a partnership that recognized the contribution that we, as a community partner, had to make. And also, was very much invested in helping us to build our own capacity to do rigorous empirical research.

Proser:

You talk about that in the article, especially in the lessons learned. Can you talk more about the challenges that you encountered in capacity development for new community PI and partner and how you ensured a smooth transition to a leadership position on this project?

Kastelic:

That's an excellent question. You know in this case our community partner is a center, the National Congress of American Indians Policy Research Center that was set within a larger organization. So the National Congress of American Indians is an advocacy organization that represents tribes from around the country. It's like a United Nations for tribal governments. So they were established in 1944 and have a long track record of advocacy for tribes.

Kastelic:

And so as a new research center in that larger advocacy organization, we are still building our capacity. Kind of growing into our own and determining what our research agenda would be and what the most important priority areas were for us to focus on. So we were just a couple of years old when we started working on this project. This was our first multimillion dollar federally funded research grant. And we had to build a lot of internal capacity to manage the grant. So in the article, we talk about things like creating processes for ongoing communications with partners, for tracking the work, for managing really complex finances, reporting to funders, coordinating the role of our scientific and community advisory council, which, as Bonnie mentioned, was so important to this project. So there was really a lot of work we had to do internally to take on the management of such a substantial grant.

I think one of the really wonderful things about this partnership was that we were able to have really open and honest communication. We were able to work in the early years in the course of the development of the proposal and then as soon as we were funded in the first year of the grant, to work hard on building those capacity pieces internally.

Then, as we put some of those pieces in place and as our capacity grew, then we had more time to devote to other aspects of the project. So we were able to work with our partners to clearly identify areas of work that aligned with our skills and with additional capacities that we wanted to develop. We were able to grow into a more significant contributing role in the research, I think. Especially with regard to thinking about how we secure the approvals at the community level for American Indian and Alaska Native tribes who are in academic community partnerships that we were trying to bring into our work. So how do we partner with them? We're able to play a leadership role in thinking through some of that, as well as guiding some important areas of the research itself. So really thinking through a variable that we're very interested in. Governance. So how are academic community partnerships governed? What's the variability in how they're governed? What are the important aspects of those relationships? And so our center took a lead role in really thinking about developing an instrument to measure governance. And, as the data come in, and as we get to the stage of analysis, we're very excited to take a lead role in helping to think about what the implications of governance are for health outcomes of meaningful community academic partnerships.

Proser:

On that note, can you talk a little bit about the hypothesis that you put forward for this research project?

Duran:

Well, we essentially have three, four research aims for this project that as you know in any type of mixed methods research like this, really generates a lot of different hypotheses. And those research aims are one, to describe the variability of CBPR projects. Because, community engagement looks is definitely there's a broad spectrum of what community engaged research looks like. That's what we're actually finding in some preliminary results. The second aim is to describe and assess the impact of governance on CBPR. That's particularly, as Sarah just mentioned, a particularly important issue for us working in Indian country.

Duran:

And I think it has something to – some important information to provide to other communities of color who are engaging academics and research about the amount of power actually has an impact on the outcomes. And particularly the outcomes benefit to the local community.

The third aim is to examine different concepts in our model. We have this comprehensive CBPR model. Looking at context such as the history of research in communities of color. The history of research in the partnering communities, the capacity of the community, to engage on this level in research and to manage complex funds. A huge amount of it depends on the university's capacity to have some amount of cultural humility and understand that knowledge and ways of knowing can be culturally determined.

And then finally, to identify, translate and disseminate best practices in CBPR to tribal leaders and other community and academic partners, to really address health disparities and to promote health equity.

Those four aims have a variety of different types of hypotheses. Some of those include things like the more a project is aligned with CBPR principles, the better the systems and community outcomes, i.e., intervention sustainability, community capacity or policy practice changes is really dependent on the authenticity of the partnership and of the capacity development.

Another hypothesis is the more a partnership integrates local beliefs, the more the project will fit within local social structures and will support cultural renewal and culturally centered interventions. Those are a few of the hypotheses we have.

Proser:

In the article, in the lessons learned, you talk a little bit about the challenges behind developing measures, especially measures for community engagement and CBPR. Can you talk a little bit about some of the – one or two of the measures that were particularly challenging and how you went about coming up with the right ways to measure them?

Duran:

Well, the National Conference of American Indian PRC, Sarah and her team actually took the lead in developing and doing a review for the governance measures. I don't know if you want to talk about that, Sarah. That was a very meaningful process I thought.

Kastelic:

The basic idea was that we wanted to explore different governance structures in community/academic partnerships. You know some more formal, some less formal. And on the more formal end of the spectrum, in many cases are tribal governments. Tribal governments themselves may serve as a body to review and decide whether or not to approve, to allow research to occur in their community with their citizens or tribal governments may choose to put in place a variety of other mechanisms to fulfill that function. They may delegate it to a tribal community review board or in some cases may have established their own institutional review boards. We know that there is a wide range of variability in terms of what governance over research looks like in tribal communities.

And then one really interesting aspect of this research is that although the funder is very much interested in research that's American Indian, Alaska Native community led and

Kastelic:

responsive to communities and benefit American Indian and Alaska Native communities, we made a really deliberate decision in the case of this study to look beyond native communities and to involve a whole other set of communities of color that faced similar challenges with health disparities. And part of our intentionality around that was that we wanted to make sure that we had representation along the spectrum of what governance looks like. What governance over research looks like in different kinds of academic community-partnerships.

The work that our team did was to review the literature thoroughly to consider what research itself means, to consider what the process of review and approval or disapproval of research in the community means. Thinking about the range of ways that those actions might happen in different communities, and to develop a set of variables for both the qualitative and quantitative work. In the case of the case studies that were happening, we developed a variety of questions that were included in key informant interviews and in focus groups to really get a better sense of how the process of research review, and approval occurred and how research was governed after an initial decision was made to allow research to occur. That was integrated in the case study protocol.

Then on the other side with the quantitative work, there are key informant surveys and also broader surveys of partnerships. We make sure to include a whole handful of variables, questions that we're asking about different aspects of governance and research. So I think that's a pretty unique contribution. I haven't heard of any other endeavors like that. We are really excited to have taken this first step in what I think will be a much larger research agenda for the policy research center around better understanding governance over research.

Proser:

You've also implied the methods approach, and it was a mixed methods study. Can you describe how you decided to go this route and what you think the mixed method provided to the study? Or what do you think the benefits of a mixed method approach was, given your research aims?

Duran:

Oftentimes, particularly for communities of color, indigenous knowledge or aspects of community knowledge and community intellectual property isn't always well defined by academic and western concepts. So on the one hand, we chose to do mixed methods because some elements of our construct, of our overall model of authentic CBPR weren't captured in the existing measurements that were out there in the field. But also, I think that we were looking for specific cases of indigenous knowledge, both in the American Indian and Alaska Native communities, but also in other communities of color. We wanted to be able to tap into indigenous knowledge and how that was so central and important. A bidirectional learning from community experts, community cultural experts, people who really understood public health and social service interventions for communities of color and how that really important knowledge could be an added benefit to more western theoretical approaches and measures that were already within the academy. That was one of the most important focuses of the qualitative research.

Kastelic:

I would just add to that that as a junior scholar, spending time with Bonnie and Nina and learning more about the academic literature about CBPR, We were very careful to develop a study that would allow us to try to fill a very critical gap in the literature, which is how to better specify how community/academic partnerships create added value for research. How these kinds of partnering practices best contribute to improved health outcomes.

We know, CBPR is more costly, it's more time intensive, it's more labor intensive. But we're seeing in some cases better outcomes. But we want to be able to better explain, to specify, to quantify what these better outcomes are. What is the benefit? What's the payoff to using CBPR methods? And how do these methods – what are the best practices around these methods if you will, that really lead us to the best outcomes, the best health outcomes in community?

Proser:

Can you talk a little bit about your dissemination plan in terms of getting this out to communities and academic partners and how you hope your research findings will shape policy or practice and future research?

Duran:

As Sarah said in the beginning, we are just now finalizing or finishing data collection. Actually, data collection will be finished in about two weeks. This article in your wonderful special edition is our first publication from this study. So we're so delighted and honored to be included in the special issue, which is really of vital importance to community engagement and research. But once we have more data, we're continuing to work on ways to make sure that this is beneficial to local communities.

One way is that we actually just submitted a renewal of this grant yesterday. The newest NARCH seven was due on July 10. And we just, actually National Congress of American Indians Policy Research Center just submitted the renewal of this. And the research project within that, it has an educational component and a administrative component. But the research component is actually to do disseminations and implementations research and to develop a tool kit of outcomes from this project. So that's one way that we're hoping to do some dissemination that's really meaningful for local communities.

Kastelic:

I would just add, the initial decision to participate in this partnership with University of Washington and University of New Mexico, some of those early conversations about what the proposed project was and how it would benefit us, the community partner, how this kind of project aligned with our values and our mission and the work that we were already doing. This issue about dissemination was central. We talked quite a bit about the fact that dissemination in nontraditional means was just as important as the traditional ways of disseminating information. So while we highly value academic journal articles and conference presentations, it's equally important to us to present this material in community forums and in community conferences and to really talk about other kinds of products. So thinking about fact sheets. And Bonnie just mentioned toolkits. One of our goals has long been that through the findings of this study we would be able to develop a self-administered partnership assessment.

Kastelic:

I think the idea is really to make sure or to weigh equally dissemination, both in community forums, as well as academic forums. And we put that in our formal agreements. As this article mentions, we spent a long time working on some formal agreements, some protocols for the way we work together around communicating around our project, around how we describe our work, around how we include people, academic partners, PIs, students who are working on research projects. So we have quite a lot of formal agreements in place. And this issue of dissemination is something that's included in those agreements. To say, you know other outlets are just as important as publishing in academic journals.

Duran:

Examples of those wonderful formal agreements are actually available on the NCAIPRC website for people to take a look at. You know I think NCAI has done an excellent job of making those tools available as possible models for other communities, native and nonnative communities to use. And in addition to that, the instrument matrix is also available, a link to the instrument matrix is also available at the NCAIPRC website. There is already quite a few excellent products there for all of these podcast listeners to check out and download.

Proser:

That's great. And can you give us that website again?

Kastelic:

It's www.ncaiprc.org.

Proser:

I want to follow up on something Sarah had said in her last comment in terms of messaging. And you actually talk about this in your lessons learned. Messaging the language of community benefit. Can you talk a little bit about your experience with that and the incidents that may have triggered the thought in terms of why messaging is so important and the process you went through to make sure that everybody was on board with the same messaging? And maybe even some stories about what that message actually is.

Kastelic:

The story that we relay in our article is an experience that we had pretty early in our project. Our project was funded in 2009. And early in 2010, we gathered together our scientific and community advisory council, which is a group of over 30 people who, as Bonnie said, are really experts in the field. These are preeminent scholars of CBPR and preeminent community advocates who are involved in research in their communities. And so we are really quite honored that they spent time with us and helped us think about our project and formulate our methods.

When we convened this group for the first time to talk about the study that was funded and our initial design and how we might go about this work together over the next four years, we had a really rich two-day meeting. And, as the research team, we felt like we had such terrific feedback and input. We're really excited to refine our methods and get started.

As the community partner, we were quite surprised when about two weeks after that meeting we received an email from one of the community members of the advisory council who had been at the whole meeting and had been an enthusiastic participant.

She'd interacted with the material and with us. We were quite surprised when she went home and after two weeks of reflection wrote us an email that said, you know after she'd gotten back to her community and she had time to think about the work that we were proposing she had some concerns about what our project's intention was. She questioned whether this project, after four years of work, whether it would have any eventual value for her family's health or for her community's health.

That really took us aback, especially because during the meeting she seemed to be so engaged and supportive. And then when she got back to her own community reality, really started to wonder what difference is this project going to make. And that crystallized for us how important it was to explain the story of what we're doing. What is it that we are intending to do? Why are we doing this? Why is a national Indian country organization leading the way in this project that addresses health disparities in many different communities of color? How are communities going benefit from this project?

It was a real wake up call for us to realize that sometimes as a research team, and even as the community partner in a research team, we can get really caught up in the specific objectives we're trying to meet and the methods we're using to try to determine whether there's a relationship between two variables. So we talk about this day in and day out on our research team. And we have to be really careful when we're talking to other people about the work that we're doing to be very clear about why it is that we're doing this.

As a result of that advisory council member, who did withdraw from our project, she decided that there were other things that she needed to work on instead of advising this project. But as a result of that, we, as a team, wrote a communications guide about how it is that we were going to explain our project, how we were going to consistently message to people what we were doing and why. And important part of that was actually changing the name of our project. So the name of the project on the funding proposal as it went in to NIH is different than what we call ourselves now. As a result of that experience we changed our name to Research for Improved Health. We wanted to put right front and center exactly what the intention of this research is, which is to improve community health. To improve population level health, and a better understanding of kind of best practices in community/academic partnerships will help us understand how to improve health.

I think those lessons for us around communication and how we explain what it is we're doing and why are so – they're such critical lessons for us to learn so early in the project. And although it was kind of a painful lesson to learn, I think our work from there on has been greatly strengthened by that experience. Bonnie, is there anything you would add about that?

Duran:

Well, I just want to say I think Sarah said that so beautifully. That was one area that our community partner had so much more strength than us academic partners. That is one place where we were able to really listen to what NCAIPRC had to say about messaging, about translating academic specialized knowledge into something that would really communicate well and energize some of our community representatives on the SAC.

- Duran:* We had people like Ella Greene Moton, Ernestine Willis, Jesus Ramirez Vaieg. Really wonderful community advocates. But the language to capture their imagination and to inspire them really came out of NCAIPRC. They were much better at that than either academic partner.
- Proser:* I think that's a really great point. And I think that's something that listeners are really interested in. Are there other areas or other examples that you have that really highlight how the partners' different disciplines and backgrounds became an asset to this project? And how you were able to tap each other's areas of expertise in taking on certain aspects of the project?
- Duran:* We had a pretty well defined division of responsibility from the beginning. NCAIPRC, as Sarah noted, is one of the premier national American Indian and Alaska Native organizations in the country. So they were the convener. They had the clout and the reputation and the skills to invite people to a meeting and have people actually show up. And that's often what community partners will have that the academic partners absolutely don't have. It's almost like it's a proxy trust that people trust NCAIPRC, so they will trust the academic partners by extension. And people will actually show up to hear what we have to say.
- The University of New Mexico and Nina Wallerstein's team took on the responsibility of doing the qualitative research. They have a couple of really wonderful cultural anthropologists on their team, and students working in health communication. And then the UW team, you know we're really good here at the University of Washington in qualitative analysis and in survey data collection. We used the state of the art survey data collection software to do the quantitative parts. So we had pretty well defined division of responsibilities from the beginning.
- Kastelic:* I would agree. We really drew on kind of the comparative advantages of each set of partners. There was – but one thing I appreciated is that it wasn't just kind of what are you good at or what capacity do you have and so what does that mean about the role you should play? I mean there's definitely that aspect of the conversation. But in addition to what you already bring to the table, there was definitely, as we talked about earlier, this capacity building focus. Within each of the three of our institutions there was also this sense, not just that you have a skill set, an expertise that you're bringing to the table, but also that this a place for growth. That this is a place where we can identify what other capacities we want to build. It's a place where we have open and frank communication. Sometimes we offend one another or hurt one another's feelings. But that doesn't mean we, as we say in the article, take your ball and go home. But we're still gonna stay here in this uncomfortable space and try to talk about what's going on and try to resolve things to work together.
- So I think in addition to that comparative advantage piece there is this ability to be vulnerable. Creating a space to grow. Creating a space to build additional capacity.

Kastelic:

So those were really important aspects of our work together. But I also think that this issue about diversity is a really interesting one. You know as we said earlier, the first aim of our study is about looking at the variability of CBPR partnerships, of community/academic partnerships. And so in order to look at variability, in order to look at diversity, it's really helpful to have an incredibly diverse research team. So I think the incredibly varied experience of our team members, our paper has 17 co-authors. So Bonnie and I, and 15 co-authors on that paper. And that's because they all are contributing to this work. They're the diverse group of partners who are doing this work with us.

And so I think that kind of diversity, along with this open communication I've described, has really enhanced our approach, our methods, our ability to work with partnership across the country. It's affected the way we develop instruments. And I'm sure it will affect the way we interpret findings. So that diversity has been really central to our ability to do this work well I think.

Proser:

Well, unfortunately, I think that's all the time we have. But I want to thank you both again. Assuming we can squeeze in a few more seconds, are there any other thoughts or comments the two of you would like to share?

Duran:

I would like to say in closing that community based participatory research and other forms of community engaged research is sometimes a difficult endeavor, but it's always rewarding. You know we can grow as researchers. We can contribute to the academic literature, to the scientific literature. And on a personal level, we also grow as individuals. You know if we open ourselves to understanding other people's perspectives and we don't take ourselves too seriously or get too defensive, it's a point of personal growth, as well as academic and research filling in the gaps.

Kastelic:

So, Bonnie, I really loved what you had to say about that. I wasn't intending to say this, but just in listening to you, one of the things I'm reflecting on is that one of the things I love so much about this work is that it happens on so many levels. So complexity is difficult to deal with in research. But it's part of what I love about this work. So on the one hand, as an individual person with my life experience and skill set, I'm experiencing this research project. I am also operating in a role as the principal investigator of this work. I'm also working with a team of researchers that's the National Congress of American Indians Policy Research Center. I'm also working as a member of a larger research team. I'm also a citizen of my own community, the Native Village of Ouzinkie in Alaska. And so all of these different roles, all of these experiences and skill set, all of this operating simultaneously and on different levels. And so I think that really contributes to the complexity of the work that we're doing but also the incredible meaning and promise of what we're doing.