BEYOND THE MANUSCRIPT

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Podcast Interview Transcript

Jess Holzer, Thoai Nguyen, Giang Nguyen, Rorng Sorn, Taehoon Kim

elcome 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. The Associate Editor who handles the featured article conducts our Beyond the Manuscript interview. In this episode of Beyond the Manuscript, Associate Editor Jess Holzer interviews Thoai Nguyen, Giang Nguyen, Rorng Sorn, and Taehoon Kim, authors of "Differential Role of Social Connectedness in Geriatric Depression among Southeast Asian Ethnic Groups."

Jess Holzer:	First off, I'd like to thank everybody for taking time out of their Friday to have a chat with us today. My first question is asking you to talk a little bit about the partnership. You mentioned in the manuscript how important the partnership was and how partners equally contributed to the process of the research. And I'd just love to hear an example or two about how that showed in the work and how that improved the work.
Thoai Nguyen:	This is Thoai from SEAMAAC. To me, I really think that the partnership started in 2005 when I was first appointed as CEO of SEAMAAC. Very soon after that, I met Dr. Nguyen, Giang Nguyen, from University of Pennsylvania and immediately we felt that there was a lot of synergy. I think Dr. Nguyen being, I think, a refugee like me in a very different field of health and health research and for me as an advocate and community organizer on behalf of Southeast Asia.
	I think very early on that I recognized and talked to Giang about the lack of accurate information that was out there about the Southeast Asian refugee community. Not only were the data aggregated but the data didn't really look into the subgroups within the larger Asian American monolith; or at least that's what I think the outside community would think of us.
	And when we would make a case for more funding or funding period, we would be asked to supply data. And because of the dearth of this type of data, it was a fairly frustrating exercise. You would give anecdotal examples of things that you know were actually happening in the community, were actually happening with families and individuals, and you can provide many of them but the funders would inevitably say, "well these are anecdotal information and we really can't use them. We need to have real good scientific data that has both academic and scientific rigor."

Thoai Nguyen:	So that, to me, was a challenge. So I think at some point very early on in my tenure at SEAMAAC, Dr. Nguyen and I sat down and we discussed different ways, and in fact, I think we submitted several proposals together. And I think – and they were eventually rejected, but the process really honed our partnership in the way that we would describe the community and figuring out, from my point of view, the trust and relationship that SEAMAAC has with the community and the scientific and medical knowledge that Dr. Nguyen has and also the personal experience that he carries. So I think it was a very good partnership in that sense.
Giang Nguyen:	This is Giang. I just wanted to add to that initial description that Thoai had that SEAMAAC and Penn had worked together on collecting some of the data that Thoai had identified that was missing and some of that work has actually also been published in this journal so maybe we can provide that information separately. But that was really the beginning of this partnership. And it was also through all the work that Thoai and I do in the communities where we also were able to meet Rorng and connect with the type of work that her organization has done because we all shared a similar vision and a similar mission with these communities.
Rorng Sorn:	Yes, and this is Rorng and if I can add for us as a community organization we have the same frustration as with SEAMAAC and we know our community going through a lot of depression and also post-traumatic stress disorder. And we can say that, but there's a lack of study to back us up. So this partnership really play a very important role in getting the community organizations and the researcher and the university to work together. And the really beauty of it is that we all are former refugee and we work in the community as well, so we have a better understanding of our target audience and who we're working with. And we've already established a relationship with the community.
	And the best part about it also is that our community organization and the staff who are at the ground level have an input into the study itself. So that was a good partnership that I thought mutually benefits the community, the organization, and the university who have the capacity to conduct the research.
Jess Holzer:	Alright. So, my next question is how have you used the findings from this research in your work to date?
Thoai Nguyen:	This is Thoai from SEAMAAC. I would say that a lot of the things that we were already doing, based on just pure experience in terms of service to the community members, a lot of the interventions that were already in place we knew and we base our interventions on just our own experience. Now, those experience are, whether they're deemed less or more valuable than academic pursuits or academic research, we know that this is what works for us.
	So I think that it is a question of the chicken or the egg and I would say that, at least for SEAMAAC and possible the Cambodian Association as well, that some of these interventions and these program designs were already in place. And I think what we were stuck at was the fact that we couldn't still convince the funders—the powers that be, the people who make decisions on funding allocation—that these interventions actually work.

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Thoai Nguyen:	And I think for them it was always about "well, we need to see scientific data, we need to see research, we need to see proven results."
	And so I think what the study did was to really allow us to show the interventions that we had already in place, you know back it up with scientific data, methods that had academic rigor and went through the IRB process. And we learned a lot in that process of how we can do this better. But when the research really confirmed the things that we already knew or suspected to be true, but now it's actually in data and because it's the University of Pennsylvania, for instance, a very well renowned institution, then this intervention now is going to be accepted as something that works.
	So, I think that it has an impact on how we've done our work afterwards in the sense that now we can comfortably say that "yeah, we've been doing this. And then we did research that proves that this worked" and now we can actually cite, you know we can make citations of research that is actually accurate and good when we seek additional funding.
Rorng Sorn:	This is Rorng and I do believe that once we get this it will be helpful for our future work. But, like Thoai was already saying something that we've been doing but this is, to prove to our funder that look, this is what we've been telling you and this really confirmed what we expected. So it will help us prove that it is what happening and these programs really have an impact in our community.
Jess Holzer:	So another question is about how you've involved learners in this process. You mentioned in conversation to me, but I don't think it's evident in the manuscript, that you have had students and learners along the way. And I just thing that would be a great thing to hear a little bit more about, so could you share on how you involve learners?
Giang Nguyen:	This is Giang. At the Penn Asian Health initiatives, we have endeavored to involve learners in almost every project that we do. And the main rationale for that is to ensure that the next generation of clinicians and researchers and public health workers have had real-life experience working with communities, learning from communities, and writing about that in the academic literature. So we have been very fortunate to be able to include hundreds of students in our outreach work, as well as dozens of students in our research work as well.
	And we were incredibly lucky to have Taehoon work with us on this project and I'm glad that we were able to have him be the first author because he did a lot of work on making this paper come to fruition. So I'd love to have Taehoon speak about his experience as a student on this project.
Taehoon Kim:	This is Taehoon. First of all, thank you, Dr. Nguyen. Something that I would like to touch is, you know, this was a wonderful experience for me because initially the motivation for getting involved in this project was to learn how to utilize research as a way to advocate for underrepresented populations. But very soon, as I was going through the data and going through the literature, it got very confusing for me and there were a lot of trends. And this experience was really humbling in a way because I think the nature of the work, I think you could call it symbiotic relationship between researchers and people who are actually working in the community, really helped to ground the interpretations.

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	Jess Holzer:	And do you want to tell us a little bit about what your status is as a learner—sort of what brought you to this stage—so that our readers know a little bit more about you as an individual.
	Taehoon Kim:	Sure. I'm studying neuroscience and healthcare management at Penn and I was involved with a lot of community engagement projects. On campus, I was involved with mental health advocacy work and I was working in west Philadelphia. I'm trying to advocate for homeless population and the mentally disabled population. We actually developed a program that would promote health literacy and trying to teach elders about how to access healthcare and teaching them about different insurance models.
		So that led me to seek out a project like this because, as I said, I wanted to understand how to advocate more effectively. And I think this research project was a wonderful way to do that.
	Thoai Nguyen:	This is Thoai and if I may weigh in. I would say that learners could be from many different aspects and I think that while it was a very important for SEAMAAC to have students from Penn, Drexel, Jefferson, and Temple be involved in various research projects that we've had over the years, we believe that learners actually can come from many places.
		So for our part at SEAMAAC, for instance, and I think Rorng had mentioned this earlier, but SEAMAAC staff, including myself, learned a lot through this process. So, we learned a lot about how to be better advocates. So one thing about being an advocate to deliver direct services on one level is wonderful, but how do you then use that contact with the consumer, the community members? How do you document these things? How do you help to advocate for them better if you are able to do your work, deliver quality service (direct services), but also do good intake assessment and how does that inform your work overall?
		I think that was very valuable for us. So outside of the academic walls I think there was a lot of learning. I would want to include SEAMAAC staff and community members who benefited from these interventions or these studies from the studies that we did together.
	Rorng Sorn:	And if I could say that, they for some student who never really was in a community this is a learning experience for them to really have a relationship or direct contact with the community members. And they have this understanding of the issues or the health or social issues that affecting our community firsthand at forefront so it's a great learning experience for them for their future profession or something that they wanted to do. Because I came across students, who came and participate or volunteer and then they wanted to pursue something that would benefit the community in the long run. So it is a great learning experience for them and relationship building and understanding of the whole community and what the issue we are facing as a whole.
	Giang Nguyen:	This is Giang. I would be remiss if I did not also mention the fact that those of us in the academic centers who work with communities are also learning a tremendous amount

from the community members. Because in these partnerships it truly is a two-way street and as much as they're learning about academic environments and scientific rigor, we too are learning about the realities of working in communities, about the challenges that face community members on a day-to-day basis. And we learn about how to partner effectively with communities in a realistic and feasible and respectful way.

Jess Holzer:So I think that's a great segue into my next question, which will be my last question.Which is what sort of advice do you have for other researchers or community groups and
community partners that might be trying to establish a relationship and work together?

Giang Nguyen: This is Giang. For researchers who are interested in working with communities I first want to encourage you to take the time to get to know your communities, to develop relationships, and to seek out common interests and goals before you start even talking about doing research together. It is important for you to make sure you're on the same page in terms of what the issues are and what the priorities are. I think that was very important when I started working with community partners and certainly, it was a major factor in my partnerships working with SEAMAAC and CAGP.

So that's the first step and I think the other thing for academic researchers to remember is that when you work with communities you have to take the time that it requires to nurture those relationships. These folks are very busy and understaffed and underpaid and they are really doing this hard work with a limited budget. And so for those of us who are in academia and wanting to partner with them it's important for us to remember that the time that our partners take with us is a valuable to them and to respect that.

And in speaking about time it's also important for us who are in research to remember that the community members really need to get information back about these research projects sooner rather than later. And for researchers a lot of times we take our time analyzing and re-analyzing and its often valuable to provide some information, even in a preliminary form, back to the community so that they can at least do something with it. That's something that's often hard for us as researchers to do because we feel like we're not ready yet but it is a valuable step if we can.

This is Thoai from SEAMAAC and I would add to what Giang said. You know we don't often work with academia and generally because we feel very disrespected or unvalued. I would say that most requests to interview us for a class project or a book is done very disrespectfully. For instance, a student will e-mail me the night before his paper is done and ask if he can interview me. And I think the advice Giang gives is very solid in the sense that I think that the lack of understanding about how a nonprofit organization or community-based organization, such as SEAMAAC and CAGP, is run is we really do our very best with very little time and very little resources and are most of the time just overwhelmed.

> Now we're not so overwhelmed that we'll say no but we'll say no when we do not feel that our time and our actual input will be respected. And I think that getting back to us is also very respectfully done. I like it when even if I give an interview to a student and he or she will then, after it's done, send it back to me, say thank you, Mr. Thoai, you know here is the paper. I like that. I think that's a sign of respect.

Thoai Nguyen:

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Jess Holzer:

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The thing that you, you know, I think a lot of researchers will need to understand is when you're dealing with sub or smaller ethnic groups or groups that are completely underserved and really mostly ignored by the mainstream is that you will not get very far from your ivory tower academia. If you did it yourself, it is very unlikely that anyone will answer any of your questions so it is important not just to relate to the people in the community but relate to the organizations like CAGP and SEAMAAC that are a trusted entity within the community.

CAGP has almost like 35 years of experience in the community, SEAMAAC has 31, so you can understand that we may not be able to do everything for every community member there is out here but they know that year in and year out they can always rely on us to be there through thick and thin. And that relationship means something to them. So that if I'm coming in with Dr. Nguyen with a group of Vietnamese elders or Laotian elders, it is much more likely that they will be warmer towards him, that they will respond to his questions, that they will not suspect him or be suspicious of him. So I think, you know we have a saying at SEAMAAC, "relationship before task" and I think that is extremely appropriate in this situation is that.

So yes, your study or the study that you want to happen is very important—that's your task. But before you set to task really think about the relationships will have an impact on your task.

Taehoon Kim:This is Taehoon and I'd just like to echo his comments and also say that respect is wonderful
but it also if you disrespect a community I think it could have a real negative impact on the
analysis and the research itself. As I indicated before, the statistical analyses that we ran—we
would not be able to explain them fully without consulting with community members and
leaders. So I think researchers have a duty to respect the community members and leaders
and also it really has a consequence, so something to keep in mind.

Rorng Sorn: This is Rorng. I just want to have one last comment, which is if the researcher wanted to learn more and to do it effectively also what can the researcher can do to help us as an organization or the community as a whole. A little bit of volunteer or maybe coming to help us not only can help the researcher understand really what our community looks like but also understanding the relationship that we have been building with the community member. And that would make it a lot easier for the researcher to work with the community organization and to also help get the research done.

> Anyone want to say anything? Any last words? All right, I think we'll leave it there. We've taken up quite a bit of your time. I just want to thank everyone. I think your comments were really insightful and helpful and I think they'll be super-duper valuable – that's a technical term – for everyone who takes the chance to listen to the podcast or read through the transcript.

> > And I really do appreciate the extra effort you put in not only in putting together the manuscript and bringing it up to the level that we wanted for the journal, but then putting this extra effort in to explain your partnership and explain some of your experiences and thought processes in setting this up. Thank you to everyone and I look forward to seeing what actually results in the journal.