

Beyond the Manuscript: Mi Gente, Nuestra Salud: Protocol for a People's Movement for Health Ownership

Marilyn Tseng, Mario Espinoza-Kulick, Irebid Gilbert, and Karen D'Alonzo

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, Associate Editor, Karen D'Alonzo, interviews Marilyn Tseng, Mario Espinoza-Kulick, and Irebid Gilbert, authors of "Mi Gente, Nuestra Salud: Protocol for a People's Movement for Health Ownership."

Karen D'Alonzo: Good afternoon and welcome, everybody, to today's podcast. My name is Dr. Karen D'Alonzo. I'm an associate professor in the School of Nursing at Rutgers, the State University in New Jersey, and I'm Director of our Center for Community Health Partnerships. I'm also an associate editor for the *Journal of Progress and Community Health Partnerships*.

With me today are Dr. Marilyn Tseng from the Center for Health Research at California Polytechnic State University, better known as Cal Poly. Dr. Mario Espinoza-Kulick from the Department of Ethnic Studies, Cuesta College, and cofounder and consultant at QueerProfs. And Irebid Gilbert, Executive Director of Herencia Indigena, co-authors of the article "Mi Gente, Nuestra Salud: Protocol for a People's Movement for Health Ownership." And I'm sure our listeners are very excited to learn more about this topic of health ownership, so let's get started.

Marilyn, I'm going to start with you first. Could you tell us a little bit about how you became interested in the idea of a system-oriented community ownership model? And maybe for those readers or listeners who may not be familiar, how is this model different from the type of community engagement that we commonly see with CBPR?

Marilyn Tseng: Yes. So thank you for that question, Karen. And thank you also for this opportunity to be here.

I think we became interested in the idea of a system-oriented community ownership model as a way to find a framework for the work that we were already doing. And when I say "we," I mean as a collective. Irebid has done magnificent work for several years—many years in the community. Mario has been actively involved, both in research, but also in advocacy. And our colleague who is not here, Dr. Suzanne Phelan, has also done a lot of work trying to bridge community and healthcare services. We're trying to find a framework that could capture that. We really liked the idea of community engagement that was embraced by the community-based participatory research framework. The one thing that we were trying to incorporate that we didn't see so clearly is the idea of a system, because at least the way it's laid out diagrammatically, the CBPR model seems to center the intervention. That is, if you look at that flowchart, the intervention, or the program, takes center stage, and we were

trying to figure out a way, conceptually or diagrammatically, to show that we're trying to center the whole system. Because it's not any one intervention or any one program that will do it, that really all the inputs and the outputs belong to the system.

So that was kind of a long-winded answer, but I think the idea was we really liked CBPR as a model, but we were trying to find a different way to picture it that would center the system itself.

Karen D'Alonzo:

Thank you. It's interesting, when I hear you describe that, my background is as a nurse, and I think of how many people look at a hospital in the center of a city as being the, you know, the focus of healthcare, where really the hospital is a tiny part of a much larger community system. So in a lot of ways the analogy seems to be very much the same, that we tend to think of our efforts as being central to the problem, and we're really only a small part of what most people experience on a daily basis.

The other point that I was thinking of is that—and I forget the source for this, but there's a diagram that we see a lot and use now when we talk about community engagement in terms of a continuum. And the model that you're talking about in terms of health ownership, seems way to the far right of that in terms of shared ownership with the academic community. Is that a good take on what's going on?

Marilyn Tseng:

In my view, yes. But I'll let my co-authors and collaborators weigh in. I think we see that as a principle underlying how we try to approach things. I won't say it's necessarily the complete reality yet, but it is ideal. I think it's our ideal, but not the reality yet, because the structures that have been in place make it hard to have that kind of ideal become real.

Karen D'Alonzo:

True. True. True. A lot of people in the healthcare system have a hard time really understanding that community members can share ownership of an entity with academic people. They think of the academic people as being sort of the sage on the stage kind of thing. You know?

Mario, how do you see that? Is that kind of what you're striving for, to be more on the right side of that continuum in terms of sharing power?

Mario Espinoza-Kulick:

I mean, I think for me, as someone with indigenous heritage—my family's Purépecha—I don't sort of participate in linearity frameworks. Like I think in my view, in our family's view, we think of things in more of a circular fashion, of how our we accessing these resources that are available if they're on the outside of that circle and we're not within our networks. I mean, over time colonialism, settler colonialism, and white supremacy have disrupted our kinship networks and migratory patterns. So I think for us, as academic and researchers, it's our responsibility to be able to share resources beyond the academy and into the community.

And so I feel like that shared ownership is sort of an ideal, like Marilyn said, that we are striving for that—that our community members, even my own personal experience with my family, that health ownership is central to their experience in accessing healthcare. I think that this study did push the needle forward for our community in Santa Maria and Guadalupe to be more aware of what was happening, especially during COVID, at its height of the pandemic, where people were actively talking about these resources and engaging with public health officials, not just like through formal patterns, like we're used to, but in a state of emergency, being able to break down the barrier between academic institutions, public institutions, and community organizations.

Karen D'Alonzo:

That's interesting. I'm going to get back to asking a little bit more about how some of these ideas kind of—you know, are these world views, can they be reconciled within the indigenous community in a

couple minutes. But we'll talk about then—Irebid, how do you see this? Do you feel that this initiative, you know, what came closer to looking at the community and academics as partners, or maybe not?

Irebid Gilbert:

It's a little bit different on my end, because I am boots on the ground, so I work very, very close to highly educated folks. We share the same room with nurses, doctors, and we have a really good collaboration. But it is a partnership; it is something that we—not only is it one-sided, meaning our providers educating our patients, but it's also our patients educating our providers through a liaison or through someone like a medical interpreter. So I get to see the beauty of it in a partnership that is—it's not just, you know, one-sided.

Karen D'Alonzo:

Thank you. I really appreciate that, that notation that you made about that sort of bidirectional learning, because it is such a feature of community engagement. It really is, is that we learn as much—I think it was Paulo Ferreira that that had that comment about, you know, "We're all teachers and we're all learners," and it's true that everything we do should be from that bidirectional sort of perspective.

Mario, let me ask you, in your role as a senior investigator in this study, you note that your purpose was to lead university community partnerships to close health equity gaps by creating a movement to transform engagement into health ownership. And I'm wondering, have you encountered the need to convince community members that they have the right to health ownership? Let me ask you that first.

Mario Espinoza-Kulick:

Yes. I mean definitely I think that's a constant for my family and our community, in convincing folks that they do have the right to ask questions, to request an interpreter, to be able to navigate healthcare in ways that are patient-centered. And I think that is still a struggle that we're all working towards in this field, in ensuring that people feel safe enough to advocate for their own health. And I think that's really like the goal, really, in how we're engaging the community with this study.

The university community partnerships that are mentioned here started out, you know, through a conversation at the academic level. We got—you know, we're part of a strategic research initiative's funding that helped us to make this and implement it in Santa Maria and Guadalupe. And so our goal really for how we were going to do is build an advisory board, right, a community advisory board that consisted of grassroots organizers and non-profit groups, indigenous peoples of Latinx descent. That's really, I think that major contribution of how we were able to move forward, is we convened folks to be able to identify priorities of how we were going to do this work.

And so in the community, having like to work, you know, close to community members. There is always an opportunity to convince folks that they have a right to health ownership, but it's not always like just known. Like a lot of times parents are depending on their children or their grandparents are depending on their grandchildren to accompany them to doctor's visits, to be able to advocate for them in the English language, because one, one issue I know for my mother personally is that she's not confident in her English ability. Even though she's, you know, taking English as a Second Language classes and doing all she can to be able to participate in this medical healthcare access independently, she's doing the work, but she still feels like she needs someone there to be able to feel ownership around her own health.

Because the advocacy part of that is that it comes from having that familial connection, that kinship is very strong in being able to break down barriers and understand that there is a reciprocal relationship. Right? Patients are going into medical services to access a service that they're entitled to, and the facilities are able to then do their work and their part in helping patients out. And so I think

that relationship really just feels top-down to somebody on the ground, where they have to go to the doctor because they're hurt, or they have to go to the doctor in case of an emergency, because of a lot of things, right? Could be fear of sharing your identity and having your identity shared. It could also be you won't be able to afford the visit. Right? So I think a lot of the elements around feeling ownership around your own health revolve around having the resources to be able to access it in the first place.

Karen D'Alonzo:

That's a good point. I was thinking that, you know, it's got to be sort of an uphill battle to convince people to take on more of an active role in a partnership, in an academic community partnership, community academic partnership, particularly if they are, you know, folks that are working several jobs and have very limited time available to devote to these things. So that's got to be a bit of an issue.

I am a very big fan of and use them in my own work, *promotoras*, community health workers. Do they play a role in educating community members about health ownership as well?

Mario Espinoza-Kulick:

Oh, definitely. I mean *promotoras* have been doing his work long before we entered the community, of having *talleres*, or workshops to talk about health, whether it be about adolescent health or maternal health or sexual health and things like that, all these different topics. *Promotoras* were doing that even before we started doing the study.

In terms of how they played a role in educating the community members about their own health ownership, it can be with like pamphlets, you know, bringing in resources and health promotional materials to the door of somebody or at these workshops. It could also be being able to break things down in a language they understand. There's was a lot of confusion happening before this study around the public charge rule, and *promotoras* were at the fore of educating the community about, you know, you do—this may not affect you. Right? They were having to break that down, because a lot of the rhetoric around the public charge rule was very charged. *[Laughs]* That people were not reapplying for things like MediCal because they thought they weren't going to get it.

And so *promotoras* were also not just talking about, you know, "How do we access these healthcare services. How do you protect yourself?" but also advocating for people to actually apply for services like MediCal.

Karen D'Alonzo:

Yeah, I recall we had a big problem with that in New Jersey, with the FNEP the food stamp program, that there was a huge drop-off in the number of people that were accessing services from the food stamp program because of this concern about the public charge.

Okay, Irebid, in the manuscript you talk about the fact that colonization has disconnected indigenous people from sort of a way of life that promotes good health in concert with the land and the environment. And I think this is really a fascinating idea, and one that many individuals who were born in the US don't fully understand—probably can't fully understand. So could you explain what you mean by this, how sort of the traditional way of looking at health in concert with the land and environment has been sort of taken away from indigenous people in this country?

Irebid Gilbert:

Well, I think the system that we have now is completely different, you know, than a system that maybe my ancestors were used to; very natural, very, very organic. Even though they didn't have access to let's say a lot of the things that that we have now here with like Western medicine. They were healthy, they lived for a really long time, and they weren't suffering certain things. But even now, like just having—being native and having a system that you can't even access, right? Even though they have all this land, and they have all these riches in terms of like everything that they own, there's a push

and they've lost it and they can't navigate and they can't communicate with the things that are in place now.

And I would say that in terms of that they're having—it's almost like there's a push to assimilate to these things, right, and all of these processes or procedures that are available here in the US, with, again, not really understanding what is happening to them and feeling like they can't really say no or being coerced to participate in certain things when they don't understand what's being done to them. And then having that tremendous loss afterwards, when someone that is empathetic and someone that takes the time to sit down with them to explain everything that has happened to them, then they feel tremendous loss and grief, knowing that, you know, maybe they went through a procedure that they did not want.

So that's the best way I can explain it in terms of—but if you have any specific like examples or questions that you want me to answer, happy to do that.

Karen D'Alonzo:

I think I was particularly thinking about this concept of health ownership. And, you know, we talked a little bit about that with Mario and the fact that many people sort of need to be convinced that they're entitled to ownership of their health. And that concept is something I think a lot of people in this country kind of take for granted. And I wondered how that idea of health ownership sort of fits in with the Mixteco view of the world?

Irebid Gilbert:

Yeah. I mean sometimes we see, you know, we've seen in the past where patients will share with us because they trust us. They'll say things like, "Oh, they asked me to come back" or "They sent me away," right? "They sent me to another clinic because they don't have someone who can help me in my own language." And so things like that, like would you ever—would a US citizen ever be sent away if they, you know, if they needed services? Would they be treated the same way?

So yes, I think sometimes our own community doesn't understand their right to these services, their right to an interpreter, their right to not be turned away. So we're having to do all that education on top of, you know, facilitating the communication between the provider and the patient. So in terms of you asked earlier about *promotoros* and *promotoras*, we don't view ourselves as *promotoras* or community health workers. Sometimes we're categorized into that as medical interpreters, but we are that, that middle—that facilitator between that private interaction. And we understand both sides. We understand the patient because we are from the community; we want the patient to understand all that's being done, but at the same time, empower them to engage and to say and ask questions and follow up. And I think just with Mixteco, I think the biggest, the most difficult piece is just the language, you know, getting over that. And to this day I think 50-percent of my battle is Mixteco is not Spanish, right? Being categorized in a language that they can't—or being forced or pushed to accept services into a language that they don't even speak. Right? Not recognizing that missed echoes is its own language. So that's 50-percent of my battle.

Karen D'Alonzo:

Yeah, I can imagine that that's very difficult. In New Jersey we have a lot of real—a real mixture of Latinos. We have a lot of people from Puerto Rico, we have a lot of people from the Dominican Republic. And, you know, often when someone comes into to a clinic and there's an assumption that they speak Spanish, the person who's an interpreter is likely to be from Puerto Rico or the DR. And, you know, there's no similarity at all between these indigenous languages and Spanish. You know, we've seen situations where people come here with kids, and the kids can't—the kids go right from the

indigenous language to learning English, you know, because it's just such a—the adaptation process is so tough. I can definitely appreciate that.

The next question I have here, Marilyn and Mario, what did you learn about the needs of your community partners that perhaps you didn't know before conducting this study?

Marilyn Tseng:

Mario, you want to take this first? I'm always interested to hear what you think.

Mario Espinoza-Kulick:

Yeah. This question was super-exciting for me because it took me back to the really beginnings of this study, where we invited the Surgeon General of the United States and we had these workshops with the community, and this was all on Zoom, you know, because we were following the safety guidance from the CDC. And so in the Zoom meeting we were able to have like these breakout rooms and learn from people about what they wanted to see, how they wanted—what priorities they had for us. Like regular folks on the ground that were invited to this space to help us identify what priorities there were.

And so that's really where we learned about these needs. Also, through the advisory board meetings we learned about what needs they had and they wanted to see come out of this study. And what we didn't know, one, was like there was a lot of people talking about having open spaces, safe open spaces for recreation. There was also a triangulated finding between this study and another one, called La Gente Unida that identified breast cancer as a key need for the folks here in Santa Maria and Guadalupe.

And we also learned about the opportunities, you know, about building capacity with having community research associates. How do community members themselves get to participate and have autonomy around decisions around research in the community, and also building and facilitating trust with the community that they're from? And so that was pretty cool to learn about, that people were interested in becoming research associates. The study has evolved since the publication of this article. You know, we've been working with high school students at Santa Maria High School, that were trained on how to do things like focal follows and photovoice, and interviews within their own community. And I think that was just like a really beautiful outcome of what we learned from our community partners and what they needed.

Karen D'Alonzo:

That sounds like a lot of fun really, that kind of learning process is, especially when you don't anticipate it, it's like in that sort of hybrid role of community research, or somebody's from the community, but also now has additional knowledge that kind of puts them in a whole different category. Yeah.

Marilyn, what do you think about this?

Marilyn Tseng:

Well, first I wanted to say I'm so glad Mario brought up the community research associates, because it's been such a rewarding process and experience for us. But that might be another topic to talk about.

In terms of what I learned about the needs of our community partners, I guess I would answer it at two levels. One is, depending on how we ask it, some of the needs that are expressed have directly to do with health care. Like we need access, better access to healthcare, and better treatment at those places. But then when we broaden the way we ask or the way we collect data, it actually becomes much wider. So in another assessment that we did, the number one need didn't have anything directly to do with health; it was housing. I mean, that was the number one need in the community was we don't have any place that we can afford, and the places that we can afford are just in miserable shape. So that's how I would answer it at one level.

And at the second level, what did we learn about the needs, or what did I learn? I think I just learned that there's a tremendous appreciation from any partner when we ask them to tell us what they think. Just, I think it's because it doesn't happen all the time, but just the asking people to share what they think and saying that we are listening, and that we would like to be a part of changing that, I think that struck me, that there was so much appreciation for that.

Karen D'Alonzo: Wow.

Mario Espinoza-Kulick: I just wanted to add, you know, we learned from our community advisory board, too, there were some challenges based around time. There was a need to help a specific time-limited task, but there wasn't capacity for folks to serve on an ongoing basis as volunteers to provide guidance to researchers. During this time, though, we did see that there was another collaboration underway in the same county, in Santa Barbara County, and that was the taskforce model of the Latinx and indigenous migrant COVID-19 response taskforce. Which similar to our study, had this like systems approach, or these cross-sectoral collaborations between public institutions, nonprofits, grassroots organizers, and indigenous language interpreters. So that was specific. That was really successful because it had specific aims, objectives, and also the political will to guide a time limited collaboration.

Karen D'Alonzo: Great. Irebid, similarly, what did you learn about the needs of your academic partners that perhaps you did not know before being involved in this study?

Irebid Gilbert: I guess I didn't realize—or what I learned was just that they're—again, for me we are very boots on the ground, doing the work. We don't have access, or sometimes it feels like we don't have time to dive deep into explaining all of this. But what I learned was there was so much interest, and I was invited to one of the very first like Zoom events that we have. And there was so much that we shared in terms of what we were facing, and they were able to put it in a way that connected with other very highly educated people that wanted to learn about it. So that's what I learned, that there was interest, there were people out there that wanted to hear more about it and were trying to. But also that there's a process and that that process takes time, and that there's, you know, just for funding takes time. But that's another whole like—like navigating those systems, also just how tedious it is, how time-consuming it is. And so all of that, that's the other side that we don't see.

Karen D'Alonzo: Yeah, that's very true. I think over time—I know with the folks that I work with, they have become more aware of like the whole grant process, and when we get funded they're happier than I am. And we're all happy, but they're like thrilled. I remember going through this when I got tenured, and the one woman told me that “The fact that you got tenured is evidence that the university is interested your work in our health.” And they were thrilled about that. And it never occurred to me that they had such a window into this whole process, but they did. You know, in their own way they did. So it's true, you wind up learning a lot about each other in these kinds of partnerships.

Another question for you, Irebid. As a community partner, tell us about your role in the decision-making processes of the study. For example, did you get involved at all in the design, or did you provide any kind of input on some of the data or what went into this manuscript? You know, and those are just possible examples of how you could've been involved.

Irebid Gilbert: So I was involved in the beginning, where we were invited with the Surgeon. And I'm terrible at names, so I won't even try. But Dignity Health and, you know, we all came together and we talked about a

lot of this. And it was, like Mario shared earlier, there was breakout sessions, and we got really good feedback. And for me, I was just sharing what we were seeing, right? But they took it to a whole other level of like categorizing it and putting it into a model and all of that.

But the other pieces, I did sit on the advisory board as well with Mario, and we met regularly and we talked about updates, and so that's how I was involved.

Karen D'Alonzo:

Good. How did you see yourself—and maybe this didn't happen, but if it did, if there were differences between your interpretation of something and an academic's member? Did you have that kind of thing? And then how were you able to sort of negotiate differences of opinion about a particular approach or something?

Irebid Gilbert:

Not necessarily. I think the space was very safe enough to share everything that we were seeing. And of course—and I don't know if I'm able to bring up the mobile health unit. So yeah, we provide interpreting services for the mobile health unit, which is through Cal Poly. And this is a unit that serves directly into the community, and it provides care, medical care to a lot of women that are not insured and that may not have transportation and may not have access to medical care. And so they come to the community and we staff those. And so it's been very rewarding to be able to be part of that. And that's led by Suzanne Phelan as well.

So to just answer your question, I think it was we learned from each other, both the academics, and then for us, you know, what we were doing, what we were seeing. So yeah, I wouldn't necessarily say that there was differences or something that we didn't agree on, that we couldn't really talk about openly.

Karen D'Alonzo:

That's definitely a sign of a trusting relationship, when you feel like you can talk about things that you might have differences of opinion in, and that's important.

The last question I had is really for all of you, all three of you, and in the article you mentioned that no interventions have shown long-term reductions in implicit bias or sustained and meaningful changes in behavior. So how do you think that this philosophical approach to intervention building might be different?

Marilyn Tseng:

I can get it started. So I think the way I think about it is, again, there's no one intervention or program that is going to be so important that it will really change a big thing. And I really see, much as I'd like to tout our initiative, I don't see it as a big thing; it's just another ripple that we're introducing into the system that we hope will have some effect. And the way that I hope we're doing it is through our interactions with community members, community partners, the way we approach each other, and the way we approach decision-making and things like that.

So at least that's how I see it, that this is how we are approaching things, and we'll just drop that into the system and see what happens.

Karen D'Alonzo:

That's an interesting way to put it. That's interesting. Yeah. Mario, what do you think about that? Is this approach something that you think is more likely to be successful, or time will tell?

Mario Espinoza-Kulick:

I think, yeah, like Marilyn said, it's a ripple. The systems-oriented community framework, or SOCO, does shift from "This program will help. This program will help," to more of a holistic view of community systems, while also engaging community members, experts, and diverse stakeholders. I just wanted to add one aspect of this that I contributed to was called the de-colonial inspired approach, and I feel like this discussion delves into the implementation of how de-colonial inspired methods that emphasize

collaboration with indigenous groups and community leaders, multilingual knowledge sharing, and ensuring concrete benefits to affected communities.

So this de-colonial inspired approach does build from like indigenous knowledge, activism, and traditions, and acknowledges the role indigenous communities and diverse communities, especially Latinx indigenous migrants. But it also centers on how locally relevant and culturally specific interventions are more likely to show sustained and meaningful changes in behavior, as well as systemic change that supports these patterns. So I'm leaning towards yes, this ripple effect over time will probably grow into a wave that folks will be able to then rely not solely on the system or single program, but on each other, and return to a way of being that relies on our kinship networks and fortifies our kinship networks to live a healthy life.

Karen D'Alonzo: Great. Irebid, do you have any thoughts on this topic?

Irebid Gilbert: I've just seen that there is, particularly in our community, there's just a lot of efforts to try to learn from both the community members, and gather that feedback. So I've been lucky enough to partner with different—just different folks, and they have these same questions. So I'm just excited about this being published and then being able to pull engaged knowledge from that, because there's folks trying to learn a little bit more.

And just I agree with Marilyn and Mario, yeah, you know, time will tell. But it's been great to be a part of it and just—I mean they've been the ones leading this, really doing all the work, and it's been over a year, and so I'm so excited that I was invited here today to just talk a little bit about the work.

Karen D'Alonzo: It's been really fascinating to hear the details of this from all three of you. I really thank you so much for meeting with us today and speaking on this important topic.

Mario Espinoza-Kulick: Thank you.

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