Beyond the Manuscript: A Vision for "Ethics and Community Collaborations"

Ann-Gel Palermo, DrPH, MPH, Hal Strelnick, MD, and Emily E. Anderson, PhD, MPH

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-editors-in-chief Ann-Gel Palermo and Hal Strelnick interview Emily Anderson, the journal's new associate editor for ethics and author of "A Vision for Ethics and Community Collaborations."

Ann-Gel Palermo: Good morning. My name is Ann-Gel Palermo. I'm the co-editor-in-chief of our journal, *Progress in Community Health Partnerships*, and I am the Associate Dean for Diversity and Inclusion at the Icahn School of Medicine of Mount Sinai in New York City.

Hal Strelnick: And I'm Hal Strelnick, co-editor-in-chief of the journal, and Associate Dean for Community Engagement at the Albert Einstein College of Medicine in the Bronx. And I'm going to ask Emily Anderson, our new associate editor for our new section on ethics and community collaboration, to introduce herself.

Emily Anderson: Hi, everyone. Thanks for having me today. I'm Emily Anderson. I'm an associate professor of bioethics at Loyola University Chicago Stritch School of Medicine. I teach in our online bioethics programs. I also teach medical students and graduate biomedical science students. I focus on all things research ethics, but community-engaged research and community collaborations have always been really near and dear to my heart because that's the kind of research that I started out doing when I first started my career in public health. So I'm really excited to be part of your journal.

Hal Strelnick: Emily, there's an editorial in this issue of the journal where you lay out what you envision for the new section on ethics and community collaboration. I wonder if you would describe that for us.

Emily Anderson: Yeah, so thanks. When you invited me to take on the job of being the editor of this new section, I thought I would start by doing a pretty deep dive into what you all had published in the journal before. I've been a longtime reader since this journal came out, and have published in it myself, but it was fun to just sort of virtually flip through the table of contents and see the different articles that had been published and get a sense of where there was a good deal of focus and where there were some gaps. And it was interesting to see there was a lot of attention to issues like training community partners in human subjects protection, and a lot of focus also on what can be done to support meaningful and equitable collaboration. So those were two areas where there was a lot that I saw, and that was really great.

Other areas where a lot had been published was equitable compensation and sharing of credit, and then also community-based research review processes. So I start my editorial by sort of looking back and seeing what has been in the journal, and then looking forward to what could be included, and really just try to stimulate new submissions around ethics of community collaborations, and not just in research but in collaborations more broadly in terms of wider initiatives to improve public health. I think the main gap that I would like to see addressed in new submissions would be hearing more from community partner voices about how they view some of the ethical challenges of collaboration. So I think if I had one thing I wanted to really emphasize, it would be that.

Hal Strelnick: So your own work has been in working towards new models for training community partnerships. I wonder if you might want to say something about your CIRTification project.

Emily Anderson: Yeah, thanks for giving me an opportunity to talk about that. As I mentioned, I had started my career in community-engaged research, and it was also during a time when there was a lot of focus on human subjects protections because institutions were being scrutinized for the way that they were reviewing a variety of human subjects research. And I noticed, you know, this was in the '90s, there was a challenge in teaching community partners about some of the rules around engaging human subjects in research, because as researchers we sort of take the rules for granted, but they are somewhat unique to our world. I don't want to criticize the existing training.

There's a lot of good training out there, but it really addresses the needs of researchers, people who are gonna be designing projects. It doesn't really address the needs of people who are gonna be on the ground, interacting with participants, and particularly people who are gonna be on the ground interacting with participants in their own communities. So I developed a training program, called "CIRTification: Community Involvement in Research Training," and it's available in both a curriculum that can be delivered in person and now a new online version that hopefully better meets the needs of community partners, not just introducing concepts that we know in human subjects protection, you know, informed consent, fair subject selection.

Not just introducing those in plain language, but really addressing the scenarios that arise on the ground, not just in design but what happens when you have to speak to a participant and you have to answer a question or deal with an issue on the ground. So I'm excited about that, and before I forget, I should say that CIRTification online will be available in Spanish, hopefully, this summer. There's been a little bit of a delay, as there has been with many things, because of COVID-19, and we haven't been able to get our Spanish narrator in the studio. But we're really excited about that. We've had a commitment all along to have these materials available in English and Spanish and hopefully other languages in the future. So that's where we are with that.

Hal Strelnick: So one of the issues that has been raised in the past is sort of the differences between community engagement and stakeholder engagement, and I noticed that in your editorial you go with the term "stakeholder engagement." I wonder if you'd explain your view of the differences and that choice.

Emily Anderson: Yeah. That's a very interesting question. I've thought a lot about terminology here, and I have a public health background, so I grew up learning about community engagement, right, because I was doing public health research and thinking about interventions on a community level. And really it's been more recent with the Affordable Care Act and the development of the Patient-Centered Outcomes Research Institute, PCORI, where there's also been more discussions about engaging patients, and

more specifically in clinical research. But I think when it comes to engaging people who are outside academic research in these projects, whether there is a community partner, a representative of an organization like a school, a healthcare provider, or a patient, I think the principles of how you treat them with respect, how you have equity in your partnerships, how you share ownership of data, how you make decisions together, I think all those principles are very similar.

And so for me personally, it helps to think about, to sort of think of, to come up with one word to describe those folks. And I don't want to pit academic versus non-academic stakeholders because I think now what's really exciting is we're starting to see a blurring between those lines and people getting involved in research in different ways, but I do think the term "stakeholder" for me encompasses both patients and community partners who maybe aren't patients but are participating in more prevention-related work. So that's why I use the term "stakeholder," and these terms are always evolving as well. So I'm interested to see what stakeholders want to be called, I think is what I'm interested in hearing.

Ann-Gel Palermo: I'm really excited about this addition to the journal, Emily, and seeing what we get from our community in terms of submissions. I'm curious to hear your thoughts in unpacking further this construct of ethics and what it means when unpacking the sort of general ethical principles of respecting community expertise and learning how to share power. And when you unpack each of those, it gets really nuanced, and then who claims that ethical sort of behavior as like the right one becomes even more complicated. I think about my background in doing CBPR in East Harlem largely and how we had our own ethical, our own, like the street ethics, if you will.

And I wonder if you could comment on sort of what I'm calling the street ethics. It doesn't necessarily get recognized and acknowledged in the journals and in the manuscripts and in academia. And who teaches the academic partners the street ethics, right? Because it always seems to be a one-way direction, like yes, this is ethical behavior according to research standards, but what about ethical behavior according to street standards? What are your thoughts?

Emily Anderson: Yeah. I think that's a really great question, and that brings me back to what I was getting at a little bit before about the rules for human subjects research being a little bit unique, and how the typical training programs and the way we talk about ethics doesn't necessarily address interactions between two people. When people in academia and researchers talk about research ethics, we really talk about how are we designing our studies, how are we developing our materials, and we don't really talk about those interactions between people. And two examples that I always talk about when I talk about street ethics, maybe not so street, but that are really different in research ethics, number one, I always think everyone wants to be good at their job. I sort of assume that people have the best intentions and people want to be good at their jobs.

And most other jobs, if you were trying to get people to do something, what would make you good at your job is if you did everything in your power to get them to say "yes," whether it was to sign a petition or buy something or come to something. The goal would be to do everything in your power to get people to say "yes." Well, we know that that's not how informed consent works, and so that's a difference between—I don't know if that's street ethics. That's sort of everyday being good at your job, trying, being a hard worker, which is an ethical norm in our society, right, but it's a little bit different in research ethics.

I think another example of street ethics is things about privacy. Right? So privacy is really important in research. In research we say everything is private and confidential. But on the street in the real world,

if you found out information that if you told a friend or family member that information, it might protect them from getting hurt, you would feel that you had an obligation to share that information with them. And there are instances in community-based research, research that's happening on the ground in real communities, where people who are working on a research project might find something out about someone that somebody in their family or a friend knows. And so I think those are two examples where there's some tension between research ethics rules and regulations and sort of street or real-world ethics.

And I think the most important thing to overcome that tension is to have conversations about it and explain to partners why those rules are in place and why things are different here, and hear feedback about how people struggle with some of those tensions. Because I, we, can't just tell people what the rules are without telling them why. And I think what's happening—this immediately makes me think of what's happening now with COVID. You can't just tell people to social distance or wear masks or do things without explaining what's the reason behind it. And so I think, to me, I'll just end this long rant by saying I think the greatest way to show respect is to explain and—explain where you're coming from, listen, and then adjust as necessary.

And I think those are the conversations that people are having on their projects that I'd love to see published in the journal so that people who are new or who are struggling with these issues can have a starting point from the literature.

Ann-Gel Palermo: Yeah. I really appreciate your thoughts, and it made me think about some additional examples that I've had in my work, and would love your thoughts

Emily Anderson: Maybe we can write something?

Ann-Gel Palermo: Maybe. I think about all of the sort of on-boarding and coaching I have done with researchers and other non-community partner representatives who wanted to work in East Harlem, and not asking the—just coming from a place of inquiry instead of a place of certainty around like how do you navigate this space? What are the rules of engagement? And I think this is related to this new addition to the journal because I—the street ethics that I'm also thinking about is, you know, you've got to show up. You want to engage in meaningful research partnerships, you've got to show up.

Emily Anderson: Yeah.

Ann-Gel Palermo: And it's not just sending your research assistant. It is you, the PI. You have to show up. That is a form of respect and creating an ethical relationship that's based on honesty and authenticity and respect. Another is taking the time to learn a lot about a little in terms of the issue in this neighborhood, like really drilling down. I think another ethical principle that I've found myself coaching academia on is—being open to recognizing that the research question at hand is not enough, and that, in fact, that there is, that there should always be room for the policy question. Right? And so even though there may be some co-involvement in designing the research project and submitting it and in the proposal and the methods, *et cetera*, but that there is—I'll never forget a community partner said in a meeting once, she said, "I'm not in this for the sake of science. I'm in this for the sake of change."

And this translation of like the research question and informing a policy question,—how do we translate the research findings into change in policy arenas and policymaking spaces. And I think that that is an ethical standard, because at the end of the day it's about causing systemic change. Right? Changes to structures, policies, and practices that perpetuate inequity. So I feel like there is

this whole space of an opportunity to unpack that space from an ethical lens of research to policy change or systems change or structural change. So I said a lot. Just would love to hear your thoughts on, reactions to that.

Emily Anderson: No, I think—I mean so much there what you just said are things I have been thinking about, and I teach medical students and we use the term "professionalism." Right? Teaching professionalism. And I don't think we do as good of a job talking about research as a profession, and particularly I think when you're gonna do stakeholder-engaged research there are maybe different norms around professionalism. And I think you and I probably would agree that while some things come naturally to some people, other people who are going to be doing stakeholder-engaged work, other academics who are gonna be doing stakeholder-engaged work, maybe need to be taught some of these professional norms.

And these norms certainly, in order to just, you know, for us to know exactly what they are, we need a lot of input from our stakeholder communities, and that might be a little bit different in other communities. But I think that the two things that you mentioned are things that really resonate with me and my experience. I think it's really important that any research professional who gets involved in community-engaged work understands you don't leave when you have your data. Your final product isn't your publication and your data tables. You have, by doing this kind of work, you have committed to trying to enact some sort of policy change with this, and that's part of your professional responsibility. And if you're not willing to do that, then maybe don't do this kind of work.

Ann-Gel Palermo: Right. Even when it's not a performance product for advancement and promotion.

Emily Anderson: Right. Right. And I mean and that's a whole other issue. But just at this basic level of how do you treat the communities that you—I mean that's ethics. Right? How do you treat the communities that you engage with? But I think at the beginning of the project, too, there's a lot of work to be done. I think a professional, you know, a typical professional ethics is that you don't waste people's time. You're very efficient. You are very, you know, maybe businesslike, and maybe that's changed or it's different in different institutions and different universities. But when you're doing community engaged work, you need to get to know the people that you're working with as people and as a community, and you have to be willing to—just like you said, you have to be willing to show up. And that's part of the professional ethics of working in, working out in communities.

And so I think there's a lot of work to be done there around setting standards of professionalism for stakeholder-engaged research, and also for training those folks and, again, a place where input from particularly seasoned stakeholder partners would be really, really helpful. I'm sure they have a lot of thoughts about this, and I would love to provide a platform for them to share those thoughts in our journal.

Hal Strelnick: One of the elements of professionalism that you've been describing is that you work in one community and live in another, and I think one of the challenges that certainly a lot of our frontline workers is that they're working and living in the same community, and they can't separate those roles. And I think that I know as a family physician, if you live and practice in the same community, you have other relationships with the people than your one when you're in your professional role. And I think that we have not in this country explored what that means and what obligations you have to putting your professional knowledge in the service of a larger community or, you know, what are your voluntary roles in participating in activities that, where you're not an expert.

And I think that that's one of the things that some of our community health workers who are involved, they face every day that sort of dilemma between what they would do as a family member and a community member and what they're asked to do by their employer in terms of following the professionalism of the way in which the individualistic research ethics have evolved in this country.

Emily Anderson: Yeah. Yeah. I think the very individualistic ethics that we have and the frameworks that we have to guide ethics of research are really set up for, to guide the relationship between an individual researcher and an individual subject, like an individual researcher who's the person who designed that study, and an individual subject. And we really just need to create better frameworks and better benchmarks for this research that involves people with different kinds of relationships.

And I think, too, another thing that you didn't bring up that I'll add is the distress and moral distress that stakeholder partners can experience when they're working on trying to address health problems in their communities. I think when you're a researcher who's working in a community that you don't live in, or looking at something very scientifically, you can maintain arm's length distance from some of the things that you're learning and maybe that's good. Maybe that's self-protective and maybe that's what allows people to have careers where they study drug addiction, for example, for 30 years without getting burned out. But if you're in the field day to day collecting data from people that live and work near you, and you're collecting data but you're not yet at that stage of changing anything, that can be really distressing for people.

And I think we also need to focus on how do we support our community partners with some of that, those feelings of being stuck, and trying to help them through that. So there are so many things that come up with the unique relationships that people have in their communities when they're working, and again the research, the way that research ethics has been talking for decades just hasn't focused on that. They've focused on maybe the doctor-patient relationship and how research is affected by that, but not all of these other relationships, neighbor, social service provider, pastor, teacher, friend, all of those sorts of things, and I think that's where there's some really interesting work to be done in ethics of stakeholder engagement.

Hal Strelnick: Emily, I, sort of as a last question because we're running out of time—

Emily Anderson: Sure.

Hal Strelnick: —I wonder if you would just talk about community-level risk in your perspective, because we've focused a lot on individuals in our conversation, and that I know is important to you.

Emily Anderson: Yeah. Yeah. I mean that's another big area where research ethics—the academic research ethics community has started to scratch the surface a little bit, but where we really need some input from communities is this idea of community-level risk. Right? So I've already a couple times mentioned the weakness of our current frameworks, but the Belmont principles of beneficence, respect for persons, and justice, they again are really focused on the benefits and harms that can come to a research participant and the benefits that can come to a community, but they don't really account for the risks to a community.

And we've definitely had cases in history, and the Havasupai Indian case is one that comes to mind, where researchers discovered and then published some information without the permission of tribe leaders, and that information really caused harm to the community as a whole, to people whether

or not they participated in the research, and damage to the cohesiveness of the tribe, really calling into question their origin story. And so things like that I think are, it's really important to explore ahead of time with communities and to think about, you know, if you're discovering certain data and publishing that, what harms could come to a community, and to think about—again this ties back to the question of consent and permission. Who gets to say what is, what questions are asked and what data are discovered and what data are shared.

So there's a lot of work to be done in that area as well. And again, sounding like a broken record, really, really need community perspectives in that because from the outside you don't, you can never really anticipate what those potential harms might be from research.

Hal Strelnick:	Well, I've been given the—
Emily Anderson:	The warning.
Hal Strelnick:	—time limit, so I want to thank you for—
Emily Anderson:	Thank you guys.
Hal Strelnick:	And I think it's been a very rich conversation. And thank you, Ann-Gel, as well.
Ann-Gel Palermo:	Absolutely.
Emily Anderson:	Yeah, thank you. I would love—I really am serious. I would love to write a paper about—
Ann-Gel Palermo:	Yes.
Emily Anderson:	—about professionalism. A sort of lightbulb went on when you asked that question. I was like, oh, this really could tie—that's how we need to be thinking about this in terms of professionalism. But yeah, I've had to coach some people, too. I've said—I think once I said, "You need to take your white gloves off and"—
Ann-Gel Palermo:	Yeah. I have a lot of words around—
Emily Anderson:	—"get in there and ask people about their families."
Ann-Gel Palermo:	Right. You know, it's I think to your point about really hearing from community partners, and knowing the limitation of bandwidth of time, but also maybe not even a refined or seasoned skill set in just academic writing, right, that I'm wondering, just having this conversation I'm wondering that the format we could consider as a submission is a transcribed conversation, right, that is like literally how we're doing this interview. It's like a 15-minute, 20-minute conversation that's transcribed. I know it takes resources to pay the transcription service, but I feel like it's so much more juicy in that regard because you're getting a, you know, this conversation we just had was really great, and I think if we could capture that and transcribe it and add some additional, you know, just to clean it up in any way, I feel like that's just as valid as a formal manuscript.
Emily Anderson:	Yeah. I wonder, right, I think I'm very, very much open to and interested in talking about like what are some different models we can use to get those voices into the journal, because traditional publications might not work, but and I wonder if there's also ways we can, different models we can suggest to people to do this sort of thing on their own. So I'm thinking what would be great is if there was a graduate student who could work with a community partner to help them shape that interview, and then that

way we wouldn't have to be responsible for the transcription, or something like that. But if we could sort of think about how can we support different models to get different kinds of manuscripts in, I'd be very open to that, and also to working with people to get things into shape.

You know, I was—the person that trained me to do journal editorial work definitely trained me that the goal is always to help people bring their work up to publishable quality, not to just reject people and send them off and go about your merry way, and I'm guessing the ethos of your journal is similar.

Ann-Gel Palermo: Mm-hmm.

Emily Anderson: And, you know, as your journal is around longer, you get to reject more things and be more choosy. But I've also been involved in a lot of journals that have gotten—or several journals that have started from the ground where we really, we didn't have a choice but to work with our authors. So I'm very committed to that sort of thing, too, especially if it can get community partner voices and junior faculty voices into the journal as well, so—

Ann-Gel Palermo: Yeah. It just really, I just recognize how we're asking for, you know, we're trying to create the space for community partner voices, but we're asking them to do it in the way we want it.

Emily Anderson: Well, that's what we do all the time, right?

Ann-Gel Palermo: Right. So it's still not allowing them to contribute in a way that works for them.

Emily Anderson: Yeah.

Ann-Gel Palermo: And I know there's examples out there of, you know, recording documents and community voices in a lot of things, whether it's a podcast, whether it's an interview, a recorded interview in some way, or transcribed as interviews. I just wonder if we could play around with that a little bit.

Emily Anderson: Yeah.

Hal Strelnick: And I know that Ann-Gel has been a big advocate for the journal helping community authors with bringing their work to the journal and helping them make it valuable for other readers. So we're, the journal has been struggling with that particularly since the COVID-19 has limited the options, but it's something that we have discussed among the editors, how to better support and guide community-based authors.

Emily Anderson: Yeah. Well, we can keep thinking about it, but I, like I said, I'm really open to different ideas and helping people.

Hal Strelnick: Well, thank you again.

Emily Anderson: Thank you. That was fun. I think this is my first—I might have done one a really long time ago, but that was fun. It was not scary at all.

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