Beyond the Manuscript: Challenges and Lessons Learned from a Community-Engaged Evaluation of a Community Advisory Board

Emma Tumilty, Stephanie Cargill, and Bryan Spencer

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, Emma Tumilty, interviews Stephanie Cargill and Bryan Spencer, two of the authors of two articles in this issue, "Evaluating the Process and Impact of Flint's Community Ethics Review Board: A Pilot Study" and "Challenges and Lessons Learned from Community-Engaged Evaluation of a Community Advisory Board."

Emma Tumilty:	Hi, I'm Emma Tumilty, an Associate Editor with the journal. I have the great pleasure today to talk to Stephanie Cargill and Bryan Spencer, who have a couple articles in the issue that this podcast pertains to. One is an evaluation of a community review board named "Evaluating the Impact and Effectiveness of Flint's Community Ethics Review Board: A Pilot Study." And then, the article that we're going to be talking about today is "Challenges and Lessons Learned from a Community-Engaged Evaluation of a Community Advisory Board."
	I'm going to let the authors introduce themselves. So, Stephanie, if you could go first?
Stephanie Cargill:	Sure. Hi, I'm Stephanie Solomon Cargill. I am an Associate Professor at St. Louis University in their Health Care Ethics Department. I'm also in the Public Health Department there. I'm also the chair of an IRB called Castle IRB. And my work is primarily with the interactions between community-engaged research and IRBs as well as other more broad research ethics issues.
Emma Tumilty:	Fantastic. Thank you. And Bryan, if I can throw it to you?
Bryan Spencer:	Okay. My name is Bryan Spencer and first of all, I'm a student. I went back to school for developmental psychology. But I also have a background in health administration. I've worked in the community—born in Flint and I've worked in the community for many years. For this project my connection to the community was a benefit that I was bringing, in belonging to many boards over the years and just community projects, health-related projects, education-related projects, and maintaining a connection to the community. And that's what I bring to the project. And I guess that's a little bit of me.
Emma Tumilty:	Thanks.
Stephanie Cargill:	And you were on the CBOP-CERB, which we will talk about.
Bryan Spencer:	I was, yeah.
Stephanie Cargill:	Okay.

Bryan Spencer:	I was.
Emma Tumilty:	And maybe that's where we'll start. So, CBOP-CERB, which is the Community-Based Organization Partner Community Ethics Research Board, is what all of the articles in this issue from Stephanie and Bryan relate to. And I'm going to ask Bryan if he can tell us a little bit about CERB to get started.
Bryan Spencer:	Okay. CERB started in 2009 and was put together by Kent Key, Dr. Kent Key, with the aim of protecting the community. There's long been a history of people feeling that research has not really been for them, taking advantage of them, and so he started that with the idea of a community kind of IRB. And these are residents from the community who have long been involved in research, so they understand how research works, and to protect the community, promoting benefits, and staying away from harms that any research could bring to the community.
	About 2014 the water situation in Flint really brought a lot of research here, and so CERB really kind of ramped up, and there were a lot of researchers coming through the CERB to have their projects vetted by the CERB to make sure they were providing ethical benefit for the people in the community. And when we started this evaluation they wanted to see the impact they were having on the community and also the researchers who were coming in. And so, we proceeded to look into that and see what impact the CERB was having on the researchers in the community and the work they were doing.
Emma Tumilty:	Yeah, really fascinating because it's such an important initiative, but figuring out if it's working in the way that you want it to work, if it's having the kind of impact that you want is really, really important. Stephanie, could you tell us a little bit about the article that we're talking about today, about the "Challenges and Lessons," and give us a bit of an overview of the things that came during this evaluation process with you and Bryan working together.
Stephanie Cargill:	Yeah, thank you. It was really interesting because, as we say in the article, this project was community-engaged on a lot of different levels. So, we have Bryan and I—so, we were a community academic partnership leading this project. We were also undertaking an evaluation and a research study that was really initiated by the CERB. The CBOP-CERB wanted to do an evaluation, had done some preliminary work already to kind of get the groundwork there. So, the research question really came from them and the motivation to do it. So, we as a community partnership also had to work very closely with that entity to make sure that we were asking what they wanted to ask and evaluating what they wanted to evaluate, so it was community-engaged that way.
	And then, the third way it was community-engaged was we were working very closely with the residents of Flint to do our focus groups, to engage them at the beginning, recruiting a population who was very resistant and mistrustful a lot of researchers, and also making sure that we benefited them at the end. They very much wanted to know what our results were and what we found and putting it in a way that was helpful to them.
	And so, as most of you who have done community-engaged work know, it's very complicated. It's complicated at a lot of levels. And because we were doing three levels of community engagement, really, we saw a lot of these complexities. And so, besides just publishing on the actual evaluation itself, its development and its outcomes, which is the other paper, we really wanted to take some time and talk about some of the hurdles that we faced, the challenges we faced, and the ways that we worked to, as best we could, overcome them and the lessons we learned to hopefully be helpful to others. So, that's what this article was about.

Emma Tumilty: Yeah. And as somebody who also works in this space, I really loved how specific it was. Right? I think a lot of us talk about how there are administrative issues, there are communication issues, there can be practical and logistical issues. And we talk about them sort of—somewhat generally or focus on the sort of community-level issues that are complex and not necessarily as much on the administrative ones, and I think you're doing a really great job here of being very specific about very detailed problems.

But one of the things that really struck me—and again, I think it's something we sort of think of but maybe not in much depth is this idea of you each having to navigate with each other representing institutions and organizations that the other wasn't part of and their decisions or complexities that they have. I wonder if you could each sort of give me some examples or explain some more that maybe wasn't able to fit into the article. And maybe if we start with Bryan?

Bryan Spencer: Okay. I think that just—me and Stephanie's relationship is an example of what happens in community. Before the project I didn't know her. I'd never met her before. And so, they paired us up, me as a community person and Stephanie as the academic. And when we first started to talk there was this getting to know one another, getting to bounce things off one another, getting to a point where we were comfortable with each other. It took a lot of transparency. We—I think we exposed each other's strengths and weaknesses, and we saw where we both connected to make the thing work, to make the project work. And in community you see the same thing. If you don't connect with community, it's not going to work. If you don't build some type of relationship of trust, transparency where they're comfortable with you, it's just not going to work.

And that really was the background of why research has so many problems for the community, is they felt there was an agenda, where research had then masked the agenda in the community. And so, there was a constant bumping. And when—the researchers may not be doing something that—actually trying to harm the community but it comes off that way. And if you don't have the proper connections, that's what happens. And I think it's important to keep the conversation going, to stay connected, and that's how you build viable projects and viable studies. And that's a lot of what the CERB looked into, is how well the researchers were connecting with the community.

Emma Tumilty: Excellent. Yeah. Communication is so vital. And even communicating when you're not getting on sometimes, in those moments where there might be a bit of friction until you realize that you are, you do have shared goals. But continuing to communicate through them is just crucial to the success of this kind of work.

Stephanie too, did you have other examples of ways that sort of navigating with Bryan your institutional role and the work that you were doing together was difficult, or things that you had to overcome, other kinds of issues? Yeah.

Stephanie Cargill: Yeah. I mean, I think one thing that was really great was because Bryan and I got along so well and trusted each other, when things came up that were frustrations from the outside—so, there were frustrations that came in from my university and that Bryan was just like "What do they want?" He was just very baffled by some of these things that I was kind of the mouthpiece for. And I had to be like "Look, I see the spirit behind what they're doing but I also understand why you're frustrated." And I had to kind of navigate that.

And Bryan had the same. There were some issues, political and other, with his community where I didn't understand what sensitivities there might have been or what things had to be called—and he

kind of—he has the inside scoop of what's going on there. Some of it he disclosed to me. Some of it he didn't. And that was fine because he had to sit there and navigate his role as a representative of his community and his role being on this project. And so, he had to decide how much to clue me in on and how much to be like "Take my word for it. Just—we have to do it this way." And I had to do the same.

And it was interestingly very parallel where we had—and one thing that maybe didn't come out in the paper enough was how much we had to just laugh sometimes and just be like "Reality is complicated. There's all these structures and politics. And this is just how it works." And we had to kind of look at each other sometimes and be like "We're just going to dig in and be patient and get our way through this." And I think—not laughter in the sense that we weren't taking these issues seriously, but just kind of sometimes—we just got frustrated and just—we had to kind of be like "Okay, we'll see next time how we get through this."

Emma Tumilty: Yeah, I think laughter is often a good solution to frustration. And it sounds like you were also just really charitable with each other, that you understood that you were both on the—you both had the same goal here and the same values about what was needing to be done but you were navigating other systems that necessarily weren't on the same page with those things but you needed to make them work for each other. Yeah.

Another thing that you mentioned in the piece that I thought was really interesting and deserves sort of a bit more attention is when you were talking about the feedback process with the CERB itself, that it wasn't just useful in terms of the content that you received during the feedback process but that it was also symbolic. And I wonder if you could explain that a little bit more for the audience. I don't know if one person over the other prefers to do that. Maybe if we, again, start with Bryan and then move to Stephanie, your thoughts on that feedback being both symbolic as well as useful content?

Bryan Spencer: Well, I guess I would approach that by thinking, in terms of symbolic, that it represented the—if I can say the angst of the community, what they were feeling. Sometimes you have to respond to where people are, being present in the moment where they are. And it may not mean to you—and we're looking at the long-term impact of this project. We're trying to write it out, trying to get to a point, trying to get to a goal, but that doesn't necessarily mean that's where they are. And you have to slow everything down and understand "Okay, this is what this means to them, so let's address this. Let's stop the train. Let's get off and let's talk for a while and find out what's really going on."

Emma Tumilty: I love it.

Bryan Spencer: "What does this represent to you?" And that helps things run a whole lot smoother when we do that. And I guess I also learned that with being a father. Sometimes you're trying to press things and make it happen and the children are not on the same page with you, so it's like "Okay, wait a minute. I need to slow down and I will need to connect. I need to go where their level of development is and not try to push them someplace they're not."

Emma Tumilty: I love that.

Stephanie Cargill: Yeah, and I'll add to that. As an academic sometimes I was kind of expecting a level of feedback or a type of feedback that I wasn't necessarily getting. They were just kind of like "Yeah, that's fine" or—but the frequency of checking in and the type of checking in was kind of almost independent of the amount of feedback we got, because I was kind of like "Well, if we checked in and they didn't have

any feedback, does that mean we didn't need to check in?" And it really was about more how at each stage we brought it to them independent of necessarily how much time they took on it or what they gave us back. They knew that we weren't kind of going ahead at each stage without it being brought to them.

So, I think for me that was part of the symbolism, is that—and I see this in human subjects research. A lot of times researchers are like "Well, if we know they're going to say yes, why do we have to ask?" And it's important to—the actual act of asking and you giving the opportunity to give feedback is actually the gesture itself. And I think for me that was a lot of what I learned, was that at each stage I was like "They don't want to have another meeting" and Bryan was like "Maybe not, but we need to give this to them and make sure that they have the opportunity to see it, whether or not they want to have a meeting or not, that they—we send it to everyone and they can give us their feedback if they want to."

Emma Tumilty: Yeah.

Bryan Spencer: You know, one thing that—and adding on to that, in many cases it's just—they just want to know that we care. The community, they—the community knows a lot more than what they're given credit for. And sometimes you don't share when you don't feel people really care or really want to know. But if they understand that you care and that you really want to know and you want to be connected, those times really benefit that arena.

Emma Tumilty: Absolutely. And it's funny to me because it's—not funny in a "ha ha" sense, but it sounds like the solutions at the community level were all about relationship, all about community, all about sort of transparency and trust and those kinds of things, which we would think of generally as what should be the case. But then, when they're contrasted with the kinds of problems that you seem to have at the institutional level around finance around conflict of interest policies, around IRBs—I mean, I really do recommend people read the paper because it's really clear and specific about the kinds of issues that you encountered—some of that seemed to also be about sort of institutional knowledge and relationships and what people knew and how they thought about solving problems. I wonder if you could speak a little bit more to that. Maybe Stephanie to start?

Stephanie Cargill: Yeah. This was a huge learning process for me. There were a lot of things that were hiccups with the institution that if I would have known kind of what to give them in terms of information at the start, it would have solved some of the problems at the later stages. So, we had a really great grant from MICHR, the Michigan Institute of Clinical and Health Research, to do this project, and it was specifically funding for community partnerships. And they had put in all of these sorts of things like no indirect costs and the money going independently to me and to Bryan that were really, I think, informed by their history of working with community and academic partnerships.

The problem is my institution didn't necessarily—and I didn't necessarily know the right way to approach that when I submitted my grant, that I had received this grant to my institution. And so, I thought I was being clear about what the grant was, and the people at the institution were not used to these community partner funding mechanisms, and I had to do some education there. And similarly with the IRB, just kind of talking about what is a partner—who is a partner, who is a participant, when does the human subjects research start versus when are we actually just working with a community partner? These were all things that I think if I had known how to articulate at the beginning there

might have still been some work to try to get the IRB or the grant people to understand how to work it out, but I think there were, like, six stages of misunderstanding before I even realized we had to start that conversation.

So, at the end of the day I do think there's a lot of flexibility built in at institutions to adapt to these types of things, but they often don't have experience utilizing that flexibility. So, talking to the right people and understanding—and also just not forcing it through and just being like you have to build that relationship too. And it took some work and it more took patience. And I think that was the hard thing because it was not a long—these grants aren't very long, and so you don't have a whole lot of time, and we're just spending all this time just trying to work out these steps, these administrative steps. So, I know for the next time what I need to articulate at the outset and be attuned to, which I think hopefully that paper will help others know that too, because I wish I had known.

Emma Tumilty: And it's—I'm sure it'll sound familiar to many people. And that idea of having now the relationships with certain people in finance or with the IRB, so that it might be smoother in the future, I think, is a really important point as well. One of the things that you bring out specifically—was it the—I don't think it was the IRB. I think it was the other administrative process around conflict of interest and the point of wanting to hire somebody in the community related to people on the project. And I think many of us want to expend resources from our grants in the community with community folk, and so that's a problem that comes up all the time. And I wondered if you wanted to add anything around that sort of conflict of interest problem and discussion and how it was managed. Maybe Bryan this time?

Bryan Spencer: Yeah. I guess I'm the subject here on this one. *[Laughs]* The additional person we were adding was my daughter. And she actually had been working with research in New York City, and so it wasn't just—she had the experience. And of course I've worked with her, so I know what she can do and what she's capable of, and I knew what we needed, the kind of support that we needed. And so, it got to be an administrative issue. And I think that there's been so many abuses of that in the past where I can understand why they want to kind of delve into that, but as we—I guess as we worked through the administrative hurdles it came to be understood this is not a problem. But we had to work within the system to make it look like "Okay, this is good in the things that they had already had in place."

So, it's just making the adjustments to make things work. And everyone had to be willing to make the adjustment and make the shift and be transparent about the situation. I think that was probably the most important thing, is everyone just being transparent. "This is what it is. This is what we're trying to do. This is what's happening. What's the best way to approach this?"

Emma Tumilty: Yeah. And—

Stephanie Cargill: I mean, I'll just add, working with Flint a lot, there's a lot of community organizations that are started by families that have key members who are—I mean, this was different here, but that have members who are related to each other. And I think that this is something that's somewhat foreign to the academic culture of—or at least very frowned upon in the academic culture of working with family members. And so, I don't—I think this is a longer conversation about how we see conflicts of interest and how we mitigate conflicts of interest without preventing these types of collaborations.

So, I think what we ended up doing was really just saying, "Is there a way we can keep her on because she's both from the community and has this invaluable research training, while trying to mitigate some

of the concerns that academic institutions have about people—family members working together." So, who is her direct report? And where is the accountability? And making sure it was clear to the university that she wouldn't—her dad wasn't her boss, because that's just kind of an uncomfortable situation, but that she could be part of this project.

Bryan Spencer: Yeah.

Emma Tumilty: But it is, I think, because rules are set up, especially in academic institutions, in sort of abstract ways about—often when they've thought of some particular kind of transgression and they're trying to avoid that transgression, and then they assume that everything of this kind falls into that bucket. And it's just not the case, especially in this kind of community work. And I think that transfers to the IRB discussion, right? The problems that you were having with the IRB is because IRBs are set up in one kind of way, really for one kind of research, and the work that you were doing was more iterative, it was more fluid, it was more community-informed.

Did you have trouble with the IRB—well, did the problems that you had with your IRB translate into discussions about future work and how they can be sort of more flexible or what things can be put in place into the future around community-type projects?

Stephanie Cargill: Not necessarily. I mean, honestly, this was an exempt study. I mean, that's, I think, important to say, is that sometimes you were just like "This is exempt. Why are they so attentive to these issues when really at the end of the day they've told us that this really doesn't fall under their umbrella in any rigorous way?" And so, I do think part of it is just attuning them to things that they might think are big issues that are not as big of issues so that when it is a minimal—this was a minimal-risk, nonsensitive study that whether or not it's community-engaged or not, their approach should be similar. We're not really worried about these things because there's really no significant risks involved. And if there are, really, we're more likely to notice them than they are, being community-engaged.

So, I mean, in my experience—and I've done a lot of work in this area—because every community-engaged project is kind of different from the others, setting up policies, I think, makes sense for institutions that do tons of community-engaged research. My institution doesn't. I think it's more just getting them used to being flexible, and the issue of the first time you see something, people tend to—their eyes get big and they're like "What do we do?" And the second time, they don't get as shocked. And the third time, they're even less.

And I think part of it is just building up experience over time. And again, the relationships of kind of trust and communication. I think part of our problem was just misunderstandings through an e-mail where we should have just picked up the phone and had a conversation with someone. Or the tone of an e-mail felt a certain way and maybe wasn't intended from one or the other side. Things like that that I think are actually more general IRB insights than anything specific to our project of just—it's very easy to get frustrated on both sides in IRB relationships. And I think just picking up the phone and just being like "Lets really talk about what's going on here."

And I think a big thing for us with the IRB was they were working as kind of the clearinghouse with these other administrative organizations, so they were like "We need to send this to the conflict of interest department. And we need to send this to the grants people because it's not worked out." And so, they were kind of the go-between, and that put them in an awkward position as well because, really, our issues were with the conflict of interest and the grants, not with the IRB.

Emma Tumilty: Great. Great. I completely agree. And I think you're kind of recommending exposure therapy *[inaudible]*.

[Laughter]

Stephanie Cargill: I mean, I have published and I can link to things where it is—there are kind of policy changes that can be in place. But I think in this particular situation the polices were fine. It was just kind of seeing how to fit what we were doing into the policies.

Emma Tumilty: Yeah. I'm going to try and wrap us up with two more questions for each of you, and they're more sort of general ones. I guess for those sort of doing this work moving forward, what is your sort of key recommendation from these lessons that you learned around doing this kind of work? Is there the one thing that you would say people should think of based on what we've been talking about? Is it fair to start with you, Bryan?

[Laughter]

Bryan Spencer: No, it's not. It's not. I would think that the most important thing is to stay connected and realize that there is a human part of working with each other. Sometimes we get so caught up in the administrative structure that we lose our humanity. And what I mentioned earlier about it's like being clued into the development of your children, we should be able to translate that over to working with anyone. Just being sensitive and connected to them as a person, to them as a human being. And sometimes you have to shift the administrative things out of the way. And what resonates with you as a person—and that helps you to be more transparent, it helps you to pursue more trusting relationships, you can see that. But when you throw all the administrative and structure stuff in the way, then all of these other things start to crop up. So, I think the first thing to do is stay connected on a human level so that you can work together and stay connected.

Emma Tumilty: Love it. Excellent. And Stephanie?

Stephanie Cargill: This might be—this is not for the research teams, but I really think that what we learned is how important time is, because I think a lot of the frustrations we had weren't that there were barriers we couldn't surpass, but every barrier created a delay. And then, we were doing this in the middle of COVID, which didn't help. And I guess what I would want to say is for anyone who wants community engagement to be part of their work, and especially funders, realizing how much delays happen, how much time it takes to build these relationships, to work through all of these mechanisms not really built for this type of research, and to kind of—I hope for the future that these funding mechanisms can be more flexible about how much time it takes to do this work. I mean, I think that once you do it once it's faster the second time, but I really think for both Bryan and I a lot of the frustrations could have been eased if we were like "We have another six months and we can do it then." But we were just kind of like "This is a one-year grant and we have to do it in a year." And every delay that was put in our way then just made it a little more stressful. Luckily, we did stuff after the grant was over, because we could, but I think that's not always a possibility for everyone.

Emma Tumilty: I think that's spot on. And then, so, my last question: I'm sure everybody wants to know what's happening next in this space? So, you've done the evaluation. Are you continuing to do work based on that evaluation? What can we maybe see from you in the future?

Stephanie Cargill:	I think—Bryan, do you want to talk about what's going on, the exciting stuff happening with the CBOP-CERB?
Bryan Spencer:	Yeah. Yeah, I will. One suggestion that came from the community was that the CERB would kind of expand in terms of age. A lot of the CERB members are older and one thing that they looked at is can you allow more young people? And that's just happened. The CERB did interviews for new members and many of them are young people—or younger people. I think there's one mid-to-late-20s. There's a couple of them. There's some in their '30s. And then, you have a couple who are older ones also. But it was like eight new people. And what we're bringing in can be very useful for them going forward as a tool to connect with the people in the community. And I like that we're having these new, fresh ideas coming into the CERB and fresh approaches because sometimes you work on this stuff and you get—you just get immersed in the detail and you kind of lose the flow of how you really need to be connected. And with young ideas coming in, fresh minds, fresh energy, a lot more can be done. And for the future of the CERB and taking this information and going forward to it—with it, that there will probably be more evaluations to do as they put this in play, see what the community is saying, and then go on to build stronger connections with the community.
Emma Tumilty:	Fantastic. That's really exciting.
Stephanie Cargill:	Yeah, and from my side, I mean, I'm part of lots of different projects and I think this concept of the science of community engagement keeps coming up, like how do we evaluate the impact of these—the increasing number of institutions, funding institutions who are funding community-engaged kind of projects, and then they are like "Well, prove to us that it was good." Which I think is a challenging ask because, as we've talked about, a lot of what's the value added are things like relationships and long-term goals and not just reducible to things like recruitment or retention. But doing something like this where it's like "Look, there are ways that you can evaluate CABs and their impact and what the communities want from community advisory boards"—so, for me, working in other projects where there are community advisory boards, I'm immediately like "Okay, what kinds of things can we look at to assess how important this CAB is and to prove it to the people around us?"
	And similarly with, I think, there's more work to be done of other aspects of community engagement and showing the value added in a language that funders can find meaningful so that there's increasing time and money devoted to these types of mechanisms that add so much to the research.
Emma Tumilty:	And I can only cheerlead for that, both of those things. Both fantastic. I want to thank you both for taking this time with us to explain your paper a little bit further and the other work that you're doing. I really encourage listeners to read both papers in the journal. They're really helpful, really interesting, and there can be lots that can be taken away to other communities, I think, from engaging with the work. So, thank you so much.
Stephanie Cargill:	Thank you.
Bryan Spencer:	You're welcome. Thank you.
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