Beyond the Manuscript: Defining and Measuring Community Engagement and Community-Engaged Research:

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Beyond the Manuscript: Defining and Measuring Community Engagement and Community-Engaged Research: Clinical and Translational Science Institutional Practices

Karen Calhoun, Mickey Eder, and Jessica Holzer

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 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, Jessica Holzer, interviews Karen Calhoun and Mickey Eder, authors of "Defining and Measuring Community Engagement and Community-Engaged Research: CTSA Institutional Practices." The transcript has been edited for clarity and accuracy.

Jessica Holzer:	Good afternoon, everybody. Thank you so much for joining us. My name is Jessica Holzer, and I'm an assistant professor at Hofstra and one of the associate editors of *Progress in Community Health Partnership*s. Now I'd like to introduce Karen Calhoun and Mickey Eder, who are speaking with me today. Karen, would you introduce yourself?
Karen Calhoun:	Good afternoon. This is Karen Calhoun, and I am a Community-Engaged Research Program Officer with the University of Michigan's CTSA and also a community partner in Detroit with Connect Detroit.
Mickey Eder:	I'm Mickey Eder. I'm in the Department of Family Medicine and Community Health at the University of Minnesota. I'm a researcher, not a clinician. I'm also chair of the Community and Collaboration Core of the CTSI at the University and have been involved as an associate editor with the journal for eight years.
Jessica Holzer:	And so too Karen as well, right?
Mickey Eder:	Yes.
Karen Calhoun:	Correct. For almost eight years I think. I came on right after Mickey.
Jessica Holzer:	Wow. Mickey, would you just clarify what CTSI stands for at your institution?
Mickey Eder:	Yes. Thank you. The CTSI is the Clinical Translational Science Institute. It is the center that operationalized the Clinical and Translational Science Award from the NIH.
Jessica Holzer:	Great. Thank you. And throughout the interview, if I need to, I'll just check you on acronyms if I catch them. Well thank you for taking the chance to discuss this manuscript in a little bit more depth. I think it's going to be an interesting manuscript. I personally am always interested in seeing what the CTSAs are or are not doing to move community engagement forward. So let's jump in a little bit, and

let me ask you, what was the overriding impetus for this particular project, asking these questions about definitions and measures of community engagement within the CTSA?

Mickey Eder: Shall I go Karen?

Karen Calhoun: No, I'll start. The idea for the manuscript originally occurred maybe six years ago or so, and at that point in time, we were looking at how to best organize ourselves as individual institutions addressing community-engaged research and translational science and also how to work across institutions, so the whole concept of the hub was being born. We didn't have a uniform context in terms of how we define community engagement and community, so we were looking at being able to summarize how community engagement programs across the country through the CTSA (Clinical Translational Science Award)—how they're organized, what they do, and how they report metrics or indicators that describe best practices and effectiveness.

Mickey Eder: Yeah. I would agree with that and perhaps expand a little bit. The clinical and translational science program from the NIH involves approximately 60 universities and research entities around the country. We have been challenged with identifying what are the unique skills and unique contributions each of the institutions can make to the whole. Some people have really strong transplant programs. Others have strong connections to departments of health and more primary care and public health emphasis, and in the spirit of a U Award, which is an opportunity for a variety of institutions to collectively contribute to—and in this case, using and connecting research more directly to improving health outcomes. We all wanted to do, as Karen said, get together and learn from each other, and part of the learning process was to better understand how we were defining and approaching community-engaged research, community-engaged activities, and how we were assessing the value of our own programs and projects.

Jessica Holzer: So if I'm understanding correctly, this is a form of self-study. You and your coauthors were the representatives within the Clinical and Translational Science Award awardee institutions. You were the ones who were involved in community engagement in one form or another, either as leaders or as participants in the process, part of the leadership team. Is that accurate?

Mickey Eder: Yeah, I would say so. There is an infrastructure. There was an opportunity for monthly calls among all of the community-engaged research leaders at these 60 institutions, and anyone who wanted to volunteer and participate in the development of the survey or the analysis, was welcome to do so. And so the authors on the group were those who worked directly on the manuscript. The authors were directly involved in development of the study and its ultimate publication.

Jessica Holzer: So speaking of that, related to that, since this is a group of people who know what they're talking about as authors, as well as the people who are responding to the survey that you conducted, in table four you list some suggested metrics for the CTSA institutions that were generated by the participants who responded to your survey. Is that correct?

Karen Calhoun: Correct.

Jessica Holzer: Yeah. Okay. So of those that were listed—and there are I think 17 here—of those that were listed, do any of them jump out to you as particularly valuable or potentially impactful measures that, if one had to selected, that you would say, "We should put our energy there. That would be a great

way for us to get some insight into how we're evaluating the CTSA community engagement and program activities."

Karen Calhoun: Well there's a couple that really stand out to me, and under the middle category, contribution of community-engaged research to outcome measures. The second indicator, changes in research due to community-engaged activities, and then a couple at the end—in that same category, changing communities' sense of accountability on the part of researchers, changed community perception of academic research in the university and community, and community partner perception of benefit. And also the survey reported on dissemination of research findings, so I'll add dissemination and implementation of research findings. Those to me are of vital importance.

Mickey Eder: So let me add, the table represents recommendations, suggestions, from the individuals who completed the survey, so we're actually sharing the data that we, as the people conducting the survey, received from the respondents. When we take a step back and say translational science was originally proposed by Elias Zerhouni, who was the NIH director, and looking at what was estimated to be a 15- to 20-year span of time that existed between the development of an idea and its evolution and maturation through the research process to the point where you generate enough evidence and you can demonstrate the effectiveness of the knowledge that you're producing that you can then put it into practice. So when you look at the list—and I think the things that Karen specifically highlighted, reflect important goals of translational science, which is not just to generate knowledge but to have that knowledge implemented, transforming practice. And I think when we take a step back, we were really supportive of the idea that it's not enough to just get funded to do the research and publish papers with data, but if we're genuinely to realize the goal of translational science, we have to add to the expectations we have of researchers that they are gonna be persistent in advocating for what they've learned in supporting their partners in the community so that gains in health that were produced because there were additional resources supporting research aren't lost just because the project came to an end. And in some ways, encouraging universities—I think if we were to say, "Let's adopt a metric like, 'We not only have to disseminate and implement research findings, but we should see changes in community practices and in community health, whether we wanna say that's accountability or not.'" Policy changes specifically mentioned that what we're really asking and encouraging—we're asking of ourselves and encouraging our institutions to say, "The traditional strategies around research, which is get funding and publish, isn't sufficient to genuinely realize the translational vision," and that we have some additional work to do, and I think we see now an emphasis on implementation and dissemination research, which ends with the translation of knowledge into practice. And so Karen highlighted a number of recommendations that I think we're seeing across the consortium, which is the CTSA's group of institutions, that emphasizes that publication and going out and talking about your findings, even in community context, as good as it is, isn't sufficient and that we wanna take the next step and make sure that when we've learned something and when we've demonstrated that it creates improved health, that we do our best to make sure that those gains aren't lost and that other communities can benefit by learning about and implementing those types of projects and programs.

Karen Calhoun: Yeah. And I'll just add briefly that for me, those objectives also point out the value of diversity and how diversity strengthens the science. We now, since this survey was originally done, have moved

more towards a team science approach in how we do community-engaged research; we recognize the value of the team, of the diversity of the team. And also the perception objectives that were mentioned really key in on trust and relationships, which Mickey sort of opened up his discussion with, how important it is that the relationships are there, that we're bi-directional in our approaches for both learning and for contributing. So all of those objectives really hone right in on that for me.

Jessica Holzer: Mickey, do you want to add?

Mickey Eder: Yes, I just wanted to add one thing. I think that the table demonstrates something about quantitative research and metrics that involve counting. There's also a significant qualitative aspect to this, and so we are really looking at a mixed-methods type of strategy in order to be able to evaluate and assess the contributions that community-academic partnerships are making to translational science.

Jessica Holzer: So perhaps in that vein, you mentioned that this table is effectively raw data. There was an open-ended question that allowed survey respondents, who are, themselves, representatives of the CTSAs, to identify metrics, and then there was no opportunity for anyone to endorse these measures one way or the other or to get a sense of who thinks one of them is more valuable than another. And so it is what it is, but it's not more than that, but I noted in your analysis that you mentioned that trust was not something that was widely suggested to be measured, and then Karen just brought that up in terms of how perceptive measures might capture something like trust. And from the research outside of this study, we know that trust is essential to communities and academic partners being able to move along together, be able—it's an underlying condition for any and all work to move forward, so I'm wondering if you have some suggestions for additional measures that might capture trust or if you think there are other types of measures that would be useful, even if they're not explicitly related to trust.

Karen Calhoun: Well, ways to measure the strength of the partnership would get at trust, and partnership is the basis for community engagement. You have to have a team. That would be one key thing I would recommend.

Mickey Eder: Yeah, I would think it's fascinating that in a lot of the materials, RFAs, PARs that are put out—RFAs, requests for applications, program announcements related to applications from institutions—often emphasize trust. And we were a bit perplexed that that was not specifically mentioned, but I do think that what we're learning—and I wanna specifically mention a young scholar, Julie Lucero, who studied with Nina Wallerstein and is now at the University of Nevada, Reno, is really advancing the study of trust, because we typically think about it as just a generic category—there's trust or not trust. And she's done her dissertation and has continued to publish and show that there are different types of trust, and as Karen was talking about measuring the strength of partnerships, we really have to understand that a lot of institutions are still focused on funding dyadic relationships between a community group and an academic researcher that is project-specific. What I like to see in these metrics is a movement towards recognizing that if the clinical translational science centers and institutes at each of the universities is gonna be successful, they're gonna support partnerships which exist and survive and continue beyond the individual project. If you are focused on that, then you can almost assume something like trust is gonna exist, because why would I continue to work with people that I've had a bad experience with and that the expectations that I thought were shared turned out to not be shared. So I don't think trust was explicitly mentioned, but I think that it is embedded within the goal of moving from projects to sustaining partnerships over time. So I hope that that represents a

movement forward in our ability, so when we look at something like change in the community sense of accountability on the part of researchers, that when the project is over, we don't disappear. So I think it's there, but it wasn't explicitly mentioned, and I'm hoping that as Julie's work moves forward we will be in a position to come back and look at partnership evolution, development and evolution in a way that allows us to do more than simply count how many people said they trust us and didn't trust us.

Karen Calhoun: Absolutely. Then you would be able to quantify some objectives. For example, in table four, under the first category, counts based upon program activities, community members involved in all individual CTSA-supported partnerships and researchers and projects seeking community stakeholder input, for example. So you'd be able to see an increase in numbers of engagement, and that would go directly back to trust and relationships, and it would also expand the reach and outreach of engagement to truly be more team science, as well, by strengthening the diversity.

Jessica Holzer: So I think that's interesting as a way of also segueing into a question from Hal, because what Karen just brought up in some measures listed here that are somewhat researcher-focused, so the degree to which researchers seek community stakeholder input, the degree to which they use community engagement consulting services, and I think one of the interesting questions about trust is that it's not just a question of do community members trust the researchers they're working with, but also do the researchers and institutions trust the communities? Do they give them—do they view them with the power to be co-decision-makers? Is there trust that the institution and the researchers can fulfill their missions while doing community-engaged research? 'Cause I'm sure the two of you know and most of our readers will be aware that one of the key challenges in community engagement is the degree to which you as junior researchers—I've certainly received this—are warned about the ways in which that's gonna slow you down, you're not gonna be able to publish, and there's some fear there. And I think that's really a loss of trust that this—that we can all move forward and we can all meet good goals for ourselves as part of a partnership. So I think that starts to lead me into this question that Hal had, which was you had a conclusion that there was limited attention given to assessing community advisory board advice combined with a lack of attention to reporting research results in community context, and Hal said the suggested CTSAs—or well, I think the author said that CTSAs have not generally explored this bi-directional communication, so really investing in communication from the community as well as communication to the community within translational science programs. And so his question to you was how would you encourage the CTSAs to further explore bi-directional communication, and my addendum to that is as a way of enhancing trust in bi-directional ways. That may be too much of a heave lift to come up with, but I welcome your thoughts on it.

Mickey Eder: It's a broad question. Karen, how about if I take a stab at it first?

Karen Calhoun: Okay.

Mickey Eder: And I would start with a book called *The Principles of Community Engagement*. It was revised. The second edition has a table in the first chapter that looks at community engagement as a continuum, and it starts with outreach, and it moves all the way to shared decision-making. And I think what the question really resonates with is a concern that you see in the literature and that I certainly experience in my work on a daily basis, is that there is a lot of concern in the community that we don't listen very well to advice from the community. We have moved, I think, and there's been an increased emphasis

on patient-reported outcomes. There is a group, the Public Involvement in Research, which is in England, that in 2008 published a study in which they said there is evidence that involving community members, stakeholders, patients, all of the above, in research has changed some research projects for the better. They also made the point that there is not currently a way to really systemically study that across research projects, so they had various examples, but they were almost anecdotal. In the discussion section an author would include something like, "We were doing a complementary, an alternative medicine study of people who told us that the time to really do the massage therapy was immediately after the administration of daily dose of drugs, because that's when it would make the biggest—have the biggest impact. And the researchers never even thought about how patients might respond—have varied responses depending on the time of the day, so that was one example. And I think what we're struggling with is that all research is not successful. We have hypotheses, and a lot of times we find out that what we thought or projected would happen doesn't happen. And at this point, we don't have a clear sense of what we should expect the community to provide in the way of input. How often should recommendations about the design of a study or the design of the recruitment strategies for a study—what would appropriate measures be to say, "This is worth investing in and worth continuing?" And I think what we lacked and what's interesting about the table and about the question you're asking about bi-directional communication is are we gonna support a program and a systematic study so that ultimately we can have a clear set of expectations that allow us to develop meaningful research, to assess where communities are most likely to have a positive impact? And then how do we develop the programs to maximize those forms of input and involvement? Karen, what do you think?

Karen Calhoun:

Interesting. So I had a couple of takes on this point in particular, and one I wanted to preface by beginning to share that I really consider how I function within the CTSA as a citizen scientist. I don't have a formal background in research. I've been blessed to have been groomed by a lot of colleagues from around the country and here at U of M who have taught me how to do research. I also wanted to share that when we initially did this survey and the research that CABs weren't common, among CTSA units. They were somewhat involved or included within academic health centers for project-based research, but not as a CTSA community engagement—well I would say CTSA as a whole. Many community engagement programs had some form of CAB, but they were siloed. After that, in a later funding announcement, then CABs—the requirement that all CTSAs have some sort of CAB became—that elevated the prominence of a community advisory board. And the community advisory board is one vehicle for encouraging bi-directional communication. So there's this continuous feedback loop of the benefits of that bi-directionality. One basically you're sharing or translating research in community context, so it's a form of facilitating that, and when you do that within the community, then that opens up a stronger—a better conversation on what health priorities are and what focus our academic health centers and CTSAs should be addressing. What are the most urgent community issues and needs impacting community? With that discussion, then that leads to an informed decision-making and shared decision-making process where the academic health center and CTSA begins to address those priorities that are most pressing to the community. So that feedback loop strengthens both our impact, in terms of population health, which we also are trying to address more on what are the real outcomes or impact of our work and how is it actually effecting the broader community, and also the

diversity, in terms of increased participation, the input at various levels, impacting, again, population health and grooming citizen scientists and contributions to community engagement more broadly and also contributing or allowing vehicles for the traditional form of research through individual, scholarly contributions. So all of that feedback loop just—it all starts with this bi-directional sharing and communicating with one another.

Mickey Eder: Let me just pick up with what Karen said and go back to a thread that I started and then lost track of in the comment a few minutes ago when I was referring to the community engagement continuum. I think what I heard in Karen's comments that's really encouraging is that we're looking at diverse communities and trying to address persistent challenges, and I think the elevation in the importance, at least the recognition by thefunders of the CTSA program, that we need advisory boards if we think about the continuum, for ongoing dialogue and discussion. But the engagement continuum that I was referring to in *The Principles of Community Engagement* doesn't stop there. The end product should be shared leadership and shared decision-making, which is was what Karen described. And I think if that becomes the goal, we will really have made a huge move forward in recognizing that well-developed community academic partnerships can positively contribute to research and to changes in public health. And so I would just add that it's not enough to communicate. We have to be willing to share in the decision-making process. And I think that's happening more, and it's encouraging.

Karen Calhoun: I agree.

Jessica Holzer: Well I think that's a great place to end, and let's hope that it is happening more and that maybe five, ten years from now we can redo this study and find that a lot of changes have been made and we can do a little bit of a retrospective comparison on it. So I want to thank you both, again, Karen Calhoun and Mickey Eder for speaking with me today.

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