

Beyond the Manuscript: Community-Driven Conversations: Partnership Building through CHEC-Ins

Emma Tumilty, Joanne Glenn, Henrietta Barcelo, and Janine Ntahirageza

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, Emma Tumilty, interviews Joanne Glenn, Henrietta Barcelo, and Janine Ntahirageza, authors of "Community Driven Conversations: Partnership Building through CHEC-Ins." The transcript has been edited for clarity and accuracy.

Emma Tumilty: Welcome, everyone, to this episode of *Beyond the Manuscript* podcast for the journal *Progress in Community Health Partnerships*. Today, we're really excited to have some of the authors of a manuscript called "Community Driven Conversations: Partnership Building through CHEC-Ins." Today, with me, I have Janine Ntahirageza, Henrietta Barcelo, and Joanne Glenn, who I will let introduce themselves hopefully shortly. My name's Doctor Emma Tumilty. I'm an assistant professor in the Department of Bioethics and Health Humanities at the University of Texas medical branch, and an associate editor for the *Journal of Progress in Community Health Partnerships*.

Maybe if we start off with introductions, can we maybe go to Miss Joanne Glenn first?

Joanne Glenn: Well, good morning. It's so fabulous to be on this call today. I'm Joanne Glenn. I am an RN MBA, and those initials—ABD—All But Dissertation—of 47 years. Founder of the W.O.T. Foundation—Women on Top of their game—that guide breast cancer survivors through celebration of life.

Emma Tumilty: Fantastic. Thank you. And Janine Ntahirageza.

Janine Ntahirageza: Thank you so much, Emma. It is an honor for me to be invited to this conversation about CHEC-Ins—one of the pillars of the Chicago CHEC, which is the Cancer Health Equity Collaborative, an organization that has become incredibly impactful here in Chicago. My name is Janine Ntahirageza. I'm a professor at Northeastern Illinois University here in Chicago, and I joined the collaborative about five years ago as a member of the outreach core, and since then, it's been wonderful to work with everybody—especially my colleagues here from the community—our community steering committee. So, I look forward to the conversation.

Emma Tumilty: Thank you. And last, but certainly not least, Henrietta Barcelo, could you also introduce yourself?

Henrietta Barcelo: Thank you very much. I'm Henrietta Barcelo. I'm an educator. I started my career as a health educator and I have over 25—or actually, now, 30 years of experience. I started off in health care, and rose

into health care marketing, and then, when back into post-secondary education as well, and then, finally, into high-school education for Health Sciences Career Academy at Instituto for the Instituto del Progreso Latino in Chicago.

I felt that the impact for community was very important. I needed to start at the grassroots level. So, I haven't yet gotten into the elementary school level, but I'm aiming to.

Emma Tumilty: You're getting there.

Henrietta Barcelo: Thank you.

Emma Tumilty: Wonderful. So, I wonder if, for our listeners, you could start off telling us a little bit about that community steering committee and how it brought about the CHEC-Ins?

Janine Ntahirageza: Okay. Maybe we could say something about Chicago CHEC so that we're really linking to the community work that we're trying to do. So, it is a National Cancer Institute partnership, led by Northwestern University, the University of Illinois at Chicago, and in Northeastern Illinois University, also in Chicago. So, in short, it's Chicago CHEC. And Chicago CHEC's mission is to advance cancer health equity through meaningful scientific discovery, education, training, and community engagement, and this is where we come in—community engagement.

And so, Chicago CHEC has five aims, currently, and one of the most relevant—the CHEC-Ins—is to foster community partnerships and conduct on common needs assessment to identify new areas of opportunity for community-engaged activities, including outreach research, reaching individuals from health disparities populations across Chicago. So, we really anchored in the content. This is how the CHEC-Ins came to be. And so, I'll let my colleagues here, Joanne and Henrietta—talk a little bit about the CHEC-Ins. Maybe, Henrietta, you can start.

Henrietta Barcelo: I think with the CHEC-Ins is the purpose is to get a pulse check. One of the aims with CHEC is to increase education and awareness of cancer health, as well as the resources that are so that they can affect the data. More people are aware of it, are educated, and willing to participate in their screenings, and then, get to a point where they're comfortable enough to schedule their annual examinations and be on time with it. We think that that will affect the data that we see. And the CHEC-Ins was a way—so, when you're looking at data, for example—when academics look at data—and people like myself in education and other fields—is that it's pretty black and white for the most part, right?

When we decided how are we going to impact the communities, the CSC was talking about this as a—the community steering committee of about 24 to 27 individuals, of course, adding people, as well, or organizations as well. And the idea was groups are not always as black and white, you know? For example, Latinos—we are not just one group. Only in America are we clumped together as Latinos. But, when you go into Latin America, we see ourselves individually, and we process information and seek out different venues of information at different ages, right?

So, we wanted to do a CHEC-In, and a CHEC-In's a pulse check, and the pulse check of a community, what the personality is, where is it that they get their information from. How do we approach them? Because how you approach a Mexican American might be a little different than how you approach a Cuban American or a Guatemalteco who is just recently immigrated here to United States. So, Chicago has very broad Latino presence, and this is in line, also, and this applies—this concept applies, also, to the Asian American community, the African community, and the African

American community. There's just different aspects and personalities in how we take information, where we get it, how we process it.

And how is that communication, right? And how do we do that so that we can bring and tailor the message of CHEC and our aims into the community so it's just not like another academic institution coming in with 17 XYZ million dollars and saying, "Oh, we're here to do this." And one of the challenges that was very important, that is trust, right? In Chicago, there is a concept of academia coming into our communities with money and setting up systems in our communities to address their research need in regard to a disparity, right? But what happens in those years that they have those funds—they stay, and they work with us, and we see the change.

But once that money, *A*, runs out, *B*—that infrastructure is no longer supported—it crumbles. And then, they go back to their academic offices to crunch the numbers, and what happens to community? So, community organizations are a little wary about this, and of course, that was something that was very prevalent in the '70s and the '80s, and there has been tremendous advancement, but there's still a lot of work to work on that. So, the CHEC-Ins was a way to get a personality check, how people get their information, how can we develop trust, and hear what the needs of the community were.

Emma Tumilty:

Wonderful. I think it's great to hear the reminder, again, about the fact that demographic groups are not homogenous groups, right? Like, it ignores an intersectional approach of understanding human beings and who they are and the fact that they may have many identities and variables that go into who they are and how they access information or act on that information. I think, as well, this idea of trust is a good one to pick up. I wonder if we can hear just a description of what a CHEC-In actually looks like and then, how easy or what were the things that you needed to do to build engagement with them.

Henrietta Barcelo:

So, Joanne and I sat in 2017, at a restaurant in Bronzeville for breakfast—and, since we were at a breakfast, we put everything on a napkin because that's all we had, right?

The idea of a CHEC-In is that each community steering committee member hosts 10 partnership—partner organizations—within its community. And, from there, we have a CHEC-In. We get the skinny on what they think about cancer, what are the needs from their perspective, from their individual service orientation, and then, from that 10—including the CSC member—that CSC member then—those 10 partners organization and the CSC member have a meeting of 10 people from their organization—their respective organizations. And these are individual staff.

They're people that have boots on the ground or volunteers that work directly with people in the community. And then, those 10 people go into the community and work directly with the residents of the community. So, each of those 10 individuals—they now have 10 individuals that are in the community—whether it's a church group, whether it's a cancer meeting, or something to that effect—but that people are willing to listen or a PTA meeting—those kinds of encounters. And then, from those 10 people, we want to ask, "Can you invite us into your home?"

In Spanish, we say *cafecito*, or a little coffee, around the table with 8 to 10 friends/family members so that we can talk to you about cancer help and the importance of that—of cancer help. Clinical trials. How do you get your information? What services do you need? What have been your experiences with cancer?

So, we potentially—that is just one community steering committee member. And if we have 24 to 27 members and we expand, boy, we can hit over 650,000 people on a grassroots level. And you're not

only putting it on the grassroots, but you're bringing community organizations—you're developing those partnerships and relationships to continue those touchpoints. So, that is what a CHEC-In is.

Joanne Glenn:

Let me add something, if I may. By being a clinician and a trusted voice of the community, policy advocacy is one of my specialties. So, having someone trust you—which means they'll listen to you—they're more apt to be compliant. The follow through—the care plan is easier because it's someone that looks like them, someone that has experience, and instead of just talking the talk and walking the walk, we do the work. So, as Henrietta was saying, with the CHEC-In, we've got to find a way to get that napkin in the Smithsonian, first of all, because, as you know, that's how most successful business start—with a napkin or a paper towel and an idea.

So, as community leaders, we were trying to figure out how can we get that voice heard so it makes a difference—not just a whisper, but actually, to change things so people can believe in their rights, fight for their rights, and be part of the solution. So, the CHEC-In—I hosted two with my breast cancer survivors. They call themselves The Butterflies because of the different stages of breast cancer they went through. And we had CHEC to host it. They would come out and help get information.

It would be the same questions with different groups so we can have some data that is measurable and we can know what to do with it. And by me being there as the host and someone they trusted with their health care throughout their whole navigation, the shoulders were down, the bald heads were shown, the hats came off, the heavy prostheses were thrown to the side, and they were free to speak their mind. So, with the CHEC-Ins, we got a lot of information and data that helped change some of the paradigm and choices of care. So, they were very helpful as far as someone saying something that someone else were perhaps scared to say because they were ashamed or didn't know if it was the right group. So, again, with that nod like we're doing, we're saying, "It's okay. Ask. Hold my hand."

That quiet love and hugs—it made a difference in the outcome in many of the Butterflies. And what I do as the found of the W.O.T. Foundation and the past co-chair of CHEC is facilitate breast cancer survivors across the whole platform of care, and the CHEC-Ins have been very instrumental in doing so.

Emma Tumilty:

I mean, it just sounds powerful—that level connection and communication and its ability to spread through community through the relationships that you've created. Janine, I think you were also going to add to that.

Janine Ntahirageza:

I was just going to say, from the academic institutions aside, we're listening to this—this beautiful interaction. I mean, you heard Henrietta and Joanne bring together this different—they have a different kind of communities they work with and yet, we are now—we are listening. You cannot not react to this kind of input, to this kind of needs.

When they say, "This is what we need"—when they tell us, "This is us. Know us. Know what we do and what we want" then, the academic institutions—we are compelled. We cannot not, in the partnership, we cannot not respond to that. And too, for me, as a participant in watching, I've learned so much more than what I've think I've given, as then I can speak for us as an academic institutions, really being able to respond collectively and consecutively to what we are hearing.

And again, it's because of the package that came from listening, from these CHEC-Ins. It's been powerful all around. It's been powerful.

Henrietta Barcelo:

I'd like to add to that—is that communication is the key on whatever level—whether you're at the highest levels of academia, business, or whatever, all the way down to that community—that individual,

that person that has just arrived here in the United States in Chicago. And it's being able to provide that uploading and downloading of communication and being able to serve the community in a way that affects the face of the data. And I think, also, that we started off with a line that was kind of our mantra in what we call CHEC 1.0, was that it's not business as usual. It's not business as usual. We have to think outside the box.

We cannot retain those ways that academia and health care institutions have—and community—have had. We need to change that. And so, a very good supporter and contributor to CHEC—Kareem Watson said—“Hey, if a community member hasn't yelled at you yet, you're not communicating.” And I'm not saying we're yelling at each other—it's figuratively, right? But you've got to accept push back and try to put everything else to the side so that you can listen to what is said.

So, this is why this idea of CHEC-Ins is so powerful because of that informational uploading and downloading. But it's also developing a style of communication with partners—academic, health care, as well as community—and very diverse community.

Joanne Glenn:

And I can share from the CHEC-Ins. With the two separate CHEC-Ins we have, the ladies are different. When they go back to their physician after being together with women that look like them with the same diagnosis and perhaps different care, they've now gotten that word of empowerment where they can go and ask their physicians a different kind of question. “Why not this? What's best for me in the clinical trial? What's the expectation?” Whereas, before, heads are down. There's very little eye contact, and there's no real communication. It's not bi-directional. But now, the CHEC-Ins have helped to give them that knowledge and power to say, “I want to be part of my care.” So, that voice is heard, and it's not just, “Do anything you want because I don't know if it's standards of care and I don't know if it's different because of insurance. But what I do know is—I want to live.” So, we help them to get through those stages of celebration.

Henrietta Barcelo:

And that's so important for equity, right? The striving for equity so that everyone is healthy, and everyone can have access, and everyone can express themselves without the fear of feeling shame because they can't articulate themselves. But they do have the information in their heads so, they can drive the conversation.

Emma Tumilty:

And just being conscious of time—because I don't want to keep you than I'm allowed to—but maybe jumping off that—because I think that capacity building and that social capital building are such sort of beautiful and powerful elements of this kind of work that people don't necessarily set out in their design to create specifically, but come about through the connection with people—hearing others, *et cetera*. And so, I wonder, where you hope to see CHEC-Ins go from here. What do you want to see them doing? What do you want to see the outcomes from them be in the future?

Joanne Glenn:

I'll take a first stab at that, if I may—and we chatted about this a bit just yesterday—about what's expected from the CHEC-Ins. We don't want them to be just a passerby. We want to be part of the plan of care. You know, when you come in and you establish diagnosis and treatment plan, make sure you check in and that you have your voice heard and that you're part of the care. So, we talked about possible applications, definitely documentation, and adding to the data set that your voice count and that your healing is part of the process because of the CHEC-In.

Henrietta Barcelo:

Right. And the other thing for us, as well, is that we want to make sure that these CHEC-Ins are sustainable. We do not want them to disappear. We need to affect policy—and policy not only on a community, but with an organizational capacity, but also, in terms of the health care institutions and

academic institutions that work within our communities and serve our communities—is that we need to have policy change. If Joanne and I are co-chairs for the community steering committee—I mean, we have transitioned in our members—but we lead.

We want this kind of work to continue. And we really think that there is viable and useful data that can be collected from these CHEC-Ins to provide kind of a complete perspective of the data and put a face on that data, and how do we approach our communities to increase that equity and improve those communications and impact policy?

Joanne Glenn:

Here’s a quick scenario. Being patients or going someplace with a loved one that’s a patient and you go in and you get that diagnosis of cancer. Your whole life changes immediately, right? So, you listen, but you don’t hear what’s going on, which is why you usually take someone. And then, you go to a CHEC-In and you find out what you need to know for support, what you should be asking.

So, that second follow-up visit—it’s a lot different when you go in. You’re looking at the doctor—perhaps you even had the chair by the door so the doctor can’t leave until you get through asking the questions. But now, it’s like, “Look. I want to be part of my care, and that’s not the best thing for me.” So, as we’re saying, the data count—the voice is important, and the support is here through the CHEC-Ins.

Janine Ntahirageza:

Yeah. And, absolutely, if I may add, sustainability is key as we go through these partnerships and we grow together—making sure that even the policies we come up with, we keep following up. Are they really working, right? So, going back to revisit. Do we have a system that’s in place so that we are constantly going back between the academic institutions and the communities and see that, well, the policies that we put in place are indeed working.

So, that’s really one of—again, another area that we have to keep our eyes on as we grow into this—using the CHEC-Ins to check, again, if we’re really working—if what we’re putting together is working.

Emma Tumilty:

Fantastic. I think, just re-emphasizing what you’ve said in terms of that sort of maintaining the relationships, using research to support policy, and that combination of policy in relationships to ensure sustainability long-term is the key to success with these things, I think. And I want to thank you very much for your time and giving us more detail around these projects. I think they’re so important. I think our audience will really love hearing from them, and I hope we get to hear more about that data maybe in the journal moving forward when you come back to tell us how it’s going. Thank you so much.

Janine Ntahirageza:

Good luck to you.

Henrietta Barcelo:

Thank you so much.

Editor’s Note: After wrapping up the interview, the conversation continued. Everyone on the call agreed to switch the recorder back on.

Emma Tumilty:

And as always the case when you switch off a recording, more golden nuggets come out of the conversation. So, we decided to switch the recorder back on just for a brief discussion of some of the barriers and challenges that this group faced while they were doing CHEC-Ins. If anybody wants to sort of kick off where we were going with this conversation . . .

Joanne Glenn:

So, let me just share a very common barrier—and again, a social determinants of health—it’s transportation, it’s literacy, and trust. So, when you talk about barriers to stop participation in clinical trials, stop compliance, people are counting pills, it’s trying to decide on what’s the best outcome on what I do. So, you have to have the trust factor and someone that checks in on you. “Did you take your medicine? I see you missed your lab appointment. What’s going on with you?”

And the whole family becomes involved because folks will not leave kids if they don’t have a babysitter. Folks will not eat the right food if they can’t afford. So, the barriers are many, and it’s our job, as community advocacy, to communicate what those barriers are and find the resources so we can all get the best outcomes.

Henrietta Barcelo:

From a different perspective, I think that one of the barriers is that institutions of health and education—you know, research driven, and that are serving communities in disparate areas—as well as those community organizations serving in whatever capacity the community, see the problem in terms of equity and access and services and resources not only for those who are documented or undocumented. I think that it’s really important for us to understand that we see the problem. We, the academics in the data that they create, and health care providers and community organizations see the same problem, but we approach it differently, right? And I think that the coming of the two minds is a challenge, to some extent, because we see one way of doing it and another way of doing it. And we’re speaking the same ideas, but a different language, and that’s part of the challenge that we have with this—is articulating this concept of the CHEC-Ins to academia, because they’re just like, “Wait. This doesn’t—no.”

And from my perspective, also, academia—I worked for University of Illinois Hospital clinics some time ago in the ’90s, and one other thing is that they’re full of minutia and it’s really hard, because like, this is such an easier way to do this and you gotta go through the different levels. But because of that, it’s really hard to affect policy and make changes for sustainability like that. So, one of the challenges is having community one one side saying, “This is how we see it should could be done” and academia’s thinking, “Well, no.” They’ve got centuries of how they do this and how it’s—and it’s really hard to make that paradigm shift, right?

[Others agree]

It really is.

Joanne Glenn:

You know, I would be remiss not to mention that cultural values and belief play a large part on barriers and challenges. It’s what you’re used to, what you see, and what the practice has been. So, again, education and communication is key in working towards that goal.

Janine Ntahirageza:

Yeah. If I may add—and I’d like to pick back on what Henrietta said about this relationship between—with academic institutions, our context here with the Chicago CHEC. We all are trained—we know what we’re doing in our fields. And then, here we are, we land with another group that we support—we are called to work with, to produce to get to outcomes. But then—so, we know these things, and they know these things, and so—and we think we know how to listen, but I don’t think we really do.

So, one of the challenges was to really listen. Stop. Can you turn off the things you kind of know and then listen. Go there and just listen. So, the listening part for me—and for many of us who went in—I mean, I thought I knew how to do participatory approach to research. I thought I knew it, because I’ve worked with refugees—African refugees for more than 20 years.

I thought I know how to listen. No. Until I really went with—I mean, I started working with CHEC-Ins and my colleagues here and all the other people who have participated in this endeavor—listening actually became a different—like, I’ve been defining and re-defining what listening is. And it’s been absolutely an amazing learning experience in all of it. But, again, knowing how to listen was a challenge.

Henrietta Barcelo:

It comes down, again, is what the CHEC-Ins are about. Academia and health care providers have the data. Community puts the face on the data, and it’s a partnership that, at Chicago CHEC, are trying to work together. It’s not business as usual. And when it does become business as usual, one of the challenges for sometimes community is to push back.

But with this relationship, we feel comfortable that we can, and feelings aren’t hurt or anything like it because we’re all professionals and we’re all trying to impact the health and equity for our communities.

Janine Ntahirageza:

Yeah. May I add just one more little thing? What these CHEC-Ins have allowed us to do is gel. We’ve gelled. We’ve come together.

I mean, I watch people work together today—it’s beautiful. People have gelled. There was—this, at the beginning, as expected, people were in their own silos knowing these things, but now, we have gelled. We know how to—what to expect, how to leave space for other people, and to communicate. So, it’s been wonderful. It’s been really a great journey.

Henrietta Barcelo:

But it’s not easy. It’s not easy for people to make those paradigm shifts, though.

Janine Ntahirageza:

I agree. No. It’s not easy.

Henrietta Barcelo:

It’s a work in progress.

Emma Tumilty:

Which is, I think, the best way to end, because this is the idea that multidisciplinary really extends beyond the walls of academia, right? There are expertise out in the community, and they can engage with academia through academia actually listening and recognizing that level of knowledge and skill that comes from the community as well, I think. Beautiful. Beautiful. *[Laughs]* We’ll leave it there, I think.

Thank you, again, so much for providing your knowledge and expertise and experience to our audience.