

The Rigor and Heart of the Matter: Transforming Health Through Community-Based Participatory Research

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[Intro] Stuck? Wish you knew more? Well, listen up. The information landscape is changing rapidly and the communicators of today want the latest and greatest insights for action at their fingertips. Listen Up! is a podcast series brought to you by the CDC Office of Communications. In this series we highlight hot topics with thought leaders, innovators, practitioners, and more. So, listen up and lean in as we share information to help you grow your knowledge base and improve your practice. And don't forget to tell your colleagues about us.

[Betsy Mitchell] Hi, I'm Dr. Betsy Mitchell. Welcome to this episode of Listen Up! Community engagement is at the heart of public health practice and is particularly critical to achieving health objectives. Participatory and inclusive approaches to the design and implementation of health interventions do many things. They foster trust and increase engagement among communities, they can build relational sustainability, and importantly, when community voices help shape priorities, it can make health more relevant to people. Giving community members a seat at the table is important, but today we're going to talk about making the community the head of the table. Here with me to discuss community leadership and research is Dr. Tabia Akintobi, professor and chair of the Department of Community Health and Preventive Medicine at Morehouse School of Medicine and Associate Dean for community engagement. She is a globally sought social behavioral scientist and public health practitioner, leading community driven translational research and programs contributing to the eradication of health disparities and advancing community and population health. She is extensively published and the co-author of texts, including *The Morehouse Model: How Schools of Medicine Revolutionized Community Engagement and Health Equity* and the 2nd and 3rd editions of the globally recognized *Principles of Community Engagement Primer*. We're also joined by LaShawn Hoffman, Managing Partner of Hoffman & Associates, a consultancy focused on smart community development, strategic neighborhood planning, community building, civic engagement and nonprofit management. Mr. Hoffman is a public health leader who advocates for safe, healthy, and economically viable communities and in 2010 he was elected chairperson of the Morehouse School of Medicine's Prevention Research Center Community Coalition Board. And last, welcome Dr. Rhonda Holliday, professor in the Departments of Community Health and Preventive Medicine and Psychiatry and Behavioral Sciences at Morehouse School of Medicine. Dr. Holliday has conducted research in South Africa and Swaziland and focuses on HIV and substance use prevention, minority health and community-based participatory research. She has served as the principal investigator for the Morehouse School of Medicine's Prevention Research centers, core research projects for over a decade, and is the community engagement core director for the Center for Translational Research and Health Disparities. Welcome everyone. Thank you for joining me today. Dr. Akintobi, if you would please share a little bit about the work of Morehouse School of Medicine's Prevention Research Center: what are you focused on?

[Tabia Henry Akintobi] Thank you so much for having us. So the Morehouse School of Medicine Prevention Research Center conducts interdisciplinary community driven prevention research in African American, Latinx and other minority communities of color, across the state of Georgia. We also function to train minority community-based researchers and public health practitioners. Most importantly, I think

we demonstrate the value of community coalitions in conducting research. So I'd like to say that is with, for, and led by the community. That I think in a nutshell, sums up the work of the Prevention Research Center at Morehouse School of Medicine.

[Betsy Mitchell] And building from there, what is community-based participatory research and importantly, how can practitioners go beyond principles to practice?

[Tabia Henry Akintobi] Thank you so much, I love that. Community-based participatory research really emphasizes the development, deployment and most importantly, the sustainability of community academic partnerships, that share leadership in planning, implementing, evaluating, and disseminating or telling the story of innovative, culturally appropriate, and evidence-based interventions that enhance the translation of research in ways that matter to the community. So stated differently, this is not just research that is about the community, but it really is about ensuring that the dynamics in partnership between community groups and the academy, that there is equity in that process. So CBPR is not just community-based research, but it really is a focus on the partnerships that need to be equitable in order for that research to be meaningful and to matter.

[Betsy Mitchell] LaShawn, I opened our discussion by suggesting that inclusive approaches can represent a shift in power structures with the community in leadership roles versus researchers, for example. Can you describe the importance of the Community Coalition Board for your center and more broadly community governance in your efforts?

[LaShawn M. Hoffman] Thanks, Betsy, and thank you for having me today. I want to share a little bit about kind of how I believe the work of the Community Coalition Board transforms kind of the work at the Prevention Research Center. We are a community majority and so most of the seats on the Community Coalition Board are held by community members. But also there are academic partners and other agency partners that are essential to the work that we do. I think what's really important is that, you know, I think about my own journey to joining the Community Coalition Board and that is I was not a practitioner at the time when I joined the Community Coalition Board. I was just a community leader in the space of community development. And so most of the community members that are represented on the board really care about their communities and care about the people in their communities. And so what makes us a bit unique is that our board is disease-agnostic in the way that we are formed, but also what makes us, I think a little bit unique is that our board is not an advisory board, it's a governance board. It helps to set policy. And I think that that change in dynamic, that change in power dynamics is really hard for some academic partners when thinking about, and researchers when thinking about how to move from principles to practice for community-based participatory research. Giving up power isn't, it's a huge issue, right? It's, I mean, no one really wants to cede power, but in this instance I don't look at it as ceding power. I really look at it as you know, the work that happens at Morehouse School of Medicine PRC is to better our communities and better the people that live within our communities so this notion around having a board that's led by community where the majority of the seats are held by community, so community is never voted out, right, it's always has the majority really helps I think to ground the work that happens when we think about the various interventions that are deployed from the Prevention Research Center. And so yeah, that's I think that that's kind of what makes our board a little unique, but also you know, allows us to really kind of grow our own knowledge around what does health interventions look like? How do they actually transform the people in the communities in which we live, work and play? And how we become community scientists, right, and helping to forward this opportunity to say that, you know, we all want to live in communities where people are well, there are great amenities that people like to brag on. And so I that's the work of the Community Coalition Board.

[Betsy Mitchell] I really like what you just shared this idea of community scientists, and it sounds like you're building, you know common values, building that shared vision in this process. You've referred to this approach as where people in place come together to plan, implement and evaluate and disseminate research that matters. Take us through how this actually happens, what are the steps?

[LaShawn M. Hoffman] I'll do that, but I do want to simply say that, you know, Tabia started off by saying, you know, this was about training practitioners, right? That's part of the work of the Prevention Research Center and we are practitioners, right? Ultimately, all of the interventions that happen within the Prevention Research Center is to better community. So that's why we become community scientists. I think, when I think about how we do this, there's one of the standing committees of the Community Coalition Board, which is the Project Review Committee, and that committee really reviews all of the projects, proposed, anticipated, that come before the Community Coalition Board for support and approval. Also, this is an opportunity where scientists, practitioners can come and say we want to do community-based participatory research with you. We are not quite sure kind of how that translates and looks like on the ground and Community Coalition Board members are able to work with those investigators and helping to craft their interventions to ensure that there's a community benefit, right and that it meets what we believe are our priorities, our research priorities, our evaluation measures, as well as our community values. And then there's also so that happens kind of in the front end, right, although that work happens. And the proposal is submitted and then normally what happens, projects are then funded. And then researchers go away, and what we've started to do is to say, well, how do we continue to kind of be engaged and to ensure that these research projects are successful and that the principal investigator continues to be committed to the community values and working with the Community Coalition Board and so in our latter years, we've created what we now call our Community Engaged Research Committees that are now formed with both members of the Community Coalition Board and other outside experts, depending upon kind of what the intervention focus is to work with the principal investigator, kind of like a community IRB right in a sense of saying, how do we now work with you to move towards implementation, to dissemination, to publication and allow this Community Engaged Research Committee or the CERC committee be a thought partner with the principal investigator and where the PI can really kind of think about you know, I'm, I'm dealing with this issue. There are people on the CERC committee that might be able to, you know, either open doors, provide access or just, you know, think about, help them to think about something a bit more differently that the PI may not have thought about before. And so, it's another great way to ensure that community members are not just at the table, but this table is one that's large enough that we can do power sharing instead of the power dynamics that normally exist that the researcher knows what's right, and community just comes along for the ride and kind of advises in that role. And so those are a couple of ways in how the Community Coalition Board kind of works in tandem to support the work that comes out of the Prevention Research Center.

[Betsy Mitchell] And you've described community-based participatory research as hard and heart work. What did you mean by that?

[LaShawn M. Hoffman] I'll share with you, that's actually Tabia's theme, but she's my partner in good, so I'm happy to own that and would invite her to kind of jump in and share. But I'll give you my version of hard and heart. I mean, this isn't work that comes very easy, right? We're really thinking about how do you get people to change their lifestyles, change their habits, right? Some of the habits that they've had almost all of their lives to really think about new approaches and how do you do it from this perspective that really says and we hear you and we want to be partners with you and we want you to be well, right? And so that's where the heart work comes. But Tabia you, you kind of coined this and so I look for us for you to be able to share a little bit about kind of what do you mean by heart and hard. I just became, I just started asking questions. Right, Betsy, that's not my role.

[Tabia Henry Akintobi] No, we are absolutely partners in this. So, you know the heart work I think is because you know CBPR is not just about the outcomes of research that is rigorous, but it is equally, if not more concerned with the people and the partnerships that are required for CBPR to be successful. So that means we have to attend to the relationships we have to attend to the partnership just like any other relationship we care about. We have to understand the needs of the partner, what they value and feed that. So they stay in partnership with that. You know, really that applies to any relationship that you have. So that's the heart part of it. The hard work and welcome hard work is that you know, frequently CBPR or community-engaged research is considered on this continuum of no community involvement all the way to CBPR or community-driven or community-led research. We are very clear that the hard part of this is addressing the equity indicators, those issues that LaShawn brought up, power and control, ownership, decision making, responsibility, influence, resource sharing. Those are equity indicators, but then there are also contextual factors like the history in the community, their level of trust or not with the academy, respect and transparency. So this work, it involves not just checking off boxes, but understanding those equity and contextual factors, Betsy, that really can be the determinants of whether CBPR happens well, or not, it's a welcome complex reality. But we've proven through our center that it is possible and has outcomes that benefit all of us.

[LaShawn M. Hoffman] Betsy, I would just, I would just simply add that you know, I think most of the time we think that if we share with truth, we start with truth, right, that people will get it. But I think when I think about this heart and hard work, right? It's about trust. It's continuing to build trust. And if we start with trust, then we can get to what it whatever the truth is, right, to help them move the intervention forward. So I just wanted to throw that in.

[Betsy Mitchell] You were reading my mind. I was just going to share that it really does feel like it will lead to trust within communities as well, which is so important. Dr. Holliday, would you like to add here?

[Rhonda Holliday] Sure. First, thank you for having us today, Betsy. So as a principal investigator on the Core Research Project for PRC for the last 10 plus years, one of the things that I think that is really important, and I think LaShawn alluded to this, is really for the researcher to have humility. It takes a certain level of humility to come into a community and listen to the community and listen to the community's needs. Sometimes as academics and as researchers, we want to come in and assert what we know, what we know how to do. And we have to take a step back and really listen to the community. This happened to us, I think in our last core research project where we had a really great idea to do HIV prevention work among adolescents and we brought the idea to the Community Coalition Board. And the Community Coalition Board, they were very adamant about adding another element to that project. And so it took us to really sit there and listen to them and talk through it and figure out how we can make this work as a research project. And I think that for some academicians, that can be kind of hard to do. And so having that level of humility, I think, leads into that trust when you genuinely listen to the community.

[Betsy Mitchell] And continuing on, what are some of the barriers or pain points to practice that you've experienced, Dr. Holliday, and how have you overcome them?

[Rhonda Holliday] So one of the pain points is, you will write a grant proposal in one year and say maybe six or so months later the grant proposal is funded. Sometimes it can take longer than that. And in between that time, there can be a lot of changes with your community partners. And so once you get the grant funded, then you have to come back and sort of reintroduce yourself, reintroduce the project. But you may also be dealing with new people who have different priorities for their organization or different priorities for their community. And so figuring out how to navigate those changes that happen in the

interim can be really challenging. One of the ways that I think that we've successfully overcome that is because our Community Coalition Board is so involved. We have that network of community partners, we have people on our Community Coalition Board who can come in and intervene when necessary and provide some additional guidance. Sometimes if a partnership does not work out, they can suggest other partnerships. And so it's really been, I think our Community Coalition Board has really been invaluable. And as LaShawn mentioned, we have our CERC committees which provide that guidance for the research project throughout the life of the research project. And I found that those CERC committees have been a tremendous support in terms of the work that we're doing, and particularly if we run into any challenges in the community. which often happens with community-based participatory research. Things don't go as quickly as you may like for them to go. Partners may come and go. But that CERC committee is really there for the researcher to bounce ideas off of, to talk about what's going well, what's not quite working well, and then how do we overcome those challenges. So having that circle, that constant circle of guidance, I think is really important when you're doing community-based participatory research.

[Betsy Mitchell] And I imagine there are many successes that you've observed. What are some key moments that you'd like to reflect on?

[Rhonda Holliday] Yeah, so I think one of the key successes that we had was, again, going back to our project that dealt with adolescents and HIV prevention. You know, we were running into some challenges in dealing with our local school system. And we were able to pivot and think of a new way to engage some of the students in the schools. And we wouldn't have been able to do, I don't think we would have been able to do that without the Community Coalition Board or without our CERC committee and because of their involvement in the project and their guidance on the project we were able to do our recruitment with some of the schools within the school system. That example there to me just speaks volumes about the level of influence that the community can have in ways that they can connect researchers to other resources and connect researchers to other people who can help advance the research which ultimately will help advance knowledge.

[Betsy Mitchell] Dr. Akintobi or LaShawn, are there any other successes that you'd like to mention?

[Tabia Henry Akintobi] Yes, I think, what Dr. Holliday shared is so important. She ended with the importance of advancing how community resources can support research and how those connections can advance knowledge for the research. And I think we've witnessed how, you know, the reverse is also true, and that is that the collaborations that we have really just facilitated have resulted in resources to the agendas and organizations of community leaders. And so, you know, ideally CBPR plus or beyond means that there are resources from those projects that go to the community in ways that advance their agendas separate and apart from their relationships with an academic institution like Morehouse School of Medicine. You know, LaShawn talked earlier about the fact that we are all really practitioners in our joint vision of wanting to support healthy communities that do well. And I think the ways that we've collaborated such that community-based organizations and leaders like LaShawn and others are multiple investigators in research projects and other initiatives also is a way that we're advancing equity, demonstrating that the community-based organization can have and should have as much power and leadership in the eyes of the funder. That respect, I think, is important. They have the community wisdom that coupled with academic wisdom can be more than the sum of its parts. So that respect and that power sharing, I think, are also great examples of the work that we've really facilitated as well.

[LaShawn M. Hoffman] Betsy, I also think that one of the outcomes of this is that it becomes our collective research, right? It's owned. I think every researcher wants their research to be owned by community, right? So we think about what's that sustainability plan, right? How does this work continue

to evolve after the funding goes away? And I think in these instances that we've been able to share, we've seen some of the fruit of that kind of labor through the investment of community members and PIs or the principal investigators or the researchers working in tandem, right? That this becomes our collective research. There's this sense of ownership that's by, that community says that this is our research. So when there is an issue, right? Or when there is something that comes up, this is what we've been able to do. I mean, I'm still having conversations from past projects where community member says, where's our project regarding A, B, and C, right? And it's like, that's really great when they feel as if, you know, there's some ownership in that, right? And then they're holding us accountable, collectively accountable, those of us that are on the Community Coalition Board and those of us that are staff members of the Prevention Research Center at Morehouse School of Medicine. And so...

[Betsy Mitchell] It's heart work for them too.

[LaShawn M. Hoffman] It is, it is because I mean, it's building trust, right? And so ultimately, I just want to say that I think that that ownership of the intervention and the research itself by community is a huge success that we've experienced in many of our projects.

[Rhonda Holliday] So I think another success is really the opportunity for our community members to participate in dissemination. We've had community members that have been part of publications, also presenting at conferences with us, but then they've also become really sort of important to the institution itself. So participating in strategic planning for the institution. And all of that really helps to sustain the relationships that we have with our community members, with our Community Coalition Board, and I think one of the things that we do here in PRC that I think we're really cognizant of is identifying opportunities for our community to participate in other things such as leading research projects or being part of a panel at a conference. And so we provide, we are able to uplift their work, recommend them for different activities and continue to infuse that, have them be part of larger conversations within the institution and across the nation.

[Betsy Mitchell] As you're speaking, I'm thinking about how wholly honoring these approaches are; honoring of the perspective and participation and just very honoring. So to close, I'd love for each of you to share a little bit about some key takeaways that you would want public health practitioners to know about community-based participatory research so that they can feel inspired to apply what you've talked about today.

[Tabia Henry Akintobi] Betsy, thank you again for this opportunity to share a bit of what we've learned with all of its highlights and its lowlights. So we, you know, even though we've come a long way, we are still in the learning part of our legacy. So, I would say that CBPR is not complete without a plan to really advance equitable partnerships. Feeding, supporting, and understanding the partnerships are a determinant of how successful CBPR will be. A history of and a current position of community leadership that values the pursuit of trustworthiness, I think, is important. So we talk a lot about trust, as really a destination. You want someone to trust you, but it is those behaviors of trustworthiness, valuing, sharing, letting go of control, realizing like I did that I had never been to the DC Hill to advocate for anything until I met LaShawn, who knew how to do that. And because we partnered together, that experience of learning for me was more valuable than it would have been if I had done that on my own. The other final things I would say is that community leaders have to be co-creators of the research from the idea all the way to telling the story together, whether it's in a scholarly journal or on a podcast like this one. All of that builds what we like to say with some of our partners, a learning value, a legacy value that makes all of our work important after we're done with this work. And it legitimizes CBPR when community leaders are not just supporting recruitment and retention. That is not what this is. This is about partnership together where all

wisdom, Betsy, as you shared, is considered sacred. And finally, communication and dissemination are essential and important. We gotta tell the story and the stories cannot be to the academy. They need to be to the broader global community that needs to know, not just what worked well, what those challenges were so that those coming with us, behind us, and next can know how to do it even better than we did.

[Betsy Mitchell] LaShawn your thoughts?

[LaShawn M. Hoffman] I think what I will share is that you know, the model that we use has worked for us, but we're really clear that we've been able to adopt this model or have an adaptation of this model to be used in several settings, both locally, regionally, and even at a national level of how the Community Coalition Board works. And that part to me is, I think, really exciting, where every project or every researcher may not be looking to do all of the community-based participatory research and its principles, but really want to think about how do they start doing community-engaged research, that our model can be adapted. And I think that that's what's really exciting about this. And that for us, we're continuously in this iterative process, refining what that process and how the Community Coalition Board works, right? So there's some standards that we've set, but we're also piloting and challenging, right? So we started with the Project Review Committee as one of our standing committees and we piloted what the CERC committee could look like, right, and refined it a bit more and then said, we need to implement this a bit more in all of our projects. And now it's become kind of part of our standard operating procedure that when there is a grant that's funded, that we would implement a community-engaged research committee or CERC committee to work post the funding opportunity because we've seen the success of that. And so I think, you know, if there was a... my major key takeaway is that this is attainable, that our model is adaptable, but there's various adaptations to ensure that community-engaged research is a doable thing in all research practices. And this isn't just in the social sciences, but this can also be in the bench sciences as well.

[Betsy Mitchell] And Dr. Holliday, you get the final word, your takeaways.

[Rhonda Holliday] Well, great. I like having the final word. No, really. My take, as someone, so I wasn't trained in community-based participatory research. And one of the things that through my years of engaging in this work, I think it has made me a better researcher because I am really taking into account what is it that the community wants? What is it that the community needs? And just listening to the community. So, I think it just makes you that much more of, I think it enhances the research that you do. It makes you think about how you're going to communicate what you're doing to other people. How are you going to communicate that to people who are not in the academy? So I think as a researcher, it just sort of takes your research up another notch. And the last thing that I want to say is that this work, the heart and hard work, it takes patience, and it takes time. You have to build those relationships. You have to establish that trust. It is not something that is quick and overnight, but it takes time. But the reward is well worth the effort that you put in.

[Betsy Mitchell] Well, terrific insights. Thank you all so much for sharing your expertise with me today. I learned so much and I know our listeners will really enjoy this learning as well. Thank you. Thank you.

[Tabia Henry Akintobi] Betsy, thank you so much for having us. It was it was our pleasure.

[Rhonda Holliday] Thank you.

[LaShawn M. Hoffman] Betsy. I want to say thanks and it's always great to be able to share our work and the work that we do at Morehouse School of Medicine Prevention Research Center.

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