Podcast Interview Transcript

Vida Henderson, Claudia Guajardo, and Gloria Palmisano

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. The associate editors who handled the articles conduct our Beyond the Manuscript interviews. This edition of Beyond the Manuscript features Vida Henderson, Claudia Guajardo, and Gloria Palmisano authors and community partners of "Community-Based Participatory Research and User-Centered Design in a Diabetes Medication Information and Decision Tool," and Associate Editor Shonali Saha.

Shonali Saha:	Thank you so much for agreeing to speak with us today. To start, can you provide a brief summary of how your project, including its purpose and any results you've found—if you could provide a brief summary so everybody who's listening could be oriented to the project?
Vida Henderson:	Our aim was to develop an interactive tailored web-based version of two [Agency for Healthcare Research and Quality] AHRQ consumer guides that focus on diabetes medication, and to compare the effectiveness of the web-based tool that we developed versus the AHRQ printed paper-based consumer guide.
	We called the tool iDecide/Decido, and it was designed specifically for African-Americans and Latinos in Detroit, who have poorly controlled type 2 diabetes. Basically, the goal of the program is to provide information on the pathology and complications of diabetes, to describe how different diabetes medications work, to give the participants opportunity to learn about and discuss other treatment options that they may not be aware of, and also to discuss their barriers when it comes to taking their diabetes medications as well as to set goals for their future.
	In developing the tool, we utilized the principles of community-based participatory research [CBPR] and user-centered design [UCD]. The tool is administered in the participants' homes or their place of preference with a community health worker on an iPad. The program has really great features like 3D animations, risk pictographs, and interactive issue cards. It's also tailored. Claudia, who is our community helper, has used it in the field.
Claudia Guajardo:	I enjoyed working with both groups because it was really amazing to see differences in how it was received. I can say that the participants who were in the control group weren't really aware of what they were missing compared with the intervention group, but the actual consumer guides were a great help in seeing the differences in medications, and they were glad to keep it with them, you know, something they can share with other people who are going through the same thing that they are.

Claudia Guajardo:

The participants who were in the intervention group were fascinated by the program. They loved the tool. Most didn't actually want to handle the tool themselves, but they loved the animations and seeing what's going on inside their bodies. There's nothing else that can compare with that. They were also really receptive to learning new ways to communicate with their doctors, you know, letting them know, "Well, I've learned this about medication," and they felt more comfortable with speaking with their doctors afterward about any changes or any questions that they had.

Shonali Saha:

Your partnership goes beyond the traditional CBPR model of health researchers partnering with community members to also include communication and technology experts. Can you tell us more about how that partnership was formed?

Gloria Palmisano:

I'm going to talk a little bit of how REACH was formed and then just briefly a little bit about our work and how that came to lead us to the collaboration with CHCR. The REACH Detroit Partnership, which is a community project of CHASS Center, which is a federally qualified health center, so the partnership arose from a core of members of the Detroit Community Academic Urban Research Center that had been using community-based participatory researches approach to identify and plan to address health disparities in southwest and east side of Detroit since 1995.

In 1999, REACH Detroit became a Partnership, and members of REACH Detroit consist of representatives from community-based organizations, health systems, state and local health departments, diabetes-related organizations, and the University of Michigan's Schools of Medicines, Social Work, and Public Health. With a planning grant from the CDC [U.S. Centers for Disease Control and Prevention], which was funded through the Racial and Ethnic Approaches to Community Health 2010 Initiative, the REACH steering committee developed a community action plan that was funded by CDC from 2000 to 2008. The aim of the partnership was to eliminate disparities in type 2 diabetes among people from southwest Detroit, African Americans, and Latinos.

Our community action plan directly responded to the issues and strategies outlined by community residents, so out interventions were multifaceted and linked. We had a help system intervention, family and social support groups, and community-level interventions, so the CHWs [community health workers] were central to each of those interventions. As we implemented our interventions, we gathered data and feedback from participants as well as other stakeholders that provided us with various avenues for further research and ways to enhance the work of the community health workers because our CHWs are so effective in working with our participants.

One of the areas of our intervention that we wanted to enhance and expand on was the delivery of our diabetes education by CHWs. We also learned that patients were challenged in understanding the role of diabetes medication, in managing diabetes, and the various treatment options that were available to them. So Dr. Michele Heisler, who's been a REACH Detroit research partner since 2000, was aware that we were all thinking about tools to enhance the work of the community health workers, so Dr. Heisler began having discussions with one of her colleagues, and that was Dr. Larry An from the Center for

Health Communications Research, who teaches on ways to improve health communications through computer applications. They were talking about whether the work that Dr. An and the Center for Health Communications Research does with interactive tailored web-based tools might enhance CHASS's community health workers, diabetes education, and outreach.

So Dr. Heisler facilitated that first meeting between the REACH Detroit steering committee and Dr. An and his group, and at this meeting everyone started to learn about each other and what their research priorities were, and they agreed to partner using a CBPR approach. But based on Dr. Heisler's recommendations and experience in working with Dr. An, this really opened the door for the partnership. Dr. An's expertise and those of his team allowed the partnership to investigate the use of technology in CHWs delivering health education to patients, which was one of the areas that we wanted to explore; and then at various intervals, the steering committee meets with the CHCR group to get updates on the progress of the intervention. So that's how we joined forces and developed the iDecide/Decido tool.

Shonali Saha: And what were the approaches taken by the partnership to make sure that all partners' viewpoints were heard and taken into consideration during the development of the iDecide/Decido tool?

Claudia Guajardo: Our partnership's working style was collaborative, and even though we had people with many different educational backgrounds and degrees, and some without, we all gave our input and expertise regarding what we know, and we were equal at the table. We, the community health workers, were asked directly about the needs in the community according to our previous experiences with the Latino and African-American populations, and here at CHASS we received the drafts of materials and content via email.

We had weekly meetings with the research assistants as we went over the revisions word-by-word and we came to a consensus on the content that we wanted to use. The RAs [research assistants] then returned our notes and revisions to the content developers, and we also met with all the team members on a monthly basis where we were able to go over the progress and give our suggestions.

Shonali Saha: And what are the next steps now being taken now that this interactive, tailored-for-diabetes, health information technology has been developed?

Vida Henderson: I know that Dr. Heisler, who's the PI [principal investigator], she's currently working to adapt the tool Veterans Administration settings in Ann Arbor and Detroit. That's one of the things that I know is definitely in the works, so it's definitely starting to have branches.

Gloria Palmisano: CHASS is currently in the process of integrating our community health workers into its health care team, so the CHWs' role will be that of health coaches, and the iDecide/Decido tool will continue to be used by the CHWs as they work with patients with diabetes. Also the tool will be used by CHASS nursing staff as they work with those patients whose diabetes is way out of control.

Shonali Saha:	And can you describe in more detail the theory that influenced the development of the intervention itself? Can you talk a little bit more about what is user-centered design and why you decided to apply it to CBPR model of research?
Vida Henderson:	User-centered design is really a term associated with software design. It's also called human-centered design, and it is an approach in designing a software interface or, as you say, how users interact with a program, based on information about the people who actually will use the product or the program. So user-centered design focuses on the needs of the users throughout the planning, design development, and implementation of the product, so it focuses on what the users' needs, wants, and abilities are.
	This is initially how we visualized we would create the tool, and you can see how it's very much related to the principles that guide a CBPR approach. So they have many tenets and comments, which is being centered on the user, our community that the program or the tool is being designed for, the equitable partnership in all phases of the project. The development is an iterative where there are multiple revisions done based on feedback from all of the partners, and really everyone—researchers, community partners, and the community members—we all learn from the experience.
	One of the important pieces of this is that it shows that high-tech, web-based programs can be developed successfully using CBPR. These would be approaches that can be used in health information technology to narrow the health disparities, it narrows that digital divide that we all have heard about. I'm really proud of what we did and how we did it, and I think the tool is so much better and more effective than it would have been if it weren't developed so collaboratively utilizing these principles.
Shonali Saha	Where do you see opportunities for CBPR partnerships to possibly involve technology in the way that your study did?
Vida Henderson:	I think this is why this is so innovative. It shows that health information technology does not have to be this big complex thing that community members, community partners, and researchers have to shy away from, so there are definitely opportunities for people to bridge that gap between technology and community-based work. I think that what we've done kind of lays a map, sort of, in doing that and doing it effectively, and as I said before and as Gloria mentioned, we're adopting it and adapting the program to be used in wider venues, you know, it could also be used not only with diabetes but in cardiovascular disease and a number of different health conditions.
Gloria Palmisano:	I would also like to add that CHASS being part of the Detroit Urban Academic Research Center, there's a number of projects all of which use CBPR, and more and more are going into the use of technology to enhance the work that we're doing and working directly with people from the community and a lot around education. As Vida said, I see this as kind of like a roadmap on how others can do this work.
Shonali Saha:	Just to piggyback on your last comment, Gloria, can you tell us maybe specifically some of the ways in which the partnership is using technology aside from the iPad tool that you all developed?

Gloria Palmisano:	I think the iDecide/Decido tool kit is probably the most advanced on what other folks are doing. What I'm really saying is that there is discussion from other groups on how to—we're already moving in that direction, starting to use some of the social media to reach out to folks. So I just see that as there could be more opportunities to do that. I don't have any other, other than the work we've done but I just know that there's other people moving in that direction to use technology more and using a CBPR approach in the development of any interventions that use the technology.
Shonali Saha	In closing, I don't know if any of you have any additional comments or thoughts that you may have that we didn't get to talk about so far?
Gloria Palmisano:	I think that training was very important not only important on the use of the tool itself but the training that the community health workers had that contributed to the success of delivering this intervention, so coming with empowerment theory, motivational interviewing techniques, just foundation of community health worker, what it is to interact with folks and get them to participate in these research endeavors I think was really important. There is more training that's involved other than just training on a tool itself.