

## Podcast Interview Transcript

Crystal Wiley, Jennifer Hatcher, and Katie Dollarhide

In each volume of *Progress in Community Health Partnerships: Research, Education, and Action*, the editors select one article for our Beyond the Manuscript podcast interview with the authors. Beyond the Manuscript provides authors with the opportunity to tell listeners what they would want to know about the project beyond what went into the final manuscript. Beyond the Manuscript podcasts are available for download on the journal's website ([www.press-dev.jhu.edu/journals/progress\\_in\\_community\\_health\\_partnerships/multimedia.html](http://www.press-dev.jhu.edu/journals/progress_in_community_health_partnerships/multimedia.html)). This Beyond the Manuscript podcast is with Jennifer Hatcher of the University of Kentucky, College of Nursing, and lead author of "Human Subjects Protection Training for Community Workers: An Example From "Faith Moves Mountains" and Katie Dollarhide, Project Manager for the University of Kentucky's Faith Moves Mountains, a cervical cancer intervention project. Dr. Crystal Wiley, an Editorial Fellow at The Johns Hopkins University School of Medicine, conducted the interview. The following is an edited transcript of the Beyond the Manuscript podcast.

*Crystal Wiley:* This project is entitled *Human Subjects Protection Training for Community Workers: An Example From Faith Moves Mountains*. The rationale for this study was to determine the best approach to training community workers who are involved in community-based participatory research (CBPR) projects.

I think that what you all found was that there was not much literature in the setting of CBPR on who should receive training, and what type of training should be offered. Also, there are some real-life concerns for community members in how to meet official requirements of institutions for human subjects training.

So the objectives of this study were really to develop a training package tailored to community members on protecting human subjects. What you all did was to develop a training module, which consisted of an educational module that was presented in a 1-day session, which included a PowerPoint presentation, as well as written materials for the community workers. Is that correct? Have I left out anything that you want to add?

*Jennifer Hatcher:* No. That's it.

*Crystal Wiley:* Okay.

*Jennifer Hatcher:* Katie?

*Katie Dollarhide:* No, that sounds right.

*Crystal Wiley:* Okay. Great. The only other thing I'll say is that, in order to get your results, what you did at the end of the presentation was to give each worker a written test, to evaluate the knowledge of the content that you presented.

So each of the workers were given the test, and those were scored. It sounds like you received positive feedback from all those who participated, as well as a 100% pass rate.

*Jennifer Hatcher:* Yes. So good, so far.

- Crystal Wiley:* This interview will be divided into questions directed at the origin of the project, the partnership aspect, the design and implementation of the project, and the impact and dissemination. We will start talking about the impetus for developing this training program. So can you tell me a little bit more about what led you all to develop this program?
- Jennifer Hatcher:* We developed this program in response to Katie and Sherry, who are our project staff. Katie's the project manager who took the more cumbersome human subject training that we all take as academicians. We take a CITI, or a Dunn and Chadwick. They took the same one that we take.
- They found that it was complex, and that it might have been a bit broad for community workers to take, encompassing things that they might not need to know about necessarily.
- Katie and Sherry expressed concerns about people—our lay health workers taking the same test and being intimidated by it, it being at such a high literacy level and, talking about things that they may not need to know.
- So that got us to thinking that we might need a human subjects protection module that was a bit more focused on the things that they needed to know, and that was more readable, and at a level that any community worker could certainly understand.
- Crystal Wiley:* It sounds like this program was initiated from the participants, specifically your project managers. Did your Office of Research Integrity have anything to do with the design of the project?
- Jennifer Hatcher:* The Office of Research Integrity, didn't give us the idea but I called them with the idea that we had non-key personnel that we wanted to train. I asked what were their parameters for training them? They led me to the website, so that we could base what we did on the CITI, or other things that were out there.
- They really did not participate in designing it. We had a protocol, which we included with our manuscript, that after we developed it, we sent to our Office of Research Integrity. We did call them during the process, to be sure we were on the right track.
- Crystal Wiley:* In your manuscript, you mention that in designing the educational or training modules, you drew heavily on the advice of others who were engaged in similar quests. Can you tell us a little more about who also may have helped you? How much of your input came from your community partners.
- Jennifer Hatcher:* The PI on the project, Dr. Schoenberg and I and others from other community-based projects—we brainstormed what would be the best way to attack this problem, even before we knew.
- It's kind of a general consensus that there's a problem training community workers for human subjects protection, because of the complexity and the breadth of things that we have to do for that. There's a general consensus that there's a problem. But there's no general agreement on the solution to the problem.
- Crystal Wiley:* Okay.
- Jennifer Hatcher:* So we kind of brainstormed with other people who were doing community research, some people in West Virginia, in Ohio—especially those doing rural community research such as what we were proposing to do. We talked to the people in our cancer network as well, to find out their ideas on training lay health workers or community workers to do human subjects protection. Have I covered that, Katie? Did we talk to anyone else?

- Katie Dollarhide:* I think you covered it well. I think that just as a staff and as a project, we talked about the need for getting to the principals with the right kind of language, without so much jargon.
- Jennifer Hatcher:* We also went to the literature, and looked to see what other people in this area were doing to train people in the community who didn't need, maybe, to get informed consent or some other things, but did need to know some things about human protection.
- Crystal Wiley:* In your literature search, did you come across any other training tools used by others? Or to your knowledge, is this the first type of tool that's being used?
- Jennifer Hatcher:* If people are using them, they certainly have not put them out there. We did not come across any real tool. Of course, people are probably doing it, and tailoring it very specifically to the group in their community, but we did not come across any examples.
- Crystal Wiley:* I want to move now to talking about aspects of your partnership with the community. You had three different groups of community members who were working on this project. They were interviewers who took part in collecting the data, lay health workers who delivered your educational program, and project management staff who were responsible for the overall supervision, and who served as the main links between the university and the community.
- It sounds like you also worked with your Office of Research Integrity. So I guess I'll start directing this question to you, Katie, about how, specifically, you were involved in the project?
- Katie Dollarhide:* I think it is pretty much as Jennifer laid it out. The staff here in Letcher County—Sherry and I—took the Dunn and Chadwick test. We talked to Jennifer and Nancy about how we didn't see that it was something that was necessarily appropriate for what we were doing with this project, and with the people that we were going to be working with. That's how we started and how we kind of worked in this process.
- Crystal Wiley:* Were you one of the project managers?
- Katie Dollarhide:* Yes.
- Crystal Wiley:* There were two project managers.
- Katie Dollarhide:* Well, there's a project manager and an assistant.
- Crystal Wiley:* What roles did the other community partners play?
- Katie Dollarhide:* At the time, we had not gotten our lay health workers. So they didn't play a role, other than—we knew that they were going to be coming from the community. We know what types of people we were going to be working with. So the role they played was: We knew we had to tailor it, so that it would be for them.
- Crystal Wiley:* Jennifer, do you have anything to add?
- Jennifer Hatcher:* We're very familiar—and Katie, especially, is very familiar with the women who she knew that she would be hiring to be lay health workers. Her knowledge of these women helped us to design the educational module.
- Once it was designed, we piloted it with Katie and Sherry, who are community members. They live in the community where we got the lay health workers, where we recruited those women. We

piloted it to see if it was readable, understandable, comprehensive, and applicable to women in that community.

*Crystal Wiley:*

Okay.

*Katie Dollarhide:*

And enough to make sure that we're getting the point across of what needs to be done with the human studies.

*Crystal Wiley:*

What incentives, if any, did you, Katie as a project manager—and other community members receive for participating in the project? What do you think people's motivations were to participate?

*Katie Dollarhide:*

In this human studies project?

*Crystal Wiley:*

Yes. And just becoming involved in the project overall. As you know, community members are very busy, and they have lots of other things going on. I'm trying to establish for our listeners what you think was the biggest draw for community members to participate in this project.

*Katie Dollarhide:*

I think the biggest draw is that there is a recognizable problem of cervical cancer being overwhelmingly high in this area, and that people, when we know that there is something like that wrong—people are more than willing to step up and try to address the problem. I think the motivation is definitely to get the information out, so that people are aware that women in Appalachia are at higher risk. And what are the reasons for that? And how can we help to get around those barriers? I think that's the biggest motivation.

*Jennifer Hatcher:*

I believe that the women of this community—as gatekeepers, they sense that cervical cancer is a threat to their community. They are all very willing to participate in the project overall. In terms of the human subjects protection trainingspecifically, I think Katie and Sherry were very motivated to make it on a level where we could deliver the needed information in an understandable manner, so that we could really be sure we got the lay health workers involved and onboard. So that it wasn't so intimidating, that we couldn't get the community on board to participate.

*Katie Dollarhide:*

Yeah. It wasn't so overwhelming right from the start that it turned you away.

*Crystal Wiley:*

You used case scenarios as part of your assessment of the community workers. In these scenarios, I thought that they were very plausible and very pertinent to situations that community members working on this project may actually encounter. How did you actually come up with the case scenarios?

*Jennifer Hatcher:*

Well the case scenarios, I developed from conversations with Katie and Sherry, and conversations about the women—and with the women that we were anticipating hiring as lay health workers. And coming to know about their everyday lives and how the community functions, I was able to come up with scenarios that we hoped would be based on what they really might encounter, rather than a textbook version of something.

These, we hoped, were things that they—questions that they might really have, and cases that they might encounter in their participation in the project. Just from being a part of the community closely, we were able to come up with what we hoped modeled that kind of thing.

*Crystal Wiley:*

Let me just clarify. At the time that you designed the project, did you already have the lay health workers and the interviewers on board? Or did you subsequently recruit these people after the project was designed?

- Jennifer Hatcher:* At the time we were developing this, we were in the process of interviewing ladies for lay health workers. The overall project had already begun. And Katie and Sherry had taken the CITI or Dunn and Chadwick things that they took.
- We were in discussions about what kind of ladies would be appropriate for lay health advisors, and how we were going to hire these ladies. So we had some idea of who they would be. The module was designed before those ladies were hired, is this correct, Katie?
- Katie Dollarhide:* Right. At the same time.
- Jennifer Hatcher:* But it could have been simultaneous. It could have been occurring at the same time. It was completely finished before they were hired.
- Katie Dollarhide:* It was both. Actually, we had interviewers who were ready to take the test and become interviewers. But we had not actually hired any of the lay health advisors yet.
- Katie Dollarhide:* It was all working together.
- Jennifer Hatcher:* That's correct. The interviewers were hired. The others had not begun to work, because we didn't have this module completed.
- Crystal Wiley:* Were the interviewers at all involved in coming up with the scenarios?
- Jennifer Hatcher:* They were involved, in the fact that we knew who they were, and what their lives were like, and what they might encounter. We could not involve them in the making of the test, because they had to take the test. We used our knowledge of them to build the test.
- Crystal Wiley:* To build the test.
- Jennifer Hatcher:* We couldn't have them participate so much in making it. Because they needed to take it and pass it.
- Crystal Wiley:* What were your challenges in designing and implementing the training, from—Jennifer, your perspective on the academic side, and Katie, from your perspective as a community member who was actively involved in supervision of the project?
- Jennifer Hatcher:* From the academic side, it was certainly a challenge to try to wed the academic needs with the community needs, as it always is in community research. The rigor that the ORI, the Office of Research Integrity, would have us train people with—to try to put that on a community level, and keep the same content, but change it, so that it's understandable and applicable for the community, was definitely the biggest challenge.
- It took several tries to get it to the point where we thought that it was inclusive of everything that we needed, as well as met the standards that the ORI set for us—and the community would accept it, and be open to it.
- Katie Dollarhide:* I think that you could almost flip that for the community side—that we wanted to make sure, that we were getting only what we needed to have.
- Jennifer Hatcher:* It really is a challenge to meet those two needs, and put them at a place where everyone on both ends is satisfied.
- Katie Dollarhide:* You really do want to make sure that the people that we're working with know that this is important, that confidentiality is very important, and all of this is very important. I think that we did that.

- Crystal Wiley:* What do you see as the value of this work for your community?
- Jennifer Hatcher:* Well for the academic community, I see great value in it, in that as we said, when we looked in the literature, there were no examples of this kind of work. And I think although it needs to be tailored for each specific community need, that having a model to base that on, and having the knowledge that an Office of Research Integrity is willing to work with you, is certainly going to be helpful to other people who are embarking on this kind of community work, and need to train community workers.
- Katie Dollarhide:* I think that through the community work, again you're not turning anybody away with a book that is so thick that it scares them right from the beginning. You are getting them to become involved in the project because it is a worthwhile project. I think that those tie together. The community and academic tie together that way.
- Crystal Wiley:* Does your institution, or your ORI, have any plans to institutionalize the training module that you created? Or do you see others at your institution or other institutions being able to use what you've developed in training their community workers?
- Jennifer Hatcher:* Well I think that, as I said, you could probably model other work on this. But this training module is very specifically for the lay health workers and interviewers on this project, based on their needs, and what they were going to be doing on this project. I don't think that the institution here could really make this part of a protocol, because every person would have to change it somewhat. It is really tailored to the women, and what their role in our project was. So while they may use it as a model if someone calls the office and asks a question about training community workers in human subjects protection, I'm not sure that they would ever require it.
- Crystal Wiley:* In thinking about disseminating this work, and how publishing it in a peer-reviewed journal is going to be one way to do that, have you thought about other ways that you plan to disseminate what you have done? As you have appropriately pointed out there's a lack of attention being paid to the specifics of: how do you train community workers to address human subjects protection within the confines of CBPR? That's very different from what you may do for a clinical trial, for example.
- So how else do you envision being able to disseminate what you've done?
- Katie Dollarhide:* I would imagine that colleagues, of course, would be one way to disseminate it, that you're dealing with other colleagues in the field who are working on a different type of project, but need a similar sort of solution for what they're doing.
- Jennifer Hatcher:* We have also made a couple of national presentations of it. In addition to being in this journal, we presented at a couple of conferences. We hope that if we're out there enough, that people would feel comfortable to call us and ask about it. We network at various conferences, and we talk to our colleagues. We will disseminate it that way, for sure.
- Crystal Wiley:* Do either of you have any additional thoughts that you'd like to share with the listeners? I know it is often difficult to be able to express everything that you would like for the readers to know, within the confines of the manuscript.
- Jennifer Hatcher:* Well on my part, I think that we've covered it here today. It's just the idea that this is a great model for other community-based researchers to use with community partners, and make what we do not so intimidating to the community. We can form a partnership so that everybody is happy and adequately prepared.