

TRANSCRIPT: Co-Creating Research With Patient Partners

RENEE LEVERTY: Hello, I'm Renee Leverty. I am the program lead for Stakeholder Engagement and oversee the Research Together program at Duke Clinical Research Institute.

And I am joined by Dr. Fredonia Williams, who is an educator who had heart surgery in 2008. She is the assistant regional director and volunteer for Mended Hearts, a support group for heart patients and their families. I have had the good fortune of working with Fredonia for the last four years as part of a participant advisory group.

Fredonia, would love to hear more of your experience of being a member of that patient advisory group.

FREDONIA WILLIAMS: Thank you, Renee. Being a member of that patient advisory group was absolutely the highlight of these years of dealing with heart failure. I became involved with Mended Hearts because of my surgery, and because of my diagnosis of heart failure.

When Mended Hearts approached me about being a patient on an advisory group, I would jump at any opportunity to learn all I could about an illness that I was dealing with. And so that's how I became involved with the Cardi-Yaks. There were about eight or nine of us who were initially just conversing on the phone with Renee. And it was a support experience; I learned a lot from the other patients.

And the highlight of the trip was when Renee brought us all to Duke University. We met there with Renee and the team, and it was absolutely a wonderful experience. It was a learning environment, it was an opportunity for us to talk to other patients and with health professionals and feel like we were being—that what we were talking about was real to them.

RENEE LEVERTY: It was real to us, in the sense of your voice and your experience adding just the knowledge of what it's like to be in that vulnerable place with a new diagnosis with or with a flare. And it helped us reconfigure our thinking around the clinical trial—it helped us with changing the messaging with the informed consent and all the materials.

The feedback loop that occurred through your group, through the Cardi-Yaks, that—it's feedback you don't get once a clinical trial has started. And so I see every time there was feedback given and changes made, that's an opportunity to make it easier for a participant in the clinical trial.

FREDONIA WILLIAMS: We really felt as if you guys were into us and what we said was important. I mean, you've always heard there's never a stupid idea or a dumb idea—everything that we did, we talked about, it was like you guys were glued to what we were saying.

It was the first time I had an opportunity to share that. Now I know about patient-centered engagement and I know about advocating as a patient. But, you know, when I was diagnosed in 2008, these were novels—novels ideas. It was difficult in 2008 to find forums where I had a chance to express my views as a patient because I was sitting with health professionals and one and I was the only patient. With the DCRI, there was a group of us, you know, we bonded like brothers and sisters.

And although there were maybe eight or nine of us, we didn't all have the same experiences. And that's what was so interesting because when you're trying to do a clinical study, all the patients may not react the same way even to the same meds. And so that's what was so interesting to me, is some of us were on the same medication, but we had different side effects. We had different dosages.

RENEE LEVERTY: I think that's part of the novel aspect of patient and participant engagement, is that we are—all experiences are different, and as many people who can be at the table sharing their diverse experiences, the better, inclusive, user-friendly, accessible, welcoming a project will be—a clinical trial will be.

What some of the data shows is that patient-centric design leads more likely to a drug being launched, and that there's a shorter time to the first hundred patients being enrolled, and it decreases avoidable amendments, and it also increases, improves patient experience. If you're working on figuring out some of the barriers before the project starts, or you're looking at ways that people who want to be in the clinical trial or a program can be included.

And that's some of the work we do at the DCRI; we try to create a bridge between the lived experience and the clinical trial.