

## **TRANSCRIPT: PCORnet®: Enabling More Efficient Research**

**JENNY COOK:** Hi, I'm Jenny Cook, and I'm a communications manager with the Research Communications and Engagement team at DCRI, and I have been working with Lauren Cohen, my good friend, on PCORnet for about 5 years now.

**LAUREN COHEN:** Hi, I'm Lauren Cohen, I'm the program manager for the PCORnet coordinating center, and yes, Jenny, we've been working together for about 5 ½ years now on PCORnet. So we've seen a lot change and advance over that time period.

For anyone who's not familiar with PCORnet, PCORnet is a PCORI-funded initiative, and it's a national resource that unites different networks across the United States to standardize electronic health record according to a common data model, engage patients as scientific leaders, and conduct research projects within this community of networks that has been working together over time.

**JENNY COOK:** I think, Lauren, one of the most exciting things that was going on when I started 5 years ago recently wrapped up, and that's the ADAPTABLE study. There are a lot of lessons learned from that.

**LAUREN COHEN:** Yeah, I mean, absolutely. ADAPTABLE was a really ambitious project, especially because it started at a time when PCORnet was really at a nascent stage. So ADAPTABLE ultimately went on to enroll over 15,000 participants over 3 years, with only 40 PCORnet sites, which is really unheard of and really revolutionized the way that these large trials are done.

**JENNY COOK:** I know that other recordings that we've done for the 25th Anniversary, we've talked about the importance of patient partners and ADAPTABLE. But another important key, I think, might be our common data model and a lot of folks maybe don't really understand what a common data model is and how it helps research.

**LAUREN COHEN:** So, at a high level, a common data model is just a way of translating electronic health research data into a digestible and standardized format. So within ADAPTABLE, the common data model was essential for identifying huge numbers of potentially eligible participants who could then be further screened and invited to participate in the trial. Certainly from ADAPTABLE we learned a lot about how to use the common data model appropriately, including for projects like PREVENTABLE, which has been able to incorporate a lot of those lessons learned. But I think one thing about the common data model that's important is that, although it's complex, it can be sort of explained in a way that's more familiar for lay stakeholders and patient participants. I know, Jenny, you and the communications team did some great work early on helping to translate the common data model technicalities into a format or a story that was more suitable for a broader population.

**JENNY COOK:** You know, it's true. Lesley Curtis, our principal investigator, wrote a great piece in Health Affairs a few years ago, that we helped her shape, called the Tower of Babel in Clinical Research, and how PCORnet's common data model cracks the foundation. We talked about how different systems categorize really simple things, like age or sex or condition, they all have different acronyms or different codes for different things, and it makes it really difficult to compare say, people who are experiencing heart disease in one health system in California to another one in Florida. Our common data model basically is just helping people all use the same language so that we can more quickly and more cleanly

evaluate data from one place to another. And that's what enabled the scale, I think, of ADAPTABLE, was to be able to look at larger groups of people in more places using the same language.

**LAUREN COHEN:** So, Jenny, I'm really excited because, as you know, later this year we're going to be moving towards what's being called Phase Three of PCORnet, which I think really shows how far the network has advanced over the past 5 or 6 years. Certainly, I recall early on, you and the communications team really pressed us hard to say, what can we talk about; what can we write about; what are you all doing; what research have you done? And now it's exciting that we are starting to have lots of different research projects in the form of PCORnet-designated studies that are showing how research can be done differently, and in a way that's faster, more efficient, and better for other participants.

**JENNY COOK:** Not only do we have new projects, Lauren, but it feels like also from where we started, we have a lot of information now that's actually affecting real people in their lives. I know one study that was exciting to me was on bariatric surgery, which I hadn't realized until I started this, how many different options there are for people looking for bariatric surgery. There's different surgical techniques, and there really wasn't any motive for anyone to study which one worked better for different people. PCORnet did that, and using all the tools of PCORnet—our networks, our common data model—we have answers for people who are looking at those surgeries and what's best for them. And I think that's exciting both for ADAPTABLE, the bariatric study, a lot of pediatric studies... We have real answers for people who are facing these questions.