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*Proem 00:54*

*Remember where you were when Martin Luther King was assassinated when the planes hit the Twin Towers? These events shape us and connect us as a community, as a society, as a world. Remember where you were when your Mom/Dad/Sib died suddenly. These events in life mold and bind us individually and across communities. Think about the 400,000+ deaths of COVID-19. Sometimes, we live through events, and years pass before we know the profound impact they have on us. For me, attending the [Fair Housing Rally in Cicero, IL, in 1966](#) was such an event. Martin Luther King was there. I didn't meet him, but my parents' civil rights activism that brought us there affected me deeply.*

*Introducing Regina Greer-Smith 02:34*

*I didn't meet my guest, Regina Greer-Smith, at that Fair Housing Rally, but we were both present. [Regina Greer-Smith, MPH](#), helped to build and maintain collaborations between communities and stakeholders that enable improved healthcare outcomes with the goal of increasing participation rates in research and clinical trials. She was a member of the inaugural Advisory Panel on Patient Engagement and several PCORI-funded initiatives such as the [Chicago Area Patient-Centered Outcomes Research Network \(CAPriCORN\)](#) Clinical Data Research Network (CDRN), [Pastors4PCOR](#), and the [ArthritisPower Patient-Powered Research Network \(PPRN\) also known as CreakyJoints](#). Regina has collaborated with numerous stakeholders worldwide to advance diversity, inclusion, and equity in research and clinical trials. She is a co-author of several white papers providing guidance and considerations on engagement. Greer-Smith was also named to the CenterWatch "20 Innovators Changing the Face of the Clinical Trials Industry."*

**Health Hats:** Regina. It is so good to hear you and see you. I appreciate you taking this time. I just have to say that, although we consciously met six or seven years ago at PCORI, right? We did discover that in 1966 we were at a rally in Cicero, IL, near Chicago at the Fair Housing Rally. I was 14 and what were you? It doesn't matter.



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**Regina Greer-Smith:** Let me see. I was 13. I was a high school sophomore, Catholic school activist, or trying to be.

**Health Hats:** My parents were active in the civil rights movement in Highland Park, Illinois, an upper-middle-class suburban community. I had no idea what I was going to, though I remember the giant circle and singing songs and swaying and that it was a significant day.

**Regina Greer-Smith:** We sang *We Shall Overcome*. Yes, that's right. I'm so humbled and honored to know you. I've always been intrigued by your hats and Health Hats and seeing you at PCORI and fast forward, not only from PCORI but also from life and cross paths in Illinois. My parents, too, were parents of the civil light rights era. I'm a baby boomer who's a privileged beneficiary of the civil rights era, born and bred in Chicago. Now I'm in the high desert, but that never leaves our DNA.

**Health Hats:** It doesn't, it really doesn't.

**Health Hats:** So, tell us a little bit about your journey to having this interest in advocacy.

**Regina Greer-Smith:** Okay. I'm going to roll back the clock or calendar to parents - father, United steelworker, World War Two veteran with General Patton coming from Greenwood, Mississippi. After World War II, settling in Chicago, meeting my mom, falling in love, getting married with seven children, me being the middle child, 1953. Both parents were big believers in education and good living for the children worked very hard, moved to the South Side of Chicago, and then went through the Catholic school curriculum throughout high school. After I got off the family payroll after graduating from high school, I continued my college at DePaul University. You've heard of it, Blue Demons, and then Benedictine University, where I got my master's degree. Career-wise started in banking after getting my undergrad at DePaul. Then 20, 25 years later, after doing corporate business and stuff, I had a chance to meet some cool folks at the old Northwestern University who were healthcare technicians. Healthcare stuff! You guys are cool! So, I got my master's degree in 1998 in public health because that meshed very well with my business background. I started my first job after my masters with - I don't know if you remember - Provena Health in Kankakee, Illinois. I was a policy analyst. I had a great boss and team that I worked with, who, like yourself, hired a minority and a woman on his team. I moved on to working with a private Federally Qualified Health Center system in Chicago. I learned the ground game about healthcare in the community, working at federally qualified health centers. I was a pharmaceutical project manager. I worked in communities with community pharmacies, partnerships to deliver pharmaceuticals to patients and beneficiaries, Medicare and Medicaid, mostly Medicaid, in the communities. That was 25 clinics. I was the project manager. Then I went back to corporate to work with AT&T. I was a medical healthcare IT director for the Midwest Region. I worked with network teams and sales teams. We created and delivered health IT for large healthcare systems in the Midwest region.

**Health Hats:** Wait a minute. When is this? What year?

**Regina Greer-Smith:** In 2002, 2005.



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**Health Hats:** Was this the AT&T self-funded healthcare?

**Regina Greer-Smith:** AT&T back then was a networking organization. Everybody thinks of telephones and stuff. But I worked in the network division where we created and developed the extensive technology, the infrastructure for health information technology because it was starting to get big back then.

**Health Hats:** So, was this like electronic medical records?

**Regina Greer-Smith:** Yes, exactly. I became a member of [AHIMA \(American Health Information Management Association\)](#) back then, and I worked with the large healthcare systems around the Midwest.



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Impacting Health Equity 10:22



**Health Hats:** Let's just jump right into this health equity business, because you and I bonded over sitting around having a drink in some hotel bar between meetings with several colleagues at a PCORI meeting and having this conversation about health equity and what does it mean. Here we are both committed. Our missions involve increasing health equity. How do we know we're having an impact on our work? It's such a monster problem.

**Regina Greer-Smith:** Danny, it always has been. My perspective is, my thoughts are, and my mission is, and I think it's in our DNA anyway, both yours and mine and many folks like us. It's something that you continuously engage in and recognize that continues to exist. How do we lend our voices or

amplify the issues that this is still an issue and a problem? I think back to when I first got into healthcare and healthcare for all. I did my master's internship in Chicago at the Physicians for National Health Plan, [Dr. Quentin Young](#). I was a policy analyst. Although I had been working in communities, my communities, and others, having conversations and being at the table with healthcare providers and stuff before that, I understood, and I learned that health care was not a right. It's something we get checked; we try to navigate. But we are entitled and have the right to have healthcare. You carry that



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forward and learn and experience that I'm not being treated right or observed that somebody or somebody shared with us that I had this issue. You keep hearing the same story, but you hear different stories from different communities. While you're at the table with your colleagues who you work with and share information, their healthcare experience may be different from yours. What others that you know that you're serving or working with has not been the same. So, you recognize it. The communities that I'm working with and that I'm part of are not getting the same opportunities or even experiences or level of care. It has to be recognized first, Danny. It has to be recognized. And then we have to reconcile. What's the difference? Where are the gaps? Because I live on the South Side of Chicago, or I'm an African American woman. Why is it that the breast cancer rates are higher in my zip code than in your zip code? Those types of conversations and recognition give those issues a voice and amplify them at the table with your colleagues. That's where we have to go continuously, Danny, we have to do that.

Entering the word of clinical trials 14:08

**Health Hats:** Wow. Is that how you got interested in clinical trials and all of that, through that work?

**Regina Greer-Smith:** That was part of my journey. I learned about the importance of healthcare technology back then. When our friends at PCORI called me in June 2012, they invited me to their first national conversation on healthcare IT methodology, data methodology because I had a background in dealing with IT and data from my years at AT&T. Do you remember our friend Sue Sheridan?

**Health Hats:** Oh, totally.

**Regina Greer-Smith:** Yes. Before then, we worked in the patient safety space with a lot of friends and colleagues. So, it's the relationships that carry forward and then getting my community connected with the folks at the table, which was very important. Yeah.

**Health Hats:** Sue Sheridan was important to me, too, in terms of my career at PCORI, recognizing that I had something to offer and nurturing me. I think she helped introduce me to doing reviews, Merit Reviews. So now you're working with PCORI in terms of health IT, but you have done a lot of work with clinical trials and equity in research.

**Regina Greer-Smith:** PCORI's focus was engaged research done differently, bringing many folks who have not been at the table regarding research, being part of the conversation, and being at the table. In my first meetings or collaborations with PCORI in that initial first meeting at Stanford University the way I was welcomed and respected, and encouraged. Because I'll tell you, I was a little scared. We need to hear from you. Make us or help us understand. They kept egging me on. I said, okay, I'll give it to you. There were about 500 researchers - some of them I'm still friends with - listening to what PCORI's requirements were for data transparency and working with patients and data. The last thing I said is, 'wow, you researchers got a lot to do.

I'm going to say a prayer for you.' And Danny, it got quiet. I said to myself, 'that's the end of this one.' I was so embarrassed. We all left the stage. I remember one researcher came up to me and said, 'Regina, are you a woman of faith?' I'm not one to pray out loud. She says, 'that's exactly what we needed to



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hear. That it's not all about us and that we're going to be charged and held accountable for doing the right thing.' Danny, after that, I got so many hugs and stuff. I was afraid. Then, we went to breakout rooms, and I started to have people listen and hear what I was saying. I can't remember what I was saying in this room, but when I started to embrace what PCORI is, they're listening to this black woman who was not a researcher but comes in truth with authenticity want to share, and I'm not looking for anything. So that's the beginning.

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#### Strong women-led research 19:02

*Regina spoke about the evolution of patient-led research, as opposed to academic-led research. She was involved with a [S.T.A.R. program](#), a network of networks in Chicago. Their mission has been to increase minority participation in health research and clinical trials thru community engagement, education, and empowerment. Engagement has been the key tenet to sharing important health information and resources in communities with low participation rates in research and clinical trials. As we continue engagement, we are committed to ensuring the delivery of equitable health information and education. We are also committed to the improvement of the communities we serve. We understand that health education and resources are needed for activation. Activation leads to participation (now engagement). Engagement leads to empowerment.*

**Regina Greer-Smith:** I'm sitting at my kitchen table in Hazel Crest, Illinois. For some reason, I was watching TV, and I had worked with breast cancer partners in Chicago. I said to myself, 'wouldn't it be great to have African-American women who could find their own researcher to help them through a research journey to find out what's best for them.' I think there was a show back then called the star is born or something. It was one of those reality contests. I said, 'you know what? The ladies would be the stars of the show.' But of course, you can't use that. But the thing about it is we've got to be specific about the type of researchers and how we would engage. So, I threw something against the wall and said, 'we've got to target the appropriate researchers for us strategically.' I've got a buddy; maybe I'll enter this into the PCORI stuff.

Danny, I did it at the last minute, came up with a concept, and got an award. You have got to be kidding. I designed the logo with the awareness ribbons because not only could it help African American women, but maybe other communities of color who've not been part of it, not only racial but people with specific disease states or chronic conditions. Danny, that was June 2013, and in November 2013, I got two awards from the National Networks of Libraries of Medicine of the NIH. I got an Outreach Express



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Award. These are small amounts that you take your program into the communities and share with them the promise of research and how we can make it work for us. My first engagement cluster was my faith-based partners in the South Side and the southern suburbs of Chicago.

**Health Hats:** So, how did you find the research partners?

**Regina Greer-Smith:** I worked with health systems, with health fairs, and with community partners and being from my work as a healthcare administrator at the Cook County Health and Hospital systems. And I told him, I say, 'Hey, you guys, I know we've all been talking about this. Let's work in the communities a little more under this umbrella.'

**Health Hats:** To me, so much of the health equity issue is about power, and in research, it's the money and who controls the money. Mostly, it's researchers who control the money, and then they go looking for patient partners. You're talking about the community controlling the money and looking for research partners, which I think is a foundational perspective or angle for enhancing health equity. Because the women of color are dealing with breast cancer issues, and it's the women themselves, controlling the questions that are being asked, the type of research, bringing the community in, and enrolling the community is such a model.

**Regina Greer-Smith:** Oh yeah, Danny. And that African American women and all women are the leaders, not only in their homes, but in their communities and bringing things forward, and they sometimes say behind every strong man there's a strong woman. Actually, behind every strong community, there's a strong woman.

**Health Hats:** Just look at what happened in Georgia.

**Regina Greer-Smith:** Oh my God. Stacey Abrams.

**Health Hats:** This is strong women. Strong women made that happen.

**Regina Greer-Smith:** And Danny, I will tell you this. It wasn't all about me because I was scared to death bringing PCORI or research to the communities. After all, they had had researchers come before and said they didn't want to be bothered. And so, Danny, these are people or my friends and partners I've been working with for over 20 years I got kicked out. But it's like Regina, PCORI has something that could help us help ourselves. When I first introduced PCORI June 2013, right after I got the S.T.A.R. initiative, we collaborated called the [Southland Ministerial Health Network](https://www.health-hats.com/pod108). Everybody gets an opportunity at the end of the meeting to share new business. And I said, 'Hey guys, there's this new organization called PCORI, and I got a little award. I think PCORI might be something that we could help with ourselves. Look, everybody, we've been doing health fairs, we've been doing health screenings. Let's try this research thing. And that's just what I said, research thing. Danny, I am so grateful that they listened because they have carried it forward to the point that there's no way I could have done it alone.'



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Carry it forward with Pastors4PCOR 26:18

**Health Hats:** When you say carry it forward, are you talking about carrying the research forward, dissemination, or implementation?



**Regina Greer-Smith:** I don't know if you recall when we had that first stakeholder meeting of PCORI in 2012 and one of the things or the points that somebody said, and you just said a few minutes ago, we need to flip the coin on research instead of the funding going to the academic centers and they call the shots and telling us what we need. Let's see - and PCORI did it - let's see if we can get our funding and find researchers who we can train to work with us and to help us answer our own questions. So that's what we did with the Southland Ministers' Health Network that morphed into, and I told them, you guys could be the [Pastors4PCOR](#) in 2013.

That organization now has gotten almost a million dollars in funding, had been the lead and principal investigators for their own research, have hired their own research partners from academics. They found using the model, the S.T.A.R. Initiative, they found their own research organizations and those initial partners, the first ladies from those churches to help them with the S.T.A.R. Initiative. It grew and morphed into Pastors4PCOR with 20 faith-based partners who've established a research infrastructure. That's now a faith-based model for engaging and inspiring communities of faith and patient-centered outcomes research.

**Health Hats:** Then it seems that if that's the nut of it, then the disseminating the results and then implementing those results. Then it's just like ready to happen.

**Regina Greer-Smith:** They own their work. Danny. They did their own work. They answered their own questions with guidance and partnerships with the academic centers. They got certified in IRB. They created their own survey. First, they got trained understanding data, and we'll use a lot of work, pre-work that has been done by PCORI already. We built our own, a research infrastructure using some work and some findings from prior PCORI research. We did our own data, got our own data. We built our own reports. We disseminated our own work. We did our own surveys. We've published. We've got about four publications now, in addition to a [faith-based manual on Amazon](#) inspiring faith communities and patient centered outcomes research. But what was important, Danny, having the leadership and the capabilities and community to carry this work on. Many communities have done this successfully, and using their capabilities and include research in their toolkit makes a lot of sense.



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**Health Hats:** It's very powerful. People talk about adherence; they talk about reducing variation in practice. But it seems to me that if people are involved in asking questions, designing the research, doing the research, then the translation into practice, into life flow, is just a natural, next thing, like another project.

**Regina Greer-Smith:** You know what, I'll quote you what, one of my first engagement cluster members said, and it's documented in 2014 PCORI video. And I'll share that with you.

Research without fear 30:47



**Regina Greer-Smith:** One of the ladies said, 'we've been told all along that we have to do with the doc. It was a Pastor Sylvia; I remember her name. But she says, we've been told all along, we've got to do what the doctor says, the doctor hasn't listened. And then she says, so that's why I'm so grateful for PCORI and S.T.A.R. I learned now, or I realize now that I can do and be engaged with research without fear. Research without fear. Wow. And Danny, what's important for all of us with research, and I'll take it a step forward with fascination now or with COVID-19. We need to

take the fear out of this stuff, and it's got to be translated by people who are trusted. It's not that I distrust this researcher, but I can understand what my community person who looks like me, or maybe somebody like Regina. If I've got a partnership with her or my pastor or whoever I trust, who can tell me the truth and help me understand so I can decide how I want to be treated or engaged. And if I don't make the decision or make the decision best for me. And also, the other side of possibly not taking this path or this path, but giving them full disclosure and how does it look for me? And that's important to me, how do I put this on and wear this for the rest of my life and my family members, too. It doesn't matter. And it's a matter of making it my own, putting it on like that hat and see how it looks. And if it doesn't work, this isn't working, but I got the truth. I got useful guidance. And someone says, Regina if you need anything else, let us know. But giving me the respect and the autonomy to make that decision. So, it's not about blame, but giving me the respect that I made my own decision.

Train each other how to treat each other 33:29

**Health Hats:** If you're going to share this experience with people, either community people who are young and coming up or researchers that are young and coming along, what advice would you give them?

**Regina Greer-Smith:** First of all, if you remember the [PCORI Engagement Rubric](#), I helped model, and I so believe in, and we've developed and advanced since then. But it's the respect, the truth, the



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relationships and we talk about bi-directional and it's the co-learning. One of the things that I've learned, Danny.

**Health Hats:** Co-learning and co-production.

**Regina Greer-Smith:** Oh yeah. And one of the things that I learned, and I did learn, and I share with communities, we've got some answers, but we don't have it all. So, let's find these partners at these academic centers who we want to work with and who had a desire in the heart to work with us and let's train each other how to treat each other, so it's and daily, I am just so grateful that it worked out well, it wasn't experienced on a journey, but it was one of listening and hearing. And when someone opened a door for us and invited us to that first meeting, 15 pastors, December 9th, 2013, we showed up. And the researcher, Rebecca and I, were at Northwestern, and she was a little concerned. She says, 'are they going to come?' I say, 'Oh, they will. They will come.' And we got a call from the lobby of Northwestern. They said, 'there are thirteen gentlemen down here. Now, show it to me.' And Danny, and I'll show you the picture of that. And I took a picture to memorialize it, and it was just so enduring, and I'll repeat it. I am so grateful that people listened to what I had to share, but they took action, and somebody listened to what I said. Okay.

**Health Hats:** And then did something with it. It's something. Yeah. Cause listening is the first step, but then the second step is you got to do something with it.

**Regina Greer-Smith:** Oh, yeah. Oh yeah.

**Health Hats:** Well, Regina, this is great. Thank you so much. I appreciate this.

**Regina Greer-Smith:** Thank you for allowing me to share. Yeah, this has been fun. Really has been fun. Thank you so much. Thank you. You stay well and I'll see you soon.

#### Reflection 36:26

*Regina is a pioneer and a master. Hearing the journey of a pioneer and master, we could think, how lucky she was, she stumbled from one opportunity to another – the opportunities of a good boss, working in federally qualified health systems, moving into information technology at AT&T, PCORI, S.T.A.R., the Southland Ministerial Health Network. But as [Barbara Sher](#) said, "The amount of good luck coming your way depends on your willingness to act." Regina didn't stumble; it wasn't coincidental; she acted. Luck played only a small part. Such pearls here: Research without fear. Behind every strong community, there's a strong woman. Regina is that strong woman.*



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