S3, E19: Understanding the Healthcare Needs and Research Priorities of Adults with CP with Cristina Sarmiento, MD

**Dr. Marie McNeely** 00:01

Hello and welcome to Changing What's Possible: The Disability Innovation Podcast brought to you by Cerebral Palsy Alliance Research Foundation or CPARF. I'm your host, Dr Marie McNeely, and this season, we are excited to bring you cutting edge stories and insights on research, technology, and Innovation for people with CP and other disabilities. Before we introduce you to today's guest, I'd like to take a moment to tell you about 3forCP, CPARF's grassroots fundraising initiative for cerebral palsy research and disability innovation. Whether you level up a read-a-thon, a sip-and-paint event, a comedy show, or something else that you love, 3forCP, gives you the chance to make a difference in your own signature way. Head to 3forCP.org to get started. That's the number 3, F, O, R, C, P, dot O, R, G.

**Dr. Marie McNeely** 00:53

And now we'll get started with today's episode. Today we have with us Dr Cristina Sarmiento. Listeners, Cristina is an assistant professor in the Department of Physical Medicine and Rehabilitation at the University of Colorado Anschutz Medical Campus. Today, we are looking forward to learning more about her and the exciting work she's leading to investigate research priorities for adults with CP. The study that we'll be focusing on is a CPARF-funded research project through a strategic partnership with the CP research network. So Cristina, thank you so much for joining us today. How are you?

**Dr. Cristina Sarmiento** 01:28

I'm great. Thank you so much for having me honored to be here.

**Dr. Marie McNeely** 01:32

Well, we are thrilled to learn more about you and your work, and perhaps we will start with you. Cristina, can you start by telling us a little bit more about yourself?

**Dr. Cristina Sarmiento** 01:41

Yes, so you did a great job with the introduction. So I am based in Colorado, at the University of Colorado, and I'm a physician that's trained in both pediatric and adult rehabilitation medicine, also known as physical medicine and rehabilitation, or PM & R, and I'm also trained in general pediatric medicine. So I did my residency training in all three areas here at the University of Colorado as well, and then have stayed on their faculty as a physician and a researcher.

**Dr. Marie McNeely** 02:12

Very cool — and perhaps we can get into a little bit more detail. Can you tell us what are your current clinical and research interests?

**Dr. Cristina Sarmiento** 02:18

Yes. So I think really what encapsulates both my clinical and research interests is lifespan care. For those of you who maybe haven't heard this term used before, so I'm very interested in healthcare access, health outcomes for individuals with childhood-onset disabilities, but across the lifespan.

And the portion of the lifespan that I'm particularly interested in is that transition to adulthood and beyond, so aging with a childhood onset disability or with a lifespan disability, as we're trying to reframe the perspective, which is a common theme I'll talk about today. This interest in lifespan care really stemmed from my training experiences. So by getting to train in both pediatric and adult rehabilitation medicine, I really got to see this huge gap in care after childhood. So either adults with childhood-onset disabilities like cerebral palsy or CP not having care at all, or adults remaining within the pediatric system well beyond the age of adulthood, which has its own issues. And so this really is what sparked both my clinical and research interests.

**Dr. Marie McNeely** 03:27

Absolutely. And I think you brought up an important point here. And I think a lot of people think about some conditions like cerebral palsy, as you know, something that you only have in childhood, because a lot of the attention is on children, but this is a lifelong disability, and I'm sure it's been difficult, maybe to change the way that people think about it.

**Dr. Cristina Sarmiento** 03:45

It is, and you're so right, and of course, it's so important. Childhood is a very important time to really intervene early, diagnose early, and really optimize function. But turns out, kids grow up, and more and more kids with CP and other disabilities that begin in childhood, more and more are reaching adulthood and living and thriving in adulthood. And so we really need to shift this from a pediatric disability to a lifespan disability.

**Dr. Marie McNeely** 04:15

That makes sense, and I know on the clinical side, you started the cerebral palsy transition program and also an adults with cerebral palsy clinic. So can you maybe describe or go into a little bit more detail about the medical gap that these two are filling?

**Dr. Cristina Sarmiento** 04:29

Yes, absolutely. So our cerebral palsy transition program is at our children's hospital here at the University of Colorado, and before it, there really was no formal transition program in our pediatric rehab medicine clinic.

So young adults either left the system without formal or guided process, or stayed in the pediatric system well beyond adulthood. Both of these paths have their issues, and so we started this transition program where an individual's primary pediatric rehab provider, so the person they've been seeing throughout childhood begins the discussion, I feel like that's so critical. And they talk with the young adult and their family, if their family is involved in their care, to really determine the best timing to start the transition, with the goal being to transition to adult care by 22 years of age.

Then from there, they can route them one of two ways. So since I'm also trained in pediatric rehab medicine, I have a clinic at our Children's Hospital where I can do a visit that's really focused on the transition discussion. Get to meet people in an environment that they're much more comfortable with, that they're much more familiar with. And then we get to talk about, you know, how do we transition to the adult system? Alternatively, there are definitely some young adults or their families who feel really ready to make that transition, you know, maybe they've done it with other specialists in their care, and they feel really ready. So they can kind of just come straight to my adult cerebral palsy clinic.

And my adults with CP clinic is based in our adult healthcare system, which I think is very important. And again, like name implies, it's for adults with CP. And before this, there really was no specialty CP rehab care for adults in the Rocky Mountain region. So I feel very lucky that I get to bridge the gap between these two healthcare systems.

**Dr. Marie McNeely** 06:26

Absolutely, and bring healthcare to a lot of people who maybe were not treated optimally in that region, specifically. And this is something that I think you're not alone in Colorado, and this being kind of the first in the region.

**Dr. Cristina Sarmiento** 06:37

Absolutely, you know, I get to guide a little more closely the transition for a lot of our families and patients that we see at the Children's Hospital, but I'm getting patients at my adult clinic where, you know, it's been 10, 20, 30, 40, years without CP-specific care, or never having had CP-specific care. And so I feel really fortunate that I get to help this really important group.

**Dr. Marie McNeely** 07:01

Absolutely. And I think there are a lot of clinical needs and things that we need to continue improving, and I think research plays an important role in this. So can you give an overview of the CP research landscape, and Cristina tell us why it's so important to identify some of the research needs for adults with CP?

**Dr. Cristina Sarmiento** 07:19

Of course, yes. So the CP research landscape, you know, particularly as it relates to adults with CP, is improving, but limited, and so most research is focused on much younger persons with CP. Again, this is also a very important time for early diagnosis intervention, but there's a real discrepancy between the growing population of adults with CP and the amount of research that is focused on this group.

So up to 90% of people with CP reach adulthood, and that number is just growing, and the greatest gains in life expectancy are in those with more severe CP.

And because of this improvement in medical care and life expectancy, about 80% of persons with CP are adults. And yet adults with CP, to give one statistic as an example, they're the focus of only 4% of all CP-related funding from the National Institutes of Health, which is a large federal funding source. And so there's this really big gap between how many adults with CP need evidence to guide their healthcare and their function and the amount of research that's dedicated to them. And so this gap is really what we're hoping to begin to address through the project that we'll talk about.

**Dr. Marie McNeely** 08:40

Absolutely and I think as we continue to build the evidence base in this particular area, it can be overwhelming, you know, hard to know where to start or what are the most important questions. So can you comment on why this prioritization conversation is so important?

**Dr. Cristina Sarmiento** 08:55

Yes, of course. So there is so much work to be done, and it can be hard and overwhelming to really know where to start. And so the best way to figure out where to start is to ask the people affected and so engaging community members in this prioritization of research, because there are definitely examples where well-intentioned researchers have begun research studies they think are addressing what is important to the population that they're studying, and they totally get it wrong. So we cannot pretend to know what is the priority for the community of adults with CP and so really, to begin the prioritization conversation, we need to engage with all these relevant stakeholders and community members.

**Dr. Marie McNeely** 09:43

Absolutely. Well, I love this approach that you're taking to the research project, and I know CPARF funded an accelerator award for your work within the Cerebral Palsy Research Network. So Cristina, can you share some of the background that really led to this study?

**Dr. Cristina Sarmiento** 09:57

Yes. So the goal. In the study overall, is very lofty, is just to advance research about adults with CP, and the way we're hoping to do this is by forming a multicenter research program that's focused on adults and aging with CP, and we're doing so using the infrastructure of the Cerebral Palsy Research Network, or CPRN. And so through this study, we're able to gather input and priorities from these key stakeholders so that we can co create our research agenda. And these stakeholders include adults with cerebral palsy, family members, clinicians, researchers, and community leaders. So everybody giving their perspectives on what's important.

And the reason that we're seeking this input is because of the research that we have to date and what we know about the health risks of adults with CP to date. So, many studies, including a lot of them coming from the University of Michigan adults with Pediatric Onset Disability group that's led by Dr. Ed Hurvitz, who's a co-investigator for this study, and Dr Mark Peterson, these studies have demonstrated high-risk of chronic illness in adults with CP, and this includes kidney disease, bone health so easily broken bones, poor bone health and gaps in primary and preventive care, which is key to diagnosing and treating chronic illness early.

And so we wanted to seek input through our study into which of these areas we should investigate first. So what is the priority area to the community? The other area that we're focusing on in the study is on the CPRN community registry, or the Cerebral Palsy Research Network’s community registry. And this is a live registry. It's active now, and it collects patient reported data on function, pain, and quality of life. And this is a really excellent and high-yield way to efficiently collect data from the community to better understand these important issues, and so we sought additional input through our study into how we can best recruit a diverse and representative population to participate in the registry and what questions the community would like to see answered using registry data. So that's a little bit of the background that inspired this particular study.

**Dr. Marie McNeely** 12:23

Definitely. And I think the study came from some previous research as well. You created an initial patient-centered research agenda through this ResearchCP program. So can you tell us more about what that process looked like?

**Dr. Cristina Sarmiento** 12:36

Absolutely. So in 2018 the Cerebral Palsy Research Network created a patient centered research agenda for CP, and again, they included the key stakeholders at this table, so persons with CP, family members, clinicians, researchers — and this group identified issues related to aging as the top research priority for the CP research agenda, and specifically the treatment of pain, functional decline and fatigue in adulthood. And it was in response to this research agenda that in 2019 CPRN launched their community registry, which again collects that patient reported data on these issues.

**Dr. Marie McNeely** 13:19

That makes sense. So let's talk about some of the gaps. Cristina, what are some of these previously identified gaps that people with CP would really like to have addressed? You've touched on some of them, but perhaps to go into a little bit more detail.

**Dr. Cristina Sarmiento** 13:31

Absolutely. So in terms of thinking about pain and functional decline and fatigue, prior studies have identified very high rates of chronic pain in adults with CP, so up to 70% of adults with CP living with chronic pain. Other studies have also identified high rates of functional decline, so decline in mobility, levels loss of mobility or ambulation or walking, increased need for assistive devices and equipment like walkers and wheelchairs in adulthood, and high rates of chronic fatigue. And so these issues clearly have a huge impact on a person's function, their quality of life, their well-being. And so these are really high priority areas to address.

And so a community registry like that of the CP Research Network allows us to get information on these issues from people living in the community with these issues. And by gathering that information as well as people's background or clinical experiences, you know, surgeries, they've had, treatments, they've tried, we can really collect a lot of information in a relatively short amount of time and then begin to identify and answer important questions about these issues, like, what treatments work best? Who do they work best for? How do we identify and intervene on these issues early before they're wreaking total havoc on a person's function and quality of life? And so those are some of the huge gaps. I think the other set of gaps that we're trying to address with this study is related to a lot of the work on the high risk of chronic illness in adults with CP. So this includes things like high blood pressure, stroke, lung disease, bone health issues, kidney disease, and so, you know, there's been a lot of studies that show that adults with CP are at high risk for these chronic conditions and at earlier ages than the general population or than people without CP. However, now we need to begin studies to intervene on these conditions, and for that, we really need a multisite research program to begin to address these issues. And so this study that we're talking about today really seeks to begin to address both of these gaps, the gaps and getting high quality, generalizable information from the community registry, as well as forming and identifying priorities for this multicenter research program on adults with CP.

**Dr. Marie McNeely** 16:18

And I think we'll come back perhaps later in our conversation on maybe some of the incidence of these different conditions that you mentioned, and how it's being measured, and making sure that you're getting that representative sample. But I think it's something that is really important. Like you said, it's a big problem. A lot of people are experiencing these problems, and they're not currently addressed with their current medical solutions available. So I'd love to talk about the current work that you're doing in this ongoing study. You're building off some of this previous information that was collected. But what are the specific aims of this ongoing study?

**Dr. Cristina Sarmiento** 16:50

Yes, that's a great question. So the aims of this study are to prioritize and gather input on potential focus areas for multicenter research relating to adults with CP and to also prioritize and gather input on potential recruitment strategies for the community registry. And we're doing these things from three main groups, the first being adults with cerebral palsy and family members. Second being clinical investigators that focus on adults with CP and third community organizations and community leaders. And so we are doing an iterative series of focus groups to gather input from these key groups of people.

**Dr. Marie McNeely** 17:38

Absolutely, and for listeners out there who might not have a research background. You mentioned multisite. Can you explain what this means in the research context and what sites are involved?

**Dr. Cristina Sarmiento** 17:47

Yes, great question. So multisite just means that it's a research study or research program that involves more than one health care system, university, institution, and so the sites that are involved in this specific project are the University of Colorado, University of Michigan, University of Hartford, and then we also have a co-investigator representing CPARF. And we are partnering with the Cerebral Palsy Research Network, which includes a much larger network of different centers or healthcare systems, and so a lot of our participants are drawn from the CP Research Network, or connections with the CP Research Network.

**Dr. Marie McNeely** 18:30

Absolutely. And I think there's tremendous value in bringing together people from different backgrounds, from different places, to make sure that you're getting a diverse sample, to make sure that you're getting a lot of different perspectives incorporated in the research project. So I love to see that this is a multisite study. But can you maybe go into a little bit more detail on the players here? Who is involved in the project, on the research team, and how is this study being conducted?

**Dr. Cristina Sarmiento** 18:54

So I'm part of the research team, as is Dr. Edward Hurvitz, who is a professor and physician at the University of Michigan, and his clinical and research interests focus on adults and aging with CP, and it’s his group and collaborators that have published a lot of the studies I mentioned before demonstrating the high risk of chronic illness in adults with CP.

Dr Mary Gannotti is also an investigator with this study. So she is a professor, a physical therapist, and a researcher at the University of Hartford, and her focus is also on adults and aging with CP. And she has a particular interest in how we can treat chronic pain, fatigue, functional decline in adults with CP, and she really helps to lead the charge with the community registry of the CP Research Network. And certainly, last but not least, Jocelyn Cohen, who is the Vice President of Education with CPARF, is an investigator on our research team.

**Dr. Marie McNeely** 19:53

Wonderful. And can you describe, I guess, how this dream team was created, and perhaps what went into selecting these particular people?

**Dr. Cristina Sarmiento** 20:01

We are all affiliated in one way or another with the CP Research Network, and so the research network has web-based meetings throughout the year and has different working groups for people interested in different areas. So all of us are very interested in the work that the CP Research Network is doing for adults with CP. And so this common interest really brought us together.

And actually, the idea for this specific study was born out of a room at the CP Research Network's annual meeting in 2023 and so the four of us, as well as some others, were sitting in this room and talking about these issues and trying to figure out where to start and what's the next step, and we decided to ask those same questions to the people whose perspectives matter most, and that's what led to the grant proposal for this project.

**Dr. Marie McNeely** 20:57

I think that's so exciting, and I think a good example of how these conferences are a really good venue for people to get together and have these important conversations that spark ideas for new projects.

**Dr. Cristina Sarmiento** 21:07

Definitely, yes. It was really great. And you know, some of these investigators I'd met before, some of these people met for the first time at the Research Network Conference, and I think we've just really grown such a collaborative and productive relationship. So it's been wonderful.

**Dr. Marie McNeely** 21:22

That's phenomenal. Well, Cristina, perhaps we can get into some of the details, then. Can you walk us through how this study is being conducted?

**Dr. Cristina Sarmiento** 21:30

Yes, so we have done a series of focus groups. The first round of focus groups was with adults with CP, as well as some caregivers of adults with CP. And we are doing web-based focus groups. And while that certainly has some downsides, like we just talked about, there are benefits to being in the same room, it does facilitate us having people participating from across the country, and I think particularly for this type of study where we're trying to identify research priorities, we want to make sure we're capturing this broad range of perspectives and experiences, so we are doing web-based focus groups.

So first round is with adults with CP and we did two focus groups. We then collected all that data, analyzed it, and then had our next round of focus groups, which was a single focus group with clinical investigators focused on adults with CP, we presented to them the information that we had gained and learned from the first focus groups, and then asked them for their input on these findings, these research priorities, what they see in their clinical practice day to day, what barriers they perceive to conducting this type of research or this type of recruitment for the registry, and then we analyzed that focus group data.

And then we have our third and final focus group, which was with community leaders. So a lot of leaders of different CP or disability related organizations, social media influencers that use their platform to advocate for CP initiatives or disability initiatives, and we again, took the information we had learned from all prior focus groups, presented it to this next focus group, and then got their perspectives on it in terms of how important are these potential research areas to the communities that they serve? How could their community or their organization participate in this type of research? Would they be interested what types of recruitment strategies would be optimal for the community or organization that participants serve? So it was really a great process, because we could see that knowledge building, as we did this series of focus groups.

**Dr. Marie McNeely** 23:50

I think this is remarkable, and I know it's difficult to get a complete picture to even sort of identify the biggest areas of needs. And listeners may have heard some of the statistics that you mentioned previously, you know, up to 70% of people may have chronic pain with cerebral palsy. And I think depending on the source, listeners, may see some slightly different numbers. And I think how this information is gathered in making sure you're sort of comprehensive in your approach and inclusive in your approach is important, because there are already, just in healthcare alone, so many different disparities based on location and other factors. So can you maybe comment on how you are ensuring that you're getting a diverse range of people participating in this particular study?

**Dr. Cristina Sarmiento** 24:31

Yes, that's such an important question. Thank you for asking that. So this is an example of a qualitative research study, so people may more often be familiar with quantitative research, and that is the type of research that collects numbers or numerical data and then analyzes them, whereas in qualitative research, you collect non numerical data in order to gain an understanding of people's perspective. Initiatives, beliefs, their priorities, and a couple of the methods that are commonly used in qualitative research are things like focus groups and one-on-one interviews. And so in qualitative research, because you're going so in depth with each participant, it typically includes many fewer participants than the quantitative research where you're collecting numerical data. So when we're having a smaller sample size or a smaller participant group in a qualitative research study, in order to gather this diverse range of perspectives, we use a technique that's called purposeful sampling, and so in this technique, the study team identifies and then purposefully selects what they deem are information-rich participants.

And so for our study, we use purposeful sampling, for example, to recruit adults with CP that have diverse gender backgrounds, race and ethnicity backgrounds, and CP severity in terms of their mobility function, in order to make sure we are capturing perspectives from this range of participants. And similarly, when we recruited clinical investigators, we wanted people with a variety of clinical backgrounds, so physicians from different backgrounds, like physical medicine, rehabilitation, neurology, orthopedic surgery, as well as therapists like physical and occupational therapists. And then for our third round of focus groups with community leaders and organizations, we tried to recruit participants that represented a variety of different organizations or community platforms again to make sure we were including voices from a more diverse pool.

**Dr. Marie McNeely** 26:45

That makes sense. And since these focus groups were conducted virtually, did the people who were invited or selected to participate need to be near one of the study sites, or could they be anywhere?

**Dr. Cristina Sarmiento** 26:57

No they could be anywhere. So I think that ended up being a strength of this study is we had participants from across the country, and had pretty great diversity and representation across the different geographical regions of the US. So I think that is a strength of doing web based focus groups. I do think, you know, sometimes it's a double-edged sword. Can be harder for people to engage in conversation when they're looking on their computer screen versus in a room with people, but fortunately, we had really great conversations during each of these focus groups.

**Dr. Marie McNeely** 27:34

That makes sense. I think a lot of us have gotten much more used to it in recent years.

**Dr. Cristina Sarmiento** 27:39

That's true, yes, yes

**Dr. Marie McNeely** 27:41

Absolutely. And you mentioned across the US, were there participants in other countries as well.

**Dr. Cristina Sarmiento** 27:45

We had some participants in Canada, but it was North American based. So because we were using the CP research network's infrastructure, it is a North American learning health system. And so our participants came from North America, so that certainly is the important limitation to consider. You know, the experiences and priorities of people living in North America might not necessarily be the experiences and priorities of people in other regions of the world.

**Dr. Marie McNeely** 28:13

Certainly, and I love that this virtual component of it also makes it accessible for people like you mentioned with different severity, so different levels of CP could participate without having to actually come into a laboratory or a hospital setting.

**Dr. Cristina Sarmiento** 28:27

Absolutely, I think we take for granted sometimes how much logistical work can go into a person getting from point A to point B, and so to be able to lower and remove some of those barriers is another strength of using a web-based format.

**Dr. Marie McNeely** 28:43

Certainly. And I'd love to dive into some of the detail of the content of these focus groups. So Cristina, what are some of the key discussion points that you are covering in those focus group conversations?

**Dr. Cristina Sarmiento** 28:55

Great question. It was similar topics in each focus group, but we asked the questions in a little bit of a different way based on the audience of the focus group. So in the first focus groups, which were adults with CP and caregivers or family members, we asked participants about their own experiences with three different topic areas, so bone health, kidney health, and preventive care.

And these, again, were inspired by prior research showing that these are important issues for adults with CP. And so we asked about their own personal experiences. What they feel are the gaps in their knowledge as well as their clinical care, what research questions they would want to see answered and what they felt were their priorities for the research agenda. And then we asked similar questions about recruitment strategies for the community registration. So for people that participated, who had also participated in the community registry, what inspired them to participate? What motivated them? For people that hadn't participated, they got to learn a little bit about the community registry first through a presentation by Dr. Gannotti. So what would motivate them to participate? Where do they get their information about these types of research projects from? And what might be effective recruitment strategies to try to get more people with CP from a broader range of diverse backgrounds to participate in the registry?

Then in the second round of focus groups, which was with clinical investigators. Again, we kind of summarized that information that we had gotten from the first ones, and then we got their own thoughts and their perspectives on their clinical experiences with these different issues. So with kidney health, bone health, preventive care for adults with CP, we asked them what they thought were the next important steps to improve practice, and what they perceived as potential barriers to conducting this type of research.

And then we asked similar questions about the recruitment strategies. So what would be possible in their clinical setting, what they thought would be an effective strategy, how do they talk to people about the community registry, and how feasible or successful did they think different recruitment strategies might be?

And then finally, in that third round of focus groups, which was with community leaders, we again presented information we'd gained from the preceding groups, and then we asked about their organization's experiences with these topics. How their organization might be able to engage in or support this type of research. How do they share information about different research opportunities, about new information that's coming out. How do they present that information to their community and similar information and questions related to that community registry?

**Dr. Marie McNeely** 31:49

Absolutely. Well, this is fascinating, and I think tremendously important, because I think sometimes when you're in the medical or the research background, it can be difficult to sort of take a step back and understand what someone's experience is like outside of it, and I think there's sometimes this hesitancy to participate in research, or even sometimes hesitancy to seek care for certain conditions. So how do you combat that? Are you finding successful strategies for kind of making connections with people who might feel that way?

**Dr. Cristina Sarmiento** 32:18

Yes, that's such a important point. And I think the beauty of a focus group, as opposed to something like a one-on-one interview, is that you get really this building effect, so people share a story, it reminds another person of their own, similar experience, or rings true for them. And so you really get this building and cascading of information that really just grows into such a rich, in-depth discussion. And so I think this sense of community is fostered by a focus group. I think people sharing their own experience of what has worked for them, what hasn't worked for them also is very helpful for other participants to hear be shared during the group. And you know, the overall goal is to improve the health care and the health of adults with CP. And so we want to understand what the experiences to date are, what the barriers are, so that we can really support the community, as well as the healthcare system in providing comprehensive, supportive and patient-centered care. That is the overall goal.

**Dr. Marie McNeely** 33:28

Absolutely. And from our conversation, it sounds like you've been able to include people with disabilities, particularly CP, in this case, in every stage of the research process, even going back to some of those kind of earlier information, gathering pieces of it. So can you comment on why this is so important?

**Dr. Cristina Sarmiento** 33:45

Yes, this is really key. So as I mentioned briefly before, there's a lot of examples of well-intentioned, well-meaning researchers who end up conducting research that is just not important to the community that it serves.

And so engagement is a way to help ensure that the research that you're doing is meaningful and will impact the care and the lives of the people you're hoping to impact. And so this type of engagement also includes community conversations, which is the model for our study. And I think what's really important to recognize is — true engagement is a two-way flow of information, and so the study team provides some information to the research participants, but the research participants are also equally importantly, giving their perspectives, their feedback, their knowledge, their firsthand experiences to the study team.

And so this bidirectional flow of information allows us to co create a research agenda that's community centered. And so it's not the research team that's deciding A, B, C and D — it is co-creating this research agenda, and so involving the CP community at the very earliest stages ensures that future research is important to the community. Because it can be really hard when, you know, a research team tries to engage the community, but they've already, you know, decided what they're going to study, or they've already started the study. You know, at that point, there's way less wiggle room, way less room to adapt based on the community's input. So engaging the community at the earliest stages possible is really critical and facilitates the most community-centered research.

And you know, the other hope is that, by CO creating this research agenda, future studies are important to the larger CP community, so not just those who participated in our study. And then the hope is that that facilitates participation in future studies, and the more people you have participate in studies, the broader range of backgrounds and experiences that they come from. This improves the representation in research. It improves the generalizability — so how much do the studies findings apply to the real world? And so it improves the generalizability of future study findings as well.

**Dr. Marie McNeely** 36:21

Definitely, and from our conversation so far, it sounds like you're already getting some great insights through these focus groups. So can you give us a status update, Cristina, on the progress of this study so far, and maybe if there are particular things that you've learned so far that really left an impact on you?

**Dr. Cristina Sarmiento** 36:39

Definitely, and I feel like I probably use multiple verb tenses as I was talking about this study, but we have completed our focus groups and analyzed the qualitative data from the focus groups. And so very excitingly, we are in that paper-writing stage to summarize our results and make them available, kind of in the broader research world.

And so some of the overall takeaways, or we call them themes in qualitative research, that came out of this study are, first the need for specialty CP care. And specifically, a lot of information came out about guidelines for the care of adults with CP. So this idea of precision medicine came up a lot. And so to describe this — precision medicine, it involves taking into account a person's risk factors to guide their care. So risk factors like, how old are they? What's their level of function? What other medical diagnoses do they live with? What medications do they take? What's their diet like? So taking these risk factors to really tailor someone's care based on a precision medicine model.

Secondly, another theme that we found rang true over and over again during our study was the lack of provider awareness of the unique needs and risks facing adults with CP. So, you know, we shared some of the background knowledge that we talked about, about the risk of kidney disease, bone health issues, gaps in primary and preventive care. And for a lot of participants in our focus groups, especially, you know, our initial ones with adults with CP, this was the first time they were hearing this information. And they see healthcare providers, their providers are either maybe not aware of these unique risks or are not discussing them with patients. And so there really was this lack of awareness that was problematic. And this related to the third kind of overall or overarching theme that we took away, which was really the need for education, the need for education at multiple levels. So not only healthcare providers clinicians, so that they can be aware of these health risks, discuss them with patients that they see, initiate appropriate screening and treatment evaluation, but also need to educate the community. A lot of the adults with CP that participated in our focus groups, they wanted this knowledge too. A lot of them shared stories about how they had had to be their strongest advocate in their healthcare. And knowledge is powerful in being an advocate for yourself.

And so this multilevel education was another takeaway theme. You know, we're also looking at what is the priority area among bone health, kidney health, and preventive care. So all three of these research topics were found to be very relevant. They rang true for our participants in importance. However, preventive care emerged as the top priority area. The bone health followed close behind. So that was kind of numerical wise with some of the early results that we have.

**Dr. Marie McNeely** 39:50

This is very interesting, and it sounds like you've got some really helpful findings so far, but I think oftentimes when you finish a study, it's sort of difficult to figure out. What do you. With this information, what happens next? So Cristina, what are the next steps for this area of research?

**Dr. Cristina Sarmiento** 40:05

So I think we have two next steps. So our next steps for this multicenter, multisite research agenda. So we recently submitted another grant proposal that would focus on the issue of primary and preventive care for adults with CP. So the grant proposal would develop a digital health tool to help improve awareness of and facilitate primary care interactions for adults with CP and the unique health risks that they face. Again, we just submitted that so hopefully more to come on that.

And then next steps for the community registry efforts. We are similarly looking into future funding sources, grant proposals. We want to shift from a more passive recruitment strategy for the registry, which is what we've been doing in the past. So you know, advertising on platforms, but then letting people come to us, to a more active recruitment strategy, so harnessing the power of the CP Research Network and all of its clinical sites, how can we recruit people in the clinical setting so that they can learn about the community registry, the opportunity to participate and see if they would be interested In participating? We also want to optimize the survey experience of the registry, so make sure it is accessible, make sure we are asking important questions and not asking too many of these questions. And then we got a lot of suggestions for new or additional recruitment strategies or recruitment tools that study participants shared with us that might be interested in this type of research.

**Dr. Marie McNeely** 41:47

Very cool.It sounds like you have some different lines of research or action that are going to be taken based on your findings so far, but looking at the big picture, perhaps taking a step back here. Cristina, what are your long-term goals for this particular line of research?

**Dr. Cristina Sarmiento** 42:00

Yes, so serving the overall long-term goal to advance research about adults with CP, I want to optimize the long-term health function and quality of life for persons with CP across the lifespan. And I think linked to that is focusing on health care access and spreading awareness and education about the unique health risks that adults with CP face. You know, I feel very fortunate to work in a specialty clinic for adults with CP, and I know that this doesn't exist everywhere, and a lot of people don't have a sounding board for CP-specific issues. And so how can we take this CP expertise, this CP knowledge, and make it accessible to people everywhere, regardless of where they seek their care or where they're able to seek their care.

**Dr. Marie McNeely** 42:55

Well, Cristina, I am really excited to see that you and your colleagues are dedicated to making progress on this important area of research, and I am sure we've piqued the interest of some of our listeners out there who might want to learn more about you and the work that you're doing. So what is the best way for them to learn more?

**Dr. Cristina Sarmiento** 43:13

Yes, so I would encourage listeners to check out the CP Research Network's website. So as I mentioned before, all of the study team investigators are involved with the CP Research Network. So that is CPRN.org, from here, listeners could also join the CPRN and community platform, which is called myCP. So anyone can create a profile on my CP, and you input a little bit of background information on you, and then it will send you personalized updates on the CP Research Network, invitations to their webinar series, opportunities to participate in research like this study, as well as the community registry, and access to different community forums where my CP members can ask and answer questions that are important to them and their daily lives. So I would recommend people check that out.

**Dr. Marie McNeely** 44:10

Wonderful. I appreciate you sharing these resources. Listeners, definitely take a moment to check them out and Cristina, thank you so much for joining us on the show today. It's been such a pleasure to chat with you and learn more about the work that you're doing.

**Dr. Cristina Sarmiento** 44:22

Thank you so much for having me. I so appreciate it, and I'm very passionate about this topic. So thank you to everybody that's listened as well.

**Dr. Marie McNeely** 44:32

Well, thank you again — and listeners, it has been so great to have you here with us as well. When you have a moment, please subscribe and leave us a rating or review on your favorite podcast platform to let us know what you think of the show, we look forward to connecting with you again in our next episode of Changing what's possible.