**Jill Harrison:**

Hi, this is Jill Harrison, Executive Director of the National Institute on Aging IMPACT Collaboratory at Brown University. Welcome to the IMPACT Collaboratory Grand Rounds Podcast. We're here to give you some extra time with our speakers and ask them the interesting questions that you'd want to hear most.

If you haven't already, we hope you'll watch the full Grand Rounds webinar recording to learn more. All of the companion Grand Rounds content can be found at impactcollaboratory.org. Thanks for joining.

This podcast is in honor of Thomas Doyle, a valued member of the IMPACT community who passed away in July 2022. Tom worked to enhance care and quality of life for those living with dementia and their care partners through advocacy and sharing his personal experience. We're grateful for his participation in the IMPACT Lived Experience Panel and Stakeholder Engagement Team.

**Heidi Gil:**

Welcome to the podcast on partnering with people living with dementia and care partners in embedded pragmatic clinical trials. My name is Heidi Gil, and I'm the Chief Strategy Officer for LiveWell and the project lead for the Empowering Partnerships Project that was highlighted during the Grand Rounds presentation.

Just for a little background, LiveWell is a non-profit organization with a 30-year history of pioneering services and experiences that empower persons impacted by dementia in community-based and residential settings. The Empowering Partnerships Project is LiveWell Initiative that was funded by PCORI and a Eugene Washington Engagement Award.

The goal of this project was to enhance the participation and engagement of people living with dementia and care partners in all aspects of the research process. During our Grand Rounds presentation, we highlighted the Empowering Partnerships Toolkit that is available as a result of this project and learned about additional resources available and the role of the Stakeholder Engagement Core and the Lived Experience Panel that you'll hear that our participants are a part of today.

We also heard these amazing stories of three investigators that are doing research differently through the partnership with people living with dementia. Their experiences of gauging people impacted by dementia has been described to me as both professionally and personally transformative.

For today's podcast, as a companion to their inspiring messages, we wanted to hear the inspiration of two people living with dementia and make certain that you heard from people living with dementia to underscore why partnership is so important and imperative to meaningful research.

So, with that in mind, we are so fortunate today to have LuPita Gutierrez-Parker, a retired social worker, and Thomas Doyle, a retired professor. They're both part of the Lived Experience Panel and the IMPACT Collaboratory Stakeholder Engagement Core, and are simply rock stars. Welcome, LuPita, and welcome, Thomas.

**Thomas Doyle:**

Thank you.

**Heidi Gil:**

Let's just jump right in, as they do in podcasts, with a great question for you both. I think the best question we can start with is making certain that we hear your story. So, can you start by telling our listeners highlights of your story? LuPita, would you like to start?

**LuPita Gutierrez-Parker:**

Sure. Well, my name is LuPita. I'm in Yakima, Washington. I am the fifth of six siblings, and I, so far, am the only one that has now early-stage Alzheimer's. I was diagnosed when I was 60-years-old, so I'm retired now.

I've been doing volunteer work, basically dealing with Alzheimer's. I was part of the National Early-Stage Advisory Group, and that catapulted me to other areas. Now I'm involved with research, and also I've served on different committees because of the national Alzheimer's Association.

**Heidi Gil:**

The grass doesn't grow underneath your feet, does it, LuPita?

**LuPita Gutierrez-Parker:**

No.

**Heidi Gil:**

No, it doesn't.

**LuPita Gutierrez-Parker:**

Can't stop.

**Heidi Gil:**

Thomas, do share highlights of your story.

**Thomas Doyle:**

My name is Tom Doyle. I am married to the love of my life, Levi, who's also my care partner. I have three children from a previous marriage and four grandchildren. My life was my work, and I was a professor of education for 35 years.

I remember that all of a sudden things began to become difficult. I had always prided myself on having lectures where I was extemporaneous, and all of a sudden I couldn't do that. I couldn't remember the lectures. I couldn't remember the answers to questions. And so, after dealing with this and having panic attacks and anxiety over this, I met with my chairs of the department, and I told them that I just couldn't do the job anymore.

So one day, October 7th, 2015, I was gainfully employed in my dream job. And the next day I was on disability. It was one of the darkest hours of my life. I began to isolate and was fearful of dealing with other people because I would get lost in my thoughts. I really struggled.

I remember that my husband asked me if I would feel more supported in Illinois. We were living in California at the time. And my family, my dad, my brothers, my nieces and nephews all live in Chicago. And so we moved to Chicago, which was a real test for my husband who had been born and raised in Venice Beach, California. But we went, and we packed up everything and went back to Illinois.

It was there that I was introduced to the Alzheimer's Association. It was, for the first time in my life, I felt like people understood me. And it was such a positive experience. I was involved in support groups and then was selected to be on the Early-Stage Advisory Group, where I spoke all over the country telling my story and sharing this story.

All of a sudden, my life, which had little meaning or purpose after I quit my job, all of a sudden my life had meaning and purpose. It was due to the Alzheimer's Association that my life had meaning, purpose, and joy.

That's a little bit about my story. And I've enjoyed working for the Alzheimer's Association. I was on the national board of directors for the Alzheimer's Association for two years, and continue to be very busy with the Alzheimer's Association.

**Heidi Gil:**

Mm. Well, hats off to the Alzheimer's Association. I love the parallels of your story that you began to see how you can live well with dementia through the engagement with peers and through the engagement in the organization that could bring you that meaning, purpose, and joy.

I love these stories and starting there because this is the first step, I believe and I've seen happen, where we build strong relationships and partnerships through these stories. I'd like to kind of deepen your story by understanding and listening to and internalizing with our audience, why are you interested in partnering with researchers? Would you like to go, LuPita, first?

**LuPita Gutierrez-Parker:**

Oh, sure. I feel like I'm excited about doing this because it gives me an opportunity, myself, to engage and keep learning more and challenging myself. That's been a personal goal there.

But the other part is that I think it's important that underserved populations are always represented and also people of color and all other individuals who do have Alzheimer's. It's been difficult at times trying to remember certain things, certain words, expanding on ideas, but I still continue to do that. And staying involved with what we're doing now, working with the researchers really makes me stay on task, and it gives me another opportunity to assist where I can, and use what skills I do have left towards that and giving input where I can.

**Heidi Gil:**

Well, LuPita, I've seen you in action, and your wisdom is so instrumental to the work that investigators are doing. Thomas, what is your why?

**Thomas Doyle:**

I'm also hopeful to use my background and continue to learn and apply my knowledge. I believe we have an impact on making sure the right topics are researched and the right projects are funded and then implemented.

**Heidi Gil:**

So true, Thomas. There's so much that we can cover when we think about supporting people living with dementia through this in meaningful research. And if we don't start by asking what matters most to you, we've really missed it. So thank you for that.

I'm curious about a high point experience that you can sort of recall when being engaged with research. What's an example of what's happening that gives you that joy and meaning and purpose?

**Thomas Doyle:**

I've been involved in research projects that have gone well, and it all comes down to the relationships that are formed. I think the relationship between the researcher and the person living with dementia is of the utmost import.

I'm still in contact with some of the researchers that I've worked with, and that is very rewarding. I still stay in touch with the researcher that worked with me at Northwestern, and I continue to be involved with that research. I do neuropsych testing each year with them, and they get my brain when I finish this life because I think it's important that we give back so that new items can be found to be helpful.

**Heidi Gil:**

Thomas, I'm sure that researcher has gotten so much reward and inspiration from working with you. And again, that staying in touch is obviously a great example of the impact you've had on his life.

LuPita, how about you? Is there a high point experience that you'd like to share?

**LuPita Gutierrez-Parker:**

What I would say is some of the programs that I've been exposed to with this organization now has been really good. Like your organization, that really was very interesting, and it was exciting to hear about the work that your organization has done.

I enjoy what the researchers are working on, are listening to, providing input to wherever I can that would be useful. And also being involved on the Lived Experience Panel, that was a good experience. Also gave us an opportunity to continue working towards positive change for people with dementia and researchers. I think a lot of the times that we need to continually improve our working relationships with researchers so they can understand us and we can understand them.

**Heidi Gil:**

One hundred percent, LuPita. With that in mind, I want to lean into a little bit that sometimes experience with partnerships or engagement in research has not gone so well. And I know researchers have all the right intentions when they move into this space where they want to partner with people impacted by dementia, but we can learn from understanding and knowing an experience potentially that you'd like to share when maybe it didn't go so well. So, would Thomas you'd like to share a time that maybe it didn't go so well?

**Thomas Doyle:**

Sure.

**Heidi Gil:**

What can we learn from you?

**Thomas Doyle:**

I was involved with a study with Lewy body dementia, and I had an experience that was not very positive. There was little relationship that was established. Instead, they went right to work at giving me a spinal tap, which took six tries. And then they took me to have a DaTscan into the hospital.

I went in to do the DaTscan, and when I was done, the gentleman told me, "Okay, you can go back to the research office." Well, I couldn't find it, and I became scared because he just left me there. So I couldn't find my way out of the area to go back to the research place. It was very dementia unfriendly.

I remember also standing in line waiting to go in for a research study and someone got angry. And I had to listen to this angry exchange, and that was a terrible experience. And so, I quit that research project just because I felt like I wasn't being listened to and I wasn't being heard.

**Heidi Gil:**

Yeah, Tom, it sounds like you didn't really understand the expectations or what to expect and when to expect it. So really being clear upfront about that sounds like would've been helpful as well. Does that make sense to you?

**Thomas Doyle:**

Yes, perfect sense.

**Heidi Gil:**

Yeah. LuPita, how about you?

**LuPita Gutierrez-Parker:**

I haven't had too many experiences in that respect, but I do believe that we need to sensitize researchers and people that work with us directly, and also the doctors and medical staff and care providers. What's important is that they need to look at us as a whole and not just, oh, they have a one disease, and this is the disease, and we need to monitor that, and we need to try to provide some kind of medication if that works for them, and so forth.

And I think in my opinion, they need to look at the whole person, the whole perspective, and where that person comes from. Researchers, they don't live our experiences. That's why I strongly believe that it's important for us, like Thomas and myself, and others, to continue to give input as to what's being done and what's being said.

There are times, for example, acronyms, I mean, for us, before my disease, tell you exactly what all those meant. Now it's like, I have no idea. But that is a problem for some of us, and it's important for research to remember that patience is the most important thing too. The problem is a lot of people don't have patience with us, and it takes us time to get going and finish our thoughts and search for those words that will help us in describing what we're feeling and what we're thinking.

And so, I would say patience is important. Words take time to find, of course, and any little thing can change our focus. I know for me, it does. Any interruptions, I lose total focus. I'd like to feel that they're talking with us and not talking at us. I think that's really important.

**Heidi Gil:**

Ah, such rich lessons learned for us and points that you both have made. Thank you so much. I have to say, I have learned so much through my "oops" and hearing the honesty and feedback from people living with dementia. Investigators and others that are wanting to do this sort of partnership know that we're all vulnerable and human, and it's just this kind of honest, raw communication that's needed for success.

Moving along to the next question, one that came up during the Grand Rounds presentation, a participant indicated that when working with people living with dementia this person often finds that the care partner is often speaking for the person living with dementia.

And so, the question was, when possible, do you think that we should consider having separate sessions with people living with dementia and care partners? Tom, do you want to reflect on that question?

**Thomas Doyle:**

Yeah. I've had very positive experiences where the informational sessions for support groups were done together with my care partner. And then there was a breakout session with discussions that were held separately between both the care partners and also those of us living with dementia.

It is helpful to connect with my peers. And it's also important to have opportunities that are separate. There are times when we have more to say, and there are issues that we need to get off of our chest. So, I think it's important that we meet together for a while so that the researcher understands the dynamics between the care partner and the person living with dementia, but then to separate, so that the person living with dementia can discuss their issues and the care partners can discuss their issues together.

**Heidi Gil:**

So, it's both and, it sounds like, Thomas. Yeah. Great. How about you, LuPita, what do you think we need to do?

**LuPita Gutierrez-Parker:**

I agree. It's important to have separate time. I know we did that when I was in a group before, and we learned a lot from our care partners together, but also separated I think is where you really allow... and it gives time for the care partners to have their time among their own peers and talk about what is being done and how they feel, because they need to check in with each other. They need to have a resource themselves and their opportunity to speak.

With us, the same thing, we need our time too, because, I agree with Thomas. It's just really difficult sometimes being with our care partners. I'm fortunate to have my daughter, youngest daughter living with me. She came home as soon she found out about my diagnosis to help me. And now she's my care partner.

It's really helped me a lot, but I also understand the burden that it causes and also how difficult it can be, so I'm glad she has that opportunity to be able to get in support groups and be able to talk amongst her peers so she can relate. I mean, they can relate all together as to what's being done and said, and they need that. And we need that ourselves.

**Heidi Gil:**

Well said. And thank you. I think, LuPita, you said we're all going through this together. And, at the end of the day, how we share together is so important, but being able to really understand one another's experiences maybe comes from that separation at times as well.

I would like to sort of move into thinking about topics and priorities that matter to you as it relates to doing research. Through the Empowering Partnerships Project, we experienced five priority topics that emerged that matter most to people living with dementia.

Those five categories are reducing stigma, maximizing independence, fostering close relationships, increasing social activity, and improving the diagnostic experience. I'm curious to hear from both of you, is there one topic that particularly interests you and why, or what may be missing from this list? Tom, would you like to start?

**Thomas Doyle:**

Sure. I really greatly enjoy and benefit from the concept of integrated health. I've been very fortunate to have doctors who care about the whole person, so that's very important to me.

I just became a member of PACE, which is a Program of All-Inclusive Care for the Elderly. I'm just loving it because I go once a week to the clinic. There at the clinic, I have a social worker, I have a physical therapist, I have lunch, I have transportation there. It is just all-inclusive. And I meet with all of my doctors, and they all meet together and discuss my case. Everything is right there at the center, including a gym where I can go and work out. Everything is included.

I like that because they learn to know who I am, and I know that they are watching me and taking care of me. That's one of my favorite topics, is the all-inclusive, holistic approach to dealing with people with dementia.

**Heidi Gil:**

Thomas, just to lean into that more, I'm wondering, what comes to mind is how that integrated health experience might improve the experience of being diagnosed with dementia in the first place, if you were introduced to a program like PACE. Do you think that would have been instrumental to have come earlier on when you were diagnosed?

**Thomas Doyle:**

Yes. Yes, because it's important that those of us living with dementia have a dementia-friendly environment. It's very dementia-friendly. I wish I would've had that at the very beginning of my diagnosis, but I've had to wait a couple years for it. But now I am just thrilled because everything is one stop shopping, and I know they care about the whole person. That's so important to me because they do care about me.

It's interesting that when I was in Chicago, I used to speak at neighborhood functions where neighborhoods were becoming all-inclusive for people living with dementia. And they became dementia-friendly communities. That was a powerful statement to me because they cared about people who were living with dementia and wanted to make sure that their programs were fostering a dementia-friendly environment.

**Heidi Gil:**

Yeah. That's great, Tom. Thanks for sharing more about that and how it links t not only the experience of when you're first diagnosed, but maximizing independence, probably fostering relationships and increasing social activity. I think some of what you've described really hits many of these topics. Let's find some investigators that want to delve into PACE with you to demonstrate the great things that are happening and the outcomes that are occurring for people living with dementia.

LuPita, do share a topic or what's interesting to you to see researched further.

**LuPita Gutierrez-Parker:**

Socialization and maintaining your independence have been difficult because of COVID, so that was really important to me. I honestly feel like I lost two years of my life because the socialization in the community wasn't there for me. Talking by telephone, yes, email and so forth, we had that, but it just wasn't the same as being able to connect with people. Also, being in support groups locally, that was not possible.

I just feel like that was really difficult at that time. I wish that we would have programs like Thomas was talking about all over the United States because we need to have that where all of the needs are being met.

It's a holistic approach, I think is wonderful for dementia patients because right now, what about those rural areas and the underserved populations? There's limited as to what's out there, and we need to investigate that, and we need to bring more services to people in those communities.

I think the work that's being done now and what they're discovering in programs like PACE and what they're learning from that I think is exceptional. And I really support that.

**Heidi Gil:**

Yeah. LuPita, how do we ensure that we do have this equity in healthcare no matter where you live and that choices are more abundant? I appreciate your comments and thank you so much.

The next question is around words of wisdom that you would share to create buy-in for doing research in this way in partnership. This question actually came up also in the Grand Rounds presentation. Could you give us some insights on how can we create buy-in? What's going to motivate people to partner in research with people impacted by dementia?

**Thomas Doyle:**

I think it's important that we create buy-in. We need to really listen to one another, and it's important that the researcher listens to the person living with dementia so that they can learn their story. That is building a relationship, and I think it's important that there is a relationship between the researcher and the person living with dementia.

We have an opportunity to listen before jumping into our agendas. I hope that leaders are listening to what we have to offer and how we can add great value to their work.

**Heidi Gil:**

Mm, fantastic. LuPita, your thoughts?

**LuPita Gutierrez-Parker:**

I agree with Thomas as well. How will they get the research completed without our voice at the table? I think that's really important. Researchers, they have to sit down, and everybody, administrators and so forth, have to sit down and really listen to what our perspectives are and what we have to say. Maybe that will give them insight into what research they should be doing or need to be doing and currently are doing. It would be greatly impacted by that.

And when this experience occurs, I think that people will have buy-in. I think anytime there's an opportunity to improve or to provide quality services to dementia patients, that will help them. I think they'll be very supportive.

**Heidi Gil:**

Mm. So wisely said. I want to share that I'm so pleased to be working with you both in the IMPACT Collaboratory Stakeholder Engagement Core to advance how persons living with dementia, care partners, and researchers are trained and are developing a team to identify, design, and implement, and disseminate research. We have a lot of work ahead of us, don't we?

**LuPita Gutierrez-Parker:**

Yeah.

**Heidi Gil:**

Yes, we do. You both have expressed to me a feeling of hope and inspiration for what the future holds in partnering with researchers in this way. With this in mind, my final question to you is, in one year, it's a year later from today, what progress has been made? What are the highlights and success stories that we'll be sharing about partnership in research? What are the teams doing that we've brought together that are trained and doing this work?

**Thomas Doyle:**

Well, relationships are key. I've been a part of research studies, and the researchers stay in contact with me because we built a relationship. And even when I'm not being interviewed by them, I still have contact with them.

One of the researchers that I worked with would take me out to lunch once a week, and we would just talk, and we got to know each other. And so there was a feeling of trust that developed. I think that that relationship is so important between the researcher and the person living with dementia. The person living with dementia needs to feel comfortable sharing their story with the people that are doing the research.

**Heidi Gil:**

Yeah. Thomas, it makes me feel like we have to really think about, intentionally, what that looks like. You just had an example of I had lunch once a week with the investigator I was working with. While that might be something that doesn't happen every week all the time, how do we start with that breaking of bread, if you will, and mealtime experience where we're really enjoying conversation and getting to know one another? Let's be really intentional about how relationships are formed and how they continue with researchers. I love that theme has come up a lot today, and hopefully our audience is hearing that loud and clear. How about you, LuPita?

**LuPita Gutierrez-Parker:**

One year from now, hmm. I would say researchers have listened and the dialogue has changed. It's improving. Also, the communication, that's improved, and they understand what we're going through. We've been trained to do research together. So people like myself and Thomas, people with dementia, that they also have an opportunity to be engaged in projects as well, research projects, and working with researchers.

I would say to researchers also writing in their grant funding for more funding to assist in underserved populations and finding more people in rural areas to participate in the research. And they're helping people by writing in their grants and so forth funding for their transportation, their hotel costs and so forth, because in the cities you have access to all of that, whereas in rural areas you don't.

So, I would suggest that, and I would in the future like to see that more and more for those rural populations, as well as bilingual and underserved populations being served. But communication and relationship is so important. And hopefully in the future, that will continue to be existing stronger too.

**Heidi Gil:**

Ah, LuPita, we're so lucky to make certain you have brought up that importance of rural and underserved populations, as well as how investigators go about that actual funding design of engaging people in rural and low income areas.

There's a real need to figure out funding for how people come together and get trained. As you said, we're all going to be trained in a year. Not everybody, of course, but we're going to have teams that are trained together to do research together. So, what does the funding mechanism look like for that as well? We have a bit to figure out, but all of these ideas are completely doable, and we will get it done, so thank you so much.

Before we close, I want to share for our listeners that the Empowering Partnerships Project is now becoming the Empowering Partnerships Network. This is a network of people living with dementia, care partners, and researchers and other stakeholders that care about them that are partnered to transform the experiences of those impacted by dementia, through research, as we talked about today, but also in working on policy and practice.

If you'd like to hear more about the Empowering Partnerships Network, please reach out to me. I'd love to share more detail. Please contact me at my email address at H Gil, H-G-I-L, at LiveWell, L-I-V-E-W-E-L-L, dot org.

Thank you so much, Tom and LuPita, for sharing your stories and your wisdom. And many thanks to our audience for listening. I look forward to working with you and others listening in on this call over the next year and beyond to create energy, shared purpose, and momentum to doing research in partnership.

**LuPita Gutierrez-Parker:**

Thank you.

**Thomas Doyle:**

Thank you.

**Jill Harrison:**

Thank you for listening to today's IMPACT Collaboratory Grand Rounds Podcast. Please be on the lookout for our next Grand Rounds and podcast next month.