Transcript:
Youth Participation in Research and Leaving a Data Legacy

Kyle: If my story can help out somebody, then I'm super, super happy with that, for people to be able to say he helped expand research through telling about his experience.

Amanda: Hello and welcome to this podcast about youth participation in research. I am your host, Amanda St. Dennis. I am a member of CP-NET, both their advisory committee as well as CanChild Transition Hub. And I also am a co-investigator in a research project about barriers and successes in research for participation of youth with neurodevelopmental disabilities. With me today are Anupra Chandran and Kyle Chambers. I'm going to pass to Anupra to introduce herself to the audience.

Anupra: Awesome! Thanks so much, Amanda. My name is Anupra. I'm 18 years old and I'm in Grade 12 and I'm really interested in the science behind why we age. The reason I'm really interested in this field is because the things that happen to ourselves as we age end up contributing to a lot of different diseases especially diseases related to the brain – Alzheimer's and Parkinson's – and even other conditions. So I'm really interested in researching that and how we can understand those processes better. I've done some projects on the side with places like a lab at the Krembil Brain Institute in Toronto and Apollo Neuroscience which is a startup in California. I also did some volunteer work with patients trying to help them understand different innovative clinical trials out there with the Rare Disease Clinic at the Neurology Centre of Toronto which is how I got connected to this opportunity.

One of my biggest priorities is my own startup that I co-founded with a few friends. It's called Biotein and we're trying to build a device that kind of looks like a rapid COVID test and it's under 30 dollars. But instead of detecting COVID, it would be for tracking biological level health as people age so that people around the world can understand their aging process and not wait until they get sick to understand what's going on in their biology. I know when I say that I'm interested in aging people often assume that like I'm trying to build some sort of immortality potion or something but really I'm more interested in it to help people lead healthier lives.

Amanda: Thank you so much for that introduction as well as your involvement in research. Kyle, how about you? What's your involvement in research?

Kyle: Hi everybody! My name is Kyle Chambers. I am 21 years old. I have cerebral palsy myself. I am a patient partner with CanChild and I'm really excited to be here. Thank you, Amanda, for inviting me on this podcast today.

Amanda: In your role as an advisor and patient partner, what is your experience?

Kyle: So throughout my experience as a patient partner, what my goal is with CanChild is to be an advisor to help make healthcare better for people transitioning from pediatric to adult care with brain-based disabilities including creating an app for people that are

between the ages of 15 and 17 years old to help them transition to be more independent with their healthcare both in the system of specialists and within their general lives within healthcare as well and really to be a support for people that are transitioning from pediatric to adult care as I have been transitioning myself over the last six or seven years as well. So it's been a great project.

Amanda: It's interesting how both of you although have different roles in research are both working on the idea of longitudinal success as well as trends and transitions which brings me to our next question of, what is the value that being part of the research brings to you? I'm going to ask the question to Kyle first.

Kyle: The value of the research brings to me is really interesting because it really shows me what we can do better to help improve the lives of people that have different brain-based disabilities and people's healthcare in general so they can have better lives. The more we know to help people, the better people are going to be, the better doctors are going to be and the better quality of life people are going to have in general both in the healthcare system and outside the healthcare system. So I think it is extremely valuable to know these things for research.

Amanda: That's interesting. That's one of the reasons why I also engaged in research because I bring value to myself by knowing that my efforts and my attention to detail and attention to accessibility is going to better aid generations after me. Anupra, you are working much more in the biotech side of research which I think is really interesting and it's not something we often hear teens being involved in. What drew you to being involved in research and research surrounding biotech but then also to create a startup of your own?

Anupra: I loved reading about different things in Biology, looking at things under the microscope and I think a lot of kids are curious like that. But I think a lot of kids are also told that like once you are a lot older then like you can use that curiosity to do something big in the world and, but it was through meeting a lot of different mentors at places like the Rare Disease Clinic, places like EpLink and even like entrepreneurship accelerators like one called The Knowledge Society which I was a part of. Those places really shifted my perspective in one key way. There are a lot of ways in which our mindset around health really needs to be changed. We wait until we get sick to go to the doctor when really if we could check our health even when we are feeling good we could probably catch a lot of those signs of disease. So I kind of just was really motivated by that idea of like changing mindset around health by making health tracking a lot more accessible. Like what if you could check your biological level health as easily as like checking your phone.

Amanda: That's a really interesting message that we can give to youth and to participate in research either as a patient in terms of having data collected from them and shared with other researchers or as youth advisors/partners in terms of helping to direct our study.

Anupra: Sure.

Amanda: In addition to what both of you have mentioned, what other advice would you give to youth as to why it is important to participate?

Kyle: I think it's really important to participate in research because it helps grow the field of research. So the more people that participate in research, the more background that researchers can get of how they can grow and how they can expand. So people's experiences are different and people's backgrounds are different. For example, my experience is different than Anupra's, than Amanda's, So even in that small realm of things, always participating in research where you can helps to expand the realm of research so it is more accessible to more people across the board.

Anupra: I totally agree with like trying to make a better future with research because like when I think about why I'm involved with research whether as a participant or like an actual researcher, it really is just about the future. There are so many futuristic technologies out there like different neurological implants and new drugs that could really have a huge impact on so many different neurological diseases. It's just sometimes it feels like innovation in healthcare especially is going so slow and we're not really seeing that futuristic paradigm shift. And I think a big reason for that is there're just so many root causes to why these technologies exist but can't be used affordably yet, different like materials contributing to the cost or the efficiency. There're so many little problems like that that the general public doesn't necessarily see and that there's not quite enough people working on. So I think by being involved with research whether as a participant donating your data or as a researcher, I think it's pretty cool to be able to tackle those little root causes.

The other thing is for me research really taught me to be a better critical thinker. When you're involved with the research process whether as a participant or actually going through the rigorous process of doing a research study, you really learn like how much work goes into claiming something is true or false. And as a result, you kind of gain a better critical eye towards what you read online.

Amanda: That's a really good point about the skills that research can teach you. I know for me being a co-investigator in a research project currently, being able to put what I've learned in post-secondary education into an actual product and into an actual experience has been absolutely mind-blowing. It's taught me that what I've learned is not useless information and what I have to give is also not useless information. I wonder, Kyle, has participating in research given you any skills or experiences that you don't think you would have gained as easily or otherwise?

Kyle: I think for me personally the ability to speak to adults and speak to doctors not from like a patient level but from a more professional level and to be involved on that level has been really, really interesting and I think it's helped doctors, researchers to talk to teens better as well and so we can work together. That part of it has been really cool and really interesting to see how we can work together to make research better as well.

Anupra: Yeah. If I could add on to that quickly, that's a really good point because I guess before I got into research I was a pretty shy person, didn't talk to a lot of adults but having to go through the research process and pitch my ideas to professors or investors that really just taught me to like not just be confident in my ideas but kind of explain them in a way that people will understand.

Amanda: Yeah. And I also wonder just how much more confidence that brings to youth being able to take control over in the case, as Kyle said able to take more control over their healthcare over advocating for themselves. The same with you, Anupra, you had to advocate for your project for this is why you should believe in a teen with this idea. And that's advocacy and I think that skill can help all of us. But you wouldn't realize that that's something you could get out of research. Is there any other benefit that you get out of participating in research whichever way that that looks for you?

Kyle: I think what's really cool about all of this is hearing different people's stories. So I've done different focus groups and different talks and I've spoken with different things that CanChild has done where I'm representing CanChild and doing things virtually online all over the world and some stuff in person and to be able to meet people, hear their stories, hear where they've come from and we can connect and kind of talk about each other's stories. Kind of saying, you know, you're not alone and this is my story, how I got here and this is your story.

Anupra: On the side of like building technologies and doing research for people and like understanding diseases at the personal level, I definitely agree with that. I think by being involved with research I've also been able to talk to a lot of people who would be using the ideas I came up with. A lot of the time you're thinking about like what would I want in a product or what would I want to know from this research and sometimes it's easy to get stuck in your own head and not always like have the best grasp on what patients and other people are actually looking for. So I think those types of conversations really helped me to learn how to ask better questions and understand other people's perspectives and step into their shoes.

Amanda: The interesting point is that research can bring community. I know that the work that I've done has given me connections and probably strengthened existing friendships in ways that I couldn't imagine. And especially during a global pandemic, it's been really interesting in how all these meetings that I've attended have been my lifeline to social experience and social connections. So it's really interesting that both of you actually highlighted the fact that research can lead to community which is something I think all humans need to thrive. I think we've kind of mentioned some of this in terms of contributing to society as part of research. You guys have both pointed out how being in research allows you to make a better future for others. Is there anything else that you would want to add to that idea of why research is so vital, why participation is so vital?

Kyle: Ability for people like researchers, doctors to see what different people are going through and then to see for the patient level what the doctors are working on. It brings it down to a more human level so you're not just dealing with a doctor and a researcher. You're dealing with a team of people. By having that personal level where you can all work together as a team is a really, really cool thing.

Amanda: Kyle, do you believe that this more equal footing that being a research partner allows for better understanding and better results in healthcare?

Kyle: I do think that it does allow for more equal footing. The more the doctors see the patient's side and the more the patients see the doctor's side help with everybody. I know since I was five and all the way up to now even when I was all the way down to a 1-year-old and growing up going to specialists for my Botox for my cerebral palsy, because of research and because people have talked both at the funding level at universities and talked to patients, the healthcare has increased and improved so much so not just with myself with CP but across the board. The more we can come down to each other's level or come up to each other's level and be on similar ground, the more research will improve and evolve.

Amanda: Anupra, I see the nodding head so you see some agreement with what Kyle said. So both of you have touched upon how it helps the next generation and both of you have kind of touched on how it helped currently. But is there anything else that you would add to what you feel you contribute to society by being part of research?

Anupra: Yeah, for sure. I think one big thing is just a better understanding of the body as a system. I think a lot of people assume that since we've had so many medical advancements and like we know so much more about Biology than we used to, people kind of assume that like we're set, we understand the human body. But I think the human body is like if we can get a better understanding of the body as a system we can build better solutions for different diseases that don't just tackle one part of the problem. That's a really huge impact on society. And then beyond that, once we have that understanding actually making that understanding accessible whether it's through health tracking products like I'm trying to build or just like publishing that research and like making sure it's written in a way that the general public can understand and like it's distributed in a way that they can get access to it, I think that accessibility is going to be a really important societal impact. And the more that people get involved in research as participants, the more that accessibility can spread and people can just gain more exposure to that.

And then to Kyle's point about how being involved in research kind of gives more equal footing, something I've noticed is that a lot of people in biotech research are people who've been in the field for like 20 years or more but I also think that perspectives from kind of outsiders who are just entering the field are really important as well and that's something we don't see as much of. So at least when I speak about my experience in research as someone who's been doing research for like two years, I really try to hit home the fact that like if we can get those outsider perspectives we could get really new ideas that someone who's been in the field and been very isolated in it might not have. And I think with that diversity in ideas we can create a lot of really interesting solutions for society.

Amanda: Which leads to an interesting question remembering that new ideas come from new people and that means that people need to actually be welcomed into the research communities. If, say, money and policies and everything that governs research wasn't a huge limit, what would you ideally want to see research evolve into?

Kyle: I think for me sometimes it's not always about money but it's just the way that the people at the top – the doctors, the researchers, the scientists – treat the people – the

patients and people that are using the apps or using the healthcare – realizing their perspective. There're things that you can do that don't need money. For example, my dad says it costs nothing to be nice. Basically, helping to improve the healthcare that doctors do for patients and patients can do for doctors, that part of it you can always expand on without funding or with limited funding.

Amanda: That's actually a really good point that research isn't always just about the end results and about the – lack of better words – the experimental results and the numbers and the data. There's also a social component that I think a lot of researchers and a lot of patient participants, partners forget needs to also exist. And so I do agree with you in the terms of research can get even better by remembering that there's a person component to research and that the basic skills that you learned in elementary about being nice and sharing information and treating people respectfully isn't something that you should just forget because you are doing high-level research. What about you, Anupra? If you could go anywhere with research, what would you like research to look like?

Anupra: I think a big part of that will be kind of open sourcing the whole research process to the people that this research is actually going to affect. What do people want, how can people put in their bids for like what should be researched especially like people affected by different biological conditions, I think like that level of involvement not just getting people as participants but helping people make decisions about what even is being researched, that's where I would like to see research go. I think that would be really cool.

Amanda: So we've talked about how things are changing and how we've been a part of some of that change. So with that said, what do you want your legacy to be in research?

Kyle: For me, it's not so much about a legacy in research. It's more so telling my story and telling my story kind of as a patient partner along with researchers to help expand the research. And if my story can help out somebody, then I'm super, super happy with that. If it was to be a legacy, just for people to be able to say, he helped expand research through telling about his experience and what he thinks how research should expand as well. And I think that this podcast has definitely done that today.

Amanda: Yeah. I'm in full agreement about this podcast in terms of just having it accessible is a legacy of the fact that we're having this. Like I don't think this is something that would have been thought of doing even 5, 10 years ago. What about you, Anupra? What would you want your legacy to be in research?

Anupra: Something I wish I had when I was really interested in Biology was like a window into my own biology so I could know what was going on in my cells especially like in brain-related processes. And I kind of want my legacy to be someone who like changed the mindset around health to bring that to people in an accessible way or like building health tracking products so people can understand their health and not be in the dark anymore. The same way that, you know, the iPhone changed accessibility to information, like changed the way we live, I want to do that but like where it comes to health and preventing disease, kind of like almost like a Fitbit or Apple watch but for

understanding disease. I'd want to be able to be known as someone who built solutions like that.

Amanda: Which is really an interesting way of putting it of you want to be known as building solutions and I think that's really what all research or at least I hope all research wants to be a part of is building solutions and solutions don't always have to be huge or progress doesn't always have to be huge. Is there anything else that you would want listeners to know about your participation in research or the benefits of research or anything that we've touched upon in this conversation?

Kyle: I think for me if you can get involved in research even if it's at a small level, talking to people through a Zoom call, getting on a committee even that meets once a month or a couple of times a year, your opinion does matter. So talking to people about research, about your healthcare is really, really cool. And if you can get involved, I encourage you to get involved. Even in this conversation, podcast today, we have three people. We're all from very different backgrounds and very different committees. The fact we're able to come together and have this conversation is really cool and I think it benefited all of us. It definitely benefited myself. So thank you.

Amanda: Yeah, I definitely have to say I've learned a lot from the both of you and -- Anupra, is there anything else that you would like to add or expand upon that we've discussed today?

Anupra: Yeah, definitely. I think people underestimate the power of just writing an article yourself even if it doesn't get like a billion views or whatever. I think the more content people put out there, of course, based on reputable sources not spreading misinformation -- If you've looked into an issue a lot and have an interesting perspective on it, I think people should feel free to post about it whether on a blog or on Instagram because I think there may be someone just like you looking for a resource on a very specific research issue that there just aren't very great resources for out there right now. So that's something I like to do and I think that's something that people can take part in and like take action in after this call.

Amanda: Thank you to our audience for actually listening to words coming from youth because it is just recent – at least in my experience – it's just recently that youth voices are being amplified in research and we would like to continue that. So again, thank you to the audience for tuning in and listening. I hope you've learned something along with us because I know I definitely have. And again, thank you and goodbye.

This podcast is actually part of a series dedicated to open science and data sharing. Our motto is "Discovery starts with you." If you're interested in learning more about this campaign, please visit braininstitute.ca/discoverystartswithyou. Thanks for joining us and until next time. Goodbye.