Transcript Episode 6: Research Behind the Scenes Podcast

[Music]

## Chloe: [00:00:00]

 What it did is it confirmed for me that we are overlooking a population consistently that's really capable of contributing. And so it's been a real pleasure to listen to their experience. It's been an honor in some ways to listen to their experience. And I feel grateful that I've had the ability to do this; to do this project.

## Andrea: [00:00:27]

Welcome to Broadcastability a podcast by, for, and about workers with disabilities and inclusive workplaces. It's part of the proud project at the University of Toronto. You can find out more about the Proud Project on our website, Theproudproject.ca.

## Chloe: [00:00:44]

This podcast was recorded and produced on the traditional ancestral territories of the Huron-Wendat, the Seneca and the Mississaugas of the Credit River. We would also like to acknowledge the other indigenous lands across Turtle Island where we conduct our research and record this podcast. Miigwech [thank-you].

## Isabelle: [00:01:06]

Okay, so my name is Isabelle Avakumovic-Pointon. I'm a graduate student in the Center for European, Russian and Eurasian Studies at the University of Toronto. And I'm the graduate research and production assistant for the Proud Project.

## Ahad: [00:01:19]

Hi, my name is Ahad Alingary, and I’m a third-year student at the University of Toronto, and I'm majoring in health studies and mental health studies, and I am the social media assistant for the PROUD project.

## Isabelle: [00:01:30]

And this time to change things up a little bit on Broadcastability, we decided to interview the main researchers on the Proud Project team. So that's Dr. Chloe Atkins and Dr. Andrea Whiteley. So this time it was them in the spotlight. We had an interesting conversation, covered all kinds of topics and our focus was on how they do the research.

## Ahad: [00:01:52]

Yes. So we were talking about what the PROUD project stands for, how they started, ethical issues. We talked about how they present, analyze and share data and what will happen when the research project is done.

## Isabelle: [00:02:05]

Yeah, so it was a bit more about the project itself than the outcomes of it. And I think that's really important, especially in scholarly podcasting and just for our listeners to know a bit more about the project that Broadcastability is about and, you know, how this sort of research is done, and the sort of questions that researchers ask. It's always… it's a bit of a behind the scenes tour, let's say, of the PROUD project. So we hope you enjoy.

## Isabelle: [00:02:33]

Thank you, Dr. Chloe Atkins and Dr. Andrea Whitely, for joining us today on this episode of Broadcastability. We're very happy to have you here. And so our first question for you is, what does the acronym PROUD stand for?

## Chloe: [00:02:48]

I'll take this. Since I came up with the acronym “PROUD.” “P” stands for Phenomenological Research. “R” stands for research. “O” stands for on, “U” for unemployment, “D” for Disability. Now, we speak to people who are employed and live in a disabling context. But my focus was really, what I was interested in, was the problem of the underemployment and the unemployment of individuals who live in a disabling context.

## Isabelle: [00:03:20]

And what is phenomenological research?

## Andrea: [00:03:24]

That's a great question, Isabelle, because using the word phenomenological, not only is it hard to say, but people might tune out when we start to talk academese. So just briefly, this research perspective is rooted in a philosophical approach to understanding consciousness and experience. So this philosophy is found in the works of some 20th century German and French philosophers such as Martin Heidegger and Jean-Paul Sartre and Merleau-Ponty and some others. But our use of the research approach in the social sciences that flowed out of some of this thinking tries to solve problems by understanding the lived experiences of people. So in the Proud Project, we interview people with disabilities in the workforce to try to understand the range and the depth of a problem from the first-hand knowledge and experiences of our participants, and the strength of the phenomenological perspective is that it enables researchers to capture the complexity and the richness of an issue by really engaging with people who are involved and asking them about their impressions and gathering their anecdotes to try and understand the issue more deeply. But researchers actually need to be careful, or another term we use is “reflexive” about this method of analysis. Because both Chloe and I cannot be objective or neutral observers because the phenomenological approach assumes that the researcher also needs to pay attention to their own impressions, experiences and biases as they carry out the research.

## Chloe: [00:04:58]

I mean, I was trained as a political theorist, so, which is really odd that I do work like this, but I think it arises out of my sort of gut instinct that experience matters, that your sense of how you are in the world matters, and it influences how you construct your thought and how you problem solve. And so it just was, I've done all the work in this manner on other things, and it just seemed to me an ideal format, is to draw on people's experience or at the core of it, of what we're interested in.

## Andrea: [00:05:27]

And just as another point, Chloe and I both have experiences with living with disabilities, and I am a caregiver of a person with a disability. So we also are embedded in the experience of living in a context of disability. That's one term that we really like to use now. It's something we've learned during the course of our research is that there's many ways to talk about a person with a disability or being disabled, but we really like right now that term “living within a disabling context.”

## Ahad: [00:06:06]

How did the project start?

## Chloe: [00:06:09]

So that came from me. And that's the great part about being an academic. That's sort of the joy of it, is that you can think up a question that you're interested in and then hopefully you do more work, and you write about it, and then you realize that maybe you can ask for money to go and see whether it's, you know, see whether you can find any answers. So I have a disability, it's an episodic disability. I am a bit odd in the fact that I go from passing as totally normal to extreme vulnerability, to being a quadriplegic on life support. So that's a very broad range. And so what I experienced, I've experienced in my career, is that when I pass as normal, that the workforce, the workplace has been very amenable to me. But when I don't pass as normal, in other words when I use crutches or I'm using a wheelchair or whatever, what other devices, I might need, that then suddenly the workplace becomes much less hospitable and often I'm removed from it because it's too difficult, they see, to have me. I realize that even though I had a disability, I still had a desire to think and work and contribute. And so I thought, well, you know, all these countries that I think of that are liberal democratic countries have made a lot of effort recently in terms of creating laws that should help people with minority identities, particularly people with disabilities.

## Chloe: [00:07:27]

But in fact, there have been no changes in the numbers over the years of participation in the workforce. It just hadn't changed, even though the laws have changed. And, you know, there's lots of studies that sort of reiterate this, like it keeps going, why does it keep going? So I, I didn't think I could get at that, but I began to think about, well, maybe I could speak to people who had obvious disabilities, who had been in my position in a wheelchair, who could not mask their disability, but have managed to have successful careers or get into the workplace and what actually had happened for them to be able to do that. And maybe we could learn by speaking to them about what things they did or what their environment, what were environmental things around them that allowed them to go into an environment that's usually pretty hostile to them, right, to their success, and that we might be able to learn how to add on to what our existing laws do, to advise governments or businesses about what they can or cannot do to encourage people to be more integrated, to have more integrated workplaces. And that law isn't enough, that we have to look at behaviours and contexts. And so I decided that I wanted to look at five countries and that was Canada, the US, the UK, France and Belgium.

## Isabelle: [00:08:39]

But just sort of building on that, there seems to be a lot of practical steps to starting a research project in terms of applying, getting funding. Could you walk us through that process? Like, you had this great idea to do this project, what are the practical steps that you had to take?

## Chloe: [00:08:55]

So one of the things you do is, I had an idea. I'd done phenomenological research about a problem a few years before, so I sort of knew the framework. I'd worked with a sociologist, a medical sociologist, who sort of schooled me in the way to do it. And so I use that frame to guide how I wrote the application and then used my own sort of view of trying to take a positive frame of it, like trying to look for things that worked rather than things that weren't working as a view. And you just try and you do a literature review, you try and read as much literature as possible and show that you've at least done a good… you have a good sense of what the ground is like, what people have said and done before. And then you write it up, and then you do budgets, you try and budget what it's all going to cost and who you're going to hire. Your most expensive cost is personnel. So hiring people to do the work and to bring them aboard. Part of the project is also that I really enjoy the team, like I really enjoy having you and Ahad aboard. You are different levels, you bring different things, you've different experiences. And that's important I think, because it contributes to what happens on the team. And so you sort of you also, so you create a budget for those types of expensive equipment and things like that.

## Isabelle: [00:10:13]

I'm looking down because I'm taking notes. I'm not on my phone. I'm like, “this is actually very helpful.”

## Chloe: [00:10:18]

Can I, can I interrupt a little bit? Can I ask some… I'm intrigued. Both… I want to ask, Ahad this, Ahad, you're in your third or fourth year? You're in your fourth year now?

## Ahad: [00:10:27]

In my third year, yeah.

## Chloe: [00:10:28]

So you're… I mean, you are not a novice at the university. I know that you want to go into medical school potentially or do something. What have you thought about some of the stuff you're seeing going on or what did you think research would be like? How is it different?

## Ahad: [00:10:43]

And yeah, well, I think probably the most important thing that I've learned so far is that I wouldn't call it tedious, but it's very… you have to go through all the steps, right? For example, you want to be wary of the ethical concerns. You have to be wary of privacy issues, all these things, right?

## Chloe: [00:10:58]

Yeah. No, you're right. And sometimes… I actually had a colleague laugh at me this summer and said, “Well, you've built an empire.” I said, “The most minute empire possible!” But it's required, like I felt like, I sort of feel like I know what it must be like for somebody who builds a business because there's HR [Human Resources] concerns, there’s ethics concerns, there’s financial concerns. There's like, “Is your PR [Public Relations], right?” Have you, you know, “do you have a website that's accessible?” You know, we're working in two languages. What are the… it's been… I feel like I'm juggling 50 balls in the air and it's a lot. And when we actually get -- you're right -- when we actually get down to do the research, you know, it’s a small amount of time when we actually have time to sit back and analyze it as another portion of time.

## Ahad: [00:11:43]

Exactly. I think building on that we just mentioned before. So what sort of ethical issues do you have to consider with this research?

## Andrea: [00:11:50]

That's a great question. So about a few months into the project, Chloe and I had an experience where we realized that there was a bit of a gap when it came to the security around our data, and we had to re-evaluate our whole process. And so that was about a three-month, sort of, step back. And working with University of Toronto IT Department or UTSC, University of Toronto Scarborough IT Department, working with the Ethics Board and the staff to figure out to make sure that we make our process even more, kind of, bulletproof, as bulletproof as we can, because we realized that it was really important to protect the privacy of our participants, especially our employees who have disabilities and where we've kind of approached ethics in the past. I may have thought about it and maybe especially grad students, you think about it as a hoop to jump through or a hurdle to get over, and then, oh, now I can actually get to the research once I've thought about all these things and proved to you I'm going to do it in an ethical manner. But for us, it has been integrated throughout the whole project and it's something we always reflect on. How, or should we do it this way? Is this the right approach? And so we're always sort of questioning and feeding off each other, getting feedback from each other about making sure that we're respectful in the way we communicate or discuss disability. We are including our participants in decision-making about whether they want their data included, or we make sure we keep them abreast of the project. So we try to communicate with them as to what we are doing and when publications happen and that sort of thing.

## Ahad: [00:13:34]

I was actually wondering, so how do these… so obviously there's there's privacy concerns, right? How do they apply, for example, if your participant is in Canada versus somebody who could be in France or somebody in England?

## Chloe: [00:13:48]

The main thing that I think about all the time is what do I owe my participants? They're giving me their time, they're giving me their experience. And so what is always in my head, even now, as I'm thinking of writing up something, is I at some level owe it to them that I write it up. Because even though it may be great for my career, I feel the thing that really weighs on me is that they gave me their time. They gave me, they gave me their thoughts. And they have, and their reflections, and I want to value them. And so when I'm going to another country, I think those things guide me. Because what I've learned is that the very frame or what the French might call “le cadre” of ethics is actually just that. Like, there's a lot you as a researcher at some level need to have a conscience that goes beyond just the bare bones of it. So if you become a physician or if someone you're somebody receiving health care and someone says, “Oh, here's the consent form we're going to give you. You need your appendix out,” You know, “these are the things going to happen. You should sign here. We've got to hurry.” And you sort of go, “Oh, okay, I’ll sign it.” Well, you've signed a consent form, but the quality of what the information you've got, the state you were in, whether you were in a lot of pain, like it's not really reflected in that process and only what happens between the two people getting that consent, the quality of it is that's really the ethical matter that happens, right? That's the content and that's not fully like you're taught to some extent, but that's not covered by that form. Right? So I guess what I'm saying is that I try to have a respect for my participants at all times and it's, and be aware that I'm not always going to have the answers. So that's in part why the team is really good, because often I'll say something and one of you will be like, “Well, I don't know about that.” And I think, “Oh yeah, you're right.” I mean, it's just helpful to have another voice that twigs and says, “You should think about something else.” I don't know whether that answers it, but.

## Andrea: [00:15:46]

I think that's a great answer. I'm nodding my head as you're speaking. One other thing. I would say more brains are better also. So it applies in our project, whether it's ethics or whether we're trying to understand Zoom and what to do with it. But one thing is, it's a good question about whether the ethical environment is different in different countries, because there are especially now we're talking about it because of the pandemic, but there have been sort of global regulations or, not regulations, sort of policies that have been put in place that most countries have adopted. So that's one thing. So we can assume that most countries follow the rules of sort of consent as required. Non-malfeasance of the research, meaning it's not going to harm the participant, that it's going to be done with justice, which means that you will try and take into account different communities or minority groups. That should be a part of the research. You're not discounting a whole gender like has happened in the past with a lot of medical research where women might not necessarily have been part of the study group.

## Andrea: [00:17:06]

So those things are pretty accepted amongst sort of the research community across the world. But as Chloe said, we got this approval because we are, we're situated in Canada. But the one thing that we did learn, I learned very recently, is because we're working with these colleagues for this course we're teaching from the University of Manchester, and they work in in the area of Deaf Studies. And so we have two researchers who are deaf who are working with us. And through them I have learned so much more about consent and about ethical treatment of the D/deaf community, which I had no idea about before really. And I felt a little bit ignorant when I started to understand how much better we could have been doing our consent. But again, I feel like when you're a researcher, you don't know it all at the beginning. You also learn as you go through the process. And so I'm grateful for how much I'm learning and can do it better each time I take on a new project. So.

## Isabelle: [00:18:14]

Yeah. That's really interesting to hear how it's sort of it's not a one-time thing; it's a process; it's evolving. It's something that's sort of interwoven with the whole research process. And I think, I think the scholarly community is coming to acknowledge that that's the better way of doing ethics in research. And so you're working with people trying to understand their experiences. How do you find research participants? Yeah, just generally, I, I know it's maybe a little tricky, but how do you do it?

## Chloe: [00:18:44]

 It's the bane of my existence. It's in every project in which I have sought. It's different than if you're doing a polling thing, polling data where you're just going to fill out a form that takes 10 minutes and you're black, red, white. You jump high, you jump low, you sleep well. You don't you know, it's relatively… you can send those out and you just keep throwing them out and hopefully come back. I don't know that process as well, but you don't have to be. It's much more intimate. These things, these engagements where you're doing phenomenological research. And so you're asking for an hour, sometimes a little bit more of somebody's time and it's hard to find them and their criteria. I've set up like, there are criteria I've set up, like, I'm not looking at invisible or episodic disabilities. I'm looking at obvious disabilities, evident ones, things that can't be covered. And so, and that comes out of my experience, right? That if you can cover them, you can get the job. But if you can't cover them, you may have a lot more difficulty. So it's, it's really a hard thing to do. But what you try and do is when you find someone who's willing to talk to you, you then say, would you please recommend me on to anybody you might know is in a similar situation? You may not get anywhere. It's called a snowball technique where you try and use sort of connections to and you know, sometimes you look at in a previous project, my colleague walked into sort of like a patient group. I think it was a social media group who gave consent to give her the list. She suddenly had access to just people all over the place.

## Chloe: [00:20:14]

Whereas I, the last thing that triggered, this wasn't this study, is, I went on Breakfast Television and that suddenly I had more participants than I could possibly handle, like we had way more than we could deal with, because I go on Breakfast Television. So I think it really sometimes, I'm trying to find the key to finding participants. I don't know where to find them. Media is changing so fast. I'm not sure Breakfast Television would do it anymore. People, you know, YouTube channel. Wow. Well, everybody's got YouTube. I mean, it's quite hard to find people and, you know, you say, oh, let's go to the hospitals. But we're you know, we're looking at disability. Disability isn't medical. We're looking at people in the communities living a life and sometimes also members of minority communities, whether they're refugees, whether they're women, whether they're whatever they are, they often get asked to do these types of things constantly. It's sort of like having the one Indigenous person on the committee and let's say they're only one of three people in the whole university. They constantly get asked to be on committees. So there is a fatigue-ability that occurs, right? Some people just may not want to even do it because they've been asked so many times, they've contributed so much of the time, they don't have the energy. So it's hard. Like I just I feel my way through. Like literally my last most recent thing is I sent out 250, 270 emails to various disability organizations in one country, and I got six responses. But I'm hoping through that, that took three days of work. But those six responses, I hope, will, will snowball into context.

## Andrea: [00:21:45]

You know, persistence is the key and trying all sorts of different possibilities. So just to give you an idea of how many different things we've tried, so originally we made sure we had a website where there was a form where people could fill in that they were interested. So if someone came across our website, they would be able to let us know they're interested in being a participant. And then we used every kind of social media we possibly could use to create a following and advertise using posters of various kinds, that we're doing this research. And so, we had two phases of the research where it was starting with employees with disabilities, and then we wanted to talk to employers who hire people with disabilities. So as we mentioned, most of our employees we sent out emails. And the other thing we did is we sent out a whole bunch of like formal emails to disability groups within Canada. So that was probably like what Chloe was talking about that she did in France. We did that at the beginning of the study and we contacted all sorts of disability charities or non-for-profit organizations to get them, to enlist their help. And we got maybe a few takers through that route, but most of it was, at least, the employee side. It was through snowball sampling. And then when we tried to recruit employers, we took Canada's top 100 Employers list and we went through it and we tried to find, either on their website or through their LinkedIn, people we could send a message to with a poster attached or with some sort of request to say, “Hey, we're doing this research, please let us know if you'd be interested in being interviewed or send us to someone who, you know, who might be interested.” That produced almost no response. It was quite shocking that we didn't get anything from that. Very tedious and labor intensive process.

## Isabelle: [00:23:36]

And so did you target specific employees within those organizations?

## Andrea: [00:23:40]

So, yes, we tried to go through their HR or if there was a person who was responsible for their sort of equity diversity and inclusion group. So it was. And then sometimes if you could find like… I know I actually sent a couple of emails to ministers, government ministries and the actual minister, but didn't hear back, I won't tell you who! So yeah, you really just, it's a game of, of being as persistent and creative as you possibly can. Plus, on top of that, it was a pandemic. And so we started thinking one way, oh, let's print off posters and put them in places. And then we had to completely drop that method and try a lot of other different things that were online. That also slowed us down at the beginning as well, because we were considering, like, this whole research project was set up so that we would actually travel to whoever, places where we would interview people face to face. And that really was never able to happen. So we had to re-evaluate how we were going to do this all online. And that was another ethics amendment that we had to do, which slowed us down for about like another three months. So doing research during the pandemic has been interesting because on the one hand, in some ways it's been easier for us to interview people via Zoom, and in other ways you get a different kind of connection rather than speaking with someone face to face.

## Ahad: [00:25:13]

So I think also too, its because it's very niche, right? So trying to find people, it's not easy, right. But at least now we know how you find participants. But the question now is, what does a typical research interview look like? Or maybe just, what does it look like from the moment you get an email back saying, “Yes, okay. So I think that'd be good to do.”

## Chloe: [00:25:34]

So when I get an email back, I immediately contact via email and include, then see everybody who's going to be at the interview, like who's going to be involved with it, whether it's a grad student or it's Ahad or it's I mean, it's almost always Andrea, but if there's somebody else involved, then they're included in the meeting. And I introduce them to the participants so that they know that we're working as a team. Right? That's, I think, incredibly important that we know that we have a team, that we're working together, and then I send them a consent form. Now I will say, you know, even at the time I… the consent form is an information form and consent form. So it gives information about the study and then asks all sorts of questions for them to consent to. I've discovered in previous studies, along with this one, that most people don't like reading it and they prefer to do an oral consent. I think in future, up till now, the consent forms the are the REBs. The research ethics boards (REB) have pushed for these very formal detailed forms. And I think in future I will have one of those. And then accompanying it, a simpler, more simplified version of it so that it's easier to read in just in in in more terse terms, we send that to them. We organize a date that we're all together, and then we go ahead and do the interview. And before we start, we ask whether we can record, and I almost always do a verbal consent anyway, even if they've signed and read the document, because I just want to make sure that they don't have any questions. What's really important is that they, they feel they can leave at any time, that they can stop it, that we're not going to be upset by that, that they there's no consequences.

## Chloe: [00:27:15]

We give a small gift at the end, they'll still get it. We also we ask the questions in the interview. And one of the things that I think I'm really aware of as an interviewer and again, this is the ethics of it, is that we want stories. They help us understand the lives of people. But I don't want people so that they are telling stories that make them feel terrible or feel unbalanced or isolated and so distressed by the end of it that when we walk away, we've got our information, but we've left somebody sort of not quite feeling great at the end. So there's always this balance as a, as I'm not a psychologist, I'm not there for therapy. That's not what we're doing. But some of these discussions can be difficult because even as they recount positive aspects of their life, they may be contrasted with negative experiences. And so there's always the balance of trying to allow people the space to tell you those stories, but not have them feel as though they are, this is a therapy session and that that that we are somehow professionally going to help them. We can't. So there's, there's that. So I'm always just aware that the stories are important, but not… to make sure to respect the boundary a bit, but to make sure that that that's clear that I respect them as a person and that I don't want to have them feeling like they've given everything at the end.

## Andrea: [00:28:38]

And just to add to that, that was really thorough, Chloe, Is that we approach the interviews like they are in charge in the sense that it's their stories and it's their life. We give them some prompting questions. And so when you're thinking about research methodology, you can either have like a structured interview where this interview is… an example, we put together questions in the beginning and then we're asking them in a sequential manner in the research interview. You don't do it that way at all. You let them, we sort of guide them with a few questions that we are interested in, and we give them some ideas of what the questions will be like in advance. But then they are the ones who sort of are doing most of the talking, and then we will prompt them with things that we want to know about, like we want to know about transportation. We want to know about your housing situation, we want to know about, like, so we have these in the beginning. You start the research with very few preconceived notions about what it's like. And then as you go through, you're like, “Oh yeah, we're finding we should always ask about X.” So there's this difference between a semi-structured interview and grounded theory, where you approach it with just a blank slate. We're more in the semi-structured interview category of how we approach the interviews, but still, it's very open.

## Ahad: [00:30:04]

Yeah, which is good too, because you want it to be somewhat candid, right? If you try to control the flow too much, then you kind of also stop the participant from trying to actually speak from the heart, right?

## Andrea: [00:30:14]

Absolutely. Yeah. Very good point.

## Isabelle: [00:30:16]

And so what do you do once the interview’s over? Like, the Zoom call has ended, everyone's gone off to get some more coffee, what do you do?

## Chloe: [00:30:26]

This is an incredibly important moment. And I really like this part, which is, we say goodbye. We then get on another sort of Zoom call because we're all in different sites, this team. And whoever was at the interview then just talks about their impressions, about what how did they feel, even that's really important. “You know, when she started, I started to feel really anxious when she told me that story or I got upset or I, you know, I thought about what somebody else in Canada had said about the same thing.” Like we try and talk about what we observed and what we thought about given what we know.

## Isabelle: [00:31:06]

And does that get recorded as well?

## Chloe: [00:31:09]

We're now… we originally just made notes, we now record it, and that makes much more sense. Because then actually there's a software we use called InVivo in which we can take these transcripts, of all them. We put them in, and I can do things like search for transportation, cars, buses, getting to work, like looking for phrases that might be all about mobility. And that means that if we've talked about it in our debrief, because this literally is a debriefing like what people thought, or were thinking of, is then that we'll pick it up in those conversations as well.

## Ahad: [00:31:43]

How do you analyse your data and how do you share presented data?

## Andrea: [00:31:47]

So in terms of the data analysis, it's important. So we sort of breezed over a little bit of a step, and that was once we have our recording, we then create a transcript and the transcript is then redacted. So we take away any references to personal things that could identify a participant. And then we've got a database or a lot of files, transcription files that become our data. And so every conversation is data to us. And so then once we start to analyze, we're actually analyzing at every debrief. And that's really important because it's fresh in our mind and it just happened. And we right away start thinking, “Huh?” We start drawing out themes and trying to understand kind of on a deeper level what's happening and compare between different interviews that we've done. But once we do start the formal analysis, there's, you can use technology or you can go old school. Chloe really likes InVivo. I really like old school. And it's about reading. Going over all of that data. Reading every interview again. And then using a combination of your brain to categorize things and InVivo will help you with keywords to categorize what you've heard and what that data is telling you.

## Isabelle: [00:33:10]

Just quickly, back to the, sort of, research process. You talked about this a little bit at the beginning, but just so we have it sort of in its own little category, how… so, you’re doing your interviews, you're finding new participants, how do you know when to stop doing interviews? When do you know you're done the interviewing process?

## Chloe: [00:33:29]

Just say, well, you argue as a team a lot about that, which is, I think, a good sign that you're, there's, I mean, you want discussion because those people who are reading the interviews, who are reading the transcriptions, who have been at the interviews, are in the best position to sort of have a sense of whether they’re, what they're hearing and what it's called. You arrive at some place, you hope, called “saturation”, which is the interviews now sound… Like, you've done two or three, they've been sounding much the same. They are different people. Their stories might be different, but the themes that are coming up seem to be the same. You're not really getting new things being prompted from anything else that you've heard, and that's when you've reached saturation. And you should have debates in the team about whether you have or you haven't because it is. Someone could say, “Well, that may seem like a story, but this but I think it's actually a new story about this. And we should maybe do a couple more to see if we hear more about this.” So that's where, again, not being by yourself is useful. And that's where, you know, I, there's this aspect which we haven't talked about. It's important to have people like you and Ahad is an undergraduate. You're a graduate student, Isabelle, is that we're teaching you what we do. But we're also learning from you. You are able to tell us about stuff that is going on and let's say, social media and cultural things that we don't understand in an interview, that may in fact be important just because that's not part of our generational knowledge. Or if we were doing a community that you were more familiar with, like, let's say we had we were speaking, we were doing Deaf research and we had a Deaf graduate student or somebody who was very attuned to that, that that individual might be very helpful in helping us understand whether we were at saturation or not, like we had heard everything we should have and understood. I don't know whether that covers it.

## Andrea: [00:35:35]

That's a really good explanation. Also, sometimes academics are criticized for taking a long time to do their research and there's something you have, I have to defend that a little bit. Because as you're doing research, you're also usually teaching. You're, for us, our research project has become more than was first envisioned because we're doing the podcasts, you have, you have things that are, it's not, you're not just focused on your research. But there also comes a time where you have a timeline. And so sometimes you just have to say, okay, maybe we would find a little bit more. But we're under a timeline constraint and our budget is running out. So we also have to stop because of that. It's just practical. A practical reason to stop. So we're coming up on that where we feel like there's a lot of time pressure right now to hurry up and get as much, as many interviews as we possibly can do, until we feel that that saturation is met. But on the other on the other hand, we're running out of just, time for the project itself.

## Isabelle: [00:36:46]

So once you hit that saturation point and then you've published, what happens when the project is finished?

## Chloe: [00:36:53]

I'm the primary investigator and there are all sorts of requirements. Actually, every year I'm required to, you know, make sure the budgets are fine or I receive statements. I'm sort of constantly monitoring things. But one of the things I do is I submit an ethics form every year to make sure that we haven't changed our processes, and nothing is arisen, that it's been difficult, or raise concerns or flags. But at the end, then I write a report as well about what we've accomplished, like in terms of whether we publish what we did. Did we do a podcast? Did we, how many articles did we write? How many are coming up? Are we writing a book or did we give workshops and was there other research that came out of it? Do we win other grants as a result? Or is there, you know, things that we did and are there deliverables? Do we actually change anything, like, that's really lucky. I mean, it takes, I think, seven years, maybe even longer for a bit of lab science to make it to clinical practice. I think it's actually longer.

## Chloe: [00:37:51]

So just that straight scientific research where you're getting lab results, this is social science research. And one of the things that I know that Andrea feels passionate about, as do I, in a different way. I've always felt that I want my writing to be accessible to anyone, that you don't have to be an academic, that you can just read and understand what I write. But Andrea has more of a passion and I believe in it too. That the social sciences has a lot to offer to our communities, and I think the public is really unaware of the type of work that social scientists do to help everything happen. But, so at the end, I summarize that there's no way I can go forward and ask for more money for a large-scale grant like that unless I've shown that I've been able to carry out what I ask, what I propose to do, that I've trained people in the process, that I've treated everybody respectfully, and then I've actually delivered some results that I've done something with it.

## Andrea: [00:38:46]

And there's that end of project point. There's lots of ways that a researcher, what might happen next, as Chloe alluded to, that perhaps is something that researchers could do much better, is once you finish the project, what happens with that knowledge? And so we have a term in Canada we use, it's called “knowledge mobilization” and that's when you start, well we are starting it earlier in the project, and that is about sharing knowledge. And I feel like, I call it “the trickle down.” So Chloe talked about that seven year point and the reason why it takes so long for new knowledge, once it’s created or discovered in a study. And then how long will it take before there's feedback from the community or it gets implemented somewhere is because in the past, at least in the past 50 years, researchers haven't really focused on that communication of their research outside of the academy. And so you don't necessarily in the past, you haven't, as a researcher, tried to reach the community. Like, it's pretty unusual that we'd be like, “Yeah, we want to share these results, a. with our participants and b. with the disability community in Canada and in five different countries. That is almost, it goes above and beyond what you normally would do as a researcher. But it's an idea that's gained tons of traction.

## Andrea: [00:40:16]

So some people call it Open Science. There was a movement called Open Access that I did my dissertation around. And to just think about how the podcasts are helping us with that knowledge mobilization piece, with talking about this research with n a public venue is really important because then you get feedback and that to me is also key because you might have created something and come up with an idea or a way to solve a problem. But then when implemented in the real world, does it actually work? That's the most important thing. So as a researcher, if I'm still working and I'm still like, maybe I would have retired or something, it takes that long to know whether your idea works in the real world. So as a social scientist, things move even slower than in the social sciences, the STEM community, or sort of, the sciences and technology and engineering and medicine community (STEM) where maybe that, what they call knowledge transfer, happens a little bit faster and they're a little bit more intentional about it than they have been in the past, that social scientists and humanists have been. So there's this kind of realization that that's something we have to improve, or we have to improve how we mobilize our knowledge.

## Chloe: [00:41:33]

The final part of it is, is keeping the data secure, like making sure that you maintain the security that you've promised people and that you look after that as well. That's another part that's not very public, but you need to do that.

## Ahad: [00:41:47]

How does Broadcastability fit into the research project?

## Chloe: [00:41:51]

Andrea, why don't you take that?

## Andrea: [00:41:53]

Yeah. So it was really an idea around how can we do knowledge mobilization better? So, how can we share our knowledge outside of our academic community in a better way and in a successful way? And so podcasting was something that I had kind of been interested in for a little while. I'd taken a couple of workshops and I wanted to get into it anyways. And so I suggested to Chloe, “What do you think? If we actually ask some of our participants if they're willing to participate in a different, a separate interview outside of the Proud Project, but sort of still within the larger project to talk about their experiences?” Because I have this other idea, this other thought where I, I feel that everybody does research. You know, you as a human being, have thoughts and ideas and questions, and then you go about trying to answer them in lots of different ways. So a podcast allows you, our podcast especially, gives you data to think about and analyze on your own. So I really liked that idea of sort of experimenting with a different form of knowledge mobilization, using a relatively new form of communication to do it. My background actually is in communication, so this is also really exciting for me because in a way, like you mentioned, I had, even though this feels a little cutting edge, it's not. And that has to do with Isabelle, who has been involved in other podcasts with academics and with research projects, which I was about to ask you that question, Isabelle. Let's just finish with this one. So it is all, what we're doing is a little bit experimental. So it's, it's very meta. It's an experiment within an experiment within a study.

## Chloe: [00:43:47]

And in terms of how it fits is also, you know, we, there is a private area where we do, I would say, a population of people, of participants that are private who never make it to the podcast. The podcast is a separate endeavor, in the sense that we will go back, we tell participants we're doing it, that they can tell us if they're interested. We always depend on money, etc., but that we may come back to them and they could then be re-interviewed. It's not the same interview and they make decisions about what they want to be public, about their careers and their experiences in the workplace, and if they want to do it at all. And we've had people refuse us, that they don't want to share it publicly, and that's fine, and that they remain private. But these are for individuals who are prepared to speak more publicly about their experiences. And so it is two separate things, even though we let people know what's happening. So it's a really good question that they are different one’s a public forum and one's a private and we've observed that people in private may say things certain ways that they say differently, or may not say at all, in the public forum of the podcast. And that that's fair. It's a different audience and it's a different purpose.

## Andrea: [00:45:05]

And so Isabelle, just a question for you, because somehow, miraculously, we found each other. You were somebody who had already done a few podcasts at your former university. Tell us about that, because I actually, am a little bit more curious as well about how those happened and how you got involved.

## Isabelle: [00:45:29]

Yeah. So as part of my undergraduate dual degree, we had to do a course on knowledge mobilization, which was honestly, is turning out to be one of the most useful degrees I ever, courses I ever took in my degree. And so we looked at all kinds of ethical research questions and different forms of mobilisation, like we had a Wikipedia edit-a-thon and one of our projects was to create a small podcast. So I got, sort of, dipped my toes into a bit about the audio aspect of things and how to use sound as, as a rhetorical device and sort of the specificities of, of the medium. And then for a couple of courses where you could do sort of a more creative final project, I'd make podcasts sometimes, and then I got a job with a research project that was looking at how religious communities around the world were reacting to COVID. And that was really interesting. And my main job there was to create a podcast with the different researchers and as part of their knowledge mobilisation. So that sort of started me, and then I worked for the journal *BC Studies* that had just launched their scholarly podcast program.

## Isabelle: [00:46:42]

So they're publishing their scholarly journal that publishes and peer reviews, podcasts. And so I made a podcast about podcasting for them, and what scholarly podcasting is, what it offers as a means of publishing and communication. And then I saw, I was just looking around the job boards at U of T, and I saw this project and I was like, I'm really interested in disability studies. I myself have lived experience with disabilities. I also know a lot about podcasts, so I thought I'd give it a shot. And it's been, it's been really, really interesting and I'm yeah, really enjoying it, but it definitely, it definitely fit my specific interest and skill set. So I sort of I call myself an accidental podcaster. I didn't get into it with friends. I didn't, you know, grab a bunch of friends, be like, “This is something we're interested in. Let's talk about it.” No, I wanted to get involved in scholarly research and they kept asking me to do podcasts and here I am. Yeah. So it's been really, really cool.

## Chloe: [00:47:47]

I mean. Well, the thing you've brought I mean, I'm going to go to Ahad with the same question, is that we actually interviewed both of you at the same time. And Ahad we listened to both your podcasts and it was going to be a hard choice between the two of you, and the thing that differentiates you was Isabelle was, you’d done academic podcasts, but also you were bilingual in the two languages that we needed. I didn't need Farsi for this project! But I had your, I really enjoyed your story that you told us about how you got into podcasting. So can you tell us a bit about that?

## Ahad: [00:48:21]

Yeah, my story is not as, it's not as good as hers, but with mine, it's just that I consumed a lot of content, like from a young age on YouTube and just overall like on TV. So I thought that I'm consuming all this content, I'm watching all these personalities. Why not try to become my own personality, right? So I went on YouTube and then we started a podcast mostly on just sports and just things like that. And as time went on, we found out that, yes, podcasts where it was just me and my co-host is good. But you also want to bring people who are in the public eye, right? So then we eventually turned to that. We got people in the public eye and it's very, it's similar to this, but it's different because when it comes to those people in the public eye, they're already very famous and everyone already knows about their lives. Right. So they're very comfortable to just say whatever they want to. Right. Whereas with the PROUD project, certain things that the candidates may say and may be used against them, right?

## Chloe: [00:49:23]

Yeah. I mean, that's one thing I, when you say that we should probably clarify for people who are listening, is that why “used against them” is that, you know, an employer could listen to somebody, recognize somebody and maybe not quite like the nuance of someone, what someone says or, you know, there could, they could have signed an agreement. And unbeknownst to them, they're violating it in some way, some tiny little portion, in doing some side project they're doing that's part of an insurance deal that they got after they were injured in an airplane accident or whatever. So those are things that that you have to be, I've just been very aware of that, that we need to be careful of when we're editing, that we're not imperiling people's employment, we're not imperiling their nursing care or whatever they rely on to be in this world, to be sort of functioning in our world.

## Isabelle: [00:50:11]

Yeah. So one thing we always do is we send the draft of the podcast to the interviewee and have them give it the all clear before we post it. And that's just sort of good practice, I think, to make sure that we're not misrepresenting what people are saying or including things that they actually would rather not include. And so again, you have that ethics consideration going through the whole thing.

## Andrea: [00:50:38]

And that's such a good point because I took a podcasting sort of workshop a while back and most of the people in the workshop were not doing, we'e not thinking of doing a podcast within the academic sense of it, where you are governed by, sort of, ethics requirements. We are very much needing to follow the ethical guidelines. But when you're just somebody, a person interested in podcasting, you don't have anything guiding you ethically, or requiring to do things in certain ways. Even, there's a very big difference between sort of something that's more journalistic and something more research-based. So a journalist doing an interview has a different approach and there's still an ethical, sort of, there's still an ethical framework around journalism and how you do it well. But I feel like our culture, our perspective, the lens through which we are working is going to be much different than someone who is just interested in podcasting as a medium because it's cool and fun, versus a journalist who's doing it, versus a researcher who's doing it. So that was also something we had to think about and make sure that we were acting as researchers, still within using this mode of communication.

## Isabelle: [00:52:08]

Yeah, we had one last question for you. What has for both of you, what has been your favorite moment so far in this research project?

## Andrea: [00:52:16]

I don't have anything really good yet. I'm still, like, racking my brain.

## Isabelle: [00:52:20]

Yeah. Sorry I put you on the spot.

## Andrea: [00:52:22]

You know what I really love? I love our team meetings because I feel like we have such a good rapport with the team. It was something that I think has, I'm not going to speak for Chloe, but we've both been quite pleased with is, having this team approach to what we're doing. It's different than the other previous project we worked on, and I feel like every day there's some kind of, we've gotten really good at using technology and feeling comfortable in our Teams meetings and our Zoom meetings that it's really, I look forward to them. I look forward to these weekly meetings and to just discussing things, and finding out what everybody else is doing. And it's pushed us ahead. It's -- from a management perspective -- it's been very successful at keeping the project moving. But it also, we have a nice social connection. And even though I would like it even more if we were going for drinks after work on a Friday like today, but we still, I still feel like I've gotten a lot out of that. Our connection as a team.

## Chloe: [00:53:33]

Yeah, I've enjoyed the team aspect of it too. I think the participants have really, I think Andrea summarized it very quickly quite early on. “Wow, these people are superstars.” Like, they are just, they’re forces of nature, the people we speak to and you can't bottle that. But I feel really, what it did is, it confirmed for me that we are overlooking a population consistently that's really capable of contributing. And so these people have managed to be able to contribute, but there are many people who have not managed to get through the various barriers that they've encountered to get where they're at. And so it's been a real pleasure to listen to their experience. It's been and it's been it's been an honor in some ways to listen to their experience. And I feel grateful that I've had the ability to do this, to do this project. I feel, if I ever I feel down, we all feel down at different points. I just always feel that what an immense privilege it's been. How lucky am I that I get to do this type of work and do it not just by myself, but in a team setting.

[Music]

## Andrea: [00:54:47]

We would like to acknowledge the University of Toronto, Scarborough and our podcast partner, Easter Seals Canada, for supporting the production of these podcasts. We would also like to thank our funding partners, the Canada Social Sciences and Humanities Research Council, the Centre for Global Disability Studies Technician, and the Catherine and Frederick Eaton Charitable Foundation for helping us create Broadcastability. Thank you to our guest hosts for this podcast, Ahad Alingary and Isabelle Avakumovic-Pointon. Ahad was the podcast editor. Justin Laurie provided our music, and thanks also to Isabel, Andrea and Chloe for editing and production assistance.