Making Data Collection More Inclusive

Video Transcription

ANDREW: Alright, thank you so much for joining me today to have a chat about community consultation and participation. Uh the one thing I'd like to do before we start, is acknowledge the lands that I'm sitting on - the lands of the Boon wurrung and Woi Wurrung peoples - and pay my respects to their elders past and present. Um, but otherwise we'll just jump right in, and maybe start with a brief introduction of yourselves please…

AMIE: Thanks Andrew. Hi everybody. I'm Amie O'Shea, and I'm a researcher and lecturer in the school of Health and Social Development at Deakin. Uh, my pronouns are she/her, and I'm currently on the land of the Wadawurrung people, the Kulin nation.

CASEY: And, I'm Casey Northam, um my pronouns are they/them. I'm a non-binary trans-person, and I'm currently working with Amie on a project that is working with LGBTIQ folks with intellectual disability. And I am in my car, about to meet a research participant, actually, on Yugambeh country which is up in south-east Queensland, so that's why you can't see me. It's too glary. So, lovely to meet you all.

ANDREW: Yes, students are hearing their perspective in the field as it's happening [laughing]. Um, so Amie would you like to just start with a brief overview of the project.

AMIE: Uh, yeah sure Andrew. So, uh, as Casey said our work is about um thinking about how we can use a participatory action research model um, with LGBTIQA+ people with intellectual disability. And, I think there's a great example of how we can do that right now by Casey sitting in the car ready to go in and, and um, work with somebody. Um, one-on-one in a public, uh private space. Um what we're interested in the research is understanding what happens when gender and sexuality and intellectual disability, um, come together in people's lives, and in their experiences and so of course if we're gonna do that, we need to do that alongside, and be guided by people with that lived experience.

ANDREW: Yeah, great, so Casey in your work on that project, can you talk a little bit about what does it look, and feel like to do a consultation that's inclusive of gender and sexuality diversity.

CASEY: Yeah, certainly. So, I would say, to begin with the first thing that um, none of us do automatically, but we all have to constantly keep trying out is not have assumptions about who we're meeting. And when I say assumptions, that's really broad, um, but when we're talking about LGBTIQA+ identities, um, we're talking about not assuming someone's gender identity based on how they look. So, me looking at someone and going "Oh, they have a beard" - that doesn't mean their

pronouns are he/him, for example. Um, so coming in and uh, essentially really letting a person tell you who they are, and how they want you to speak to them, how they would like you to refer to them, how you can make that as inclusive as possible. And, in this particular work, like, we do that by connecting with people, and literally um checking in with them. Like: what's their name?, what's their pronouns? Sometimes people haven't heard the word pronouns used before, and so you can give a really, like, I often will use myself as an example and be like "Oh if I walked into the other room, i'd be like 'Oh, *they're* in there, *they* burnt their toast'." Like, something that um, allows someone to understand what you're talking about, but also lets you understand what, how, do you want to, how do they want you to refer to them. So, that one's an example about pronouns, but um, really you're covering off on a lot of things, so you don't wanna be assuming what's their gender identity based on how they look. So, you can actually ask the question um, in a situation like this if it's relevant, um and I think sometimes we get uh, like nervous and uncomfortable asking people about things like this that are really essential for how we can then provide them with like, yeah inclusive um, research like, do good work with them. Um, so gender identity, not making assumptions about someone's like sexual attraction, or lack thereof, or like the ways they're partnered, so not assuming that someone's monogamous, um though that's a whole different field of things, not all LGBTIQ people aren't monogamous. Um, yeah, what do you think Amie, am I missing things? I'm sort of just brainstorming here. [Amie off screen: "yeah"]

AMIE: No, I think you're spot on and I think it's um, it's something that we have learned and developed over working together for a long time, but also over not being afraid to think about the personal, and the professional. And, so to reflect on their own experiences, and sometimes to reference those with people, or sometimes to just use that to know what we're doing in the way that we communicate with people. So, Casey's given great examples of our, our verbal communication with people, but we're also always informed by written communication that we receive, from researchers as well. So, you know as a researcher I'm always happy to be a participant in other people's research because I know how hard it can be to find people, so I'm, I'm always putting my hand up. Um, and I did one recently where I was asked in this box to draw my family tree, my family um and my children, and it said "For boys put them in a square, and for girls put them in a circle." And, it was, it was like all those times that you go to the doctor and you're asked if you're married, or um at Vic Roads when they want your title, when you just think actually what does that have anything to do with what I'm doing here, why does, why does your idea of uh there only being two genders and those being relevant to me describing my family tree. So, the paperwork experience, like the written communication that um, we give but also that we've gotten from researchers, it doesn't just have to be if your research is about um a sexuality or gender or a disability, it could be about anything. I'm part of all sorts of different things, and I get asked all the time like "who are my children's mother?, and who is their father?", and obviously there's only one of each, and obviously there's only one home address, and um, the whole heap of the assumptions that are under it, and what happens, uh and I know this as an individual but also as a researcher, um is that people won't trust you, is that you are presenting yourself as a safe or inclusive space. And, so if you want to do research on breast cancer, um and make sure that you can really include people from a range of experiences then you need step back and recognise that that's not all women, it's, you're not addressing just women, um and all of the pink-ness, and the um you know the "awareness raising" around help or conditions or um other sorts of things. If it's just, if you're just

gonna buy into reinforcing those stereotypes then you can't be inclusive because from the start you're telling people what you think it is.

ANDREW: Yeah, that's a really great point to line up with some of what other people have talked about. Um one of, one person I spoke with made a really great point that whichever community, or communities you're gonna work with, and of course communities are just massive overlapping intersecting identities there's no such thing as '"clean-cut communities" that go around just one identity, um but whenever you're gonna go out and reach out to a person who you know is part of many communities, doing a bit of research first and making sure you know some basics about it so that you do know how to be respectful to them initially, um but then also not assuming that you could ever be an expert in that persons identities and going in as you were saying Casey, without assumptions and humbly and being willing to ask questions and make mistakes. Um, that all comes together in rooms of building that trust over time. So, it, it's great hearing those concrete examples from both of you and that, and that perspective on it too.

CASEY: Hmmm, um and Amie's mentioning of um like, not all women, essentially like not assuming stuff about people's bodies. So not all women will have uterus's, some men have uterus's, not like we can't assume so many things based on when we look at someone. Um, but at the same time, like realising while I happily sit here and say "don't have assumptions", well we've all got assumptions so actually be really reflective of who you are, and what you're bringing to something. So as a white person, I might go into a space and like my first thought isn't to name, like isn't, like think about what you're bringing in and the things that are hidden. So whatever privilege you have, you're probably not thinking about the questions and the access needs and the, the things you could be asking about that. And, a really good example of that is um, walking into a room and, and not assuming if you're walking into a room of people who you perceive as white that they're all white people. Like, making sure we're asking everyone '"Are you an Aboriginal or Torres Strait Islander?." Um, yeah like leaving spaces to describe gender identity, not prescribing like boxes, like, like uh Amie was saying with um, the like department of roads. A pet peeve of mine is when I have to put my title, and they only give me like "Mr" or "Ms", and I'm like hmmm mine's Mx actually like, really love you to make space for that.

ANDREW: Definitely, oh that's great. So that throws in, in addition to kind of doing your research ahead of time, getting some information, being humble and um [Casey hmmm] learn, also reflect and be self aware and think about that which is definitely another theme of this unit with the students is thinking about what does self-reflection mean and how do you bring that to a consultation process. Um, so you both have shared quite a bit of really great information for students and lots for them to think about, um but just to wrap up, I think you know the students that are in this unit, they'll be going into the field in a year, two years, possibly sooner if they're doing a placement, um so just thinking about new professionals and people that are new to working with community, what's a top tip that you'd offer somebody new to uh, uh of where to get started, and what can they do to work with, work well with community?

CASEY: Do you wanna go first Amie?

AMIE: Hmmm, oh look I think I'm uh you know, my experience and my tip top tip to myself is always that I'm still learning. Uh, and I'm still encountering um the need to as you said, the need to be humble and ask people um and to avoid the urge to overgeneralise, or make assumptions. Um, so going in with uh, an attitude of respectful consultation, and asking people um in that instance how can we do this, and what might this look like? But also a critical eye I think to your own processes, and paperwork um or language, and thinking about um how you can in those really small ways reach people for whom those are really big ways.

CASEY: Hmmm.

ANDREW: That's great.

CASEY: Yeah, and I'm going to use the example of where I'm at right now. Um, is this, this going to be a video recording hey Andrew [Andrew of screen: yeah], yeah so I'm literally, don't know if you can see I'm in a car park, and it's a Hungry Jacks car park because what we realised is some participants don't have access to public transport to get them to the space that we otherwise would do our research in. So, my top tip is actually try and give yourself as much time and resourcing as possible to make things accessible, and that might mean not just assuming that I haven't heard back from that one email that the person doesn't wanna participate, but actually they may need different forms of communication to, for it to be accessible to them. So, try multiple things um, be creative. This happened to be finding a private space that was a room available at a takeaway place next to the highway, um because that's what was accessible for this participant. So, and I know that's always subject to your resourcing and time constraints, but if you can go out of your way to make things work for people, your research is going to actually reflect a breadth of people rather than just the people who happen to meet all the access requirements or identity things that feel comfortable to be a part of it.

ANDREW: Yeah, that's, that's a really practical and great tip and definitely, it's absolutely relevant to research but it would be relevant to whether the students work for local government, health service another, an NGO, um that same principle applies over and over again. We've gotta be creative and inclusive in terms of the ways that we reach people and connect with them so..

CASEY: Yeah. Oh, can I share one more, a personal one?

ANDREW: Go for it.

CASEY: So, I'm a non-binary trans-person, and I love it when I do research cause, like Amie, I also put my hand up for a bunch of research, if it's not just gendered toilets. So, thinking about is there an accessible toilet that's available to all genders will make, everyone needs to pee, it's really great if you made sure that tiny little thing is um accessible in all the ways including to folks who are gender diverse, and would prefer not to use male or female toilets.

ANDREW: Excellent that's, that's another really practical and great tip for the students to think about. Well, thank you both so much for your time. We might wrap up there unless there's anything that you'd like to add? No?

AMIE: No, I think you've, you've summarised it so well Casey. Um, it's wonderful to hear that students are interested in how to work with communities and um engaging people in the sort of space that, that they want to work. I think that we can only see positivity from that so I just want to send some encouragement to everybody in the unit.

ANDREW: Excellent, thank you so much.