Impact of and Factors Supporting Collaboration and Participatory Design

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Background

Effective and inclusive collaboration with people with disability in research is an intricate practice. Researchers and service providers who engage in collaborative practice describe a range of strategies that can foster meaningful inclusion of people with disability in research, such as upskilling co-researchers with disability to be able to perform essential research tasks (Hollinrake et al., 2019; Jennings et al., 2018; Rochette et al., 2022). For instance, Hollinrake et al. (2019) trained researchers with disability to conduct interviews with other people with disability while in the presence of two academic team members. The team observed that researchers with lived experience built a stronger rapport with interview participants through the genuine empathy they could share.

Adequate training for co-researchers with disability is important for ensuring their meaningful contribution, as is understanding the unique capabilities of each research team member when assigning tasks (Embregts et al., 2018; Schwartz et al., 2020). Further, research teams must consider the continuing resources or assistance that co-researchers will require, citing flexibility and accessibility of resources and research tasks as key (Schwartz et al., 2020), and be mindful that the fast pace of academic work and use of academic language, especially abbreviations, may not be comfortable or accessible for team members with lived experience of disability (Embregts et al., 2018).

Leaders in collaborative research advise teams to listen to researchers with disabilities and address their unique participation needs (Stevenson, 2010; Jennings et al., 2018; Robinson & Notara, 2015; Terrill et al., 2019). This tailored support is likely to require frequent engagement with co-researchers, including meetings (Jennings et al., 2018; Robinson & Notara, 2015; Terrill et al., 2019). Bigby et al. (2014) also warn that organisations and researchers (including co-researchers with disability) will need sufficient time to prepare for inclusive engagement.

Alongside inclusive practice during the 'work' stages of research (e.g., data collection, data analysis, and recruitment), several studies have examined the collaborative processes involved in acknowledging and documenting the input and impact of co-researchers with lived experience (Jennings et al., 2018; Mulvale et al., 2019; Stevenson, 2010; Terrill et al., 2019). Mulvale et al. (2019) describe this

as ensuring research team member input is not simply tokenistic, and that the research team is able to demonstrate to the researchers with a disability how their input has been implemented, and the potential impacts of this input.

Having worked together for almost two years, the Lived Experience Advisory Group (LEAG) and the Deakin research team collectively decided we would like to explore and document our experiences of collaboration. These insights are shared below to encourage the wider adoption of participatory research methods in sport and recreation research, and as a resource for other teams embarking on participatory work.

What we did

We interrogated our own experiences as a group through a combination of methods including document review (meeting agendas and minutes), a reflexive focus group, and a collaborative analysis and writing process. The focus group was comprised of the Deakin research team (n=6), LEAG members (n=6) and a TAD representative (n=1). To prompt individual reflection, all participants were sent a Mentimeter link where they could answer some preliminary questions, prompting reflection and outcomes. This preliminary input would be used as discussion points during the focus group. A research team member led the discussion, allowing for the conversation to occur naturally. The focus group was audio-recorded and transcribed. The data were then coded into initial themes with relevant quotes. These themes were shared with the Deakin research team and LEAG members for co-analysis. Themes were coded into NVivo (QSR International) in preparation for dissemination.

What we learnt

Several themes were identified during the reflexive process, regarding the factors that made our collaborative research efforts successful. These included the disruption of power, cultivating an open atmosphere, social dynamics, and the valuing of diverse lived and professional experiences. Collaborative research expectations, processes and the translation of knowledge were also discussed.

Disrupting power structures

Disrupting power structures was a strong theme making numerous appearances, though unique to the individual. One researcher appreciated the group's approach of being open to what the project could look like. A LEAG contributor expanded on this notion:

> *"I think the ambiguity has really served us well. We were a bit like, well let's bloody do it. You know,*
>
> *and so really there was no expectations because we just didn't know where we're going so, then I*

think that's what made it really open as well, because we were just like - we will trial this, what about that? Well, I don't know, how do we feel about this?"

The Deakin research team and LEAG worked closely together, sharing power when designing the various research tools and protocol. This was not lost on one LEAG contributor: *"I saw that there were still open discussions about how we can mend it or how we can bend it".* The Deakin research team also realised the potential to push current boundaries in research accessibility, fuelled by the group's level power dynamic: *"… the second part of the research project is the interviews that we're conducting with people and, what did you say [LEAG member name], really just …, 'go rogue'. That was the phrase that you used: 'Can we go rogue in terms of how we allow people, enable people to participate?'…"*

From one researcher's perspective, the team's openness to share power around the design of research tools and protocol could have been more clearly established from the beginning, as this may be a trait not all researchers would be comfortable or familiar with, or that all community collaborators would immediately expect. *"… we didn't say to you: 'we're not your traditional researchers, yeah you can embrace the chaos, yeah just go with it… we're just going to see what comes…'. That's, something we possibly next time I think you know, set that scene."*

Open atmosphere

Members from both the LEAG and research team appreciated the open atmosphere, noting it was *"Okay, to be who I am".* Our group's atmosphere provided comfort and became a place where we could openly learn from each other. Insight into the partner organisation's practice was a helpful outcome of this atmosphere, with a research team member recalling that when it came to grassroots knowledge and context, *"everything that we do when we're planning the research takes that into account."*

A potential contributor to the open atmosphere was the flexible leadership style of the MAL National Project Manager. This flexibility allowed research project members to *"… evolve, and suggest, and push a bit, because you [project manager] didn't have a set leadership direction and that's good".*

Group social dynamics

The openness of the group led to meaningful changes, learning, and a welcoming environment. Reflecting on our time together, members found the group *"… just challenged my own prejudices"* and that they had *"… absorbed and learned so much".* One LEAG contributor beautifully summarised the scope of the LEAG's social connections: *"… we have a purpose, we got some synchronicity going on".* However, these group dynamics only evolved with time, with most members agreeing we started out quite formal, and over the course of many meetings transformed into the dynamically vibrant partnership that made the project.

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Everyone's lived experience is valued

It was the combined lived and professional experiences of all group members that ultimately fuelled its success. Everyone, with or without disability, brought their own perspectives and experiences into the research, and the project team believed this intersectional richness should be valued. *"… They bring their worldly skills, and you know there's a lot more that a person can contribute [aside from their disability identity]."*

One LEAG member shared a story of their personal experience in both using assistive technology and working in the disability field, typifying the complex intersections of expertise that existed across the team. Several LEAG members and researchers also shared common experiences of being a family member of a person with disability. Indeed, the group's philosophy of questioning everything, which was lovingly described as *"going rogue",* was borne from one LEAG member's experiences of being the parent of an autistic child: *"… I think some of that comes from being a parent of a person with autism. Because the way she processes information is very different… she questions everything, including me".* A background in sports management assisted another LEAG member in engaging with the project's complex data *"... I know how to interpret it, and maybe undertake that process to get more impact or getting an outcome from that data ...".*

LEAG members experiences and perceptions of research

Members of the LEAG entered this project with differing views and past experiences of research. It was clear these shaped their perceptions of research and what being part of the project might entail. *"I had to remind myself to stay open just let them lead it, they're the researchers and hopefully it won't have the same outcome [as past projects]".* Perceptions of research had also led to an increase in hesitancy to engage in a research project: *"Because for research I normally run the other way."*

"I feel you know started off… kind of straight to business at the start, you know we're here, what are we going to do, but over time it's become much more relaxed, and I feel like it's because we've all gotten to know each other a lot more".

LEAG members had held varying expectations around being part of the LEAG. These ranged from general uncertainty about research or the MAL program, to uncertainty in what they may be asked to individually contribute. While the group's social dynamics were previously mentioned as a key factor in making the LEAG work, participants still felt on the outside at

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times: *"I've always felt I've been on the outer, to be honest, of this group. Because I felt like a lot of people were somehow connected to Solve. I thought the lived experience people had a previous connection to Solve... I didn't know what anything was to be honest…".*

Outcomes of the LEAG

It is clear the LEAG's combined experiences and perceptions had a profound impact both on, and beyond, this project. This included impact at the personal and organisational levels through the transfer of knowledge across various settings. As one LEAG contributor explained: *"[the group] has been instrumental in making that common sense - so uncommon - making it common again".* For example, this return to "common sense research practice" was key in the development of an accessible interview schedule, which ended up being centred on one core question: *"I remember vividly, spent like an hour nutting out these complex interview questions… I can't remember who it was, said that basically it's just like: 'what is life like with a bike?'. And that question … it came from the discussions that we've had".*

The learnings gained from the LEAG did not just stay within the realm of the research but was observed to travel throughout the TAD Australia Network, reaching the *"Steer Co"* (Steering Committee) and the *"operational parts of the business".* Lived experience feedback provided grounding for operational negotiations: *"… we got a bit of push back on that didn't we? 'Come and try', we won't call it 'come and try' and I said we've got a LEAG for a reason - they told me not to call it that. So you wanna keep calling it that? Knock yourself out. But I'm just telling you that the people behind us that we've asked said it's a bit patronising."*

Similarly, the LEAG's knowledge also gave weight to the researchers' arguments when they were negotiating with the University's Human Research Ethics Committee, particularly around any accessibility modifications that Ethics reviewers saw as unconventional or potentially risky.

"If I approached the ethics committee and they pushed back on something that actually just makes …good, practical sense, it's going to improve the experience of participants… It makes such a difference, to able to say research participants, consumer advisors, consumer partners, co-researchers have told us that this is what they want. And it leaves very little room for universities to kind of push back against that".

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Transfer of knowledge gained from the LEAG

All members discussed how their time working on the project had influenced their professional work. For example, the group experiences had shaped how one LEAG member now encourages their workmates to consider differing points of view: *"... to continually remind them to just look at things differently".* Transfer of knowledge to the workplace was also seen in personal work practices:

> *"Being part of this group and how the research team goes into the details of every word, every pause, every comma and what would make what difference. That's what I'm taking away in the last two years. I have been very more mindful of what I speak, and what words I choose".*

The transfer of knowledge also had significant impact for the research team. Reflecting on the learnings gained, one university researcher reported a shift in worldview, with resounding transfer of knowledge to numerous individuals outside of this LEAG: *"I think that they're influencing [our] supervision of [student's] project greatly, and the approach that we're taking. I'm doing my PhD at the moment, it's influenced greatly how I'm looking at what I'm doing. And beyond…"*

The Deakin research team valued the sage wisdom granted by LEAG members during meetings: *"This is so useful for us. We would debrief after it and go wow! It blew our minds".* Debriefing and knowledge translation for the research team also extended beyond internal discussions, when they shared insights and resulting recommendations with other research teams.

Knowledge on what this team has achieved has also been shared in a range of formats. The accessible online survey is be shared in an online repository for other researchers wishing to engage participants with a streamlined, accessible survey. In addition to this, the group have talked about other ways they plan to share our experiences with audiences outside of the academic community, for example using podcasts, story-telling, and a *"… one-page statement how this group has helped a person's life".*

"I probably mention the work that we do at least once a week, so other people other researchers people in policy… I talk about you know, about working with an advisory group we've found these things or you know. That's… a pretty big outcome…"

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Conclusion

A collaborative approach was beneficial to both the research team and LEAG members. The findings from this reflexive study paint a clear picture of outcomes that not only influenced this project but transferred to other domains of professional, personal and academic life. By sharing these learnings, we hope to encourage other organisations who are working with people with disability to engage with a LEAG or other forms of consumer partnership. These findings also show how established research approaches, methodology and standardisations may not be relevant to people with disability, and how a LEAG can provide strong justification for necessary amendments. To assist other teams, we are pleased to provide a set of practical guidelines for inclusive research as a component of our main project report.

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