

# Exploitation of disability and rehabilitation research participants – resolving to do better

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## **Abstract**

Contemporary disability and rehabilitation researchers would probably be affronted by the idea that they may be exploiting research participants. The probable reality is that subtle and unintentional exploitation is occurring. The researcher stands to gain reputational and career enhancement while the participant's reward may be a sense of having done something altruistic. Based on my own research experience, feedback from disabled allies, reading about what others are doing and thinking about the ethical guidance provided by the NHMRC, I propose a framework for addressing this form of subtle exploitation. I call it the 6-C Approach to Meaningful Engagement. The six elements of the framework are communication, comfort and convenience, cash, credit and capacity building. The 6-C Approach requires additional resources beyond a traditional disability and rehabilitation research paradigm but such an approach has the potential to add greater quality, value and equality to disability and rehabilitation research processes, outputs and outcomes.

**Key words:** Disability and rehabilitation research, participant exploitation, participant remuneration, consumer engagement, consumer involvement.

## **Introduction**

I am a disability and rehabilitation researcher, but I'm not a person with a disability. Nor am I working within an emancipatory framework, so how do I avoid my work becoming exploitative of those I seek to help? The recent death of renowned sociologist Emeritus Professor Mike Oliver has focused many of us on his contribution to this area. Oliver advocated for the social inclusion of people with disability by challenging the dominant biomedical model of disability which focuses on treating the individual's problems. Instead he promoted the social model of disability, which recognises the disabling influence of the physical and social environment (Oliver, 1990). As a physically disabled researcher, Oliver also advocated for a change to the social relations of research activities, putting disabled people front and centre in the knowledge production and change creation processes (Oliver, 1992). Oliver controversially invoked the image of disability researchers as "parasites" where their research failed to serve the interests of disabled people (Oliver, 1999).

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Prominent Canadian occupational therapy academic, Karen Whalley Hammell, continues to echo Oliver's concerns that research can all too easily become exploitative and oppressive when undertaken with marginalised people (Hammell, 2006). Hammell cautions that despite a shift towards person centred practice in health and social care, disability and rehabilitation research does not necessarily reflect this philosophy (Hammell, 2007). She argues that it is assumed that the intentions of disability and rehabilitation researchers are basically good, however maintains that this has not been critically examined (Hammell, 2006).

Including people with disability and their perspectives in the research which effects them, is a core expectation in contemporary disability and rehabilitation research (National Health and Medical Research Council (Australia) & Consumer Health Forum of Australia, 2016). Inclusion is respectful of the people who stand to be impacted by the research, and fosters the prospect of more relevant research. Selection of research topics that matter to people with disability; collection of richer data; development of a deeper understanding of results; and, improved uptake of research, are all conceivable when people with disability are actively involved in the research process (National Health and Medical Research Council (Australia) & Consumer Health Forum of Australia, 2016). Conversely though, it is important to note that even when people with disability are actively involved as research consultants and collaborators, this does not ensure that exploitation will not occur.

Contemporary disability and rehabilitation researchers would probably be affronted by the idea that they may be exploiting research participants. I suspect that most, if not all, would be at pains to explain that their research is conducted under strict ethical controls and that their ultimate intention is to discover evidence to benefit people with disability. The probable reality of exploitation of research participants by disability and rehabilitation researchers, is that it is subtle and unintentional. Disability and rehabilitation researchers, like myself, stand to gain paid employment, reputational enhancement and career opportunities from the research they conduct. What is the equivalent gain for research participants?

The National Statement on Ethical Conduct in Human Research acknowledges that it is likely to be altruism that drives research participant involvement (National Health and Medical Research Council (NHMRC) (Australia), Australian Research Council, & Universities Australia, 2007). Is this a fair trade? Career and reputational enhancement versus a feeling of doing good? The National Statement also says that research should be "just" and one of the cornerstones of this justice is the absence of exploitation. How then can disability and rehabilitation researchers negotiate this complex territory? Even at the "softer" end of research, as people with disability tell their stories through spoken, written, photographed or filmed media, researchers like me become the recipients of privileged information. So, shouldn't these research participants quite rightly ask 'What's in it for me?'

Based on my own research experience, collaboration with disabled allies, reading about what others are doing, and thinking about the ethical guidance provided by the NHMRC, I have identified a number of principles, which can be summarised in a useful framework for addressing participant exploitation, namely the 6-C Approach to Meaningful Research Engagement. The six elements of the framework are communication, comfort and convenience, cash, credit and capacity building.

## **Communication**

A key starting point for reducing exploitation is communication. All aspects of a research project, from conception, through ethics submissions, grant applications, participant recruitment, data collection and analysis, and reporting of results, must be intelligible to a lay audience, and openly communicated to persons with disabilities. Lay summaries are often included in research documentation, but researchers are seldom challenged on their quality.

Developing documentation in plain language is not just a courtesy to participants but a highly beneficial prompt for researchers to critically reflect on what lies at the heart of their work and communicate this to others beyond their discipline. Researchers owe it to participants with disabilities to facilitate their understanding of the insights arising from the research to which they are contributing their expertise. If disability and rehabilitation researchers are not doing lay communication very well, then perhaps it is timely to invest in training for researchers and start to hold all of their outputs to account.

## **Comfort and convenience**

Second, meaningful engagement for research participants may come from simple gestures that acknowledge a shared humanity. Food is an important symbol. Providing a good coffee and a nice sandwich during data collection sessions, indicates to participants that they are significant in the research process. Even more symbolic is when a researcher chooses to share a meal and an extended chat with participants.

Research data collection must also become more flexible. It is short sighted and even disdainful if researchers insist on making data collection exercises convenient to them – during office hours and in the location of their choosing. Researchers must be willing to do the hard yards. Meet research participants where they live, work and play. There will be inevitable trade-offs to the rigor of the research data collection, however this will be offset by the quality and richness of the data that is collected and the deeper understanding of participant in context.

When it is unavoidable that data are collected in a laboratory or clinic setting, researchers must ensure that the environment is optimised for participant comfort. This may include regulation of temperature or lighting; provision of comfortable seating; adequate space for wheelchairs or walking aids; and, maintenance of participant privacy. Researchers must be prepared to work around individual participant routines related to such things as work, family commitments, social activities, medication and self-care. And they must be ever mindful of physical and cognitive fatigue of participants and accommodate accordingly. Efforts researchers take to ensure the comfort and convenience of participants will not go unnoticed. There is no downside to engendering goodwill through simple acts of courtesy and kindness.

## **Cash**

Disability and rehabilitation research participants should understand that their contributions are valuable because of their importance to the research outcomes. The most tangible way of valuing an input is through a financial transaction. Some researchers will argue that monetary inducements may bias recruitment and tarnish the quality of the data. Further, most research budgets would not stretch to the real cost of engaging participants as lived reality experts. But is it equitable when a person with disability participates in a focus group panel and receives their cab fare, while the health professional next to them is paid their considerable salary for the hours spent? Health Consumers Queensland provides guidelines for remuneration and reimbursement for consumer representatives sitting on panels and focus groups (Health Consumers Queensland, 2015). The ability to tangibly value a participant's contribution must start being reflected in research budgets in the form of meaningful and equitable stipends.

Conversely, it is also important to note the NHMRC guidance on payment of research participants which states that "payment that is disproportionate to the time involved, or any other inducement that is likely to encourage participants to take risks, is ethically unacceptable" (National Health and Medical Research Council (Australia), Australian Research Council, & Universities Australia, 2007, p.17). An appropriate and respectful balance is required.

## **Credit**

Notwithstanding issues of participant confidentiality, where it is appropriate and mutually agreed, research participants should be duly credited or acknowledged for their contribution to research outputs. In some instances, participants might even be co-authors on peer reviewed papers. This could involve a significant commitment on the part of the researcher to provide appropriate support to a participant, so their contribution is meaningful to the outputs. The NHMRC provides a useful guide to establishing the threshold of individual contributions which may warrant authorship (National Health and Medical Research Council (Australia), 2019). It is important to consider that participants may prefer to be acknowledged as contributors to a research output rather than assume the responsibility of authorship.

Another way of acknowledging participants, as contributors to new knowledge, might be through co-creation of research translation materials. Participants might wish to take an active role in production of materials such as infographics, video vignettes, newsletters or magazine articles. These outputs should place the voice of the participant front and centre and be appropriately credited. Participants should be able to see the value of their contributions through these alternative channels, which are more likely to be engaging to practitioners, policy makers and others with disability (in comparison to peer reviewed papers).

## **Capacity building**

If research participants feel good about having participated, then that is certainly a positive outcome. Beyond this, researchers may be able to enrich the research experience so that participants are also able to learn and grow through the process. The research process should be a means by which disabled participants and allies (and not just researchers) can enhance their CVs. Of course, this deeper involvement in research will not be of interest to all participants, but researchers should be proactively looking for capacity building opportunities. Today's research participant might be tomorrow's advisory panel member, lived experience educator, or even a future disability and rehabilitation researcher.

## **The growing need for meaningful research engagement**

Major research funding schemes such as those administered by the NHMRC, as well as some publishing houses, now seek evidence that people with a disability have been consulted on the design and implementation of research which affects them. In my own research centre, The Hopkins Centre, meaningful engagement of people with a disability has become a central pillar of our activities. This includes convening an Ambassador Council with members who are researchers with a disability. The aim of the Council is to promote the relevance of research, appropriate engagement and positive impact. It is the intent of The Hopkins Centre to adopt principles such as those articulated in the 6-C Approach, to acknowledge the value of the voice of people with a disability.

The 6-C Approach to Meaningful Research Engagement requires additional resources beyond a traditional paradigm of disability and rehabilitation research. In part this will require increased research budget, but mostly it will require time, effort and imagination on the part of able-bodied researchers and their disabled collaborators and colleagues. Importantly, such an approach has the potential to add greater quality, value and equality to disability and rehabilitation research processes, outputs and outcomes. Surely, a win-win situation for all.

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## Biographical Notes

**Delena Amsters** is the Senior Research Officer at the Spinal Outreach Team, Princess Alexandra Hospital. Delena is a PhD candidate in the School of Human Services and Social Work at Griffith University. Her topic of research is an examination of determinants of participation in life after spinal cord injury. Through her PhD program she has developed a passion for advancing the meaningful engagement of people with disability throughout the research cycle. She has a background as a rehabilitation physiotherapist and has significant experience in rehabilitation service planning and workforce development.