

Engaging Consumers and Community Members across the Research Spectrum: A Stepped Approach to Implementation by the RECOVER Injury Research Centre

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Introduction

Consumer involvement in research is fundamental in developing research priorities, healthcare policy, and clinical practice guidelines. RECOVER Injury Research Centre, embarked on a journey to develop and implement a genuine consumer involvement strategy. The aim of the strategy was to include consumers and community members with a lived experience of injury, their carers, and health professionals not only as research participants, but across the entire research spectrum.

Method

Guided by the National Health and Medical Research Council’s Model Framework for Consumer and Community Participation in Health and Medical Research, we followed a stepped approach to facilitate consumer involvement in research at RECOVER.

These steps included:

- Formed a working group to facilitate the development of a consumer involvement program
- Learned from the experience of others
- Conducted an audit of existing consumer activities
- Considered the barriers and enablers
- Conducted staff training
- Gained management support and budget
- Identified consumers who may be interested in our research
- Developed feedback mechanisms for consumers
- Held consumer forums



Who are RECOVER consumers?

- People affected by injury, particularly those injured in a road traffic crash
- The families/caregivers of people affected by injury
- The general community & community groups that represent consumers
- Health professionals
- Other stakeholders such as policymakers & compulsory third party insurance providers

Summary feedback from consumers - Consumer and Community Forum 2020

What do you think are the benefits of engaging consumers in research?

"At the end of the day, it is all about the consumers. We are the ones who are going to go on various journeys: health issues, illness, hospital system, legal. "

"Being able to give some productive input is important as not everyone can see your injury."

"Involving consumers in research can add weight to the authenticity of the research and help drive it."

"As a patient, you lose your sense of agency...so it is very nice to be asked and have some input into the whole process and not just be constantly told 'this is how things are, and this is what you have to do.'"

"Consumers and carers have access to broad knowledge, interventions, lived experience and networks, which can be helpful for researchers."

Do you have feedback on the draft of consumer engagement framework?

"Researchers have almost a duty to 'inform' about what they are planning...I think that should quickly move to 'collaboration' and possibly even consumer-led research."

"I think the foundation should be on collaboration."

"In terms of the consumer being informed about the research, it would be great to have a repository of all the previous reports and surveys."

"Keep in mind people with a vision impairment or other disabilities when presenting materials."

Who would you expect our consumers to be?

"I would like to re-emphasise the interdisciplinary nature of rehabilitation....having the holistic experience is really important."

"Health professionals certainly need to be involved, GPs, Pharmacists, Physios, Occupational Therapists, Psychologists."

"So much research I do see is single discipline focussed and not multidiscipline."

"We need to engage everyone, especially people with co-morbidities, their carers and health professionals too."

In what ways would you suggest we connect with you & other consumers?

"I have found email newsletters can be very helpful."

"Flyers can work because not everyone is active on social media."

"Having a URL or a central repository to be able to point people back to here is the list of the emails, here is the research we have done, here are the groups, that kind of thing."

"Networking events works."

Results

The stepped approach to facilitate consumer involvement at RECOVER was a practical approach and proved successful.

The strategy has seen the implementation of a genuine consumer involvement in research, whereby consumers and community member have engaged with researchers at different phases of the research spectrum.

Research process and levels of consumer involvement

Conclusions

A number of lessons have been learned from the implementation strategy and different levels of RECOVER consumer involvement in research including:

- It takes time for all members of the research team to reach a point of confidence to proceed
- The first forum was the hardest!
- It is possible to bring different consumers (e.g. injured persons, health professionals and industry regulators) to the same room & have meaningful discussions
- It takes skill to keep forum presentations and other materials in plain language
- Finding the right consumers for some projects can be challenging
- It is important to have an appropriate budget to support activities & reimburse consumers for their time
- Having an active program requires someone to drive and requires time commitment
- It is hard to keep traction – need internal protocols
- Little things are important – e.g. Online Zoom links need to be made public