

Consumer Involvement Framework

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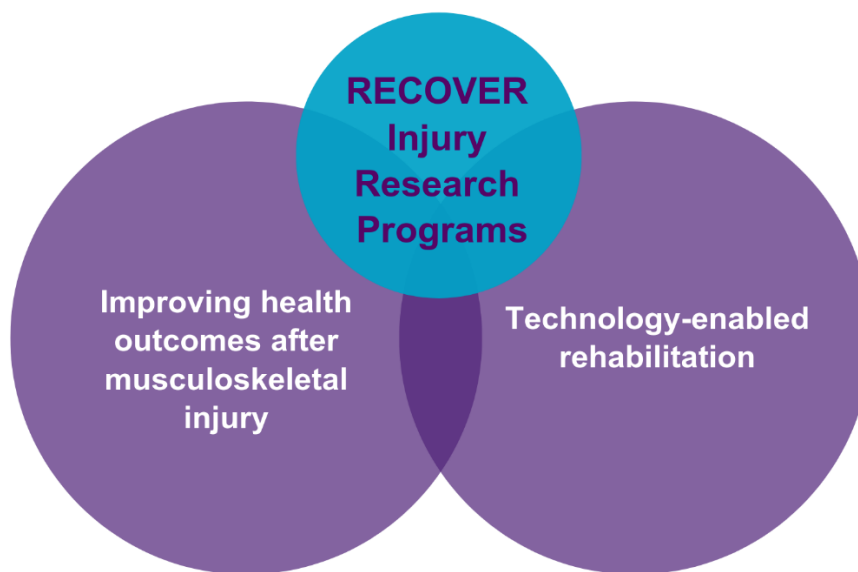
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Background

RECOVER Injury Research Centre

RECOVER Injury Research Centre conducts research to improve the lives of people who have had an injury, especially injuries caused by road traffic crashes.

There are two research streams at RECOVER, which intersect to produce research designed to optimise the recovery process following injury.



RECOVER's research focuses on:

- Better treatments
- Better predictors of recovery
- Better service delivery (e.g. using technology)
- Better support for returning to everyday life and work

Some examples of research conducted at RECOVER include:

- Research investigating pain, disability, and mental health of individuals after an injury such as whiplash, brain injury or musculoskeletal injury.
- Research that explores the challenges people with a pain condition experience during driving and other everyday tasks.
- Research designed to identify people at risk of poor recovery following injury.
- Developing more effective and efficient health services supported by technology innovation.

Who are RECOVER consumers and community members?

RECOVER's consumer and community involvement program includes:

- People affected by injury and their families/caregivers
- Community groups or advocates that represent consumers
- The general community (with interest in RECOVER research activities)

Other end-users (sometimes called Stakeholders) of our research include:

- Health professionals
- Policymakers (e.g., Motor Accident Insurance Commission)
- Compulsory Third Party (CTP) insurance providers

What is consumer involvement in research?



What is consumer involvement?

“ Consumer and community involvement is about research being carried out with or by consumers and community members rather than to, about or for them.

NHMRC statement on consumer and community involvement, 2016

Definition of consumer involvement

Consumer involvement can mean different things to different groups. Some research groups¹ make a distinction between the terms 'consumer involvement' and 'consumer engagement' and define the terms as:

"Involvement is consumers and community working alongside health professionals and researchers, in partnership, to shape what research or project is done, how it is carried out and how results are shared and applied in practice."

"Engagement involves the sharing of the findings and outcomes of a project."

¹ For example, Monash Partners. Academic Health Science Centre <https://monashpartners.org.au/education-and-training/ccj/>

At RECOVER, we have adopted the definition of consumer and community involvement as outlined by McKenzie and Hanley (2011),² whereby **consumers work in partnerships with researchers to shape decisions about research priorities, policy, and practice.**

We, at RECOVER, believe that consumer involvement includes all the activities that encourage people with a lived experience of injury, their carers, health professionals and other interested community members to actively contribute to research. The level of consumer engagement can vary across the research spectrum and within different research projects.

Further, we engage (and inform) consumers, community members and stakeholders to share our research findings via several mechanisms:

- Annual research symposiums
- Consumer engagement forums
- Workshops
- Website news items
- Social media channels

Opportunities for questions and feedback is provided for consumers in all engagement activities.

Benefits of consumer involvement

Involving consumers in research is a way to make research more relevant to community needs. It can increase public awareness and confidence in research, improve accountability over public funds, and improve research findings' quality and reach³.

Other key benefits of consumer involvement include¹:

- Improves the quality of research;
- Provides researchers with a unique perspective on people's lived experience; and
- Empowers consumers by having a 'voice.'

The role of the consumer

The role of the consumer representative⁴ is to:

- Keep health consumers at the centre of discussions;
- Raise consumer concerns;
- Speak beyond the clinical perspective by sharing emotional, spiritual, cultural, geographical, and financial perspectives;
- Provide connections to other consumers and consumer networks; and
- Provide feedback.

² Anne McKenzie and Bec Hanley (2011) Consumer and Community Involvement in Research: A training workshop for researchers on implementing involvement.

³ Statement on Consumer and Community involvement in Health and Medical Research, National Health and Medical Research Council (2016), Consumers Health Forum of Australia.

⁴ Health Consumers Queensland (HCQ) <http://www.hcq.org.au/> Consumer perspectives and consumer role lists provided by HCQ and adapted with permission.

Consumer involvement framework

Background

Inspired by the co-design and research partnership work conducted by other research groups, the RECOVER Injury Research Centre at The University of Queensland embarked on a journey to develop and implement a genuine consumer involvement strategy. The strategy aims to involve consumers and community members across the entire research spectrum. The development of a *Consumer Involvement Framework* is an essential part of this strategy.

RECOVER would like to acknowledge consumers' valuable contributions to the Framework during our 2020 Consumer and Community Online Forum.

Purpose

The Framework's goal is to increase consumer engagement in all research phases conducted at the RECOVER Injury Research Centre.

We hope the Framework will **support researchers** to engage with consumers more often and more effectively. The Framework is designed to assist researchers in understanding:

- What consumer involvement is and why it is important;
- When and how consumer involvement can take place; and
- What strategies researchers can use to connect with consumers.

We hope the Framework will also **support consumers** to engage with researchers more often and more effectively. The Framework is designed to help consumers understand when and how they can engage with researchers at RECOVER.

Research and consumer involvement

How does involvement differ from research participation?

Consumer *involvement* in research is where consumers work *with* researchers to shape the research design and conduct research. The level of consumer involvement can vary across the research spectrum and within different research projects.

Research *participation* is when consumers are recruited to be participants in a project. Researchers collect data (information) from the participants.

Ethical considerations

Genuine consumer involvement is not research and should not require Human Research Ethics Committee (HREC) approval.

However, as consumer involvement is relatively new in research, researchers must carefully consider whether ethical approval may be required for certain activities.

The University of Queensland research ethics committee advises that researchers consider what they will do with information contributed by consumers.

For instance:

- Suppose you invite one or more consumers to be on the research team or an advisory group to contribute to the project concept or development. In that case, you *do not need* ethical approval.

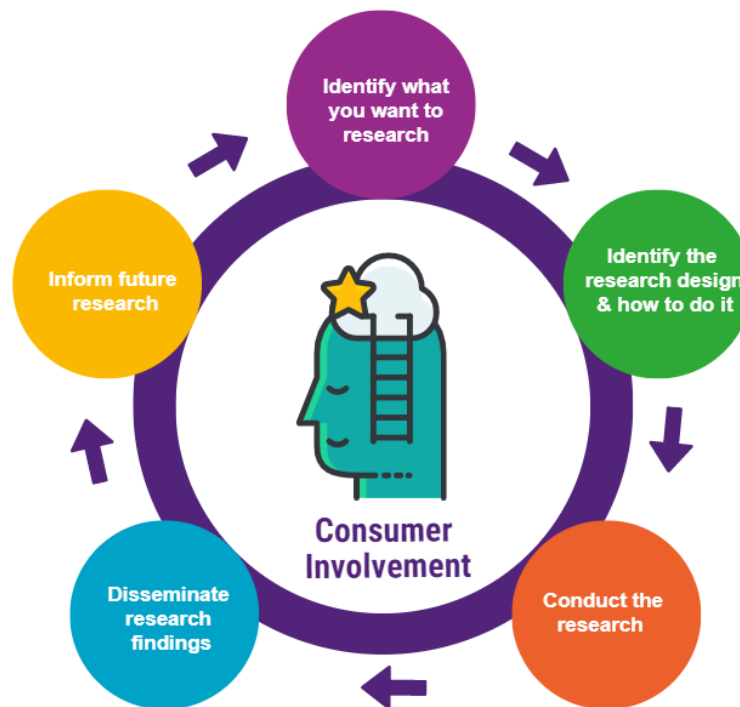
- If you invite one or more consumers to review study recruitment material and provide feedback, you *do not need* ethical approval.
- If you bring in consumers for a focus group style of consultation at the design phase (or any stage) and wish to publish their contribution as part of your methodology, ethics approval *is* required.

Research cycle

The research cycle below demonstrates the usual sequential phases of a research project and adds two new steps:

- Identify the target consumer, and
- Identify the level of consumer involvement.

The research cycle reminds researchers to consider consumer engagement right from the beginning of a research study.




Types of consumer involvement

The International Association of Public Participation (IAP2) spectrum⁵ is a practical way to guide consumer involvement with health organisations⁶. RECOVER generated the following table based on the IAP2 spectrum and consumer involvement in other research settings⁷. The table provides concrete examples of consumer involvement activities that can occur within each of the research phases.

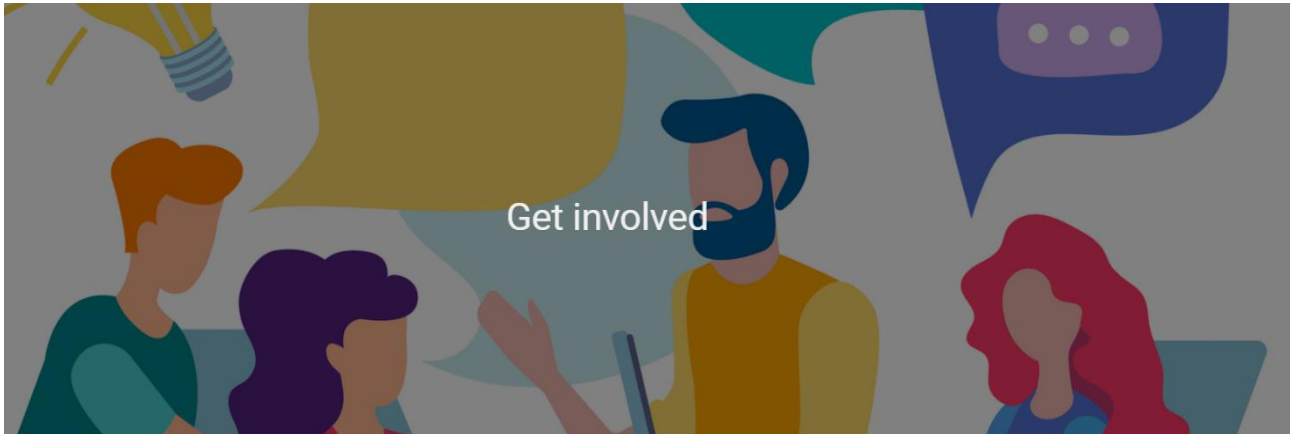
⁵ International Association of Public Participation (2016). IAP2 Public Participation Spectrum. Available from: <https://www.iap2.org.au/Resources/IAP2-Published-Resources>

⁶ Health Consumers Queensland. Consumer and community Engagement Framework 2017. Brisbane: Health Consumers Queensland.

⁷ Cox R, Kendall M, Molineux M, Miller E, Tanner B. Consumer engagement in occupational therapy health-related research: A scoping review of the Australian Occupational Therapy Journal and a call to action. Australian Occupational Therapy Journal. 2020.

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| | Passive | | | | Active | |
| | Inform consumers about our research and activities. | Consult with consumers to seek feedback. | Actively involve consumers in research planning. | Partner with consumers through phases of the research cycle. | Consumers initiate research. | |
| Research Phase examples | | | | | | |
| Preparation | Identify what you want to research. Generate a project plan which includes consumer involvement. | Information about upcoming projects to be advertised: <ul style="list-style-type: none"> on our consumer webpage social media physical locations | Consumers provide one-off feedback: <ul style="list-style-type: none"> on research topic and protocols data collection tools participant information sheets and consent forms | Ongoing consultation and feedback with consumers about the direction of a research idea and plan. The consumer 'voice' is heard and incorporated. | Researchers partner with consumers in the preparation phase of a research project. Consumers are equal partners. | Research topic or direction initiated by community organisation or industry group. A project steering committee led by consumers. |
| Execution | Project recruitment, data collection, analysis, and write up. | Information about new and active research projects to be advertised: <ul style="list-style-type: none"> on our consumer webpage social media physical locations | Opportunity for consumers to provide one-off feedback: <ul style="list-style-type: none"> on data collected (e.g. interview transcripts) on results/summary of findings. | Consumers involved in reviewing and contributing meaningfully to recruitment strategies. May assist in recruiting participants through consumer networks. | Consumers invited to be members of an advisory group. | Consumers are lead or co-investigators. Project decision making led by consumers. |
| Translation | Share findings. | Findings presented: <ul style="list-style-type: none"> at research and consumer forums on the website and social media channels | Feedback sought from consumers: <ul style="list-style-type: none"> on any presented or published findings | Consumer contributions acknowledged in publications. | Co-authorship of presentations or publications. | Consumer representatives lead the planning and execution of dissemination activities. |

How can researchers connect with consumers?



Mechanisms for connecting with consumers

RECOVER researchers can connect with consumers through the following methods:

- Consumer web portal '[Get Involved.](#)'
 - For example, researchers can post advertisements on the '[Calls for consumer feedback](#)' page.
- RECOVER consumer e-mailing list
- Consumer brainstorming/consultation forums
- RECOVER consumer advisory group (to commence in 2021)
- Health professionals and health professional organisations (e.g. GPs, Pharmacists, Physios, Occupational Therapists, Psychologists)
- Social media channels
- Printed flyers at places where injured consumers may go. For example:
 - Health services (e.g. Pain clinics)
 - Carer organisations
- Hospital and health services QLD Health

Additional resources and training for researchers and consumers

The following resources are designed to inform consumers and assist researchers to conduct and embed consumer engagement in their research:

Monash Partners Academic Health Science Centre.

Consumer and community involvement training modules <https://monashpartners.org.au/education-and-training/cci/>

Health Consumers Queensland

Recruiting consumers: <http://www.hcq.org.au/home/recruiting-consumers/>

A guide for consumers partnering with health organisations: http://www.hcq.org.au/wp-content/uploads/2018/06/HCQ_ConsumerGuide.pdf

A Guide for Health Staff: Partnering with Consumers 2018. Brisbane: Health Consumers Queensland. http://www.hcq.org.au/wp-content/uploads/2018/06/HCQ_StaffGuide.pdf

Consumer and community engagement framework for health organisations and consumers 2017. Health Consumers Queensland. <http://www.hcq.org.au/wp-content/uploads/2017/03/HCQ-CCE-Framework-2017.pdf>

Published research involving consumers

Cox R, Kendall M, Molineux M, Miller E, Tanner B. Consumer engagement in occupational therapy health-related research: A scoping review of the Australian Occupational Therapy Journal and a call to action. Australian Occupational Therapy Journal. 2020.

Project team

Members of the Working Group

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