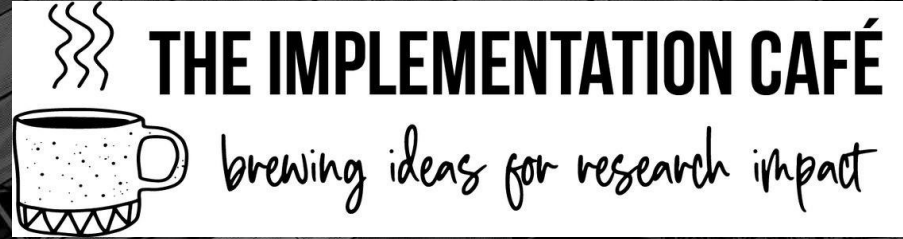


WELCOME

- We will start promptly at 12:00pm
- Q&A is OPEN - we encourage you to post questions for today and for future seminars.
- Resources (recording, slides, links & more) will be available after the presentation.
- The session will be recorded, and we will be sharing the recording publicly. Please contact us if this raises any issues for you.



Supported by

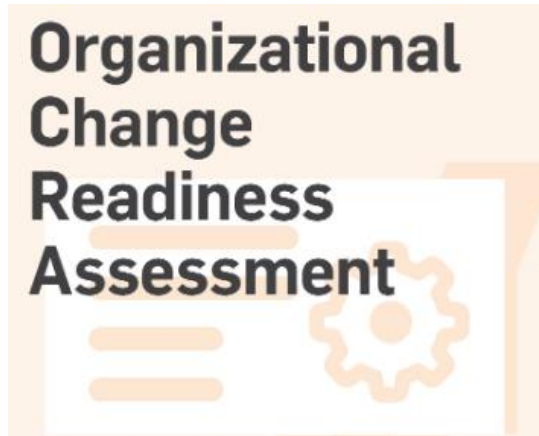
Acknowledgment of Country



Edith Cowan University acknowledges and respects the Noongar people, who are the traditional custodians of the land upon which its campuses stand and its programs operate. In particular, ECU pays its respects to the Noongar Elders, past and present, and embraces their culture, wisdom and knowledge.

September Journal club...

- What is organisational readiness?
- Measuring organisational readiness
- Prof. Nigel Spry – Boundary spanner and ‘champion’
- Strategies to success – CFIR, Inner-outer setting,
- Implementation climate – no one best way - so dive in!



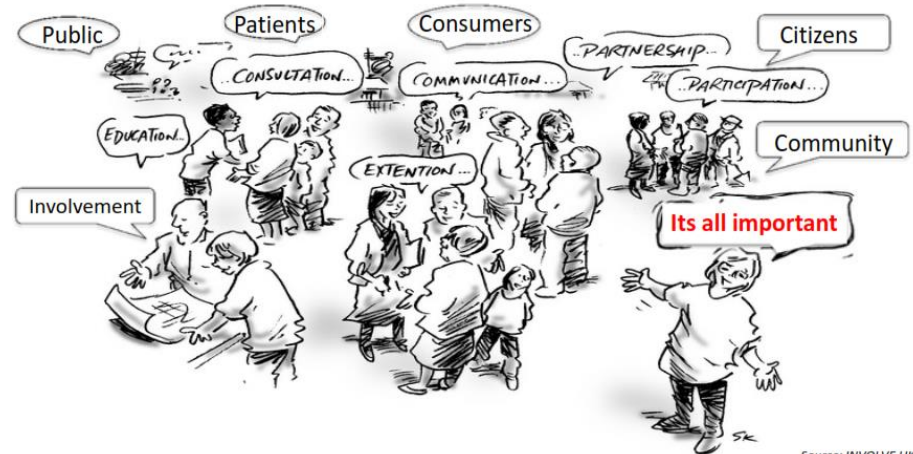
Consumer and Community Involvement (CCI)

Key terms and definitions

Consumers and community members include people with lived experience of a health condition or service, their support people, carers, advocates and people from patient advocate group.

Involvement (Engagement) is a bi-directional relationship between consumer stakeholders and members of a research team.

CCI is conduct of ethical research that happens **with** the community rather than **to** or **for** the community (Think co-design! Collaboration! Co-production!).



Journal articles

Practice & Innovation

Consumer engagement critical to success in an Australian research project: reflections from those involved

Annaliese J. Symon^{A,B,1,3}, Catherine L. Cherry^{C,D,E}, Michael P. Summers^A, Rvth Stuckey^A, Catherine A. Milne^D, Dianne B. Lowe^A and Sophie J. Hill^A

¹Centre for Health Communication and Participation, School of Psychology and Public Health, College of Science, Health and Engineering, La Trobe University, Kingsbury Drive, Bundoora, Vic. 3086, Australia.
²Department of Infectious Diseases, The Alfred Hospital and Monash University, Level 4, 553 St Kilda Road, Melbourne, Vic. 3004, Australia.
³Cochrane Australia, School of Public Health and Preventive Medicine, Monash University, Level 4, 553 St Kilda Road, Melbourne, Vic. 3004, Australia.
⁴Department of Health, Behavior and Society, Johns Hopkins University, The Burnett Institute, 85 Commercial Road, Melbourne, Vic. 3004, Australia.
⁵Faculty of Health Sciences, University of Technology Sydney, Private Bag 3, WITS 2050, Johannesburg, South Africa.
⁶Centre for Ergonomics and Human Factors, Health and Engineering, La Trobe University, Bundoora, Vic. 3086, Australia.
⁷Squidney Health Ethics, School of Public Health, University of Technology Sydney, NSW 2006, Australia.

Abstract. This paper describes the challenges of engagement in a complex research project and the importance of consumer engagement in the development of a research project. The 2.5-year integrative online consumer survey advisory group members were experienced in managing a survey. The 2.5-year integrative online consumer survey advisory group members were experienced in managing a survey. The 2.5-year integrative online consumer survey advisory group members were experienced in managing a survey.

KEY WORDS: community participation, health service research, patient experience and public involvement

Engaging consumers in health research: a narrative review

Ania Anderson^{1,3}, MPH, Research Associate
Karen Conroy^{1,2}, BScSc(Hons), PhD, Head, Commissioned Research
Greg Fairhead^{1,3}, RN, BA, MPH, PhD, Nurse Consultant, Patient and Family-Centred Care Research, Sydney Research
Laila Hallam^{1,3}, BBA, MBA, Health Consumer Representative, Health Consumer Advisor, History of Alliances (CDB)
Alan McPhail², BAppSc, MEngSc, PhD, Consumer Representative
Vicki Taylor^{1,3}, RN, RCUGB, BHA, Adjunct Associate Professor, Executive Director, Sydney Research

¹The George Institute for Global Health, Level 5, King Street, Newtown, NSW 2042, Australia.
²Sydney Local Health District, Level 11, King George V Building, Misericordia Road, Camperdown, NSW 2050, Australia. Email: Greg.Fairhead@health.nsw.gov.au; Laila.Hallam@health.nsw.gov.au
³University of Sydney, Faculty of Medicine and Health, Level 11, King George V Building, Royal Prince Alfred Hospital, Camperdown, NSW 2050, Australia.
⁴The University of Sydney, Centre for Disability Research and Policy (CDRP), 92-94 Parramatta Road, Camperdown, NSW 2050, Australia.
Corresponding author: Email: anderson@georgeinstitute.org.au

Abstract. Objective. Consumer and community engagement (CCE) in research is increasingly valued in a contemporary healthcare environment that seeks to genuinely partner with consumers and the wider community. Although there is considerable guidance as to how best to proceed with CCE in research, there is little available guidance on how to manage and overcome the challenges of CCE in research. This narrative review was conducted to develop a practical review of CCE in research. Methods. A narrative review of CCE in research was conducted. Following this, a case series among consumers who had been engaged in research was explored. Results. In all, 121 papers were identified. The most important findings were the need for a clear understanding of the relationship between consumer and research barriers and help address the barriers. Conclusions. This practical review provides a practical review of CCE in research.

Researcher Perceptions of Involving Consumers in Health Research in Australia: A Qualitative Study

Jean Carlini^{1,2,3,4}, Rachel Muir^{2,3,4}, Annette McLaren-Kennedy³ and Laurie Creahy^{2,3,4}

¹ Department of Marketing, Queensland University, Nathan, QLD 4111, Australia
² Menzies Health Institute Queensland, Gold Coast, QLD 4222, Australia
³ School of Nursing & Midwifery, Queensland University, Nathan, QLD 4111, Australia
⁴ Department of Emergency Medicine, Gold Coast Hospital and Health Service, Gold Coast, QLD 4222, Australia
⁵ Nursing & Midwifery Education and Research, Gold Coast Health, Southport, QLD 4222, Australia
Correspondence: jcarlini@qut.edu.au; Tel: +61 07 5552 9094

Abstract: There is growing recognition internationally of the importance of involving consumers, and the public in research. This is being driven by political mandates for policies, funding, and governance that demand genuine and meaningful engagement with consumers. Funding, needs, improved quality of care and outcomes, and enhanced public confidence in patient care. This literature highlights that efforts to incorporate patient confidence in research. However, there is a limited understanding of the psychological factors that can impact researcher attitudes, intentions, and behaviours when working with consumers in research. To address this gap, this study conducted 25 semi-structured interviews with health researchers in Australia using the qualitative one-stage method. The study aims to explore the underlying reasons for researcher attitudes and when involving consumers in health research. The results identified several factors that influence researchers' attitudes and a shift in research culture and expectations as major drivers. However, barriers that researchers would hinder research and expectations as major drivers. However, barriers that researchers would hinder research and expectations as major drivers. However, barriers that researchers would hinder research and expectations as major drivers.

Google Scholar Consumer Community Involvement

Articles About 17,300 results (0.04 sec)

Any time
Since 2023
Since 2022
Since 2019
Custom range...

Sort by relevance
Sort by date

Any type
Review articles

include patents
 include citations

Create alert

... attitudes and purchase intentions towards internet celebrity self-brands: an integrated view of congruence, brand authenticity and internet celebrity involvement
TH Tseng, HY Wang - Journal of Product & Brand Management, 2023 - emerald.com
... media brand communities were collected via online surveys of consumers with ... involvement, consumers' perception of celebrity involvement may have more influence on consumer ...
☆ Save Cite Cited by 6 Related articles

Consumer partnerships in research (CPR) checklist: A method for conducting market research with vulnerable consumers
J Carlini, J Robertson - International Journal of Market ..., 2023 - journals.sagepub.com
... consumer involvement in market research. We propose that research conducted about vulnerable consumers must include consumers as co-... to consumer and community involvement ...
☆ Save Cite Cited by 4 Related articles All 3 versions

... of healthy lifestyle interventions for people with disability living in supported accommodation: a scoping review of intervention efficacy and consumer involvement
K Hatziirakidis, D Ayton, A O'Connor... - Disability and Health ..., 2023 - Elsevier
... Seven studies described the co-design of interventions via consumer and community involvement. Five of these studies examined education and training, 93, 99, 100, 107, 123 while ...
☆ Save Cite Cited by 1 Related articles All 3 versions

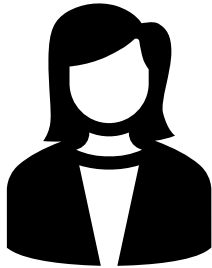
The Importance of Community Involvement in Public Management Planning and Decision-Making Processes
S Rijal - Journal of Contemporary Administration ..., 2023 - journal.literasains nusantara.com
... Increased Community Satisfaction. Community involvement ... Recognising the importance of community involvement in the ... to delve deeper into community participation in public decision...
☆ Save Cite Cited by 14 All 2 versions

... anchor traits on shopping intentions in a live streaming marketing context: The mediating role of value perception and the moderating role of consumer involvement
Y Zhou, W Huang - Economic Analysis and Policy, 2023 - Elsevier
... (SOR) theory and involvement theory, we investigate the ... the moderating effect of consumer involvement on purchase ... intention, while consumer involvement plays an important negative ...
☆ Save Cite Cited by 6 Related articles

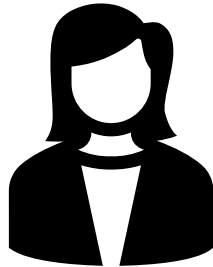
Recruitment of the consumer advisory group...

The researchers sought to include people affected by MS (both genders, different MS types) having some familiarity with research and connection with the broader MS community.

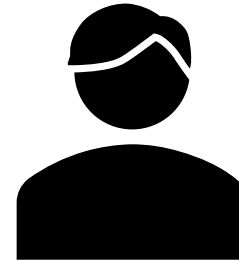
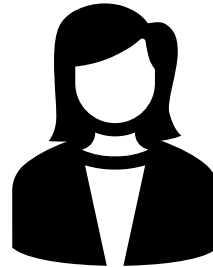
Four consumers were approached by M. P. Summers (all accepted the invitation), with this number felt sufficient for meaningful interaction while still providing opportunity for all to contribute.



- Lived experience >10 years.
- Healthcare and academic backgrounds.
- Actively involved in MS consumer groups.



- Represented people with MS for 30+ years.
- Actively involved in MS consumer groups.
- Involved in research projects.



- Content specialist.
- Previous experience with developing information resources for people with MS.

Consumer engagement activities

Table 1. Detailed consumer advisory group member engagement activities and methods of engagement, mapped against research stages and phases
IN-DEEP, Integrating and Deriving Evidence Experiences and Preferences; MS, multiple sclerosis

| Research phase | Advisory group activities | Methods of engagement used |
|-------------------------------|---|---|
| Planning | Input into focus group questions and structure | Face-to-face meeting, where proposed focus group approach was presented and feedback sought. |
| Conduct | Suggested networks for recruitment | Suggestions sought over email, with request to forward on the e-invitation to others. |
| Dissemination and translation | Provided advice on implications of findings for Stages 2 and 3 | Face-to-face meeting using facilitated discussion (each person individually invited to provide reflections and advice). Provisional focus group results (thematic analysis) were emailed 1 week in advance. |
| Planning | Prioritised which reviews to include on website | Emailed list of potential reviews, along with proposed criteria for selecting reviews. Invited to comment on appropriateness of proposed criteria, and nominate up to 10 reviews for the website. |
| Conduct | Reviewed and revised early website testing materials | Face-to-face meeting, using facilitated discussion to seek feedback and revisions from each person individually, followed by group discussion. Provisional website structure and materials were circulated 1 week in advance over email. |
| Dissemination and translation | Reviewed and edited website documents after review panels with participants | Face-to-face meeting, in which the results of the review panels and a list of proposed changes were presented to the group, followed by facilitated discussion. All documents were circulated 1 week in advance over email. Additional <i>ad hoc</i> input sought over email, for advice about how best to report or describe specific aspects of the website material. |
| Planning | Reviewed evaluation questions | Draft questions provided over email, and feedback invited. |
| Conduct | Suggested networks for recruitment | Suggestions sought over email, with request to forward on e-invitation to others. |
| Dissemination and translation | Spoke at website launch | One advisory group member (C. L. Cherry) spoke about her experiences of being involved in the study at the launch held at the MS Australia offices. |
| | Disseminated website to networks | Emailed promotional materials and invited to forward on to networks, including by social media. |
| | Co-authored journal article | Emailed an early outline and pre-final drafts of manuscripts for comment and contribution. |
| | Discussed ideas for future research | Face-to-face meeting, free discussion of ideas for possible future research projects that could be developed into funding proposals. |

Benefits, enablers of CCI

For advisory group members, the key benefit was making a valued contribution to research that would assist the MS community, drawing upon their personal experiences or years of talking to people with MS. For example, C. L. Cherry felt the researchers

Advisory group members also felt valued, empowered and satisfied. R. Stuckey found it empowering to draw on often difficult previous personal experiences, challenges and disappointments to provide useful, constructive input to others. She found combining personal experience and professional expertise to inform and enrich the work very satisfying.

conversations. R. Stuckey felt it was particularly important she could share the experiences of people who would not have the confidence or opportunity to participate in research themselves.

and appropriately used. Seemingly small things, such as involvement by advisory group members in the website launch and presentation, made involvement seem valued and not token.

happening and found the opportunity to be involved was 'just amazing'. Having spent years talking to people with MS and their

The researchers were sometimes concerned their idealism to share research-based treatment information was a 'researcher aim' and not necessarily relevant for people facing decision-making dilemmas in the 'real world'. Regular discussions with advisory group members provided a more balanced perspective and helped confirm researchers' view that aiming to share evidence was beneficial, even if it did not meet all of peoples' needs.

A critical enabler was the brokering or boundary-spanning role played by M. P. Summers. The term 'knowledge broker' is more commonly used in evidence to policy and practice literature, meaning someone who can 'facilitate transactions and the flow of information between people or groups separated or hindered by some gap or barrier' (Long *et al.* 2013, p. 1). Such barriers can

For both researchers and advisory group members, the primary challenge was that MS is a chronic, disabling, unpredictable condition. This directly affected the group, with one member unable to continue past the first meeting. Subsequently, careful attention was paid by researchers to the physical needs of and demands on members, including selecting meeting venues with adequate air conditioning (people with MS often experience heat sensitivity) and easy parking and access.

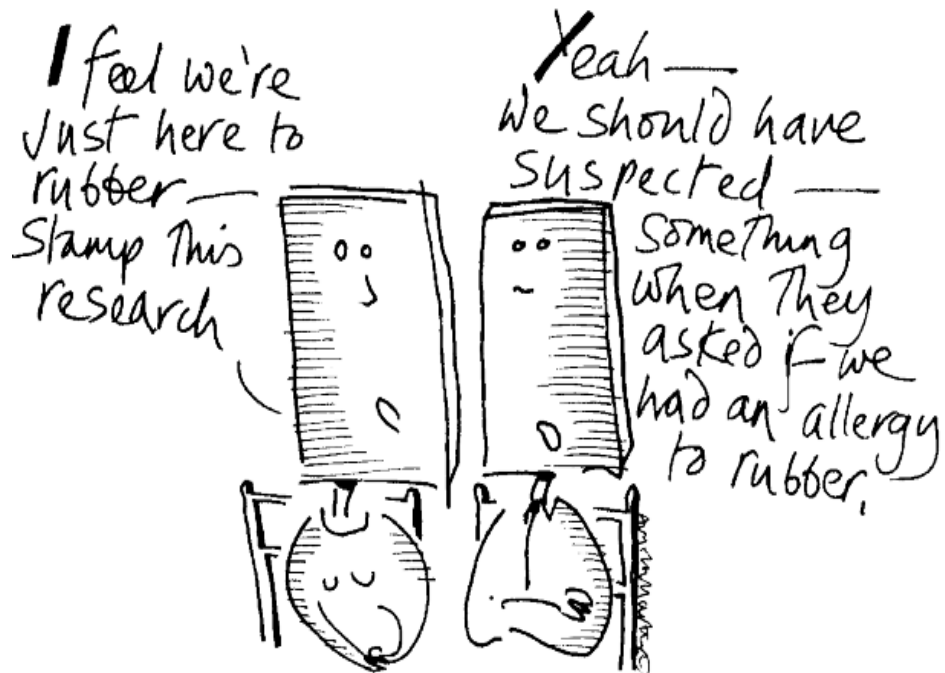


Case examples:

- Women's views/experiences of maternity care
- Midwives' views/experiences of their practice environment

When you work with populations who give or who use health care ...

1. Not a bad idea to adopt a trauma-informed approach
2. Budget more time than you think because of peoples' differing...
 - priorities
 - sense of urgency
 - energy levels
 - attention capacity
 - clarity / lens
 - etc.



MARY!

1. Funding bodies and grant writing.
2. Human Research Ethics Committee requirements (Segway into Nov journal club)



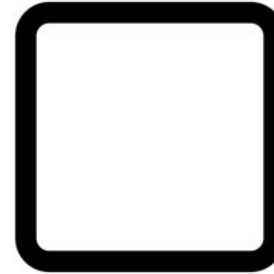
What it's not about...

Researchers just raising awareness of their research.

CCI being treated as 'participants' taking part in research.

An opportunity to 'tick the box' on grant application.

Securing funding and publications.



The difference...

Collaboration

Involvement

Engagement

Support & advice available for WA researchers



The Consumer and Community Health Research Network



Website: www.involvingpeopleinresearch.org.au

Resources



www.involvingpeopleinresearch.org.au



ECU INTERNAL LINK: <https://intranet.ecu.edu.au/research/for-research-staff/research-journey/getting-started/wahtn-consumer-and-community-involvement>

12.00
OPEN

Topic of the Month

28TH AUGUST

How do I know when the time is right?
Needs assessments in implementation

SPECIAL

18 SEPTEMBER

~~25TH SEPTEMBER~~

Assessing organisational
readiness for implementation

30TH OCTOBER

Effective consumer engagement
for implementation

27TH NOVEMBER

Including implementation
when writing grants

Next session
27th November

Including implementation
when writing grants