



University of  
South Australia

# Consumer Engagement

# Researchers needing or wanting to understand the what, why and how of consumer engagement in research

Participants will gain:

- An understanding of why consumer engagement is important in many areas of research
- The principles underpinning CE
- Appreciate the different levels of engagement,
- the research methodologies that underpin different levels (and how to choose)

We will use case studies and real world examples to illustrate

- How to identify stakeholders and consumers for various roles and stages
- Develop relationships that are productive and respectful

We will use examples from successful grants to illustrate how to operationalise consumer engagement into grants via

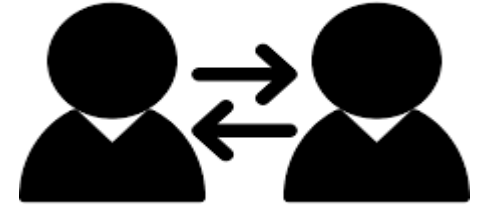
- The aims and objectives, methods, budget and implementation plans

# What is Consumer engagement?



*“an informed dialogue between an organisation and consumers, carers and the community which encourages participants to share ideas or options and undertake collaborative decision making, sometimes as partners”*

# What is Consumer engagement?



Based on the principle that:

- Policy, research and services are in the public interest and people have the right to be engaged with and contribute to decisions which will affect them

And aims to:

- capture the plethora of community perspectives,
- enable consumer responsibility,
- examine acceptability of approaches to generate evidence,
- and lead to research of greater quality and (clinical) relevance and better application of findings

	<b>INFORM</b>	<b>CONSULT</b>	<b>INVOLVE</b>	<b>COLLABORATE</b>	<b>EMPOWER</b>
<b>Public Participation Goal</b>	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions	To obtain public feedback on analysis, alternatives and/or decisions	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution	To place final decision making in the hands of the public
<b>Promise to the public</b>	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.
<b>CE methods</b>	<ul style="list-style-type: none"> <li>• Mass media</li> <li>• Website</li> <li>• Press releases</li> <li>• Mail outs</li> <li>• Fact sheets</li> <li>• Hotline</li> <li>• Displays and exhibitions</li> <li>• Presentations</li> </ul>	<ul style="list-style-type: none"> <li>• Focus group</li> <li>• Patient surveys</li> <li>• Feedback and complaints</li> <li>• Story-telling</li> <li>• Social media</li> <li>• Planning meetings/forums</li> <li>• Suggestion boxes</li> <li>• Patient diaries</li> <li>• Mystery shopping</li> </ul>	<ul style="list-style-type: none"> <li>• Forums for debate</li> <li>• Health panels</li> <li>• Shadowing patients</li> <li>• Workshops</li> <li>• Public meetings</li> </ul>	<ul style="list-style-type: none"> <li>• Patient advisory councils/committees</li> <li>• Expert patients</li> <li>• Charette(interdisciplinary planning group)</li> <li>• Constituent assembly</li> <li>• Delphi process</li> <li>• Retreats</li> <li>• Round tables</li> <li>• Impact assessments</li> <li>• Ethics committees</li> <li>• World Cafe'</li> <li>• Town hall meetings</li> <li>• Revolving conversation</li> </ul>	<ul style="list-style-type: none"> <li>• Citizen jury</li> <li>• Consumer managed project/service</li> <li>• Consensus</li> <li>• conference</li> <li>• Deliberative polling</li> <li>• Search conference</li> <li>• Study circles</li> <li>• Study groups</li> <li>• Sustainable community development</li> <li>• Think tanks</li> </ul>

# When?

Can be at any (or all) stage of research

- Development
- Implementation
- Monitoring
- Evaluating (writing up)



# Who?

## Characteristics of consumers:

- Relevant background or experience as the intended participants
  - Lived experience
  - Cultural, ethnic , diagnostic, sociodemographic
- +/- special training in engagement and/or advocacy



# How?

Examples include participation in:

- Service delivery (develop, deliver/implement, evaluate)
- Professional training
- Priority setting
- Information (development and delivery)
- Conducting research activities (develop processes, doing interviews/recruitment, data collection)





# Evidence for consumer engagement

RESEARCH ARTICLE

## Consumer engagement in health care policy, research and services: A systematic review and meta-analysis of methods and effects

Louise K. Wiles<sup>1,2,3</sup>, Debra Kay<sup>4</sup>, Julie A. Luker<sup>1</sup>, Anthea Worley<sup>1</sup>, Jane Austin<sup>5</sup>, Allan Ball<sup>6</sup>, Alan Bevan<sup>4</sup>, Michael Cousins<sup>7</sup>, Sarah Dalton<sup>8,9</sup>, Ellie Hodges<sup>10</sup>, Lidia Horvat<sup>11</sup>, Ellen Kerrins<sup>12</sup>, Julie Marker<sup>4</sup>, Michele McKinnon<sup>13</sup>, Penelope McMillan<sup>4</sup>, Maria Alejandra Pinero de Plaza<sup>4,14,15</sup>, Judy Smith<sup>16</sup>, David Yeung<sup>3,17,18</sup>, Susan L. Hillier<sup>1</sup>\*

developing patient information material results in material that is more relevant, readable and understandable for patients, and can improve knowledge. Mixed effects are reported of consumer-engagement on the development and/or implementation of health professional training. There is some evidence that using consumer interviewers instead of staff in satisfaction surveys can have a small influence on the results. There is some evidence that consumers may have a role in identifying a broader range of health care priorities that are complementary to those from professionals. There is some evidence that consumer engagement in monitoring and evaluating health services may impact perceptions of patient safety or quality of life. There is growing evidence from randomised controlled trials of the effects of consumer engagement on the relevance and positive outcomes of health policy, research and services. Health care consumers, providers, researchers and funders should continue to employ evidence-informed consumer engagement in their jurisdictions, with embedded evaluation.

**Systematic review registration:** PROSPERO [CRD42018102595](https://doi.org/10.1186/1745-6215-102595).

### Abstract

To assess the effects of consumer engagement in health care policy, research and services. We updated a review published in 2006 and 2009 and revised the previous search strategies for key databases (The Cochrane Central Register of Controlled Trials; MEDLINE; EMBASE; PsycINFO; CINAHL; Web of Science) up to February 2020. Selection criteria included randomised controlled trials assessing consumer engagement in developing health care policy, research, or health services. The International Association for Public Participation, Spectrum of Public Participation was used to identify, describe, compare and analyse consumer engagement. Outcome measures were effects on people; effects on the policy/research/health care services; or process outcomes. We included 23 randomised controlled trials with a moderate or high risk of bias, involving 136,265 participants. Most consumer engagement strategies adopted a **consultative** approach during the **development** phase of interventions, targeted to **health services**. Based on four large cluster-randomised controlled trials, there is evidence that consumer engagement in the development and delivery of health services to enhance the care of pregnant women results in a reduction in neonatal, not maternal, mortality. From other trials, there is evidence that involving consumers in

PLOS ONE 2022

<https://doi.org/10.1371/journal.pone.0261808>



University of  
South Australia

## Inform

*Mass media  
Open access  
Fact sheets*

## Consult

*Focus groups  
Surveys*

## Involve

*Delphi  
groups*

## Collaborate

*Advisory  
groups and  
co-design*

## Empower

*Citizen panels  
Consumer-  
managed  
projects  
Citizen/Clinician-  
scientists*

Consumers, Lived Experience,  
Communities, Industries and Organisations

University  
Researchers

UniSA  
Consumer  
Engagement  
Framework

# Principles of Consumer Engagement in Research

Those affected by research have a right to be involved in that research;  
from setting priorities and directions through to design, execution and dissemination;

The engagement is sustainable, meaningful, and acknowledged;  
and founded on respectful communication and information/knowledge exchange.



University of  
South Australia



**University of  
South Australia**