DRAFT Framework for Consumer and Community Involvement (CCI) in Health Research

Developed by the
Health Translation Queensland CCI in Research Alliance

March 2025

Please note: this is a draft and does not reflect the final design of the document

DRAFT Framework for CCI in Health Research

Health Translation Queensland (HTQ) leads the Consumer and Community Involvement (CCI) in Research Alliance to collaborate on CCI initiatives across the HTQ partnership.

The Framework for CCI in Health Research is one of those initiatives.

HTQ brings together many of Queensland's major hospital and health services, universities and research institutes.

HTQ's partners are: Children's Health Queensland, Metro North Health, Metro South Health, West Moreton Health, Mater, The University of Queensland, Queensland University of Technology, Griffith University, QIMR Berghofer, Translational Research Institute, Australian eHealth Research Centre, Queensland Health.

www.healthtranslationqld.org.au

What is CCI in Health Research?

It is involving consumers, community and clinicians as core stakeholders / partners in health research projects. Being inclusive of consumer and community voices can tell us where research is most needed, how people are affected by health issues or conditions, and how new health measures can be adopted by the people who need it most.

Why involve consumers and community?

Consumers and community have a right to be involved in research that is about them. The personal experiences of health consumers, patients and their carers add a rich source of evidence that contribute to the rigour, relevance and acceptability of health research.

Prioritising diversity of voices in CCI

CCI is about bringing together **different** people with something in common to share ideas about a problem in a safe and supportive environment. Consumer and community voices involved in health research must represent a mix of identities (e.g. underserved communities, ethnicity, age, gender, culture or faith, LGBTIQA+ identity, location, education or profession, etc.)

What is a framework?

A framework provides a structure to support understanding and application of a theory or concept.

Who is this framework for?

The framework is for health researchers to guide how and when to involve consumers and community into their research.

What is included in the framework?

- Principles for involving consumers, community and clinicians in research
- Stages of research for involvement
- Methods for consumer and community involvement for different stages of research and level of involvement / decision-making

Principles for CCI in Health Research
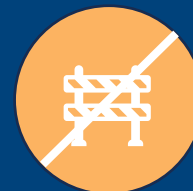

Respect, Transparency and honesty

Involve consumers as early as possible

Value all contributions and acknowledge different opinions

Involve a diversity of voices including underserved communities

Reduce hurdles to involvement

CCI across the research journey

STAGES OF RESEARCH ^	1 Building relationships	2 Developing the research idea	3 Developing the project and seeking agreement	4 Collecting data
CCI goals	• Understand lived experience. • Establish trust with consumers, clinicians and community.	• Establish a clear research idea that will provide value to consumers, clinicians and community and all other stakeholders.	• Identify how data will be collected through consumer, clinician and community involvement. • Ensure the research process is accessible and inclusive.	• Gather data that is usable for the research question, meets legislative requirements, and clear rules for the collection of personal data. • Ensure a diverse sample is collected using appropriate methods.
What to ask consumers, community or clinicians?	• What health needs are unmet and could be assisted by research? • How would you prefer to be involved, e.g. method?	• How could we involve consumers, clinicians and community? • Is this the right question we need to be researching?	• Is anything missing? • Are there any barriers to consumers, clinicians and community to be involved in this process? • Are the tools we are using able to be understood?	• How do we build trust and reach the right people? • Questions relating to the research
Methods to use #	• Surveys, online forms • Face-to-face conversations • Casual group discussions • Art spaces, • Kitchen teas • Advisory groups • Submissions • Cultural events • Citizen science	• Focus groups • Open group discussions • Meetings • Scientific conferences	• Workshops • Meetings	• Focus groups • Surveys, online methods • Face-to-face meetings/conversations • Art spaces • Kitchen teas • Games • Cultural events • Citizen science
Who to involve? *	• Consumers, clinicians and community with differing health situations • Carers & family members	• Consumers, clinicians and community members	• Consumers, clinicians and community members previously involved in Stage 2	• Diverse range of consumers, clinicians and community as identified in the earlier stages

^ The stages of the research cycle used for this Framework are taken from NHMRC's Keeping Research on Track II (2018).

See page 5 for further examples of involvement methods.

* This Framework does not include consumer organisations that are co-funding the research. In this instance the consumer organisation would become a partner who jointly sets the CCI program.

CCI across the research journey

STAGES OF RESEARCH ^	5 Analysing the data and making sense of the findings	6 Report writing	7 Sharing and translating the results into action	8 Learning from experience
CCI goals	• Identify research limitations and data gaps associated with reach and access of consumers.	• Prepare consumer-facing report that is clear and easy to understand for consumers and community outlining the key findings. • Prepare a separate more detailed report for researchers outlining all details from the research process.	• Share clear CCI outcomes/results to integrate into existing or new research projects and/or health processes.	• Evaluate the research process and identify improvements, what worked and what didn't work for CCI.
What to ask consumers, community or clinicians?	• Is there missing consumer/community/clinician representation? • Is the consumer voice reflected? • What does this research mean to consumers / community? • Is there anything from your consumer / community perspective that we haven't considered?	• What is the best way to present the findings / results so that consumers / community can understand them? • Have we acknowledged the contribution of consumers?	• How can we share this with consumers / community that would encourage behaviour change or implementation of findings? • What's the best way to get clinician attention?	• Do the findings identify a new research need? • How could we apply the results? • Can consumers, clinicians and community be involved differently?
Methods to use #	• Framework analysis • Debriefing sessions • Advisory group	• Meetings	• Journal publications • Infographics/animations for consumers/clinicians/community • Conference presentations • Social media • Kitchen tea • Citizen science	• Workshops • Conferences • Reflections/reviews • Forum • Advisory group • Scientific conference • Citizen science
Who to involve? *	• Consumers, clinicians and community involved in the research process • Oher researchers for an unbiased view	• Consumers, clinicians and community involved in research process • Broader network for further evaluation on findings	• Researchers • Staff at relevant levels for change management • Consumers, clinicians and community	• All involved with the research process

^ The stages of the research cycle used for this Framework are taken from the NHMRC' Keeping Research on Track II (2018)

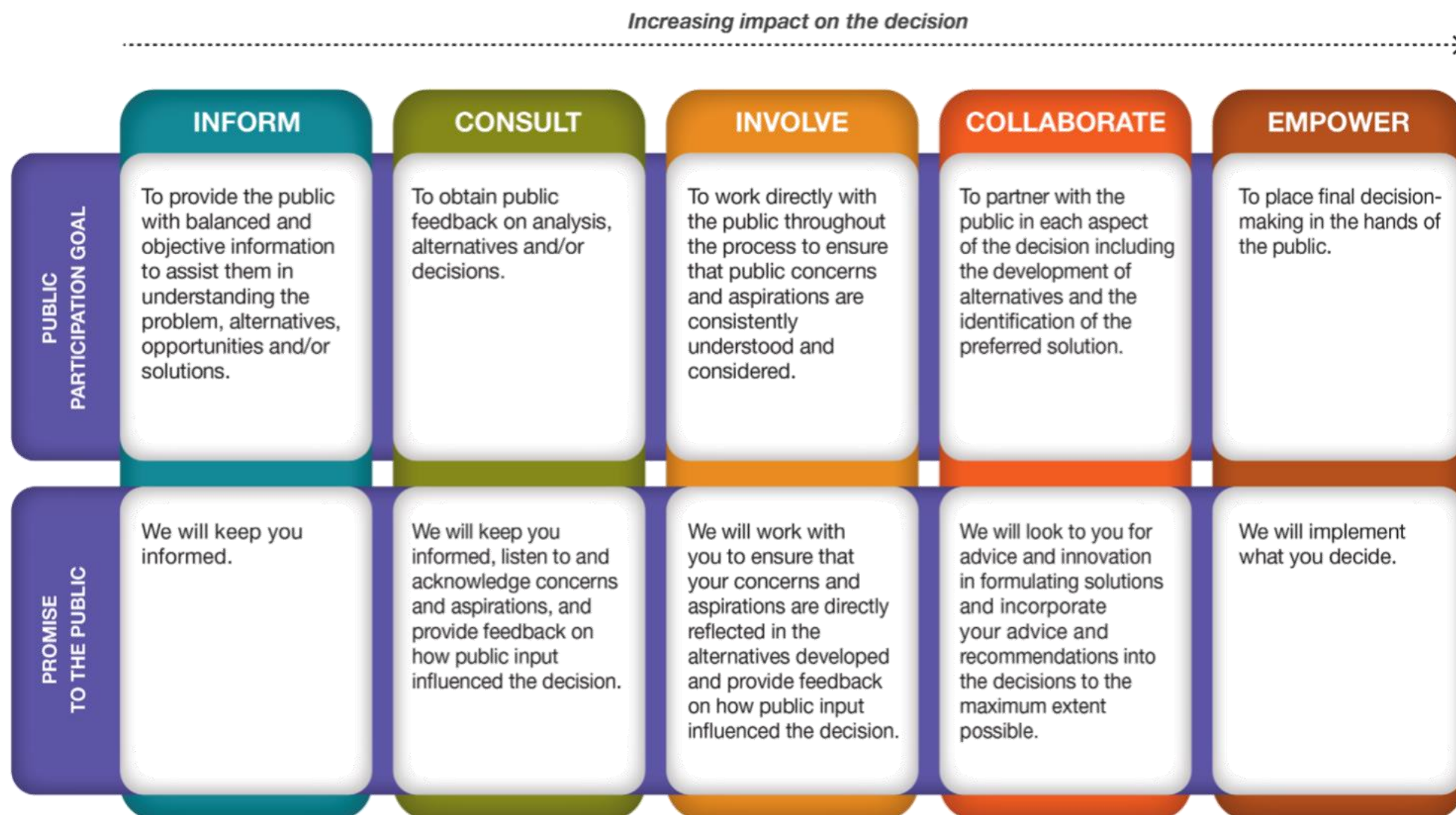# See page 5 for further examples of involvement methods

* This Framework does not include consumer organisations that are co-funding the research. In this instance the consumer organisation would become a partner who jointly set the CCI program.

Community involvement practices

*Engaging and involving community in decision-making can occur along a spectrum. The International Association for Public Participation (IAP2) has identified the **IAP2 Spectrum of Public Participation** below to help you determine the impact of decision-making, or **level of involvement**, consumers and community members can have in your work and the behavior, or promise, expected of you in return.*

*For more details see the **Quality Assurance Standard for Community and Stakeholder Engagement***
https://iap2content.s3.ap-southeast-2.amazonaws.com/marketing/Resources/IAP2/IAP2+Quality+Assurance+Standard+Booklet.pdf

Increasing impact on the decision ➔

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	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.
PROMISE TO THE PUBLIC	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.

Figure 1. IAP2 Spectrum of Public Participation

Community involvement methods

Select your method and level of involvement based on what you are trying to achieve with your work.
Also consider the preferences of the people you are trying to engage.

INFORM

- Letters
- Emails
- Social media
- Fact sheets
- Flyers
- Tours
- Video explainers
- Augmented reality, e.g. games*
- Virtual reality*
- Journal publications
- Traditional media, e.g. news reports, media statements
- Animations and infographics
- Scientific conferences

CONSULT

- Interviews
- Surveys
- Polls
- Submissions
- Comment forms
- Discussion boards

INVOLVE

- Workshops
- Focus groups
- Roundtable discussions
- Meetings
- Working groups*
- Summits*
- Kitchen teas^
- Yarning circles
- Advisory group
- Art spaces
- Open forums^
- Cultural events*

COLLABORATE

- Codesign
- Deliberative forums^
- Consensus conferences
- Committees^

EMPOWER

- Votes
- Citizen juries^

*commonly at this level, but can be further to the right
^commonly at this level, but can be further to the left