Framework for Consumer and Community Involvement in Health Research

---

Why is consumer and community involvement (CCI) important?[1]

Effective CCI ensures that research is responsive to national consumer and community priorities. It reflects the growing expectations of the public, funding bodies and ethics committees for meaningful consumer involvement in health and medical research. Effective involvement of consumers and communities improves public trust in research and facilitates the translation of research findings into practice. The benefits of such involvement are clear. It strengthens the research process, makes it more responsive to the needs of the community, and ultimately leads to more effective and relevant health outcomes.

What is the purpose of this Framework?

To guide those conducting health research on how and when to involve consumers and community in their research based on good practice and the stages of the research cycle.

What does the Framework include?

- Principles for how to involve consumers and community in health research
- Guidance to embed meaningful involvement at each stage of the research cycle
- Links to resources

Who should use this Framework?

- Researchers
- Consumer researchers
- Clinician researchers
- Research institutions

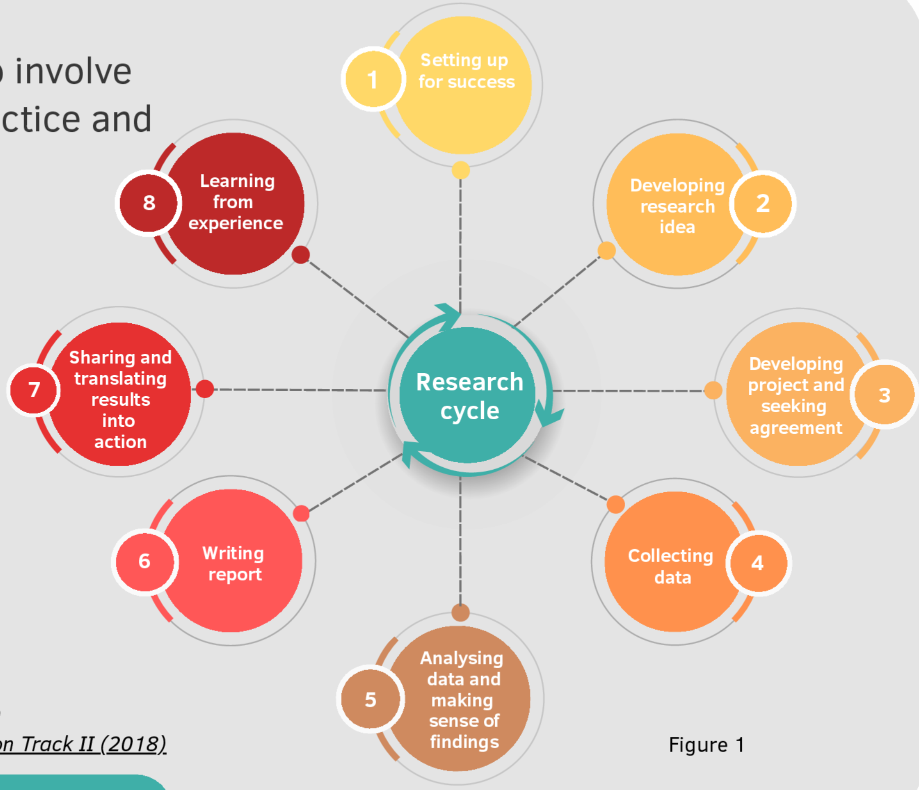


Figure 1

---

[1] *Taken from NHMRC and CHF Draft Statement ond Consumer and Community Involvement in Health and Medical Research*

Figure 1: The stages of the research cycle used for this Framework have been adapted from NHMRC's Keeping Research on Track II (2018)

www.healthtranslationqld.org.au

We acknowledge the Traditional Owners and their custodianship of the lands on which we operate. We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country. We recognise their valuable contributions to Australian and global society and the need to involve First Nations peoples in research to address health equity.

Who has developed the Framework?

This Framework is an initiative of the Health Translation Queensland (HTQ) led Consumer and Community Involvement (CCI) in Research Alliance. The group brings together consumers and CCI leads from across the HTQ partnership and beyond to deliver activities that support good practice CCI in health research in Queensland. The Framework and complementing resources are available on the HTQ website. For enquiries, please contact consumers@healthtranslationqld.org.au.

Consumer and Community Involvement in Research Alliance members:

Queensland Government
Children's Health Queensland
Metro North Health
Metro South Health
West Moreton Health
Gold Coast Health always care
mater
The University of Queensland Australia
QUT the university for the real world
Griffith University Queensland, Australia
QIMR Berghofer
TRI Translational Research Institute Australia
CSIRO Australian e-Health Research Centre
HCQ Health Consumers Queensland
SCHI Sunshine Coast Health Institute
University of Southern Queensland
Health Translation Queensland

www.healthtranslationqld.org.au

Principles for consumer and community involvement in health research

Authentic relationships and partnerships

- Be respectful, transparent and honest in your communication and decision-making.
- Listen and seek to understand the views of people with different values and beliefs.
- Show empathy, humility and curiosity to build trust and create an openness to new insights and ideas.
- Set clear expectations about the intent, purpose and parameters for involvement.
- Prioritise regular opportunities for open two-way communication and create feedback loops.
- Enable collaborative spaces for communication and working together.
- Prioritise power sharing and promote consumer leadership.
- Prepare and plan to enable successful partnerships that are mutually beneficial.

Inclusive of diverse perspectives

- Identify communities who are impacted by health issues for research.
- Be approachable to enable communities to self-identify (i.e. come to you with a research idea).
- Reduce barriers to involvement:
  - Be flexible by offering more than one option for getting involved. Ask *"What assistance can we provide to support your involvement?"*
  - Language can empower or disempower. Using inclusive and non-judgemental language empowers.
  - When communicating, be mindful of unconscious bias and potential for stigma.
    If in doubt, ask.
  - Involve or seek guidance from formal or informal community networks.

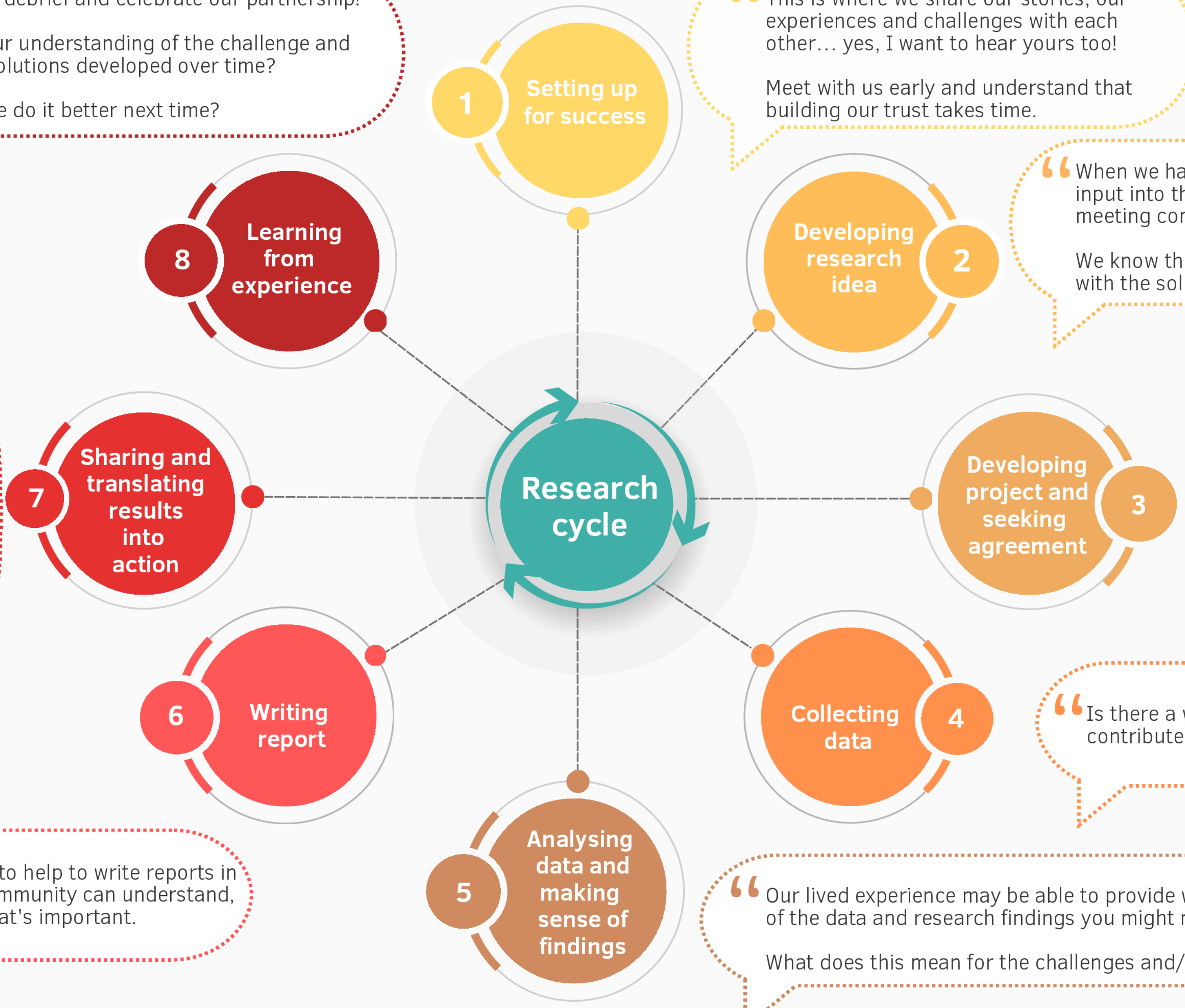
Valuing contributions

- Value people's time. Only involve people where there is a clear prospect for them to influence the research process and outcomes.
- Recognise and acknowledge contributions by:
  - supporting learning and growth
  - reimbursing reasonable out-of-pocket expenses
  - appropriately remunerating consumers for their contribution
  - providing a personalised letter of thanks
  - celebrating milestones together.

Trauma informed approach

- "Check in" and review involvement with consumers at regular intervals during the research journey.
- Recognise that telling or re-telling traumatic experiences can cause distress.
- Enable a supportive environment that enables physical, psychological and cultural safety.
- Offer pre-briefing, debriefing and peer support or external counselling services, such as an employee assistance program.

Consumer and community perspectives on involvement in health research



Research cycle

1 Setting up for success

“This is where we share our stories, our experiences and challenges with each other… yes, I want to hear yours too!

Meet with us early and understand that building our trust takes time.

2 Developing research idea

“When we have early lived experience input into the research it ensures it is meeting community needs.

We know the challenges, let's come up with the solutions together.

3 Developing project and seeking agreement

“This is where we agree on our roles and ways of working.

We now use our shared vision to decide on our roles and expectations for the way forward.

4 Collecting data

“Is there a way we can meaningfully contribute to this?

5 Analysing data and making sense of findings

“Our lived experience may be able to provide ways of making sense of the data and research findings you might not have considered.

What does this mean for the challenges and/or solutions?

6 Writing report

“We may be able to help to write reports in language the community can understand, and focus on what's important.

7 Sharing and translating results into action

“We have ideas and networks that can help us to communicate what we found.

We need to use the right language to share our solution with those who need to know about it.

How can we present this to build on other research out there?

8 Learning from experience

“It's time to debrief and celebrate our partnership!

How has our understanding of the challenge and potential solutions developed over time?

How can we do it better next time?

Figure 1: The stages of the research cycle used for this Framework have been adapted from NHMRC's Keeping Research on Track II (2018)

Consumer and community involvement across the research cycle

Stages of the research cycle[1]	1 Setting up for success	2 Developing research idea	3 Developing project and seeking agreement	4 Collecting data
Consumer and community involvement (CCI) goals	• Find consumers and community representatives. • Set expectations. • Gather and understand consumers' and community needs	• Establish a clear research project that will provide value to consumers and community and all other stakeholders.	• Identify how data will be collected through consumer and community involvement. • Ensure the research process is accessible and inclusive.	• Gather data using appropriate methods. • Have clear rules for the collection of personal data and meeting legislative requirements. • Ensure a diverse sample is collected.
What you can ask consumers and community[2]	• Why do you want to be involved? • How would you prefer to be involved? • What supports do you need?	• What health needs are unmet and could be assisted by research? • Is this the right question we need to be researching?	• Is anything missing? • Are there any barriers to consumers and community being involved in this process? • Are the tools we are using able to be understood?	• How do we build trust and reach the right people? • How do we support consumers who are involved in data collection?
Examples of involvement activities[3]	• Face-to-face conversations • Casual group discussions • Focus groups • Meetings • Advisory Group • Steering Committee	• Citizen science • Workshops • Roundtables • Public forums • Scientific conferences • Cultural/community events	• Art spaces • Games/interactive play • Surveys/online forms • Infographics/animations • Social media/media case study	• Journal publications • Conference presentations • Framework analysis • Debriefing sessions • Reflections/reviews
Building relationships	• Get to know each other - "How are you?" - "What are your interests and experiences?" • Share vulnerability and understanding of each other's lived experience. • Establish trust with consumers and community. • Work together for mutual benefit. • Establish regular, two-way communication.			

---

1 The research cycle stages used in this Framework have been taken from the NHMRC's Keeping Research on Track II (2018)

2 These are examples and are in no way an exhaustive list of possible options.

3 Consider conducting involvement methods in different attendance formats to be more inclusive for consumers and community (i.e. in-person, online or hybrid, over the phone)

Consumer and community involvement across the research cycle - *continued*

Stages of the research cycle[1]	**5 Analysing data and making sense of findings**	**6 Writing report**	**7 Sharing & translating results into action**	**8 Learning from experience**
Consumer and community involvement (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 outlining the key findings. • Prepare a separate more detailed report for researcher stakeholders.	• Share CCI outcomes and results to integrate into existing or new research projects and/or health processes.	• Evaluate the research process and identify key learnings and improvements for CCI. • Ensure consumers are acknowledged for their contributions.
What you can ask consumers and community[2]	• Is there missing community representation? • Are consumer voices reflected? • What does this research mean to consumers and community? • Is there anything from consumers' perspectives that hasn't been considered?	• What is the best way to present the findings so that community can understand them? • Have we acknowledged the contribution of consumers?	• How can we share this with community in a way that would encourage behaviour change or implementation of findings? • What is the best way to get clinicians' attention?	• Do the findings identify a new research need? • How could we apply the results? • Can consumers and community be involved differently?
Examples of involvement activities[3]	• Face-to-face conversations • Casual group discussions • Focus groups • Meetings • Advisory Group • Steering Committee	• Citizen science • Workshops • Roundtables • Public forums • Scientific conferences • Cultural/community events	• Art spaces • Games/interactive play • Surveys/online forms • Infographics/animations • Social media/media case study	• Journal publications • Conference presentations • Framework analysis • Debriefing sessions • Reflections/reviews
Building relationships	Continue to: • get to know each other and communicate regularly • share vulnerability and understanding of each other's lived experience • build trust and understanding • work together for mutual benefit.			

GLOSSARY

Community

A group of people sharing a common interest (e.g. cultural, social, political, health, economic interests) which may or may not include a particular geographic association. Different communities are likely to have different perspectives and approaches to their involvement in research.

Community representative

A person representing a community of interest. In a health context this can include people with shared experiences of a health condition.

Consumer

Patients and potential patients, carers and people who use health care services. Collectively, ‘consumers’ and ‘community representatives’ may be referred to as ‘the public’.

Diverse/Diversity

Taking into account representation of people with different identities.

Framework

A broad system that outlines principles and structure to guide an approach.

Health and medical research

Research with a human health focus.

Involvement

When consumers and community representatives actively work with researchers and research institutions to help shape decisions about health research priorities, policy, and practice.[1]

Learning and growth

Opportunities for capacity and capability building, education, training or access to conference attendance.

Lived experience

Knowledge based on someone’s perspective, personal identities, and history, beyond their professional or educational experience.[2]

Reimbursement

The act of compensating someone for an out-of-pocket expense by giving them an amount of money equal to what was spent (Merriam-Webster Dictionary).

Remuneration

Payment provided in return for work that has been done or services that have been provided (Cambridge Dictionary).

Research

The concept of research is broad and includes the creation of new knowledge and/or the use of existing knowledge in a new and creative way so as to generate new concepts, methodologies, inventions and understandings. This could include synthesis and analysis of previous research to the extent that it is new and creative.[4]

Researcher

Person (or persons) who conducts, or assists with the conduct of, research.[3]

Research institution

Includes universities, independent research institutes, hospitals or any other organisation that conducts research. It may refer to one or multiple institutions.

Stages of research

The steps that a research team undertakes when conducting research.[4]

Trauma-informed

Understanding, recognising, and responding appropriately to signs of trauma, and seeking to prevent re-traumatisation.[1]

Unconscious bias

Unconscious favouritism towards or prejudice against people of a particular race, gender or group that influences one's actions or perceptions (Oxford English Dictionary).

---

1 Definition adapted from Involve Australia - Guidelines for Community Involvement in Genomic Research
2 Definition from Health and Human Services – What is lived experience?
3 Definition from US Department and the Australian Code for the Responsible Conduct of Research (2018)
4 NHMRC’s Keeping Research on Track II (2018)