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Monash Partners
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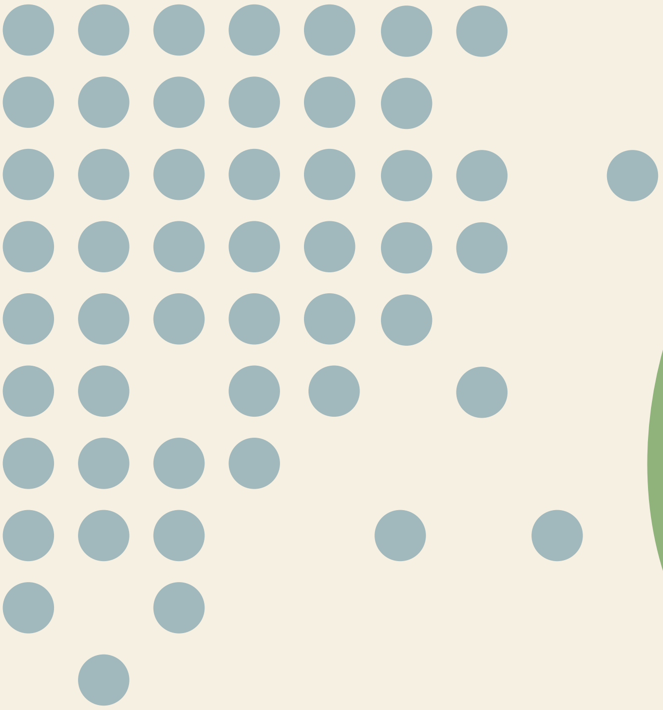

CONSUMER AND COMMUNITY INVOLVEMENT IMPLEMENTATION GUIDE FOR RESEARCH ORGANISATIONS

Embedding consumer and community involvement in health and medical research into organisational systems.

IN COLLABORATION WITH: AHRA HEALTH RESEARCH HUB

> “THE COMMUNITY ARE THE FUNDERS AND BENEFICIARIES OF BOTH RESEARCH AND HEALTHCARE IN AUSTRALIA AND DESERVE TO BE FRONT AND CENTRE IN DRIVING A HEALTH SYSTEM FULLY INFORMED BY RESEARCH THAT MEETS THEIR NEED.

Teede, H., & Wesselingh, S. (2018)
Turning research push into implementation pull for health benefit. MJA InSight Plus.
https://insightplus.mja.com.au/2018/40/turning-research-push-into-implementation-pull-for-health-benefit

Preface

The *Consumer and Community Involvement Implementation Guide for Research Organisations* is underpinned by national empirical evidence and implementation science to provide a range of evidence-based practical strategies on how to embed consumer and community involvement into research organisational systems. This guide has been developed for entities that undertake health and medical research including, but not limited to, medical research institutes, academic institutions, and health services.

The Australian community are the funders and beneficiaries of our health care system and health and medical research. They have an inherent right to be involved in the priorities and problems we are trying to solve, through to the solutions, how we implement them and their impact. Funders of health and medical research expect consumers and communities to be involved in the research they fund[1]. Similarly, an update to the Declaration of Helsinki has declared that meaningful involvement of consumers and communities is an expectation of ethical research involving humans[1]. Consumers and communities are experts in their own health, life, culture and beliefs and their involvement in research brings many benefits.

Despite recognition of the need for consumer and community involvement (CCI) and related policy mandates, a growing evidence base, and diverse benefits from involving consumers and communities in health and medical research, slow progress has been made towards systems change. To embed and systematise CCI in research organisations, we have undertaken behavioural and implementation research led by Monash Partners Academic Health Science Centre and the Monash Centre for Health Research Implementation (MCHRI) in collaboration with the Australian Health Research Alliance (AHRA), the Western Australian Health Translation Network (WAHTN) and other National Health and Medical Research Council (NHMRC) accredited Research Translation Centres.
This work (the Consumer and Community Involvement: Implementation Research for Impact (CCIRI project) was funded by the Medical Research Future Fund (MRFF) and has included extensive stakeholder engagement, consultation, involvement and co-design.

This guide has been informed by data from a national survey and workshops conducted as part of the national stakeholder consultation around revision of the 2016 NHMRC Statement on Consumer and Community Involvement in Health and Medical Research. These data sources, combined with evidence-based frameworks underpin this evidence-based guide that covers ethical, policy, logistical, and structural considerations for implementing CCI at a system level in research organisations.

Quotations used throughout the guide have been drawn from the Consumer and Community Involvement: Implementation Research for Impact (CCIRI) project funded by the MRFF (MRF2019278).

Acknowledgement of Country

We acknowledge the traditional custodians of the land and waterways on which our Australian Partners stand. We pay our respects to these cultures, their Elders past and present, and continue to uphold their ongoing relationship to the land.

Statement of funding

The Consumer and Community Involvement: Implementation Research for Impact (CCIRI) grant was supported by the Medical Research Future Fund grant number (MRF2019278). The contents of the published material are solely the responsibility of Monash Partners and MCHRI do not reflect the views of the Commonwealth.

The national stakeholder consultation to support a review of the Statement on consumer and community involvement in health and medical research was facilitated by Monash Partners on behalf of the Australian Health Research Alliance (AHRA) and was supported by the National Health and Medical Research Council (NHMRC) (2023-24C001).

Suggested citation

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CONTENTS

> IT WOULD BE INCREDIBLY REMISS OF US, TO SHAPE WORK, IDEAS AND DIRECTION WITHOUT CONSULTING THE PEOPLE WHOSE LIVES IT OFTEN DIRECTLY IMPACTS.
>
> *– Healthcare Improvement Staff, CCIRI Project*

Terminology[1]

CO-DESIGN (CO-APPROACHES, CO-CREATION, CO-DEVELOPMENT CO-PRODUCTION, PARTICIPATORY APPROACHES) Active engagement of diverse stakeholders in understanding and solving complex problems to design, implement, monitor and evaluate relevant solutions together. Active involvement of consumers and communities in setting research priorities.

CONSUMER Refers to patients, family members, carers and members of the public with lived experience of a health condition or the health system.

CONSUMER AND COMMUNITY INVOLVEMENT (CCI) Refers to the development of meaningful relationships and active partnerships, underpinned by trust and mutual respect, a commitment by all involved and active dialogue.

CONSUMER ADVISORY COMMITTEE (such as a reference group, consumer council, lived experience group, involvement group) Can be set up for an organisation, institute or project. Consumer Advisory Committees assist researchers by providing strategic advice on projects and research matters from a consumer perspective.

COMMUNITY A group of people sharing a common interest (e.g., cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Different types of communities are likely to have varied perspectives and approaches to their involvement in research.

MEANINGFUL INVOLVEMENT Respectful, dignified and equitable inclusion of individuals with lived experience in a range of processes and activities within an enabling environment where power is transferred to people; valuing lived experience as a form of expertise and applying it to improve health outcomes.

RESEARCH ORGANISATION OR INSTITUTE A place where research is conducted.

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[1] **References**

World Health Organisation, WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions. 2023, World Health Organisation, Geneva.

National Health and Medical Research Council, Online engagement report for the review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research. 2024: Canberra, Australia.

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02

Introduction

As funders, beneficiaries and users of healthcare and services, consumers and communities must be involved in the health research that affects them. For transformative change in healthcare and services, it is vital that researchers do not presume to know what communities experience and need. Genuine consumer and community involvement (CCI) in health research ensures their lived experience and perspectives are reflected in research priorities, processes and outputs and that research is relevant, impactful and sustainable. To enable consumers and communities to effectively collaborate with health researchers, an organisation's culture must promote and exhibit the values and principles necessary for genuine and meaningful CCI. Developing organisational infrastructure and processes for CCI is key to developing a culture in which consumers are shaping health and medical research outcomes that matter to them.

A systems approach to CCI implementation is needed across policy, organisational and individual level change (Figure 1). At a system /policy level, the Health and Medical Research Office, Australian Government Department of Health and Aged Care (Medical Research Future Fund), and the NHMRC have developed many informative documents to raise awareness about key values and principles for CCI and their expectations when granting taxpayer funded health research[2]. At an organisational level, supporting these policy priorities as the foundation for successful implementation and sustainable CCI in health research starts with organisational leadership commitment. This guide has been designed to facilitate the implementation of CCI into the systems of research organisations. The guide provides a range of evidence-based and practical strategies for embedding the structure and processes necessary for cultural change so researchers, consumers and communities can genuinely partner to undertake health research.

Health Research Hub symbol

Resources to support organisations with CCI implementation are available on the Health Research Hub (denoted by this symbol) and can be adapted to varying contexts.

At an individual level, extra resources to support health researchers, including discovery and laboratory-based researchers are also available on the Health Research Hub.

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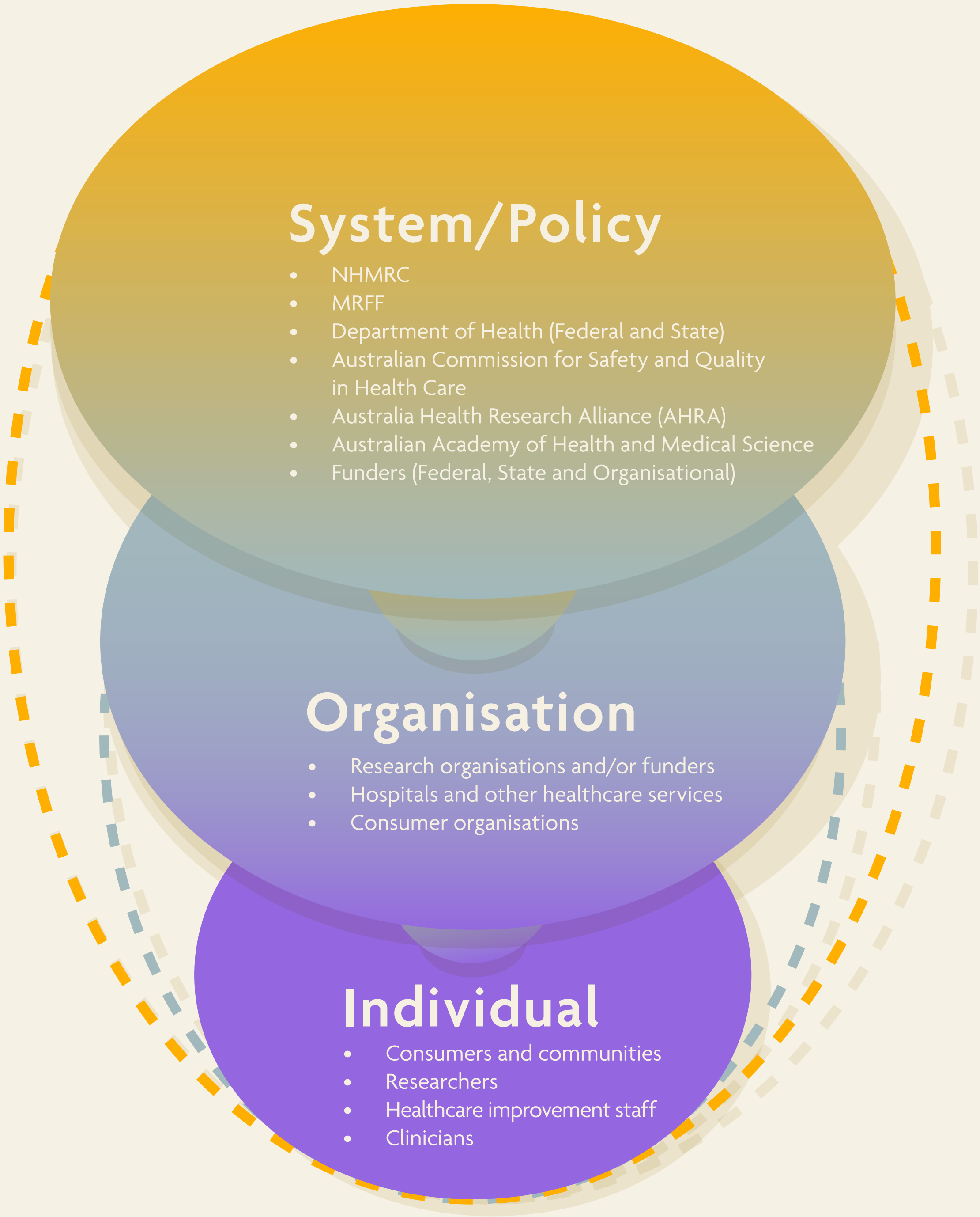
[2] **References**

National Health and Medical Research Council and Consumers Health Forum of Australia, Statement on consumer and community involvement in health and medical research. 2016: Canberra, Australia.

Medical Research Future Fund, Principles for Consumer Involvement in Research. 2023, Medical Research Future Fund.

Change is needed at all system levels.



System/Policy

- NHMRC
- MRFF
- Department of Health (Federal and State)
- Australian Commission for Safety and Quality in Health Care
- Australia Health Research Alliance (AHRA)
- Australian Academy of Health and Medical Science
- Funders (Federal, State and Organisational)

Organisation

- Research organisations and/or funders
- Hospitals and other healthcare services
- Consumer organisations

Individual

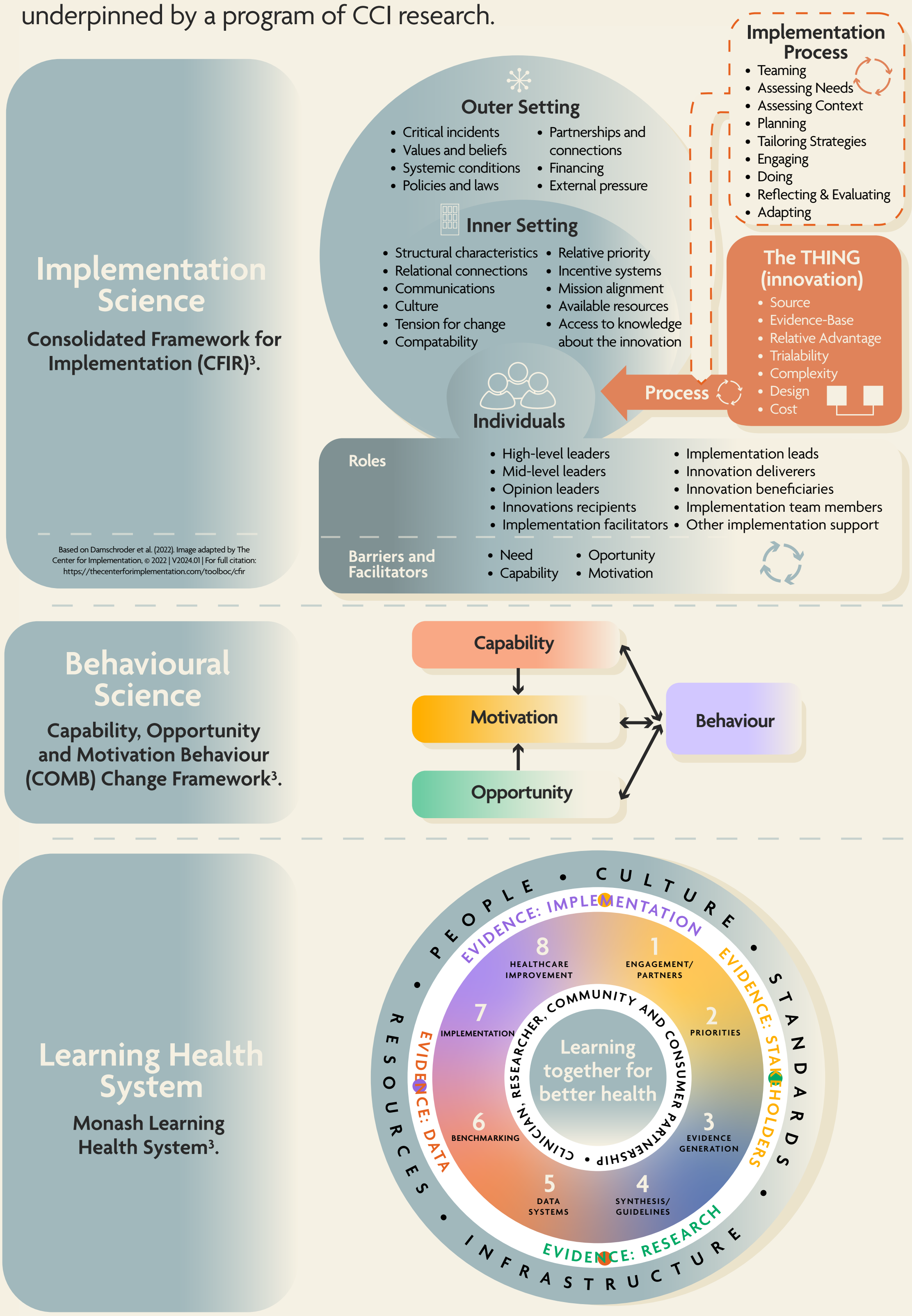
- Consumers and communities
- Researchers
- Healthcare improvement staff
- Clinicians

Figure 1: Modified Consolidated Framework for Implementation Research (CFIR) to show CCI system context

Evidence-based Approaches

Evidence-based frameworks

This guide was developed using robust evidenced-based approaches (Figure 2) and qualitative participatory methods[3] underpinned by a program of CCI research.



Implementation Science

Consolidated Framework for Implementation (CFIR)[3].

Based on Damschroder et al. (2022). Image adapted by The Center for Implementation, © 2022 | V2024.01 | For full citation: https://thecenterforimplementation.com/toolboc/cfir

Outer Setting
- Critical incidents
- Values and beliefs
- Systemic conditions
- Policies and laws
- Partnerships and connections
- Financing
- External pressure

Inner Setting
- Structural characteristics
- Relational connections
- Communications
- Culture
- Tension for change
- Compatability
- Relative priority
- Incentive systems
- Mission alignment
- Available resources
- Access to knowledge about the innovation

Implementation Process
- Teaming
- Assessing Needs
- Assessing Context
- Planning
- Tailoring Strategies
- Engaging
- Doing
- Reflecting & Evaluating
- Adapting

The THING (innovation)
- Source
- Evidence-Base
- Relative Advantage
- Trialability
- Complexity
- Design
- Cost

Process

Individuals

Roles
- High-level leaders
- Mid-level leaders
- Opinion leaders
- Innovations recipients
- Implementation facilitators
- Implementation leads
- Innovation deliverers
- Innovation beneficiaries
- Implementation team members
- Other implementation support

Barriers and Facilitators
- Need
- Capability
- Opportunity
- Motivation

Behavioural Science

Capability, Opportunity and Motivation Behaviour (COMB) Change Framework[3].

Learning Health System

Monash Learning Health System[3].

Figure 2: Evidenced-based Frameworks

Evidence-based Approaches
(continued)

Previous national CCI work

Previous work undertaken by the Australian Health Research Alliance (AHRA) in CCI includes an environmental scan of published evidence, national survey, national workshop, recommendations, and priorities (Table 1).

Environmental Scan	**Over 200 publications and reports identified.** Key themes: inconsistency around commitment, capture and reporting; inaccessibility of tools and resources; need to build capacity, commit resources, evaluate **value and impact and establish best practice.**
National Survey	**868 participants (490 Researchers, 145 Health Professionals and 233 Consumers).** The key factor influencing consumer and community involvement was having pathways for connecting people and access to tools and resources.
National Workshop to determine recommendations and set priorities	**Representatives from consumer advocacy groups, and AHRA Centres as well as community members and researchers established four priorities:** **1. initiate formal alliances with leading agencies** **2. sponsor research and evaluation projects** **3. facilitate sharing of resources and expertise** **4. develop minimum standards for good practice**

Table 1: Previous work undertaken by AHRA[3]

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[3] **References**

Australian Health Research Alliance. 2018. Consumer and Community Involvement in Health and Medical Research. An Australia-wide Audit. (AHRA) https://ahra.org.au/wpcontent/uploads/2021/02/AHRA_CCI_Final_Report.pdf

Damschroder, L. J., Reardon, C. M., Widerquist, M. A. O., & Lowery, J. (2022). The updated Consolidated Framework for Implementation Research based on user feedback. Implementation science: IS, 17(1), 1-75. https://doi.org/10.1186/s13012-022-01245-0

Michie, S., van Stralen, M. M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. Implement Sci, 6(1), 42-42. https://doi.org/10.1186/1748-5908-6-42

Teede, H., Jones, A., Enticott, J., & Pigott, C. (2021). A Learning Health System: Learning together for better health - Brief Report. https://bridges.monash.edu/articles/report/A_Learning_Health_System_Learning_together_for_better_health/14821791

Vaughn, L. M., & Jacquez, F. (2020). Participatory Research Methods – Choice Points in the Research Process. Journal of Participatory Research Methods. https://doi.org/https://doi.org/10.35844/001c.13244

Evidence-based Approaches (continued)

Data sources

Building on and incorporating past work, this guide is underpinned by mixed methods research, consumer partnerships, participatory approaches, and data collection aligned to evidence-based frameworks. The recommendations in this guide are drawn from multiple data sources that altogether form the largest available national dataset on CCI experiences and perspectives in health research (Table 2).

Data Sources	Methods and Number of Participants
Stakeholder engagement workshops to support the review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research[4].	**22 national workshops** engaging 440 consumers, researchers, health professionals and funders of health and medical research.
NHMRC online engagement for the review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research[4]	**90 survey responses** from consumers, researchers, administrators and organisations nationally.
MRFF funded Consumer and Community Involvement: Implementation Research for Impact Project (CCIRI)[4]	**59 national semi-structured interviews** with consumer and community members, health and medical researchers, healthcare improvement professionals, clinicians, funders of health and medical research. **287 national survey responses** from consumers, researchers and health professionals. **Document analysis** of terms of references, vision and mission statements, organisational structure and policy document etc. and field notes from stakeholder engagement. **4 case studies** from emergency care, critical care, Indigenous health and stroke.

Table 2: National Data Sources

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[4] **References**

Australian Health Research Alliance. (2024). Report to the National Health and Medical Research Council: National engagement in response to the Review of the Statement on Consumer and Community Involvement in Health and Medical Research 2016 Position Paper. Australian Health Research Alliance.

National Health and Medical Research Council. (2024). Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research. Online Engagement Report https://www.nhmrc.gov.au/about-us/publications/review-2016-statement-consumer-and-community-involvement-health-and-medical-research-online-engagement-report#block-views-block-file-attachments-content-block-1

Ng, A., Reeder, S., Jones, A., Cahill, A., Langridge, D., Baker, S., Heiss, L., Dorin, A., & Teede, H. (2025). Consumer and Community Involvement: Implementation Research for Impact (CCIRI) – Implementing evidence-based patient and public involvement across health and medical research in Australia – A Mixed Methods Protocol. Health Research Policy and Systems.

Evidence-based Approaches (continued)

The implementation activities and processes recommended in this guide are presented in a framework that was developed from a systematic review on organisational strategies for effective leadership of culture change[5]. The implementation strategies are presented under the five main domains of the framework: **Organisational Processes, Leadership Commitment, Support Tools, Mentoring and Networking, and Awareness and Engagement** (Figure 3). Where resources have been developed and are available for adaptation you will see this icon which will take you to the resources section of the online Health Research Hub (national website for CCI).

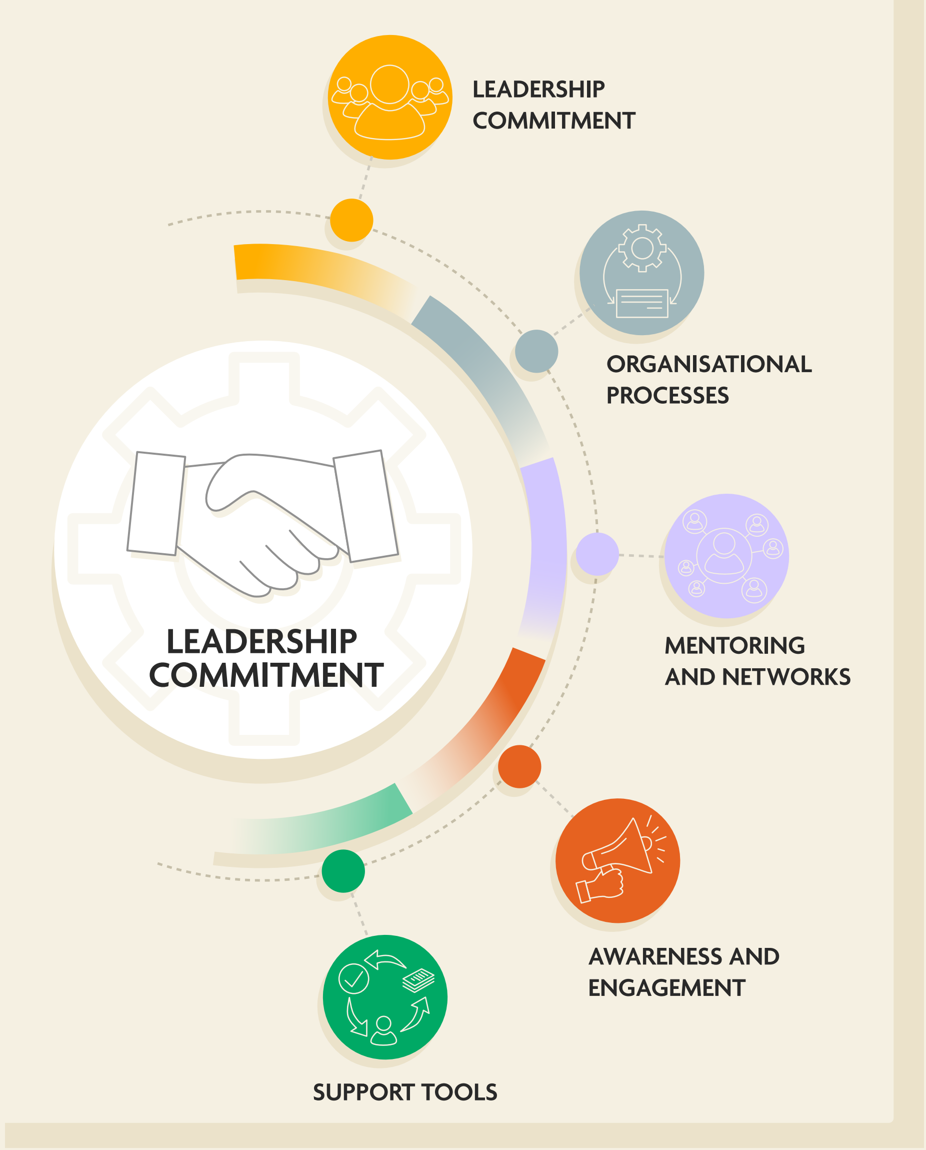

Figure 3: Domains of Organisational Change

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[5] **Reference**

Mousa, M., et al., Advancing women in healthcare leadership: A systematic review and meta-synthesis of multi-sector evidence on organisational interventions. EClinical Medicine, 2021. 39: p. 101084-101084.

08

The ‘Why’: System and Policy

Organisational Leadership in Consumer and Community Involvement for Health and Medical Research. **Why is it needed?**

The ‘Why’

Consumer and Community Involvement – research and innovation in partnership with the community, rather than for the community.

POLICY ALIGNMENT

Opportunity to strategically align with priority policy directions as highlighted in national and regional policies for funding bodies, government organisations, and research institutions.

STRATEGIC VALUE

Consumer and community involvement is essential for securing competitive research funding and improving research innovation and quality.

EVIDENCE-BASED PRACTICE

Evidence shows – and continues to grow – that consumer and community involvement has a positive impact on healthcare and health research outcomes.

ORGANISATIONAL RESPONSIBILITY

Enhancing organisational credibility and reputation by respecting the right for consumers and community members to help shape and innovate the healthcare services and research that affect them.

Read more at: HealthResearchHub.com

The ‘What’: Organisational Strategies

To embed consumer and community involvement in organisations, multiple strategies for implementation are needed. The following are a range of actions recommended for research organisations.

Leadership Commitment

To shape our health and research system in ways that best serve the communities which fund and benefit from it, strategic leadership and commitment to implementing genuine consumer and community involvement in research organisations is critical to driving change. Appropriate organisational structures, processes and culture will create an enabling environment and active promotion of consumer and community involvement as an organisational priority will drive uptake.

A clear consumer and community involvement strategy and vision for the organisation

- Develop and communicate a clear consumer and community involvement strategy and vision for the organisation, aligned to policy/funder.
- Promote and make visible the documented strategy and vision across the organisation and to external partners.
- Use the organisational strategy and vision to develop evidence-based policies and adapt existing policies to embed consumer and community involvement in organisational operations.
- Partner with organisations that have an aligned vision and strategy for consumer and community involvement, such as Research Translation Centres.

Align organisational activities with consumer and community involvement vision and strategy

- Role model consumer and community involvement at the senior levels of the organisation to show its priority, value and expectation.
- Showcase consumer and community involvement work undertaken within the organisation such as celebrating successes, impacts, co-presentations and co-authorship at events and sharing case studies on organisational websites and in communications.
- Advocate for consumer and community involvement in health research within and outside the organisation, promoting its benefits to stakeholders, policymakers, and funders.
- For non-clinical researchers working in fundamental discovery and laboratory-based research with unclear human health outcomes or impacts, direct consumer contact is generally not recommended. The following alternatives should be considered:
    - Undertake consumer and community involvement at an organisational level (e.g., involvement with relevant consumer or advocacy organisations such as the Heart Foundation, Diabetes Australia, Breast Cancer Foundation etc)
        - Connections to organisations may be facilitated through dedicated local consumer and community involvement coordinators.
    - Review and draw on existing literature for research priorities and publications/reports that incorporate consumer and community perspectives.

Leadership Commitment
(continued)

> **YOU NEED TO HAVE SOMEONE WITH ENOUGH CLOUT TO LEAD THE GROUP, OTHERWISE NOTHING CHANGES BECAUSE NO ONE LISTENS... IT'S HAVING SOMEONE THAT'S RESPECTED AT THE TOP TO SORT OF LEAD THAT.**
>
> *– Researcher, CCIRI Project*

Allocate and develop resources to build sustainable consumer and community involvement infrastructure and engagement

- Invest in resources to build infrastructure that supports the organisation's consumer and community involvement vision.
- Leverage existing tools, guides and education.
  Adapt and implement as required
- Provide training for capacity building of staff, researchers and consumers (identified as a critical need).
- Establish and build connections with internal and external consumer networks.
- Establish small grants to enable consumer and community involvement in early research problem ideation.

Monitoring and transparency for consumer and community involvement within the organisation

- Strongly recommend and expect meaningful consumer involvement in organisational activities and in health and medical grant applications and research.
- Embed consumer and community involvement expectations, for example, in Key Performance Indicators (KPIs), governance structures and processes, position statements, internal grant processes, and manager and researcher appraisals and promotions criteria.
- Promote and monitor consumer and community involvement education and training for employees and consumers.
- Consider prioritising training for some groups (e.g., people writing health and medical grant applications) to ensure alignment with organisational, funder and policy expectations and standards.

Organisational Structures and Processes

Appropriate and aligned organisational structures and processes are vital for embedding consumer and community involvement into complex systems. Supportive infrastructure will enable high level and middle level managers and individuals in the organisation to adopt the attitudes and processes needed to normalise and streamline consumer and community involvement.

Establish governance structures

- Embed consumers within organisational governance structures and processes to ensure their perspectives are shaping research agendas and outcomes.
- Develop policies and guidelines relevant to consumer and community involvement as well as organisational level information resources.
- Establish core consumer advisory committees across the organisation that are linked to key executive committees and organisational boards, and have formal governance arrangements. Provide supporting documents such as terms of references and position descriptions etc.
- Optimise consumers sitting on organisational committees such as for research ethics, strategic planning, research funding and grant reviews, diversity and inclusion, data and outcome evaluation, technology and innovation, communications and marketing, and project steering.

Policies and processes to implement a sustainable consumer and community involvement strategy and vision

- Develop organisational policies for consumer and community involvement and add to existing policies to show legitimacy and system integration into clinical and non-clinical health research. Ensure policies are clear for fundamental discovery researchers where organisational (not individual) level consumer and community involvement only is recommended.
- Ensure organisational procedures reflect and align with the organisation's consumer and community involvement vision statement and strategy, for example, research, governance, ethics codes and reviews, intellectual property, evaluation, publication, payment, conflicts of interest policies.
- Leverage existing guidelines for consumer and community involvement adoption with practical actions to undertake and integrate into policies.

Organisational Structures and Processes (continued)

Centralised and coordinated consumer and community involvement within the organisation

- Establish a centralised focal point within the organisation dedicated to consumer and community involvement coordination, networking, education and advancement (identified as a critical need).
- Appoint a centralised person to lead and coordinate activities such as training and education, mentoring, internal and external networking, evaluation, committees, consumer enquiries and feedback etc.
    - Centralised coordination can support internal and external organisational promotion and communication of consumer and community involvement successes.
    - Centralised coordination can facilitate local and organisational networks that match a program's needs throughout the research cycle and translation continuum.
- Assign a local coordinator to support consumer and community involvement at an individual level.
    - Support non-clinical researchers that have pathways to human health outcomes and impacts with direct consumer contact and relationship development (identified as a critical need).
    - Connection should be made to multiple consumers or networks of consumers consistent with best practice.
- Leverage existing organisational consumer and community involvement activity, roles and resources to plan and scale.
- Widely promote coordinator and consumer lead roles and Health Research Hub within the organisation.

Accountability for genuine and meaningful consumer and community involvement

- Demonstrate accountability through centralised and continuous monitoring, transparent reporting and external benchmarking of consumer and community involvement practice and outcomes. Promote and celebrate organisational CCI activities.
- Consider developing metrics for impact and evaluation with consumers that reflect the organisation's consumer and community involvement vision, policy and governance standards.
- Adopt cyclic evaluation processes to drive consumer and community involvement improvement and foster evidence-based practice, innovation, and sustainability in health research.
- Transparently report evaluations accompanied by actionable plans to reinforce consumer and community trust and collaboration.
- Develop reporting strategies that directly engage consumers, as understanding the 'impact' of their involvement supports reaching their goals and serves as a source of motivation.

Mentoring and Networking

Develop organisational programs and systems for internally and externally connecting researchers and consumers for support, education and research. Externally network to advance best practice and evidence for consumer and community involvement.

Internal networking and connection within organisation

- Use centralised and coordinated processes, such as a coordinator whose role is to internally connect consumers and researchers and reduce siloed and duplicated activity.
- Connect consumer and community involvement champions, local coordinators, consumer leads and people in existing consumer and community involvement positions, and strategically embed trained champions in areas of organisational need.
- Develop and connect to communities of practice and mentoring programs that foster a collaborative learning environment for sharing ideas and resources across varying research contexts, problem solving, and innovation.

External networking

- Establish multi-sector relationships and partnerships with consumers and leaders in the field (locally, nationally and internationally).
- Partner with centres where consumer and community involvement is a core strategy (e.g., local Consumers Health Forum, Health Consumer Council, and research translation centres).
- Use external networks to leverage diverse perspectives, expertise, innovation and resources that address key challenges and support best practice in consumer and community involvement in clinical and non-clinical health research.
- Strategically establish external connections that support researchers with finding multiple appropriate and diverse consumers and with developing meaningful relationships.
- Broker organisational agreements such as formal memorandums of agreement with appropriate external organisations to establish ongoing relationships with consumer groups, including priority populations.

Advance consumer and community involvement practice

- Evaluate involvement in the organisation and use it to drive continuous improvement and alignment with best practice.
- Use internal and external networks to collaborate and identify core metrics to monitor and benchmark consumer and community involvement processes, practices, experiences and outcomes in clinical and non-clinical health research across organisations.

> **"YOU HAVE TO BUILD RELATIONSHIPS AT THE SPEED OF TRUST, NOT AT THE SPEED OF YOUR GRANT CYCLE.**
>
> *– Consumer, CCIRI Project*

Awareness and engagement

Awareness of the importance of, and organisational expectation for, engagement with consumers and communities, and how to conduct meaningful and inclusive consumer and community involvement are essential for its adoption within organisations. Further, ease of access to diverse consumers is needed to foster involvement.

Capacity building for consumer and community involvement

- Build capacity in staff, researchers and consumers through centrally coordinated education and training programs.
- Offer programs tailored to different knowledge and experience levels, such as introductory courses and programs to develop consumer and community involvement champions.
- Encourage engagement in education and training by offering accessible programs with flexible learning options.
- Consider prioritising training for researchers who apply for health and medical grant funding.
- Offer communications training for all types of researchers to support effective and meaningful communication with consumers.
- Provide resources for follow-up guidance and support beyond initial training, such as consumer and community champions, central and local coordinators, advanced training, mentoring programs and communities of practice.

> **WE OFTEN ASSUME WE KNOW WHAT THE CONSUMER WANTS, AND I THINK WE'RE OFTEN QUITE SURPRISED AT THE FACT THAT WE DON'T.**
>
> *– Healthcare Improvement Staff, CCIRI Project*

Culture of consumer and community involvement in organisations

- Integrate and normalise consumer and community involvement by ensuring organisational leadership expectations and supports for consumer and community involvement are clear and available at all system levels (identified as a critical need).
- Facilitate access to consumers by embedding consumers visibly throughout the organisation including at decision making levels. Additionally establish and maintain collaborations with consumer organisations, and employ a coordinator to facilitate consumer activities, connections and/ or matching.
- Set up consumer and community advisory committee/s at departmental (and/or faculty levels) to ensure researchers can easily engage with consumers to, for example, design projects, understand priorities, prepare funding or ethics applications, or translate research findings.
    - Frame early consumer and community involvement at the research or project ideation stage as ‘core business’.

Create an inclusive organisational culture for consumer and community involvement

- Cultivate an environment of trust and inclusivity where all consumers feel valued, listened to, and empowered to contribute meaningfully to clinical and non-clinical research with clear pathways to human health outcomes.
- Adopt simple actions such as providing training and mentoring for consumers, researchers and other staff, enabling access to interpreter services, introducing easy processes for orientation and remuneration, publicly acknowledging and showcasing work achieved by consumers and researchers, and supporting engagement with consumers off campus as required.
- Provide consumers with a central point of contact within the organisation for orientation, feedback and support.
- Ensure organisational policies and role descriptions are up to date, accessible (such as produced in multiple languages) and include appropriate approaches for fundamental discovery and laboratory-based research contexts.

Support Tools

Support tools such as monitoring and engagement frameworks for research and evaluation, and centralised resources for consumer and community involvement are vital for evidence generation, problem identification, accountability and degree of practice implementation. Centralised resources and processes streamline and support consumer and community involvement and adoption.

Integrate consumer and community involvement evaluation and research

- Integrate, adapt and leverage existing evidence-based evaluation tools.
- Commit to and establish centralised systems to facilitate monitoring and reporting of consumer and community involvement practice in clinical and non-clinical research and impact within the organisation.
- Ensure consumer and community involvement is included in individual project, operational/strategic and annual organisation/department reports to demonstrate and make visible the commitment and culture of consumer and community involvement in best practice research.
- At Faculty or School level collect impact and evaluation data from multiple perspectives in all types of health research. Include assessment of satisfaction, experiences, and outcomes.
- Monitor impacts of organisational consumer and community involvement policy implementation including best practices such as diverse engagement, respectful engagement, robust governance etc.
- Leverage feedback and evaluation outcomes for continuous improvement, growth, advancement and effectiveness of consumer and community involvement.

Adapt specific resources in a centralised organisation location and commit to streamlining consumer and community involvement efforts

- Link to and adapt evidence-based national resources.
- Commit to use of and referral to the evidenced-based national Health Research Hub resources, guidelines and tools for consumer and community involvement information and connection.
- Adapt, leverage and promote education, training, opportunities, roles, committees, policies, remuneration and other consumer and community involvement documents
- Centrally locate adapted information and resources for ease of access.

“I THINK SUCCESS LOOKS LIKE THAT YOU'VE GOT CONSUMERS AT THE HEART OF WHAT YOU DO AND THAT CONSUMERS ACTUALLY FEEL LISTENED TO AND VALUED.

– Researcher, CCIRI Project