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MACH
Melbourne Academic
Centre for Health

Increasing Consumer and Community Involvement in Medical Research

A Short Guide for Medical Research Institutes

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Terms and Definitions

- Consumer and Community Involvement (CCI) – community members and researchers working in partnerships, making decisions about research and collaboratively being part of the research process together. Research that is “with” and “by” the community rather than “for” or “done to” the community.
- Consumer – patients and potential patients, carers, and people who use health care services.
- 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 different perspectives and approaches to their involvement in research.
- Consumer representative – someone who voices consumer perspectives and takes part in the decision-making process on behalf of consumers. This person may be nominated by, and may be accountable to, an organisation of consumers. This consumer representative however may have a narrower view as they are speaking on behalf of their organisation and not necessarily that of the wider community. A consumer representative may be appropriately trained or may undergo training and be supported to advocate for consumer-centred health care.
- Health and medical research – research with a human health focus.
- Research – an original investigation undertaken to gain knowledge, understanding and insight.
- Research process – the planning, funding and conduct of an individual piece of research in addition to implementation of research findings and publication of research findings.
- Researcher – a person who conducts research.
- Note: Different terminology is used to describe consumer and community involvement in different parts of the world. When looking for resources and references, Patient and Public Involvement (PPI) is typically used in the UK, and Patient Oriented Research (POR) is more commonly used in Canada and the USA. ‘Involvement’, ‘Engagement’ and ‘Participation’ are often used interchangeably in the literature. However, they can have specific meanings, usually: “Involvement” to describe patients/consumers as collaborators in the research process such as design or development (the focus of this document); “Engagement” to describe sharing research outcomes with the wider community or public (eg: outreach or education programs, science exhibitions or public lectures); and “Participation” to describe patients/ consumers involved as subjects in research projects where data are being actively collected about them.

(Sources: NHMRC Statement, 2016; Monash Partners <https://monashpartners.org.au/education-training-and-events/cci/>)

Overview

This guide was developed as part of a Melbourne Academic Centre for Health (MACH) project to evaluate the Consumer Buddy Program at the Walter and Eliza Hall Institute (WEHI) in Melbourne, Australia. The Medical Research Future Fund (MRFF) supported the project. WEHI is part of the MACH collaborative group of outstanding health and medical research organisations that focus on research to improve community health and wellbeing and is one of Australia's leading biomedical research organisations. Much of WEHI's work is laboratory-based, discovery and basic science research.

In 2013, WEHI was one of the first medical research institutes in Australia to actively involve consumers working in partnership with researchers. The WEHI Consumer Buddy Program has evolved organically since this time, from approximately 20 participants to more than 160 consumers and researchers working collaboratively across the organisation. A Consumer Advisory Panel, comprising consumers and WEHI scientists, has supported this development and provides governance to the Program. In the past 2 – 3 years, the Program has grown significantly, with a core team including the Program Coordinator (a WEHI staff member) and three lead consumer volunteers working on program policies, systems and operational support. Given this unique history and the evolving Consumer and Community Involvement field in Australia, it was timely to evaluate the Program to explore the experiences, benefits and impacts and identify opportunities to strengthen, improve and grow. A central aim of the project was to identify key success factors and program elements that could be applied in other medical research settings.

This Short Guide draws on the evaluation outcomes and a selection of published resources available to support consumer involvement activities. It is intended for use by medical research organisations that are exploring opportunities to develop a consumer involvement program. The guide is tailored towards organisations whose *primary focus* is health and medical research. The principles, examples and suggestions in this guide could be helpful to healthcare providers who conduct research, however, laboratory-based, discovery and basic science organisations are the main target audience.

The Consumer and Community Involvement (CCI) field in Australia is constantly evolving, with many more organisations actively involving consumers in medical research activities and programs. The National Health and Medical Research Council (NHMRC) supports CCI, identifying that, “.....it is now widely accepted that consumers and community members add value to health and medical research and have a right and responsibility to do so.” (Expectations and Value – Framework for Effective Consumer and Community Engagement in Research, NHMRC 2020)

Involving “end users” in the research process is now expected by national research organisations, funders and government bodies; by consumer and advocacy groups; by networks that translate research into health care practice and policy; by people with lived experience of health conditions and by the wider community. There are multiple, interconnecting reasons for this:

1. “Nothing about us without us” in health and medical research reflects the expectation of research ‘with’ and ‘by’ consumers and community members, not ‘to’, ‘about’ or ‘for’ them.
2. Involving consumers in research grounds the work in ‘real world’ perspectives and people’s lived experiences of health conditions. This improves the conduct of research and delivers outcomes that have greater relevance, are of higher quality and, ultimately, are more directly transferrable to healthcare practice and health outcomes.
3. Health and medical research is a ‘public good’. For accountability and transparency, the public should be involved to at least some degree in decisions about what health and medical research is done, how it is done and interpreted, and how it is shared and applied. In practice, this is reflected in policy and increasingly, through research funding requirements.

(Greenhalgh et al, 2019, NHMRC 2016, NHMRC 2020, MRFF 2018, UK Public Engagement Framework, 2019)

Whilst CCI is required in health care settings and is increasingly common in clinical and translational research, it is still relatively unusual in laboratory-based, discovery or basic science research settings. Consumer

involvement approaches range from consultation through to research co-design and consumer-led activity and there is an ongoing tension in discovery and basic science settings about the feasibility and applicability of some CCI models, particularly in highly technical laboratory-based research. The evaluation of the consumer involvement program at WEHI, a leading Medical Research Institute (MRI), explored the CCI experience and found that:

- Consumers can and do make a valuable contribution to keeping research grounded in lived experience.
- When consumer involvement activities and consumer-researcher relationships are genuine, mutually respectful and well supported, they have positive impacts on individual consumers and researchers, on the research process and outcomes, and for the organisation.
- There is a clear role for consumers to contribute to setting research agendas, planning and developing research direction and in communicating and disseminating research outcomes.
- The opportunities for co-design and consumer led research are complex and require thoughtful development and implementation in discovery research settings.

Key success factors for involving consumers in a MRI setting include:

1. Organisational readiness, leadership and resourcing. CCI activities need organisational support, formal governance and an investment in coordination, management and evaluation.
2. Good relationships are essential, with well-matched consumers and researchers and effective management of expectations and partnerships.
3. Acknowledgement of contributions, and regular communication.
4. Involving consumers as early as possible in the research process.
5. A diversity of consumer voices that reflect the wider community and “end users” of research.
6. Systems and support for relationship and program management, program evaluation and improvement.
7. Researcher and consumer training and ongoing support.

Consumers and researchers can collaborate effectively within medical research institutes at a strategic level and within individual laboratories and research teams to plan, do, and share research. Consumers contribute to grant applications, and help to hone the messages about science and discovery. Consumer and Community involvement can have profound impacts for those involved and for research outcomes. The success and value of CCI relies on building and maintaining a culture of mutual respect and genuine collaboration among consumers, individual researchers and the organisation. Impactful outcomes can be achieved when a diverse range of people with lived experience of health conditions is engaged in a wide range of research activities across an organisation. Successful consumer involvement requires a willingness to work together towards discovery, greater understanding and ultimately, the delivery of better treatments and cures for people with health conditions and a healthier community.

Medical Research Institutes and CCI

The Policy and Funding Context

Independent MRIs in Australia are not-for-profit organisations, largely funded by competitive and priority grants from Federal government (eg: NHMRC and MRFF) and other government sources, philanthropic foundations and fundraising, clinical trials and commercialisation activity. Many are based in or closely linked with Universities and major health services (<https://www.aamri.org.au/medical-research-institutes/>). They range in size and complexity and cover the breadth of medical research from discovery focused, basic science through to clinical trials and translation.

The policy and funding context for these organisations is changing, with clear shifts towards early engagement with “end users” and a greater focus on research translation. For example, the NHMRC Statement of Intent – a response to the Australian Federal Government Statement of Priorities - includes a commitment to meet strategic objectives on partnership with end-users of research:

“We balance the needs of the community, government and the research sector and we encourage meaningful engagement between researchers and the community at all stages of research.”

“NHMRC grant guidelines and supporting policies, such as the Indigenous Research Excellence Criteria and the Toolkit for Consumer and Community Involvement in Health and Medical Research (2020), also promote and provide guidance on engagement with consumers and communities in the planning and conduct of research.” Prof Anne Kelso, CEO, NHMRC 10th March, 2021 (NHMRC Statement of Intent 2021)

Advocacy groups such as the Consumers Health Forum of Australia (CHF) and Cancer Councils also emphasise the importance of authentic consumer and community involvement throughout the research process. Consumers are expected to contribute to grant development and review, with funded projects required to demonstrate how consumer-researcher collaborations work in practice.

The MRFF highlights consumer engagement and collaboration as one of the five challenges facing the health and medical research sector in Australia. The MRFF 10-year investment plan (2018 – 2028) allocates \$633 million to emerging priorities and consumer driven research and the MRFF 2020-2022 Priorities include an expectation of *“.....crowdsourcing consumer priorities and purposefully connecting researchers to consumers with the intent of enhancing evidence translation into everyday clinical practice”*. The MRFF adopted this priority focus to ensure that what researchers want to research matches the lived experiences, values and priorities of consumers, carers and clinicians. They identify the importance of focusing on partnerships and meaningful consumer involvement (pg 6 – Australian Medical Research and Innovation Priorities 2020 – 2022).

With CCI in health and medical research now widely endorsed in Australia, authentic consumer and community involvement in research is a strategically important thing to do as well as being ‘the right thing to do’.

Guiding Principles

The Australia Health Research Alliance (AHRA) represents over 94% of Australia’s health and medical research community and focuses on research translation into healthcare practice and policy. The CHF is a national consumer representative organisation. Together, they recently released a Position Statement on Consumer and Community Involvement in health research. They endorse the following guiding principles for involving consumers and community members in research:

- *Consumer and community involvement in research relies on an equal commitment to partnership based on mutual trust with a shared belief in the value of research.*
- *Involving consumers and community members in research should be planned from the beginning of the project, resourced, monitored and acknowledged appropriately in reporting.*
- *The roles and responsibilities of consumers and community members should be understood and agreed. Such involvement should be meaningful, rigorous and genuinely contribute to the research process.*

- *Training and support should be provided to consumers, community members and researchers to work together effectively.*
- *The contributions made by consumers and community members should be fairly and appropriately recognised and acknowledged.*

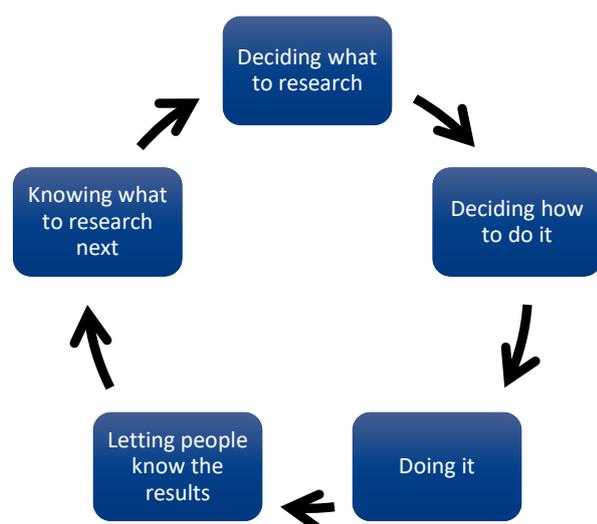
(Source: pg 3, Position Statement – AHRA and CHF: Consumer and Community Involvement in Health Research, Sept 2020)

These principles are applicable for any organisation planning to build consumer and community involvement into their research activities and programs.

Different Approaches

There are many ways to involve consumers in research. The NHMRC Statement of Consumer and Community Involvement in Health and Medical Research (2016) was co-authored by the CHF. The Statement outlines the benefits, definitions, elements and levels of involvement and gives practical suggestions about how to put CCI into practice. The NHMRC Toolkit (2020) builds on the Statement and offers checklists and reflection tools to support researchers and research organisations that are engaging with consumers. Consumers and the community can contribute to any or all research stages (Figure 1) in a variety of ways that reflect different levels of depth and collaboration (Box 1).

Figure 1 – The Research Cycle (NHMRC Statement, 2016)



Box 1: Consumer contribution

Lead – consumers involved in strategic direction, active decision-making, setting priorities.

Partner – work together with researchers to plan, develop, do, analyse and translate research.

Involve – Review or share expertise and experience about the research or activity. Supporting research development or research dissemination.

Consult – Community conversations or consultations e.g.: crowd-sourcing input to research planning or prioritising research

There are many ways that consumers can become involved with a project or organisation including:

1. Join or access a brokerage or consumer representative agency (eg: Consumer and Community Involvement Organisation in W.A.; Cancer Voices Australia) – individual consumers register with independent organisations that recruit, train and support consumers and these groups advertise or ‘broker’ researcher requests for consumers to engage in the research process.
2. Join an organisation’s Consumer Program. Some organisations have a coordinated program that recruits, trains, matches, and supports cohorts of consumers and researchers to be part of the research process.
3. Join an individual laboratory or researcher for a specific project (not part of a wider program). There are many ways a connection could occur, however, the responsibility for recruiting, training, involving and supporting consumers rests with the individual research team.

A wide range of available resources and tools offer detailed information on the steps to follow to develop and implement consumer involvement activities and programs. A selection of these is listed in the “Australian Resources” section of this guide. The selected resources focus on consumer involvement in medical research rather than in health service development.

Planning, Implementation and Evaluation

There are many ways to implement CCI. When planning a project or program it is important to have a clear picture of the specific aims of involving consumers, and of all the elements that contribute towards achieving the desired outputs, impacts and outcomes. A Program Logic model can help with designing, implementing and evaluating a CCI activity or program. A program logic model is a schematic representation of how a program is intended to work (Centre for Epidemiology and Evidence, 2017). Developing a program logic helps to make the aims, expectations, responsibilities and resource needs clear, places the program or project in context and provides an ideal framework to enable evaluation. Using this design approach can foster a collaborative process that involves both consumers and researchers in co-design. MACH used a Program Logic model to guide the evaluation of the WEHI consumer program.

Evaluation of the WEHI Consumer Program – An Example of CCI in a Medical Research Institute

About the WEHI Consumer Buddy Program

WEHI was established in 1915 and is one of Australia’s leading biomedical research organisations. As a member of MACH, WEHI is part of a collaborative group of outstanding health and medical research organisations that focus on research to improve community health and wellbeing. In 2013, WEHI was one of the first medical research institutes in Australia to actively involve consumers working collaboratively with researchers. The WEHI Consumer Buddy Program (<https://www.wehi.edu.au/research-research-fields/clinical-translation/consumers-and-research>) has evolved organically since this time, from approximately 20 participants to more than 160 consumers and researchers now working in partnerships and teams. A Consumer Advisory Panel, comprising consumers and WEHI scientists, has supported this development and provides governance to the Program. In the past 2 – 3 years, the Program has grown significantly and a core team including the Program Coordinator (a WEHI staff member) and three lead consumer volunteers has worked on developing Program policies, systems and operational support.

The team recruits and actively matches volunteer consumers with WEHI researchers and supports them to develop collaborative partnerships that enhance WEHI research. Consumers share their lived experience of health conditions – as a person with a health condition, a survivor of a health condition or as a carer, or person with an interest in science or health and medical research. Researchers share their research ideas and plans, specific projects and proposals and explore communication strategies and ways of sharing science with a lay audience. Consumers are typically involved in reviewing grant applications – particularly where there is a granting body requirement for consumer involvement – and fostering science communication. Consumers can also work with a research team to guide research direction and priority or to support dissemination of outcomes, deliver presentations, support publication or engage the wider community.

The Program is particularly important because many WEHI researchers come from science backgrounds with no clinical experience. Working with consumers therefore provides a direct and rare opportunity for researchers to hear first-hand about the lived experience of a health condition. The WEHI experience is also important as an example of active consumer involvement in a medical research institute that focuses predominantly on discovery research and basic science. In organisations with a strong basic-science focus, consumers need to be aware that many research successes and outputs could be years away from clinical translation in the “real world”. It is important that everyone clearly understands the potentially long lead times in much of the work.

The Evaluation

With funding from the MRFF, MACH supported an evaluation of the WEHI Consumer Buddy Program with two aims:

- 1) to identify any impacts, strengths and development opportunities for the WEHI Program; and
- 2) to explore success factors and identify elements of the WEHI program that could be applied in other health and medical research organisations.

The evaluation gathered feedback from almost 100 consumers, researchers and leaders about their experience of the WEHI Program specifically, and of consumer involvement more broadly. The study included online surveys and in depth semi-structured interviews, together with review of program documents and resources, and organisational context.

A summary of key findings relevant to other medical research institutes is included in this Short Guide.

Why include consumers in the research process in a medical research institute?

Project participants identified a range of benefits of consumer involvement including:

- Grounding the research in the lived experience of people with health conditions
- Positive influence on research direction, particularly at an individual scientist and laboratory level
- Positive feedback from granting bodies, with many researchers attributing some of their grant successes, at least in part, to the collaboration with and input from their consumers
- Personal and professional development reported by researchers
- Personal development and learning reported by consumers
- Strengthened communication skills and improved researcher ability to better communicate their science – particularly to community and lay audiences and for grant applications
- Valued opportunities for consumers and community members to contribute to WEHI research, to WEHI as an organisation, and to enhance WEHI's reputation.

“There's nothing more confronting than sitting with consumers and them telling you their day-to-day struggles to remind you what you should be doing.” (WEHI Researcher Interview)

Successful Program outcomes rely on well-matched consumers and researchers, and on support structures that enable them to develop genuine relationships founded on mutual respect and trust. When these conditions exist, participants identify a range of positive personal impacts including:

- For researchers and consumers: confidence boosting, a renewed sense of purpose, personal growth and development, an increased motivation to contribute and to work collaboratively on the science.
- For researchers: support and mentoring that helps them ‘ride the rollercoaster’ of a science career and learn new skills, particularly in communication.
- For consumers: a sense of belonging, a sense of altruism and contribution to a worthwhile endeavour, an opportunity to “give back”, and an opportunity to learn.

“.....if somebody is interested in, in you know, getting under the bonnet at the basic science level. And helping, helping the next generation of research almost, and researchers, then yeah, it's, it's an awesome place. It's an awesome program to be a part of.” (WEHI Consumer Interview)

“...[my] general communication skills were improved through [consumer involvement] in terms of speaking to a lay-audience rather than my research colleagues.....and then just like the personal growth as well, in talking about your project and your work to someone who is really interested - you know they're really interested and they want to help.” (WEHI Researcher Interview)

Advice for Organisations – Key Success Factors

This list of success factors for consumer involvement is not exhaustive. It highlights the key factors identified through the experience of implementing and sustaining a comprehensive and active consumer involvement program in this large medical research institute.



Organisational readiness to involve consumers is a key success factor. CCI needs active support from leaders, a formal CCI policy and a governance structure that includes consumer representation. **Infrastructure and resourcing** should enable program leadership, investment in consumer and researcher training and support, and effective operational management. A consumer involvement program at scale in an organisation needs dedicated coordination – an individual or a team additional to the researchers and consumers who can support coordinating and managing the partnerships. Core elements of this role are good communication skills, an ability to “read” people, a professional and welcoming approach and an ability to match the right consumer with the right researcher. Policies, structures and systems are needed to ensure streamlined operational management and that consumers and researchers have appropriate training and ongoing support. Organisational readiness is also reflected in how **consumers are integrated into the organisation**. Consider how to involve and support consumers at all levels of the organisation and throughout the research process: priority setting, question generation, project development and review, grant application, translation, dissemination and community advocacy.



Relationships are key. Successful consumer involvement in research relies on genuine, mutually respectful, equal relationships. Many factors contribute to achieving this: finding the right people; carefully matching consumers and researchers to create effective teams; clearly articulating expectations; training and support for both consumers and researchers; opportunities for informal connection; and program structures, strategies and supports that foster collaboration. It is important to remember that research happens in teams. Each team should have *at least* two consumers with complementary attributes and skills (and more in a large team or complex activity). Researchers and consumers lead busy lives, and have many different reasons for getting involved in research. Research has many time pressures, particularly around funding applications. Research can also have long lead-times from discovery to translation. Implementing a consumer involvement program requires flexibility and adaptability to manage these many competing demands, and to **manage individual, organisational and external expectations and needs**.

One of the key factors that enables or inhibits collaborative consumer-researcher partnerships is researcher attitude. It is enabling when researchers are open minded, prepared to listen to consumers input and learn from consumers sharing their lived experience of a health condition. It is a significant barrier when consumers feel that the engagement is not authentic, relationships are unequal or consumers feel they are just being asked to “tick a box” on a funding application.



Acknowledge contributions, celebrate successes and communicate. Acknowledging and thanking consumers genuinely and regularly for their contribution to the research and to the organisation is important. Organisations need a clear policy to guide practice on consumer acknowledgement and reimbursement. There is guidance on this in many of the CCI resources and tools. Profiling the CCI Program within the organisation and externally to the organisation supports recruitment and is a good way to celebrate collective successes. Consumers also need feedback on process and on outcomes – not just to be involved for a grant application and then hear nothing about the final application or project outcomes. Regular, frequent communication about CCI processes and outcomes is important for all involved.



Early involvement - Getting consumers involved as early as possible has many benefits for individuals, for projects and programs. This includes:

- Early in careers – consumers working with students and early career researchers

- Early in employment – when new researchers join the organisation to establish the importance of consumer collaborations as part of induction and on-boarding.
- Early in the research process to involve consumers at a project, program or organisational level in deciding what to research, planning a project or program, or starting a grant application.



Diversity – Consumers reflect community perspectives, and ideally the consumers involved in medical research will be broadly representative of the wider community. This is an ongoing challenge for consumer involvement in medical research. Organisations need to develop and implement strategies and practices to actively foster participation by a diverse range of consumers who are reflective of the community and of the key groups or “end users” that the research will benefit.



Training and Support Provide training in a variety of ways (workshops, experiential learning, shadowing, lectures, in-person and virtual), with clearly articulated learning objectives and expected outcomes. Consumers value opportunities to interact with one another, as well as with individual researchers and the wider Institution. For example, WEHI offers ongoing training, access to seminars, laboratory tours, social events and activities that help to keep consumers informed and involved.

- For Everyone, include: Program Purpose/Consumer Involvement in research; Overview of the organisation and how consumer involvement fits; Program and individual expectations and the potential outcomes of consumer involvement; Case studies and examples of consumer-researcher partnerships and different ways of collaborative working.

Provide ongoing training in specific areas where consumers and researchers intersect – e.g. lay statements, science communication, co-design, communication or collaboration approaches.

- For Researchers, specific preparation, training and support in: How to engage with and effectively work with consumers; How to have a conversation about someone’s lived experience; Lay communication. Training and development can foster attitudes of openness, collaboration and valuing the consumer contribution
- For Consumers, specific preparation, training and support is needed in: How to engage with and effectively work with researchers; Basic science education relevant to the research area they will work in; Research processes and how grants and funding systems work; Advocacy, caring for self and moving from personal experience to the bigger picture. Consumers need support to undertake the consumer role, an opportunity to give feedback and a mechanism for safely raising any issues that may arise, with a commitment that concerns will be acknowledged and addressed.



Evaluation and Improvement - Set up targets and key performance measures for consumer involvement and review and report on these regularly, to participants and to the organisation. Using a program logic model to design the activity or program can provide a helpful framework for evaluation.

“.....the purpose of having consumer or community representatives involved is to present another perspective for researchers. Because it seems as though what happens is [the researchers] all work together. All very bright, but they will – they will sit in the same corner. They all see things the same way, whereas people like myself tend to see things differently and my obligation in getting involved in something like this.....is to present my point of view. And to try and work as a team with the researchers to broaden out their scope and perspective of what they're doing. That's how I see it.”(WEHI Consumer Interview)

“...there needs to be an effort made to engender the point of view, in everybody involved in this, that we're all in this together.” (WEHI Consumer Interview)

Australian Resources

It is easy to become overwhelmed with the thousands of publications and resources that focus on consumer and community involvement in medical research. This guide includes links to some of the *key* Australian websites that provide policy guidance and practical tools to support organisations and research teams involving consumers in medical research. The resources listed have some carry over and application to consumer and community involvement in health care and health service delivery, however, organisations interested in this area should start with the National Safety and Quality Health Service standards (Standard 2: Partnering with Consumers <https://www.safetyandquality.gov.au/standards/nsqhs-standards>) and Safer Care Victoria (<https://www.bettersafecare.vic.gov.au/support-and-training/partnering-with-consumers>) for tools and resources to support consumer involvement in health services.

For organisations and teams from medical research organisations that are focused mainly on establishing or building Consumer and Community Involvement in research, the following resources are a helpful place to begin:

- Medical Research Future Fund
<https://www.health.gov.au/resources/publications/australian-medical-research-and-innovation-priorities-2020-2022>
<https://www.health.gov.au/sites/default/files/documents/2020/01/medical-research-future-fund-mrff-10-year-investment-plan.pdf>
- NHMRC Statement of Consumer and Community Involvement in Health and Medical Research (2016)
<https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research>
- NHMRC Toolkit for Consumer and Community Involvement in Health and Medical Research (2020)
<https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>

The Toolkit is downloadable from the NHMRC Website. The same page offers links to other valuable resources that describe Consumer and Community Involvement in different settings.

- Good, general resources that provide a starting point are:
 - **The Australian Health Research Alliance (AHRA)** facilitates the integration of healthcare, health and medical research, and health professional education to deliver better health outcomes for all Australians. AHRA has a national platform focusing on consumer and community involvement. <https://ahra.org.au/our-work/consumer-and-community-involvement/>
 - **AHRA Handbook.** This “how to” handbook provides practical tools and resources for organisations and research teams planning to implement programs or partnerships specifically in research. <https://wahtn.org/platforms/consumer-community-involvement-program/>
 - **Monash Partners** is an AHRA member. Their website includes a comprehensive range of training modules, resources and links on consumer and community involvement. <https://monashpartners.org.au/disciplines/consumer-and-community/>
 - **Melbourne Academic Centre for Health (MACH)** is an AHRA member and has completed a project with the Health Issues Centre, exploring engagement of CALD communities in health and medical research. <https://machaustralia.org/projects/engaging-older-italian-australian-and-vietnamese-australian-communities-in-medical-research/>

- **Consumer and Community Involvement Organisation** <https://cciprogram.org/>
This Western Australian-based organisation recruits, trains and supports consumers and works with researchers to help foster CCI in research. The website includes practical resources and guidance, and they offer a range of training programs and videos accessible nationally.
- **Telethon Kids Institute, Western Australia** was the first group in Australia to establish a formal program to involve consumers in research (2004). They have a range of downloadable resources: <https://www.telethonkids.org.au/be-involved/help-shape-our-research/>
This includes two comprehensive guides to support individuals and organisations who want to implement consumer and community involvement. *Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical research organisations* and *Planning for Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical researchers*. These resources contain useful, practical guidance on many aspects of consumer and community involvement.
- **Australian Clinical Trials Alliance (ACTA)** – The website includes resources specifically geared towards consumer and community involvement in clinical trials.
<https://clinicaltrialsalliance.org.au/resource/consumer-involvement-toolkit/>
- **Cancer Australia** is an example of consumer involvement with a specific health condition focus. The National Framework for Consumer Involvement in Cancer Control describes the way in which consumers can be involved in all aspects of cancer control – including research. The Consumer Involvement Toolkit has many elements that focus on treatment, management and services, with some components specifically about research.
<https://www.canceraustralia.gov.au/about-us/who-we-work/consumer-engagement>
<https://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/national-framework-consumer-involvement-cancer-control>
- **Health Translation SA** (an AHRA member) and the **South Australian Medical Research Institute (SAHMRI)** have a range of resources to support consumer and community involvement. SAHMRI has developed an organisational framework for CCI using a collaborative co-design process. They also have a Community Orientation Guide – a handbook for consumers engaging in research. <https://healthtranslationsa.org.au/community-engagement-toolkit/>
- **Walter and Eliza Hall Institute (WEHI)** has details about their consumer program online at <https://www.wehi.edu.au/research-research-fields/clinical-translation/consumers-and-research>

References

Australian Health Research Alliance and the Consumers Health Forum of Australia, *Consumer and Community Involvement in Health Research Position Statement*, (Sept 2020). [AHRA-CHF-Position-Statement-Final.pdf](#)

Cancer Australia, *National Framework for Consumer Involvement in Cancer Control*, (2011).
<https://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/national-framework-consumer-involvement-cancer-control>

Centre for Epidemiology and Evidence. *Developing and Using Program Logic: A Guide*, Evidence and Evaluation Guidance Series, Population and Public Health Division. Sydney; NSW Ministry of Health, 2017.

Greenhalgh T, Hinton L, Finlay T, et al. Frameworks for supporting patient and public involvement in research; Systematic review and co-design pilot. *Health Expect*. 2019; 22:785-801. <https://doi.org/10.1111/hex.12888>

Medical Research Future Fund (MRFF), *Medical Research Future Fund 10-year investment plan*
<https://www.health.gov.au/sites/default/files/documents/2020/01/medical-research-future-fund-mrff-10-year-investment-plan.pdf>

Medical Research Future Fund (MRFF) *Australian Medical Research and Innovation Priorities 2020-2022*
<https://www.health.gov.au/resources/publications/australian-medical-research-and-innovation-priorities-2020-2022>

National Health and Medical Research Council, *NHMRC Statement of Consumer and Community Involvement in Health and Medical Research* (2016) <https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research>

National Health and Medical Research Council, *Toolkit for Consumer and Community Involvement in Health and Medical Research* (2020). <https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>

National Health and Medical Research Council, *NHMRC Statement of Intent* (2021)
<https://www.nhmrc.gov.au/about-us/who-we-are/statement-intent#>

UK Public Involvement Standards Development Partnership, *UK Standards for Public Involvement: Better public involvement for better health and social care research*. November 2019.



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