


# Position Statement

Community and Consumer Engagement in Research at SAHMRI  
February 2021



The South Australian Health and Medical Research Institute (SAHMRI) is South Australia's independent flagship health and medical research institute. Our researchers work together to tackle the biggest health challenges in society today.

SAHMRI's vision is to conduct inspired research that will lead to better health outcomes. A core objective of SAHMRI is to produce high quality and high impact health and medical research. Furthermore, SAHMRI is committed to ensuring our research reflects the needs and priorities of the communities we serve.

To achieve our vision and objectives, SAHMRI has, and remains committed, since its inception, to meaningful Consumer and Community Engagement (CCE) in research (sometimes referred to as Community and Consumer Involvement (CCI)). SAHMRI partners with Health Translation SA (HTSA) in its efforts to implement CCE activities across the institute. Together, SAHMRI and HTSA are committed to consistently increasing the culture and practice of quality and meaningful CCE in the research conducted at SAHMRI and advocating for the practice more broadly.

## Context

### National Health and Medical Research Council (NHMRC) and Consumers Health Forum of Australia (CHF) Statement

SAHMRI acknowledges the leadership of the NHMRC and the CHF in promoting consumer and community involvement in health research, and shares the Vision set out in their 2016 Statement on Consumer and Community Involvement in Health and Medical Research [1] :

*Vision: Consumers, community members, researchers and research organisations working in partnerships, to improve the health and well-being of all Australians through health and medical research.*

NHMRC recognises that involving consumers and community members can add value to health and medical research and they have a right and responsibility to do so and provides resourcing to assist researchers (see More Information below).

The Australian Code for the Responsible Conduct of Research (2018) is the primary guidance for institutions and researchers in responsible research practices, along with the *National Statement on Ethical Conduct in Human Research* (2007). SAHMRI research is conducted under the Code and National Statement and SAHMRI supports the statements by the NHMRC including that appropriate consumer involvement in research should be encouraged and facilitated by research institutions and researchers.



## Evidence for Community and Consumer Engagement in Research

SAHMRI is an organisation that is committed to evidence-based policy and practice. It is well-established in the literature that there are benefits for research quality and impact from meaningful community and consumer engagement.

Community members benefit from CCE in research through increased research literacy, empowerment and a sense of purpose by giving back to the research community.

Adding the perspectives of the end-users helps ensure research addresses policy objectives and consumer and community needs. It may also improve recruitment and retention, ensure appropriate language is used in research tools, and improve translation and dissemination of research findings into the community. Finally, community engagement enhances grant application processes and may improve the likelihood of funding.

These benefits for researchers, research organisations and community members have been outlined in a recent review of evidence conducted by SAHMRI on behalf of the Australian Health Research Alliance (AHRA) [2].

SAHMRI previously commissioned a review on the evidence to guide the development of SAHMRI's strategy for Consumer and Community Engagement [3].

## Principles for Community and Consumer Engagement (CCE)

The following principles guide community and consumer engagement in health and medical research at SAHMRI and reflect the values and beliefs that underpin SAHMRI's Position:

- Consumers affected by, or paying for, health and medical research have an ethical right to be involved in and influence how and what research is undertaken
- CCE improves the quality and impact of research
- CCE can and should, where possible, occur across all phases and stages of research.
- Engagement of consumers and community members in research should be based on collaborative partnerships that ensure benefits for all parties
- CCE includes the promise that community and consumer contributions will influence research.
- Consumers and community members should be kept informed about research directions, opportunities for engagement and how their input has, or can, influence and inform health and medical research and research priorities.

- Consumers, community members and researchers should be provided with opportunities to develop their knowledge, skills and abilities in meaningful consumer and community engagement in health and medical research.
- A culture of open communication should be fostered to ensure issues impacting on the purposeful engagement and participation of consumers and community members in health and medical research can be identified and managed.
- Systems and resources to support consumer and community engagement in research should be sustainable, evidence-based and integrate the perspectives of both community members and consumers as well as researchers.
- SAHMRI will drive the shared vision for community and consumer engagement, and actively contribute to the evidence base including development of best-practice approaches for CCE.

## SAHMRI Consumer and Community Engagement Framework

In 2013-14, SAHMRI partnered with Health Consumers Alliance of South Australia (HCASA) to bring together researchers and consumers to develop a SAHMRI strategy for meaningful community engagement in health and medical research.

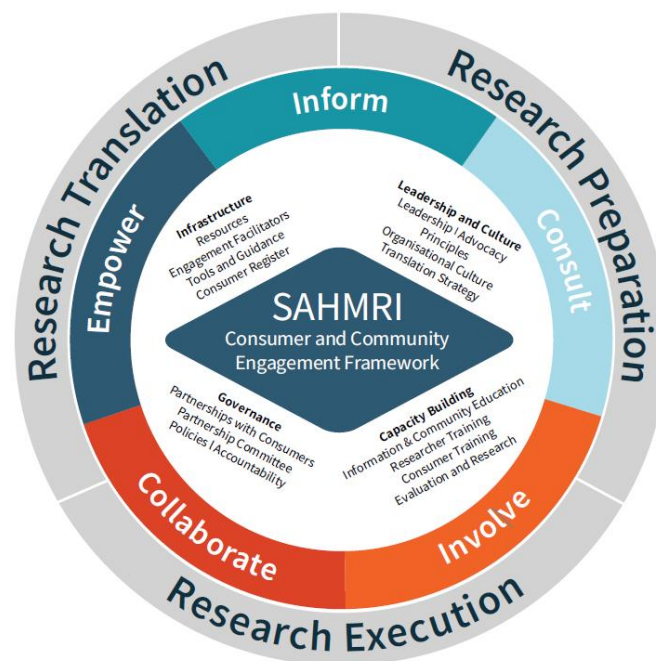
A key achievement of the partnership has been the co-design of an evidence-driven Consumer and Community Engagement Framework [4] which has subsequently been published [5].

The Framework (See Figure 1 for visual overview) includes:

- The stages of research in which CCE can and should take place:
  - Research Preparation (phases: agenda setting and securing funding);
  - Research Execution (phases: research design; recruitment; data collection; data analysis)
  - Research Translation (phases: dissemination; implementation; evaluation)
- The Spectrum of Public Participation [6] outlining the various levels of potential participation for community members and consumers in the research process. The five different levels offer increasing potential impact on decision making. Different levels will be suitable for different projects and purposes:
  - Inform
  - Consult
  - Involve


- Collaborate
- Empower
- Four domains of CCE work at SAHMRI, with multiple actionable elements for implementation under each domain. Some elements have been completed and others are ongoing:
  - Governance
  - Leadership and Culture
  - Capacity Building
  - Infrastructure

Figure 1: SAHMRI Consumer and Community Engagement Framework (2014)



The Framework guided subsequent CCE strategy and practice at SAHMRI and continues to exist as a resource. Elements of the published Framework have been adopted by other health and medical research organisations.

Implementation of the Framework, has been overseen by a SAHMRI Community Advisory Group since 2014, comprising community members and consumers and SAHMRI researchers and staff with responsibility for CCE. An annual work plan focusses on implementing the Framework across the Institute and evaluating its impact. Progress in CCE work and against SAHMRI's Framework and Strategic Plan is reported to the SAHMRI Board. To further



advance CCE, the SAHMRI Board has a Community Engagement Ambassador role held by one of the Directors.

## SAHMRI 2020-2025 Strategic Plan

In line with SAHMRI's commitment to CCE, SAHMRI Strategic Plans have all included objectives relating to Community and Consumer Engagement, informed by the SAHMRI Framework. The current SAHMRI 2020-2025 Strategic Plan includes the Strategic Objective: 'Develop, progress and enhance research that meets community needs' and identifies three key performance indicators to monitor and measure community engagement:

- *Continue to consult with the community about their research needs*
- *Double the number of community members who have formally registered their interest in engaging in SAHMRI research*
- *Provide an annual report on community engagement, including the projects that have community members*

## More Information

Updated information on SAHMRI's current CCE activities and resources to assist in the practice of CCE in research can be accessed via:

- <https://www.sahmri.org/consumer-community-engagement/>

SAHMRI, in partnership with Health Translation SA, maintains a Community Interest Register where South Australian residents who have an interest in being involved in health and medical research can register their interest

- Community Interest Register: <https://www.sahmri.org/community/>

SAHMRI is partnering with organisations locally and nationally to advance a shared vision around CCE. These agencies also offer to assist in the practice of CCE in research, including:

- Health Translation SA: <https://healthtranslationsa.org.au/our-work/platforms/consumer-and-community-engagement/>
- Australian Health Research Alliance (AHRA): <https://ahra.org.au/about-us/>

NHMRC Consumer and Community Engagement

- <https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>



## References

1. Consumers Health Forum of Australia and National Health and Medical Research Council, *Statement on Consumer and Community involvement in Health and Medical Research*, Canberra: National Health and Medical Research Council and Consumers Health Forum of Australia; 2016.
2. Miller C, Caruso J, Gancia A, Michelmore A, Keech W, Overton J, Kerrins E. *The Value of Consumer and Community Involvement in Health and Medical Research - A Narrative Review*. Adelaide: South Australian Health and Medical Research Institute and Health Translation SA; 2020.
3. Johnson A. *What strategies for consumer engagement in health and medical research have been effective for consumers and researchers? A Review of the Literature*. Adelaide: South Australian Health and Medical Research Institute and Health Consumer Alliance of South Australia; 2013.
4. South Australian Health and Medical Research Institute and Health Consumer Alliance of South Australia. *A Consumer and Community Engagement Framework for the South Australian Health and Medical Research Institute*. Adelaide: South Australian Health and Medical Research Institute; 2014.
5. Miller CL, Mott K, Cousins M, Miller S, Johnson A, Lawson T, Wesselingh S. Integrating consumer engagement in health and medical research - an Australian framework. *Health Research Policy and Systems*. 2017; 15(9).
6. International Association for Public Participation. *IAP2 Spectrum of Public Participation*. Toowong: IAP2 Australasia; 2019.