Community Engagement
Partnering for Better Health Outcomes

SAHMRI Community Engagement

Yearly Review 2019-2020

SAHMRI
South Australian Health &
Medical Research Institute

Health
Translation SA
> RESEARCH > ACTION > IMPACT

1. Acknowledgement

SAHMRI pays respect to the Kaurna people as the traditional custodians of the Adelaide region. We also acknowledge the deep feelings of attachment and the relationship of the Kaurna people to their country. We pay our respects to the Kaurna peoples' ancestors and the living Kaurna people today.

2. Introduction

The active involvement of community members in health and medical research has become increasingly central to the research policy agenda of Australia and other countries.

In 2016, the National Health and Medical Research Council (NHMRC), Australia's leading research funding body, published a joint Statement with the Consumer Health Forum of Australia to guide research institutions, researchers, consumers and community members in the active involvement of consumer and community members in all aspects of health and medical research (NHMRC 2016).

The NHMRC Statement strengthens the need for SAHMRI to commit to community engagement across all levels of the Institute, not only because it's a basic human right, but for the value in which community member contributions can make to research development, conduct and communication within South Australia, and nationally (NHMRC 2016).

Active engagement with community members is also fundamental to SAHMRI effectively delivering on its aspirational statements which include undertaking research that will:

- Deliver the right interventions, to the right people, at the right time in their lives to optimise health
- Be translational and deliver health outcomes with global impact to communities
- Provide a focus and leadership for health and medical research

SAHMRI continues to implement its Community and Consumer Engagement Framework (2014), aiming to increase the engagement of community members across SAHMRI scientific activities. This evidence-based framework was co-designed in partnership with Health Consumers Alliance of South Australia (HCASA). Its implementation is governed by the SAHMRI Community Advisory Group which provides guidance on effective translation of the framework into practice, as well as advice to the SAHMRI Board.

The SAHMRI 2020-2025 Strategic Plan has the community engagement objective to 'Develop, progress and enhance research that meets community needs' and identifies three key performance indicators to monitor and measure community engagement:

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

Work at SAHMRI focuses on facilitating and promoting the input of community members, people with a lived experience of a specific condition or illness, or community groups into the planning, delivery and translation of research. It works to build the capacity of research teams to better engage with community members to ensure the research that is done at SAHMRI is informed by community needs and recognises the lived experiences of people affected by it.

Community engagement at SAHMRI is connected to state and national consumer and community involvement activities. SAHMRI's Consumer and Community Engagement work is closely coordinated with that of Health Translation SA (representing 9 academic, research and health care partners across South Australia). At a national level, Health Translation SA works with the eight other Advanced Health Research Translation Centres through the Australian Health Research Alliance (AHRA). AHRA has a national Consumer and Community Involvement project.

This report outlines the community engagement activities and achievements of SAHMRI and HTSA between July 2019 – June 2020.

3. Our aim

To create a culture where our research is informed by the people who are affected by it.

4. 2019 Community engagement activities at a glance

The activities listed below are presented in general alignment with the key performance indicators identified in the SAHMRI 2020-2025 Strategic Plan.

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

SAHMRI Community Engagement Key Performance Indicators

Continue to consult with the community about their research needs	**SAHMRI and HTSA joint activity** Through March and April 2020, all members (n=56) of the Community Interest Register were reached for a short telephone interview with the Senior Project Officer (SPO) as a first point of contact to better understand their motivations and needs in community engagement in research.
	The first Induction event for community members on the Community Interest Register will be held in July 2020. Feedback from the interviews informed planning of the content. It is intended that two induction events will be held per year, targeting any new members of the Registry.
	A Community Engagement in Research Toolkit was launched in May 2019. The toolkit is comprised of resources to support researchers and community members. A working group was created with members of the SAHMRI Community Advisory Group to contribute to the development of the resources available on the toolkit.
	The SPO has continued to support Community and Consumer involvement across a range of initiatives and research projects. In 2019-2020, Nine projects were supported, across SAHMRI and 4 partner organisations : o Breast Cancer project, UniSA o Artificial Intelligence project, Royal Australian College of Surgeons o Machine Learning and COVID-19 project, Royal Australian College of Surgeons o No Australians Dying of Bowel Cancer Initiative Project Consumer Advisory Group, SAHMRI o SAHMRI Women's and Kids Research Theme o Stroke information support project, University of Adelaide o AI2 Digital Support Tool, SAHMRI o Health Analytics Research Collaborative, HTSA Support included drafting a consumer engagement plan, recruitment of community members, and providing the research teams with appropriate tools to undertake consumer and community engagement.
	The Second annual 'Connecting with Community' Forum was held in October 2019, bringing together over 60 consumers and researchers currently undertaking consumer engagement activities across SAHMRI, HTSA and Adelaide Bio-Med City. The SAHMRI Community Advisory Group has decided to postpone 'Connecting with Community' forum scheduled for August 2020, until 2021.

Health Translation SA activity

In October 2019, HTSA collaborated with Flinders University to run a 'Partnership in Research Workshop'. The workshop aimed to match research teams to consumers. Several researcher and consumer partnerships are formed, and a second event is planned.

Currently HTSA is leading the development of a capacity building curriculum for researchers. This would be available to research teams and consumers across HTSA and its state-wide partners (including SAHMRI) and cover the principles and methods of consumer engagement in research.

Active involvement with the Australian Health Research Alliance AHRA - Consumer and Community Involvement (CCI) Steering Committee enables participation in a national conversation on community engagement in health and medical research. The purpose of this Committee is to lead and coordinate greater consumer and community involvement in AHRA's research and health improvement activities to optimise the relevance of their research and its potential for translation into meaningful health outcomes. The priorities for 2019-2020 include:

o   That AHRA develops minimum standards for good practice in consumer and community involvement in translational research in consultation with other national bodies.
o   That AHRA facilitates sharing of existing resources and expertise to support consumer and community involvement in translational research.
o   That AHRA sponsors research and evaluation projects to identify:
    1. how to effectively increase consumer and community involvement in health and medical research
    2. how to effectively measure the impact of consumer and community involvement in health and medical research
    3. how to effectively measure the efficacy of existing consumer and community involvement tools and resources.
    4. That AHRA initiates formal alliances with leading agencies promoting consumer and community involvement in health and medical research.

This year, SAHMRI and HTSA contributed to *Project 3* by undertaking a review of the benefits of engaging consumers and community members in research. This work is in preparation for publication. It will underpin a value statement for AHRA.

SAHMRI (via ROSA) is an active member if the HTSA Consumer and community Action Group. The purpose of the Action Group is to assist Health Translation SA in exploring and implementing state-wide initiatives to increase the active

	involvement of consumers and community members in health and medical research within South Australia.
Double the number of community members who have formally registered their interest in engaging in SAHMRI research	The Community Interest Register was launched in June 2019. The primary purpose of the register is to record information about community members who are interested in being involved in health and medical research at SAHMRI and across Health Translation SA partners. Current enrolments are 81.
Provide an annual report on community engagement, including the projects that have community members	The SAHMRI Community Advisory Group provides strategic oversight of the SAHMRI Framework implementation, reporting progress to the SAHMRI Board via this Yearly Review and interim updates.
	A SAHMRI Board Ambassador was appointed in February 2020. Ms Jenny Richter will liaise between the SAHMRI Community Advisory Group Chair (Ms Ellen Kerrins) and SAHMRI's Executive Officer (Prof Caroline Miller).
	SAHMRI Community Advisory Group Chair provides a bi-monthly update on activities, shared with the SAHRI Community via the newsletter, the Grater Community.