

Community Engagement Report

2018 - 2019



Acknowledgement of Country

SAHMRI is located on the traditional lands of the Kaurna people. SAHMRI and Health Translation SA research communities acknowledge and pay respect to the Kaurna people as the traditional custodians of the Adelaide region.

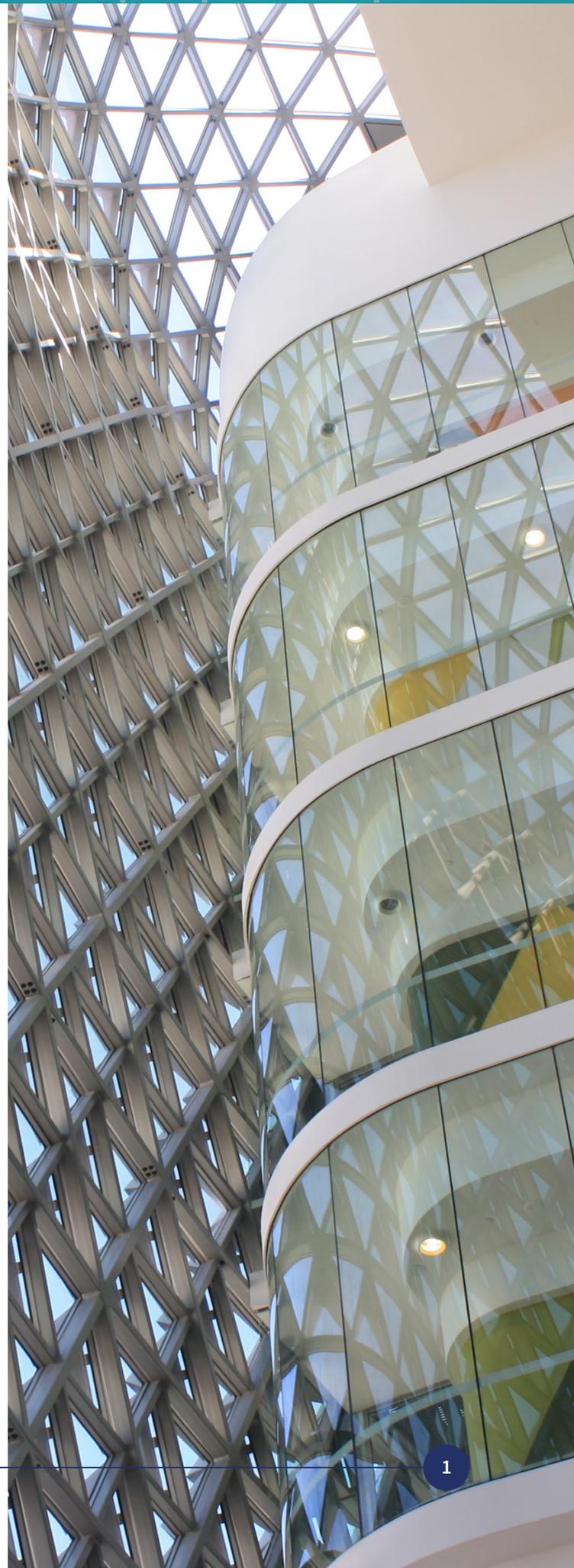
We also acknowledge the deep feelings of attachment and the relationship of the Kaurna people to their country. We pay our respects to the Kaurna peoples' ancestors and the living Kaurna people today.

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Our Vision

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



Introduction

The South Australian Health and Medical Research Institute (SAHMRI) and Health Translation SA (HTSA) are committed to progressing community engagement in health and medical research.

In 2018 a full-time Consumer Engagement, Senior Project Officer was employed to lead consumer engagement activities across SAHMRI. This role also had a brief to influence work across the nine HTSA partner organisations and contribute, at a national level, to consumer and community involvement work being undertaken by the Australian Health Research Alliance (AHRA).

The SAHMRI work has focused on mobilising activities across the Institute to facilitate and promote the input of interested community members into the planning, delivery and translation of research.

Within HTSA the objective has been to influence and support the nine partner organisations to embrace community members as valid participants in the research process and consider the organisational governance and operational requirements to enable this to occur in a systematic way.

At a national level, the position has contributed to new learnings and knowledge sharing about ways to collectively improve the involvement of community members in AHRA's research and health improvement activities to optimise the relevance of their research to the people it impacts and its potential for translation.

This 2018 -2019 Report outlines the community engagement activities and achievements of SAHMRI and HTSA over the past year and showcases examples of how community members have been involved or influencing research projects. The Report also 'looks back' over the past four years and highlights the achievements of SAHMRI since the development of the SAHMRI Consumer and Community Engagement Framework.



SAHMRI is South Australia's first independent flagship health and medical research institute.

SAHMRI is home to more than 700 medical researchers, working together to tackle the biggest health challenges in our community today. Everything SAHMRI does is geared towards conducting inspired research that will lead to better health outcomes.



Health Translation SA brings together nine academic, research and health care agencies, and the community, to enable research findings to be translated into action, as quickly as possible and in a practical way, to ensure that health research can positively impact on the health of individuals and the community.



At a national level, Health Translation SA works with the eight other Advanced Health Research Translation Centres through an Alliance called the Australian Health Research Alliance. Through AHRA, the centres work together on four national systems projects.

Highlights

(July 2018 - June 2019)

- Employing a dedicated full-time Consumer Engagement, Senior Project Officer to lead community engagement activities within SAHMRI and HTSA.
- Appointing a SAHMRI Community Advisory Group who are providing strategic oversight in implementing the Framework and reporting progress directly to the SAHMRI Board.
- Capturing information to inform the evaluation of the Framework.
- Supporting Community and Consumer involvement in a range of initiatives and research projects including:
 - Cardiac Rehabilitation Think Tank
 - No Australians Dying of Bowel Cancer Initiative Project Consumer Advisory Group
 - MRFF Project Showcase event
 - Department of Molecular and Biomedical Science (Adelaide University) and Neurobiology Section in the Hopwood Centre for Neurobiology (SAHMRI) Alzheimer's Disease Lunch and Learn Event
 - Round 2 MRFF project review panels
 - Redefining Healthy Ageing Together Symposium
 - HTSA Stakeholder Forum
 - SAHMRI Women's and Kids Research Theme
- Holding the first 'Connecting with Community' Forum, 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 are planning the second forum.
- Collaborating with Flinders University to run a 'Partnership in Research Workshop'. Several researcher and consumer partnerships are formed, and a second event is planned.
- Planning and developing tools and resources requested by researchers and consumers involved in health and medical research.
- Supporting community engagement in the Round 3 MRFF Transformative Translational Research process with community members working on the strategic round tables; ranking research proposal(s) and contributing as members of the review panel.
- Establishing a brand for community engagement to assist consumers and researchers in recognising community engagement resources and activities promoted across SAHMRI and HTSA.
- Launching the Community Interest Register, enabling access to a database of community members who are interested in being involved in health and medical research within South Australia.
- Developing a Community Orientation Guide for community members involved in research projects which provides them with information about SAHMRI and HTSA, how to get to SAHMRI and our approach to community engagement.
- Collaborating with the Australian Health Research Alliance Consumer and Community Involvement Steering Committee to disseminate their national survey to measure the extent and nature of community and consumer involvement in health and medical research.
- HTSA, HCA and SAHMRI participating in the national AHRA workshop reviewing the survey results and developing ways for AHRA to strengthen consumer and community involvement in health and medical research nationally.

Senior Project Officer Report

This is my first year in the role of Consumer Engagement Senior Project Officer across SAHMRI and HTSA and I'm proud of what I've achieved with the help and guidance of the newly formed SAHMRI Consumer Advisory Group, HTSA Consumer and Community Engagement Action Group, SAHMRI and HTSA staff and other key partners across our stakeholder organisations.

Our vision within both SAHMRI and HTSA is to create a culture where research is informed by the people who are affected by it. While progress had been made in realising this vision, particularly with the development of SAHMRI's Consumer and Community Engagement Framework, having a dedicated full-time consumer engagement project officer role to drive this work has been able to positively influence progress and achievements.

This year's work plan has required a balance between:

- Needing to establish good governance and management structures across SAHMRI and HTSA;
- Getting out and about to meet researchers, community members and other stakeholders interested in community engagement; and
- Developing new resources to build the capacity of researchers and community members.

Some attention has also been given to supporting the AHRA's national initiative on consumer and community involvement which has looked at understanding the current level of community involvement within health and medical research across Australia.

December 2018 saw the first ever, 'Connecting with Community Forum' held at SAHMRI. The forum brought together over 60 consumers and researchers to discuss what was currently happening at a state and national level around community engagement in health and medical



research and showcase local examples. Feedback from participants will see the next Forum's program co-designed by community members and researchers.

A significant achievement has been the launch of our Community Interest Register (the Register). The Register provides a new way for SAHMRI and HTSA to engage with people who are interested in being involved in health and medical research. Implementation of the Register has also seen the development of several resources including a Community Orientation Guide to ensure that community members involved in our research have information to support them in their role.

Now that much of the groundwork has been done, I'm excited to see how we can build on this work over the coming year and continue to promote the importance of community member involvement in health and medical research. Our next priority will be the development of a toolkit of resources to support researchers and community members. Keep an eye out for this on the HTSA website in the coming months!

I would like to extend my personal thanks to the staff across SAHMRI, HTSA, HTSA partner organisations, and community members I've interacted with so far for their support and commitment to working towards the achievement of our vision.

Alex Michelmore



A Look Back

2014 - June 2018

In 2013 - 2014, the South Australian Health and Medical Research Institute (SAHMRI) partnered with Health Consumers Alliance of South Australia (HCASA) to bring together researchers and consumers to advance 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 (the Framework) which has subsequently been published (Miller et al, 2017).

The Framework aims to improve the engagement of community members across the research spectrum in the planning of research priorities, in the research projects themselves, and in interpretation of findings and driving translation to ensure health and medical research improves the health of individuals and communities.

Elements of the Framework have been adopted by other health and medical research organisations, for example, Robinsons Research Institute, Adelaide Bio-Med City and Health Translation SA, and it has also attracted national and international attention through organisations such as the Comprehensive Cancer Centre, Victoria.

Implementation of the Framework was governed by the former SAHMRI Health Consumer and Community Engagement Committee and Health Consumer Executive Committee. The work of the Committees focused on the seventeen elements aligned to the four domains of the Framework; Governance, Capacity building, Leadership and Culture, and Infrastructure.

With the commencement of the Consumer Engagement, Senior Project Officer in 2018 to drive consumer and community engagement across SAHMRI and Health Translation SA, it was timely to take a 'look back' over the last 4 years and note the achievements. Work that has been undertaken in 2018-19 has built upon these achievements, and the learnings and insights that they have provided.



Governance

- Established a Memorandum of Understanding with Health Consumers Alliance of South Australia (2013-2018) to support collaborative activities that ensured health consumers and the community could effectively engage in the work of SAHMRI.
- Formed the SAHMRI Health Consumer and Community Engagement Committee and Health Consumer Executive Committee to provide strategic oversight in implementing the Framework and report on progress to the SAHMRI Research Executive.
- Published the SAHMRI Consumer and Community Engagement Policy for Reimbursement and/or Sitting Fees of Advisory Groups (2017) and the Partnering with Consumers in Research: SAHMRI Consumer and Community Engagement Co-research Policy (2017).
- Members of the SAHMRI's Health Consumer and Community Engagement Committee reviewed and provided input into SAHMRI's draft Reconciliation Action Plan and a Cochrane Review: Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material.
- Developed a plan to evaluate the Framework.



Capacity Building

- Facilitated training for both researchers and consumers on the principles of consumer engagement and how to involve consumer and community representatives across all phases and stages of research. The training was evaluated and will inform future training and development opportunities.
- Established a dedicated consumer and community engagement page on the SAHMRI website to keep the public informed about progress towards implementing the Framework and engagement opportunities across SAHMRI.
- Community members invited to attend relevant SAHMRI events including the SAHMRI public seminar series and Annual Scientific Symposium.



Leadership and Culture

- Sought formal endorsement of the Framework by members of the SAHMRI Management, Executive and Board.
- Published the Framework in the Journal of Health Research Policy and Systems: Integrating consumer engagement in health and medical research – an Australian framework (2017). This has led to SAHMRI being approached by national and international contacts to discuss the Framework and its implementation within SAHMRI.
- Contributed to the activities of AHRA Consumer and Community Involvement Steering Committee which has lead activities to optimise the relevance of research and it's potential for translation into meaningful health outcomes.
- Interacted with National Health Medical Research Council, encouraging its support of consumer engagement in research and providing feedback on their Consumer Involvement Module.



Infrastructure

- Undertook a SAHMRI wide consultation process to inform the development of the Community Interest Register and commenced building the Register within the REDCap System.
- Consumer engagement reporting mechanisms were developed and included in SAHMRI's institute-wide research management and reporting system called PURE.

Committees and Groups

SAHMRI Community Advisory Group

In November 2018, a decision was made to transition the exiting SAHMRI Health Consumer and Community Engagement Committee to an Advisory Group. It was envisaged that this will allow the group to have a greater influence in shaping the strategic direction of consumer and community engagement activities across the Institute, and South Australian research community.

The new Group is known as the *SAHMRI Consumer and Community Advisory Committee* (the Advisory Group) and reports directly to the SAHMRI Board. The purpose of the Advisory Group is to support continued implementation of the Framework and provide strategic advice to the Board on how it can effectively be translated into day-to-day practice across the Institute.

The strategic priorities for 2019 include:

- Launching the Community Interest Register
- Holding a community engagement forum
- Making community engagement resources more accessible to SAHMRI and HTSA researchers and community members
- Establish key performance measures for monitoring the effectiveness of activities implemented under the SAHMRI Consumer and Community Engagement Framework

SAHMRI Consumer Advisory Group Members (March 2019)

Front row (left to right): Merryn Netting, Julia Overton, Caroline Miller, Ellen Kerrins, Penelope McMillan, Tony Sangster, Ellen Skladzien, Alex Michelmore
Back row (left to right): Mike Musker, Alan Bevan



HTSA Consumer and Community Engagement Action Group

In November 2018, HTSA formed a Consumer and Community Engagement Action Group with representatives across each of our nine partner organisations; SAHMRI, SA Health, The University of Adelaide, University of South Australia, Flinders University, Health Consumers Alliance of South Australia, Aboriginal Health Council of South Australia, Adelaide Primary Health Network and Country Adelaide Primary Health Network.

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.

The priorities for 2018-19 included:

- Actively promoting the Community Interest Register, and other community engagement opportunities initiated by HTSA across the partner organisations.
- Partnering with Flinders University to pilot a Partnering in Research Workshop, with the aim to expand it to include involvement from other HTSA partner organisations.
- Providing advice on local implementation of national initiatives under the AHRA Consumer and Community Involvement Project.

AHRA Consumer and Community Involvement Steering Committee

In 2017, AHRA established a Consumer and Community Involvement Steering Committee with representatives from each of the nine Advanced Health Research Translation Centres across Australia.

The purpose of this Committee is to lead and coordinate greater consumer and community involvement in research and health improvement activities to optimise the relevance of research and its potential for translation into meaningful health outcomes.

The priorities for 2018-19 included:

- An environmental scan of relevant literature about consumer and community involvement in health research, and the work of leading international national agencies advocating and supporting consumer and community involvement.
- An Australian-wide survey to capture the extent and nature of consumer and community involvement across AHRA member organisations.
- A national workshop with relevant stakeholders to review the findings from the environmental scan and survey.
- Developing recommendations for AHRA to strengthen consumer and community involvement in health and medical research.

Health Translation SA Partner Organisations



Community Engagement in Action

SAHMRI Bowel Cancer Research Interest Group

Dr Susan Woods, a mid-career investigator in the field of cancer research, attended a ‘Consumers in Research’ workshop in December 2015. It was at this workshop that she met Julie Marker, a consumer representative with a lived experience of bowel cancer, and the idea was born to establish a Bowel Cancer Research Interest Group (the Interest Group). The Interest Group first met in January 2016 and have been meeting regularly ever since.

Forming the Interest Group has meant that Susan, and her team, have learnt how to describe their work involving bowel cancer ‘organoids’ grown from mice or human cancer cells in their lab to community members. In a ‘two way’ exchange, the Interest Group members and Susan’s research team have come to a shared understanding of each other’s interests and robust discussions about a range of topics have contributed to projects going in new directions that align more closely to consumer priorities.

Julie’s strong community networks played an integral role in establishing the Interest Group and engaging other consumers who could provide a range of consumer perspectives and enable different consumers to be involved in different aspects of the research process along the way.

It hasn’t all been smooth sailing though... Susan and Julie both acknowledged that it was a little awkward at the beginning, particularly wondering how the consumers could contribute. However, the ongoing nature of this group has meant that strong partner relationships have developed overtime, and with the expanding knowledge (from both sides) has produced novel ideas for co-creation.

SAHMRI Bowel Cancer Research Interest Group members
(First meeting January 2016)

Left to Right: Dr Tammy Lannagan, Paul, Antonina, Julie, Dr Susi Woods, Tony and Caroline





Alzheimer's Disease Lunch and Learn Event
(November 2018)

Brett, Dr Hannah Brown, Cathy, Dr Ville-Petteri Makinen and
George

Alzheimer's Disease Lunch and Learn Event

In November 2018, researchers from the Department of Molecular and Biomedical Science (The University of Adelaide) and Neurobiology Section in the Hopwood Centre for Neurobiology (SAHMRI) approached Health Translation SA to seek advice on how they could involve community members in their basic research into Alzheimer's Disease.

To get the ball rolling, HTSA hosted a 'Lunch and Learn' event at SAHMRI with 6 community members who had a lived experience of Alzheimer's Disease either as a carer, friend, family member or partner. During the session the group heard from the research teams about their efforts in trying to solve the puzzle of what causes Alzheimer's Disease. Community members also had the opportunity to share their personal stories and views on what researchers should be prioritising, such as the importance of researching effective treatments for symptoms rather than just focusing on research into early detection and cure and discuss ways they could be involved going forward.

While the event created opportunities for mutual learnings in a safe and informal setting, the researchers felt a big part of the learning process had taken place prior to the event. Preparing the set of presentation slides required them to take quite a different approach to normal research presentations. The researchers were advised that they needed to keep their message very simple and genuine and use pictures and language that were easy to understand and engaging.

"I was surprised that I could not use the words 'pathology' or 'assay' and so the language we use as scientists is really important in effectively communicating our message".

–
Dr Louise O'Keefe, The University of Adelaide.

Feedback from community members reinforced the need for the research teams to inform the public more about their work and why it is important, and it was agreed that an annual information session on research into Alzheimer's Disease, potentially linking with Dementia Australia SA, would be of value. Connections made during the session have also led to one of the community members working closely with Dr Tim Sargent, Head of Neurobiology, Lysosomal Diseases Research Unit at SAHMRI, to offer a community perspective on an NHMRC grant application. It is hoped that this is the start of an ongoing researcher – community member partnering relationship.



NADBCI Consumer Advisory Group members
(June 2019)

Left to Right: Alex Michelmore, Margie, Heather, Jules, Lynda
and Carol Holden

No Australians Dying of Bowel Cancer Initiative: Our Community Engagement Journey

The No Australians Dying of Bowel Cancer Initiative (NADBCI), formerly the known as the Beat Bowel Cancer Project, was established in 2017 as a state-wide initiative that is working towards the vision of zero deaths from bowel cancer. We know that death from bowel cancer is preventable if the best available evidence is applied. A state-wide, cross-disciplinary Executive Committee was established to drive the translation of research outcomes into evidence-based practice to improve bowel cancer outcomes for the South Australian population.

The start of the NADBCI consumer engagement journey began in 2017 with the recruitment of consumers onto the NADBCI Executive Committee, which includes health service providers, academics, policy-makers, non-government organisations and clinicians.

At the end of 2018, the NADBCI Executive Committee recognised that it could be doing more to involve our consumers in the broader project. After consultation with our current consumers, Jill and Jules, and with the support

of the SAHMRI Consumer Engagement Senior Project Officer, the decision was made to enhance our community representation with the establishment of a Consumer Advisory Group (the Advisory Group).

2019 has seen a positive turnaround in consumer engagement for the NADBCI. Jules has been a driving force in leading, advising and recruiting other members to the Advisory Group, which will regularly report to the Executive Committee. Members bring different reasons and experiences for being involved, but all share a passion for the consumer voice in research and health service provision. Importantly, members also bring their wealth of experience as consumer advocates to provide mentorship and support to the NADBCI consumer engagement journey. It is through their safe hands, that the NADBCI will learn how best to engage consumers in the work that ultimately impacts on their lives and those of their loved ones.



Flinders University Partnering in Research Workshop
(February 2019)

Presenter: Professor Johnathan Craig, Flinders University

Flinders University Partnering in Research Workshop

In February 2019, Health Translation SA collaborated with Flinders University to run a ‘first of its kind’ workshop which matched researchers together with consumers who had an interest or lived experience in their research area.

Researchers and consumers had the opportunity to learn about what ‘partnering in research’ can look like through a real-life researcher and consumer partnership story and practical exercises. Professor Johnathan Craig, Vice President and Executive Dean, College of Medicine and Public Health at Flinders University also shared his own experience and insights into the value of consumer and community engagement in health and medical research, and his vision for Flinders University as an organisation that strongly supports researcher and consumer partnerships.

More than 50 people attended, with senior clinicians as well as mid and early career researchers talking around tables with their matched consumer representatives. Research topics discussed at separate tables included heart diseases; various cancer types e.g. brain, gastrointestinal; eye diseases and autoimmune diseases.

The ‘buzz’ in the room reflected the genuine interest and engagement between researchers and consumers and helped create a positive environment for learning and formation of new partnering relationships that could continue beyond the workshop.

“It was a very interesting and thought-provoking workshop”

Workshop Participant

Feedback received following the workshop has been extremely positive. We also know that several of the researcher and consumer partnerships have continued to meet in the months following the event.



Aboriginal Chronic Disease Consortium Community Reference Group Members

Aboriginal Chronic Disease Consortium Community Reference Group

It is well documented that Aboriginal and Torres Strait Islander people experience disparities in life expectancy and that chronic disease is the major contributor. In SA, the Aboriginal Chronic Disease Consortium (SA ACDC) has been established to implement priority actions from 3 chronic disease plans - the South Australian Aboriginal Cancer Control Plan 2016-2021, South Australian Aboriginal Heart and Stroke Plan 2017-2021 and the South Australian Aboriginal Diabetes Strategy 2017-2021.

Each of these plans describe the unacceptable gaps in care experienced by Aboriginal patients in primary care, while in-hospital, as well as the issues confronting patients when leaving hospital and returning home. The priorities across the 3 plans have been synthesised into the Consortium's Road Map for Action 2017-2021.

The Medical Research Future Fund funding is supporting two SA ACDC projects: (1) to develop the Monitoring and Evaluation Framework for the five-year Road Map for Action; (2) to design and implement systematic discharge, referral and follow up of Aboriginal patients hospitalised with the priority chronic conditions, focusing on effective discharge and referral pathways between hospital and community-based primary healthcare service providers.

The Consortium is working closely with its many members and stakeholders, as well as Aboriginal community representatives, to ensure a collaborative approach to these

two projects. Aboriginal community representatives are at the core of the Consortium's governance structure with an Aboriginal Community Reference Group having a strong voice.

The Community Reference Group has cross representation from many South Australian Aboriginal communities and plays an instrumental role in providing high level cultural and community knowledge across the Consortium.

Aboriginal community members have been actively involved in co-designing and sharing their lived and cultural experiences to inform the development of projects based on the priorities of the Roadmap for Action. Members have contributed to the development of cultural attributes within some of written work produced through the Consortium and are assisting with the progress of specific models of care, particularly in relation to Cancer. Community representatives have also contributed across condition specific leadership groups and the Executive Committee.



**SA ABORIGINAL
CHRONIC DISEASE
CONSORTIUM**

What our Partners are Saying

In May 2019, SAHMRI and HTSA distributed an online survey to community members, researchers and partner representatives who had been involved in community engagement activities to seek their feedback on what we've been doing well and how we can do things better in the future. The survey will be repeated next year in-line with the annual reporting cycle and will be expanded to include a broader group of people including community members registered on the Community Interest Register.

Our partners are:

- Enthusiastic to expand the impact and reach of our work across the state, particularly in the areas of:
 - Training for both community members and researchers;
 - Diversity of community members engaged in health and medical research; and
 - Community member influence in the type of research conducted.
- Acknowledged the launch of the Community Interest Register as a significant milestone for SAHMRI and HTSA.
- Highlighted the need to continue to promote SAHMRI and HTSA's commitment to community engagement and the work that is being achieved more broadly.

Connecting with Community Forum
December 2018

Researcher and community member forum participants





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