

# Report

## Stakeholder and Community Forum

Wednesday 10<sup>th</sup> August 2022



## Purpose of the Stakeholder Forum

The Stakeholder Forum is a key component of Health Translation SA's (HTSA) governance, and its **purpose is to inform, consult and involve key stakeholders** in the development of priorities, projects, enabling platforms, capacity building and advocacy activities of HTSA. Stakeholders are defined as *any individual, organisation, sector or community that has a 'stake' in enhancing the rate of translation of research into healthcare to create a self-improving, sustainable and high-quality health system.*

In 2022, Kerry Rowlands, CEO Cancer Council SA was endorsed by HTSA's Board of Partners as the Chair of the Stakeholder Forum.

## Program

The 2022 Stakeholder Forum was held on Wednesday 10 August 2022 from 3.00 to 5.30 pm in the South Australian Health and Medical Research Institute (SAHMRI). The Forum was chaired by Kerry Rowlands and there were 46 attendees - 30 in-person and 16 online.

The purpose of the Forum was to

- share key updates from HTSA regarding the work we are doing in engaging people who use the SA health system and the broader community in health and medical research
- understand current 'consumer engagement' activity in South Australia, and
- discuss future opportunities to partner together.

The program for the Forum included several presentations and an interactive session on 'mobilising consumer involvement in research translation'.

## Presentations

### Welcome

The Chair, **Kerry Rowlands**, welcomed participants and reflected on the 'value of the consumer voice' and the role consumer engagement plays in building trust and driving innovation and better service outcomes. The importance of intentionally building and funding the consumer voice in every aspect of health and medical research, translation, and health service improvement.

Key points included:

- Three themes as to why the voice of the consumer is important
  - Better service outcomes
  - Drives innovation
  - Builds trust
- To successfully embed the voice of the consumer into 'your' decision making, it needs to be supported from the most senior leaders in the organisation.

### HTSA Update

HTSA CEO, **Wendy Keech**, provided an update on the following key points

- The Commission for Excellence and Innovation in Health, CSIRO and Torrens University have joined HTSA's Board of Partners
- HTSA's role as an independent catalyst and broker to mobilise collaborations that address major health system challenges



## Involving Consumers in Research Translation – HTSA

**Dr Nadia Corsini** (Chair, HTSA Consumer Engagement Action Group) and **Dr Agustina Garcia** (Capacity Building and Consumer Engagement Lead, HTSA) provided an update on HTSA consumer engagement activities and available resources. The breadth of HTSA consumer engagement activity is outlined in Figure 1.

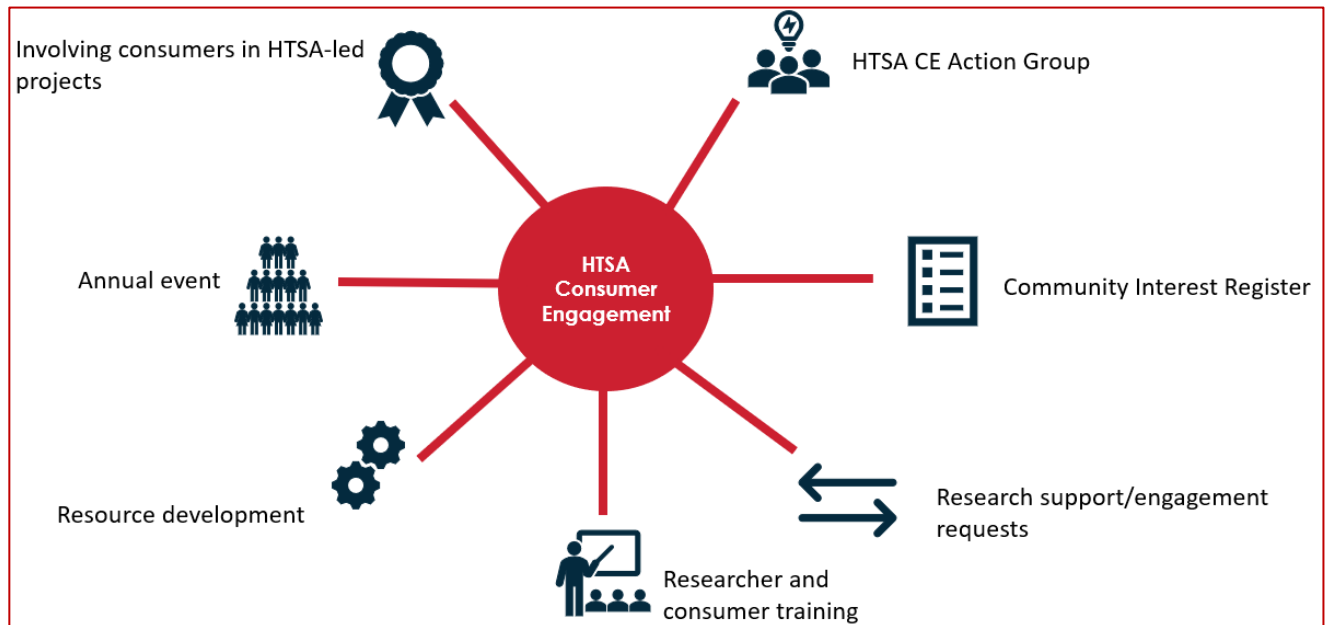


Figure 1. HTSA's Consumer Engagement Activity

### ➤ HTSA Consumer Engagement Action Group

The purpose of the Action Group is to increase active involvement of consumers and community members in research and research translation activities across partner organisations.

Activities include:

- Promoting consumer engagement within partner organisations
- Improving systems and processes for engaging and reimbursing consumers
- Championing consumer engagement and providing mentoring and guidance
- Raising awareness about HTSA's consumer engagement resources:
  - [Consumer engagement toolkit](#)
  - [Consumer engagement register](#)
- Receiving training in the evaluation of consumer engagement process and impact
- Contributing to a Community of Practice involving consumers, health services, NGOs, and research groups
- Annual Consumer Engagement summit
- Working Groups: currently developing a position paper and/or best practice guidelines on consumer authorship.

### ➤ Consumer Engagement Support Provided by HTSA

HTSA also provides consumer engagement support to research teams. Support includes consumer and researcher training, the development of an engagement strategy and recruitment via our Community Interest Register. Additional resources are provided via the HTSA Consumer Engagement Toolkit, which includes templates, policies, reports, and a consumer orientation guide. The HTSA website also lists a variety of other consumer engagement [training options](#) for both consumers and research groups.

The Community Interest Register is a database of community members who are interested in being involved in health and medical research. There are currently 125 active participants with interests in key areas listed below. HTSA is currently focusing on increasing the cultural, gender and age diversity of the register. We welcome suggestions on how NGOs can work with HTSA to broaden the cross-section of the community engaging with health and medical research and health service improvement.

HTSA Consumer Register - Areas of Interest	
Aboriginal Health	Heart & Vascular Health
Ageing	Infection & Immunity
Cancer	Mental Health
Child & Youth Health	Nutrition & Metabolism
Databases & Registries	Population & Public Health
Dementia	Pregnancy & Birth
Diabetes	Resilience & Wellbeing

## Interactive Session Outcomes: Mobilising consumer involvement in research translation

The objective of the interactive session was to understand how HTSA and the broader stakeholder group can work together to help build a thriving SA research environment that translates into impact for the community, patients, carers and their families.

### Members of each table were asked to provide feedback and discuss the following

- > Identify current formal and informal structures their organisations use to engage with consumers
- > Identify any mechanisms their organisations use to distribute opportunities for consumers to be involved in research
- > How could organisations identify issues/problems that matter to consumers that could become research questions?

There was consensus that across stakeholder's, consumer engagement initiatives are at the core of their work and represent an untapped opportunity to link the consumer voice with the research agenda and research projects. The problem is not lack of engagement per se, but the lack of a mechanism to join up existing consumer networks with HTSA's Consumer Interest Register and health and medical research more broadly. There was positive support to consider how best to enable this, understanding that there may not be a one-size-fits-all solution.

There was also discussion around the appropriateness of the term 'consumer' and the one-sided, transactional approach this term engenders. It was suggested that we use more contemporary language that supports consistency across the sector – e.g. People with Lived Experience.

## Outcomes

At the close of discussion all table groups reported back, and both written and verbal responses were collated. A summary of the responses is provided below.

<b>Current formal &amp; informal structures for consumer engagement</b>
Organisational boards and committees
Advisory councils, reference groups, consumer and community boards
Dedicated consumer engagement person or team
Membership, volunteer, ambassador databases
Volunteer databases
Case studies and patient stories
Drop-in opportunity
Phone calls, emails, letters, social media

<b>Mechanisms to distribute opportunities for consumers to be involved in research</b>
Digital newsletters & bulletins
Offline council newsletters, libraries, brochures
Social media campaigns
Roadshows
Through partnerships with other organisations (extended reach)
Volunteer databases
Case studies and patient stories
Drop-in opportunity
Phone calls, emails, letters, social media

<b>How could organisations identify issues/problems that matter to consumers that could become research questions?</b>
Offer different ways to provide feedback
Webforms/websites easy to register
Listening posts
Develop a platform or repository to where existing researchers/teams/projects can park consumer ideas that have been captured but were out of scope for that project
Develop a mechanism for organisations 'consumer needs analyses' to be fed back into the research sector
Ask people what they want research on. However, define the scope, target the right audiences and frame the questions appropriately
Consumer surveys developed by consumers
Community conversations, intersect interviews, pulse surveys
Using patient reported experience and outcome measures (PRMs)

## Next Steps

- > HTSA will work with each interested stakeholder organisations to identify the preferred contact and distribution mechanism to enable consumer engagement for their area of interest.
- > Once these are documented they will be promoted and a two-way information exchange to enhance health and medical research will be established.
- > HTSA will meet with key stakeholders to understand existing needs analysis that can be used to identify and inform research agendas and priorities in SA.
- > HTSA will support consultation/training for Stakeholder organisations with our Consumer Engagement Experts.

## Attendee List

Organisation	Representatives
Adelaide University	Neil McMillan
Aged & Community Care Providers Association (ACCPA)	Anne Liddell
Cancer Council SA	Kerry Rowlands' Laleh Rej
Community Representative	Tony Sangster,
Commission on Excellence and Innovation in Health	Melissa Bond
COTA SA	Rachael Nielsen, Jodi Slater
Dementia Australia	Sarah Jay,
Diabetes SA	Fiona Benton, Angelique Pasalidis
ECH	Josh Harris, Marleesa Ly
Flinders University	Alline Beleigoli, Cobi Calyx,
Heart Foundation	Marie Ludlow
Health Translation SA – Consumer Action Group	Nadia Corsini,
Other	Jennifer Richter
Royal Australian College of General Practitioners (RACGP)	Sophie Nash, Daniel Byrne
Royal Flying Doctor Service	Hannah Allert
SA Govt.	Ben Shores, Danica Liu, Leanne Galpin, Lee Gagliardi, Samantha Welke, Susie Batusic
SAHMRI	Karen Best, Kate Colmer, Olivier Ryan, Alicia North,
Save the Children	Breony Carbines
Silverchain	Helena Williams
The Hospital Research Foundation	Jim Deed
University of South Australia	Helen Radoslovich,
Women's & Children's Hospital Foundation	Jane Scotcher, Verity Gobbett, Karen Rogers
WCHN	Karen Rogers
HTSA	Wendy Keech (CEO), Leanna Read (Board Chair), Agustina Gancia, Nicole Sargent, Rebecca Perry, Tamara Hooper, Alexandra Harris