



# CONSUMER & COMMUNITY ENGAGEMENT SUMMIT 2021: EVENT REPORT

*Consumers, community members, researchers and other professionals shared their insights and experiences of engagement in health and medical research at the 2021 Consumer and Community Engagement Summit.*



The 2021 Summit was proudly co-hosted by Health Translation SA (HTSA) & SAHMRI Registries Consumer Engagement Community of Practice (led by ANZDATA), with support from the HTSA Consumer & Community Engagement Action Group.

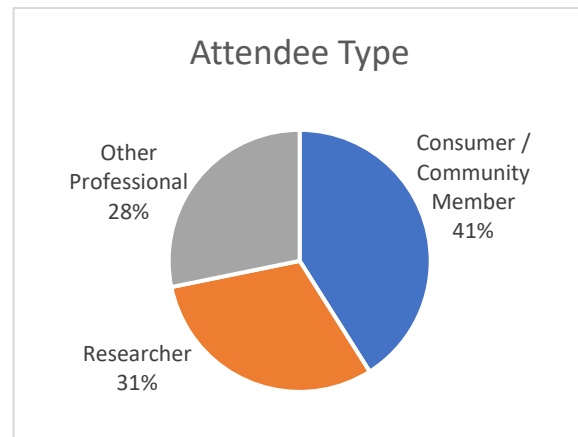
Thanks also to the consumer representatives who contributed to the planning and presentation of this event.

## EVENT SUMMARY

On Thursday 17 November, Health Translation SA (HTSA), in partnership with the SAHMRI Registries Consumer Engagement Community of Practice (CoP), was delighted to welcome more than 50 consumers, community members, researchers and health professionals to the 2021 Consumer and Community Engagement Summit.

The Summit provided an opportunity to bring community members and research professionals

together to learn about strategies for effective community engagement in research, listen to consumer stories, and share perspectives on how to improve engagement in all stages of the health research life-cycle. See appendix A for details of the full program.



Interactive discussions at the Summit highlighted new opportunities to bring the voice of consumers and community members into research projects, as well as providing feedback on learning needs for future training opportunities and events.

*"The interaction, the activities, and the knowledge gained throughout was amazing. Well done team!"*

Thank you to all the consumers, community members and professionals who presented on the day, as well as those who attended. The Summit provided a highly valued opportunity to bring together attendees from more than 10 different organisations, as well as independent consumers and community members and the knowledge and experiences shared on the day are greatly appreciated.

HTSA looks forward to continuing to engage with our community members and consumer representatives in 2022 to;

- Build the skills of consumers, researchers and professionals;
- Promote the value of consumer engagement in research; and
- Increase the quality and quantity of consumer engagement in research across our partner organisations.



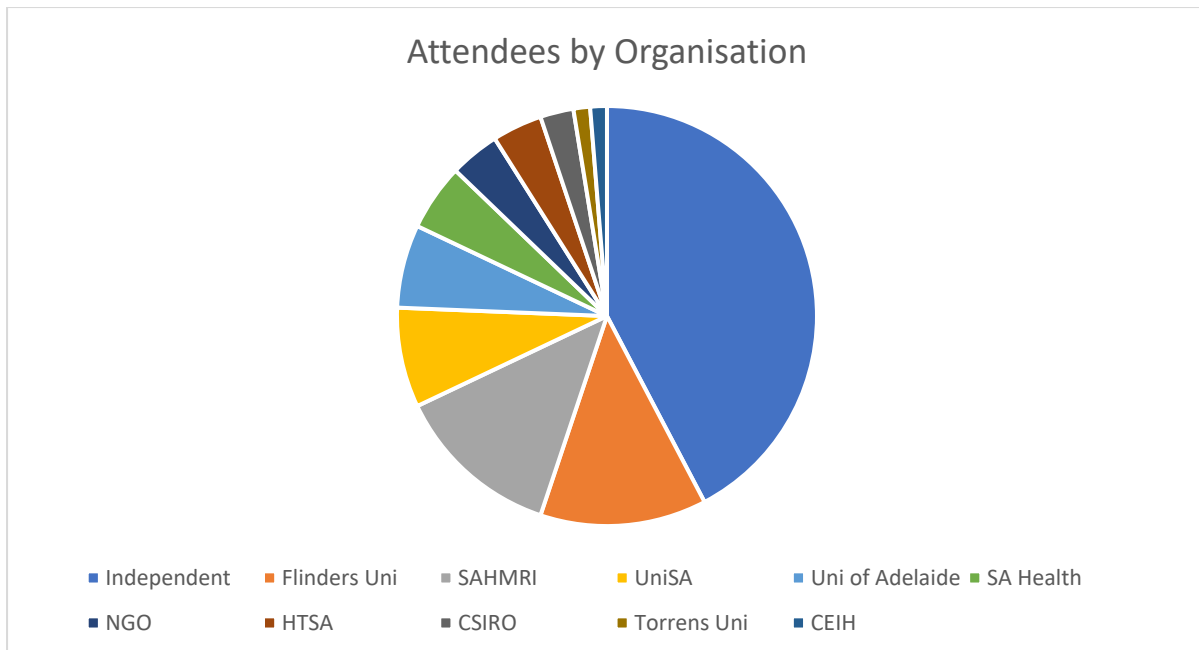


Figure 2: Attendees by organisation

## INTERACTIVE SESSION ANALYSIS

During the Summit, there were two interactive sessions, comprising five discussion and feedback activities, which enabled discussion and networking, as well as an opportunity to share and document insights from community and professionals involved in engagement activities.

*“What did I like most? Hearing from consumers lived experiences; interacting with researchers and consumers; networking...very engaging!”- Attendee*

Session One explored the enablers and barriers to participation in community engagement, and considered strategies to support successful, meaningful engagement.

Session Two addressed learnings from the Summit content, as well as inviting attendees to consider how they might change their practice or progress their engagement efforts into the future.

### Value of Consumer & Community Engagement – popular vote activity

During the first activity, attendees were presented with a range of value propositions that had been identified as known benefits of consumer and community engagement in research as articulated in the previous SAHMRI/HTSA narrative review (Miller et al., 2020). Attendees were asked to vote for the single value propositions they saw as *most* important or add any additional benefits they personally saw as most important. Each attendee was to vote for only one value proposition. As seen in Figure 3, there was an obvious disparity between value propositions seen as important to researchers and health professionals, as compared to those seen as important to consumers and community. Three of the 11 value propositions received no votes, whilst two others stood out as the most important to a greater number of both consumers and researchers.

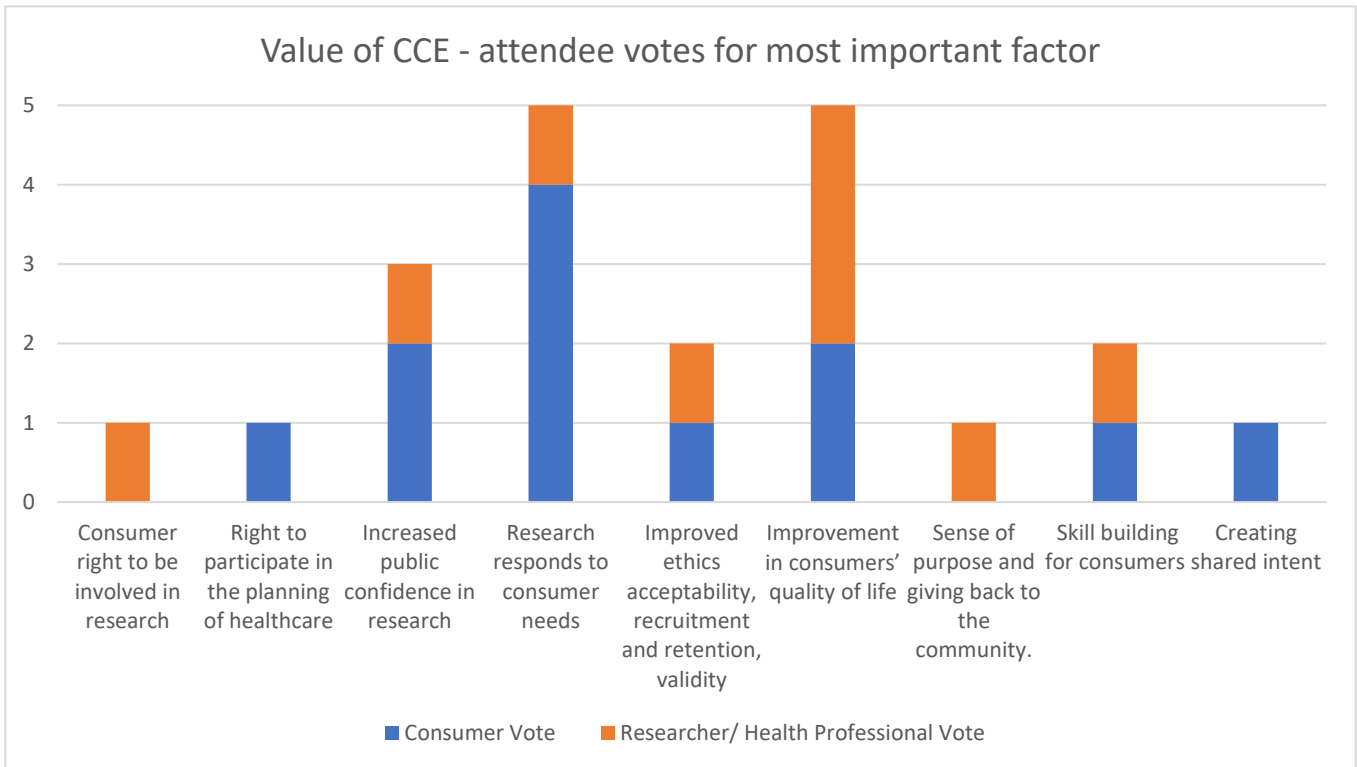


Figure 3: Value of CCE – popular vote activity

Reference: 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. November 2020.

## Rewards & Challenges of Consumer and Community Engagement (CCE)

Summit attendees were invited to reflect on the challenges and rewards they have experienced participating in engagement in research. The rewards described by consumers predominantly related to positive experiences of sharing their personal story with descriptions given such as ‘having a voice’, ‘being listened to’ and ‘being involved’. Other rewards included having contact with researchers and making a difference to others.

Researchers identified benefits in relation to themselves, their research and the consumers they had worked with, describing rewards such as building consumer literacy, establishing research priorities and seeing consumers lead research.

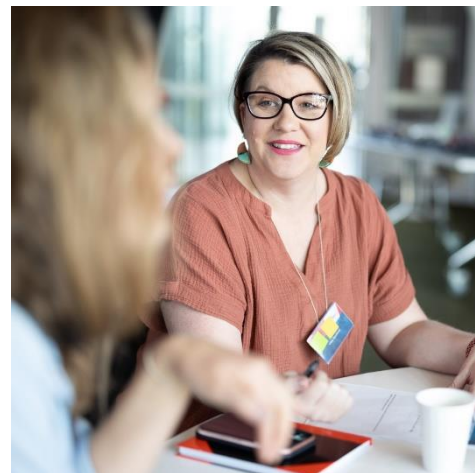


Some of challenges associated with engagement were identified by both consumers and researchers, including time constraints, budget and resourcing difficulties and lacking opportunities to meet or ‘find’ each other. Consumers additionally identified challenges related to understanding complex scientific or technical language and concerns about understanding the research context. Researchers also reflected challenges relating to contacting and engaging with consumers through the variety of channels required.

## Barriers & Enablers of CCE

Further exploring the notion of how to achieve effective and meaningful engagement, attendees went on to complete activities and discussions to identify key enablers that support effective engagement and barriers that prevent optimal engagement becoming embedded in research processes.

The most commonly reported barriers to achieving effective engagement, described by both consumers and researchers, related to resource constraints, particularly in relation to time limitations and costs. Consumers additionally reported barriers relating to conflicting priorities (caring duties, paid work, family commitments), limitations relating to their own health status (being too unwell to participate, needing more flexible participation arrangements), and uncertainty as to how to establish relationships with researchers in their field of interest. Researchers further identified a lack of previous experience and insufficient knowledge relating to consumer engagement practices as significant barriers, as well as concerns regarding how to identify a suitable diverse pool of consumers to be involved in their work.



For the consumer and community attendees, there were a number of socio-emotional factors reported as barriers to engagement, which were not identified by researcher attendees. These included anxieties around being the only non-academic voice on a project, fear of not being valued or respected in the engagement process and difficulties in relation to triggering of previous trauma experiences.

Both groups further reported a series of barriers relating to information sharing and communication, the key barrier being use of jargon or complex language and how to minimise this to ensure shared understanding. Consumers further reported challenges associated with poorly articulated expectations for the role of the consumer in the engagement process and lack of updates or regular communication during and following participation.

## Barriers & Enablers of CCE (*continued*)

Despite the many and varied barriers to effective engagement that were identified by both the consumer and researcher groups, there were equally lively and productive discussions held to explore factors that enable meaningful and effective engagement to be achieved. Many attendees were able to articulate positive examples of when engagement practices have succeeded, and how these could be replicated in future projects.

Many of the enablers described by attendees related to the ‘human factors’ in the engagement process; building meaningful, two-way relationships, respecting the varied experiences and breadth of knowledge brought by different parties to a project, opportunities to be heard and to listen to others’ lived experiences, and strategies to maintain regular, clear communication to ensure clarity of expectations and confidence in the engagement process.



Other reported enablers related predominantly to accessing a range of resources, including staff and administrative mechanisms to support consumer/researcher connections, formal and informal training opportunities, access to appropriate technology, and funding to support both reimbursement of consumers as well as researcher time to undertake meaningful engagement practices.



## Training & Resources Required

One of the most important discussions held during the Summit was to identify aspects of engagement where further training and resources are required to improve engagement practices across HTSA’s partner organisations. HTSA prides itself on building the capacity of researchers, as well as community members and consumers, and as such, identifying targeted training opportunities is an important step in planning training programs for the future.

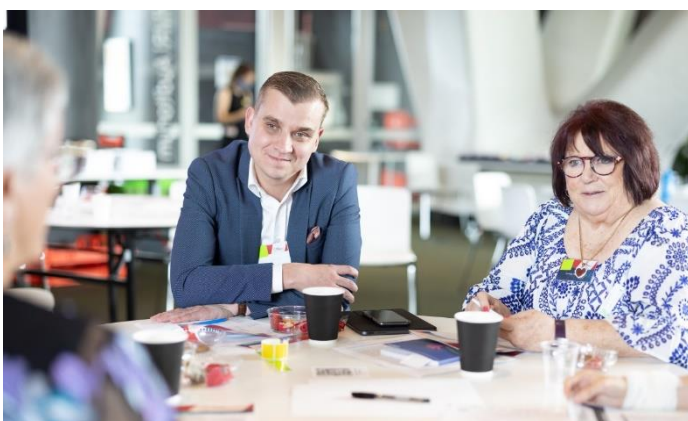
*“I loved hearing case studies & engaging with consumers. Listing some of the areas that need to be addressed which HTSA will take on board- thank you. A fabulous day.” - Attendee*

Table 1 shows the specific skills relating to consumer and community engagement that were identified as requiring further resources and training. Following the Summit, these suggestions have been reviewed by HTSA staff and potential resources and activities to support development of these skills have been proposed.

**TABLE 1: REQUIRED SKILLS AND IDENTIFIED RESOURCES**

<b>SKILL/RESOURCE REQUIRED</b>	<b>POTENTIAL RESOURCE TO MEET THIS NEED</b>
Facilitation skills: Researcher-led facilitation skills When and how to source an external facilitator Navigating divergent perspectives Building relationships and rapport	Relevant sessions in CoP program Identify and promote online learning opportunities Consider developing list of facilitators to be accessed via HTSA
Self care: Support for consumers experiencing triggering of trauma responses Self-care methods Peer support groups	Develop factsheet of support services Links to webinars/podcasts relating to self-care Consumer support session for CoP
Access to facilities and services – e.g. internet, computer, carparking, venues	SAHMRI & SA Health Policies on consumer reimbursement to cover costs Promoting resourcing and provision of facilities across partner organisations Use of libraries or organisational venues
Communication support: e.g. face to face or phone support, assistive technology for consumers	For further consideration
Accessing consumers: Networks & opportunities to connect consumers & researchers e.g. via engaging with GPs or health professionals, databases, advocacy groups) Sourcing diverse consumers (ages, culture, languages, fields of study & experiences)	2022 networking events/forums to be held by HTSA & partner organisations
Mechanism for consumers to communicate ideas to researchers	For further consideration

<p>Consumer training: How to read grant application How the application process works Consumer mentor training Research life-cycle Types of research involvement</p>	<p>Consider webinar with experienced consumers &amp; researchers to summarise grant application process and overview of what a consumer should look for when reviewing a grant. Community Interest Register induction training Consider developing factsheets for CCE toolkit</p>
<p>Evaluation of CCE: What are the outcomes of the engagement activities?</p>	<p>Australian Health Research Alliance CCE Evaluation (Project 3) – 4 frameworks available to evaluate CCE activities. HTSA CCE Action Group undertaking training for new tool “making change visible” in May 2022</p>
<p>Capturing &amp; sharing stories: What are the norms, successes, barriers? Accountability for language Respect for others’ stories Checking in/how did you feel, did you get to say what you wanted? Detailed examples of engagement in projects and how they are run</p>	<p>HTSA to consider initiatives such as: Case study videos Networking events Written case studies such as ‘impact report’ stories Consumer stories shared at CoP</p>
<p>Researcher training: How to include consumers at different stages of research Specific models/methods of community engagement Checklist/practice guide for researchers</p>	<p>Researcher Education Sessions currently provided by HTSA, to promote further in 2022 CoP program expansion, now open to all researchers WAHTN Consumer and Community Involvement Handbook (published Dec 2021).</p>
<p>Clinician engagement: How to better involve Allied Health clinicians in healthcare research Linking to Primary Health Networks and other clinical networks</p>	<p>For further consideration</p>
<p>Information to show how CCE fits into institutions &amp; project cycles</p>	<p>Consider HTSA CCE Action Group sharing org charts showing CCE structures as examples</p>
<p>Consumer access to journals behind paywalls</p>	<p>To be raised with HTSA CCE Action Group as to how this can be supported</p>
<p>“One stop shop” for information regarding consumer opportunities.</p>	<p>For further consideration</p>







Members of the HTSA CCE Action Group

## Key Learnings from Summit

The final interactive session at the Summit asked attendees to describe their key learnings from the day. This activity served as an opportunity for attendees to reflect on what had information had been most valuable to them in attending the Summit as well as inform HTSA in planning the program for future consumer and community engagement events.

Two key learnings were identified to be of benefit to a large number of attendees, being described repeatedly as the main topic of new knowledge learned through attendance at the Summit. The first of these was a greater understanding of the variety of methods & levels of engagement, and how these may be used at different stages of the research lifecycle. The second was an improved awareness of pre-existing, publicly available consumer and community engagement support resources that can be used to further develop effective engagement practices.

Beyond these two primary topics of benefit, attendees further reported a wide variety of new learnings including a better understanding of:

- The validity of consumer lived experience
- Moving beyond tokenism to meaningful engagement
- Importance of involving consumers to validate research
- Funding involved & importance of sufficient financial resources for consumer engagement
- Diversity (ethnicity, language, demographics)
- Communities of practice – how to build and sustain them
- Evaluation of engagement process
- Seeing consumers are more than their disease – draw on the person’s whole lived experience and skillsets
- Types of consumer groups and networks that can be utilised
- Importance of informing and providing education for consumers
- Importance of self-care for consumers
- The power of hearing directly from consumer presenters

*“What I found most valuable about the Summit was the stimulating speakers and topics with clear presentations, and the inclusion of consumers in the speaking was a highlight.” - Attendee*

## Appendix: Consumer &amp; Community Engagement 2021 Summit Full Program



# CONSUMER AND COMMUNITY ENGAGEMENT SUMMIT

## PROGRAM



Thursday 18 November 2021, 8:30am - 2:30pm, SAHMRI Auditorium

TIME	TOPIC	SPEAKER
8:30	Arrival & introductions	
8:50	Welcome	Wendy Keech <i>Health Translation SA</i>
9:00	Consumer Engagement in Health and Medical Research – navigating & pioneering through 30 years in the field	Anne McKenzie <i>Telethon Kids Institute</i>
9:25	Communities of Practice – an overview	Barbara Chappell <i>Simply Speaking</i>
9:45	Case Study: ANZDATA Community Engagement in a Registry context	Shyam Muthuramalingam, & Erandi Hewawasam, ANZDATA Adela Tolic, <i>Consumer</i>
10:05	Case Study: CCE in Translation - the Acute/Community Interface Project	Ecushla Linedale <i>Health Translation SA</i>
10:20	Morning tea & conversation	
10:45	Consumer Voice: reflections on involvement in research as a consumer and advocate	Lynda Whiteway <i>Chair of Health CAN SA</i>
11:05	Benefits & Barriers for effective CCE in research	Kate Laver & Vikki Bedford <i>FHMRI</i>
11:30	Interactive Session: Barriers & Enablers of effective CCE in research	Nadia Corsini <i>UniSA, Chair HTSA CCE Action Group</i>
12:10	Lunch & conversation	
12:55	Case Study: Consumers as Researchers and co-design models in Stroke research	Liz Lynch, <i>Flinders University</i> , Fawn Cooper, <i>Consumer &amp;</i> John Mitchell, <i>Consumer Co-Researcher</i>
13:20	Elevating CCE; an overview of HTSA CCE support mechanisms, resources and learning opportunities	Annelise Morris <i>Health Translation SA</i>
13:35	Interactive Session: Today & Tomorrow – exploring what we have learnt and future opportunities	Nadia Corsini <i>UniSA, Chair HTSA CCE Action Group</i>
14:10	Wrap Up	Shyam Muthuramalingam, ANZDATA
14:15	End	