

# Consumer Involvement Strategy Policy Document

## Centre for Health Exercise and Sports Medicine

### Purpose

The purpose of this policy is to guide the involvement of consumers in the health and medical research work of the Centre for Health Exercise and Sports Medicine (CHESM). In this policy, a consumer refers to a person with lived experience (or at risk of) the health condition of interest and/or their support network (e.g., family, friend, carer).

### Our Vision

The Centre for Health Exercise and Sports Medicine will deliver research that is integral to, and designed around, the needs of consumers and the community.

### Our Commitment to Consumer Involvement

We will seek, value, and respect the views and insights of consumers, and work to ensure that the diversity of people giving their views reflects the diversity of the local population.

We will provide information that is clear, jargon-free and accessible.

We will ensure people are adequately supported in their consumer-involvement role.

We will be clear about what decisions consumers can and cannot influence.

We will review our consumer involvement activities and continuously improve our processes.

### Our Strategic Aims

*Promote inclusivity and establish a supportive culture:* we will strive to deliver clear, meaningful and accessible opportunities for consumer involvement and establish a supportive and safe culture.

*Build capacity:* we aim to integrate consumer involvement throughout CHESM, in each research program and at the Advisory Board level.

*Build capability:* we will promote awareness and understanding of consumer involvement within CHESM and ensure all parties have the knowledge and skills required to undertake consumer involvement activities.

*Continuously improve:* we will evaluate CHESM consumer involvement activities and continuously improve our processes to ensure that the time our consumer representatives dedicate to activities has the maximum value and the best possible influence on our research.

*Collaborate, network and disseminate:* we will share resources and expertise locally, nationally and internationally.

## Implementation Plan

- 1. Promote inclusivity and establish a supportive culture:** we will strive to deliver clear, meaningful and accessible opportunities for consumer involvement and establish a supportive and safe culture
  - a. Develop our methods of communication with consumers
    - Develop and implement a framework for CHESM’s consumer involvement activities in collaboration with consumers.
    - Ensure all parties are clear about their roles and responsibilities at the outset of any consumer involvement activity.
    - Regularly evaluate, update, and improve our existing consumer involvement materials (e.g. newsletters).
  - b. Identify and address potential barriers to involvement
    - Consider the individual needs of our consumers when planning and scheduling involvement activities and tailor involvement accordingly.
    - Ensure materials and venues for involvement activities are accessible and suitable for the needs of the attendees. This includes consideration of physical, cultural and communication access barriers that may be faced by consumers. For example, provide translated version of key materials to culturally and linguistically diverse consumers, ensure materials
    - Ensure all consumer involvement materials use inclusive language to encompass gender, sexuality, race, age, health literacy levels.
    - Ensure consumer representatives are appropriately acknowledged for their time for their time.
  - c. Establish a supportive and safe culture
    - Promote a culture that recognises people and their experiences as assets.
    - Define role descriptions and terms of reference for consumer involvement activities to ensure consumers are empowered to voice their opinions (e.g. role descriptions).
    - For group activities, ensure mutually agreed ‘ground rules’ are devised and respected.
    - Ensure that consumers are not harmed in any way through their involvement in a CHESM consumer involvement activity. This includes minimising the wastage of their time and ensuring involvement does not cause financial loss, privacy violation, and emotional or physical harm.
    - Seek feedback from consumers about their involvement to improve processes.
    - Ensure consumer representatives are informed about their involvement's impact and are recognised for their contributions.
    - Maintain the authority to exclude any individual who causes harm to either staff or other consumer representatives extending to individuals who exhibit disruptive/offensive behaviour or hinder the progress of the activity.

Milestone	Timeframe
Develop and implement a CHESM Consumer Involvement Strategy that encompasses all of CHESMs consumer involvement activities.	August 2023
Tailor and provide <i>Consumer Role Description</i> documents for consumer involvement activities within Levels 2-4*.	Ongoing
Devise and adhere to mutually agreed <i>Ground Rules</i> for all group-based consumer involvement activities that outline behavioural expectations that consumers and researchers must meet.	Ongoing
Conduct monthly meetings to review existing consumer involvement materials, including CHESMs Knowledge Translation Network (KTN) registration process and content for monthly KTN consumer newsletters.	Ongoing

Where a grant budget allows for unlimited expenses related to consumer involvement, CHESM's <i>Honorarium Schedule</i> will be adhered to for consumer involvement activities. <sup>#</sup>	Ongoing
<i>Process evaluation</i> forms (REDCap) completed independently by the consumer and lead researcher for consumer activities associated with Levels 2-5*. They should be completed immediately after consumer involvement activity ends or 6 monthly if a consumer involvement activity is planned to span greater than 1 year.	Ongoing
Regular research progress updates must be sent to involved consumers at key research milestones. Where relevant, updates should be provided regarding grant outcomes, trial recruitment commencement, when data collection ceases, and when publication is accepted.	Ongoing
<i>Thank You Letter</i> sent to consumers following participation in any consumer involvement activity acknowledging their contribution, its perceived impact/value, providing detail of when they may expect relevant research progress updates and when/how the honorarium will be delivered (if applicable).	Ongoing
All CHESM team members are to undergo training in processes/procedures for implementing CHESMs Consumer Involvement Strategy.	August-September 2023

Italics identify documents/templates that have been created for CHESM staff/students to modify for specific consumer involvement activities.

\* CHESM Consumer Involvement Levels: 1: Knowledge Translation Network (KTN) Consumer Member; Level 2: Project-Specific Consumer Advisor; Level 3: Consumer Research Investigator: Academic-Led Research; Level 4: Consumer Advisory Panel Member; Level 5: Consumer Research Investigator - Consumer-Led Research

<sup>#</sup> Honorarium provided across projects will be variable and will be dependent on the project's grant funding. Projects with allocated grant funding for consumer involvement activities will adhere to the CHESM Consumer Involvement Honorarium Schedule. This will be clearly outlined in all Consumer Role Description & Terms of Reference documents.

**2. Build capacity:** we aim to integrate consumer involvement throughout CHESM, in each research program and at the Advisory Board level

- a. Increase organisational capacity for consumer involvement
  - Expand the number of consumer representatives in our database (e.g., the KTN)
  - Establish groups specific to our key research areas as needed.
  - Ensure CHESM staff and students are allocated sufficient time to implement CHESMs Consumer Involvement Strategy.
- b. Reach underrepresented audiences
  - Strive to have consumer involvement representatives who reflect the diverse characteristics and backgrounds of our research audience.
  - Collect and monitor the demographics of our consumer representatives to identify areas of underrepresentation, where possible.
  - Devise and review methods of engaging underrepresented populations e.g., Aboriginal and Torres Strait Islander Peoples and culturally and linguistically diverse consumers.
- c. Accurately predict the resources needed for consumer involvement
  - Complete accurate costings for consumer involvement activities at the outset.
  - Ensure consumer involvement is fully budgeted in grant applications.
- d. Fully integrate consumer involvement throughout all levels of CHESM.
  - Setup a Consumer Involvement Strategy Action Group for the development, implementation and ongoing review of our research and consumer involvement strategy and define its remit and accountabilities.
  - Ensure consumer representation at the Advisory Board level.
  - Ensure consumer involvement is routinely included in CHESM research activities.

Milestone	Timeframe
Set annual targets for KTN consumer member registrations. Review progress at monthly KTN meetings and discuss marketing strategies to increase KTN registrations/consumer interest.	Ongoing
2023 target for KTN consumer member registrations is 8, 000	Dec 2023
Routinely capture age, gender, sex, ethnicity, and socioeconomic participant data in all research trials to better understand the diversity of our research audience.	
Annually review demographic diversity across research participants (our research audience) and CHESM consumer involvement representatives to inform the following year(s) diversity target(s)	Ongoing
Wherever possible/permitted by the funding body, costings for consumer involvement activities are to be completed as per CHESMs <i>Honorarium schedule</i> .	Ongoing
Include a Consumer and Community Involvement statement in all clinical trial protocol documents	Ongoing
Ensure the reporting of all clinical trial findings adheres to the GRIPP2 reporting checklist short form. This checklist is universally accepted as a guideline to improve reporting of patient and public involvement in research	Ongoing

**3. Build capability:** we will promote awareness and understanding of consumer involvement within CHESM and ensure all parties have the knowledge and skills required to undertake consumer involvement activities

- a. Provide guidance for researchers and students to facilitate consumer involvement activities within CHESM
  - Make guidance/template documents accessible and provide additional resources based on researcher feedback.
  - Conduct periodic staff and student educational sessions to improve knowledge/skills in areas relevant to implementing CHESMs Consumer Involvement Strategy.
- b. Provide researchers and students with the skills required to carry out effective, meaningful consumer involvement
  - Integrate consumer involvement training into CHESMs professional development schedule i.e. periodic educational lectures at CHESM meetings and/or workshops.
  - Regularly review consumer involvement processes to identify staff/student training needs and areas of improvement.
- c. Provide consumer representatives with the knowledge and skills required to carry out effective, meaningful consumer involvement in our research
  - Provide all consumer representatives with clear details outlining expectations/duties/timelines for their role.
  - Provide learning and development opportunities to our consumer representatives.

Milestone	Timeframe
Create a suite of document templates for staff/students to use to support the implementation of CHESMs Consumer Involvement Strategy and make these available online via the internal CHESM research drive	August 2023
Conduct training to orientate staff/students to CHESMs Consumer Involvement Strategy and how to implement it	August 2023
Conduct annual staff/student educational sessions on engaging and respectfully working with Aboriginal and Torres Strait Islander Peoples as consumer representatives (led by guest speakers)	By Dec 2023
Conduct annual staff/student educational sessions on engaging and respectfully working with culturally and linguistically diverse consumers (led by guest speakers)	By Dec 2023
Conduct annual staff/student educational sessions on LGBTIQ+ inclusive practices in research and consumer involvement (led by guest speakers)	By Dec 2023
Each year, nominate a Student Consumer Involvement Representative who is responsible for upskilling/training new research higher degree students in the implementation of this policy.	Jan, annual
Provide CHESM's recommended Consumer Representative Support Resources to consumers involved in consumer involvement Levels 2-4*	Ongoing
Include consumer involvement as an agenda item in CHESM's monthly team meetings	Ongoing
Review consumer and staff/student consumer involvement process evaluation surveys (REDCap survey) to identify training needs and areas of improvement. Report findings at monthly CHESM team meetings	Ongoing

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**4. Continuously improve:** we will evaluate CHESM consumer involvement activities and continuously improve our processes. This will ensure that the time our consumer representatives dedicate to activities has the maximum value and the best possible impact on our research

- a. Optimise the value of our consumer involvement activities by establishing mechanisms and standards for monitoring and reporting activity
- Set specific, measurable, achievable, realistic and timely objectives for each consumer involvement activity, and share these with consumer representatives in advance in the *Consumer Role Description*.
  - Collect feedback from consumer involvement representatives to monitor how effectively we are conducting consumer involvement activities (e.g. adequacy of communication, timeframes, honorarium) and identify staff/student/consumer training needs or areas of improvement
  - Collect feedback from staff/students involved in consumer involvement activities to monitor how effectively consumer involvement is being conducted (e.g. adequacy of resources and available time) and identify staff/student/consumer training needs or areas of improvement

Milestone	Timeframe
Consumer representatives are to complete a process evaluation survey (REDCap) for all activities related to consumer involvement Levels 2-5*. The survey should be completed immediately after consumer involvement activity ends or 6 monthly if a consumer involvement activity is planned to span greater than 1 year.	Ongoing
Lead researchers to complete a process evaluation survey (REDCap) for all activities related to consumer involvement Levels 2-5*. The survey should be completed immediately after consumer involvement activity ends	Ongoing
Consumer Involvement Representative will review (monthly) the consumer/staff/student process evaluation surveys (RedCap survey) to identify training needs and areas of improvement. They will report findings at monthly CHESM team meetings	Ongoing

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## 5. Collaboration, networking and dissemination

### a. Sharing of best practice

- Make examples of success and learnings publicly available.
- Contribute ideas and examples of best practices to other centres.

Milestone	Timeframe
Publish the development of CHESMs Consumer Involvement Strategy and its associated resources in an open access, peer-reviewed medical journal	September 2023
Present CHESMs Consumer Involvement Strategy and its development at a relevant national conference in 2023-2024 (e.g., Australian Clinical Trial Alliance annual scientific meeting)	Pending
Promote CHESMs Consumer Involvement Strategy via our social media channels	September 2023

## Monitoring and review

Consumer representatives will be involved in the ongoing monitoring and review of this policy and its associated work.

**Current Policy finalised:** 1/07/2023

### Policy developed by:

The Consumer Involvement Strategy Action Group

Dr Rachel Nelligan (Chair)

Dr Belinda Lawford (Academic representative – Research Fellow)

Mr Travis Harber (RHD representative)

Jennie Marlow (Person with OA)

Neil Bidgood (Person with OA)

Prof Kim Bennell

Prof Rana Hinman

### Policy reviewed by:

CHESM staff:

A/Prof Fiona Dobson (Head of the Department of Physiotherapy)

Dr Thorlene Egerton (Research fellow)

Jesse Pardo (Research assistant)

Sarah Stratulate (Research assistant)

Bridget Graham (Research assistant)

Sam Shearer (Research assistant)

Gabby Knox (Research assistant)

A/Prof Kade Paterson (Research fellow)

A/Prof Michelle Hall (Research fellow)

CHESM RHD students:

Julia Zhu

Patrick Rowe

Consumers:

Jan Dixon  
Carolyn Ross  
Chris Leslie  
Barbara Capewell

**Current Policy version: 1**

**Policy review due (annual):**  
Mid 2024