### **Consumer Role Description & Terms of Reference**

### **[Insert name of role]**

[Please customize this document to best suit the project, the grant funding available and the needs of the consumer representative(s) you are looking to involve. For example, if you plan to work with consumers whose first language is not English, please use simpler language accordingly or have the document translated. Please ensure all RED text is modified or deleted]

The following pages will provide you with information about this role, so that you can decide if you would like to take part as a consumer representative on this project. If you do decide to take part, please keep this document for your reference.

## Who we are

The Centre for Health, Exercise and Sports Medicine (CHESM) is a multidisciplinary centre within the Faculty of Medicine, Dentistry and Health Sciences. It is part of the Department of Physiotherapy. Our main research focus is on the role of conservative strategies (like exercise), in promoting overall health and well-being. A particular focus of ours is the prevention and management of musculoskeletal conditions such as osteoarthritis.

## About this role

We are seeking members of the public with experience of, or interest in, clinical research and [insert health condition] who are willing to help in the design and running of our research activities. Each member brings a different perspective, experience, and knowledge to the trial team.

This specific project is about [Insert a paragraph about the project e.g. exploring, comparing, investigating].

………

………

………

## The aims of this role

* + To involve members of the public with experience of [insert condition] to ensure our research activities are considered from a patient perspective
  + To provide the research team with valuable insights and understanding of [insert condition] to ensure the research is relevant to the needs of the public
  + To empower individuals who live with [insert condition]
  + [and/or insert specific aims relevant to project].

## Your Contact Person

The main contact person for this role is [insert name, email and phone number – **put in bold**]. Please feel free to contact them with any concerns or queries. They are available between [insert working hours].

## Who is involved in this project

The research team members are:

[List research staff names]

[number of consumer representatives] consumer representatives

#### Person specifications for this role [below to be edited based on consumer group]

#### Essential attributes

*Experience*: Experience of living with the condition being researched

*Knowledge:* Knowledge of perspectives from the group you represent

*Skills*: Well-developed written and oral communication skills. Confidence to give feedback to researchers to help develop research projects. Basic computer skills (e.g., using email, using Microsoft word)

*Personal qualities*: Ability to listen to others and express own views. Openness to other people’s views. Reliability.

#### Desirable attributes

*Knowledge:* To have some understanding of research or willingness to learn. Willing to familiarise yourself with some medical and research language.

## Your involvement and responsibilities:

If you take part, you will be asked to:

* + [insert specific tasks]
  + Read and keep this document.
  + Declare any conflicts of interest.
  + Review CHESM’s recommended consumer representative resources (approximately 1 hours).
  + At the end of your involvement, complete a feedback survey about your involvement.

## Your Time Commitments

Your involvement in this project is expected to be from [insert month/year] to [insert month/year]. If this changes at any point, we will let you know and give you the option to extend your involvement if appropriate.

You are being asked to give the following time commitment:

* + [Describe the meeting(s) that the consumer member will be expected to attend - frequency and length]
  + [Insert an estimate for the time preparing and attending the meeting(s)]
  + [Insert an estimate time they may be expected to spend reviewing documents or working on other items such as lay summaries]
  + [Insert an estimate for any time that they may be asked to be in virtual meetings or telephone conference calls]
  + [Insert an estimate for any other time commitment that relates to your work]

This will not be significantly changed without your agreement.

## Details Relating To Meetings

Meetings will usually be held [insert venue giving directions and travel / parking / public transport arrangements or Zoom instructions]. If you are unable to attend please let your contact person know. We will give you plenty of notice if the meeting details change.

## Support For Your Role

We want you to feel fully able to contribute to this project. If you have any specific support needs please let us know. If there are any needs that arise at any time, please do not hesitate to let [your contact person] know.

## Expenses And Payment

[Delete if not applicaple…] We will reimburse expenses incurred from your particiption in this project related to parking. Expenses should be agreed with your contact person in advance of your particiption. You will need to complete an **Out-of-pocket Remuneration Form**, provided to you by your contact person. Please provide original receipts, sign the form, and give it to your contact person for authorisation and processing.

Payment provided across CHESM projects varies depending on the project’s grant funding. There [is/is not] payment for your work on this project. [Delete if not applicaple…] The payment for this project is [insert agreed payment based on the Honorarium Schedule include time duration and amounts]. This will be provided as Gift Vouchers at the end of your involvement (or as negotiated with your contact person).

Please note: The Australian Tax Office (ATO) has the authority to treat gift voucher payments as taxable income. Please be mindful of any potential impacts this may have on your personal tax situation or if uncertainty, check with a professional financial advice service.

## Conflict Of Interest And Confidentiality

As a member of this [group/committee/panel/project/investigator team] you will be required to disclose any involvement you may have with other organisations, government bodies or companies which could result in a conflict of interest with the work you undertake for this project. Your contact person will provide you with a **Conflict-of-Interest Form** to complete.

While working on this project, it is possible that you will hear, see or be given confidential information as part of your role. This information may include personal details about patients, their families or healthcare staff. It may also include details about future plans, projects or money matters. In line with the Australian Privacy Act (1988), during your involvement (and after your involvement ends) all confidential information must be treated in the strictest confidence. You must not remove, destroy, share or discuss any personal information unless a CHESM researcher says that it is acceptable and lawful to do so.

## Employment Status

Consumer representatives are not considered to be employed by CHESM or the University of Melbourne. However, you will need to conduct your involvement activities as set out in this agreement. If you no longer want to be a consumer representative you can resign at any time. If possible, we very much hope that you will give notice and let us know why you want to stop. The research team may also cease your involvement earlier than anticipated. If this occurs, you will be given notice and informed of the reason for doing so.

You and [insert name of contact person] will [speak/meet] at various points during this project. This will be an opportunity for you to ask additional questions and give feedback on how you are finding the role. But if you have an urgent issue, please contact them earlier. Please also let us know if at any point you have any additional training or support needs.

We hope that you will enjoy being a consumer representative on this project and very much appreciate and valua your help

**Our commitment to you**

We have a dedicated research team who will;

* + work closely with you to understand and support your needs
  + ensure that meetings are set up in a way that suits you, including the location, timing (with breaks), refreshments, parking, and any necessary resources
  + provide you with learning materials and an opportunity to improve your understanding of research activities and clinical trials
  + keep you informed about the project's progress in a suitable and timely manner
  + send you a follow-up email to thank you for your time and provide you with an opportunity to give feedback on your involvement and how it was conducted
  + actively listen to and address any feedback you provide
  + be open to your ideas and suggestions on how we can make consumer involvement more worthwhile.

If you do want to take part in this role, please tell [contact person] by [phone call/replay email] before [date]. By agreeing to participate, you are accepting the responsibilities described in this document.

Before you start the role, [contact person] will contact you via telephone. This will be a chance to ask any questions and let us know any specific support needs you may have. During this call, you will also be able to discuss any changes you would like made to this role description. If changes are made, you will be given an updated version of this document with the agreed changes listed at the end under a heading “Discussed amendments to the Consumer Role Description”.

With best wishes,

[Signature;

Name;

Job title]

[if no amendments delete]  **Discussed amendments to the Consumer Role Description**

[Include this paragraph if the consumer member has refused the honorarium] You have told us that you do not want payment for the time you spend working with us on this project. We appreciate that gesture. If at any point in the future you change your mind, please speak to your contact person who will arrange for future payments (for work completed post the new agreement).

[Include any other negotiated changes to this Consumer Role Description]