MONASH
PUBLIC HEALTH
AND PREVENTIVE
MEDICINE

CONSUMER ENGAGEMENT HANDBOOK

Pharmacoepidemiology
Research Group

Contents

Welcome and Introduction

We are delighted to officially welcome you to the Consumer Engagement Group within the Pharmacoepidemiology and Real-World Evidence Group (PERG) at Monash University.

Your earlier contributions to our research on medication adherence were incredibly valuable, and we're so pleased to have you join us in this new role. As a member of the group, you will represent the voices of people with lived experience in managing chronic health conditions and using medicines. Your unique perspective will help shape the way we design, carry out, and share our research—ensuring it stays grounded in the real needs of patients and communities.

About the PharmacoEpidemiology Research Group (PERG)

PERG is an independent academic research group committed to improving how medicines are used in real life, so that healthcare can be safer, more effective, and more equitable for all.

Our work focuses on:

- Understanding how medicines are used in everyday settings
- Making sure medicines are safe and work as expected
- Identifying challenges people face in taking medicines regularly (like cost, side effects, or complexity)
- Exploring the effects of using many medicines at once (polypharmacy)
- Making sure patients' voices are heard in healthcare decisions

We work with real-world health data and bring together patients, researchers, doctors, and policymakers to answer important questions that affect healthcare policy and practice in Australia and around the world.

Our Purpose

- To be a leading centre for research into how medicines are used across the community
- To focus on areas like chronic conditions, medicine safety, adherence, and what matters most to patients
- To support partnerships between researchers and the people who use healthcare services
- To provide advice that informs health policy, government funding (like the PBS), and regulatory decisions about which medicines are used and how

Our Vision for Consumer Engagement

We believe that people with lived experience are essential partners in research. Through the Consumer Engagement Group, we aim to create research that is practical, inclusive, and meaningful. Your insights help ensure our work reflects the needs and realities of the people it is meant to serve.

Together, we will co-design studies, interpret findings, and share results in ways that are accessible and relevant to communities. We want to make sure our work leads to real change in the healthcare system, improving health outcomes, safety, and quality of life for all.

Our Mission

To make healthcare better by using real-world evidence, valuing lived experience, and working closely with consumers to create impactful, patient-centred research.

We are committed to:

- Building lasting partnerships with our consumer members
- Involving consumers across all phases of research
- Generating outcomes that drive sustainable, patient-centred improvements in healthcare

About the Consumer Engagement Group

This group serves as a collaborative forum where consumers and researchers work together to guide the research process. As a member, your contributions may include:

- Shaping research design and implementation
- Providing feedback on clarity, relevance, and accessibility
- Helping ensure our work remains respectful and impactful
- Identifying research priorities and opportunities for translation
- Co-developing new research ideas and outputs
- Advising on community engagement
- Participating in governance and decision-making
- Disseminating findings to the public
- Evaluating the impact of our research

Meeting Schedule and Format

Meetings will be convened at established intervals relevant to the specific project and level of involvement. We will send reminders and meeting details closer to the dates. Meetings will be 1–2 hours long and held either virtually via Zoom or in-person (for Melbourne based members). We encourage full attendance. If you’re unable to join a meeting, please let us know in advance.

Meeting Protocol

You’ll receive:

- An agenda and materials 2 weeks ahead
- Action items and relevant background information
- Research documents or study protocols (where applicable)

Meetings typically include:

1. Updates on ongoing projects
2. Review of study resources
3. Open discussion and feedback
4. Planning for future co-design opportunities

After each meeting, we'll share:

- Minutes and summary notes
- Relevant follow-up communication

Roles and Responsibilities

Table 1 outlines the roles and responsibilities for both the consumers and the researcher.

Consumers	Researchers
Share lived experiences related to medication use and chronic conditions	Present and explain research projects and materials
Provide feedback on documents and tools	Respond to feedback and improve relevance
Suggest research areas of interest	Clarify project goals, timelines, and expectations
Attend meetings and respond to communications	Maintain timely, respectful engagement
Request support if needed or notify of absence	Provide onboarding and technical support

Note: Roles may evolve over time, but you will be updated throughout the process.

Expectations and Group Agreement

We are committed to fostering a respectful and inclusive space. Our group values include:

- **Respect** – All voices are heard; one person speaks at a time
- **Confidentiality** – Shared information stays within the group
- **Openness** – Constructive dialogue is encouraged
- **Support** – We're here to help you engage meaningfully

A formal **Group Agreement** will be introduced and confirmed during our first meeting to guide our collaboration throughout the year.

Communication and Deadlines

Our primary communication channels are **email and phone**.

You'll be contacted:

- In advance of meetings
- When input is needed (e.g., reviewing a document or survey)
- With clear timelines for responses (especially for grant-related deadlines)

Please notify us if you're unable to complete a task or attend a meeting.

Activities You May Be Involved In

Depending on your interest and availability, you may participate in:

- Reviewing participant-facing materials (e.g., surveys, consent forms)
- Advising on inclusive recruitment strategies
- Helping shape research questions or interview guides
- Providing input on ethics and research relevance
- Assisting in sharing research results in accessible formats
- Evaluating the potential impact of research on care, policy, or outcomes

Honorarium and Recognition

Your time and insights are valued. Compensation is provided according to Monash University and national consumer engagement guidelines.

- **Standard rate:** $55/hour (depending on your role and activity)
- **Additional tasks** beyond meetings will be paid accordingly
- **Payments** are made through the Monash Disbursement Form (assistance available)

Table 2 outlines the payment structure, indicating that the level and type of activity will determine the payment amount.

Level	Type of Activity	Payment
A – Inform	Learning about consumer engagement	No payment
B – Consult	One-off feedback (e.g., reviewing documents)	$40/hour
C – Involve	Ongoing project engagement	$45/hour
D – Collaborate	Active research partner	$55/hour
E – Lead	Chairing a group, training delivery, or community leadership	$65/hour

Please contact us if you need help completing forms or submitting receipts.

Onboarding and Support

We offer the following to help you get started:

- This handbook and a copy of the Group Agreement
- Optional orientation session
- Zoom and tech support
- A dedicated contact person for assistance

Contact Us:

PERG Email: perg-sphpm@monash.edu

Privacy and Confidentiality

We respect your privacy. Any information you share will remain confidential unless you give explicit permission for it to be shared or published.

Duration:

This Consumer Engagement Group is intended to be a long-term initiative. The initial appointment will be for a period of two years, with the possibility of extension depending on the progress and needs of the project. Any decisions regarding the extension or shortening of this term will be made in consultation with the group. Please note that this handbook will be reviewed and updated annually.

Thank You

Thank you for your commitment to improving healthcare research. We are honoured to have your voice guiding our work. Together, we aim to co-create research that leads to meaningful, lasting change for individuals, families, and communities.

Let’s build research that truly matters.

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