Best Practice Guidance for Consumer Engagement in Arthritis and Musculoskeletal Research

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Arthritis and musculoskeletal research is strengthened when it meaningfully incorporates the voices and lived experiences of consumers—those directly impacted by the condition. Research and its translation become more impactful when we value diverse perspectives and work together effectively. This guidance outlines core principles and suggestions for consumer engagement (also known as consumer involvement), building on the insights from Australian arthritis and musculoskeletal consumers and the research sector and aligning with global standards including the European Alliance of Associations for Rheumatology.

Meaningful consumer engagement in research is crucial for several reasons. It ensures that research addresses the questions most important to those living with the condition, aids in communicating and translating outcomes, helps prevent unconscious bias and include diverse opinions and perspectives, and keeps the arthritis and musculoskeletal research sector aligned with international standards for consumer involvement, ensuring competitiveness for future funding.

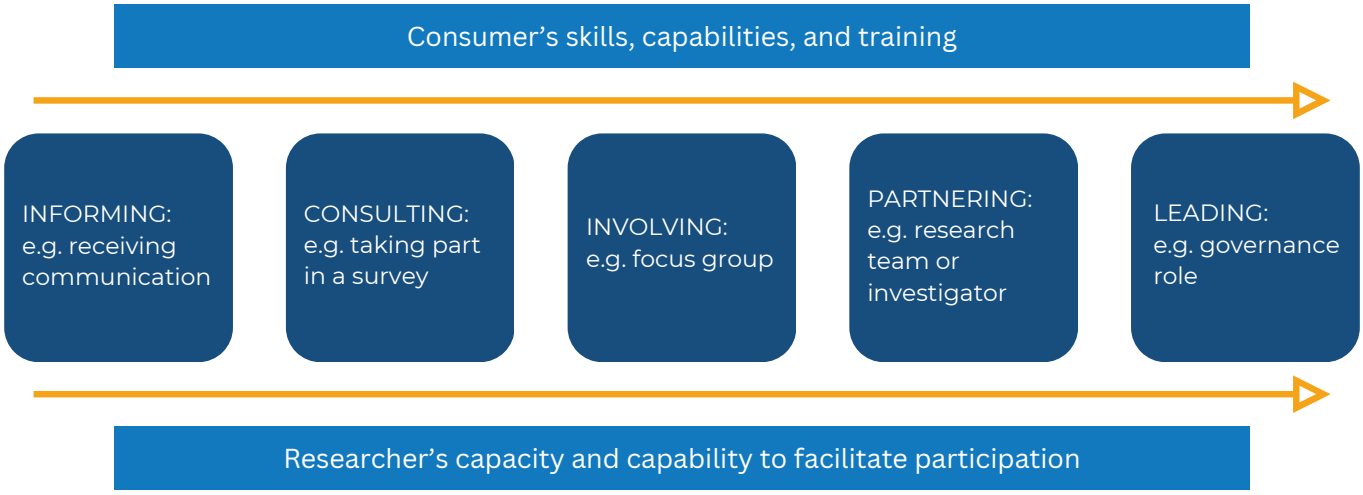
This guidance offers a framework for inclusive, transparent, and impactful consumer engagement, adaptable to the Australian research landscape.

What is consumer engagement in research?

Consumers are individuals with lived experience of a disease or condition, meaning they have been diagnosed or have received healthcare services in the past. Sometimes, consumers can also refer to carers or family members of someone diagnosed. Consumer engagement in research involves ensuring that every stage—conception, design, analysis, input, output, translation, communication, and publication—or as many as possible, reflects consumer insights.

This approach moves beyond merely involving consumers; it provides evidence that their engagement has actively shaped the research, leading to outcomes or findings that better align with consumer needs or addresses questions important to them.

Consumer engagement exists on a spectrum, representing both the consumer's capacity to contribute and the researcher's ability to support meaningful involvement. Ideally, a project will involve consumers at multiple stages along this engagement spectrum.



Consumer engagement varies significantly depending on the type of research being conducted. The ways consumers participate in discovery science, for example, will differ greatly from their involvement in translational research. Accordingly, the expectations for assessment of consumer engagement will also vary. However, it remains essential that consumers play a driving role in aspects of the research, regardless of its stage or scope.

Some examples are provided below.

Stage	Discovery or basic science	Preclinical research	Clinical research	Translational research	Program, practice or policy research
Example consumer activities	Provide early insights on areas of importance. Review research questions. Assist in communication of findings.	Provide insights on areas of importance. Review research questions. Assist in communication of findings. Assist in grant proposals.	Review research questions, protocols, documents. Assist in ethics considerations. Advise on diversity and inclusion. Provide insights on areas of importance (e.g. pain management, quality of life). Disseminate findings.	Act as an associate or chief investigator. Co-design study protocols. Advise on diversity and inclusion. Provide insights into translational barriers and opportunities. Disseminate findings.	Act as an associate or chief investigator. Co-design study protocols. Advise on diversity and inclusion. Provide insights into translational barriers and opportunities. Disseminate findings, advocate for adoption.

Meaningful Consumer Engagement

To show that consumer engagement has led to meaningful consumer input, it is crucial to document when and how consumers were involved, including the engagement activities and considerations for diversity, inclusion, and accessibility. It's equally important to clearly explain how this engagement influenced the project's design or approach—what was changed, reconsidered, adapted, or included as a result of consumer input. This can be captured through simple change logs, a consumer engagement or impact statement, or even designed directly by consumers themselves, empowering them to demonstrate their contributions to the research.

Remuneration and Recognition

Considering consumer remuneration is vital when planning research projects. Arthritis Australia advocates for offering remuneration whenever possible while also recognising the need for flexibility to accommodate consumer preferences and the realities of research projects.

Recommended Approach for Researchers

Researchers should strive to incorporate allowances for consumer remuneration into project budgets. The type and level of remuneration should reflect the consumer's contribution and be determined in consultation with them. For instance:

- Low-Intensity activities: Consumers participating in surveys or short focus groups may be willing to volunteer their time, or may do so for a small token of appreciation.
- High-intensity engagements: Consumers involved as co-investigators or partners may require formal remuneration and additional accommodations due to time spent away from paid employment or care duties.

Appropriate forms of remuneration and recognition may include:

- Hourly rates: Standard compensation for time at a fixed and mutually agreed rate.
- Tokens of appreciation: One-off gifts, such as gift cards.
- Expense reimbursement: Coverage for travel and related costs.
- Accommodations: Accessibility support such as assistance with childcare.

Acknowledge Contributions

Researchers should also meaningfully acknowledge consumer contribution in a way that is agreed upon consultation with consumers, especially regarding any privacy concerns when naming consumers. Examples of recognition can include:

- Formal listing as a co-investigator or co-author in the study.
- Acknowledgment in publications.
- Letters of thanks or of recommendation.
- Follow-up meetings to gather feedback and acknowledge contributions.

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Core Values and Principles

The following principles guide our approach to consumer engagement, emphasizing the importance of diversity, accountability, collaboration, and empowerment.

1. Diversity and Inclusion

- **Respect for diversity:** Value the unique perspectives of individuals with lived experience of arthritis and musculoskeletal conditions, acknowledging the breadth of their contributions.
- **First Peoples' leadership:** Recognise the self-determination of First Peoples and incorporate their knowledge and contributions in research.
- **Lived experience as expertise:** Consumers and carers bring valuable insights, and fostering respectful debate is crucial to advancing research.
- **Inclusive partnerships:** Ensure consumer engagement includes diverse perspectives across cultural, socioeconomic, and demographic backgrounds.
- **Community of practice:** Cultivate networks among consumers with lived experience to support ongoing dialogue and shared learning.

2. Accountability and Transparency

- **Involvement at all levels:** Engage consumers in management, leadership, and decision-making roles within research programs.
- **Clear communication:** Maintain respectful, accessible, and transparent communication channels with consumers to foster trust and collaboration.
- **Continuous improvement:** Regularly assess and refine consumer engagement approaches based on feedback and evolving health needs.

- **Resource stewardship:** Ensure sustainable use of resources, prioritising quality and impactful outcomes in consumer-driven research.
- **Responsiveness:** Create mechanisms to capture successes and opportunities for improvement, ensuring ongoing consumer involvement.

3. Collaboration

- **Early-stage engagement:** Engage consumers from the outset of the research process, allowing their perspectives to shape priorities, design, and methodology.
- **Stakeholder partnerships:** Collaborate with a broad range of stakeholders, including clinicians, policymakers, and the public, to maximise collective impact.

4. Empowerment and Capacity Building

- **Resource provision:** Equip consumers with the necessary tools, education, and support to contribute meaningfully to research.
- **Researcher development:** Provide training opportunities for researchers to learn effective methods for consumer collaboration.
- **Long-term relationships:** Encourage sustained engagement between consumers and researchers to build trust and deepen collaboration over time.

Guidance for Best Practice Consumer Engagement in Arthritis and Musculoskeletal Research:

1. Defining Consumer Roles: Clearly define consumer roles in research, ensuring they are recognised as integral contributors. Consumers should be treated as co-designers or investigators, rather than passive participants. A diverse range of strength-based engagement opportunities should be offered that recognises consumer's varying capacities and desires to engage.

2. Remuneration and Support: Provide appropriate and flexible remuneration and support for consumer involvement, including training and resources, to enable equitable participation. Flexibility in engagement models should also be offered to accommodate health conditions and diverse life circumstances.

3. Meaningful Involvement in Research Design:

- **Early involvement:** Consumers should be engaged from the beginning of the grant application process, not as an afterthought.
- **Clear expectations:** Ensure consumers understand their role and how their contributions shape the research, with regular feedback and updates.
- **Demonstrate impact:** Record and provide evidence of meaningful consumer input, including where protocols or designs have changed in response to consumer feedback.

4. Diverse Representation:

- **Diversity:** Make concerted efforts to include consumers with diverse characteristics and life experiences, including different genders, ages, levels of education and socioeconomic background.

- **Cultural and linguistic diversity:** Make concerted efforts to include consumers from diverse cultural backgrounds. Consider appropriate tools and support such as interpreters when needed and consider the barriers faced by non-English speaking communities.
- **Paediatric engagement:** Ensure the engagement of children is meaningful, not limited to their parents' or guardians' perspectives.

5. Training and Mentorship:

- **Upskill consumers and researchers:** Offer ongoing education to both consumers and researchers to enhance their collaboration. Training programs should cover the roles and responsibilities in the research process, and consumers should be supported in navigating complex research environments.
- **Mentorship models:** Facilitate mentorship between experienced consumers and researchers, allowing for knowledge sharing and capacity building.

6. Evaluation and Impact:

- Consumer involvement in evaluation: Develop metrics for assessing the impact of consumer engagement, including qualitative feedback from consumers on their lived experience and contribution.
- Long-term impact: Distinguish between short-term outcomes and long-term impact, acknowledging knowledge gains as valuable outcomes, particularly in pre-clinical research.

7. Tailoring Communication: Use diverse communication styles that suit different consumer needs and consider offering topics or questions ahead of time to allow for better preparation.

8. **Incorporating Rural and Remote Communities:** Address the barriers to participation for rural and remote communities and develop strategies to ensure their inclusion such as travel for in-person meetings.

9. **Continuous Improvement:** Seek feedback and input from consumers involved in research to constantly seek to improve meaningful engagement methods. Revisit guidance and positions regularly in consultation and collaboration with consumers and the research sector, including review of international guidelines and evidence regarding consumer involvement in research to seek to always uphold best practice.

Guidance for requesting consumer involvement from consumer organisations

When planning a project, it is essential to consider the involvement of consumers for their diverse skills, knowledge, and lived experience. Arthritis Australia, and other organisations connected to people with a lived experience, can assist in engaging consumers with appropriate projects through its networks. These consumers bring valuable expertise that enhances the relevance and impact of your work by offering perspectives grounded in personal experience, an understanding of challenges and issues faced by those with arthritis and musculoskeletal conditions, and familiarity with research, policy and advocacy priorities. Their professional and personal backgrounds further enrich their contributions, making them an asset to projects, studies, and committees aimed at improving outcomes for people living with arthritis and musculoskeletal conditions.

To ensure that consumer engagement is meaningful and not tokenistic, researchers should adhere to the principles outlined in this guidance, which includes a focus on respect, accessibility, diversity, inclusion, communication and collaboration. Early involvement of consumers is crucial, so we strongly encourage you to request assistance from Arthritis Australia as early as possible to facilitate the appropriate matching of consumer(s) to your project in a timely manner.

To acknowledge the significant time and resources invested by Arthritis Australia and similar organisations in supporting consumers through training, mentoring, skill-matching, and other activities, it is appropriate to allocate a portion of the budget to these organisations in recognition of their efforts. This consideration is particularly relevant for larger external grant funding opportunities. Collaborating with the relevant consumer organisation(s) is essential to determine appropriate budget allocations that align with the consumer engagement being sought.

For more information on how an Arthritis Australia Consumer Representative can collaborate with you, please contact Arthritis Australia directly.

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