



Global Healthy Living Foundation Australia
Tower 1, Level 2,
495 Victoria Avenue, Chatswood, NSW 2067
ABN: 82 609 039 134
+61 439 600 312
info@ghlf.org.au
www.ghlf.org.au



Global Healthy Living Foundation Australia and CreakyJoints Australia

Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research

To the Consumer Statement Advisory Committee,

Thank you for the opportunity to provide input into the Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research. These comments are submitted by Global Healthy Living Foundation Australia (GHLF Australia) and CreakyJoints Australia on behalf of our patient communities.

Our submission includes an introduction to our organisation and our responses to questions 16 to 32 of your Position Paper.

About our global organisation

CreakyJoints was co-founded in the US in 1999 by arthritis patient and advocate Seth Ginsberg (diagnosed with spondyloarthropathy at age 13) and social entrepreneur Louis Tharp. In 2007, the Global Healthy Living Foundation was established as the umbrella organisation.

GHLF advocates for improved access to healthcare in many countries both locally and nationally, amplifying education and awareness efforts within its social media framework for people living with chronic conditions including inflammatory arthritis, psoriasis, osteoporosis, alopecia areata and many others.

Central to this advocacy is GHLF's commitment to educating the community about the importance of early diagnosis and intervention, optimal condition management and long-term lifestyle improvements for improved health outcomes.

About Global Healthy Living Foundation Australia and CreakyJoints Australia

Established in 2014 and incorporated in 2016, [Global Healthy Living Foundation Australia \(GHLF Australia\)](#) is the parent organisation of [CreakyJoints Australia](#), and both are proud to be part of GHLF. Founded in 2015, CreakyJoints Australia is a leading source of information for Australians living with the many forms of arthritis and related conditions, along with their families.

Drawing on nearly two decades of foundational knowledge, success and the reputation of GHLF and CreakyJoints, GHLF Australia and CreakyJoints Australia aim to localise, mobilise and engage Australian health consumers and to provide education, advocacy, research and co-design opportunities for better health outcomes. (For this submission, our use of the term “health consumers” includes patients and those who care for them along with people who use health services more broadly.)

As an organisation, we participate in a range of health advocacy activities, including writing submissions for new/updated treatments to be considered by the Pharmaceutical Benefits Advisory Committee

(PBAC), joining other stakeholders to promote relevant health awareness campaigns and providing input for health research projects.

We provide personalised opportunities for Australian health consumers to:

- Advocate for important state and national health care policies that directly impact their access to care via providing us with comments for submissions and sharing their stories for awareness campaigns.
- Have their voices heard through personal stories and comments published by our organisation across our media platforms and in content published by other parties such as Rheumatology Republic.
- Be directly involved in research and health policy design via opportunities we share on our platforms.

Essential to our work as a consumer organisation is our regular engagement with representatives from industry bodies (such as the Australian Rheumatology Association and Arthritis Australia) and pharmaceutical companies. This allows us to receive important information from these parties and to share our expert knowledge of our health consumer community, their needs and their opinions with these parties. We act as an effective intermediary between pharmaceutical companies and the consumer communities they serve.

Our responses to questions 16 to 32 of the Position Paper.

Stakeholder Engagement and Consultation

16. What parts of the current Statement have or have not worked well?

We are not familiar with the implementation of the 2016 Statement so we have no response to this question.

17. Why is consumer and community involvement in research valuable? And,

18. Why does consumer and community involvement in research matter to you?

Our organisation has always advocated that consumer-centred care is a top priority across all healthcare systems. It is at the core of everything we do. This is evident in the following statements from our CreakyJoints Australia Patient Charter:

- Our experience is at the heart of medicine; thus, we must be at the centre of all medical decision making.
- We can empower ourselves and others to make our voices heard if we are provided with the right education and tools.
- Elected officials, drug manufacturers and all associated healthcare professionals must make it their goal to ensure patients are central to all decisions.
- We must be treated with dignity, transparency and respect by everyone involved in the healthcare process.

We believe that any research project that aims to benefit cohorts of health consumers should be co-designed with representatives of these same cohorts. Representatives with lived experience of the conditions and issues the research aims to address can share their understanding of what such

conditions *feel* like, how they are managed each day and the mental, emotional and social effects of the symptoms of and treatments for these conditions.

For example, researchers exploring ways to improve access to health services in specific areas need to talk to the people about the barriers they face accessing those services. The researchers could likely list the most obvious barriers but may have never even suspected others. When consumers share these barriers, their comments and suggestions can be used change how the services are accessed more effectively.

Value statement

19. What overarching values are essential to include in the value statement of the revised Consumer Statement, and why? And,

20. The values that underpin the 2016 Statement are ‘shared understanding, respect and commitment’. How might this be strengthened and improved in the revised Consumer Statement? And,

21. Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the revised Consumer Statement?

While we believe the values in the 2016 Statement are important, they do not adequately reflect the broader values of the multidisciplinary partnerships that exist in research today. Therefore, we believe *all* the suggested values listed in Q21 should be included in the revised Statement.

Better practice principles for consumer and community involvement in research

22. What do you regard as the most important principles that should be included in the revised Consumer Statement?

We believe all the principles listed in the Position Paper are important. However, we have worded our suggested principles to better reflect our organisation’s values:

- Consumers and community members should be involved at all stages of research.
- Consumers and community members should represent a broad cross-section of society reflecting the diversity of the community they represent.
- All research parties should be treated with equal respect.
- The lived experience of consumers and the expertise of community members should be considered equal to the experience of other parties involved.
- Consumers and community members involved in research should be fairly remunerated in proportion to the time and effort they contribute to the project.
- All parties should act honestly in the development, undertaking and reporting of research, including presenting information truthfully and accurately in proposing, conducting and reporting research.
- Research should be undertaken with respect to the wider community and the environment.

Roles and responsibilities of consumers and community members

23. What roles and responsibilities for consumers and community members should be included in the revised Consumer Statement?

We support maintaining the list of roles and responsibilities of consumers and community members included in the 2016 Statement.

Roles and responsibilities of researchers

24. What roles and responsibilities for researchers should be included in the revised Consumer Statement? And,

25. Should involvement of consumers and community representatives be an expectation of research? And,

26. Is there an ethical imperative to involve consumers and community representatives in research?

We believe there is an ethical imperative to involve consumers and community members in research and this should be an expectation of all health research. We believe the Standard should include the following roles and responsibilities of researchers.

- Research institutions, researchers, consumers and community members all have a responsibility to consider the best person(s) for a particular role or task, taking into consideration issues such as age, gender, disability, cultural background and experience, health system experience and availability.
- Researchers should consider consumers and community members as equal members of the group or team.
- Researchers should consider how they will involve consumers and community members in the development, conduct and communication of their research.
- Researchers with experience in consumer involvement should be encouraged to champion the benefits of consumer engagement and advocate to improve the level of understanding amongst their peers.
- Researchers and consumers should be encouraged to learn from each other's knowledge and experience and to undertake professional development together as relevant.

Roles and responsibilities of research institutions

27. What roles and responsibilities for research institutions should be included in the revised Consumer Statement?

- Research institutions, researchers, consumers and community members all have a responsibility to consider the best person(s) for a particular role or task, taking into consideration issues such as age, gender, disability, cultural background and experience, health system experience and availability.
- Research institutions should commit to the involvement of consumers and community members in various levels of research activity.

- Governance structures, including boards, committees, policies and procedures, should incorporate the principles, values and elements for effective consumer participation.
- Research institutions should seek feedback from researchers and consumer and community members involved in research and evaluate processes and outcomes accordingly.
- Research institutions should offer researchers, consumers and community members with education and training in best practice research collaboration processes.

Roles and responsibilities of funders

28. What roles and responsibilities for research funders should be included in the revised Consumer Statement? And,

29. Should funders of research mandate the involvement of consumer and community representatives in the research they fund?

We believe funders of research should mandate the involvement of consumer and community representatives in the research they fund. We also believe the following roles and responsibilities for research funders should be included in the revised Statement.

- Governance structures, including boards, committees, policies and procedures should incorporate the principles, values and elements for effective consumer participation.
- Through policy guidance and other processes, research funders should set expectations for how people consumers and community members should be involved in research projects.
- Research funders can involve consumers in reviewing funding applications, setting priorities, identifying research topics, designing and developing programs and supporting funded projects.

Implementing the revised Statement

30. How should researchers involve consumers and community representatives in their research? And,

31. What issues should be considered once the revised Consumer Statement has been finalised and published?

Researchers should involve consumers and community members in their research as soon as they decide to seek funding for their research. They should do so by seeking the same cohort of consumers and community members that would be affected by the outcomes of the research. Researchers should then get input from this group regarding the need for the research and the appropriate ways to conduct it within the parameters of the Revised Statement.

Permission to publish

32. Do you agree to your submission to this survey being published?

Yes, we give permission for this submission to be published.