Dementia Alliance International

Submission to the NHMRC: Review of the Consumer Involvement Statement 2016

Submission from: Dementia Alliance International (DAI)

Submitted by: Ms. Theresa Flavin, Human Rights Advisor, on behalf of the Board of Directors and Australian Membership of people with dementia.

Submitted on:

Submission to the NHMRC in relation to the revised Consumer Involvement Statement 2016

About Dementia Alliance International

Dementia Alliance International (DAI) is a registered international charity, whose mission is to provide support globally including in Australia for people with dementia, and local, national and global advocacy for timely and accurate diagnosis, improved post diagnostic support and services including access to rehabilitation, to ensure a higher quality of life and independence for longer. DAI campaigns for the human rights of all people living with dementia, in community and residential care and for equitable inclusion in the community, and for dementia to be supported as a condition causing disability (WHO:2024). DAI is the global voice *of* people with dementia, whose vision is a world where all people are valued and included.

Notably, for this submission, Dementia Alliance International is the only NGO exclusively representing people diagnosed with any type or cause of dementia of any age in Australia, who are also people with disabilities with equal human rights and disability rights to all others including access to the Convention on the Rights of Persons with Disabilities (CRPD) and the Optional Protocol to the Convention Against Torture (OPCAT).

DAI is the only organisation representing people living with dementia exclusively in Australia and globally; it is the only independent and autonomous voice of people of any age, diagnosed with any type of dementia in Australia, and globally.

Opening Remarks

Language Conventions

Much progress has been made in understanding the power of language in influencing attitudes, beliefs and behaviours across the community. This power is magnified when the language comes from our government funded organisations. Language presented in the Statement and associated guidance including internal policies and procedures and associated materials will have a strong influence on the wider community including researchers, research participants, research organisations, and other associated stakeholders in how the involvement of living experience, NGO's Carers and other interested parties is perceived, valued, respected and operationalised.

In the context of research, the confabulation of dementia with ageing is outdated and inappropriate, and inaccurate. It is well known and acknowledged across the world that dementia is a disability, and not a 'normal' part of ageing. Childhood dementia and younger onset dementia (YOD) in particular are a poor fit when grouped with age related research. DAI contend strongly that dementia research be decoupled from ageing research. They are not the same and are not interchangeable. Continuation of the present model continues and perpetrates the stigma that dementia is a product of ageing, and that it is inevitable. This myth needs disrupting. The model also subjects people living with dementia to the further stigma of being perceived through an ageist lens, and is out of scope of the requirements of the Convention for the Rights of Persons with a Disability (CRPD).

DAI advocates for a high-level discussion of language conventions used in the NHMRC particularly in the context of dementia research, as we feel that this is an important pillar in changing attitudes towards a rights based, person led and partnership based collegiate model of research into the future.

Definitions

The term consumer is a contentious one, as it implies that people in the community have some choice in the health and medical research being undertaken. The term is often misunderstood and is often conflated with the term stakeholders more generally. This was clear in the grant assessment process where one of the assessor's was very certain that the consumers would actually be clinicians.

Another unfortunate and unintended outcome of the term consumer is that almost anyone in the community can be considered a consumer. Again, while the concept of community and public participation in research is useful, we have the unhelpful and misleading spectre of well-meaning and often self-appointed advocates speaking on behalf of the cohort being researched, in this case older people and people living with dementia.

Hopefully we can all agree, there are a number of types of 'consumers' involved in research, but as discussed, we are not interchangeable. DAI advocates for the removal of the term consumer, and for the purposes of the statement title - community involvement may serve. However, for the purposes of guidance material, the term community will require definition, as there are a number of important differences in the subcategories of lived/living experience (contemporaneous), care partners and family supporters (past and current) professional advocates (individuals), government funded professional advocacy organisation representatives, other professional advocacy organisation representatives and various other proxies.

DAI welcomes further, and importantly, direct involvement in all future consultations in relation to the genuine need for contemporaneous living experience in research and ensuring that this is not interchangeable with the other sub types of consumers noted above, and that this involvement is not diluted by representations by other organisations and individuals.

Other organisations do not necessarily represent us, nor do they speak for us. We further refer to the inadvertent harm to both the people with living experience by grouping us with other stakeholders without appropriate training or support. There is much work to be done to ensure the physical, psychological and emotional safety of people involved in the research process at all levels.

Title of the Statement

The current title describes the 'involvement' of 'consumers', however the term and the concept of 'involvement' is obsolete. In 2024 the Australian Community have increased awareness of their right to participation in research at all levels.

This awareness doesn't seem to be reflected by the NHMRC and the concept of keeping the voices of living experience at arm's length with a minority voice, or a voice provided for us by others purportedly representing us', and in a place of a power vacuum is no longer acceptable, particularly for people living with a disability due to dementia.

This passive, or perhaps purposed exclusion of the autonomous voice of living experience of dementia perpetuates the self-referencing in the research community, and greatly limits the value of intellectual and cognitive diversity, which is critical for innovation, creativity, veracity, fidelity and utility of research.

Recommendation 1

DAI recommend that the NHMRC consider exactly what they want to achieve in bringing the voice of lived/living experience into the research cycle.

If the objective of the exercise is to provide the optics of partnership to the Australian Community, then this should be openly disclosed.

However if the NHMRC are genuinely interested in working in a manner of true, safe, trauma informed and robust collaboration with the people they wish to research, DAI suggest “Embedding lived/living experience and community involvement in Health and Medical Research” as an alternative title that provides clarity and Leadership to the research community.

While it is understandable that the first version of the statement ‘encourages’ participation of people with lived/living experience, DAI believes that now is a good time for the NHMRC to updagte the statement to the tone of ‘expectation’ of quality partnerships between researchers and their community of interest.

Rationale

It was rather demoralising for people with dementia living in the community to see the questionnaire from the NHMRC still asking for the justification of participation of people with the lived/living experience in the research process.

This importance has already been widely researched and is tacitly embedded in many government policies at both State and Federal level, as well as in our International Obligations through the Convention for the Rights of Persons with a Disability (CRPD) which is of particular note in the context of Dementia Research.

Funding of research grant applications, is also often dependent on the inclusion of people with the lived/living experience of dementia.

Recommendation 2:

DAI contend that a useful example of the quality of involvement in the research cycle expected in the community can be found in the following framework, https://www.nswmentalhealthcommission.com.au/report/lived-experience-framework-nsw

Value Statement Recommendation 3:

DAI recommends that values include:

- Safety,
- Fidelity,
- Veracity,
- Ethical,
- Professional, and
- Risk aware.

Better Practice Principles

It is pleasing to see that the NHMRC are revising the statement, as the current version seems to present the concept of partnership with people with the lived/living experience of dementia almost as an optional extra to the research cycle.

The sense that many in the community get when they/we read the statement is that researchers can choose the level of involvement, and that any form of lived/living experience bolted onto a research project is acceptable to the NHMRC.

We believe that the current messaging implies that better practice is something to be undertaken by researchers from a place of personal goodwill or pity, and is a form of paternalism and benevolent othering.

Recommendation 4:

DAI recommends that consideration be given to the following suggestions:

Principles to include

Accessibility, diversity and equitable inclusion - including cognitive and intellectual diversity across the research team.

DAI contend that intellectual diversity is not interchangeable with cognitive diversity.

Intellectual diversity is when a non-researcher is given a place of equal power to the researcher, and can interrupt a self-referencing cycle which is common in the research community. Often this diversity results in creativity and improved outcomes. DAI reference the success of 'equal representation' on the boards of industry non-profit superannuation funds which typically provide better returns than the Boards comprised of people with similar professional backgrounds and levels of education regardless of lived/living experience.

Cognitive diversity also interrupts the self-referencing cycle, but in addition, it challenges the researchers to produce accessible materials, and to communicate the project in plain English.

This challenge provides researchers the opportunity to deepen their understanding of what they are attempting to achieve and receive the benefit of understanding barriers and opportunities from the perspective of the ultimate end user - the person in the community. This opportunity for reflection, also embeds true accessibility into the research cycle.

It is commonly understood that if a researcher cannot adequately explain their research, then they may not fully understand all of the consequences both intended and unintended.

Taking this into consideration in the writing of grant applications would further enhance the clarity of exactly what community members are contributing to through their involvement and give true opportunity for genuine consent to the research involvement by the community, as presently this can be somewhat vague as the verbal description from the researcher is often quite different to what we read (i.e. if people with dementia are offered the opportunity) the grant application that is finally submitted.

Recommendation 5:

DAI further recommend that supported decision making principles (facilitated through accessible documentation as per above) are embedded into the research cycle, in particular with priority populations including people with cognitive disabilities due to dementia.

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Recommendation 6:

Dai finally recommend that the principles include:

Adequately planned, resourced, risk aware, supportive and safe processes in the involvement of the community in research.

DAI recommend that at a minimum standard, that research projects embed https://www.iso.org/iso-31000-risk-management.html/ to ensure safety of the researchers, research participants and the community involved with the research, in particular a 'pandemic plan', a 'continuity plan' particular in the context of dementia which is a progressive disease.

Many projects are planned to spread over 5 years, and when recruiting people living with dementia, this is a difficult time frame to commit to; if the disease progresses to the point that someone has to step aside, plans must be in place to ensure continuity of involvement with adequate accessible briefing materials for the handover.

Roles

Recommendation 7:

DAI recommends end to end embedded participation of lived/living experience of people with dementia including at the translation, interpretation, accessibility, utility to the community as well as funding to allow them to co-present at webinars, symposiums, conferences and any other events highlighting the research.

Research Institutions

DAI contend that the research institutions themselves must step into an elevated role in ensuring that genuine and safe living experience is embedded at every level of the research process, including within the research institution themselves.

Further to this, it is vital that ethics committee reference material be mapped to the lived experience framework (hopefully to be developed by every research institution) to ensure harmonisation of expectations. IT is currently somewhat inverted to see the care and diligence of ethics committees ensuring the dignity and safety of research participants (at a high level) that is not reflected in the operationalisation of the research, or in the involvement of the researched subjects lived/living experience contribution to the project, which has no clear oversight mechanism.

Recommendation 8:

DAI recommend at a minimum that:

Research institutions develop adequate risk management strategies and risk management plans to the quality of ISO3100 that are mapped to the individual ‘consumer engagement plan’ of every research project

Recommendation 9:

Research institutions develop and roll out an accessibility plan to address all the current barriers in place that impede community access to the research process.

People living with dementia for example face difficulties with complex reimbursement processes, parking and general access to campus, inaccessible locations and IT support for complex online security systems.

Another very concerning matter is that of people living with dementia travelling with or without support to various locations. We are not typically provided with a detailed or safe travel plan. Locations are often difficult to access, with parking and security barriers resulting in confusion, fear, feelings of inadequacy and inferiority.

DAI believe that it is only a matter of time before someone with the lived/living experience of dementia goes missing in their unpaid efforts to contribute meaningfully to the research and dementia community.

Recommendation 10:

Research institutions must ensure that any proposed research project send their ISO31000 compliant ‘community involvement risk assessment and risk management plan to the ethics committee for review.

Recommendation 11:

Research institutions must also ensure that a modest reserve fund is created to ensure remuneration for people in the community to participate properly in the grant application preparation process. The current situation of researchers needing to rely on the goodwill of others is conflicting for them and makes it difficult for young researchers to attract a competitive level of community involvement when they don’t have equal access to experienced researchers who have established relationships.

Overall NHMRC Operations

While this is out of scope in the review of the Statement, DAI note that the current operating model of community involvement in the grant review process is unsatisfactory.

Community engagement is passively mandated but there is no evidence of any systematic review of grant applications to ensure even a minimum standard of consistency. People in the community who become involved in research at any level have no consistency of expectations. Furthermore, grant reviewers from the community must pick carefully through often quite inaccessible documents to try to understand how exactly the research team plans to involve the community through the life of the project.

From personal experience as a grant reviewer, I found the guidance was poor, particularly for those of us without a research background. There were fourl data points in the guidance, but two of those were duplicates - so we were limited to comments around only 3 stages of the cycle.

In practice, I found that the narrative was not mapped to the risk plan, the KPI's of the project or indeed, the budget. I was surprised that grant applications that did not actually make sense regarding their community involvement were in the final round. This indicated that the community involvement was not material to the final funding decision, and this was also reflected in the scoring of the other researchers.

Recommendation 12:

Training of Reviewers

It is apparent that there are varying levels of understanding of the meaning of community involvement across the research community.

This was apparent in the strongly worded argument that the community involvement should really be understood as the practitioners using any tool developed - as opposed to the people the tool would be used upon.

This is somewhat demoralising for people with the lived/living experience of dementia. Improved guidance through uplifted definitions of living experience, consumers and advocates etc may address this going forward.

Recommendation 13:

Priority Populations

DAI suggests that neurodiversity and cognitive diversity become priority populations.

Broader context of community involvement and living experience in the research cycle.

In the past, researchers tended to view their participants as something of a passive resource - available for data mining, with little else to do but contribute their pain and/or experiences for the greater good - public interest.

While progress has been made both in Australia and internationally to address this power imbalance, there is still much work to do. DAI have accounts of numerous encounters with researchers who still perceive ‘co-design’ to be something of a social construct, in effect, a nuisance impediment to ‘hard science’.

Extraordinary levels of perceived ‘academic hubris’, ‘paternalistic ethics that do not map to operational practice’, inconsistency of practice and frank disingenuous practice have been reported.

Recommendation 14:

DAI recommends that each area of the NHMRC employs a ‘living experience consultant’ or a ‘living experience group’ to advise on the operationalisation of living experience involvement across the scope of the NHMRC.

Grant Review Process

As previously noted, the ‘consumer involvement’ aspect of the grant review process is potentially not working as intended. The person from the community is expected to read broadly inaccessible worded lengthy document, with little guidance and speak for three minutes on the quality of the consumer involvement.

There is no opportunity to comment on the utility of the research project from the living experience perspective, or to rebut misunderstanding of other researchers, potentially outside of the field.

Recommendation 15:

DAI looks forward to contributing to the review of NHMRC processes in relation to community involvement in research, with a view to the safety of people living with dementia, providing input into potential upskilling of researchers in communicating with people living with disability, networking for researchers, mentoring programs, and development of basic understanding of the importance of risk management in the context of research more broadly.

DAI also advocate for funding applications to accommodate mental and physical supports required to include people living with dementia in the research cycle in the same manner as any other disabled priority population.

We look forward to working with your team, on the issues we have raised.

Thank you,

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Prepared and submitted on behalf of the Board of Directors and Members

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