

**ECCV Submission  
to the  
National Health and Medical Research Council Review  
of the  
Statement on Consumer Involvement in Health and Medical Research**

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**September 2014**

The Ethnic Communities' Council of Victoria Inc. (ECCV) is the Voice of Multicultural Victoria. As the peak body for ethnic and multicultural organisations in Victoria, we are proud to have been the key advocate for culturally diverse communities in Victoria since 1974. For 40 years we have been the link between multicultural communities, government and the wider community.

The ECCV is a member driven organization that advocates and lobbies all levels of government on behalf of multicultural communities in areas such as human rights, access and equity, service improvement, addressing racism and discrimination, community harmony, employment, education and training, health and community services, disability, child protection, law and justice, and arts and culture. We advocate on those issues that are of most concern to our members

**The aim of revising the Statement is to improve language and accessibility. Are there further improvements that should be considered?**

The Ethnic Communities' Council of Victoria (ECCV) applauds the efforts of the Working Committee to revise the Statement on Participation and the resulting document is shorter and more concise than the one developed in 2001. It also commends the achievements of the Committee to use simple and less ambiguous language when drafting the new Statement and therefore improving its readability and comprehension. However, ECCV suggests several small modifications to enhance the Statement.

**1. Inclusion of case studies**

ECCV proposes that case studies should be included in the section '*Elements for consumer and community involvement*' to illustrate the effective involvement of consumer and community in medical research. This will help readers to conceptualise how an effective involvement of consumer and community in health research works.

**2. Minority groups (second dot point – page 12)**

It is recommended that the expression 'minority groups' be removed and the sentence be rewritten as follows – 'ways to reach vulnerable and disadvantaged groups'. In general, the term 'minority' is used when describing people identified on religious, cultural, linguistic, ethnic and sexual orientation grounds. The term 'disadvantaged' is broader and also encompasses people who cannot participate in medical research because of their health status, financial situation, age, education, gender and class.

**Recommendation 1**

That case studies be included in the Statement to help stakeholders understand its practicality.

**Recommendation 2**

That the word 'minority' be replaced with the word 'disadvantaged'.

**The draft revised Statement contains five definitions: Community, Consumer, Consumer Representative, Involvement and Stakeholders (refer page 4). Are the definitions satisfactory? Are additional definitions required?**

ECCV is satisfied with the five definitions proposed in the revised Statement. However, it suggests that additional definitions outlining the role of consumer in medical research should be included in the Statement. Cancer Australia has developed a number of definitions concerning the role of consumer in medical research and cultural engagement in its report - *National Framework for Consumer Involvement in Cancer Control*. The Working Committee should consider inserting these definitions in the Statement. The defined terms are as follows – personal engagement, the advocate, the advisor, the expert, the partner and cultural engagement.

**Recommendation 3**

That additional definitions be included in the Statement.

**The draft revised Statement outlines the Key Elements that underpin effective involvement and Levels of Involvement (refer page 5). You are invited to comment on the identified Key Elements and Levels of Involvement.**

ECCV welcomes the range of models mentioned in the draft document and believes that they empower consumers and communities to have a greater say in medical research. However, it recommends that the Statement should include provision to dealing with any risks or issues that may arise from the partnership's implementation. This could take the form of dispute resolution mechanisms consisting of counselling, mediation and arbitration.

**Recommendation 4**

That a problem-solving process be established to resolve any disputes that may occur between researchers and consumer or community.

**The draft revised Statement includes information about how the Statement should be put into practice (refer page 5). You are invited to comment on this section, including whether additional information should be added.**

ECCV notices that steps suggested to put the Statement into practice do not take into account cultural competence in the consumer and community involvement in medical research. Therefore, ECCV

proposes that research institutions and researchers should consider cultural norms, practices, traditions, intra-familial relationships and other culturally appropriate values when partnering with multicultural communities to conduct medical research.

**Recommendation 5**

That researches are offered cultural competence training and beliefs and values be taken into account when involving people from culturally diverse communities in medical research.

**NHMRC is considering placing Appendix 4: Useful Resources on our website so that stakeholders can access examples of consumer and community involvement in health and medical research. Please tell us about exemplars that should be included.**

ECCV proposes that stakeholders should be made aware of the following example of consumer and community involvement in medical research. This example consists of involving communities in health research through small grant allocation and applying community-based participatory research approach. ECCV invites the Working Committee to visit the following links for more information about the use of small grant program to involve consumer and community in medical research and the community-based participatory research approach.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2885839/>

[http://obssr.od.nih.gov/scientific\\_areas/methodology/community\\_based\\_participatory\\_research/](http://obssr.od.nih.gov/scientific_areas/methodology/community_based_participatory_research/)

**Recommendation 6**

That information on community-based participatory research approach and the case study on the use of small grant program be placed on the website of National Health and Medical Research Council.

For more information, please contact Me'ad Assan, Policy Officer on 03 9349 4122 or [massan@eccv.org.au](mailto:massan@eccv.org.au)