

## **Submission to Draft Statement on Consumer Involvement in Health and Medical Research**

The draft *Statement on Consumer Involvement in Health and Medical Research* was jointly written by the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia, and is an update of a version released in 2002, *Statement on Consumer and Community Participation in Health and Medical Research* and its companion *Summary Statement*. The statement provides advice on how institutions and researchers can ensure their research is as inclusive as possible of consumers, as well as informing consumers of how they can become more involved in research.

The following submission to the public consultation on the draft *Statement on Consumer Involvement in Health and Medical Research* is provided by cohealth, Australia's newest, and one of the country's largest not for profit community health organisations. cohealth was established 1 May 2014, through the merge of three leading community health services – North Yarra Community Health, Doutta Galla Community Health, and Western Region Health Centre. cohealth provides vital local health and support services including health services, to people in Melbourne's northern, western and inner northern suburbs.

The draft Statement and supporting documentation can be found at [http://consultations.nhmrc.gov.au/public\\_consultations/consumer\\_involvement](http://consultations.nhmrc.gov.au/public_consultations/consumer_involvement)

### **1. Language and Accessibility of the Statement**

cohealth has a focus on working with the most marginalised and vulnerable. This has been a lens through which we have viewed the Statement, aiming to highlight issues of accessibility, participation and equity.

Using the Microsoft Word readability tool, the substantive part of the Statement (not including appendices) has a Flesch-Kincaid grade level of 16.58, and a Flesch Reading Ease score of 14.5. The Flesch Reading Ease scored ranks writing between 0 and 100, with 100 being the easiest to read. A score between 0 and 30 are best understood by university graduates.

The Statement says it is for consumers and community members as well as for researchers and institutions. Health service consumers tend to be people who use, have used or are eligible to use health and social care services, particularly on a long-term basis. Groups particularly associated with being health consumers include people with learning

difficulties, those with disabilities, mental health service users and the elderly. To make this Statement accessible to these groups, as well as culturally and linguistically diverse communities and those with lower education and literacy levels:

- a plain language version should be developed,
- the document should be translated into languages other than English, and
- consideration should be made to it being available in accessible formats (braille, large prints etc.)

## 2. Definitions

Unless attention is paid to addressing diversity in user involvement in research, it may reinforce rather than challenge existing marginalisation, to the potential detriment of attempts to understand and address health inequalities<sup>1</sup>. Therefore, in the definitions, it is important to highlight that communities, consumers and stakeholders are as diverse as the full range of people living in Australia. This includes children, women and men, people living with a disability, people from diverse religious and cultural backgrounds, socio-economic status and social circumstances, sexual orientation and gender identities, physical and mental health and illness conditions.

In the context of mental health, 'consumer' refers to people who have direct experience of mental illness, people who have previously used or are currently using mental health services. The inclusion of people who have previously used services is broader than the current definition included in the Statement.

A distinction should be drawn between 'service users' and 'carers'. While there are similarities in experiences, differences in role, interests and perspectives should be highlighted in order to avoid one group speaking on behalf of another, or one being seen to represent the other<sup>2</sup>.

## 3. Key Elements that underpin effective involvement and Levels of Involvement

### Key Elements for effective involvement

The identified elements for effective involvement are laudable, but ambitious if appropriate supports are not put in place. In order for these to be feasible, cohealth

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<sup>1</sup> Beresford, P. (2003) *User involvement in research: exploring the challenges*. Nursing Times Research, 8 (1), p 36-46

<sup>2</sup> Beresford, P., (2007), *User involvement, research and health inequalities: Developing new directions*, Health and Social Care in the Community, 15 (4), p 306-312

would recommend the following strategies for effective and meaningful participation of consumers and community members in research processes:

- Ensuring power and ownership of the research process between researchers and consumers/community members is clearly addressed to allow participants to discuss, challenge, or reject the opinions of principal investigators.
- Minimising status differences between researchers and participants
- Creating opportunities for consumer and community members to communicate research findings, such as co-presenting at conferences
- Ensuring consumers and community members receive adequate recognition for their time, expertise and contribution, be it financial or otherwise.
- Building capacity of consumers and community members through training, coaching/mentoring and other appropriate resources and support structures
- Building capacity of researchers to be inclusive of community members and consumers through training, coaching/mentoring and other appropriate resources and support structures
- Providing comfort, safety, and care for consumers and community members who may be unwell or vulnerable, such as adequate travel time, appropriate, and comfortable accommodation (if necessary), compensation for child care, transport, and so on.
- Allowing extra time for the participatory research process
- Budgeting adequately for the participatory research process
- Ensuring researchers have support from their managers/institutions to take a participatory approach, and are allowed the necessary time to do so.
- Dividing tasks – not overloading consumers and community members, or expecting them to do tasks beyond their capability or capacity.
- Encouraging consumers to make their own decisions about participation.
- Using innovative participation tools such as citizen juries
- Developing accessible information to explain why it is important to involve particular groups of service users in research and to identify what the benefits and drawbacks might be.
- Including members with lived-experience on ethics committees

In preparing this submission, cohealth consulted with members of its Community Engagement Advisory Committee (CEAC). All CEAC members have been involved in research in some form, and reported a mixture of experiences in ways they had been involved in research.

Themes that emerged from the consultation included the importance of engaging consumers in research design, not just delivery or as subjects:

- *I've been involved in lots of research as a participant but never had the opportunity to be part of the design.*
- *I was involved in the delivery of research on lifestyle and obesity. I was asked to use a form to collect information. As far as I know there was no involvement of participants in the design of it.*
- *I've also been involved in delivering research. I know that customers were not involved in designing the research.*
- *Researchers need to listen to us. For starters, they should balance out the number of consumers involved in designing and all parts of research.*

The flexibility of researchers to work with consumers, and willingness to change aspects of their research design, was also raised:

- *I'm a simulation patient and involved in research about why people want to be simulation patients. The first time I met with the researcher there was a list of structured questions. I found the questions restrictive, like I couldn't say what I wanted to say. But the next time I met with the researcher, she was much more open and we could talk like a normal conversation. I was also given feedback on how my information was used. This made me feel like my contribution was useful and I was able to educate the public and GPs.*

CEAC members emphasised the importance of receiving communication back from researchers about the progress and results of a study:

- *As a participant in research I've requested that they [the researcher] send me information on the results, but they never told me or let me know the outcome of the study.*

Finally, CEAC members discussed that their role in the research process needs to be tangible:

- *It was important that I could see [staff member] taking notes on what I said. I felt I was being heard and my voice would make a difference. Also, we kept getting updates so we could see how what we said had improved the survey.*
- *Consultation needs to be real. Make consultation so it doesn't feel tokenistic.*

### Levels of involvement

Rather than direct readers to third party websites and frameworks for models on involvement, one model should be selected to guide researchers thinking. The *Ladder of Participation* adapted by the University of Western Australia and the Telethon Kids Institute is particularly useful as it is succinct, easy to understand, and specific to research, as opposed to the IAP2 *Spectrum of Public Participation*, which while useful is not research specific.

Alternatively, the Statement could reference Peter Beresford, Professor of Social Policy at Brunel University London and Director of the Centre for Citizen Participation. Beresford is internationally renowned for his work on consumer research. His particular areas of focus are public, patient and service user involvement in policy and practice; democratisation and participatory approaches to research, particularly in relation to user controlled and user involvement research.

Beresford has identified three levels of consumer participation in research.

1. User involvement research, where consumers act as advisors to varying degrees in the research. For example, consumers are consulted for advice about certain aspects of a project such as questionnaire design, the review of plain language statements or to contribute as members of an advisory committee
2. Collaborative research, which refers to a partnership between consumers and researchers in all aspects of the research process.
3. User research, where research is initiated, directed and led by consumers, and has a strong commitment to equality in the relationship between researchers and research participants.

## **4. Putting the Statement into practice**

Cohealth feels that this section of the draft Statement provides good strategies for effective and meaningful participation of consumers and community members in research processes. However, cohealth would suggest that strategies addressing diversity in involvement should also be included.

The contribution that consumers and community members have already made to health research highlights the need to address diversity and the barriers that can preclude

involvement of diverse groups. If these are not addressed, then participation is likely to be partial, and reflect broader social divisions and exclusions<sup>3</sup>.

The social determinants of health - the conditions in which people are born, grow, live, work and age - are mostly responsible for the unfair and avoidable differences in health status seen within and between countries. The social determinants of health are shaped by the distribution of money, power and resources at global, national and local levels. Health inequity particularly affects people who are vulnerable and face exclusions, and who are more difficult to engage. Groups who are particularly susceptible to such exclusions include:

- newly-arrived refugees and asylum seekers,
- migrants,
- Aboriginal and Torres Strait Islanders,
- injecting drug users,
- homeless people,
- aged people,
- people with varying degrees of mental illness,
- people with low literacy and/or living in poverty
- people who have experienced or are experiencing abuse
- gay, lesbian, bisexual, transgender and intersex (GLBTI) people

All these are people who are overrepresented among groups experiencing health inequities. Because of this participatory research must make specific provision to engage and include these groups who are marginalised and excluded. There are a range of ways in which marginalised groups can be more effectively included in research. These include:

- offering time and resources to support their involvement;
- providing choice about getting involved;
- structuring research meetings to be inclusive;
- providing advocacy opportunities through research
- reaching out proactively to marginalised groups; and
- recognising the importance of language in ensuring inclusion, and developing appropriate language policy and practice

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<sup>3</sup> Beresford, P., (2007), *User involvement, research and health inequalities: Developing new directions*, Health and Social Care in the Community, 15 (4), p 306–312

## 5. Examples of consumer and community involvement in health and medical research

Two examples are provided of consumer and community involvement in health research:

1. Collaborative research with a marginalised community
2. Engaging consumers in research ethics in a community health setting

### Collaborative research with a marginalised community: *Listening to North Yarra Communities about female genital cutting*

cohealth has provided services to women and girls affected by FGC for many years, and have long standing relationships with relevant communities in Melbourne's inner north. In 2012 cohealth approached the University of Melbourne requesting assistance with research to better understand the current impact of FGC in local communities. Staff reported that gaps in contemporary knowledge about FGC made it difficult to design, deliver and evaluate appropriate services for affected women and families living in inner Melbourne.

Subsequent discussions with staff at The Royal Women's Hospital confirmed that they also saw a need for locally grounded research that could improve the quality and reach of the health care and information available through their services, for women and girls who have experienced FGC.

A new research partnership was formed between the university, cohealth and the Royal Women's Hospital. The partnership was successful in attracting funding from the University of Melbourne Partnership and Engagement Office (MEPO) to conduct consultations with relevant communities in late 2012 and early 2013. These consultations were to establish whether the communities thought that a research project focused on FGC was warranted and appropriate, and if so, what research questions were the highest priority for communities. The consultations also served to gather community members' views on the most appropriate methodology for such a research project. In the past, policy and legislative development with respect to FGC has often been informed by policy makers' assumptions and perceptions about the practice, failing to take into account the experiences and views of the communities in which the practice occurs. Therefore it was an explicit aim of the partnership that community members' views be foregrounded and a collaboration approach to the research developed. The research project that was subsequently developed was funded through an Interdisciplinary Seed Grant from the Melbourne Social Equity Institute at the University of Melbourne.

Prior to data collection, or indeed deciding whether the research project should proceed, the research team held consultations with relevant community groups in the

North Yarra catchment area. These consultations sought to confirm community interest in the project and willingness to discuss FGC. If community members were receptive to a project focused on FGC, it was also intended that these consultations provide an opportunity for community input into the research approach and objectives.

Six consultations were held with community groups, and one with sexual and reproductive health service providers. In total, 91 people participated in these consultations.

Consultation meetings were held in local community facilities and were facilitated by a member of the research team, with or without an interpreter and/or childcare (as requested by the community group). Community members were asked whether or not they thought research around FGC would be useful (and why or why not). If the group suggested that they did think such a research project had value, community members were asked what questions they thought the researchers should focus on, and what they perceived to be the most appropriate methods for answering these questions.

While some community members questioned the importance of a research project looking at FGC all consultations – including with health professionals – suggested that there was value in better understanding the health service experiences of women who had undergone FGC, and whether their needs were being met. Community members also wanted to better understand differences within and between groups, in terms of their attitudes towards FGC. There was some concern as to whether knowledge of the Australian law was as high among newly arrived migrants and refugees as it was among the more established members of the communities.

Feedback from these consultations showed that if FGC is discussed respectfully and in a non-judgemental manner, community members were appreciative of the opportunity to present their views. It was clear, even during this early consultation phase, that there was a diversity of attitudes towards FGC held by community members. It was also clear that many people wanted an opportunity to 'speak back' and counter the negative representations of their communities, with regard to FGC, that were circulating in the media at that time. Following the community consultations, the research team agreed that there was sufficient community interest in and support for the research, and that we should proceed to seek funding to go ahead with the project.

The final project report can be found at <http://cohealth.org.au/wp/wp-content/uploads/2014/06/Listening-to-North-Yarra-Communities-WEB.pdf>

## Engaging consumers in research ethics in a community health setting

cohealth is a non-Government not-for-profit organisation and a registered community health service that delivers vital primary health and support services including, including medical and dental, allied health, refugee health, child youth and family, homelessness and community mental health to people in Melbourne's northern, western and inner northern suburbs.

Cohealth aims to build the capacity of individuals to control their own lives and decisions and support communities to play a role in improving health outcomes. Cohealth is committed to meaningful consumer participation at all levels of the organization, actively engaging with our consumers and community members to design, develop, deliver and evaluate our services.

All research activities undertaken under the auspices of cohealth requires some level of ethics review in order to ensure it conforms to the requirements of the National Statement on Ethical Conduct in Human Research. To do that, cohealth resources a Human Ethics Advisory Group (HEAG).

The primary function of the HEAG is to offer an assessment and recommendation to ensure research and evaluation projects involving human participants at cohealth are consistent with relevant ethical and human rights guidelines, standards and laws. As the HEAG is not a registered ethics committee, any projects with more than minimal risk are referred to an external, registered, ethics committee – usually at a partnering university.

The HEAG is a lay group made up of service delivery, policy and research staff, as well as consumer representatives. Current and former clients of cohealth services (including service users, consumers, family or carers), and community members with ties to the western and northern regions of Melbourne are invited to join HEAG as consumer representatives.

The role of the consumer representatives are to Assess research and evaluation projects regarding the ethical and human rights implications; recommend alterations to proposals to make them of lower, negligible or no ethical risk, or to place less impactful limits on protected human rights, support cohealth to bring a consumer and/or community perspective into research ethics consideration and participate in review of cohealth's research and evaluation planning to inform future directions and priorities

Consumer representatives bring their experience, knowledge, perspectives and connections to their role, but do not represent any community or organisations to which they are connected.

Cohealth supports the involvement of the consumer representatives by providing orientation and training, interpreters and other supports if required. Whilst this is a voluntary role, cohealth is committed to maximising opportunities and reducing barriers to participants. Cohealth acknowledges the contribution made by participants by offering payment for their time, commitment and expertise as per cohealth's Honorarium Policy. In addition to an honorarium for meeting attendance, cohealth reimburses out-of-pocket expenses that are associated with participation, including parking; childcare; travel expenses and printing costs.

Having consumer representatives on the HEAG supports a consumer voice and involvement at an organisational level, and a different and very important perspective on the research proposals that come before the committee.