

Draft Statement on Consumer Involvement in Health and Medical Research

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Contact Details

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| | |
|----------------------|---|
| Name (please print): | Michael Cousins |
| Signature: |  |
| Date: | 1 October 2014 |

Note: It is acceptable to type your name in the signature box of this form as your electronic signature.

1 October 2014

Mr Owen Cox
Publications and Web Manager
Information and Communication Management
National Health & Medical Research Council
Via email: owen.cox@mhmrc.gov.au

Dear Mr Cox

Revised Statement on Consumer and Community Involvement in Health and Medical Research

The Health Consumers Alliance (HCA) is the peak body for health consumers in South Australia, established in 2002. As an independent alliance of health consumers and health consumer organisations, we work together with our members to achieve our vision of consumers at the heart of health care. A strong and effective voice for the promotion and protection of health consumer wellbeing and rights, HCA promotes health equity and provides systemic advocacy to inform, shape and sustain consumer centred care.

Consumer Engagement

Health consumer and community engagement informs all of HCA's work – we seek out the lived experience of health consumers and carers to inform our policy and advocacy positions. HCA participated in the national workshop held in 2011 to inform the revision of the Statement. Since then, in 2013, HCA led a mixed-method qualitative study to investigate the evidence for and develop a Consumer and Community Engagement Framework for the new South Australian Health and Medical Research Institute (SAHMRI). This project included a review of the literature, consumer and stakeholder consultations, and a consensus workshop with the SAHMRI Research Executive. The learnings from this project inform our response to this revised Statement on Consumer and Community Involvement in Health and Medical Research.¹

Language and accessibility

The revised Statement contains many important principles, strategies and commitments that could facilitate consumer and community participation in health and medical research. The Statement appears to have two principal audiences: consumers and the community, and health and medical researchers. Unfortunately the Statement does not serve either audience well. For consumers and community the Statement fails the plain English test – the statement is long, repetitive and laden with jargon. HCA recommend that the Statement be subject to a plain English and design review and edit.

The vision for the Statement is worthy:

Consumers, community members and researchers will work in partnerships based on understanding, respect and shared commitment to research that will improve the health of all Australians.

¹ A copy of the Project Report is available from HCA.

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HCA questions whether this is a vision for the Statement, or rather a vision for health and medical research in Australia more generally? HCA recommends that this vision be more prominent in the Statement.

The Statement overview is long and contains historical information not pertinent to the revised Statement (it may be usefully included elsewhere). HCA recommends that the Statement overview be a short summary of the Statement, which may include a diagram.

The Statement overview includes reference to the values of NHMRC as outlined in its Strategic Plan. If these values inform this Statement then they should be explicitly named in the Statement. A review of the NHMRC Strategic Plan 2013-15 does not easily identify these values.

Consistency of language – for most of the document consumer and community is used, but in the 8th paragraph on page 4 the phrase patient is used. This should be amended to consumer.

Key elements and levels of involvement

This section seeks to identify the key elements and levels of involvement that support consumer and community participation in health and medical research. The two key elements identified: involvement and inclusion, are important and supported. This section also contains reference to the principles identified in the Roadmap II: Strategic Framework for improving the health of Aboriginal and Torres Strait Islander People through Research. The merging of these elements and principles, while worthy in concept, is poorly expressed in writing. It is unfortunate that the revised Statement does not reference the contemporary literature on consumer and community participation in health and medical research.² HCA recommends that this section be rewritten to present a unified set of elements and/or principles that support consumer and community participation and is informed by contemporary research and literature.

Putting the Statement into practice

This section contains suggested actions that would support consumer and community involvement in health and medical research. The suggested actions are worthy and supported. In reviewing this section HCA believes that the NHMRC and CHF should be informed by the experience of implementing the previous Statement. The previous Statement (and Resource Pack and Model Framework) provided a clear expression of commitment, strategies and tools to support consumer and community engagement in health and medical research in Australia.

² Examples include:

Johnson A. What strategies for consumer engagement in health and medical research have been effective for consumers and researchers? A review of the literature. Health Consumers Alliance of South Australia. 2013.

Saunders C and Girgis A. Enriching health research through consumer involvement – learning through atypical exemplars in Health Promotion Journal of Australia 2011: 22(3).

Shippee ND, Garces JPD, Lopes GJP et al. Patient and service user engagement in research: a systematic review and synthesized framework in Health Expectations. 2013: 1-15.



Unfortunately the good work expressed through the previous Statement was largely wasted, due to there being neither an implementation plan nor specific requirements for consumer and community engagement as an essential component of the NHMRC research grants process. This appears to be a significant weakness for the revised Statement and an opportunity missed. HCA strongly recommends that the NHMRC commit to mandatory consumer and community participation, that this commitment is expressed in the revised Statement, and that the NHMRC incorporates assessment of consumer and community participation into its grants processes.

Useful resources

HCA recommends the addition of the SAHMRI Consumer and Community Engagement Framework when it is published and publically available.

Conclusion and recommendations

In conclusion the revised Statement identifies important elements, strategies and actions that could support consumer and community participation in health and medical research in Australia. However this revision will be a missed opportunity for the NHMRC, CHF, researchers and health consumers and the community if the NHMRC does not commit to specific actions, strategies, outcomes and performance measures to improve consumer and community participation in health and medical research.

To ensure that the revision of the Statement results in real action that enhances consumer and community participation in health and medical research, HCA recommends that the NHMRC consider and commit to the following actions:

1. include an explicit commitment from the NHMRC to improve consumer and community participation in health and medical research in Australia within the revised Statement
2. allocate resources to further build the capacity of the health and medical research sector to engage in consumer and community participation across all phases and stages of research
3. allocate resources and assign responsibility within the NHMRC to ensure consumer and community participation across the organisational domains of governance, infrastructure, capacity and advocacy
4. make consumer and community participation a mandatory component of the NHMRC grants process, with consumers involved in the assessment of this component.

Thank you for the opportunity to contribute to the revision of this important Statement. The NHMRC has a real opportunity to lead by example in the practice of consumer and community participation. HCA is happy to share our knowledge from the development of the SAHMRI Consumer and Community Engagement Framework should there be the opportunity to do so.

Yours sincerely



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