

# **From Desert to Oasis: Community Engagement in Australia's National Health and Medical Research Council**

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## **Abstract**

In 1992, the *National Health and Medical Research Council Act 1992* introduced formal requirements for public consultation whenever the NHMRC undertook certain activities. This was the first time such a requirement had been made explicit through the parliament, although the National Health and Medical Research Council (NHMRC) already had an environment of consultation with key stakeholders.

Since 1992, the NHMRC has grappled with the concept of 'public consultation' and how this can best be achieved, especially when the subject matter can be quite technical. Over time, there was a shift from meeting the letter of the law to addressing the spirit of the law.

With the start of the new century the NHMRC has moved further towards community engagement, entering into dialogue and partnerships between researchers and health professionals and the community. The result has been an enriching of the NHMRC's programs and clearer directions for future involvement by the community in the work of NHMRC.

## **Keywords**

Research, community engagement, NHMRC, consultation, participation

## **Introduction**

Australia's National Health and Medical Research Council (NHMRC) has been in existence since 1936. Over the past almost 70 years, the NHMRC has shifted not only its thinking but also its actions towards a stronger policy of community engagement. This paper sets out to describe the NHMRC and its former and current practices in community engagement. Through this description, it will be demonstrated that the NHMRC has made a significant move from passive to active community engagement.

### **What is the NHMRC?**

The NHMRC is a statutory body first established by an Order-In-Council on 24 September 1936. The functions expected of the NHMRC in 1936 are listed in Box 1.

“To advise Commonwealth and State Governments on all matters of public health legislation and administration, on matters concerning the health of the public and on medical research;

To advise the Commonwealth Government as to the expenditure of money specifically appropriated as money to be spent on the advice of this Council;

To advise the Commonwealth Government as to the expenditure of money upon medical research and as to projects of medical research generally;

To advise Commonwealth and State Governments upon the merits of reputed cures or methods of treatment which are from time to time brought forward for recognition.” (NHMRC 1996, p. 67)

#### **Box 1. The functions of NHMRC, 1936**

The structure of NHMRC was little changed until 1992 when the *National Health and Medical Research Council Act 1992* (the NHMRC Act) was enacted. The NHMRC Act was an initiative of the then Australian Government Minister for Health and was intended to ensure that the NHMRC existed for the long term. The functions of NHMRC today, as set out in the Act, are listed in Box 2.

1. To inquire into, issue guidelines on, and advise the community on, matters relating to:
  - (i) the improvement of health;
  - (ii) the prevention, diagnosis and treatment of disease;
  - (iii) the provision of health care;
  - (iv) public health research and medical research; and
  - (v) ethical issues relating to health.
2. To advise, and make recommendations to, the Commonwealth, the States and Territories on the matters referred to in paragraph 1.
3. To make recommendations to the Commonwealth on expenditure:
  - (i) on public health research and training; and

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| <p>(ii) on medical research and training; including recommendations on the application of the Medical Research Endowment Fund.</p> <p>4. Any functions incidental to the foregoing.</p> |
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**Box 2. Functions of NHMRC, 1992 onwards**

The NHMRC is a body independent of any single vested interest. Its membership includes: representatives of commonwealth and state and territory health authorities; and people with expertise in research, academia, clinical and nursing practice, social sciences and public health, Indigenous health, environmental, industry and consumer issues. It is perhaps best well known for its funding for health and medical research, totaling some \$AUD420 million a year.

However, research is not all that NHMRC covers as can be seen from the functions above. In effect this means that the NHMRC is a unique organisation. Its responsibilities combine the provision of advice on a range of health issues; making recommendations on, and subsequently managing funding for, public health and medical research; and providing advice on ethical issues in health, including setting the frameworks for the ethical conduct of research involving both animals and humans.

The NHMRC comprises a hierarchy of committees. Cascading from the council itself — a committee of 29 part-time members — is a series of Principal Committees (one for each of the major programs of NHMRC) which, in turn, are underpinned by subject-specific expert committees. In total, the NHMRC's network of experts numbers more than 800 people around Australia.

As an aside, the NHMRC has been given additional responsibilities through other legislation enacted in 2002, namely the *Prohibition of Human Cloning Act 2002* and the *Research Involving Human Embryos Act 2002*, the latter of which introduced the Licencing Committee as a Principal Committee of NHMRC. Thus the NHMRC now has four major programs:

1. Health advice and policy
2. Research management and policy
3. Ethics in human and animal research and in health generally
4. Regulating sensitive research.

## **Consultation and the NHMRC**

The NHMRC Act sets out for the first time the specific requirement that the NHMRC must engage in public consultation when it undertakes certain activities. The NHMRC Act says two things. Firstly, section 3 of the NHMRC Act makes it clear that the Australian parliament intended that NHMRC would consult with the public on as many occasions as possible. Secondly, as a minimum requirement, sections 12-13 of the NHMRC Act require the NHMRC to undertake either one or two rounds of public consultation when developing regulatory recommendations (two rounds) or issuing guidelines (one round).

The Regulations to the NHMRC Act stipulate where notices about consultation should be placed (on the Internet and in the *Government Notices Gazette*) and for how long (30 days). In cases of emergency the Act allows the NHMRC to issue an interim guideline first and undertake consultation second; however, within a tightly defined timeframe.

Thus it is clear that the parliament expected, and continues to expect, that NHMRC will consult the public during the conduct of its business. The key questions to be addressed are how that consultation will take place and what level of transparency this demonstrates.

## **The shift from desert to oasis**

It could be said that the requirements of the NHMRC Act describe a desert of public consultation. The requirements of the legislation do not fully empower the community to participate. After all, not every citizen has access to the Internet and it is a fairly certain assumption that most citizens will never have heard of the *Government Notices Gazette*. In fact, businesses are the largest number of readers because that particular gazette includes information about forthcoming contract work.

The NHMRC has recognised this potential problem of the letter of the law and has chosen to exercise the spirit of the law as well. In other words, the Australian parliament wanted the community engaged in the NHMRC's work although the legislation does not, of itself, facilitate what could be called full and proper engagement. The NHMRC has recognised this and has been working, increasingly, to improve transparency through community engagement.

The remainder of this paper will describe in more detail how the NHMRC has made this shift from the desert to the oasis. Community engagement in NHMRC takes several forms, namely: community participation as members of the many committees; community participation through consultation; and community participation in building the research agenda.

### **Community engagement through direct participation in committees**

As noted above, the NHMRC operates through a series of expert committees and has long had the philosophy that the community should be involved in those committees. As far back as 1937, the first meeting of the full NHMRC included an appointed Layman<sup>1</sup> and this was confirmed in the NHMRC Act, which includes a membership category of “a person with a background in, and knowledge of, consumer issues”. With one exception, there is no such legislative stipulation that a ‘consumer’ should be included as a member of other NHMRC committees.<sup>2</sup>

However, until very recently, appointing consumer members was as far as the NHMRC took this particular form of engagement. In 2003 the NHMRC recognised that its consumer members represented a vast and untapped resource — not only in terms of providing expertise to the NHMRC, but also in terms of communicating with the broader community. At this stage, the NHMRC made an explicit decision to provide more support to its consumer members and established the NHMRC Consumer Members Network. Initially the Network comprises the consumer members of the council, its four Principal Committees, and two special expert working committees. The Network thus has eight members who are considered the ‘senior’ consumer members of NHMRC.

The Network has conducted most of its business by teleconference and email to this point and was particularly instrumental in identifying a series of activities that are designed to provide greater support to consumer members on NHMRC committees and to ensure that staff working for the NHMRC (i.e. the NHMRC Secretariat) are fully aware of their obligations to facilitate community engagement.

The Network is just beginning to bear fruit. For example, the network is now developing a strategy for community engagement that is intended to become a formal part of the NHMRC’s next Strategic Plan. In this way the NHMRC will be held to account, in a very open way, for its strength of and commitment to community engagement. A key relationship for the Network, and thus for NHMRC, is the relationship of the Network with the Consumers’ Health Forum of Australia Inc. The Consumers’ Health Forum is Australia’s peak body advocating on behalf of health consumers. Whilst the Consumers’ Health Forum does not have formal membership status on the NHMRC’s Consumer Members Network, liaison with the Forum and inclusion of Forum observers at the Consumer Members Network meetings, provides an additional point of contact

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<sup>1</sup> Women were not involved in 1937.

<sup>2</sup> The exception is the Australian Health Ethics Committee, the membership of which is stipulated in the NHMRC Act and which includes consumer representation. It should be noted that the newer Licencing Committee is also required to have a consumer member.

with the community and, importantly, supports NHMRC's intentions by ensuring the NHMRC is properly informed of community concerns.

### **Community engagement through consultation**

The NHMRC has a long history of undertaking consultation with key stakeholders and the NHMRC Act was instrumental in formalising the idea of public consultation as a routine activity. However, there is a question about whether the process described in the NHMRC Act can truly be called 'community engagement' as distinct from 'public consultation', that is, consultation meaning asking the public what they think about something without necessarily engaging to a greater degree. It should also be stressed that the NHMRC Act only requires formal public consultation when developing regulatory recommendations or guidelines. The NHMRC produces advice in other forms including manuals, toolkits, information papers and advisory documents. According to the legislation this work program would not require public consultation.

This paper has already suggested that the formal public consultation requirements contained in the NHMRC Act and Regulations to the Act may not empower the community to engage in NHMRC's activities. Fortunately, the NHMRC has increasingly become aware of this potential problem and has taken steps to go beyond the letter of the law. The most important step the NHMRC has taken is that of seeking community input into its broader work program and not restricting consultation to regulatory recommendations and guidelines. This means that the products of NHMRC's four programs are strengthened by being informed of public opinion and nowhere is this more valuable than in the area of ethical issues in human research and health.

The second step the NHMRC has taken is, quite simply, making sure that messages about the NHMRC's work, and especially requests for input or other forms of comment, are placed where the community will see them. This means placing advertisements in the national print media as well as capital city newspapers and, when appropriate, in a range of other print media. For example, notices relating to issues about Aboriginal and Torres Strait Islander health would be placed in the *Koori News*, and notices relating to clinical practice would be disseminated through the Divisions of General Practice.

As well as newspaper notices — which supplement use of the Internet and the *Government Notices Gazette* — the NHMRC undertakes targeted consultation by ensuring that requests for comment are sent direct to as many relevant organisations as possible. This activity requires the NHMRC to consider a formal communication strategy for each project, identify and seek out stakeholders, and engage them directly.

The results of these newspaper advertisements and direct mailings are many high quality and very thoughtful written submissions that are taken into account by the NHMRC when it finalises its recommendations, guidelines or other advice.

### **The Xenotransplantation (animal to human transplantation) experience**

It is worth taking time to describe in more detail the NHMRC's departure from the normal round of newspaper advertisements for one particular project. Commencing in 2001 the NHMRC worked to develop advice about the use of animal cells and tissues for transplantation into humans. This issue was and remains highly topical due to the shortage of human organs for transplantation and the increasing focus on possible alternative sources of therapy.

Knowing that this issue was highly emotive and likely to excite community opinion, the NHMRC decided that it would engage the community in a different way — it would hold public meetings, as well as seek the usual written submissions. This was a challenging decision for NHMRC because never before had it put its work on such open, public display with no opportunity to anticipate who might attend and what they might say.

After writing a discussion paper which would be the focus for comment, three public meetings were held in 2002, one each in Perth, Melbourne and Sydney. Advertisements inviting attendance were placed in a variety of capital city and local area newspapers and community-friendly venues were hired.

Attendance at each of the meetings was gratifying for a first effort although the strength of feeling was not fully anticipated. Most people who attended each of the three meetings were not in favour of animal to human transplantation and were very vocal in their opposition. Very few people in favour of animal to human transplantation attended, whether potential transplant recipients or researchers, which meant that the meetings did not result in a balanced discussion. In addition, members of the NHMRC hosted and managed the meeting which some participants saw as a less than total commitment to community engagement (the criticism was that the NHMRC could control the meetings and bias who spoke and for how long and on what topic).

The NHMRC learnt a number of lessons from this process. First and foremost, it was clear that the community did not fully understand this very technical subject and so there were many misconceptions and ill-grounded fears — this resulted in the NHMRC developing a community guide to animal-to-human transplantation (NHMRC Xenotransplantation Working Party 2003). Secondly, the NHMRC learnt that it was not possible to reassure the community about the genuine nature of its engagement if the community felt that such meetings were 'fixed' to achieve

a certain outcome. This resulted in the NHMRC engaging an independent facilitator when it undertook a second series of public meetings. Finally, whilst acknowledging that the three meetings held were an initial foray into this style of community engagement, the NHMRC learnt that Australians in other parts of the country felt excluded from the debate — this resulted in the second round of meetings occurring in all capital cities.

In early 2004 the NHMRC conducted a second round of public meetings, with the same open invitation to any citizen to attend. Similar numbers of people attended each meeting as with the 2002 meetings but this time there was an independent facilitator to make sure that everyone who wanted to speak had an equal opportunity and to reassure the community that there was a genuine desire on the part of NHMRC to receive community input.

The end result of the NHMRC's deliberations, informed by community engagement, can be found in detail at <<http://www.nhmrc.gov.au/ethics/human/issues/xeno/index.htm>>.

What this total exercise showed was that the community is interested in participating in decision making in health policy and that it is necessary to find appropriate ways for this to occur. This might mean undertaking an increased amount of preparation to ensure that the community has sufficient, relevant information upon which to form opinions and contribute to debate.

### **Community participation in building the research agenda**

The xenotransplantation experience was an exciting one for NHMRC because it took the organisation into uncharted waters. Equally exciting and uncharted was the NHMRC's active collaboration with the Consumers' Health Forum of Australia Inc. to develop the joint *Statement on Consumer and Community Participation in Health and Medical Research* (NHMRC/CHF 2002) (the Participation Statement).

The genesis of this work goes back to 1999 when the report of the strategic review of health and medical research (Commonwealth of Australia 1999) called for greater community engagement in the development of the research agenda. The NHMRC and the Consumers' Health Forum of Australia collaborated in the development of the Participation Statement. The development process was consultative and included workshops of researchers and consumers. The workshops provided a valuable opportunity for each group to listen to and understand the concerns of the other and resulted in the development of a series of principles to be applied to community engagement in research.

The Consumers Health Forum and the NHMRC collaborated again during 2004 to implement the Participation Statement. This work took the form of pilot testing the Participation Statement in two research organisations with a view to developing a Model Framework (NHMRC/CHF 2005a) and Resource Pack (NHMRC/CHF 2005b) for consumer and community engagement in health and medical research. The Model Framework and Resource Pack were launched in July 2005 and together provide a blueprint for the partnership between researchers and consumers based on understanding, respect and shared commitment to improving the health of all Australians (NHMRC/CHF 2002, p. v).

The Participation Statement is an exciting initiative for two reasons: firstly because it represents a significant collaboration between the NHMRC and the peak health consumer body; and secondly because it provides explicit support for community engagement. On this latter point, the NHMRC now requires that applicants for its research funding provide details of how they will engage consumers or the community in the research project as well as how the results will be disseminated.

### **What does the future hold?**

In this new century the NHMRC has taken bold steps towards greater community engagement in its work. It could be said that the activities of the past five years have been the pilot for stronger community engagement in the future. The NHMRC has proven that a national body of its stature can and wants to engage and listen to the community and has tried new ways of improving this engagement. In the future, the NHMRC will have a stronger role in community debate especially when it comes to sensitive issues that tend to be highly emotive and polarise the community. In such instances, the independence and nature of NHMRC makes it well placed to ask questions and receive input, and to weigh the science with the community's contributions in order to advise health policy makers.

### **Conclusion**

There are clearly several oases of community engagement in the NHMRC. Since 2000 the NHMRC has demonstrated its commitment to moving out of the desert towards these oases of active community engagement by: increasing support for its consumer members and using their knowledge and skills in different ways; establishing the framework for community engagement in health and medical research; and shifting to alternative methods of consultation to facilitate greater community comment on and input to the NHMRC's work. In the past four and a half years this shift has seemed like slow progress to those advocating for greater engagement. However, strategies are now bearing fruit and it is obvious that the NHMRC will be enriched as a result of this greater community engagement.

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