

## **Submission to the Strategic review of Health and Medical Research in Australia**

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The volume and extent of health and medical research in Australia has increased dramatically over the past 40 or so years. University-based researchers and professional researchers within allied research institutions have been in the forefront of the research undertaken. The standard of research conducted has been of a high order, with peer review and other quality control mechanisms undergoing commensurate development and refining over the period.

Alongside this burgeoning activity however, has been a growing recognition of the strategic value and improved health outcomes derived from involving “the public” in health and medical research. This is a part of a wider recognition that research involves a process of knowledge and expertise *exchange*, and a move away from the idea of ‘knowledge transfer’ that characterised university research of the past. Universities around the world have responded to changing expectations of their role by developing better pathways for working with their local, regional and international communities. To date however, Australia has lacked a nationally driven commitment to ensuring that the “community” whether as consumers or as civically-minded, disinterested participants, have been engaged in this research enterprise. A priority for Australian health and medical research therefore, is the development of policy which will foster, support and promote the adoption of community-engaged research as part of the mainstream health and medical research agenda.

To be clear about what this proposal entails, it is important to define the terms being used. Of most significance is the definition of “community engaged research”. Engaged research is sometimes found under definitions of action research and community based participatory research, but whichever descriptive title is adopted, engaged research is now widely accepted as the research philosophy which, ‘requires academic members to become part of the community, and requires community members to become part of the research team. This cooperation creates a unique working and learning environment before, while, and after the research is conducted.’<sup>1</sup>

For Duke University’s Centre for Community Research, the community capacity development outcomes deriving from the process of community engaged research needs to be valued as an important component in research outcomes. For Duke, engaged research means:

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<sup>1</sup> National Human Genome Research Institute, Community Engagement at the NIH,  
<http://www.genome.gov/27541346>

a framework or approach for conducting research, not a methodology. A community-engaged research study may incorporate both qualitative and quantitative methods. This approach encourages recognition of the strengths of community institutions and individuals and encourages people and groups to build on those strengths. What characterizes community engaged research is not the methods used, but the principles that guide the research and the relationships between researchers and the community.<sup>2</sup>

Equally important to this definition is the concept of community. Often in health and medical research 'the community' is understood to be consumers, or individuals with clear interests in the outcome of the research: cancer patients in cancer research, people with Alzheimer's in Alzheimer's research and so forth. However this does not encompass the full potential of community engaged research. For example, the Centres for Disease Control and Prevention (CDC) define community-engagement as: "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people."<sup>3</sup>

The outcomes from such research are a crucial component for its adoption. As was recently conceptualised following a recent NIH initiative in research translation:

Community engagement can be difficult to define clearly, but at its heart, it is the intersection of the complementary efforts of members of the lay community, community non-profit organizations, health practitioners and medical and public health researchers to improve health.<sup>4</sup>

International experience illustrates the value to be gained from promoting and supporting community engaged health and medical research. A few key examples will suffice. In the US, one of the leading sites for community engaged activity, key institutions in the policy development and research funding arenas have initiated pathways for supporting and encouraging community engaged research. As one researcher in the field noted, "Community engagement has become a major contributor to medical research during the past 10 years and is an essential component of the

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<sup>2</sup> Duke Centre for Community Research, <http://www.dtmi.duke.edu/dccr/community-linked-research/>

<sup>3</sup> CDC/ATSDR Committee on Community Engagement. (1997). Principles of Community Engagement. Atlanta, GA: Centers for Disease Control and Prevention Public Health Practice Program Office. (p.9)

<sup>4</sup> The Clinical and Translational Science Award (CTSA) Consortium's Community Engagement Key Function Committee and the CTSA Community Engagement Workshop Planning Committee. (2009). *Researchers and Their Communities: The Challenge of Meaningful Community Engagement*. Bethesda, Washington: NIH.

current National Institutes of Health (NIH) Roadmap and the Clinical and Translational Science Awards program.”<sup>5</sup>

The National Institutes of Health (NIH), is probably the largest and most influential health and medical research organisation in the world with a budget in 2008 of US\$29.4 billion. In 1998 a Commission of Inquiry into NIH research funding and support was undertaken.<sup>6</sup> One outcome of this review saw the NIH adopt provisions to enable community engagement, arguing that “engaging the public is a national priority, it is not an option.”<sup>7</sup> The NIH now expressly promotes community engagement in its deliberations and functions through the Council of Public Representatives.<sup>8</sup>

Adopting the principles of engagement by the NIH was not simply a matter of improving ‘transparency’ of decision making, crucial though that is. It was also about supporting and promoting better science, and better health outcomes. As the authors of the report on the Commission of Inquiry noted:

there is a single theme that runs through [our recommendation]. It is that NIH must revamp its approach to public input and outreach—at every level—without delay. This will strengthen the priority-setting process in many ways. It will underscore that openness is as important to the process as such other valued qualities as expertise, innovation, and objectivity. It will provide NIH leaders more ways to demonstrate that they share the public's view that NIH exists to improve health through research.<sup>9</sup>

In the fifteen years since this Inquiry into the systems used by the NIH in connecting with its publics, the role of public participation in health and medical research has expanded dramatically. It has done so in recognition of the multiple positive outcomes that flow from engaged research processes. As a 2011 examination of the research conducted under the NIH community engaged program argued,

Community involvement in the research process can increase the relevance and quality of health research, even in clinical studies. For example, increased public participation in all

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<sup>5</sup> Westfall, J. M., Fagnan, L. J., Handley, M., Salsberg, J., McGinnis, P., Zittleman, L. K., et al. (2009). Practice-based Research is Community Engagement. *The Journal of the American Board of Family Medicine*, 22(4), 423-427. (p.423)

<sup>6</sup> Institute of Medicine (US) Committee on the NIH Research Priority-Setting Process. (1998). *Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the National Institutes of Health*. Washington (DC): National Academies Press (US).

<sup>7</sup> U.S. Department of Health and Human Services, National Institutes of Health, Council of Public Representatives, [http://copr.nih.gov/COPR\\_singles\\_508.pdf](http://copr.nih.gov/COPR_singles_508.pdf)

<sup>8</sup> [http://copr.nih.gov/COPR\\_singles\\_508.pdf](http://copr.nih.gov/COPR_singles_508.pdf)

<sup>9</sup> Institute of Medicine (US) Committee on the NIH Research Priority-Setting Process. (1998). *Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the National Institutes of Health*. . Washington (DC): National Academies Press (US).

stages of the research process has been identified as critical to achieving diverse representation and sufficient enrolment of participants for clinical studies. Community representatives and patient advocates can contribute substantially to identifying important research questions, designing effective informed consent processes and research protocols, and disseminating research results. Engaging community-based primary care clinicians in research can improve the effectiveness and efficacy of interventions.<sup>10</sup>

An additional motivation for this dramatic expansion by the NIH into engaged research came in 2006 in response to what was described as “frustration at multiple levels of society that the U.S. spends more money per capita on health care than any other nation for health outcomes that are similar or worse than peer nations.”<sup>11</sup> One response to this was the enactment by the US Congress of the 2006 NIH Reform Act which among other outcomes saw the creation of the Clinical Translation Science Award (CTSA) program – which includes one key outcome: “to enhance and nurture community engagement efforts”.<sup>12</sup>

These NIH developments did not occur in a vacuum however. Preceding the 1997 Inquiry into NIH management, units within NIH had begun opening pathways for community involvement in their work. Primary among these was the Centers for Disease Control and Prevention (CDC), which with the Agency for Toxic Substances and Disease Registry (ATSDR) in 1995 set up the Committee for Community Engagement.<sup>13</sup> In 1997 this consortium produced a guide for researchers wishing to pursue this research framework, *The Principles of Community Engagement*. This guide has now gone into a second edition.

The second example comes from the UK. In 2008 the development of community engagement in British universities was initiated with a UK£9.2 million funding program through the UK Funding Councils, Research Councils UK and the Wellcome Trust. One outcome of this initiative was the establishment of the National Coordinating Centre for Public Engagement (NCCPE) a joint venture between the universities of Bristol and the West of England. Through the NCCPE, the Beacons

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<sup>10</sup> Hood, N. E., Brewer, T., Jackson, R., & Wewers, M. E. (2010). Survey of community engagement in NIH-funded research. *Clinical And Translational Science*, 3(1), 19-22. (p.19)

<sup>11</sup> The Clinical and Translational Science Award (CTSA) Consortium’s Community Engagement Key Function Committee and the CTSA Community Engagement Workshop Planning Committee. *Researchers and Their Communities: The Challenge of Meaningful Community Engagement*.

<sup>12</sup> The Clinical and Translational Science Award (CTSA) Consortium’s Community Engagement Key Function Committee and the CTSA Community Engagement Workshop Planning Committee. *Researchers and Their Communities: The Challenge of Meaningful Community Engagement*.

<sup>13</sup> CTSA Community Engagement Key Function Committee Task Force. (2011). *Principles of Community Engagement*. Bethesda, Washington: NIH Publication No. 11-7782.

Project coordinates and supports a coalition of universities from across the UK who tendered for Beacon status and which operate as centres for engagement excellence.<sup>14</sup>

In 2011 specific support for engaged research was introduced through the Concordat program. Under the auspices of the UK Research Councils (RCUK) funding has been earmarked, and is being disbursed through the NCCPE to foster engaged research. The RCUK is seeking to use this initiative to help “embed public engagement in universities and research institutes. This will enhance the future of research and benefit the UK society and economy.” For the RCUK ‘engaging the public with research helps empower people, broadens attitudes and ensures that the work of universities and research institutes is relevant to society and wider social concerns.’<sup>15</sup> Equally significant the RCUK recognise that engaging the public in research also benefits research and researchers.

RCUK is working with other funders of research to create a culture where public engagement is regarded as an important and essential activity by the research community. By establishing an ongoing dialogue between the research community and the public, society can benefit more fully from the outputs of research.<sup>16</sup>

Again, fostering this form of research activity has been underpinned by a commitment to provide financial and other support. Working with the NCCPE, workshops, seminars, websites and documentary guidance is available, as is support for senior management of universities and research institutions to help develop internal policies that support the objectives of the engaged research program.<sup>17</sup>

Recognising that for engaged research to be successful it needs researchers who are free to choose this form of research, institutional support and skills development opportunities, a number of key principles were built into the Concordat, including that,

- *UK research organisations have a strategic commitment to public engagement.*
- *Researchers are recognised and valued for their involvement with public engagement activities.*
- *Researchers are enabled to participate in public engagement activities through appropriate training, support and opportunities.*

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<sup>14</sup> Beacons for Public Engagement, Higher Education Fundi <http://www.hefce.ac.uk/econsoc/buscom/bpe/ng> Council for England (HEFCE),

<sup>15</sup> Research Councils UK: Public Engagement, <http://www.rcuk.ac.uk/per/Pages/Home.aspx>

<sup>16</sup> Research Councils UK: Public Engagement, <http://www.rcuk.ac.uk/per/Pages/Home.aspx>

<sup>17</sup> Concordat for Engaging the Public with Research “NCCPE Briefing for Researchers”  
<http://www.rcuk.ac.uk/documents/scisoc/NCCPEbriefingsResearchersp5.pdf>

Vitae, The Engaging Researcher, 2010

[http://www.vitae.ac.uk/CMS/files/upload/The\\_engaging\\_researcher\\_2010.pdf](http://www.vitae.ac.uk/CMS/files/upload/The_engaging_researcher_2010.pdf)

- *The signatories and supporters of this Concordat will undertake regular reviews of their and the wider research sector's progress in fostering public engagement across the UK.*<sup>18</sup>

It will be obvious that despite the clear benefits for health and medical research having an engaged dimension, researchers need additional steps to be taken by research funding bodies to ensure these practices are undertaken. Why? At present in Australia, as was the case in the US and the UK, structural impediments currently exist to this form of research. Researchers are required to develop research proposals which meet criteria in use by research funding bodies. There is currently no incentive for researchers to undertake engaged research, as it is widely recognised that this form of research is more resource intensive, particularly in time requirements. That it produces positive outcomes cannot be taken into account if researchers wish to remain competitive. As was clearly articulated in the RCUK Concordat,

In many HEIs, staff and students feel they get little or no acknowledgment for the work they do around public engagement, evidenced for instance in the Royal Society's 2006 report 'Factors Affecting Science Communication: A Survey of Scientists and Engineers'. If people feel that their career prospects are not improved (or even sometimes jeopardised) by engaging with the public then many of them will choose not to.<sup>19</sup>

In contemporary Australia, as has occurred around the world, 'the public' has become increasingly involved in questions relating to their health and well-being. They wish to play a role in the work that is done to investigate health and medical questions. Increasingly too, researchers are recognising the value of engaging with the community when structuring, undertaking and developing outcomes from their research. It is time that Australia's national policy on Health and Medical Research reflected this new reality and promoted pathways to develop and support Australian community engaged health and medical research.

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<sup>18</sup> Concordat for Engaging the Public with Research "NCCPE Briefing for Researchers"  
<http://www.rcuk.ac.uk/documents/scisoc/NCCPEbriefingsResearchersp5.pdf>

<sup>19</sup> Concordat for Engaging the Public with Research "NCCPE Briefing for Researchers"  
<http://www.rcuk.ac.uk/documents/scisoc/NCCPEbriefingsResearchersp5.pdf>