



**National Aboriginal Community Controlled  
Health Organisation**  
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30<sup>th</sup> March 2012

To the McKeon Strategic Review of Health and Medical Research in Australia 2012

Thank you for the opportunity to provide comments into this important area for Australia's health care. Please see attached NACCHO's submission.

Yours sincerely,

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## Submission – McKeon Review 2012

The National Aboriginal Community Controlled Health Organisation (NACCHO) is the national peak Aboriginal health body representing over 150 Aboriginal Community Controlled Health Services throughout Australia.

An Aboriginal Community Controlled Health Service (ACCHS) or an Aboriginal Medical Service (AMS) is a primary health care service initiated and operated by the local Aboriginal community to deliver holistic, comprehensive, and culturally appropriate health care to the community which controls it (through a locally elected Board of Management).

In keeping with the philosophy of self-determination, Aboriginal communities operate over 140 AMSs across Australia. They range from large multi-functional services employing several medical practitioners and providing a wide range of services, to small services without medical practitioners, which rely on Aboriginal health workers and/or nurses to provide the bulk of primary care services, often with a preventive, health education focus. The services form a network, but each is autonomous and independent both of one another and of government. The integrated primary health care model adopted by ACCHSs/AMSs is in keeping with the philosophy of Aboriginal community control and the holistic view of health that this entails.

*'Aboriginal health is not just the physical well being of an individual but is the social, emotional and cultural well being of the whole community in which each individual is able to achieve their full potential thereby bringing about the total well being of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life.'* (NAHS, 1989).

The solution to address the ill health of Aboriginal people can only be achieved by local Aboriginal people controlling the process of health care delivery. Local Aboriginal community control in health is essential to the definition of Aboriginal holistic health and allows Aboriginal communities to determine their own affairs, protocols and procedures.

Thus, NACCHO represents local Aboriginal community control at a national level to ensure that Aboriginal people have greater access to effective health care across Australia. NACCHO provide a coordinated holistic response from the community sector, advocating for culturally respectful and needs based approaches to improving health and well being outcomes through ACCHSs/AMSs.

### **Research and the National Aboriginal Community Controlled Health Organisation**

Strategically, NACCHO is committed to promoting research that will build evidence –informed best practice in Aboriginal health policy and service delivery. This includes directions to prioritise research and evaluation in Aboriginal health that is conducted, commissioned or initiated by the ACCHS Sector.

NACCHO will work with relevant organisations to source funds to undertake collaborative, independent and commissioned research and evaluation; as well as recommend how research institutes allocate existing funds or source funds to address ACCHS Sector priorities.

NACCHO has been heavily involved in primary health care research for a number of years and currently has some large scale research programs underway. These directly contribute to better health outcomes for Aboriginal people as they are done in response to health service need, done by/with our services (and partners) and the outcome evidence promulgated by NACCHO to, national health policy representatives, the professional health sector, as well as our member organizations. This is true research translation.

In 2002, a double blind, multi center, randomized control trial was conducted by NACCHO (NACCHO Ear Health Trial) and in 2003 it was judged the best research published in the MJA. Of note was the fact that this project had several key elements that demonstrated the “community participatory” nature of research that can be conducted with Aboriginal community controlled health services. That is, Aboriginal people, not just as subjects, but in control of their own research. Currently the REACCH (Research Excellence in Community Controlled Health) project focusing on sexual health and blood born virus’s research, with partner the Kirby Institute and five Aboriginal community controlled health services continues. The Talking About The Smokes (TATS) projects are being conducted as well with up to forty Aboriginal community controlled health services involved. The QUMAX, (Quality Use of Medicines Maximised for Aboriginal and Torres Strait Islander peoples) program with partner, the Pharmacy Guild of Australia continues along with a plethora of high level research projects carried out by our affiliates and their partners. At local level, many Aboriginal community controlled health services are directly involved in research, and contribute the evidence base in Aboriginal and Torres Strait Islander health, often at significant resource cost to their own services. The lack of support means that services are sometimes forced to reluctantly decline to be involved in research because they do not have the resources to engage in it effectively. This underpins the need for significant capacity development thinking in health research funding and planning. Hence, NACCHO and Affiliates are involved in significant effective research effort.

### **Crosscutting NACCHO, NHMRC research themes**

#### **NHMRC Roadmap 2 a strategic framework for improving the health of Aboriginal and Torres Strait Islander people through research**

While the key principals of the NHMRC Roadmap 2 were developed in consultation with NACCHO and consistent with NACCHO approaches, there are seven new themes that are important to note, most significantly, working with NACCHO, the final of the new action areas for research.

- Increasing participation by Aboriginal and Torres Strait Islander researchers in NHMRC programs and in health and medical research generally
- Promoting and linking NHMRC’s activities in Aboriginal and Torres Strait Islander health with the activities of other stakeholders in Aboriginal and Torres Strait Islander health
- Contributing to the Australian Government’s *Close the Gap* health initiatives in Aboriginal and Torres Strait Islander health
- Supporting researchers in biomedical, clinical, health services and public

- health research to work collaboratively
- Supporting research endeavours that generate accessible and effective Clinical and public health medicine *in partnership with the Aboriginal Community-controlled health sector*.

### **Aboriginal and Torres Strait Islander health context of the McKeon review**

The terms of reference for the McKeon Strategic Review of Health and Medical Research are divided into four key sections across which Aboriginal health and research issues may sit. The more specific areas from NACCHO perspective are the final two areas, these are:

#### **Terms of Reference Key Section 3 - What are the strategic health and medical research directions and priorities and how might we meet them?**

##### **Our Comments**

- Aboriginal and Torres Strait Islander health should remain as a key priority in Australian health and medical research.
- One of the major constraints to improving Aboriginal health is the policy environment where the high levels decisions impacting on Aboriginal health and health care are constantly changing, inconsistent, and not based on evidence. There is insufficient research into the Aboriginal health policy environment, particularly within the Commonwealth government and public service. This neglect should be addressed as a priority.
- It should be noted that the key Australian strategic directions may not always reflect the Aboriginal priorities ( for example, the research priorities for health system responses to an ageing Australian population versus priorities for the relatively young and middle aged Aboriginal population)

#### **Terms of Reference Key Section 4 - How can we optimize the translation of health and medical research into better health and wellbeing?**

##### **Our Comments**

- The fact that there have only been generally small incremental changes in Aboriginal and Torres Strait Islander health from research translation means we need to get more serious about the structure of Aboriginal and Torres Strait Islander health research in Australia
- The current structural context for translation of new Aboriginal health research evidence into programs is ad hoc in terms of driving both policy and funding in Australia. There is a clear need for better linkages between researchers and policy makers, and critically, the need for Aboriginal expertise to ensure data is analyzed and translated in context for policy and funders to be effective in bringing about better health outcomes.
- A key issue is that the research is not being conducted in true partnership with the Aboriginal primary health care sector from the start. Even in so called “partnership grants’, the community controlled sector is often approached when the research is fully

developed. Research developed from the ground up with the sector will be much more likely to lead to changes in systems and processes of care than those that are developed by researchers in isolation with the only major decision to be made by services being whether they participate or not. Funding of research into ongoing critical infrastructure and system changes (such as changes to Clinical Information Systems) is also more likely to lead to sustainable changes in practice.

- While the policy environment and government implementation of research to policy to health programs can be challenging for all - the Aboriginal population is more sensitive to poor health policy and program implementation, than more healthy communities and hence will fare worse with poor research translation that occurs across Aboriginal affairs in Australia generally.
- The focus on academic track records, alone, is problematic as this doesn't necessarily contribute to improving Aboriginal health or Aboriginal health research. A different approach would be to give actual translation of research into results on the ground as high or higher priority than a CI's track record publications in peer reviewed journals. Success in this field should be measured by results not just publications.
- NACCHO has a proven track record in ensuring the research done in and with the Aboriginal community controlled sector is effectively translated into practice by the sector.

#### **Key broad linkages for strategic Aboriginal health research**

- Close The Gap activities and continuing poor health in Aboriginal communities
- National Health Reforms and opportunity to address Aboriginal health issues ( for example , clinical governance and the lead clinicians groups )
- Biomedical/Social health / cultural interface – influence of social determinants on physical health, qualitative and quantitative methods.
- The NHMRC Roadmaps 1 and 2
- Health data management and control principals set out by The National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID)
  
- Other important linkages are referenced below:
- *Approach to Research* – CRCAH website:  
<http://www.crcah.org.au/research/approachtoresearch.html>
- *Research Transfer* – CRCAH website: <http://www.crcah.org.au/research/researchtransfer.html>
- *Guideline for Ethical Research in Indigenous Studies* – AIATSIS (2000):  
[http://www.aiatsis.gov.au/\\_data/assets/pdf\\_file/2290/ethics\\_guidelines.pdf](http://www.aiatsis.gov.au/_data/assets/pdf_file/2290/ethics_guidelines.pdf)
- *Keeping Research on Track – A Guide for Aboriginal and Torres Strait Islander peoples about health research ethics* – NHMRC (2006):  
<http://www.nhmrc.gov.au/publications/synopses/e65syn.htm>
- *Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* – NHMRC (2003): <http://www.nhmrc.gov.au/publications/synopses/e52syn.htm>
- *National Statement on Ethical Conduct in Human Research* – NHMRC (2007) – Ch 4.7:  
[http://www.nhmrc.gov.au/publications/2007\\_humans/section4.7.htm](http://www.nhmrc.gov.au/publications/2007_humans/section4.7.htm)

- *National Aboriginal and Torres Strait Islander Health Data Principles – AHMRC (2006):*  
[http://www.aihw.gov.au/committees/nagatsihid/nagatsihid\\_data\\_principles.doc](http://www.aihw.gov.au/committees/nagatsihid/nagatsihid_data_principles.doc)

### **Key Principals**

While there are here are several key areas for strategic research with Aboriginal people in Australia that can be broadly addressed through this review process, which we will list, there are also a number of **key principals** and ethical and considerations that should underpin strategic directions.

- Respect for Aboriginal community control and holistic concepts of health and well being.
- Partnerships between NACCHO and government to ensure research analysis is contextualised and translated into meaningful policy and programs that capture broader aspects of culture and protocols to increase effectiveness.
- Cooperative partnerships that build aboriginal community controlled primary health care organisations research capacity
- Aboriginal participation in research on equal terms
- Understanding and building in to planning, the longer lead time and relationship building often required for researchers working with Aboriginal communities to ensure effective projects.
- “Community- controlled” model of *participatory* health research modeled by NACCHO in the ear health trial.
- Aboriginal participation in ethics committees
- The importance of primary health care research in addressing Aboriginal health
- The importance of research on capturing the evidence on effective programs and systems rather than just a deficits approach to documenting need or poor health.
- Research projects that include in their design and implementation, effective strategies for the transfer of knowledge and information related to the research to Aboriginal communities as well as to health services, governments and others who may use it.
- *Cultural security*: Health research must be culturally intelligible to Aboriginal people and must not compromise or endanger their legitimate cultural rights, values and expectations.
- *Cultural safety*: The conduct of research must provide an environment which is spiritually, socially, emotionally and physically safe for people; where there is no assault, challenge or denial of their identity, of who they are and what they need.
- *Intellectual and cultural property rights*: Researchers must respect the intellectual and cultural property rights of Aboriginal peoples in relation to knowledge, ideas, cultural expressions and cultural materials and ensure that culturally-restricted and culturally-sensitive information is protected from inappropriate use or publication.
- *Partnership* is an important element in performing research with the Aboriginal community controlled health services sector, but the term is often used too broadly, and is not reflected in the actual power relations, between Aboriginal community controlled health services and the academic institutions, research funders, or other research collaborators. Real partnership requires robust structures put in place with all partners fully accountable for their roles in the relationship and the process continuously monitored to ensure this mutual

accountability. In context, the Aboriginal community based partner often has less resources to support them fulfill their role, and this needs to be considered in the submissions.

- Regional partnerships for prioritization of Aboriginal and Torres Strait Islander Health research - A model developed in the Kimberley is a regional one stop shop for Aboriginal health research (the Kimberley Aboriginal Health Planning Forum Research Subcommittee). This partnership (where the Kimberly Aboriginal Medical Services Council is a key partner) has the function of being a point of contact for researchers who want to work in the region and provides advice to people as to how they may go about developing partnerships and addressing regional research priorities. This is not an ethics committee but is a way of assisting researchers to develop appropriate partnerships so that research might both be effective, useful, and to limit the burden on communities. This type of process requires funding for administration for it to be efficient. In this region, the actual work of the committee is provided by volunteers, and if done on a regional level this would work in many parts of Australia and have an important role in reviewing projects and assessing feasibility and priority at a regional level.

#### **Specific NACCHO strategic directions:**

- Support for NACCHO to build capacity in collaborative research. NACCHO proposes an investment in a NACCHO research coordinator to develop and promote strategic linkages with appropriate research organisations to pursue NACCHO research priorities. This position could be supported through research capacity building programs.
- Investment in building research capacity in NACCHO affiliates for both stand alone and collaborative research programs. For example: Potential for regular special initiative grants for ACCH Sector led research, for larger ACCHS or representative bodies to work in partnership with academic institutions, with the ACCHS sector as the lead.
- Ensure that Aboriginal health research and evaluation projects must have a clear purpose that respond to ACCH Sector priorities and help identify improvements in health experiences and outcomes for Aboriginal Peoples,
- Ensure that the learning gained must have the capacity to shape decisions about service delivery needs and models, funding, management and monitoring in Aboriginal health.
- While the NHMRC allocates 5 percent of its research budget to Aboriginal and Torres Strait Islander research projects, there is a need to ensure a significant proportion is allocated specifically to Aboriginal investigators and Aboriginal community controlled health services collaborations, rather than just external researchers, unless they have formal partnerships with local Aboriginal community or Aboriginal community controlled health services. If there is a dearth of Aboriginal and Torres Strait Islander specific health research applications this unused funding should be made available to building the obvious lack of capacity in this sector.
- Acknowledgment and recognition of regional and local Aboriginal community controlled health services HRECs. While it may be logistically and culturally challenging to have a single national Aboriginal HREC (and to have a mandate and responsibility to speak for local cultural protocols) there is a need to review and develop how Aboriginal and Torres Strait Islander people are engaged in HREC arrangements.
- Increased Aboriginal *community based Action Research* methodologies – this has mainly been qualitative and patchy in the past, but there is a need to develop more of the

methodology with respect to clinical and intervention research based on the principals documented in the NACCHO Ear Trial.

- In addition to intervention and evaluation research, there is also a strong need for implementation research – how do we put into practice what we already know is likely to be effective in the range of settings where interventions that could improve Aboriginal health are implemented? What works in practice for transferability and scaling up.
- There is a need for more research on the newer health data linkages work, in terms of the cost effective use of health related information, and, examining data governance ownership and control principals from Aboriginal and Torres Strait Islander perspectives. This includes critical research on how this data is contextualised analysed and used and its limitations.
- Supporting the development of the structure of Aboriginal and Torres Strait Islander primary health care research with regards to NACCHO as the national peak body, therefore necessarily, involvement and leadership in any national Aboriginal health research programs. Following on from this the importance of the NACCHO state and territory affiliates as jurisdictional research leaders, and local services at local level. This may require significant resource support. In addition, there is a strong need for a sustainable resourcing model for ACCH sector roles of providing support to the research sector to facilitate the conduct of high quality Aboriginal health research. This includes sustainable adequate funding for Ethics Committees, such as the AH&MRC Ethics Committee, and also for the large amount of advice and support that is (or could be if we had capacity) provided to an increasing number of researchers and research teams about research methods, community engagement strategies, appropriate structures for Aboriginal community governance of research, analysis, interpretation, relevance for policy and practice, dissemination and feedback. Building research support infrastructure within NACCHO and Affiliates would be an investment in improving the quality of Aboriginal health research, as well as providing a mechanism for this research to be put into both policy and practice because our sector is very active in each of these areas, and their intersection.
- Because improvements in Aboriginal and Torres Strait Islander health are intractably related to social determinates and the lived context of Aboriginal and Torres Strait Islander peoples, there is a need for qualitative research that captures these relationships.
- There is a need for realistic lead time for this type of process to ensure genuine partnerships between ACCHS and academic institutions are in place.
- The RGMS system and the complicated application process is a potential barrier to ACCHS Chief Investigators and this needs to be addressed. This process could include experienced external researchers providing mentorship, alongside Aboriginal leadership, to improve the project.
- Ideally, funding for Aboriginal and Torres Strait Islander primary health care research would be for 5 years to allow plenty of time for development of the project with ACCHS / communities, carrying out the research, and starting to translate research findings into health service policy and delivery.
- There needs to be an acknowledgement that research in Aboriginal primary health care is more expensive, often take longer, and that each project should incorporate capacity building of local Aboriginal people and organisations.

- The development of MOUs between NACCHO and research bodies and the importance of compliance with the principals agreed to.
- Increased NACCHO involvement and influence over the collection, analysis and translation of Aboriginal health information and research. This could be addressed by a formal partnership agreement between the Department of Health and Ageing, the Australian Institute of Health and Welfare and NACCHO

The Canadian experience in creating the First Nations Information Governing Center (FNIGC), with the tribal leadership in Canada is a model where First Nations health data collection and research is *controlled and operated by the FNIGC as mandated by the tribes*. The First Nations principals are OCAP, that is, Ownership, Control, Access and Possession, and this center performs the major RHS (Regional Health Survey) for First Nations communities and is the repository of this data. Implicit in the creation of the FNIGC was the investment in building research and data collection capability in First Nations peoples.

### **Key Conclusions:**

- Aboriginal and Torres Strait Islander health remains a key priority for medical and health research in Australia.
- NHMRC continue to fund at least five percent of its research budget to specific Aboriginal health research, with a specific proportion directed to Aboriginal investigators and the Aboriginal community controlled primary health care health sector.
- The review considers real reform of the way in which research funding is driven by investigator publication success alone, rather than successful outcomes of research in practice.
- Support health research that examines the key role of high level policy and bureaucratic structures in the slow improvements in Aboriginal and Torres Strait Islander health.
- Ensure the “principals” listed are considered in health and medical research in Australia
- Ensure NACCHO is formally structurally involved in Aboriginal primary health care research and any national Aboriginal primary health care research projects
- Support increased development of community controlled PAR process’ with the Aboriginal community controlled health services sector
- Increase the investment in developing the strategic research capacity of NACCHO and its members, hence the capacity of all Aboriginal and Torres Strait Islander primary health care research.
- Ensure research in Aboriginal primary health care is prioritized and is relevant and responsive to our sectors need.

NACCHO gratefully acknowledges the Aboriginal Medical Services Alliance of the Northern Territory (AMSANT) Research Protocols used in this submission and the contribution by the NACCHO Affiliates.