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ESTABLISHING *a* COMMUNITY- CONTROLLED MULTI-INSTITUTIONAL CENTRE *for* CLINICAL RESEARCH EXCELLENCE *in* ABORIGINAL *and* TORRES STRAIT ISLANDER HEALTH

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■ Abstract

The Queensland Aboriginal and Islander Health Council (QAIHC) lead and govern the Centre for Clinical Research Excellence (CCRE), which has a focus on circulatory and associated conditions in urban Aboriginal and Torres Strait Islander communities. The CCRE is a partnership between QAIHC and Monash University, the Queensland University of Technology, the University of Queensland, James Cook University, the National Heart Foundation, and the University of Wollongong. The establishment of the CCRE under the community-controlled model of governance is unique and presents both opportunities and challenges for innovative partnerships between universities and Aboriginal and Torres Strait Islander community organisations. This paper outlines the processes and strategies used to establish a multi-institutional research centre that is governed by the Aboriginal and Torres Strait Islander community-controlled health sector.

■ Introduction

The Queensland Aboriginal and Islander Health Council (QAIHC) lead and govern the Centre for Clinical Research Excellence (CCRE), which has been funded by the National Health and Medical Research Council (NHMRC). The CCRE research programme focuses on the prevention and management of circulatory and associated diseases, such as heart and kidney disease, in Aboriginal and Torres Strait Islander peoples living in urban areas. Circulatory and related conditions are one of the major causes of excess morbidity and mortality in Aboriginal and Torres Strait Islander people in Australia. This is heightened when circulatory disease is combined with other co-morbidity diseases (e.g., Valery et al., 2005). The CCRE is a partnership between QAIHC and Monash University, the Queensland University of Technology (QUT), the University of Queensland (UQ), James Cook University (JCU), the National Heart Foundation (NHF), and the University of Wollongong (U of W). The establishment of the CCRE under the community-controlled model of governance is unique and presents both opportunities and challenges for innovative partnerships between universities and Aboriginal and Torres Strait Islander community organisations to improve the burden of illness through community-driven research. This paper will outline the role of QAIHC, why circulatory disease and associated conditions in urban Aboriginal and Torres Strait Islander communities is a focus, and the processes and strategies used to establish a multi-institutional research centre that is governed by the Aboriginal and Torres Strait Islander community-controlled health sector.

Who is QAIHC?

The Queensland Aboriginal and Islander Health Council (QAIHC) is the State peak body for Aboriginal and Torres Strait Islander community-controlled health services in Queensland and is the

State Affiliate of the National Aboriginal Community Controlled Health Organisation (NACCHO). QAIHC was established in 1990. Since establishment, the number of Aboriginal and Torres Strait Islander community-controlled health services in Queensland has grown significantly to 23 (AIH&W, 2005). QAIHC also has significant partnership arrangements with other health-related community-controlled sectors in Queensland through the child protection and alcohol and other drug organisations. The role of QAIHC is to:

- Build the capacity of Aboriginal and Torres Strait Islander health services in relation to planning, development and provision of health care to their communities.
- Provide the link between the Aboriginal and Torres Strait Islander health services and the government and non-government sectors.
- Promote, increase, develop, and expand the provision of health services through the community-controlled services model.
- Liaise with government, non-government and private sector health service providers on matters relating to Aboriginal and Torres Strait Islander health and health research.
- Assess the health needs of Aboriginal and Torres Strait Islander communities and take steps to address identified needs.

QAIHC leads and governs the Centre for Clinical Research Excellence. How QAIHC undertakes this leadership will be explained after outlining how the core area of research was determined.

Why circulatory and associated conditions in urban Aboriginal and Torres Strait Islander communities?

Although a large proportion of the Aboriginal and Torres Strait Islander population is located in urban areas (ABS, 2002), there is a significant gap in the health research literature about the health needs and health outcomes of this population group. Much of the work done has been through cross-sectional studies (Grove & Brough, 2003; NHMRC, 2002). This gap in the literature has also been recognised by the National Health and Medical Research Council's (NHMRC) Roadmap to Improve Aboriginal and Torres Strait Islander Health through Research (NHMRC, 2002).

Aggregate health statistics cannot be easily applied across the whole of Australia. Contrary to popular misconception, there is considerable heterogeneity on a state and regional basis and between remote and urban populations. There is marked heterogeneity in mortality, hospital separations, rates of renal replacement therapy (RRT), self-harm, rates of chronic diseases, child health, and infant mortality and birth weights. Of the few population-based studies

reported, most have been in remote communities (NHMRC, 2002). Much less is generally known about the health needs and outcomes of Aboriginal and Torres Strait Islander people living in and around major cities even though this urban and peri-urban population represents approximately two-thirds of the entire population across Australia (ABS, 2002; Grove & Brough, 2003; Ivanitz, 1999; Queensland Health, 2006). Aboriginal and Torres Strait Islander people access health care services differently to the non-Indigenous population with under utilisation of the Pharmaceutical Benefits Scheme, the Medicare Benefits Scheme, specialist services, and general practitioner consultations. There has also been limited research exploring the differences between rural and remote Aboriginal and Torres Strait Islander populations and urban and peri-urban populations in relation to access, availability of and delivery of general medical, specialist medical and hospital services.

A suggestion for this gap in knowledge is due to the difficulty associated with identifying and targeting urban Aboriginal and Torres Strait Islander people as they are not in a defined geographical area like their rural and remote counterparts (Hunt et al., 1998; Queensland Health, 2006). This notion is further compounded by the knowledge that under-identification of Aboriginal and Torres Strait Islander people (in health service settings especially) has always been of concern (AIH&W, 2005; Jackson Pulver et al., 2003). A major challenge is the issue of correctly identifying and targeting those individuals at need. A suggested method for researchers to specifically target Aboriginal and Torres Strait Islander people living in urban areas is to form strong collaborations with community-based organisations such as community-controlled health services (Groves & Brough, 2003). Community-controlled health services are governed by a board of directors, which are representative of their local Aboriginal and Torres Strait Islander community. These services provide comprehensive primary health care services, population health services and programmes, facilitate access to secondary and tertiary care services, and support and enable advocacy within the community. Some studies have worked closely with the community-controlled health sector to access the urban Aboriginal and Torres Strait Islander population, and different sections of the population such as mothers and babies in Townsville (Panaretto et al., 2005), the utilisation of pap smear services by women in Darwin (Hunt et al., 1998), the health and well-being of Melbourne youth (Brady et al., 2002) and cardiovascular risk in adults in Perth (Thompson et al., 2003). Limited work focusing on prevention and management of circulatory and related conditions in urban Aboriginal and Torres Strait Islanders has been undertaken.

■ The development of the CCRE research programme

In January 2004, a collaboration of non-government and university organisations and individuals met to discuss strategies in which they could address the gap in knowledge on prevention and management of circulatory and related conditions in urban Aboriginal and Torres Strait Islander communities. They represented a variety of organisations including the Queensland Aboriginal and Islander Health Council (QAIHC), the Queensland University of Technology (QUT), University of Queensland (UQ), James Cook University (JCU) and the National Heart Foundation of Australia (NHF). The Brisbane Aboriginal and Islander Community Health Service (AICHHS), Kambu Medical Centre and the Townsville Aboriginal and Islander Health Services (TAIHS), all community-controlled health services, were involved in these strategic discussions, as was the Inala Indigenous Health Service, which is a Queensland Health service. As a result of these discussions a full submission was prepared to the NHMRC to acquire funding for a Centre for Clinical Research Excellence (CCRE), dedicated to bridging the gap in urban Aboriginal and Torres Strait Islander health. The CCRE's overarching aims are to support research to improve health outcomes in the community, support training and professional development of Aboriginal and Torres Strait Islander health workers and health professionals, increase the opportunities for Aboriginal and Torres Strait Islander researchers, and translate research findings to improve health service practice, influence policy and investments in Aboriginal and Torres Strait Islander health. The proposal was successful in gaining funding from the NHMRC for the next five years.

The CCRE research programme aligns with the NHMRC Roadmap to improve Aboriginal and Torres Strait Islander health through research with all research conducted under the major thematic areas:

- Descriptive research that outlines the pattern of risk, disease and death as it related to circulatory disease in urban populations.
- Identifying points in the life cycle when interventions are likely to be most effective and the life skills and knowledge needed for this.
- Health services research that will inform decision-making in relation to practice and funding for health services.
- Research that will improve outcomes in relation to circulatory disease in Indigenous communities through other sector initiatives.

The CCRE research programme has four programme areas that interconnect with the Roadmap's thematic areas. These are:

- Improving the prevention and management of circulatory and associated conditions.
- Improving access to health services and programmes.
- Health system development and reform.
- Building capacity and enabling health research.

In May 2005, a planning workshop was conducted at Mt Tamborine in the Gold Coast hinterland which brought together all of the key stakeholders involved in the CCRE. This marked the first occasion that the QAIHC Executive and CEO, all Chief Investigators, most Associate Investigators and representatives from each of the participating health services met face-to-face. The purpose of the workshop was to hold a series of discussions in order to set short-, medium- and long-term priorities that needed to be achieved to ensure the success of the CCRE. At the conclusion of the planning workshop, a work plan was produced which expanded all elements of the research programme that was outlined in the original grant application. Monash University was not a partner institution in the original grant application. They became a CCRE partner institution in 2007.

■ CCRE Research Principles

The CCRE Research Principles were developed and designed as a guide for researchers wishing to undertake projects and study within the CCRE and the community-controlled health services sector in Queensland. They are based on the National Health and Medical Research Council (NHMRCs) Criteria for Health and Medical Research of Aboriginal and Torres Strait Islander Australians, which are:

- Community engagement and participation
- Benefits
- Sustainability and transferability
- Capacity-building
- Priority and significance

The CCRE Research Principles which have been presented to all stakeholders involved with the CCRE and endorsed by the QAIHC Board of Directors require any research project undertaken within the CCRE and the community-controlled health services sector in Queensland to be based on:

Identified need

Research projects must be in response to identified community and health service needs and priorities. Having the AICHHS involved in the development of the full project brief will assist this process as the respective board of management needs to endorse any research projects undertaken.

Action oriented

Research projects must contribute to change within the health service and demonstrate benefit to the community. Outcomes need to be direct and tangible – for example, funding, human resource management, education and training, clinical practice, workforce development and planning, building the evidence base, community development, and capacity-building.

Skills/knowledge transfer

The methodology of research projects should reflect Aboriginal and Torres Strait Islander people's involvement at all levels of the research project. A clear strategy for knowledge and skills transfer should be an explicit component of any research project. Skills and knowledge transfer strategies should be agreed to with the health service at the start of the project.

Acknowledgement

Research projects must explicitly recognise the contributions of individuals, community groups, and health services in the research process.

Consultation

The research project must have appropriate consultation strategies in place to ensure that the information collected is interpreted in a true and accurate way. Within local Aboriginal and Torres Strait Islander communities and health services there are existing processes for consultation and engagement.

These consultation strategies should occur at the critical stages of a research project, including:

- initial engagement in the research project (telling people about the project brief and confirming support for the project);
- agreement on strategies for consultation, information collection, and working with the health service and community;
- the feedback processes that will be put in place for verification of the information collected;
- acknowledgement of the individual(s) and community-controlled health service's involvement in reports, materials, publications etc resulting from the research project; and,
- agreed mechanisms in place for disseminating information and translating skills and information.

Aboriginal and Torres Strait Islander ownership of information

Recognition that information and data collected or related to the Aboriginal and Torres Strait Islander

community is owned by the community. Therefore, decisions about the interpretations of, and ways in which this information is to be used, need to be agreed to by the community.

Aboriginal and Torres Strait Islander ways of working

Recognition and demonstrable support in the research project for Aboriginal and Torres Strait Islander ways of working as culturally valid and valued in research input, output, and outcomes. This means that there is also recognition of diversity between Aboriginal and Torres Strait Islander people and communities.

Community control

Community control of health is the fundamental premise on which Aboriginal and Torres Strait Islander community-controlled health services develop. These services are initiated by their local Aboriginal and/or Torres Strait Islander community to provide high quality, culturally appropriate comprehensive primary health care.

These are the agreed upon core CCRE Research Principles which are required for any research project undertaken within the CCRE and the community-controlled health services sector in Queensland. This is not to say that additional principles may not be included when working with an individual health service or community.

■ *Governance and community control of the CCRE*

The governance structure and processes of the CCRE is underpinned by the operating values and principles of self-determination and community control. The principle of community control requires that ownership and governance of the CCRE is vested in Aboriginal and Torres Strait Islander people as reflected by the management and research strategies. The CCRE is led by the QAIHC, the governing and peak body for Aboriginal and Torres Strait Islander health in Queensland. The key partner institutions include Monash University, QUT, UQ, JCU, U of W and the NHF, as well as the four participating health services. A CCRE Executive Committee has been established and includes representatives from each partner institution and whose role is to set the strategic direction of the CCRE Research Program. A CCRE Research Advisory Group (RAG) has also formed whose role comprises technical oversight of the development, implementation and evaluation of the CCRE Research Program.

One to the key milestones of the CCRE Work Plan was the establishment of a dedicated CCRE office and the employment of staff within QAIHC. A transition CCRE Manager and a Senior Research Officer were employed to co-ordinate and establish the operational

framework and research beginnings of the CCRE. Since this time, the Manager has now transitioned into the CCRE Director (Leilani Pearce) and the Senior Research Officer position has transitioned into the Research Manager (Bronwyn Fredericks) to better reflect the roles and functions of the CCRE. The CCRE and QAIHC are extremely grateful to Simone Nalatu (CCRE Senior Research Officer) for the hard work and dedication she provided to the CCRE's establishment. The CEO of QAIHC has overall responsibility for the administration of the CCRE.

Parallel to the formalisation of processes and procedures for the CCRE, has been the incremental development of specific research priorities of each of the four participating health services, that is, the pieces of work that will be undertaken. In order to accomplish this, a series of meetings were organised. First there was a workshop which was specifically dedicated to the health services and was organised to provide opportunity for health services to voice their concerns, clarify issues and ask questions. The purpose of the meeting was two fold. Firstly the CCRE unit was extremely keen to gain advice from each of the health services about the operational aspects of the Centre – how the projects would be conducted, who would conduct the research, and what were the health services expectations of the CCRE. The second purpose of the workshop was to encourage the health services to collectively start thinking about the pieces of work they wanted undertaken. At the conclusion of the workshop there was a clear indication from each of the health services about the types of work/projects for the CCRE. The health services also had general agreement about those operational aspects of the CCRE that needed to be in place. These operational aspects included – the development of an information package, an endorsement process with the respective boards of management within each service, the development of CCRE Research Principles to guide research within the Aboriginal and Torres Strait Islander health services sector.

Second was a joint meeting between the Research Advisory Group and the health services. This was organised in order to inform the Research Advisory Group of the outcomes from the Health Services Workshop, and to then commence discussions to select and prioritise the pieces of work that would be undertaken by the CRE in the short-, medium- and long-term. This was a significant step in the progression of the research programme as it provided the chief investigators and members of the health services the opportunity to discuss and debate how and when the work would be carried out as well as who would lead the work. At the conclusion of this meeting a document outlining the work to be completed was produced.

Practical health service research, which has full and formal participation and is led by Aboriginal and Torres

Strait Islander people, is the platform of the CCRE. The Research Program is being implemented and the Profiling Health Services Project is currently profiling each health service and describing the delivery of chronic disease prevention and management services and programmes within their community.



Developing a base of Indigenous health researchers and knowledge

The CCRE has as one of its goals to develop a base of Aboriginal and Torres Strait Islander health researchers. The term “Indigenous researcher” brings about a range of labels. It could be assumed that the researchers will work with Indigenous people as the objects of research and that the researchers are Indigenous. Both of these assumptions would be correct. However, there are other aspects that also need to be considered. It could be considered that Indigenous researchers are both subject and object. What additionally needs to be considered is that many Indigenous people who undertake formal academic studies or who have worked within mainstream services previously have been taught how to teach and research using Western frameworks and disciplinary methodologies that at times can further colonise and apply imperial measures on Indigenous knowledges. The CCRE Aboriginal and Torres Strait Islander researchers will be encouraged to interrogate what we have learnt, look at how we use what we have learnt, how we act, and how we can assist in perpetuating the negative type of research that has happened within Aboriginal and Torres Strait Islander communities in the past.

Nakata explains that one issue for Indigenous scholars is how to speak back to the knowledges that have been formed around what is perceived as Indigenous positionings within Western worldviews (1998, p. 4). Nakata essentially asks “how do we speak to what is known about us, written about us and not owned by us?” We as Aboriginal peoples and as Indigenous researchers need to challenge what is written about us and what knowledges are controlled about us, otherwise we will continue to perpetuate the untruths and the ways in which we are marginalised and misrepresented/represented (1998, p. 4).

If we are to bring about change to the way people think about us, know us as Aboriginal and Torres Strait Islander peoples in theoretical, learnt settings, then we must be part of these environments. We must challenge the current knowledge bases and ways of acquiring knowledge about us. In this challenge, Rigney asserts that we as “Aboriginal researchers who wish to construct, re-discover and/or re-affirm Indigenous knowledges must function in traditions of classical epistemological methods of physical and/or the social human sciences” (1997, p. 6). Nakata argues that “in order to understand our position better and to ultimately act to improve it, we must

first immerse ourselves in and understand the very systems of thought, ideas and knowledge that have been instrumental in producing our position" (1998, p. 4). This is not to say that we need to embrace or fit within the classical epistemological methods of these sciences. We need to know how these sciences are constructed. We need to know how they are used and how they impact upon us, as Indigenous peoples. If we do not, we serve to assist in further colonisation and maintaining our positioning.

Some Indigenous researchers such as Rigney (1997, 1999, 2001) and Warrior (1995, 1999) give varied suggestions as to how best research Indigenous peoples and determining what is Indigenous research and who are Indigenous researchers. They both discuss ways of decolonising, repositioning and supporting Indigenous knowledges. Rigney (1997, p. 2) suggests the concept and principles of an Indigenist methodology, as a, "step toward assisting Indigenous theorists and practitioners to determine what might be an appropriate response to de-legitimise racist oppression in research and shift to a more empowering and self-determining outcome" (1997, p. 2). Rigney's work builds on the scholarship from the work of a number of African-American researchers (e.g., Asante, 1987, 1988, 1990) who discuss Afrocentric emancipatory methodology while critiquing dominant epistemologies. Asante's (1987, 1988, 1990) work in particular provides inspiration for viewing and challenging knowledge usage and positionings of marginalised peoples. Rigney (2001) additionally builds on the work of Warrior (1995, 1999) whose research efforts have stressed the need for Indigenous intellectual sovereignty (1995, 1999). He maintains that Native American intellectual traditions need the freedom to break away from the constraints of the Western academy (1999, p. 11). In his argument, Warrior outlines that sovereignty is the path to freedom via a process of emergence for Indigenous peoples, as a group or collective (1995, p. 91). He provides direction that intellectual sovereignty is a process; it is not about outcome (1995, p. 91). It is about the speaking, reflecting and articulation through a range of means about the Indigenous struggle and what strategies to freedom are needed. Rigney, in his interpretation of Warrior's writings, outlines that

If Indigenous intellectual sovereignty is to be emancipatory it must be 'process driven' rather than outcome oriented ... it is now for Indigenous scholars committed to sovereignty to realise that we too must struggle for intellectual sovereignty and allow for the definition and articulation of what that means to emerge as we critically reflect on our struggle (2001, p. 10).

In order to bring about the required changes within the knowledges bases, there must be a link between research and the political struggle of our

communities. This link needs to be in and through those Aboriginal and Torres Strait Islander Australians who are simultaneously engaged in research and the Aboriginal and Torres Strait Islander struggle. From this understanding, the CCRE and QAIHC are well positioned. As the peak body for Aboriginal and Torres Strait Islander health and the community-controlled health services sector, QAIHC is within the day-to-day broader political struggle for improvements in Aboriginal and Torres Strait Islander health. As the CCRE is positioned within and governed by QAIHC and it will increasingly inform and support the work of QAIHC; it is intrinsically linked within this struggle too. It is within this realm that the Aboriginal and Torres Strait Islander health researchers will dwell. The simultaneous linkages and engagement will be in action within QAIHC, the community-controlled health service sector and the CCRE. Rigney asserts that "only in this way can research responsibly serve and inform the political liberation struggle" (1997, p. 2). With Rigney's words in mind, the CCRE is well positioned to research responsibly and to serve and inform the struggle for better health for Aboriginal and Torres Strait Islander peoples.

■ Conclusion

This paper has outlined the development of the Queensland Aboriginal and Islander Health Council (QAIHC) led and governed National Health and Medical Research Council (NHMRC) Centre for Clinical Research Excellence (CCRE) in Circulatory and Associated Conditions in Urban Aboriginal and Torres Strait Islander communities in Queensland. The CCRE is a partnership between QAIHC and Monash University, the Queensland University of Technology (QUT), the University of Queensland (UQ), James Cook University (JCU), the National Heart Foundation (NHF), and the University of Wollongong (U of W). The establishment of the CCRE under the community-controlled model of governance is unique and presents both opportunities and challenges for innovative partnerships between universities and community organisations. This paper has outlined the role of QAIHC and why circulatory disease and associated conditions in urban Aboriginal and Torres Strait Islander communities was pursued as the area of focus for the CCRE. It has additionally outlined the processes and strategies used to establish a multi-institutional research centre that is governed by the Aboriginal and Torres Strait Islander community-controlled health sector. The words of Rigney (1997, 1999, 2001), Nakata (1998), Warrior (1995, 1999) and others give us inspiration that we can foster ways of working within the CCRE that are responsive to Aboriginal and Torres Strait Islander peoples, that encompass empowering strategies, education approaches, skills development, broadening ownership and in returning the outcomes of this research in ways

that Aboriginal and Torres Strait Islander peoples can use and incorporate for Aboriginal and Torres Strait Islander peoples. As the community-controlled health sector moves forward to realise the increasing capacity of the CCRE to influence and work towards change for the health of Aboriginal and Torres Strait Islander peoples, it is useful to reflect on the words of Kenny:

Aboriginal research is an opportunity for us to create innovation and change for our people. If we develop an approach to research which is unique and reflects our values and beliefs, we will be reflecting the spirit of our ancestors, the spirit of our people who are alive today, and the spirit of our Aboriginal children who are yet to be born (2000, p. 148).

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Bronwyn Fredericks has been actively engaged with Aboriginal and Torres Strait Islander controlled community-based organisations for over 25 years. She has worked as an educator and activist within schools, universities, and communities.