Improving the management of chronic conditions of Indigenous Australians through Indigenous research

Glenn Giles, Merridy Malin, Peter Harvey, Centre of Clinical Research Excellence in Aboriginal and Torres Strait Islander Health

It should be well understood by Australians that Aboriginal and Torres Strait Islander Australians are among the most, if not the most, disadvantaged people in Australia. It has become more widely appreciated over the past decade that one dimension of this disadvantage is that Indigenous Australians are afflicted by chronic, or long-term, illnesses at much higher rates than other Australians. For instance, diabetes occurs among Aboriginal Australians at about four times the rate as for other Australians. (The more colloquial expression, ‘long-term conditions’, is apparently being preferred to ‘chronic conditions’ in the United Kingdom’s health system.)

Rather than focus on statistics about the greater burden of ill-health among Indigenous Australians, this paper outlines the creation of a research partnership, the Centre of Clinical Research Excellence in Aboriginal and Torres Strait Islander Health (CCRE) based at the Aboriginal Health Council of South Australia (AHCSA). The project focus is chronic illnesses among Aboriginal Australians. We aim to develop the ability of Aboriginal Health Services and Aboriginal patients to work together to manage the impacts of ongoing serious illnesses. Research and evaluation work about social services and programs for Aboriginal peoples show better service access where Aboriginal people deliver those services. Longitudinal studies of Aboriginal people in the Northern Territory (NT) have shown that the growth of Aboriginal Medical Services in the NT has had positive effects on the health of the communities they serve.

Research is important as it can help reveal the reasons for outcomes and identify ‘what works’, providing vital information for policy makers. The research practice we are pursuing, and our support increasing the research capacity of Aboriginal health services (AHSs) and Aboriginal people, aims to reform research practices involving Aboriginal people and communities. We aim to increase their involvement in, control of, and determination of such research. The Co-operative Research Centre in Aboriginal Health has strongly articulated this agenda. This agenda is partly informed by the analysis that Aboriginal patients receive more effective health services from Aboriginal health workers and professionals.

A symposium of senior researchers and others involved with this CCRE project, at about its half-way point, reflected on its progress so far. Symposium contributors from the Aboriginal Health Services (AHSs) with which we are working highlighted some major issues external to research that impact on the partnership’s research work. These constraints on the AHSs have slowed progress on individual research projects and associated work. It is not yet possible to report clinical results from these research projects. Progress is being made in individual projects, and there are others lessons to be drawn from the work thus far. In general it can be said that the capacities of AHSs varies significantly, and often their ability to engage with research projects is restricted by a range of matters, including staff resources and demands involved in participating in research work.

The work of this CCRE is pursuing research with AHSs in an ethical way that respects Aboriginal identities and rights to self determination, and helps develop the research capacities of AHSs and Aboriginal people in the ‘health sector’. This approach unavoidably involves a longer ‘start-up’ time frame than commonly permitted in academic research. There is a shortage of Aboriginal people with recognised research skills to work on research projects, and AHSs don’t have adequate funds to have enough staff dedicated to research work.

These lessons about AHS research capacities need recognition and appropriate policy responses. To increase the ability of AHSs to engage in health research with their communities the AHSs need resources—financial, technological and human. The main research and project work of this CCRE is focused on clinical approaches to managing Aboriginal patients with chronic or long-term illnesses.
Research partnership in Aboriginal and Torres Strait Islander health

The Centre of Clinical Research Excellence in Aboriginal and Torres Strait Islander Health (CCRE) was established with a National Health and Medical Research Council (NH&MRC) five year grant to conduct high quality Aboriginal controlled health systems research in Aboriginal communities focusing on preventing and managing chronic and complex conditions, eg diabetes and cardiovascular disease. Our projects develop the health research capacity of Aboriginal communities by supporting and providing training for Aboriginal Health Workers and community members that focuses on developing research skills. Research evidence from work associated with the Centre is used to influence primary care, clinical practice and health policy. This evidence informs workforce training that is conducted by various researchers involved in the project.

The overall objective of this CCRE is to contribute to improving the health of Aboriginal and Torres Strait Islander Australians. The rationale behind the Centre is that it is essential, in clinically addressing the high rates of long-term illnesses among Aboriginal Australians, to identify and develop more effective approaches to managing these conditions. This includes building the capacity of AHSs to deliver the most effective approaches. Good quality research can be an important element of achieving improvements in Aboriginal and Torres Strait Islander health, to the extent that its implications inform policies, from the operation of services to national government policies.

Our focus on chronic conditions is a response to the growing incidence of chronic conditions among Australians, recently manifest among Aboriginal and Torres Strait Islander Australians at substantially higher rates than for other Australians. Prior to establishing this partnership, working relationships existed between parts of the Aboriginal community health sector and various health researchers. The work of this project builds on the previous projects. A common element across these projects is that they address developing the ability of Aboriginal patients and health services to manage chronic conditions. This paper covers some of this work. From the Aboriginal health services directly involved in this project, and as also indicated in reports of other organisations in the sector, an ongoing issue for them to maintain their involvement in research project work is that such work can impact on their ability to meet the demands of patients with issues needing immediate attention.

The range of projects associated with this CCRE includes the following.

Care Plans and Integrated Self-Management

An important focus of much of the work associated with this CCRE is developing and using patient care plans as part of integrated approach to managing patients with chronic illnesses. This work aims to support increasing the capacity of Aboriginal health services to develop systems and processes involved in ongoing monitoring and caring for patients with ongoing chronic illnesses. It includes ‘skilling-up’ Aboriginal health service staff in the use of various interview tools with patients. These tools increase patients’ knowledge of their illness(es) and encourages them to be more involved with health professionals in making decisions about their treatment, be more committed to following an agreed care plan, and be better equipped to deal with the range of impacts on their life from the conditions they endure, including adopt life habits more conducive to improved health.

Mental Health Issues

Researching mental health issues in metropolitan, rural and remote Aboriginal communities is another area CCRE partners are involved in. One area of focus has been the Aboriginal people in the Eyre Peninsula area, where data shows there are many in the community who are affected in complex ways, with issues including substance misuse, grief and loss, other physical health problems, social isolation and often having ‘trouble with the law’. The research found a great deal of similarity in issues in different areas of South Australia. A central focus was on medication management for Aboriginal people with mental health disorders. The research found a lack of education about medication, insufficient services lacking co-ordination, and unsafe practices. Informed by principles of participatory
action research, the study team’s response included, where they had the capacity, education of the workforce and community; improving access to and safe handling of medications; co-ordinating care of Aboriginal people with mental health issues; organising safe care of intoxicated people; and assisting with advocacy for increasing capacity of Aboriginal services and communities. The team is striving to continue its work of improving the safe management of medications.  

Aboriginal Self-Management Program

A key element of the work of this CCRE is a self-management course created by Aboriginal Australians for Aboriginal Australians, which has initially been developed through Pika Wiya Health Service (in Port Augusta). At Pika Wiya, the self-management team, with support from the Spencer Gulf Rural Health School (SGRHS, based in Whyalla), developed a self-management approach based on the work of Professor Lorig and her colleagues (of Stanford University, California). To make the program more culturally acceptable to Aboriginal people, Kate Warren (SGRHS) and Fiona Couthard (Pika Wiya), who are both Aboriginal women, worked with Aboriginal chronic illness patients in the Sharing Health Care SA chronic condition self-management project. They developed a course aiming for an integrated model of chronic conditions management, including self-management training and health promotion. Kate and Fiona have called this the LIFE course (Living Improvements For Everyone).

We aim to test this self-management model across several sites. The program entails training health service staff and patients. For staff it has implications for the nature and range of their work, with more focus on delivering preventative and maintenance services rather than acute services. This can impact on the health service’s ability to meet demands from the community for other services. For patients this approach engages them more in making decisions about the services they access. They gain greater understanding of their medical situation, and become more active in managing their own health situation through applying their greater understanding. In order to implement this approach there are significant demands on the staff resources of the health organisations involved. The organisations we are working with are finding it difficult to maintain the level of staff time required for ongoing involvement, including in the range of systems and information management tasks involved in this work.

Point of care technology

Another area of the work of this CCRE is Mark Shephard’s work with point-of-care-technology. Shephard’s work has involved extending this technology’s use across Australia to some 60 Aboriginal health or medical services. The technology, and skilling of Aboriginal health workers to utilise the technology, is important to enabling the provision of effective ongoing monitoring of patients with various chronic conditions. Delivering these services to Aboriginal people will enable greater control over complications arising from failure to intervene appropriately to delay and prevent the development of long-term illnesses.

With the Port Lincoln Aboriginal Health Service (PLAHS), Shephard has introduced point-of-care-technology, increasing PLAHS ability to monitor patients and adjust treatment appropriately. Combined with care planning, there are early indications of health improvement and reduced risk of complications for patients with diabetes, with indications of improved glycaemic control. At the Port Lincoln Aboriginal Health Service (PLAHS) a trial of the LIFE program is being implemented. The aim is to maintain this work, which linked with use of technologies and systems to monitor patients over time will give indications of how effective the approach is for a group of Aboriginal patients. Also at PLAHS a trial of the LIFE program is being implemented, enabling further evaluation of its effectiveness.

Through projects designed in collaboration with individual AHSs, we are helping to increase the ability of the Aboriginal Health Service to collect, manage and analyse data. This work will enhance their ability to engage with academic researchers, increase their capacity to participate in research projects and develop Aboriginal approaches to research. It will also build capacity in overall organisation and service management. We are pursuing projects at Pika Wiya Health Service, Port Lincoln AHS (PLAHS) and Ceduna-Koonibba AHS. Our plans include expanding further afield, developing collaborations with other deliverers of Aboriginal health services.
Aboriginal people doing Aboriginal health research

It is common among Aboriginal people to be suspicious of research and researchers, for a range of reasons resulting from how research has usually been conducted in communities and the lack of benefits that Aboriginal people see from research. Furthermore, the research hasn’t translated into improved health service delivery. Over the past two decades, new approaches to research in Indigenous communities have developed. Indigenous people have increasingly asserted that it is essential that research contribute to improvements in their community and not just be carried out for its own sake or for the benefit of non-Indigenous researchers or research bodies. Research needs to contribute to developing knowledge, skills and capacity building within the communities where it is conducted. Research needs to be controlled by Aboriginal people if it is to be effective.

Around the country important work is being undertaken to develop Aboriginal research capacity. This is positive, but more needs to be done. One example of such work is a project about Alice Springs town campers’ views of measures to manage access to alcohol. The researchers were from the community being researched. They believe that this enabled them to achieve a greater level of communication with the community and produce more relevant information:

We achieved much more discussion and information from the Town Campers because they felt comfortable with us, and could talk and not feel embarrassed or ‘shamed’. Many people would not provide good answers to non-Aboriginal people, whereas we could talk about many other things to make people feel comfortable and could help them understand more about the questions, allowing people to feel proud to be involved. If research is conducted in this way—with Aboriginal people in control and recognising Aboriginal expertise—the results will be more valid.

They believe that their method of research with Aboriginal people can be applied:

... by other Aboriginal organisations and that it can improve the quality of research ... Aboriginal people can conduct their own research, and carry it out more effectively, because they know their communities; they know how to manage the research process, ensuring that the work is completed; can ensure that analysis is comprehensive and appropriate; and can make the results immediately available for the community.

The CCRE is influenced by the approach of this Alice Springs group of Aboriginal researchers. Our work aims to increase the ability of Aboriginal health services to conduct research based on what they determine are the priorities.

Capacity building

Other countries that Australia is sometimes compared with, in relation to Indigenous peoples, are influenced by similar concerns to those in Australia. The objective of enhancing the capacity of Indigenous people and organisations in the health sector (and in other sectors) to engage in the ‘mainstream’ is widely recognised. A cautionary view has been expressed in relation to the Indigenous peoples of the United States. Chino and DeBruyn argue that

for many tribal communities, the conceptualization and implementation of capacity-building strategies are themselves disparate in that they are based on imported Western frameworks rather than on indigenous epistemologies and indigenous ‘ways of knowing’.

Chino and DeBruyn advocate using Indigenous models, stressing recognition and use of Indigenous ‘ways of knowing’. Their recommended approach involves four flexible steps which incorporate the goals of building relationships; developing the interpersonal and practical skills of participants working together in an interdependent, integrated and holistic way; and promoting commitment of participants to families and communities.

Approaches to Aboriginal health research in Australia are increasingly informed by similar principles. This Centre focuses on developing the capacity of AHSs and Aboriginal Health Workers
(AHWs), and other Aboriginal people working in the health sector, to participate in health research, working towards increasing their ability to determine and undertake research projects with their peoples and communities. This includes providing scholarships to Aboriginal people undertaking studies in the field of health; providing (with the leadership of Professor Paddy Phillips) a workshop for key personnel of Aboriginal health services on understanding and demystifying health research. We are also developing a health research and evaluation training course which will provide a pathway from TAFE to University. The course is designed to have practical application by way of local workplace projects. We will evaluate the course and make recommendations about research capacity building in Aboriginal health services.

**Increase Aboriginal health workers and professionals**

It is increasingly being recognised that more effective delivery of health, and other services, to disadvantaged and marginalised minority groups can be achieved by people from those groups being involved in delivering the services. There is a well documented shortage of Aboriginal people working in the health professions, especially considering the apparent greater level of ill-health among Aboriginal Australians. Efforts aimed at “capacity building” are part of a response to the serious shortages of well-experienced and qualified staff that Aboriginal health services encounter.

Increasing the number of Aboriginal staff would produce more culturally appropriate health services with more effective communication between health service staff and patients (and families), producing more effective health services. Research has shown that Aboriginal people receive services at lower rates than other Australians, even though their collective, and individual, disease burden is much higher as reflected in higher death rates. Research also shows that increasing the delivery of health services by Aboriginal staff to Aboriginal people and communities improves the services received by Aboriginal people, and results in better health outcomes for the patients.

Findings from a study of Co-ordinated Care Trials run from 1997 to 2002 that introduced new processes for managing patients with diabetes at two remote areas in the Northern Territory emphasise “…the importance of AHWs in the health workforce and are consistent with reports of the perceived importance of AHWs in the Indigenous primary care setting.” The study found that delivery of improved diabetes services via AHWs increased the likelihood of patients taking medicines as recommended, increasing the “likelihood of good intermediate outcomes”. They argue: “Our study underlines the need for strategies to increase the numbers of AHWs employed and to clarify and support their roles in the multidisciplinary primary health care setting.”

**Assessing the project at half way—some indications for policy**

At about half-way through the project (September 2006), we convened a Symposium of the projects’ key CCRE researchers and partners from the AHSs to report on projects in which they were involved. This facilitated a critical overview assessment of the project’s progress. The university-based researchers gained a clearer appreciation of the dynamics involved for the AHSs in maintaining their involvement in ongoing research work. Aboriginal people from the AHSs learnt more about their comparative situations, and further understanding of other projects of the Centre.

Although there are significant differences between these AHSs, a critical theme that emerged from their presentations and comments was that they faced significant difficulties in maintaining participation in research projects associated with the CCRE. A common issue was resource constraints. Developing and maintaining involvement in research project work often had implications for the AHSs ability to meet the demands of delivering more clinical oriented services. At times very high staff turnover, especially in regional and remote areas, effectively cut short AHS participation in research project work. Other questions were raised about the range of ‘non-clinical’ issues requiring investigation with regard to the high incidence of chronic conditions among Aboriginal people. Along with our more clinically focused research, we are exploring the implications of AHS resource and other issues for their ongoing involvement in health research.
The projects associated with this CCRE in Aboriginal and Torres Strait Islander Health indicate that gains in Aboriginal health can be achieved through increasing the ability of Aboriginal health organisations to deliver more integrated health services that are designed to be culturally appropriate for Aboriginal community people. Rather than seeing this challenge as a burden, we could see it as an opportunity for developing and identifying successful approaches to long-term illnesses that could provide valuable insights for application with the rest of the Australian population.

To maintain and further develop health service improvements, initiatives and programs focusing on developing the ability of Aboriginal health services to improve their practices and systems need to be initiated and continued. Sustaining and developing the ability of Aboriginal health organisations to undertake research is important so as to identify the most effective approaches. Ongoing research of new systems and processes implementation can evaluate those initiatives so as to inform policy responses in a most up-to-date way. That research needs to be conducted in the most collaborative and participatory ways possible.

The work of this CCRE is developing the capacity of AHSs to engage effectively in and utilise research of their services. There are indications from the work of this CCRE team of researchers that programs developing the technological and systems capacities of AHSs will produce improved health outcomes for their communities. Given the long-term nature of chronic conditions, it is likely that programs will need to be maintained over the medium to long term to realise their positive potential.

An afterword

Various people, including doctors, have commented in recent times that the magnitude of the issue of Aboriginal health in Australia is relatively minor when compared, for example, with the societal issues confronting the peoples of Africa, and that Australia as a wealthy country can well afford to put in the resources needed to make serious advances in improving the health outcomes of Aboriginal Australians. In saying this we do not at all belittle the range of important work of many in the Aboriginal health field.

One view, powerfully expressed by winner of the MJA’s 2006 Dr Ross Ingram Memorial Essay Competition, Dennis McDermott (Aboriginal psychologist and Indigenous health lecturer), in his “Unknown family at the taxi stand”, is:

“The greatest difficulty in improving Indigenous mental health is not finding data, but finding mechanisms to convince governments—ultimately, the program funders, workforce developers and agenda-setters—and, in particular, the current federal government, that to connect the unresolved trauma of dispossession, child removal, missionisation, racism and over-incarceration to contemporary distress is not adopting a "black armband view of history". The dots are on the page. There is a lack of political will to join them up.

Presenter

Glenn Giles is the Translation Officer at the CCRE in Aboriginal and Torres Strait Islander Health, located at the Aboriginal Health Council of South Australia (AHCSA). Glenn has been there for two years; before that he was at the Aboriginal Research Institute at the University of South Australia. He hopes to contribute to achieving social justice for Indigenous Australians—which would enhance the health of all Australians.
Notes

1 Please note that in this paper I use the terms ‘Aboriginal and Torres Strait Islander Australians’, ‘Aboriginal Australians’ and ‘Indigenous Australians’ interchangeably. Apologies if this offends. I pay my respects to and acknowledge the traditional owners of all the traditional Aboriginal lands of this country, Australia. Where I write from, Adelaide, the Kaurna are the traditional custodians.


5 Thomas DJ, Long-term trends in Indigenous deaths from chronic diseases in the Northern Territory: a foot on the brake, a foot on the accelerator. MJA, 2006; 185 (3): 145–149.

6 Atkinson VJ, Graham J, Pettit G, Lewis L. Broadening the focus of research into the health of Indigenous Australians, We know the problems—we need to seek solutions rather than more statistics. MJA, 177, 16 September 2002, 286–287.

7 Many significant publications were issued by the CRCAH, as it was in the early 1990s, the Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH), now the CRC for Aboriginal Health (CRCAH).


9 Wakeman J et al. Sustainable chronic disease management in remote Australia. MJA (Supplement), 21 November 2005, 183, S64-S68.


16 For a recent article on this work see Emden C, Kowanko I, de Crespigny, Murray H. A Nursing partnership for better outcomes in Aboriginal alcohol, other drugs and mental health. Contemporary Nurse 22(2):xx, 2006


22 Professor Paddy Phillips, Head of Department of Medicine, Flinders University, is a Chief Investigator with this project.


27 Dr Peter Ford, Advertiser, 7 July, 2005.