

# Putting the users of research in the driver's seat: the Cooperative Research Centre for Aboriginal Health's new approach to research development

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**Abstract:** *Research has a bad name in many Aboriginal communities. There is an often quoted phrase that 'Aboriginal people are the most researched in the world', and that researchers take from communities in order to gain academic qualifications with little benefit returned to Aboriginal peoples. But, like most things, research can be both 'good' and 'bad'. Increasingly, since the 1980s, Aboriginal peoples have been asserting their right to control research. Often this control has been applied through ethics processes, or through the use of Indigenous methodologies.*

*The Cooperative Research Centre for Aboriginal Health represents a further development in the control of Aboriginal health research by Aboriginal peoples. It provides a mechanism for directing the development, funding, conduct and dissemination of research in ways designed to maximise the likely benefits of the research for Aboriginal peoples—to do 'good' research. This has led to the development of a new model for the research industry, in which research priorities are set by the Aboriginal health sector, research projects are developed through facilitated collaboration with research users, and even the peer review or quality assurance process is very different.*

The Cooperative Research Centre for Aboriginal Health (CRCAH) is part of the Cooperative Research Centres (CRC) Program, funded by the Department of Education, Science and Technology. Cooperative Research Centres are strange but surprisingly effective beasts; a CRC must be a partnership of universities or research institutions, and industry (the users of research), each of which contributes both money and effort to achieving the goals of the partnership.

The CRCAH's industry partners are Aboriginal health services, and government agencies with a key interest in Aboriginal health. They include one of Australia's oldest and largest Aboriginal medical services, the Central Australian Aboriginal Congress in Alice Springs, Danila Dilba Health Service in Darwin, the Commonwealth Department of Health and Ageing, and the Northern Territory Department of Health and Community Services. The research partners are: AIATSIS, Charles Darwin University, Flinders University, the Menzies School of Health Research, Queensland Institute of Medical Research, the University of Melbourne and the University of Queensland.

The CRCAH grew out of a previous incarnation as the CRC for Aboriginal and Tropical Health (CRCATH). This was a much smaller and more localised body, with all but one of its six partners based in the Northern Territory. It took considerable effort to establish; the long-standing enmity between Aboriginal health services, government and research institutions made it a prickly partnership. Yet observers commented that one of the CRCATH's most significant contributions was that it provided a safe environment for these three combatants to recognise their shared commitment to improving Aboriginal health, without being at loggerheads over funding arrangements or control—and to realise they could work together.

## Indigenous research reform agenda

Another major achievement of the CRCATH was a substantive body of work looking at the issues that underpinned the apparent ineffectiveness of research in terms of addressing Aboriginal health, and doing so from an Aboriginal perspective. This work stemmed from an internal project, known colloquially as the Links Project,<sup>1</sup> that combined action research on the effectiveness of the organisation's own activities with a broad exploration of national and international approaches to both Indigenous research reform and health research reform more generally. A series of publications known as the Links Monographs (CRCAH 2006) helped to synthesise and articulate 'a long and well documented history of reform proposals aimed at improving the usefulness of health research to Indigenous peoples'. However, there were key elements of an Indigenous research reform agenda that were still to be achieved (Dunbar et al. 2004:ix):

- Indigenous control of the research agenda;
- Indigenous control of the research process;
- Improved processes for quality control;
- Improved processes for consultation and negotiation of research; and
- Improved processes for transferring research findings into policy and practice.

The CRCATH's core focus was on research that would improve Aboriginal health; but alongside research sat two key elements of that platform: research transfer and capacity development. With the health status of Aboriginal peoples providing a strong imperative for ensuring that research had an impact, it was essential for the CRCATH to understand how research really could be used to make a difference, or how research could be transferred into practice. Similarly, it was vital that the CRCATH used its research—supplemented by education and training activity—to ensure that there was increased capacity within Aboriginal communities, and within the research community more broadly, to carry out and contribute to high-quality effective research into Aboriginal health.

### *Putting research into practice*

In the area of research transfer, the CRCATH drew considerably on the work of Jonathon Lomas and the Canadian Health Services Research Foundation (CHSRF 2001; Lomas 1997) to inform both its thinking and practice. Lomas had argued that there were

major barriers to the uptake of research because of the cultural differences and lack of communication between researchers and research users, such as policy makers and managers. He highlighted the importance of presenting research in forms that were appropriate and relevant to its potential users: in concise, easy-to-read formats, with an emphasis on potential implications and main messages relevant to the audience in question.

The CRCATH also carried out its own research into how research could be made most effective in the Aboriginal health context (Brands n.d.; Matthews et al. 2001). This work identified priority setting as an important step to ensuring that the CRCATH's research would be relevant, and most likely to be used. If research was requested or desired by its potential users, then plainly it was more likely to be put into practice than if it were driven by researchers' interests alone. Brands' (n.d.) review of cases of successful research transfer in Indigenous health contexts identified other common success factors for the successful uptake of research into practice:

- Stakeholders (potential users of research) are involved throughout
- Research is outcomes focussed from the start
- Syntheses of findings are used rather than one off reports
- Strong relationships exist between researchers and stakeholders
- Research targets multiple levels of change (i.e. does not simply operate in one domain)
- Research is credible and of high quality.

### *Building research capacity in Indigenous health*

The CRCATH had a focus on building overall capacity to carry out high-quality research in Indigenous health. It was acknowledged that there was a very limited workforce able to carry out the sort of multi-disciplinary, complex and collaborative research required by the CRCATH. Indigenous researchers were particularly rare. In education and training, the CRCATH supported both Indigenous and non-Indigenous scholars to undertake postgraduate work, in an effort to increase both numbers and quality of available researchers. Its most successful capacity development work was through traineeships that supported Aboriginal persons to begin careers in health and health research. All nine trainees taken on remain in continuous employment in health or other services or research organisations (Anon. 2006).

The Links Project identified that in research projects in which there was a significant exchange of learning—or shared learning—between Indigenous and non-Indigenous researchers the outcomes could be much richer. This was true both for individuals and for the research itself, with the combination of research and community perspectives creating methodologies that were not only more inclusive but also more effective (Dunbar et al. 2004:31–2). However, this type of research partnership occurred only infrequently, and capacity development and professional development were rarely included in the original planning of research projects.

As the CRCATH was drawing to the end of its life span (CRCs are funded for seven-year periods), the Links Project identified that a number of barriers remained in ensuring Aboriginal direction of the research agenda. These were (Dunbar et al. 2004:53):

- the power imbalance between Indigenous and non-Indigenous research participants;
- the entrenched privileging of Western research traditions;
- the under-valuing of Indigenous knowledge and perspectives; and
- the widespread influence of 'investigator driven' approaches to research.

## The Cooperative Research Centre for Aboriginal Health

The CRCAH commenced in July 2003. It had a rocky start: within six months the organisation had lost much of its corporate memory, with the departure of both Chief Executive Officer Tony Barnes and Deputy CEO Terry Dunbar (who was the driving force behind the Links Project). Recruiting a new CEO took more than 12 months, and in that time the organisation struggled to maintain operations, while at the same time trying to begin to deliver on the ambitious agenda it had set itself. By September 2004 the tide was beginning to turn as the CRCAH board endorsed a new approach that would integrate somewhat disparate components of the organisation (research, research transfer, and education and training) into one combined approach, and that would focus the research agenda on a more achievable set of goals.

### *The programmatic approach*

From the work of the CRCATH, much was learnt about what was needed to do 'good' Aboriginal health research, and quite a lot about how to do it.

However, the organisational structure and processes carried over from the CRCATH did not provide the mechanisms to achieve these things. Major restructuring was carried out under the leadership of the new CEO, Mick Gooda, that would support the implementation of the research agenda. More significantly, the new structure could carry the processes needed to ensure real engagement of Aboriginal people and organisations, and other research users, in every stage of the research process.

The first step of this was to sharpen the organisation's focus: instead of trying to cover almost everything to do with Aboriginal health, five main programs of work were identified:

- Comprehensive Primary Health Care, Health Systems and Workforce
- Chronic Conditions
- Social and Emotional Wellbeing
- Social Determinants of Health
- Healthy Skin.

Within and across these programs, the CRCAH would bring together bodies of work being carried out by their partners, in order to consolidate their combined efforts and make a sum greater than the whole of its parts. In bringing together the combined efforts of a range of funded and in-kind projects, this programmatic approach provides greater opportunity for effective targeted transfer of research findings into policy and practice through a synthesis of a range of evidence or bodies of knowledge, rather than the promotion of one-off research projects. For example, the Healthy Skin Program incorporates a major body of work by CRCAH partners, ranging from laboratory studies of scabies mites, to community development approaches to the prevention and management of skin disease. Within the broader programmatic approach, linkages can be built between that work and the environmental health and housing work being carried out in the Social Determinants of Health Program, in order to bring a more comprehensive focus on what is needed to make a difference to Aboriginal skin health problems.<sup>2</sup>

Different staffing structures were also required, particularly in order to support the degree of user involvement in the process that the CRCAH wanted to put in place. User involvement is built into the very structure of the organisation, with board members including representatives of the government and Aboriginal health service partners, along with independent Aboriginal members who are usually drawn from the Aboriginal health sector. However, at an operational level, there had been little capacity to

ensure real engagement with Aboriginal clients and other research users.

This engagement was identified as critical to establishing a research agenda that would not only have credibility with a sceptical Aboriginal audience but also ensure the relevance and effectiveness of research aimed at improving Aboriginal health. International evidence had also identified ongoing 'linkage and exchange' between researchers and potential users of research as one of the keys to effective research transfer (Lomas 2000:237):

Bringing decision-makers who can use the results of a particular piece of research into its formulation and conduct is the best predictor for seeing the findings applied...The one-on-one encounter consistently emerges as the most efficient way to transfer research findings.

This concept of linkage and exchange between researchers and research users was then built into every layer of the CRCAH's operations. Within the research leadership, the new approach established Program Leaders who would provide the intellectual and linkage leadership of each program. Each program has a Program Leader with the relevant research expertise, and Program Leaders from government and from the Aboriginal health sector. Wherever possible, these Program Leaders are Aboriginal. These roles are generally in-kind (contributed at no financial cost to the CRCAH). To support these Program Leaders, full-time salaried positions of Program Managers were established to carry out the essential hands-on operational work, to 'grease the wheels of the machinery'. These Program Managers are an essential component of the process developed by the CRCAH, as they broker not only information but also, and more importantly, relationships and processes.

The role of the Program Manager is one variant of the 'knowledge broker', a term used increasingly in health and other research to refer to a hybrid role that acts as a facilitator between researchers and research users. As the Canadian Health Services Research Foundation (CHSRF 2006) defines it:

Knowledge brokering links decision makers and researchers, facilitating their interaction so that they are able to better understand each other's goals and professional cultures, influence each other's work, forge new partnerships, and promote the use of research-based evidence in decision-making. Knowledge brokering activities include finding the right players to influence research use in decision-making, bringing these players

together, creating and helping to sustain relationships among them, and helping them to engage in collaborative problem-solving.

### *Setting research priorities*

Research users have greatest input into the CRCAH's research agenda in the setting of research priorities. The board, with its strong representation from the Aboriginal health sector, sets the main research priorities on which the CRCAH will focus: the program areas. The programs include two main components of work:

- new research projects commissioned by the CRCAH
- work either continuing from previously funded projects, or contributed by partners as in-kind projects.

To date, the major developmental activity has been around the commissioning of new projects. The synthesis and transfer of the broader bodies of work will receive greater attention once the commissioned research is up and running.

In order to commission new research, the CRCAH convenes an 'industry roundtable' for each program area. This is a meeting of some 20–40 persons from the Aboriginal health sector and relevant government organisations who have a particular interest in the focus of the program. This group then discusses its most pressing needs that research may be able to help address. As an example, an industry roundtable for the Chronic Conditions Program identified making health promotions messages more effective as a key priority for research that would help health services target and deliver their services more effectively.

The priorities identified by the industry roundtable are then taken back to the board, which considers them and prioritises them again, according to where the CRCAH can make the most impact. There may be areas where a limited amount of expenditure or effort can produce significant results, or where it is most timely to undertake research. As a partnership, rather than a representative body, the CRCAH can achieve best leveraging of effort by drawing on its partners to address particular areas in which the partners have expertise.

These priorities are then worked up into research questions by the Program Leaders and Program Manager. This iterative process requires not only the application of the expertise of the research Program Leader to translate what are essentially issues of

concern into researchable questions, but also the input of the industry Program Leaders to ensure the research questions are likely to produce results that will be usable by governments and health services.

### *Facilitating the development of research projects*

The involvement of research users continues throughout the development of specific proposals. However, in the drafting of research protocols or proposals, researchers must take a much greater prominence in the process, providing expertise about valid research methods, research management and necessary resources. As with the refining of research questions, the input of research users remains important. To ensure that this occurs, the CRCAH facilitates the development of research protocols, mainly through the knowledge brokering role of the Program Manager.

Once the research questions have been developed by the Program Leaders, they are circulated throughout the CRCAH community. Researchers, health service managers and staff, government officers, and other interested parties are invited to nominate for involvement in the development, review or conduct of the projects. A project leader will be identified for each project, and the Program Manager facilitates the bringing together of those with an interest in each project to talk with the project leader and begin developing a formal research protocol.

This process was developed in response to the findings of the Links action research project, and the experience of the CRCAH in conducting more traditional investigator-driven funding rounds, where research interests continued to dominate over the priorities of the Aboriginal health sector. For a researcher, research is their job, their bread and butter, and their career. For research users, research is often an add-on to already over-committed time, and small hurdles can easily put the research user off contributing or participating in research. The facilitated development process aims to make the process as easy as possible for research users to take part in, with the CRCAH Program Manager brokering the relationships between research users and researchers, and the process.

This process can take some time, and is resource-intensive. While delays can be frustrating, particularly for the researchers, so far even delays in progress have proven useful in strengthening both the methodological rigour of the project and the partnerships being forged. With its national partnership and networks, the CRCAH has the potential to link those in various

parts of the country with similar interests, particularly researchers with industry bodies such as health services. Knowing that an Aboriginal health service is unhappy about a proposed methodological approach may take a little while to negotiate through to resolution, but is likely to ensure the methodology will work more effectively in the context of Aboriginal health.

### *Quality assurance*

The CRCAH had been interested for some time in the issue of the effectiveness or otherwise of peer review as a measure of quality control within research. As an essential element of the academic tradition, there was a concern that peer-review processes with a purely scientific focus could further marginalise Aboriginal researchers and research methods of importance to doing Aboriginal health research. A small project was carried out to look at these issues, and to talk with stakeholders (including researchers) about how peer review might or might not work for the CRCAH (Baum & Street in press).

One clear message was that in a 'cooperative' research centre the competitive processes of traditional peer review in a grant-assessment process were not only counter-productive but actively destructive. This research fed into the development of the facilitated research process, but also crucially helped inform the development of broader quality assurance processes.

The quality assurance process that has been adopted by the CRCAH involves a group of reviewers for each project under development. These reviewers include relevant scientific expertise, along with reviewers from Aboriginal organisations and government agencies that are potential users of the research findings. They provide feedback on the project in terms of both technical and merit review, and meet face to face with the project team in order to ensure the strongest possible quality of the project protocol. It is anticipated the review team may maintain a watching brief throughout the life of the project.

### *Receptivity: building the interest and capacity of research users*

The various phases of the facilitated development approach provide a number of opportunities for research users—both from government and from Aboriginal organisations—to engage with research in a way that is both accessible and non-threatening. Probably the most successful points for this engagement are at the industry roundtables, where the research agenda

begins to be defined, and at the quality assurance stage.

As an example, at an industry roundtable to develop research priorities in the Chronic Conditions Program, senior bureaucrats were impressed with the opportunity to be part of a group in which Aboriginal health service managers, workers and others articulated their most pressing needs for answers to help them provide better services. This direct experience—in a relatively informal consultative process—was identified as being particularly useful in helping policy makers ground their decision making.

Several Aboriginal health workers from the Northern Territory also attended the same industry roundtable. At the start of the day, they expressed some doubt as to what they could contribute. As the day progressed, and they heard issues of shared concern being voiced by health service managers, they began to recognise the validity of their own points of view in such a forum. By the end of the day they were actively contributing to helping set the research agenda. Similarly in the review process, several health-service managers asked to carry out reviews expressed doubts that they would have anything to offer. But their participation in the face-to-face meetings—combined with background discussions with the Program Manager and other CRCAH staff—encouraged them to such an extent that one has now taken up research work in their own right.

In the context of the bad reputation of research with Aboriginal peoples, these small steps are nonetheless significant in the development of a culture in which research can be seen as a useful—and usable—tool for improving health service planning, delivery and evaluation.

### **But will it work?**

The facilitated development process is still in its infancy, and still evolving, thanks to the good-will and invaluable constructive feedback of those who have given their time and energy to taking part in it. The early signs are encouraging, with positive feedback received from participants, including:

- For research users, the opportunity to have research done on what you believe is important and will help you do your job better, and the chance to take part in that research.
- The number of research users having positive experiences of research by engaging with the process.

- The positive response from the Aboriginal health sector and governments to the research questions and research protocols, suggesting that the shift from a research issue to a research project has retained the key elements of what the research users hope to gain from the project.
- Research users feeling encouraged to engage directly with research from within their own organisations.
- For researchers, the excitement and rewards of working on a project that the Aboriginal health sector has specifically identified as a priority and that is therefore likely to be used.
- The opportunity to plan the development of a project according to what is required to make it work, rather than the constraints (on what can be included or what must be excluded) of a funding organisation.
- The face-to-face quality-assurance process and the robustness it contributes, particularly to the contextual realities of carrying out the research and producing results that may be usable.
- For all participants, the opportunity to build new partnerships and networks.

The CRCAH's new approach to the development of research is not without its tensions, though. So far, these tensions include:

- The difficulty of finding project leaders to take on complex, often multi-site projects to address research priorities that are not necessarily the project leader's own. This is a challenge in terms of the sheer lack of numbers of potential project leaders with appropriate expertise, the existing workloads of those who do have the expertise, and the desire of potential project leaders to shape projects to meet their own specific interests.
- The availability of very busy people, both researchers and research users.
- The shortage of Aboriginal researchers with project management or senior research expertise.
- The bringing together of partners who, while sharing some common interests, have different priorities and timelines, and who may not like each other or be able to work together.

These tensions largely stem from the way in which the CRCAH's new approach to research development is attempting to use what one researcher described as 'the best bits of both the commissioned and investigator-driven approaches', but they particularly arise from the challenges that the process makes to a research culture more accustomed to a far greater degree of investigator control.

### *How will we know if it works?*

The CRCAH is evaluating the facilitated research development process as it continues to evolve, but it immediately faces the challenge of how to measure successful outcomes or impact, the same challenge confronting the university sector more broadly in relation to the Research Quality Framework currently under development in Australia (RQF 2006a, 2006b). Measuring research impact has received considerable attention internationally, though with no simple solutions (Beacham et al. 2005:3). However, one model which would appear to lend itself well to the CRCAH's context is that developed by Lavis and colleagues (2003), which identifies three different ways in which research might be used and proposes strategies for measuring these in relation to different groups of research users. Lavis (et al. 2003) argue that research may be used instrumentally, conceptually and/or symbolically, and that intermediate steps towards achieving outcomes should be measured, as well as outcomes themselves.

Instrumental change, or change in policy, practice and behaviour, is the sort of change that most will want to see from the CRCAH. If its efforts do not result in such change, it will probably be viewed as having failed. However, instrumental change is the least likely of any type of change to result from individual pieces of research. Davies (et al. 2005:13) comment that:

Many empirical studies have shown that only rarely will research impacts be direct, instrumental and clearly identifiable, such as when research leads directly to specific policy choices, or when research is neatly captured and codified in tools and instruments such as guidelines, protocols or organisational processes. Instead, much important decision making is diffuse, and characterised by 'non-decisional processes' and the progressive establishment of new routines (providing) 'a background of empirical generalisations and ideas that creep into policy deliberation'. Research may also be absorbed and internalised into professional tacit knowledge as it emulsifies with many other sources of knowledge (experience, anecdote, received wisdom, lay knowledge etc.). In doing so, it may leave few tell-tale signs of its passage, role or impact. Thus research can contribute not just to decisional choices, but also to the formation of values, the creation of new understandings and possibilities, and to the quality of public and professional discourse and debate.

CRCAH projects—both funded and in-kind—are already leading to instrumental change. As an example, the Audit and Best Practice in Chronic Disease (ABCD) project has influenced health service practice in the Northern Territory in the adoption of continuous quality improvement processes, demonstrating some impressive health improvements in Aboriginal communities as a result. The project has also influenced the policy practices of the Commonwealth Department of Health and Ageing, with the ABCD model contributing to the development of a major initiative, the Healthy for Life Program. A major mental health project, AIM-HI, has developed resources and care plans for Aboriginal mental health patients in remote areas which are now being implemented through curriculum development and delivery of training, along with ongoing engagement of mental health practitioners, across the NT's Top End. An in-kind project, led by Professor Bart Currie at the Menzies School of Health Research, has dramatically decreased the rate of death from melioidosis (an infection carried in some Northern Territory soils).

Conceptual use of research is that which 'changes people's level of knowledge, understanding, and attitudes'. The CRCAH's new approach to research is already resulting in conceptual change, as it is creating a positive experience of research among members of the Aboriginal health sector. (An illustration of this is the snowballing demand from Aboriginal services to attend CRCAH industry roundtables—the first roundtable was attended by 10 people, the second by 35, the third by 35, and a fourth has been inundated by so many requests to attend that not all can be accommodated.) Similarly, by putting into practice radically different research development processes, the CRCAH is already demonstrating to research funding organisations, researchers and others that there are different ways of doing research.

Symbolic use of research might also be referred to as political use; it is the use of research to justify, validate or support decisions already made or practice already in use. The ABCD project, for example, provides evidence to support existing assumptions that quality improvement processes would lead to better service provision and, ultimately, better health outcomes in remote communities. This evidence can then be used symbolically to justify allocation of resources to support quality improvement processes.

And it may be through conceptual and symbolic use of research that the CRCAH can contribute most

to improving Aboriginal health. The overwhelming message from its growing body of work is that there is no 'magic bullet' that will suddenly 'fix' Aboriginal health. Instead, most projects indicate that it is commonsense management approaches (planning, resourcing, measuring impact), the provision of and sustainability of services, and the involvement of Aboriginal people in decision making about their own health services that are likely to make most impact.

A recent report from a CRCAH in-kind project in the *Medical Journal of Australia* (Thomas et al. 2006) showed that, while the gap between Aboriginal and non-Aboriginal Australian health continues to grow, there are signs that Aboriginal health may be starting to improve. Promoting the report, the CRCAH's Research Director Ian Anderson (2006), one of the authors of the report, commented that:

There's a sort of policy myth in Aboriginal affairs that...it's all getting worse. And what this leads to is a sort of policy crisis where we put a lot more energy into talkfests, administrative reforms and trying to reinvent strategies rather than committing ourselves to the sorts of long term strategies that we think are making a difference here, (like) primary health care for chronic diseases and infectious diseases, but also too strategies to build better housing programs, to deal with environmental health issues, to improve people's access to employment and education. These are things that we know make a difference in health, and we know this from international evidence as well as from a growing body of local evidence. These are the things that we need to continue to do. So rather than reinvent a problem every three years when we get a new minister who actually starts to see the nature of the problems for the first time, we need to have a lot more continuity in terms of our investment.

That evidence also conveys an important message to Aboriginal people—the health consumer, as articulated by the CRCAH's Chairperson, Pat Anderson (2006):

When you're constantly told that nothing's changing, and that we're as sick as we ever were—though people are trying to comply with the public health messages, eating better, exercising, stop smoking—now this confirms that we are on the right track. I think for the consumer this is excellent news because now they can all take heart.

It may be that this sort of evidence—presented through credible, high-quality research and strong, consistent messages—can bring about the conceptual

and symbolic changes at the policy, service provision, and community levels that are needed to bring about real and sustained instrumental change in Aboriginal health. The challenge for the CRCAH is to find cost-effective ways of demonstrating these results in ways credible to its stakeholders and funders. In that way perhaps the significant work the CRCAH is now doing in bringing together the skills and expertise of the research and Aboriginal health sectors may be able to continue beyond the current seven-year life-span of a Cooperative Research Centre.

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## NOTES

1. The Links Project's formal title was: Action Research into Managing, Undertaking and Dissemination Aboriginal Health Research for Improved Outcomes.
2. Skin problems, while themselves highly unpleasant, also lead to life-threatening illnesses such as rheumatic heart disease, renal failure and other chronic conditions.

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