

Turning the Oil Tanker: Shifting to User-driven Research

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Before I begin, I'd like to acknowledge the traditional Aboriginal ownership of this area, and the leading work done by organisations like the Aboriginal Health Council of South Australia in asserting Aboriginal control of research and providing an inspirational model to all of us.

Yesterday those of you who attended the plenary session with Jonathon Lomas will have heard a lot of stories about the ways that the Canadian Health Services Research Foundation is working to change the ways that researchers and decision makers – as he called them – work together – or in many cases, don't work together.

Today I'm going to tell you the story of an Aboriginal controlled research organisation that – drawing on the work done in Canada, Australia and other places – is following a similar though by no means identical path – in the context where Aboriginal Australians living in one of the wealthiest countries in the world experience health conditions more like that of the Third World.

Listening to Jonathon Lomas' talk yesterday it surprised me to hear how very much the framework he outlined parallels that which has been adopted by the Cooperative Research Centre – or CRC - for Aboriginal Health – but also how some of the very fundamental elements of what a CRC is give us opportunities to do things which most research funders can only struggle towards.

It shouldn't have surprised me – the work of Jonathon and the CHSRF have greatly influenced the CRC for Aboriginal Health over many years. But it still felt almost uncanny to hear the same things that we live and breathe being talked about by such a guru as Jonathon is.

I should begin by talking a little bit about what a CRC or Cooperative Research Centre is – because this is also fundamental to the story I'm going to tell.

Some years ago the Australian Government decided to set up a program to fund research which would be centred around exactly the things that Jonathon was talking about yesterday – partnerships between industry or research users – and researchers. CRCs involve

the likely users of research – ranging from mining companies to governments to small business, investing in a partnership with universities – to carry out research to try to solve problems facing that particular industry.

Now already you can see that the whole idea of a CRC is something where those two domains of decision makers and researchers begin to merge into one body. It doesn't make it any easier for them to talk to each across their own language and cultural divides – but it does create an organisation which is perhaps a little more like the IBM or BHP model that Jonathon referred to – where research and its use are part of one endeavour.

In the case of the CRC for Aboriginal Health – its industry partners – or decision makers – are two government departments intimately involved in the delivery and funding of Aboriginal health services, and two community controlled Aboriginal health services, Danila Dilba in Darwin and the Central Australian Aboriginal Congress in Alice Springs.

Its research partners include universities and research institutions in the Northern Territory, Victoria, Queensland, South Australia, the ACT and WA.

CRCs are traditionally funded for a life cycle of 7 years and this CRC began its life as the CRC for Aboriginal and Tropical Health. It was a partnership of strange bedfellows initially.

The long history of research ABOUT Aboriginal people – in which Aboriginal people had very little control – meant that researchers were viewed as highly suspect. Research was seen as benefiting the careers of white researchers – not Aboriginal people's health.

As for a partnership with Governments, back then when the CRC was forming, that seemed an equally risky venture.

But as the CRC's current chairperson Pat Anderson said in a recent address she gave, years of persuasion from John Matthews, the former head of the Menzies School of Health Research, somehow

managed to lure both the Aboriginal controlled organisations and the NT Government to get into bed together.

And by that very act – of establishing a partnership between these three groups whose relationship at the very best could only be described as PRICKLY – the CRC for Aboriginal and Tropical Health achieved one of its most important outcomes.

It provided a space where these three prickly partners could talk together about something other than who was going to get what funding to sustain their medical service and found they actually had a whole lot of shared concerns.

Much of the work of the CRC for Aboriginal and Tropical Health was about setting some fundamental principles about how research should be done when it involves and affects the lives of Aboriginal people.

And it wasn't a simple process – many of these principles challenged the very basis of the traditional culture of research; control, research aimed at achieving specific outcomes and, specifically, better Aboriginal health.

And that rather than concentrating knowledge with elites – research should build capacity amongst Aboriginal people to do research themselves, and in Aboriginal communities and organisations to control their own destinies. This was about developing practical capabilities not about publishing journal articles or getting PhDs, although those things clearly have their own roles in the place of the academic world.

In the early days, there were often arguments about, for instance, the validity of community based research versus scientifically proven methods, but gradually over time, the CRC began – like the Canadians – to build up evidence that not only were these principles ethically and morally essential but integral to the conduct of effective research in Aboriginal health.

The CRC's former deputy director, Terry Dunbar, played a particularly important role in leading the articulation of what is known as the

Indigenous research reform agenda, through a major evaluation of how effectively the CRC itself was performing in trying to meet these principles.

And small but significant victories began to occur. In one project, renal specialists at a major hospital asked the CRC to help them improve their communications with their patients – almost all of whom are Aboriginal, and almost all speaking Aboriginal languages as their first and often second or third languages before English. A small action research project got the patients, their families, and the medical professionals sitting in a large group and talking – with the help of interpreters.

For the specialists – this was excruciatingly slow and frustrating. Then patients and specialists were videoed during consultations, and the discussions analysed, and discussed with patients and their families. The findings shocked the nephrologists – with one saying, ‘We knew we had trouble getting our message across – we didn’t know we were getting virtually NOTHING across.’

Three years down the track – the renal unit is now organised so that particular language groups come for their dialysis on particular days, making interpreting easier and allowing families to be together, and the hospital in question has dramatically increased its use of interpreters and the working relationships between medical staff, interpreters, Aboriginal liaison officers and patients and their families are shifting.

Now the CRC is facilitating the spread of these ways of working to other hospitals in the NT, and to health services throughout Arnhemland – at their request. And this illustrates one of my themes in this story of the CRC for Aboriginal health – when you get the formulae right – you don’t have to work hard to get research transferred into practice – if it’s really got the goods, it spreads like a contagion.

But except for those occasional significant success stories, research in the CRC for Aboriginal and Tropical health was not necessarily achieving the successful research transfer that was essential if the

CRC was to achieve its goal of really making a difference to Aboriginal health.

Plainly, it was essential for the CRC to be good at research transfer. We looked to the experts for an evidence based lead – naturally enough, to Canada.

Initially, our focus was on better dissemination, and we advocated the use of the 1:3:25 ratio for user friendly publications - one page of key points, 3 pages of executive summary highlighting the findings and implications for potential users;; and the entire report not more than 25 pages.

The CRC also recognised that it would need to set priorities to ensure that the priorities of Aboriginal people and potential research users could be addressed.

Learning from the experiences of others, particularly the Canadians, and from the CRC's own experiences and research, we learnt that there were some fundamental requirements for getting research to be used. These include:

- Stakeholders being involved throughout;
- Research is outcomes focussed from the start;
- Synthesis of findings rather than one-off reports;
- Strong relationships exist between researchers and stakeholders;
- Research targets multiple levels of change; and
- Research is of high quality.

So we knew what needed to be done, and were struggling towards it...but the struggle was very difficult.

The process for developing research was essentially still researcher driven.

And we simply didn't have an operational structure that could enact the vision that had been articulated so clearly by the CRC for Aboriginal and Tropical Health.

Then last year the CRC Board slammed the motor into reverse, with what must be said was quite a great deal of associated trauma, and began to turn the oil tanker and shift the control of the research process from researchers to research users.

Ironically the Board's action emerged largely as a result of complaints from researchers about not getting their way in the funding rounds - but the complaints opened up a forum for a wider debate.

One of the major issues was that while most CRCs focus on quite specific fields with clear boundaries the CRC for Aboriginal Health seemed to be about everything to do with Aboriginal health.

Trying to be everything to everyone meant resources were spread too thin, and there was a risk of achieving nothing while trying to achieve everything. In comparison, the Vision CRC for instance is mostly about fixing short and long sightedness not every single thing about eyesight.

So one of the important shifts for the CRC for Aboriginal health was to develop a programmatic approach, in which 5 key areas would be addressed, with an emphasis on achieving particular outcomes in each area. Each program would bring together research that the CRC funds with research that its partners are already doing, or research funded by other bodies and synthesise the combined outcomes of all this research to make it as powerful as possible a tool for change.

Perhaps most importantly, new positions were created for program managers who – like the boundary spanners Jonathon Lomas referred to – facilitate the development of research ideas, making sure that research is user driven, will translate into practice or policy, and will help build capacity in Indigenous communities.

These positions were the critical change – the idea of giving priority to the needs of Aboriginal community health services and other research users was fine, but without those positions to lead the facilitated development of research, the control of the research process had inevitably fallen back to the researchers.

So now we are in the process of developing a program of research around comprehensive primary health care – one of our five programs of research - which starts with the outcomes that our industry partners want instead of starting with a research idea and then looking for how it can translate into an outcome.

What we're finding is that from some relatively simple ideas about what needs to be done, a very broad range of research users that had been quite critical of the CRC, are now enthusiastically welcoming what we propose to research and wanting to be part of it – and so they should – the ideas for what needs to be researched are coming from them!

So we're seeing that if the basic research idea is to provide an answer to something that's a major challenge to our research users....they WANT to use it.

And because the CRC for Aboriginal Health includes both community health services and government agencies – the Commonwealth Department of Health and Ageing and the NT Dept of Health and Community Services – a decision to proceed with this primary health care projects will include a commitment from these departments to be a part of the process something I must say they are indicating a great deal of enthusiasm for so far.

And finally – people are starting to get the message that the CRC is NOT just another funding bucket.

What we're also seeing is that increasingly the CRC is being asked to play a role as something other than a research institution.

Government agencies, academic and community controlled organisations are asking us to act as a broker to help break down the silos and barriers between them, in a sense, in the same way as the original CRC broke down the barriers between Aboriginal health services, government and researchers in the NT.

For instance, earlier this year we were approached by a researcher working on otitis media, middle ear infection, which is a major cause of deafness in Aboriginal children. She'd noticed while doing her

research work that community clinics had very limited resources for the prevention and management of otitis media, and particularly for talking with Aboriginal parents about these things. She approached the CRC to consider funding the development of resources.

But instead of saying, 'Yes, that's clearly a need and we should put some money into it', the CRC took the approach of saying, 'Lets find out what others are doing in this field and what resources are already out there.'

Within about 48 hours we'd set up a teleconference of people doing work around otitis media, particularly in service provision, around the country. All these people were doing similar work, in similar or slightly different contexts but most had never spoken to each other before. It emerged there were already a great deal of resources around about otitis media – though with some notable gaps but the best outcome was the network of people connected who are now in regular contact and sharing their knowledge and experience.

In a similar way, the CRC recently helped a community controlled organisation overcome a four year impasse of buck-passing between governments – using the Commonwealth governments own new arrangements for the funding of Aboriginal affairs.

In the Western Desert, west of Alice Springs, renal failure is amongst the highest in the world. Most patients who need to go on renal dialysis are forced to move hundreds of kilometres to Alice Springs leaving their families and country behind for good.

Many elect not to make that choice – and stay in the community to die where they belong, rather than dying more slowly in exile.

It's a similar story across much of the Northern Territory, and indeed across remote Australia, and communities have repeatedly asked for dialysis to be provided in their home communities.

The NT Government has recently begun introducing home dialysis, but long before that, the communities of Kintore and Kiwirrkura decided they would take matters into their own hands. They raised more than a million dollars by selling paintings through the auction

house of Sotheby's and set up a program which allows patients on dialysis in Alice Springs to make regular visits home to their communities – what they're calling respite from treatment.

As well as dramatically improving the quality – and length – of life of the patients themselves – this community effort is also reducing the costs of emergency evacuations because patients have left dialysis and gone home.

This little community organisation operated for four years largely on its own resources with some short term support from the NT Government. But the long term viability of the organisation was continually in question, as the Commonwealth and Territory governments tiptoed around who had responsibility for what.

The CRC's very small contribution to this was to help the community organisation to link into the Office of Indigenous Coordination in Alice Springs – whose role under the new Commonwealth arrangements about Aboriginal affairs is to broker agreements between various government agencies.

Now within a matter of months the NT has made commitments of ongoing funding ... the Commonwealth has committed several hundred thousand dollars and there are plans to explore further agreements to help ensure the Western Desert communities can get access to healthy foods and help prevent renal failure in the first place.

So what we are seeing now is an increasing trend for the CRC to be NOT so much a doer or funder of research – but of a builder of bridges between research that is already there policy and service provision and particularly the **implementation** of evidence based practice which is where so many times the whole thing falls down.

Time after time our research and its translation into practice by service providers show that it is not the medical magic bullet which improves health – though that can be the case – but basic systems-change, often very simple management processes such as the introduction of cycles of quality improvement.

In much the same way, the CRC is also working with users of research, particularly community organisations, to make research less intimidating, to reveal its more practical and grassroots benefits for small organisations struggling to keep their heads above water in what's often a day-by-day management of crisis.

One project has worked with both government and community controlled health services to help them set up basic systems which not only deliver services but provide ways of seeing how well those services are being provided.

Now you know health service staff are likely to react against a proposal to set up systems to measure and assess performance – not necessarily through any fear of the assessment, but because it's an additional burden of work. Yet this project has targeted its work and its language so perfectly to the needs and interests of clinic staff – that they're embracing the process and flying with it as they start to see it making their work more effective. How has this been achieved? The project works in the clinic environment, and its "researchers" are either former remote nurses or other health practitioners.

This project has just gone into a further extension with requests from health services wanting to join the project in northern Queensland, western NSW, South Australia, Western Australia and Central Australia.

In some cases that involvement is being driven from both the health service and GOVERNMENT levels. As our former CEO, Tony Barnes, said, "In relation to research and research transfer....it either has it or it hasn't....and this one definitely has it....and so the contagion spreads quite easily."

Of course we still have many challenges ahead of us.

One of the most important is whether researchers are willing to work this way, with the agenda set by research users and with research development being facilitated rather than being researcher led.

The extraordinary commitment of researchers who chose to work in Aboriginal health gives us a great deal of confidence that most will be

willing to work this way – they WANT their research to make a difference.

We've had an example of this just yesterday – when a researcher from a strongly biomedical perspective bravely decided to commit to a program of work around scabies and skin sores that will include looking at housing, water, hygiene and changing service provision – as well as scientific research - a prospect she's frankly admitted scares her and challenges her desire to work inside the boundaries with which she's familiar and confident.

But it won't be easy – for anyone. Everyone involved is extremely busy and Aboriginal-controlled organisations in particular are very stretched to seriously engage in this sort of work.

The CRC is supporting this engagement, both through a number of positions designed specifically to work with the community sector, and through the facilitated research development which evens out the playing field between researchers and the community sector. But the ability of people to commit time to this process will always be a challenge.

And the basic cultural divide between research and decision making remains. Bringing together groups of health service decision makers and practitioners – health funders – Aboriginal communities, families and patients, and cross discipline groups of researchers – means getting together people who come from very different perspectives, have different priorities and timelines, and very different ways of relating to each other.

Our program managers will help to facilitate these relationships – but it will require lots of hard work, frustration and compromises from everyone involved.

And I'm reminded of the question yesterday about the challenges of working in politically charged arenas – and Jonathon Lomas' reply that if you're not into the hurly burly of the political fray, you're better to stay in a less high profile area of health research.

You couldn't get a much more politicised arena of research than Aboriginal affairs – particularly in the current political climate when the administration of Aboriginal affairs funding is undergoing the most profound change that's ever occurred in Australian public administration.

Yet that same upheaval and change also opens doors. Times of dramatic change, chaos and crisis often allow opportunities for evidence to sneak through the usual barriers around governments and managers – who are desperately looking for solutions to help them navigate through the chaos.