Indigenous-led Intervention Research: The Benefits, Challenges and Opportunities

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Abstract

This article is based on a presentation to the 2011 Indigenous Studies Research Network and Faculty of Health Symposium *Healthier Futures Thru Indigenous Led Research* held at the Queensland University of Technology. It critically examines the proposition that, in the context of the current health reform in Australia, an Indigenous-led and -developed research agenda should be prioritised to inform Indigenous health policy and programs. I argue that such a strategy is the best way to bring about improved Indigenous health outcomes. I draw on my experience over 15 years of working as a member of multi-disciplinary teams in public health intervention and health services research in urban, regional and remote areas of New South Wales, Australia. I reflect on the ways in which Indigenous leadership has figured in my research in the field of injury prevention. Finally, I identify some of the challenges and opportunities for enhancing Indigenous research leadership capacity.

Introduction

To begin, it is important to ask what we mean by 'Indigenous-led' research'? Is it community-controlled and community-driven research? Can it include academic research in partnership with community organisations? Is it research which is led and driven by Indigenous chief investigators or senior researchers with or without community partners? Can it refer to any research in which Indigenous people, for example as research associates, research assistants or project managers, take a leading role? Or is it research which follows a specific Indigenous research agenda or paradigm or which incorporates Indigenous participation into every phase of the research?

The first of these answers is to see 'Indigenous-led' research as research which is controlled and driven by Indigenous communities. The literature on Indigenous health research over the past two decades draws attention to the negative impacts of past research practices on Indigenous communities, both in Australia and overseas, emphasises the need to protect the rights of vulnerable Indigenous communities and individuals, and highlights the important role which communities have in leading research by determining future research directions, questions and methodologies (Rigney 1999; Smith 2006; Dunbar and Scrimgeour 2006; Anderson 2011). Moreover, the principle of Indigenous community leadership and control of research has become firmly embedded in the guidelines for the ethical conduct of research with Indigenous Australian peoples (National Health and Medical Research Council 2003, 2005; Australian Institute of Aboriginal and Torres Strait Islander Studies 2011). Despite this, as Kowal et al (2005) point out, the nature and purpose of Indigenous participation in research and, importantly, its relationship to improved health outcomes, is often unclear.

It is also important to ask why we should prioritise Indigenous-led research in the current climate of health reform in Australia. After all, given serious Indigenous health workforce gaps and too few trained and experienced Indigenous health researchers, does it matter who conducts the research as long as we obtain the evidence needed to make advancements in Indigenous health? If we accept that improved health outcomes are what matters, what should be the nature of Indigenous involvement or participation in research? Are there additional benefits which can be gained by having Indigenous people lead Indigenous health research, and if so, what are they?

In this article, I review some of the developments in Indigenous health research ethics over the past few decades. Applying the knowledge gained from this literature, I advance the argument that a broadly defined concept of Indigenous-led research provides the best way forward in providing the evidence base needed for Indigenous health policy and program development in order to close the gap in health inequities between Indigenous and non-indigenous Australians over the coming decade. I highlight the importance of an Indigenous research paradigm which prioritises community needs and voices. However, there is much more to be done to increase and enhance Indigenous leadership capacity.

Early thinking on Indigenous-led research

In her seminal work *Decolonising Methodologies*, first published in 1999, Maori researcher Linda Tuihwai Smith re-conceptualised research from being 'one of the dirtiest words in the Indigenous world's vocabulary' to 'a vehicle for self-determination' (Smith 2006: 1). Her book provided the catalyst for two decades of development in Indigenous research and ethics, particularly in countries such as Australia, New Zealand, Canada and the United States which share similar histories of British colonisation. Research, Smith claimed, is one of the ways in which the underlying code of imperialism and colonialism is both regulated and realised.

> *It is regulated through the formal rules of individual scholarly disciplines and scientific paradigms, and the institutions that support them (including the state). It is realized in the myriad of representations and ideological constructions of the Other in scholarly and popular works, and in the principles which help to select and recontextualise those constructions in such things as the media, official histories and school curricular* (Smith 2006:7-8).

Smith defined an 'Indigenous research agenda' as a program or set of approaches situated within the decolonisation of politics of the Indigenous peoples' movement which followed the end of the World War II, but particularly from political and civil rights movements of the 1960s. It is research which: is undertaken from the framework of self-determination and social justice; insists on Indigenous protocols; is underlined by a set of values and principles consistent with the beliefs and values of Indigenous people; places Indigenous people in control of the research process; and has clear and obvious benefits for Indigenous people.

Smith points out that there are two distinct pathways through which an Indigenous research agenda is advanced: one through community action projects and the other through 'the spaces gained within institutions by indigenous research centres and studies programs' (Smith 2006:125). These two pathways, she says, are not at odds with each other, but simply reflect two distinct developments; they intersect and inform each other at a number of different levels. 'Indigenous-led' research can, therefore, be seen as research which is led and driven by Indigenous researchers within the academy, in partnership with community organisations (Eades and Read 1999) or through the development of collaborative approaches which incorporate the principles of community involvement at each stage of the research process (Anderson et al 2005).

Over the past ten to fifteen years, a model of Indigenous research has emerged which puts into practice these ideas by insisting on meaningful participation of the people once referred to as 'research subjects' into all stages of the research, insists on formal research agreements, clear benefits, negotiation of intellectual property and Indigenous knowledge and the incorporation of capacity building within the research design. In Australia, these developments occurred from the 1980s as a result of concerns about the failure of research to address the poor state of Indigenous health. The 1989 National Aboriginal and Torres Strait Islander Health Strategy detailed a comprehensive program based on holistic Aboriginal primary health care, but was never implemented by the government.
By the 1990s, research ethics became a central concern. Decades of research in Aboriginal and Torres Strait Islander communities had yielded few tangible health benefits and Aboriginal people were recognised as vulnerable to unethical practices. In 1991, the National Health and Medical Research Council approved the Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research (1999) and institutional ethics committees were set up within Aboriginal community-controlled health organisations.

These guidelines remained in place until 2003 when they were replaced by the current *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (National Health and Medical Research Council 2003) which ask researchers to take into account the principles and values of Aboriginal and Torres Strait Islander cultures in the conduct of their research. Throughout this whole period of thinking and development of ethical guidelines for Aboriginal health research, the inherent right to Indigenous self-determination has remained the central principle.

Health policy and evidence in Indigenous health

The past five years has seen Australia take a number of giant steps forward in addressing the disastrous state of Indigenous health. Soon after it was swept into office in 2007, the federal Labor Government commenced work on its health reform agenda, shifting the focus of health systems to preventive health and tackling major equity and access issues. Improving the health outcomes of Aboriginal and Torres Strait Islander people remains the first priority under this goal (Australian Government 2009). The long awaited National Apology to Australia's Indigenous Peoples in 2008 which followed was an essential step towards healing the impact of past policies (Rudd 2008). In the same year, the Council of Australian Governments (COAG) made an historical commitment to closing the gap on Indigenous health inequities (2008).

As a result of these efforts, we are now seeing a range of policies, funding and programs being rolled out under the Closing the Gap strategy (Department of Families, Housing, Community Services and Indigenous Affairs 2009). However, having achieved the strong commitment to addressing Indigenous health inequities and having set up a complex policy framework for closing the gap, little change appears to have occurred on the ground. There are still enormous health service gaps across most health areas and partnership between Aboriginal people and government agencies has been described as 'a somewhat piecemeal, fragmented approach rather than the systematic comprehensive long term action plan to which national leaders signed up in the Statement of Intent' (Ring 2012).

Government health policy, including the National Health and Hospitals Reform Commission *Final Report* (Australian Government 2009), consistently emphasises the need for evidence-based policy. This included research and evidence-based improvements to the delivery and organisation of health services, as well as building the evidence base as to what works in preventive health. But policy makers are often confronted with a lack of 'clear evidence' from scientists; there may be multiple interpretations and solutions and best guesses frequently prevail. Evidence, where it exists, can be used selectively; too often, lack of 'evidence' can be an excuse for no action. Policy decisions occur within the context of an electoral cycle which favours short-term gain over long-terms solutions. There is rarely one solution for the complex health problems which confront Indigenous communities. Addressing the social determinants which underlie health invariably involves action across many portfolio areas, by both government and non-government organisations.

Indigenous health strategies such as the National Health and Medical Research Council's Road Maps 1 and 2 (2002; 2010) place a strong focus on intervention research to deliver health outcomes. But better evidence requires good quality data and rigorous approaches to develop and evaluate interventions. There are numerous challenges in producing good evidence for Indigenous health improvements. Because no good-quality research, or no research at all, has occurred, there is a lack of evidence. This has resulted in a lack of policy attention, and therefore funding, often for problems which many people would identify as obviously needing attention.

There are a number of important issues which impede research in Indigenous health. One is data quality, which includes the accurate recording of Indigenous status for routinely-collected health data (Australian Institute of Health and Welfare 2010), an issue which is currently being addressed as part of the Closing the Gap Strategy (COAG 2008). Another problem which is identified in the literature is the lack of large scale studies, particularly randomised controlled trials to provide the 'gold standard' evidence preferred for policy implementation.

There are a number of practical and ethical issues in conducting such studies (Sidthorpe et al 2002), including difficulty in establishing a cause–effect relationship for complex health issues. We need better indicators to evaluate health improvements or outcomes, but it is essential that these reflect the values of Indigenous people.

We also need research which helps us to understand qualitatively how change is possible, that is, qualitative research which focuses on processes and contexts as well as on the way effective partnerships and collaborations work.

Injury prevention research

Research which I have conducted over the past decade has focused largely on the development and evaluation of interventions to reduce or prevent injury and its associated risk factors, and to promote safety, particularly among Indigenous children and young people. Safety is an important, but often unrecognised, health equity issue. Most injuries are preventable and research conducted, particularly over the past 30-40 years, has provided good information about how to prevent injuries occurring. Across the globe, people living in poor communities experience a disproportionate burden of injury.

In Australia, Indigenous people disproportionately suffer this burden. Fatal injuries in the Indigenous population occur at nearly three times the rate for the rest of the population (Helps and Harrison 2004). The injury hospitalisation rate for Indigenous people is twice that for non-Indigenous people (Helps and Harrison 2006). There is also a significant burden of disability which affects Indigenous individuals, families and communities. There are unacceptably high rates of injury from particular external causes of injury, notably violence and transport. Among Indigenous Australians, road traffic injuries and violence (including suicide) are the leading causes of injury death (Helps and Harrison 2004; Helps and Harrison 2006). There are high rates of preventable child injury from intentional and unintentional causes (Australian Institute of Health and Welfare 2011). Intervention research promises to deliver results by developing programs that can be effectively delivered in real world settings.

There are a number of data limitations for research which aims to prevent and reduce injuries from occurring within the Indigenous population. Firstly, this is an under-researched area which has not received the same attention as other health issues, so there are few studies. Also, injury problems which confront Indigenous communities are complex and most often interlinked to numerous other factors, including socio-economic disadvantage, social marginalisation, geographical isolation, family and/or community dysfunction as well as a host of other factors specific to particular injury types.

For a similarly complex array of reasons, effective injury interventions have led to improvements in injury mortality and hospitalisation for most Australians but have not had the same uptake within Indigenous communities. The net result of this lack of research effort and output is that there is a lack of the sort of evidence which would prompt policy makers to invest in much-needed targeted interventions. So with a lack of uptake of 'mainstream' interventions and a lack of any investment in targeted interventions, Indigenous Australians have been left behind. This helps to explain the inequitable injury statistics. Lack of seat belts and child restraints, overcrowding of cars, long distances to travel, poorly maintained cars, and alcohol use explain much of the excess Indigenous injury deaths and hospitalisations. Indigenous people are also more likely to be pedestrian casualties due to the places where Indigenous people live, the lesser likelihood of private car ownership, fewer licensed drivers and poorer access to public transport. Child injury can occur as a result of riskier home environments, exposure of children to violence and lack of adult supervision, as well as socio-economic factors and poor educational status.

There is a pressing need for research which contributes to understanding how known, effective interventions will work in a range of Indigenous community settings which would help to translate the results of mainstream research into effective policy for communities most in need. Addressing safety is necessarily a multi-sectoral activity or set of activities. It requires the input of government and non-government organisations, academics from various disciplinary perspectives, and of course community input. For Indigenous communities, we need to undertake research which will increase our understanding of how to improve the uptake of known effective interventions (for example, the correct use of children's car restraints); how to deliver safety messages in culturally appropriate ways; how to develop new programs that address the specific contexts and priorities of Indigenous communities; and how to enhance the capacity of communities to deliver sustainable programs. I will go on to describe a number of injury prevention research projects in which I have attempted to develop these themes.

From 2007–09, together with colleagues from the University of Sydney and the George Institute for Global Health, I engaged in an Australian Institute of Aboriginal and Torres Strait Islander Studies and National Health and Medical Research Council the funded study, *Safe Koori Kids: Community Based*

Approaches to Aboriginal Injury Prevention, which involved the development and evaluation of a school and community based injury intervention program in urban New South Wales, Australia. The study combined public health prevention research and community-based participatory 'empowerment' approaches, and addressed safety knowledge, attitudes and self-efficacy in an urban Aboriginal community in south-west Sydney. Some of the key features of the research project were that it was conducted by a multi-disciplinary team, used a mixed methods approach, involved numerous community partners including the local Aboriginal Medical Service, and utilised an Aboriginal advisory committee with key Aboriginal community workers. The project successfully developed a school safety program, trained teachers and included a range of parent/community safety promotion activities. The school based program included a culturally-affirming safety program which was embedded in the school curricula, teacher and student materials and an online game (http://www.georgeinstitute.org/safekoorikids/). After piloting in a number of schools in south-west Sydney, the program was finally implemented in five schools by teachers over a school term and involved a total of 790 students in middle and upper primary school. The intervention was evaluated using a 'pre-post' test design with questionnaires administered to children and parents, as well as post-test focus groups with teachers. The results showed that the program had led to improvements in the safety knowledge and attitudes of children. There were statistically significant positive results in terms of children's self efficacy. This finding shows that Indigenous children were more likely to achieve a sense of confidence in regards to keeping themselves safe. Teachers reported improvement in safety knowledge and teaching practice around safety as well as an increase in teacher's knowledge of Indigenous culture. There was also a reported increase in participation of Indigenous families at school events as a result of the program.

Another study, *Aboriginal People and Road Safety in NSW and SA,* funded for three years by the Australian Research Council, involves the in-depth examination of factors underlying the high involvement in road crashes and licensing by Aboriginal people in Australia. The study uses Aboriginal medical services in New South Wales and South Australia as sites for the research. Road injury is a leading cause of fatal and severe injury for Aboriginal Australians. Obtaining a driver's licence can be a major challenge for Aboriginal people leading to high rates of unlicensed driving and ongoing problems with debt and sometimes the police. There has been very little policy attention or assistance, partly because of the lack of research on Aboriginal road safety or licensing in Australia. The aims of the study are: to provide accurate estimates of the factors that impact on road safety and driver licensing for Aboriginal people, from the perspectives of Aboriginal people, their communities and service providers; and to document the extent to which these factors and their consequences contribute to inequalities in health and social outcomes; to determine the capacity of Aboriginal community-controlled primary health care services and local communities to address road safety and licensing; and to build an evidence base for development of programs to address road safety and licensing and identify opportunities for intervention, both in the Aboriginal community-controlled health organisation setting and in the general community.

Another project, *Safety Promotion and Injury Prevention Program for Rural and Remote Aboriginal Health & Community Workers*, was a capacity building project conducted over 18 months in 2007 with support from the Department of Health and Ageing Injury Prevention Community Grants Program. Working with colleagues at the George Institute of Global Health, the research team targeted remote area health and community workers in the Bourke local government area, which has one of the largest Aboriginal populations in western New South Wales. The project arose as a result of the Bourke Aboriginal Health Service approaching the George Institute to undertake workforce training to address the complex injury issues within the community. The health service had observed an increased numbers of injuries from alcohol related violence and transport related injuries and identified the need for injury prevention skills development for health and community workers. The project developed and delivered a practical training package for workers. Built around the development, implementation and evaluation of locally identified injury prevention projects, the project also aimed to enhance the collaboration between Aboriginal health and community workers, other health professionals, and increase the capacity of Aboriginal health and community workers to prioritise safety in the course of their work across various agencies.

Lessons learned, challenges and opportunities

One of the key lessons learned from my research in the injury prevention field over many years is that research works best when it is invited, informed and led by members of the Indigenous community or group which is the target group for the research.

This may be a local group or a broader community; that is, the 'community' which can best identify the most pressing safety issues and the potential solutions. But issues and solutions are not always straightforward. They often need to be debated, agreed upon and 'owned' by the community. This is essential if research efforts are to be sustained.

According to Bailie and Paradies (2005), research which is valued by Indigenous people is: multidisciplinary; community-controlled; focused on interventions; focuses on positive models of health and wellness, and on the social determinants of health; and is transferred back to communities and into policy. But Indigenous leadership at both the community and academic level is crucial to the success of such research. There is no one 'right' model of Indigenous leadership for projects. In the projects I have described, Indigenous people have been chief investigators, members of the researcher team, research assistants, community brokers and government workers, and not in tokenistic roles. It is important that Indigenous people have leadership roles regardless of the position that they occupy within organisations, in both the academic team and the community partners. Aboriginal medical services, for example, have a key role to play as drivers and partners in research. For Aboriginal community-controlled health organisations, there are many challenges. They are responsible for the delivery of health care for Indigenous populations with highly complex health needs, poverty and racism, usually in the context of understaffing and overall under resourcing for the scope of the problems they confront. There is often a lack of control over health programs imposed from outside and sometimes a lack of control over research. Participation in research can understandably be an added burden.

It is important, then, for academic researchers to find ways of creating partnerships which have real benefits for the community based organisations. There are many practical ways in which this can be done which are sometimes overlooked by researchers. One of the most important challenges in enhancing Indigenous research leadership is to increase the number of Indigenous research students. Honours and higher degree research programs have been the traditional ways of achieving this, but other more innovative approaches are also needed. There is an opportunity to build research capacity through postgraduate coursework training, to better match supervisor and Indigenous students to retain potential research students and to recruit Indigenous people into established research teams. Capacity building of Indigenous health workers, though formal training and on-the-job experience alongside 'professional' researchers provides another opportunity for expanding the Indigenous research leadership capacity.

Taking a research leadership role also poses challenges for the novice Indigenous researcher. Yvonne Cadet-James (2009) describes this as wearing many 'hats', or being lured into the research field without career planning or research training. The examples she offers are of being used as project officers, data collectors, cultural brokers and cultural mentors on research projects, or being the Indigenous person named on a grant application to meet funding criteria or show 'Indigenous involvement'.

At the university level, the challenge is to greatly increase the cultural capacity and competence of researchers and research teams. This can be done through peer education such as seminars and by increasing the awareness of Indigenous issues at the departmental or faculty level. Aboriginal academics often play a difficult but important role as 'brokers' between academia and community. There are a range of skills that are required to be developed and fine-tuned in working between research institutes, academia and community organisations and there is still much work to do in building and enhancing existing capacity within mainstream university departments and research institutes.

The Indigenous community is often perceived as (too) difficult to deal with, as (too) political and is too often overlooked for research projects, leading to a lack of engagement in many important research areas. Many academic researchers have no organisational networks or experience or knowledge of where to start, who to consult with, or who to go to for approval for a proposal. There is an increasing amount of information and guidelines around Indigenous research ethics, particularly in the health field. One important task for many Indigenous academics is to educate about the importance of ethical committees and guidelines which may be seen as obstacles to research.

Ethical guidelines do provide information and guidance about what needs to be considered in gaining access to participants. Indigenous researchers, therefore, have another leadership role to play, in acting as 'brokers' within institutions, in enhancing partnerships between other academic researchers and the community, in ensuring that researchers understand ethical practice.

Concluding remarks

In trying to reach the ambitious targets set for Closing the Gap, governments need to be mindful not just of measuring outcomes but also of the processes for achieving change. Indigenous communities have seen the revolving door of policy and are rightfully cynical about the ability of government to achieve change for them. We need better quality evidence on what works. However, this will be of only short-term value unless we also improve our understanding of the policy, social and economic context that is critical to the success, transferability and sustainability of interventions. We need better evidence and data systems but we can't just wait for data systems to be perfected before we act. We need to work on what we know now.

It is imperative that Indigenous health policy recognises the need for Aboriginal and Torres Strait Islander communities to take leadership in this process. Having achieved a national commitment to closing the gap on Indigenous health inequity, it is more important than ever that we continue to prioritise Indigenous ethical principles, community control of research and partnerships with research institutions. We need to greatly enhance investment in capacity building at all levels. An Indigenous research paradigm which prioritises community needs and voices continues to be imperative for improved Indigenous health.

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