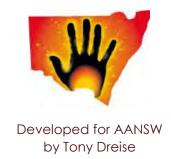
# On our terms: obtaining Aboriginal community consent for social research

A literature review and case study

2018



#### About the author



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### What this paper is about

This paper has been developed for Aboriginal Affairs New South Wales (AANSW), in the context of ongoing conversations with community and the ongoing evaluation of *OCHRE¹*, the NSW Government's community-focused plan for Aboriginal affairs. The paper contains a case study which provides an account of the experiences of researchers, evaluators, and government employees with responsibility for the evaluation of OCHRE, along with a literature review on the topic of Aboriginal community consent for research. The paper captures the experiences of practitioners involved in obtaining community consent and their reflections on what needs to change to improve community consent processes moving forward. The paper also discusses some of the challenges and tensions that are likely to be encountered in seeking community consent, and areas where the direction provided by human research ethics committees and research institutions could be enhanced. While the scope of this paper centres on social research and public policy evaluation, the author nonetheless acknowledges that other scientific research (such as archaeological studies and medical studies) will similarly need to consider the efficacy of their community consent processes in Aboriginal contexts.

The next section of this paper presents the *findings* of the research. This upfront presentation of what was found allows busy readers to 'cut straight to the chase'. The paper then presents a case study drawing upon the experiences of the researchers and public servants involved in the OCHRE evaluation, followed by a review of relevant literature principally from NSW and Australia (and some internationally). The paper then discusses, analyses and proposes a way forward (in the form of practical tips) to improve processes for obtaining community consent for Aboriginal research. An explanation of how the paper was developed (i.e. methods used in the development of the paper) is outlined toward the back of the document. An Appendix at the very back of the paper provides examples of various principles to underpin Aboriginal research, including principles relating to community consent.

<sup>&</sup>lt;sup>1</sup> OCHRE stands for Opportunity, Choice, Healing, Responsibility, Empowerment

## What the paper finds

Obtaining community consent is, more often than not, the bedrock of Aboriginal social research. Not only is the principle of 'informed consent' consistent with widely accepted ethical practice in social and human research, but 'community consent' is particularly important in Aboriginal contexts given the collectivist nature of Aboriginal societies, coupled with an unfortunate historical backdrop of research being done to Aboriginal people. Gaining an Aboriginal community's permission or agreement for research or evaluation activity, therefore, goes to the very validity and integrity of research in contemporary Aboriginal contexts. And yet, as this paper has found, gaining such permission and obtaining community agreement can be both time-consuming and complex, especially in situations where it involves 'whole of community' engagement. Furthermore, and on the research side of things, there is little published evaluation or research literature about strategies, techniques and processes to effectively seek and obtain Indigenous community consent for research. The literature is extensive where it comes to the principles and protocols for Aboriginal research (as outlined in various guidelines by bodies such as the NSW Aboriginal Health & Medical Research Council, the Australian Institute for Aboriginal and Torres Strait Islander Studies, and the National Health and Medical Research Council). These protocols and principles are clearly set out, but as this paper confirms, it is often easier said (principle) than done (practice). That is, the literature is not strong when it comes to implementation advice. This paper has therefore sought to shine a light on processes and strategies for obtaining community permission.

Through both a literature review and the OCHRE case study, the paper finds five critical success factors regarding Aboriginal community consent for social research, namely:

- Community empowerment
- Time
- Trust
- Local tailoring, and
- Clear and constant communication.

#### Community empowerment

'Research' has not always enjoyed a good name in Aboriginal communities, and for good reason. Over the course of Australia's post-colonial history, Aboriginal communities have too often been the unwitting subjects of, and unwillingly subjected to, research. Far too often, research and evaluation have been conducted on the researcher's terms. In more recent years, research, evaluation, and academic communities have had to recalibrate their relationship with Aboriginal communities. The relationship between the research community and Aboriginal communities is, by necessity, changing. While historically it was largely a one-sided affair (favouring researchers), the advent of Indigenous research agendas and broader Aboriginal political empowerment agendas means that the rules are changing. Communities are now less likely to provide 'consent' or permission for research if the terms of the research are not understood or negotiated in good faith. In other words, communities are now more likely to demand research 'on our terms' before projects even commence.

There is little question that OCHRE represents an ambitious agenda of reform in Aboriginal affairs in NSW. It not only seeks to achieve positive outcomes in the areas of Aboriginal languages, healing, local decision making, economic development and employment, but it also aspires to positively change the way in which business is done between government and communities – including in the research and evaluation space. That is, it aspires to move relationships from 'paternalism' to 'partnerships'. The OCHRE evaluation program has been designed in a spirit of community empowerment and coproduction. OCHRE works from a premise that if community owns data and is involved in collecting it and reporting it, then this empowers them. The strategic approach to the evaluation of OCHRE is therefore consistent with the broader OCHRE agenda of empowering communities. For instance, AANSW and the Social Policy Research Centre (SPRC) of the University of New South Wales (as independent evaluators) have engaged with each evaluation site to 'co-design' the evaluation approach. Furthermore, SPRC will not release any findings without the community's explicit agreement.

This approach to community empowerment and co-design has meant that every stage of the evaluation, including community consent, has had to be negotiated, and that takes time.

#### Time

In one OCHRE evaluation site, it took 18 months before the community eventually provided consent. This is illustrative of how complex research permission can be in Aboriginal contexts; something that is not unique to Australia. A First Nations researcher in Canada (Castleden et al., 2012) said that they 'spent a year drinking tea' in order to gain trust with the community in which they were intending to research.

This paper finds from the literature that researchers (both Indigenous and culturally competent non-Indigenous researchers) can become frustrated by consent processes, especially when funding or sponsoring bodies have set tight timeframes; where multiple ethical processes are required; and where the community of study does not have a 'one stop shop' for community coordination and research engagement. As the case study within this paper finds, in situations where research is 'whole of community' in nature and seeks to cut across differing community organisations (and the disciplines in which they operate such as education, health, land and culture), then reaching community consensus (let alone consent) about research value, methods, and directions can be more challenging. In addition, in the case of something as sensitive as Aboriginal languages, researchers often have to engage across diverse cultural interests and vast geographical areas. Why? Because no one person owns an Aboriginal language.

The case study affirms that Aboriginal communities generally prefer face-to-face engagement. This can be partly explained by the orality of Aboriginal cultures and the flat decision making structures in Aboriginal communities. While social media and information technology are increasingly being used by Aboriginal young people and families, meetings and forums are critically important especially when Elders are involved. This means that researchers have to find sufficient time to visit communities often - as a minimum three times: to explain the research, to undertake the research, and to validate research findings.

Researchers will especially need adequate time to build the single most important prerequisite of community consent, trust.

#### Trust

While researchers are expected to engage in their research in an impartial way, they can nonetheless ill afford to walk blindly into community contexts. This paper affirms the fact that researchers and sponsoring bodies will need to assign significant lead time at the outset of a project to sufficiently allow for community engagement, to develop an understanding of various dimensions that comprise a community's context and identity, and to garner trust and build positive relationships. This may include a process of identifying and supporting community-based researchers or research assistants to help broker and sustain partnerships, as has been used in the OCHRE evaluation.

This paper further finds that researchers and evaluators will need to adopt an inclusive approach so as not to fuel any perception of 'siding' with particular bodies or families at the expense of others. In addition, investigators will need to appreciate that community dynamics often have cultural, historical, geographical, and community (or small 'p') political dimensions to them. By understanding these dynamics - without buying into them or playing with them - researchers will appreciate that Aboriginal communities are far from homogeneous. The principal ethical role of a researcher is to do no harm.

The case study finds that the role of the regional offices of AANSW has been instrumental in garnering community trust in the OCHRE evaluation. Many AANSW staff are local people who are working on 'Country'. This provides them with deep and nuanced insights into community, including how to go about local tailoring.

#### Local tailoring

As with all human ecologies throughout the world, Aboriginal communities are dynamic and complex, and not always predictable and rarely static, and never homogenous. In NSW, there are at least 70 different language groups. The dynamic nature of local communities can make for highly productive and rewarding research for communities and researchers alike, but as earlier noted, this will take time, especially if research is to be, as it should, community-driven and inclusive in nature. In other words, in order for research to be effective, it needs to ideally embrace grassroots relationships as the foundation stone of its methodology. Such relational approaches have been key features in the OCHRE evaluation to date.

Communities are highly complex entities. Their governance arrangements and decision making processes are often consensus-based and dispersed as opposed to hierarchical in nature. Furthermore, communities remain apprehensive about government and research agendas. Some community programs have been burnt by previous evaluations. In addition, the case study affirms the fallacy of there being 'one voice' in communities. The interviews with participants revealed that even community organisations can have their 'representativeness' challenged. In at least one OCHRE site, a question emerged as to 'who has the authority to speak?' Aboriginal societies have never had chiefs or bosses.

At a local level, this paper has found that obtaining community consent for OCHRE has been relatively straight forward in some contexts/communities, and more problematic in others. Localism, history, diversity, suspicion, and innovative (that empower) ways of working have meant consultation and consent processes (done properly) take time. The OCHRE evaluation has been strengthened through an investment in community capacity building measures, including the employment of Aboriginal research assistants living and working in the field and, in some cases, on 'Country'.

The case study finds that AANSW regional staff have played a critical role in tailoring information to local audiences. More specifically, the staff have recognised the importance of *clear and constant communication*.

#### Clear and constant communication

There is an old adage in politics, 'if you don't understand it, you won't vote for it'. This sentiment is equally true where it comes to community consent for research or evaluation. Communities need to know what the research means, its processes, and its potential impact. Particularly, they will want to see clear signs that research is likely to have some tangible benefit to community. Also, communities want to know the researchers are, not just name and title but their trustworthiness.

This paper finds that clear and constant communication has been a central feature in the OCHRE evaluation to date. Again, the AANSW regional staff have been instrumental in tailoring communication for local audiences. They have developed local 'flyers' and hosted local meetings to explain the evaluation in plain English. They have used local artistic or photographic images that 'talk to community'. Their efforts have been complemented by communication material developed centrally in Sydney, including Frequently Asked Questions (FAQs) and the Continuing Conversations website. Using the word 'consent' has proven to be problematic in some OCHRE evaluation sites. Local players have replaced 'consent' with other words that community are more comfortable with such as 'permission', 'agreement', and 'working together on Country'.

The introduction of community-based researchers in some OCHRE evaluation sites has meant that the evaluation team can draw upon local people to maintain clear and constant communication. While it is too early (and outside the scope of this paper) to evaluate the effectiveness of the community-based researchers' initiative, the case study finds that they are complementing the work of SPRC and AANSW regional staff. Community-based researchers have the potential to recognise and respect cultural protocols, including in working on Country. They are in a position to engage Elders which is an important cultural protocol.

The literature review within this paper finds that accurate and appropriate information - using plain English accompanied by visual props, video, diagrams and drawings - is fundamental in gaining community consent. The literature also highlights the importance of research/evaluation being relationally driven not milestone driven.

Communication is a big challenge in the context of the OCHRE evaluation (as it is with Aboriginal affairs more broadly) owing to the tyranny of distance. Much like Aboriginal languages, OCHRE initiatives can span across footprints of 200, 300 or 500 kilometres apart.

#### What was found in the literature

#### Introducing and categorising the literature

The literature on Aboriginal community consent for research - while sparse in documenting researcher experience at a level of practice - nevertheless highlights a number of risk and success factors. For instance, Putt (2013) recognises that the research process in Aboriginal contexts, from a non-Aboriginal perspective, can be 'difficult, subject to change and negotiation over time and the ceding of control and re-orientation in thinking' (p.3). Equally, Jackson-Barrett et al. (2015), from an Aboriginal perspective, recognise that research 'on Country' can be complex, including at the early stages of obtaining consent. Meanwhile, Russell et al. (2005) affirm the fundamental importance of gaining informed consent from Aboriginal communities or their agencies when undertaking research in their communities. However, Russell et al. (2005) also found that there are no clear guidelines to help shape and steer the process of obtaining community consent.

This literature review is divided into two parts. The first section records the emergence of Aboriginal research agendas and protocols (and ethical guidance) for undertaking Aboriginal research. The emergence of Aboriginal research agendas is important in locating and understanding that community consent for research sits in a larger political context of Aboriginal community empowerment. This first part also discusses definitions and meanings of Aboriginal identity and diversity, including some reflection on the traditional, historical and contemporary forces that have led to this diversity (and complexity) within Aboriginal communities. This part of the literature review also provides cautionary tales about the homogenisation of Aboriginal communities.

The second part of the literature review draws upon prior research and researchers' experiences in obtaining community consent for research. Of the literature now available on Aboriginal community consent for research (particularly in the field of Aboriginal health), various key themes emerge from it, including:

- Obtaining community-level consent versus individual-level consent
- Empowering Aboriginal-led research
- Embracing Aboriginal ways of knowing
- Communicating 'proper way'
- Researching 'on Country'
- Embarking upon cross-cultural and cross-disciplinary research, and
- Bridging gaps between theory and practice.

The first theme relates to a distinction between consent at an individual level and consent at a community (collective) level. This distinction often means that the researcher can encounter tensions within community about who (or which organisation) has the authority to provide the community's permission. The second relates to the principle of Aboriginal-led research; that is, the principle that research needs to be ideally community-led, or at the very least, coproduced by, or actively involving, Aboriginal communities. In other words, the idea that research should empower Aboriginal communities, as opposed to Aboriginal communities being mere subjects of, or subjected to, research. Thirdly, the literature highlights the notion of Aboriginal ways of knowing (Indigenous epistemologies). Undertaking research by drawing upon Indigenous ways of knowing represents an increasingly specialist skill within the academy and has led to the pursuit of Indigenist research agendas driven by Indigenous academics and knowledge-holders working within Aboriginal epistemological and ontological frameworks. Fourthly, various authors point to the critical importance of nuanced and tailored communication to ensure that Aboriginal communities fully understand the intention and steps involved in research, before they give consent. Fifthly, the literature points to a dual importance of not only cross-disciplinary research, but cross-cultural research, within Aboriginal research contexts. Sixthly, researchers working within Aboriginal contexts are

invariably having to consider ways of working 'on Country'. Finally, certain aspects of the literature indicate the existence of gaps between theory and practice. That is, prior research shows that in spite of good intentions, there are gaps between the principles of community participatory research and the timeframes set, and resources provided, by funding agencies.

It is important to recognise Aboriginal community consent for research within a broader context of principled and ethical research. When developers of human subject research (especially academics) began to fashion the notion of 'informed consent' at an international level, there appeared to be a strong preference on consent from an individual, due in large part by the fact that the principle emerged primarily in the field of medical research. Sparks (2002) helped record the advent of informed consent:

Advances in protection for human subjects have often come in response to particular abuses or scandals. The German atrocities of World War II, some of which were committed in the name of science, led to the Nuremberg Code of international ethics, which in part spelled out the requirement that any human subject must give informed consent to the research undertaken. Between these unfortunate incidents, groups of regulators and researchers have worked to refine the protections provided to human subjects. By the 1990s, federal policy (in the United States) was made consistent across multiple agencies, and a series of ethical organizations and government commissions have continued to contribute to the literature of human subject research.<sup>2</sup>

Moving from this generic approach to consent, to an Aboriginal specific context, of the research that is available, Gower (2015) noted that:

The value and importance of appropriate levels of consultation with Indigenous communities and organisations throughout the research process is very prominent in the literature (e.g., NHMRC, 1991, 1999, 2003, 2007a; Cruse, 2001; Manderson et al., (1998); and Smith, 1997). Furthermore, the importance of establishing appropriate mechanisms for consultation to occur is also highlighted. (p34)

Gower (2015) draws upon literature to highlight a number of key factors in undertaking Aboriginal communityrelated research, including obtaining community consent. He promotes the importance of accurate and appropriate information regarding the proposed research, including purpose and proposed benefits and the right to voluntary choice. These are all important considerations for researchers before and at the time of approaching communities for consent. Gower further noted that 'consent' within Aboriginal contexts often requires consent beyond that of an individual, meaning consent at an organisational or communal level. Gower (2015) further argued that while researchers '...may have the best intentions to ensure informed consent and ongoing informed consent among participants regarding each stage of the research process, the interest demonstrated by those involved in the research may not always be evident' (ibid).

When it comes to Aboriginal consent for research or evaluation, the notion moves very often from an individualist frame to a collective frame. In a recent systematic review of community consent in Indigenous research, Fitzpatrick et al. (2016) highlighted the myriad research guidelines that exist in Indigenous contexts across colonised countries such as Canada, the United States, New Zealand, and Australia. These guidelines include principles on how researchers can undertake culturally sensitive and culturally appropriate research; which will need to be embraced if researchers are to successfully receive community consent. Fitzpatrick's (2016) review, however, found that literature tends to focus on principles and protocols (the why) rather than implementation and communication advice (the how). The authors produced an initial search that yielded 1,447 articles, with 56 articles across these jurisdictions being studied in more depth. In their analysis of the literature and prior research, Fitzpatrick et al. (2016) drew the following conclusion:

We found few publications that describe specific communication methods for seeking informed consent for Indigenous research and even fewer that evaluate participants' understanding or preferences for the process. This may be explained by publication bias or simply reflect lack of attention to the consent

<sup>&</sup>lt;sup>2</sup> https://history.nih.gov/about/timelines\_laws\_human.html

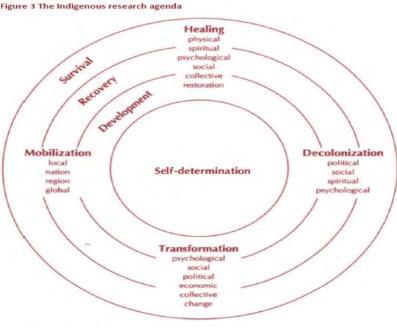
process in these vulnerable populations. As mentioned previously there are over 90 countries with Indigenous populations, however this review is limited to reports published in English and might also exclude research from countries in which the majority of the population may considered to be Indigenous, but have not necessarily specified that they are working with an 'Indigenous' population. The only original research study evaluating the consent process, Russell *et al.* had a very small study sample, with only twenty mothers who identified as Aboriginal. (p.13)

Notwithstanding the data limitations Fitzpatrick *et al.* (2016) identified within their systematic review, their work nonetheless indicates that scholarly and peer-reviewed publications about practical steps, strategies, communication processes, and case studies about community consent for Aboriginal research appear to be limited.

# Section One: What the literature tells us about Indigenous research agendas including...

#### ...the emergence of Indigenist approaches

As earlier noted, community consent for research needs to be seen in a wider policy and research context of Aboriginal empowerment. First Nations communities in NSW, across Australia and internationally have long suffered from research being done 'to' and 'about' Aboriginal people, as opposed to it being done 'with' and, more ideally, 'by' Aboriginal people (Dreise, 2016.) In other words, during the majority of post-colonial Australia, Aboriginal people were either unwittingly subjects of, or unwillingly subjected to, research. Against this backdrop, Aboriginal researchers have in more recent decades pursued an agenda of empowering Aboriginal communities in research. Jackson-Barrett *et al.* (2015), for example, captures the emergence of Aboriginal researchers, research methodologies and Indigenous research agendas that have sought to decolonise and empower Aboriginal communities in research and evaluation. The emergence of Indigenous scholars in colonised countries (such as Australia, New Zealand, the United States, and Canada) has seen the pursuit of Indigenist research agendas, spearheaded by Indigenous academics such as Smith (1999) in New Zealand. In her seminal work on decolonising research, Smith (1999; p.117) posited that Indigenous research has to be seen through a lens of self-determination, healing, decolonisation, and transformation of political landscapes and discourses, as reflected in her model below:



Source: Tuhiwai Smith, 1999 p117

#### ...Indigenous research, guidelines, principles and protocols

Researchers (Indigenous and non-Indigenous) who are looking to undertake research in Aboriginal contexts are generally expected to adhere to a number of principles identified by peak research bodies in Australia, including the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS). In the health sector, both the National Health and Medical Research Council (NHMRC) and the NSW Aboriginal Health and Medical Research Council (AH&MRC) have articulated a number of protocols and guidelines to underpin research in Aboriginal health across Australia and in NSW respectively. The key messages of the guidelines go to fundamental principles such as respect, reciprocity, tangible community benefits, and most importantly in the context of this paper, informed consent. The principles outlined in the guidelines are further discussed in the Appendix.

#### ...a call for a rationalisation or alignment of guidelines

Gower (2012) highlighted that a number of guidelines nationally and across jurisdictions in Aboriginal health research share the same or similar principles. He nevertheless points out that problems might arise for researchers when research 'involves the combination of more than one industry partner and multiple sites.' (p.158) Gower (2012) added, 'The number of ethical reviews that were required for (Gower's) project was extraordinary high despite NHMRC guidelines at the time supporting the minimisation, where possible, of the duplication of ethical reviews.' (p.158) Gower (2012) went on to explain that steps taken conjunctively by the Australian and Western Australian health departments have helped minimise the duplication of ethics processes where multiple sites are involved. Gower (2012) suggested that this 'new process not only reduces the duplication of ethics application forms but importantly, will invariably minimise possible delays that may occur under a multiple approval process.' (p.159) It is highly noteworthy here that guidelines and procedures such as those of the AH&MRC require researchers to obtain community consent before they submit their ethics application and require researchers to maintain community consent throughout the course of the research project. Gower (2012) further contends that informed consent requires a commitment of resources and timeframes to enable community negotiation and decision making process. The issue of adequate resourcing is particularly important in cases when clearance is required by more than one organisation, one field (discipline), more than one university, or more than one community. Gower (2012) suggests that:

This [multi-faceted diversity] raises the issue of compatibility between institutional and/or organisational ethics guidelines. The compatibility of ethical guidelines of organisations requires further discussion amongst the organisations involved to clarify processes as the need for multiple clearances can lead to lengthy delays in the approval process. (p.159)

#### ...dehomogenising community

Along with understanding definitions of 'consent', it is also critically important for researchers to understand the diverse nature of Aboriginal 'community' or 'communities'. Aboriginal communities in New South Wales are not homogenous as they continue to reflect traditional societal constructs, as well as take on an evolutionary nature driven by a number of voluntary (moving for work, education and other services) and involuntary (namely colonisation and forced removal from lands) forces of change. As such, Aboriginal NSW is both solid and shifting (dynamic) at the same time. It is also very diverse and cannot, and should not, be homogenised.

In traditional terms, Aboriginal societies in the state now known as New South Wales, comprised dozens of Aboriginal nations each with their own language or dialect, each with their own customs, lore, and law. As with Indigenous Australia more broadly, ceremony exchange, trade and negotiations between nations were common. Over tens of thousands of years, protocols and norms were established. In other words, Aboriginal Australia has always been fundamentally diverse. This diversity, in traditional terms and to this day, is perhaps best illustrated by Tindale's map of Aboriginal nations (right), notwithstanding certain contentions about where some boundaries start and end, as evidenced by Native Title disputes.



In traditional Aboriginal societies, land, plants and animals were seen as fundamental to Aboriginal world view. As Sutton notes, 'in traditional Aboriginal thought, there is no nature without culture.' (p.18) Aboriginal leader, Mick Dodson, further explains the centrality of land or 'Country' to Aboriginal people:

When we talk about traditional 'Country'...we mean something beyond the dictionary definition of the word. For Aboriginal Australians...we might mean homeland, or tribal or clan area and we might mean more than just a place on the map. For us, Country is a word for all the values, places, resources, stories and cultural obligations associated with that area and its features. It describes the entirety of our ancestral domains.<sup>3</sup>

In traditional societies, Aboriginal people adopted flat (as opposed to hierarchical) approaches to decision-making. Hiatt (1996) helps capture the essence of this approach among traditional Aboriginal societies:

The business of everyday life was conducted informally through unspoken understandings, quiet consensus or noisy agreement. In general, the authoritarian mode in public affairs was discountenanced. Vanity and self-importance were mocked. Nearly everywhere men insisted on speaking for themselves and, conversely, evinced a reluctance to speak on behalf of others. Such characteristics belong to the anarchist tradition. The tenacity of their roots, embedded deeply in the indigenous polity and temper, has helped to make assimilation of Aboriginal communities into the imported structure of British government a task of notorious difficulty. (p.99)

In contemporary terms, Aboriginal communities are neither static nor homogenous. The *Working with Aboriginal Communities* Guide developed by the NSW Aboriginal Education Consultative Group and the NSW Board of Studies (2001) helps explain the diversity of Aboriginal communities and peoples in NSW:

In NSW there are over 70 different Aboriginal language groups. As a result of past government legislation, practices and policies, many Aboriginal people were dispossessed from their land and forced to resettle in different designated areas. Such forced relocation of individuals and family groups has contributed to the current diversity within many communities. As a consequence, many Aboriginal people identify with more than one community. A key component of a community's identity will be drawn from their identification with a particular language nation. Even if people have moved, their sense of belonging and their family connections still associate them with this home country. (p.6)

The NSW Office of Environment and Heritage helps capture the history of forced removal of Aboriginal people from their traditional lands in NSW:

Missions were set up in the 19th century, usually by clergy, to house, protect, and 'Christianise' local Aboriginal people. Using Christian texts to guide and justify their actions, missionaries encouraged Aboriginal people to move into mission settlements and join small European Christian communities. Many Aboriginal people disliked the mission system, and started to demand their own land. The colonial government responded by setting up Aboriginal reserves or stations. Often, these had previously been mission settlements. The reserves had their own machinery, and farmed their own crops and livestock.

The three best-known 19th-century missions in NSW were Cumeragunja, Warangesda and Brewarrina. In 1893 these places were taken over by the government and run as stations or reserves. In 1911, at the height of the government's program of reserve lands, there were 115 reserves. Of these, 75 had been created because of Aboriginal demands for land. The stories of missions and reserves tell of a time when Aboriginal nations had been devastated by disease, pastoral expansion and conflict. Aboriginal people were heavily restricted in their access to land and freedom of movement. Missions and reserves remain important today because of their ongoing use by Aboriginal people, and because of the deep and personal attachments many people still have to missions and reserves.<sup>4</sup>

 $<sup>^{3}\</sup> https://www.reconciliation.org.au/wp-content/uploads/2013/12/QA-welcome-to-country.pdf$ 

<sup>&</sup>lt;sup>4</sup> http://www.environment.nsw.gov.au/nswcultureheritage/Missions.htm

Understanding traditional Aboriginal governance and decision-making processes is fundamental to nuanced and tailored engagement (and negotiated consent for research) today. Hunt and Smith (2005, p.5) point out that each community is different (with differing dynamics, relationships, institutions and structures) and that the following considerations are important when it comes to local decision making groups:

- how they are constituted as a group—i.e. who are 'they'?
- who is the 'self' in self-governance?
- how they manage their affairs and negotiate with outsiders;
- who has authority within their group, and over what;
- what their agreed rules are to ensure that authority is exercised properly;
- who enforces the decisions they make;
- how their decision-makers are held accountable; and
- what are the most effective arrangements for achieving their goals.

Holcombe (2004) also helps explain the complexities in engaging with non-stratified and stateless (in a Western sense) societies such as Aboriginal communities. In drawing upon Clastres (1987), Holcombe noted that '[hunting and gathering] society is the place where separate power is refused, because the society itself, and not the chief, is the real locus of power'. (p.6) While Aboriginal societies have evolved beyond hunter-gatherer only status, flat governance structures often remain the norm in communities. Holcombe (2004) further noted that Aboriginal societies did not have 'bosses' or 'chiefs' or 'headman'. This has posed – and continues to pose – problems for the state in engagement and decision making. During early stages of colonisation, frustrations among the colonists led to the introduction of 'breastplates' whereby colonists anointed 'kings' to expedite corrupt land 'transfers'. Holcombe further points out that the kinship-based nature of Aboriginal communities often promotes 'brokers/leaders' to act as buffers between communities and bureaucratic processes. Communities also develop strong sentiments over time about 'local identity' and 'ethnocentricity'. Holcombe further posits that these strong local identities can lead to rivalries with other communities. This in turn, can lead to intra-community and inter-community competition for resources. Tsey et al. (2012) suggest that lateral violence, gossip and jealousy can be attributable to the need for greater 'leadership capacity' and the need to 'heal past trauma'. (p.7)

In contemporary terms, the advent of Native Title Act 1993 (NTA) is the area that has perhaps caused the highest degree of intra-community and inter-community tension and conflict. While the quest to deliver land rights to Indigenous people is vitally important, the process has had unintended consequences. Burnside (2012) cites a number of Indigenous leaders who are concerned by health effects of Native Title-related conflict, including the risk of lateral violence. Burnside writes:

The existence of intra-Indigenous disputes has also been dissatisfactory for many of the 'reliable supporters' of Indigenous rights to land within what could be termed the broad Left, and it is frequently lamented that the NTA has proved divisive within Aboriginal and Torres Strait Islander communities. (p.5)

This historical and cultural backdrop, contains a number of salient lessons for researchers. Researchers need to exercise care in ensuring their practices do not harm or exacerbate existing tensions within and between communities. The above discussion about defining 'community', the traditional practices of Aboriginal people, the upheaval of traditional societies, and consequential contemporary factors all provide additional lessons for researchers who will need to work within these diverse (and at times, conflicted) environments when striving for community consent for research.

<sup>&</sup>lt;sup>5</sup> http://web.archive.org/web/20150905124951/http://www.nma.gov.au/online\_features/aboriginal\_breastplates/home

#### ... Aboriginal identity

Researchers will need to be careful in their assumptions about what constitutes 'Aboriginal identity'. Identity is a very personal matter.<sup>6</sup> The most common definition of an Aboriginal person is three-part; with the following definition generally acceptable to Aboriginal people themselves:

An Aboriginal person:

- is of Aboriginal descent
- identifies as an Aboriginal person
- is accepted as such by the community in which they live.

Grieves (2014) helps explain the development of Aboriginal identity. She draws upon more than 200 Aboriginal biographies and autobiographies over vast geography and timeframes to gain deeper insights into identity. Grieves also notes that the way in which Aboriginal people define themselves has little to do with race. Rather identity is tied to kinship, family histories, and ties to country. Grieves (2014; no page number) writes:

The answer to this is culture, more particularly the intangible aspects of culture that are transmitted through families and kinship systems.

A person is Aboriginal when they have living Aboriginal relations; this is the primary aspect of cultural connectedness.

Those Aboriginal leaders were thinking of kinship when they developed the three items that form the basis of this identity: descent, identification and acceptance as an Aboriginal person.

Family, kinship, relatedness and connectedness are the basis of Aboriginal world-views and the philosophy that underpins the development of Aboriginal social organisation.

In a 'Practice Resource' produced for employees of the NSW Department of Community Services (2009), the authors help define community structures and help distinguish between traditional and historical influences within community structures:

While community structures vary, most Aboriginal communities will operate based on traditions of extended family and community care, particularly in rural and remote areas. It is essential that we start to develop an understanding of the diversity within different language and kinship groups living in one area. This will help us to become more aware of local dynamics as we continue to build strong relationships with different communities.

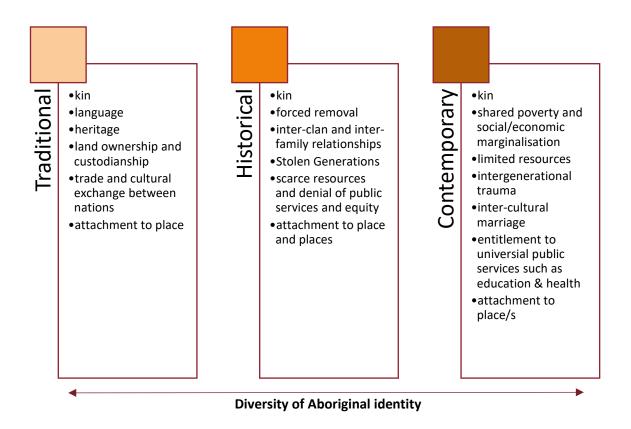
Traditional custodians may not always occupy the land where we are working. The assimilation era displaced many Aboriginal people from their traditional land and moved people all over the country. Aboriginal people who were placed on missions and homes in areas other than their traditional or original country have in many cases stayed in those areas and created family units. These people are sometimes referred to as 'historical people'.

In some communities there is a mix of traditional people and historical people, or historical people and no traditional people or vice versa. This could be important when addressing the community in acknowledgement of land and Welcome to Country ceremonies. It may also indicate why there may be rivalries or conflict between families and/or community organisations.

Understanding community structures will also be helpful in locating the Elders of the community or the key people that are seen as representatives of the community. Many of these people will be involved in local government steering committees and organisations. (p.33)

 $<sup>^6\</sup> http://www.alrc.gov.au/publications/36-kinship-and-identity/legal-definitions-aboriginality$ 

In summary, the Aboriginal community of NSW is large (in terms of its share of the Indigenous Australian population), diverse, dispersed, and mobile. Researchers will appreciate this diversity by working with it an inclusive manner. The following table summarises various dimensions (traditional, historical, contemporary) that researchers will need to be cognisant of.



#### ...one voice fallacy

In a recent literature review on Indigenous evaluation for Aboriginal Affairs NSW, Katz *et al.* (2016) help explain the diversity of Aboriginal communities and the flaws of 'one-size-fits-all' thinking. The authors note:

In reality there are tensions between some of the principles, for example between community consultation/ownership and minimising burden on communities, who may be required to manage many research programs. There are also tensions between the bureaucratic requirements of research and the needs of communities. For example, many ethics committees require lengthy project explanations and complex consent forms, which can be intimidating to Aboriginal participants because they replicate the bureaucratic processes they are subjected to by authorities.

Another issue often missed in the literature is that many Aboriginal (and other) communities are not homogenous; the community may be divided about the research and there may be very diverse views about the value of research as well as findings. Furthermore, much research and evaluation focuses on the most vulnerable members of communities who are marginalised from the recognised community structures; this may create barriers to accessing those participants or may suppress findings (Katz, 2007). In some communities there are also cultural barriers for certain community members to talk to outsiders. (p.38)

As Katz et al. (2016) note, Aboriginal communities are not homogenous. The idea of 'one community' or 'one voice', requiring 'one consent' for research is therefore flawed. Aboriginal communities are diverse for the reasons outlined earlier, such as geography, history, culture (nations), intercultural marriage, and varying degrees of disruption and upheaval as a result of colonisation.

Aboriginal diversity also extends to political and ideological diversity among its leadership. Maddison (2009) helps capture the multiplicity of ideological and political opinion among Aboriginal leaders (and their right to hold differing views). Maddison identifies a number of underpinning tensions with the Aboriginal polity and argues that the notion of community 'speaking with one voice' is fraught. She categorises tensions within the Aboriginal polity through a series of theses and antitheses:

- autonomy and dependency,
- sovereignty and citizenship,
- tradition and development,
- individualism and collectivism,
- Indigeneity and hybridity,
- national unity and regionalism,
- community and kin,
- mourning and reconciliation,
- gender and customary law.

On the issue of 'national unity and regionalism', Behrendt (1995) suggests that 'despite the fact that Australian Aboriginal people are the only peoples that have united under one flag, Aboriginal communities remain intensely local.' (p.27) This localism naturally leads to a state of immense diversity across Aboriginal Australia. Behrendt (1995) further notes that the diversity of Aboriginal people and creation of new constructs (such as land councils and other community organisations) has meant that Aboriginal people will need to negotiate and sometimes resolve disputes within these relatively new governance constructs. Behrendt (1995) reflects on how Aboriginal people approach these negotiations and resolutions in a contemporary sense, although based on and underpinned by traditional cultural practice, as presented in the following diagram (p.30):

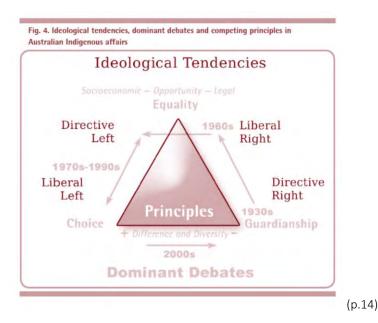
Behrendt on cultural differences between Aboriginal and non-Aboriginal Australians

| Contemporary Aboriginal Values | Non-Aboriginal Values |
|--------------------------------|-----------------------|
| Communal                       | Individual            |
| Egalitarian                    | Hierarchical          |
| Co-operation                   | Competition           |
| Respect for Elders             | Youth oriented        |
| Consensus                      | Authoritarian         |

From the point of view of research, and community consent more specifically, Behrendt's presentation of Aboriginal values (above) often means that researchers will need to ensure that their research projects provide sufficient time for cooperation and communal (inclusive) engagement.

The multiplicity and diversity of political opinion and ideological preferences within Aboriginal affairs can be partly understood through Sanders' (2009) schema which captures various Indigenous affairs dominant debates since the 1930s. While Sanders considers the ideological tendencies from the perspective of big picture political debate (meaning both Indigenous and non-Indigenous discourses), his paper nevertheless touches upon debate within Aboriginal communities. Sanders (2009) contends that is too simplistic to plot Aboriginal affairs debate on political continuum that runs left to right; where the left is broadly speaking in favour of self-determination, affirmative

action and positive discrimination and the right is calling for assimilation, self-responsibility and an absence of 'special treatment'. In his 'Fourfold Categorisation of Ideological Tendencies', Sanders charts the predominant discourses in Aboriginal policy and politics (embracing social and economic dimensions), as illustrated here:



Sanders posits that 'the entry of ideologies into Indigenous affairs policy debates is, in some sense, inevitable rather than avoidable' (p.15). He poses the following questions:

Can actors be neutral about their judgments of the goodness of modern large-scale industrial economic processes in comparison to remnant hunter-gatherer production, and about social directiveness and liberalism? And if they could, would they be useful participants in policy debates? Ideological tendencies, in this more analytic sense of large underlying ideas about the nature of society and economy, would seem almost a prerequisite for contributing to Indigenous affairs policy debates, rather than something to be avoided as a bad influence. Ideology, thus understood, is fundamental to making a contribution to policy, rather than something which is bad and either can or should be avoided. (p.15)

When you consider these philosophical and political struggles, it is perhaps not surprising that Aboriginal people can be found at different points within today's political spectrum. For instance, within community there will be those who are pro-mining as mining can be a source of income, employment, and economic development, while there are others who oppose mining because of concerns about environmental damage and hurting Mother Earth. Another timely example of diversity of Aboriginal voice can be found in the debate about Constitutional Recognition, with some groups in favour of it, while others call for a Treaty instead. Again, researchers will need to be aware of and, depending upon the research topic, responsive to a multitude of community voices.

#### ...undertaking community engagement effectively

As with other professionals, researchers will need to be mindful of a number of principles when engaging with Aboriginal communities. Hunt (2013), for instance, identifies a set of key success factors in engaging successfully with communities, these include:

- an appreciation of—and the cultural competency to respond to—Indigenous history, cultures and contemporary social dynamics and to the diversity of Indigenous communities;
- valuing the cultural skills and knowledge of community organisations and Indigenous people
- clarity about the purpose and the relevant scale for engagement, which may call for multi-layered processes: engagement needs to relate to Indigenous concepts of wellbeing
- long-term relationships of trust, respect and honesty as well as accessible, ongoing communication and information

 $<sup>^{7} \</sup> See, for example, http://www.abc.net.au/news/2016-04-27/confusion-surrounds-push-for-indigenous-recognition-constitution/7360084$ 

- effective governance and capacity within both the Indigenous community and governments themselves
- appropriate time frames (including for deliberation and responsive funding, where applicable). (p.2)

Hunt (2013) further suggests that participatory processes, such as those required in social research, should be a 'deliberative and negotiated process, not just information giving or consultation, and it starts early in the program or project development.' Hunt adds, 'Engagement is based on Indigenous aspirations and priorities, within an Indigenous framework, process, context and time frame; that is, it is an Indigenous-driven process with government as facilitator/enabler within a framework of Indigenous self-determination.' (p.2)

With regard to Hunt's first dot point on cultural competency, the Harvard Clinical and Translational Science Centre describes cultural competence in research in the following terms:

Cultural competence in research is the ability of researchers and research staff to provide quality research that takes into account the culture and diversity of a population when developing research ideas, conducting research, and exploring applicability of research findings. Cultural competence in research plays a critical role in study design and implementation processes, including the development of research questions and hypotheses, outreach and recruitment strategies, consent activities, data collection protocols, analysing and interpreting research findings, drawing conclusions and presenting results. (p. 6)8

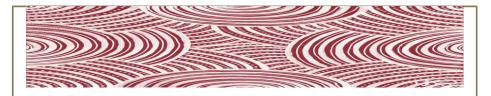
#### ...obtaining permission from communities for research

Muir and Dean (2017) have produced a Practice Resource to help drive an improvement in evaluations as they relate to Indigenous families and communities' programs. Muir et al. (2017) observe that there is a lack of evidence (publicly available information) for the efficacy and impact of most programs targeting Aboriginal families. To counteract this problem, the authors argue that:

- Outcomes or impact evaluations should be built into program design. However, even when evaluations are not built into program design, evaluations should be carefully planned and thought out to ensure that the evaluation is properly resourced, the questions and methods are culturally appropriate and the process is locally acceptable and appropriate.
- Respectful relationships and opportunities for meaningful involvement by Indigenous people should be built into all stages of an evaluation, including evaluation planning and design.
- Community consultation and relationship building are essential components of evaluations of programs for Indigenous people and families, but they can be time consuming and stretch evaluation time frames; this needs to be acknowledged in evaluation planning and resourcing.
- The evaluation method should be appropriate to the evaluation questions and the type of program or intervention. Using a method poorly matched to the evaluation questions can waste time and resources.
- In practice, the precision and rigour of the evaluation method will likely be balanced with other factors such as the available resources, the complexity of the program, the sample size, levels of intercultural understanding, and community or organisational capacity.
- Overcoming or mitigating challenges to good evaluation requires careful planning. It can also require additional resources or support from funders and sponsors. (p.1)

The case study in northern NSW, developed by Muir et al. (2017), on the following page helps illustrate culturallyresponsive approaches to evaluation.

<sup>&</sup>lt;sup>8</sup> Retrieved from https://catalyst.harvard.edu/pdf/diversity/CCR-annotated-bibliography-10-12-10ver2-FINAL.pdf



# Extract from Muir & Dean 2017

#### The following Case Study appears in Muir & Dean's Practice Resource

Box 3: Case study: Empowering participants to engage with the evaluation process Kids Caring for Country is a program based in Murwillumbah, New South Wales, that facilitates an Aboriginal All Ages Playgroup and After School Group out of which several other activities operate. The program is designed to empower participants to take an active role in determining program activities, including how the program is evaluated.

In approaching the evaluation process, staff were concerned that overly intrusive or culturally inappropriate evaluation tools would have negative effects on the ongoing trust and operation of the program. Responding to these concerns, program staff sought to empower parents and family members to engage with the process early on, beginning with evaluation design.

Staff started this process by introducing the need for evaluation to participants during regular Yarning Circle sessions, where staff asked for their input on the proposed evaluation tool, the Growth and Empowerment Measure (GEM). Staff discussed each question in the GEM with parents and carers, who were able to suggest changes to better represent their priorities of culture, family and spirituality. This process took several weeks, to ensure that all participants had a say in determining how their project would be more meaningfully evaluated. Proposed amendments were then presented to designers of the tool to ensure that its validity was maintained.

In planning for the evaluation survey, staff determined that a special workshop led by the family support worker and cultural advisor would be set-up to facilitate a supportive group evaluation process. Participants, who were already familiar with the evaluation tool, were reminded about the workshop a week in advance and a separate program for kids was run in parallel to allow parents and carers (including teenagers with caring roles) time to reflect on their experiences and emotional wellbeing and to complete the survey. (p.6)

#### Section Two: What the literature tells us about community consent including...

#### ...obtaining community consent versus individual consent

Lea et al. (2005) reflect upon the differences between obtaining permission for research from Aboriginal communities as opposed to consent from individual research subjects. With regard to community consent, Lea et al. (2005) note that seeking permission at a collective (community) level can be problematic where it comes to who or what body can speak for the community. The authors further note that researchers have 'at times failed to engage with appropriate Aboriginal representative structures (deliberately or unwittingly) and may instead rely on informal community linkages with a few individuals and so generate conflict' (p.100). Lea et al. (2005) further note that 'it is not uncommon for Aboriginal representative bodies to have their 'representativeness' challenged' (p.100). In the area of Aboriginal health and medical research, Lea et al. (2005) suggest that Aboriginal community controlled health services or affiliates of the National Aboriginal Community Controlled Health Organisation (NACCHO) are appropriate representational bodies for researchers to seek consent from. The authors also highlight the importance of community bodies being fully informed of the expectations of research up front, including a sense of what burdens it may impose, and how community will be supported in meeting such burdens.

In order for consent to be successfully gained in Aboriginal contexts, Mundine et al. (2001) argue the following:

Communities must be provided with all the relevant information and explanations on the intent, process and methodology, evaluation and potential use of any research proposal. Researchers must comply with any request for further information from relevant community controlled agencies associated with the research proposal (p.9).

Mundine et al. (2001) explain that community decision-making processes will reflect varying social and cultural values, and that researchers will need to grow an appreciation of these values and processes. The authors highlight the importance of engaging with Aboriginal community organisations, for example, Aboriginal medical services in the area of health, but warn that researchers cannot simply cherry pick their points of engagement in communities, by arguing:

This (obtaining community consent) does not mean a selective discussion with a group of Aboriginal people one happens to support or a group of people one first encounters upon arriving at an Aboriginal community. Nor does it mean the mere discussion with an individual Aboriginal employee within an Aboriginal organisation or even an AMS (Aboriginal medical service). The community needs time itself to consider all the issues; seek advice from its own Ethics Committee and then, through careful consideration, have an appropriate Consent Agreement signed by all parties so that no circumvention of agreed procedures occur. (p.9)

Obtaining community consent is potentially problematic given the political nature of communities (Aboriginal and non-Aboriginal). Clapham (2011) finds that researchers often perceive Aboriginal communities as being difficult to deal with due to political complexity. Clapham also finds:

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. (p.45)

Putt (2013) finds that research in both urban and remote Aboriginal contexts is 'never easy or straightforward', and that successfully navigating community decision-making and engagement processes can involve significant amounts of time on the part of the researchers. Putt explains:

Considerable time may be required to plan and develop a partnership or collaborative arrangement with Indigenous communities or organisations and to obtain letters of support from key representatives prior to submitting an application. For example, Coram (2011) describes a 12-month application process to obtain approval from an ethics committee, for a small scale study of a community project involving young people. (p.4)

#### ...empowering Aboriginal-led research

Clapham (2011) describes Aboriginal (or Indigenous) led research as 'research which is controlled and driven by Indigenous communities.' (p.40) Clapham explains that the movement toward greater control of research in Aboriginal health has been fuelled by decades of 'negative impacts of past research practices on Indigenous communities', meaning that Aboriginal communities are increasingly determined to shape 'future research directions, questions and methodologies.' (p.40) Clapham (2011) argues that research which is most highly valued by Aboriginal communities is community controlled and asset (or strengths) based, and that leadership at both community and academic levels is a critical success factor in such research. She suggests that Aboriginal involvement as chief investigators, research team members, research assistants, and community brokers is one way of ensuring Aboriginal control. Boosting opportunity for Aboriginal research students and capacity building of Aboriginal health workers are also recognised as key steps in going forward. Clapham (2011) further argues that building cultural competence among non-Aboriginal researchers is a key challenge, by posing the challenge in this way:

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 (p.45).

Putt (2013) reflects on community-based participatory research as one way to facilitate Aboriginal control in research, through 'collaboration teams' which incorporate both academic (Western) and Indigenous community knowledge holders (p.5). In the area of criminal justice, Putt (2013) identifies 'legal services, victim support services, healing and wellbeing centres, night patrols, Indigenous courts, and community justice groups' as examples of potential community-based participatory research partners (p.5).

#### ...embracing Aboriginal ways of knowing

Kendall et al. (2011) argue that Aboriginal research needs to move beyond participatory research to embrace Aboriginal ways of knowing and epistemologies. Kendall et al. (2011) posit that:

Although considerable progress has been made toward a general acceptance that research methods need to change in Indigenous communities, we must move beyond the rhetoric of participatory research toward a model of research in which Indigenous knowledge, processes, and ways of knowing are respected and—as much as is possible—understood, felt, and acknowledged through relational ethical frameworks, appropriate epistemology, and negotiated agreements (p.7).

Kendall et al. (2011) find that Aboriginal ways of knowing represents a major challenge for Western academic contexts. They suggest that these are likely to be both 'time-consuming and fundamentally life-altering' for non-Indigenous educators, researchers and practitioners (p.7). The authors further argue that Australian research needs to further progress down a path of research maturity whereby researchers are actively examining the 'epistemologies that underlie their work and the ways in which they relate to entire Indigenous communities' (p.8).

#### ...community 'proper way'

Gower (2012) highlights the importance of written consent material and information materials being written clearly, including for those where English is not their first language. Gower argues that research information material should be 'provided to participants in a way that it is clearly understood by them and for decision making to be based on these understandings' (p.156). These communication channels would ideally mean face to face communication between researchers and participants 'when discussing research and informed consent in order to minimise misunderstandings when written communication is being used' (ibid).

Where Standard Australian English is not a first language, Russell et al. (2005) found that researchers can convey information to Aboriginal people verbally and by using videos, written information including flipcharts, and participant information booklets. Russell et al. (2005) also explain that research information material is sometimes translated into first languages or other appropriate languages. In their evaluation of appropriately communicated informed consent materials, Russell et al. (2005) identified a number of design principles and delivery practices that are summarised here:

- Consult widely on the design and content of materials including with Indigenous staff and enlist the help of local design experts and trained interpreters;
- Minimise written text and use multiple means of delivering materials: spoken, written, visual;
- Use clear, appropriate visual materials (for example, videos, diagrams) and pre-test the materials;
- Have an Indigenous health worker (preferably known to/trusted by the participants in the case of health research) present the materials;
- Explain the meaning of 'research';
- Plan to make presentations more than once and allow time for discussion and questions at presentations;
- Be flexible in regard to presentation setting, time, numbers, etc. (p.494).

#### ...researching 'on Country'

Jackson-Barrett et al. (2015) explore strategies to conduct research 'on Country' in a way that is appropriate and respectful. The authors have developed a 'grounded in country framework' to help others in conducting research in a culturally-appropriate and ethically-responsible manner. Bird-Rose (1996, p.7) explains 'Country' in the following terms:

Country is a place that gives and receives life. Not just imagined or represented, it is lived in and lived with. Country in Aboriginal English is not only a common noun, but also a proper noun. People talk about country in the same way that they would talk about a person; they speak to country, sing to country, visit country, worry about country, feel sorry for country and long for country. People say that country knows, hears, smells, takes notice, takes care, is sorry or happy. Country is not a generalised or undifferentiated type of place such as one might indicate with terms like 'spending a day in the country' or 'going up to the country'. Rather, country is a living entity with a yesterday, today and tomorrow with a consciousness, and a will toward life. Because of this richness, country is home and peace: nourishment for body, mind and spirit.

Given the significance of 'Country' to Aboriginal tradition, identity, meaning and existence, Jackson-Barrett argue that researchers need to observe proper protocol by understanding 'the connection, relationships, and significance of 'country' for Aboriginal peoples' (p.41). Jackson-Barrett et al. (2015) argue:

More importantly, it is imperative for researchers to come to terms with the fact there are protocols that preside over each 'country' and that these protocols govern the way in which they are able to work 'on country (in country) and off country (out of country)' (ibid).

Jackson-Barrett et al. (2015) acknowledge that undertaking research in Aboriginal contexts is multifaceted and complex, 'whether you are an Indigenous or non-Indigenous researcher' (p.41). They highlight the importance of researchers advising Elders about the proposed research 'on Country' and in turn, obtaining advice from Elders about appropriate protocols, approaches and methodologies. These protocols may include acknowledgement of Elders and country, and a protocol of deep listening. Jackson-Barrett et al. (2015) also reaffirm the importance of researchers negotiating appropriate timeframes with communities, by 'bearing in mind that communities are not static entities and if particular situations arise and these situations take priority over the research', then researchers will need to be fluid and flexible (p.42). With regard to methodology on Country, Jackson-Barrett et al. (2015) highlight 'yarning' as a formal process of sharing knowledges that is reliant upon relationships, expected outcomes, responsibility and accountability between the participants, country and culture, a process that is valued by many other Indigenous nations' (p.43). The authors further explain:

Yarning 'on country' can/will be less intimidating and intrusive for Indigenous people and is far more culturally appropriate than other research methods. What is more, 'yarning is undervalued and underutilised as a potentially rich source of data collection' (p. 43).

Jackson-Barrett et al. (2015) caution against using 'academic speak' when engaging with communities. Academic language can be problematic in Aboriginal contexts. For instance, Jackson-Barrett et al. (2015) reflect upon the fact that a research term such as 'Chief Investigator' could be misinterpreted in communities to mean 'Chief Protector' which is likely to unsettle communities and Elders. When it comes to consent, the authors argue that generally speaking consent forms are 'too formal, too long and written in academic jargon that is not easily understood' (p.45). The authors invite researchers to consider different approaches to written consent, such as filming the verbal consent of participants. Jackson-Barrett et al. (2015) further promote the importance of ensuring enough time is assigned in the research to 'yarn' with Elders and other stakeholders on Country.

#### ...embarking upon cross-cultural and cross-disciplinary research

In its Guidelines and Protocols for the Conduct of Research, the North Australian Indigenous Land and Sea Management Alliance (NAILSMA, 2007) hypothesises that research in Aboriginal contexts can be represented on a continuum, by offering the following:

At one end is research in the natural sciences that uses empirical methods and takes place on Indigenous estates. Here Indigenous input involves setting the behavioural codes and protocols governing access and the conduct of the research, and coming to agreement about intellectual property and reporting arrangements. At the other end is research completely controlled and undertaken by Indigenous researchers. Most research is likely to fall between the two extremes and is likely to reflect some characteristics of cross-cultural, collaborative and participatory, cross-disciplinary or multidisciplinary and cross-cultural research modes (p.7).

Against this backdrop, NAILSMA's (2007) Guidelines identify a number of appropriate methods for researchers to consider in Aboriginal contexts, including collaborative and participatory research methods, cross-cultural research, and cross-disciplinary or multi-disciplinary research. With regard to collaborative and participatory research, NAILSMA (2007) suggest this method can be beneficial when such research 'strives to manage the divergent interests, agendas, resources and expertise of multiple partners working together towards shared goals' (p.7). Such an approach, NAILSMA (2007) adds:

- fosters links between communities, research institutions and agencies,
- promotes knowledge exchange, seeks new and innovative forms of research,
- builds links between research and practice,
- locates control with communities and the people affected, and
- promotes cross-cultural understanding and reconciliation (ibid).

NAILSMA (2007) suggests that cross-disciplinary or multi-disciplinary research is appropriate in drawing upon people and institutions from different disciplines to add value to research programs. NAILSMA (2007) explains that in this mode, 'researchers work together but across diverse areas of inquiry and they need to negotiate research methods and techniques' (p.7). The Guidelines go on to suggest that 'successful research of this kind displays respect for alternative ways of acquiring knowledge and a commitment to negotiation' (ibid). Cross-cultural research on the other hand, is defined by NAILSMA (2007) as a mode of research that 'is usually collaborative and

participatory and involves participants who come from different cultural backgrounds, speak different languages, live and work in different places and possess different intellectual traditions, knowledge and practices' (p.7). The Guidelines further articulate that research in cross-cultural contexts generally includes:

- a focus on community priorities and needs,
- negotiating the processes of research, including the evaluation of outcomes and their dissemination,
- ensuring informed consent,
- intellectual property protection,
- ethical standards, and
- recognition of different forms of knowledge production (ibid).

The NAILSMA Guidelines (2007) provide a 'checklist' for researchers who are looking to engage Aboriginal communities in research pertaining to land and water management. A summary of outcomes that NAILSMA consider as appropriate research and community consent are outlined below:

- Meets community and landowner goals and aspirations.
- Promotes Indigenous management and control and helps protect Indigenous rights under Aboriginal law.
- Promotes and supports NCRM-based enterprise and economic activity, especially when linked to customary practice.
- Increases respect, understanding and the use of traditional knowledge and skills.
- Assists getting Indigenous people 'on country'.
- Has a realistic time frame that takes account of the dictates of Indigenous life patterns.
- Supports and strengthens Indigenous leadership.
- Yields results that can be of direct and immediate benefit.
- Helps record, collate and store Indigenous knowledge for generational transmission, education and management (p.9).

In addition, the NAILSMA protocols highlight the need for proposed research be presented and explained to Aboriginal communities in clear and understandable terms. One way in which this can be done is by involving Aboriginal people 'at all stages of the research process, including early planning and formulation' (p.9). The Guidelines also call for the employment of Aboriginal people as researchers, informants, cultural advisors, translators and technical support using levels of remuneration in line with mainstream scales' (ibid). Finally, the NAILSMA protocols also urge flexible and adaptable approaches to research which allow for modification of project methodology once the project is underway.

#### ...bridging gaps between theory and practice

A number of researchers (Fitzpatrick et al., 2016; Putt, 2013; Russell et al., 2005) have highlighted gaps between (a) research protocols that articulate the why obtaining community consent for research is vitally important and (b) documented case studies, evaluations and guidelines on how to obtain community consent. For example, and as earlier noted, Fitzpatrick et al. (2016) found 'few publications that describe specific communication methods for seeking informed consent for Indigenous research and even fewer that evaluate participants' understanding or preferences for the process' (p.13).

The literature indicates the existence of disparities between protocols and principled intent (including ethics approval) and the time and resources that are provided to build trust, relationships and consent with Aboriginal communities on the ground. Putt (2013) argues that although 'no-one would argue with the core values and principles underpinning the current Australian guidelines (for ethical and Indigenous research), there has been a range of criticisms made about the process of ethics approval in Australia' (p.3). Putt (2013) highlights the fact that considerable amounts of time is required to garner collaborative partnerships with Aboriginal communities and to obtaining 'letters of support from key representatives prior to submitting an application' (p.3). Putt (2013)

goes on to cite one small scale study that took 12 months to obtain approval from an ethics committee. Putt (2013) couches tensions in Aboriginal research processes in the following terms:

Despite the best of intentions, there are inherent tensions between a commitment to the principles of participatory and ethical research and the expectations of funding agencies and academia. Strict adherence to ethical guidelines and research protocols does not necessarily translate into day-to-day good practice. Nor may there be the funding, capacity and timeframe to allow all parties to devote the energy and resources to follow through on the ideal. (p.4)

In citing Anderson's (2008) work with Indigenous communities in Canada, Putt (2013) documents a number of practical suggestions to overcome current tensions and obstacles to Aboriginal research, including:

- More robust and documented 'network' sampling in urban contexts, which are followed up over time.
- Quantitative research that generates policy oriented evidence of outcomes. He (Anderson) found communities were interested in this type of research, arguing that qualitative research mainly assists non-Aboriginal researchers to understand the context and Aboriginal worldviews.
- Investment in 'tools for sharing and socialization of evidence' including stakeholder meetings, presentations, videos, comics, radio coverage and scientific publications.
- Building Aboriginal skills and confidence to lead research so that Aboriginal researchers have the capacity to balance self-reflective cultural investment and practice with non-Indigenous empirical research methods (Anderson 2008) (in Putt 2013, p.5.).

The literature clearly highlights the need for funding agencies to (i) recognise complexity and diversity in Aboriginal research contexts, (ii) allow for sufficient time to plan and collaborate with communities, and (iii) provide appropriate levels of resources (financial and human) to allow researchers to develop relationships, build trust, negotiate methodology, dissemination and publication, build community capacity, and obtain consent from Aboriginal communities in order for research to be mutually beneficial to communities and academia alike. With regard to building trust and negotiating the terms of the research, both community and research parties will need to give consideration to intellectual and cultural property rights. Both parties will need to be clear about where intellectual property sits, how it is to be negotiated, and community permission about the dissemination and publication of findings; all of these are key considerations before community provides consent.

# What was revealed in the case study

N.B.: For confidentiality reasons, the names of participants and communities referred to in this Case Study have been de-identified.

#### Background context: OCHRE and its evaluation

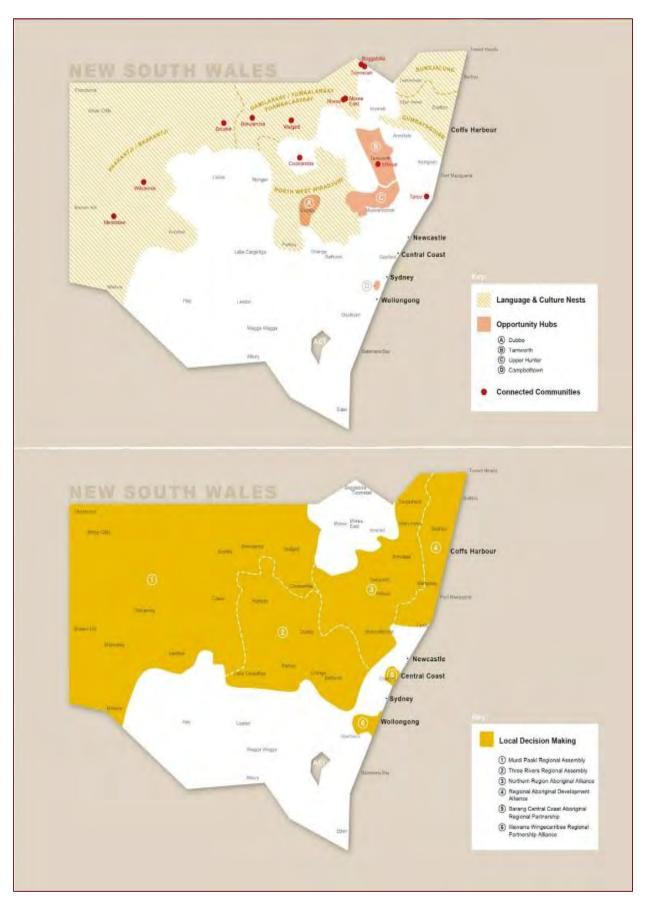
This paper stems from the experiences of Aboriginal communities, researchers and government employees of Aboriginal Affairs NSW (AANSW) when obtaining community consent for the evaluation of OCHRE. AANSW works with Aboriginal communities to promote social, economic and cultural wellbeing through the *OCHRE*, the community-focused plan for Aboriginal affairs in NSW. *OCHRE* embraces Opportunity, Choice, Healing, Responsibility and Empowerment.

In 2012 and 2013 some 2,700 Aboriginal people in NSW stated that Aboriginal language and cultures, education and employment and accountability are important priorities for Aboriginal communities. The NSW Government responded with *OCHRE*. Launched in 2013, *OCHRE* supports

- Connected Communities where schools work in partnership with Aboriginal leaders in the local community to improve education outcomes for young Aboriginal people
- Opportunity Hubs which provide young Aboriginal people with clear pathways and incentives to stay
  at school and transition into employment, training or further education
- Industry-Based Agreements partnerships with peak industry bodies to support Aboriginal employment and enterprise
- Language and Culture Nests to revitalise and maintain languages as an integral part of culture and identity
- Local Decision Making where Aboriginal communities are given a progressively bigger say in what services are delivered in their communities, and how they are delivered
- An Aboriginal Economic Prosperity Framework that drives the long-term and sustainable economic prosperity of Aboriginal people and their communities across NSW
- A Deputy Ombudsman (Aboriginal Programs) to provide independent oversight over Aboriginal programs.

*OCHRE* initiatives are located in a number of Aboriginal nations, communities and regions within NSW. The location of Connected Communities, Opportunity Hubs, Language and Culture Nests, and Local Decision Making are shown on the following page.

OCHRE (Opportunity Hubs, Language and Culture Nests, and Local Decision Making) & Connected Communities Sites



The OCHRE plan represents a recalibration of the relationship between the NSW Government and Aboriginal communities by building strong working partnerships that have at their heart respect for local Aboriginal culture, leadership and decision making, a move from 'paternalism' to 'partnership'. OCHRE differs from previous regimes in Aboriginal affairs in so far as it is equally concerned with 'the way business is done' as it is with 'what the outcomes of business are'. Further information about OCHRE can be found at http://www.aboriginalaffairs.nsw.gov.au

There is a robust accountability process for OCHRE to make sure that it develops as community intended, including an independent evaluation. Recognising that it will take time to reach the destination where Aboriginal and non-Aboriginal Australians in NSW achieve an equal footing, the independent evaluation is planned to continue for 10 years - long enough to learn about what works and does not work and some of the outcomes that have been achieved.

In 2011, the NSW Government and Aboriginal communities of NSW started a conversation that resulted in the OCHRE initiatives. Conversations in 2017-2018 have centred on Stage 1 of the OCHRE evaluation, that is how an independent evaluation focused on how OCHRE is progressing, what is working well, and what needs improving from the perspective of Aboriginal communities. The evaluation is being undertaken by the Social Policy Research Centre (SPRC) at the University of New South Wales (UNSW). Further information can be found at http://www.aboriginalaffairs.nsw.gov.au/ochre-a-continuing-conversation

Consistent with the underlying philosophy of OCHRE, that facilitates the self-determination of Aboriginal peoples in NSW, the evaluation is based on the principles of decolonising research and adheres to the NSW Aboriginal Health and Medical Research Council (AH&MRC) five principles of research with Aboriginal communities set out in the AH&MRC's Guidelines for Research into Aboriginal Health. The AH&MRC Ethics Committee approved the application in August 2016 (ref. 1192/16).

The AH&MRC Guidelines advise that Aboriginal community consent is necessary for the collection and use of health-related community information if any one of the following factors apply:

- The experience of Aboriginal people is an explicit focus of all or part of the research; or
- Data collection is explicitly directed at Aboriginal peoples; or
- Aboriginal peoples, as a group, are to be examined in the results; or
- The information has an impact on one or more Aboriginal communities; or
- Aboriginal health funds are a source of funding (AH&MRC, September 2016, p. 4).

These factors apply to the OCHRE evaluation.

AANSW has established a role in each of its regional offices to support Aboriginal communities to take part in the conversations and link communities and the SPRC evaluation team. This role includes preparing Aboriginal communities to engage in research processes, including community consent.

#### Case study overview

This case study seeks to document the experiences of researchers and AANSW employees involved in seeking or gaining community consent from Aboriginal communities involved in the implementation and evaluation of OCHRE. As such, the case study was guided by the following two-pronged, overarching research question:

How have key players gone about obtaining community consent for the evaluation of OCHRE in NSW and how can future endeavours in similar contexts improve?

The case study documents the experiences of researchers and public servants in their pursuit for community consent across a number of Aboriginal communities in NSW. At a high level, the process to community consent is usually described as a three-step process, namely:

- 1. Ethics approval to undertake the study;
- 2. Informing potential communities and participants about the study purpose, methods, demands, risks and potential benefits of the research; and
- 3. Negotiating with, and obtaining consent from, communities.

The case study begins by unpacking these three steps. Sitting around these steps are the broad principles governing research with Aboriginal peoples including reciprocity, respect, equality, survival and protection, responsibility, and spirit and integrity (NSW Aboriginal Health and Medical Research Council {AH&MRC} Guidelines). Translating these values into practice can be difficult. The iterative nature and organic process attached to the OCHRE evaluation, and that process was equally important as outcome. Put simply, OCHRE differs from previous regimes in Aboriginal affairs in so far as it is equally concerned with 'the way business is done' as it is with 'what the outcomes of business are'.

Following a discussion of the three steps, the case study then reflects on the challenges that researchers and public servants faced in seeking and obtaining consent.

#### Steps taken in OCHRE and its evaluation

#### Step One: Ethics approval

Participants advised that as the evaluation is NSW-based and is an Aboriginal-related research project, the AH&MRC was approached to provide ethical clearance. The Social Policy Research Centre (SPRC) of the University of NSW, prepared, submitted and received clearance for the ethics application from AH&MRC. One participant felt that the process was relatively straight forward, however noting that due to the various initiatives within OCHRE and the multiple sites involved it was not as clear-cut an application as, say, an Aboriginal health-related research proposal developed in conjunction with an Aboriginal community controlled health organisation would be. A member of the project team explained that an early frustration in the ethics process was the requirement to have 'community consent' before ethics approval could be provided. The participant felt that this fails to recognise that community consent is a process that by its very nature includes discussions about the subject of the evaluation, in this case the initiatives. The consent process delivers critical data that because ethics approval is not in place cannot be used. As such, one participant argued that this process 'puts the cart before the horse', given that considerable work had to be done across a number of sites, with significant diversity involved both in terms of the nature of initiatives and the communities themselves.

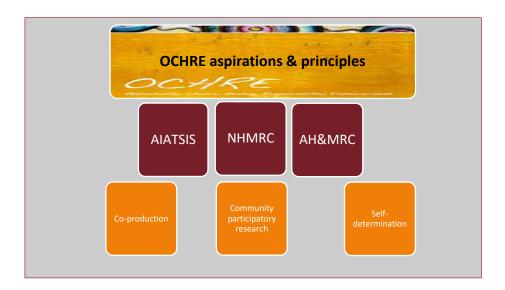
Another participant felt that while adhering to principles such as Aboriginal involvement at all stages of the research was largely uncomplicated, what is more difficult in environments of time and resource constraints is the ability to invest in community capacity building measures in research and 'giving back' to community in the form of professional development, partnership support, reciprocal learning, and in-kind/pro bono contributions.

A participant intimately involved at the outset of the evaluation expressed the importance of trying to strike a balance in the early stages between those who wanted 'action now' and the principles of community participatory research. The participant reflected on the fact that an Aboriginal preference toward a community participatory model was initially resisted within some government circles. 'It required a lot of presentations and briefings about the approach and why it was the way to go,' the participant explained. They further explained the importance of getting a balance between ethical research as required by universities and cultural standards as expected by Aboriginal communities. Another participant explained that the principles and aspirations contained in the OCHRE Plan itself – such as self-determination, empowerment, and changing relationships – were fundamental in the evaluation design.

The participant noted that the OCHRE approach had 'never been done before' and that a large gap existed between principle and practice when it came to Aboriginal related research and evaluation. 'The OCHRE evaluation is unique in that it is a government-sponsored long term evaluation with community control,' the participant

observed. 'It couldn't be more different to the Northern Territory Intervention, let's say, which completely removed control from communities.'

A number of principles and aspirations helped shape the evaluation design (and the ethics application). The following schema illustrates (and summarises) the various themes, protocols and documents that underpin the ethical and participatory approach to evaluating OCHRE:



The schema shows three levels of 'drivers' that have influenced the evaluation design, including the principles and aspirations of OCHRE (which were in a sense, overarching), various ethical guidelines from research bodies (which were essential), and larger goals in Aboriginal research and development (which were highly desirable to the point of being compulsory). In addition to the various principles that feature in the literature, participants on the ground in the OCHRE evaluation highlighted a number of larger drivers that they felt were important in shaping evaluation and research in community. One participant explained these drivers as including:

- Empowering local community,
- Respecting that authority rests in community, and
- Being upfront and honest.

#### Step Two: Informing communities

A range of communication methods were used in seeking informed community consent. The use of locally developed and contextualised communication materials in plain language was vital. General information and resources were also assembled centrally to assist regions and communities in understanding the evaluation of process. This included Frequently Asked Questions or FAQs and a website (A Continuing Conversation) to enable communities and regional staff to develop their understanding about consent and co-produced research. 'This way, we were being very transparent,' one participant explained. Two participants highlighted the importance of 'tailoring information' to local context. 'We developed an information flyer to give it a local touch. We used local pictures with clear and simple (de-jargonised) language so that mob could understand it and buy into it,' one participant explained. 'We wanted to symbolise community ownership.' The flyer was devoid of jargon and used language such as 'moving forward together' (as opposed to 'consent').

Participants highlighted the need for ongoing dialogue with communities, as opposed to one-off visits. Some communities were visited several times by AANSW regional employees and information sessions held with community groups to explain what was involved by AANSW regional staff prior to researchers visiting. Email and telephone contact was avoided, given communities' preferences for face-to-face engagement.

In one community, a regionally-based participant acknowledged the best way to proceed is through local engagement, even if the initiative is regional in nature. Therefore, the participant established separate briefing sessions for several local communities. The participant further explained that meetings and information sessions were established, visits from researchers were arranged, and that lunches were hosted to provide a welcoming space for Aboriginal involvement.

Participants highlighted the importance of being flexible when engaging and informing communities about research and evaluation. 'Be flexible, it's an organics process,' one participant noted. Another participant stressed the importance of respecting the community's ways of doing things and processes around decision-making. The participant noted that building bridges between 'white research and black ways of knowing and doing (epistemologies and ontologies) is difficult', both culturally and intellectually. Respecting that there can be more than one community and more than one group that should be consulted was also a key recurring theme. Participants spoke of unique social and cultural structures in each community. In one community, a participant shared the story of a respected Aboriginal Elder, who was nonetheless reluctant and expressed a lack of cultural authority in speaking for all communities within the Aboriginal nation.

There was variation across sites in the extent to which community groups felt authorised and empowered to provide consent on behalf of all communities involved in their particular OCHRE project. One regional group felt it appropriate for them to go back to their respective local communities before providing consent for the evaluation. In another, it was originally intended for representatives from two locations to come together to discuss community consent; but this was declined by the smaller community as it wanted its voice heard at a local level.

Another participant felt that a sizeable 'tension' sat within the middle of the OCHRE evaluation initiative. That tension was described as a wrestle between establishing and adhering to academic and ethical research rigour and political players who are keen for rapid reporting. In the case of Aboriginal researchers and Aboriginal people involved in the program, they felt it important for the evaluation to be done 'proper way' (that is with community), as opposed to it being done quickly, incompletely, and entirely by outsiders. Another participant reflected on the limitations of a 'milestone-driven' approach to evaluation, when what was required was a 'relationally-driven' approach.

A participant working on the ground with communities explained that communities can sometimes hesitate because they either do not understand the process, or there are higher priorities within community at various points in time. 'You've gotta give community a bit of a push sometimes.' To help steer community thinking, the participant highlighted the benefits of community participatory research and explained to the community that 'if Canada and New Zealand can do it, then we can do it here too.'

Another participant explained the socio-cultural and political complexities in communities. 'There's mistrust of government and researchers,' they explained. 'They want to know who's evaluating, what's the outcome going to be, and what are the funding implications downstream?' Such concerns in communities meant that AANSW and the research team had to spend considerable time and tread carefully to shepherd a community engagement process that communities were satisfied with. The participant further noted that some parts of the community can 'push back' on research, given the poor historical reputation of research, its questionable value in some cases, coupled with the seeming overabundance of it in some communities.

In one community, stakeholders remained upset with a previous government decision that they felt was disempowering of Aboriginal community. As such, they were reluctant at first to engage with the research team and AANSW representatives. One participant also recognised that because research and evaluation may have a bad name, it may not feature as a priority in Aboriginal communities. They noted the misgivings about research and evaluations. 'Community programs have been burnt before because of evaluations,' one participant observed.

The adoption of an Aboriginal research paradigm and embracing cultural protocols was central to informing community decision-making. Participants highlighted the importance of giving the information material a symbolic feel. A small ceremony was hosted in one community whereby permission was launched in the form of a document with the headline 'The (name of organisation) on behalf of (local) community, give permission for...'

Members of the organisation signed-off on the document. 'In some ways, it was like a modern message stick approach,' the participant reflected. 'We ended up taking photos of the signed permission because we wanted to celebrate the symbolism of community ownership,' the participant further explained.

Information sessions were held in appropriate (culturally safe) venues with catering which brought the right stakeholders to the table. Several participants spoke of the important role of AANSW regional staff. 'They were critical in brokering relationships between the researchers and community,' the participant reflected. 'In the community's eyes, AA staff are seen to be there for community,' they added. Another participant involved in the community consent process advised that the research team was heavily reliant and guided by AANSW regional staff on the ground. 'They have the networks, so they are key in getting access to the right people in the community. They know who to talk to,' the researcher noted. 'We (as researchers) were able to build on their (AANSW regional staff) foundation. They did the initial legwork,' the researcher added. Trust between Aboriginal staff of AANSW and local communities was the bedrock from which consent processes generally emerged. Another participant highlighted the critical role of AANSW regional staff in translating principles into practice. 'AA staff have been the linker between researchers and community. We can do this because we know community and we're a trusted voice,' the participant said. The participant further explained that AA staff in their region could 'pull community together' because 'we're in the business of listening and translating their messages.' The participant added, 'We have both family connections and professional skills-sets that allow us to do this effectively.'

Early advice from the ground with regard to community engagement, was that communities were all diverse and at varying stages in terms of OCHRE implementation. One participant explained that given that each site within the evaluation is vastly different, then a tailored approach was required. Not only were the communities diverse in terms of their historical, social, economic, cultural and geographical circumstances, but also in terms of the nature of the OCHRE initiatives (local decision making models, language nests, etc.), how far they were down the implementation track, and also their preparedness to engage in evaluation. One participant added, 'every site is at different stages and we were naïve at the outset in thinking consent would be straight forward and given straight away.' Another participant observed that obtaining community permission to participate in the OCHRE evaluation was 'very straight forward' in some locations, harder in others, and not possible to date in one particular location. More straight forward sites to achieve consent, were those with firmly established organisations that enjoy community support and trust was critical, especially those who adopted inclusive practices of all clans, Elders, and local families. In one OCHRE site, the presence of a strong performing Local Aboriginal Land Council (LALC) meant that obtaining community's authority was relatively straight forward. 'The LALC members have authority and trust. They've developed a good reputation over the past decade,' a participant observed.

Another participant noted that AANSW had decided to develop FAQs and a website (A Continuing Conversation) to enable communities and regional staff to develop their understanding about consent and coproduced research. 'This way, [AANSW] were being very transparent,' the participant explained. The participant also reflected on the limitations of a 'milestone driven' approach to evaluation, when what was required in the early stages is a 'relationally driven' approach.

#### Step Three: Negotiating consent

As mentioned above, participants observed that obtaining community permission to participate in the OCHRE evaluation was 'very straight forward' in some locations, harder in others, and not possible to date in one particular location. Of the easier locations to achieve consent, it was apparent that firmly established organisations that enjoy community support was critical. In one community, a well-run LALC was in a position to enter the consent process with the full support of its constituents. The fact that the local AANSW office had a strong working relationship with the LALC meant that obtaining appropriate community consent was a relatively straight forward process.

In another location, the process was not as easy but was achieved in the end. The consent process in this community was 'tricky', because it involved multiple sites (principally, a large regional centre and a small regional town.) The localities are approximately 50 kilometres apart. AANSW and the research team had intended for representatives from the two locations to participate in a forum about the evaluation; but this was declined by the smaller community. The communities were represented by two community organisations intimately involved

in one component of the OCHRE initiative. In another community, the LALC did not feel that this particular initiative was core to its priorities and felt that other Aboriginal organisations 'closer to the action' were more appropriate. The researchers noted that the expectations and involvement of LALCs across the OCHRE evaluation sites differed according to their priorities and capacity.

One community involved in OCHRE is represented by a peak regional representative body which appeared to enjoy community support within the region. This body was able to sign off early and confidently on the consent process as it felt that it had authority to do so. In another community, however, community participants in a regional meeting with AANSW and the research team felt that they had to go back to their respective local communities before offering consent for the evaluation project. They felt that they were not in a position at a regional level to commit local communities to the evaluation. In the end, community representatives did advise of local consent. The approach of community representatives in this particular community contrasted significantly with representatives from other communities who felt authorised and empowered to provide community consent.

In another community, obtaining community consent proved highly problematic early on. There appear to be three principal reasons behind this. Firstly, community stakeholders remained upset with a previous government decision that they felt was disempowering of Aboriginal community. As such, they were first reluctant to engage with the research team and AANSW representatives. Secondly, miscommunication between the parties at an important juncture in the project meant that valuable time was lost and reciprocal trust was temporarily eroded. Thirdly, political tensions between the two major Aboriginal non-government organisations (NGOs) in this particular community meant that AANSW and the research team had to spend considerable time and tread carefully to shepherd a community engagement process that both NGOs were satisfied with. The reasons for the tensions between the two NGOs, was explained by participants as 'community politics'. When asked what underpinned this, one participant felt that it was part personality, part historical, and part competition for resources and political/policy attention.

A participant described the process of obtaining community consent for research purposes in one region, as a 'dog's breakfast'. The region comprises at least eleven communities all sitting within an 'Aboriginal nation'. There is, however, a strong feeling of localism within the region. What troubled another participant was the fact that obtaining community consent has been highly problematic, which begged the question (in the participant's mind) - 'who gave community consent for the project in the first place?' While the initiative in this region has been spearheaded by a respected Aboriginal Elder, the Elder nonetheless expressed a lack of confidence/cultural authority in speaking for all communities within the Aboriginal nation.

Adopting appropriate language was critically important in negotiating and obtaining community consent. Participants observed that the word 'consent' was problematic in some communities. 'What does consent even mean?' one participant posed. The participant further explained that the word 'consent' was not the right language, and that alternatives such as 'permission to work on Country' was more appropriate. Several participants in the regions felt that 'consent' could be complex for a number of reasons; including ambiguity about the word itself. On the ground, a number of alterative definitions emerged including 'permission for research', 'endorsement', 'approval to work on Country', and 'moving forward together'.

'Who can give consent?' was a central question in a number of communities. Participants felt that some individuals may not be appropriate to give community consent if they are not well connected or respected by the local community and truly able to advocate for local needs. They further explained that some communities had working parties or other arrangements in place locally for OCHRE purposes, while others did not. The involvement of LALCs was a feature in some sites, Aboriginal regional alliances in others, and non-government Aboriginal organisations in others. Participants stressed the importance of getting the right people at the table and working with them. One participant noted that retaining ongoing interest and participation in projects is difficult because 'the same players are being called upon time and again'. They added, 'Aboriginal leaders are incredibly busy and it seems that they're constantly at risk of burn-out.'

The engagement of Elders was of paramount importance across communities. Participants highlighted the importance of an inclusive and responsive approach to evaluation design, including the centrality of obtaining Elders' buy-in, wise counsel, and blessings.

#### Challenges encountered

As can be seen, it has not been an easy process in a number of communities for a number of reasons. Firstly, communities are not homogenous, static, nor one-stop-entities that can be easily visited, have a document signed, and away you go; rather, communities are complex environments with differing traditions, histories, economies, governance arrangements, dynamics, and political personalities. Secondly, communities remain suspicious of government and research agendas. Participants noted that some community programs have been burnt by previous evaluations. Third, OCHRE itself represents a multifaceted breadth of reform - from governance, to economics, to healing, to languages. As a result of this breadth and diversity, the idea that any one organisation can represent these interests with absolute authority across NSW, is flawed.

The Case Study finds that obtaining community consent for OCHRE has been relatively straight forward in some contexts, and more problematic in others. What readers of the Case Study may take away is that localism, history, suspicion and scepticism, and new ways of working have meant such processes (done properly) take time. One way that these types of research and evaluation agendas is being strengthened is via investment in community capacity building, including the employment of Aboriginal researchers and research assistants (including Aboriginal public servants undertaking certain research tasks) living and working in the field and on 'Country'.

In the early stages of the consent process, key players (from AANSW and SPRC) reported experiencing 'push back' from some communities. On the other hand, the project team were being encouraged by government players to 'just get on with it' (the evaluation). Early advice from the ground was that communities were all vastly different and at varying stages in terms of OCHRE implementation. The regions felt that 'consent' could be complex for a number of reasons; including ambiguity about the word itself, let alone the process of obtaining it. It is important to reflect on this phenomenon beyond it being just about semantics or nomenclature about 'consent'.

The term 'conversations' is important to note in the OCHRE context. Rather than overtly using the terminology 'evaluation' (which can off-putting for Aboriginal people as it historically has been disempowering), the term 'a continuing conversation' has been adopted to reflect the iterative and cooperative nature of OCHRE, and demonstrates a commitment to continuing the dialogue that commenced with the initial OCHRE Taskforce. Furthermore, 'conversations' reflects one of the intended objectives of OCHRE, namely that it is a co-produced enterprise. While the term 'coproduction' does not feature heavily in literature on Aboriginal evaluation (unlike the preferred term 'community participatory research'), the principle of coproduction is nonetheless highly relevant in the OCHRE context. Katz, et al. (2016) observe that evaluation projects can involve socially marginalised groups in 'the design of the project and are involved in collecting and analysing data, interpreting findings and disseminating the research (p.10).' In citing Robinson, Fisher, and Strike (2014), Katz et al. (2016) highlight the following point on inclusive and coproduced evaluation:

Inclusive approaches to evaluation aim to engage the people who are intended to benefit from social support programs as active agents in evaluation processes with the transformative goals of improving the programs in their interests. The approaches can offer opportunities for increased breadth and quality of data, an ethical schema, a clear conceptual and methodological framework for practice, and the potential for addressing the human rights and social justice of marginalised groups (2014, p.1). (in Katz et al., 2016, p.10).

Such approaches to evaluation (that are inclusive, participatory and coproduced in nature) often mean that evaluation processes take longer and cost more. With OCHRE, it should be noted that long lead times have frustrated some within government who are keen 'to just get on with it.' The key players involved in OCHRE however remain committed to adhering to the principles of participatory research and the spirit of co-design and co-production.

Participants felt there were a number of factors that have made the project difficult to date (but far from insurmountable), including impatience among those who want data, lack of community unity on the ground, limited resources, and pressing timelines. Participants felt that while having more 'time on the ground' is ideal, it is difficult to achieve within tight budgets and politically charged environments.

Participants also noted a tension between 'fulfilling community expectations' and budget constraints. An example of this tension is the number of field visits and on-ground presence that the research team can literally afford. In addition, the participants felt that community-based Aboriginal researchers could be ideally recruited and nurtured as part of the evaluation, but again a limited budget may not be able to accommodate this. One participant lamented the fact that, '(a major consultancy and accounting firm) can simply walk in, talk to a few, walk out, publish, and that's where their commitment to community starts and ends.' The participant felt that this was damaging to communities as generally speaking such private sector firms are not required to seek and obtain ethical clearance and are not obliged to 'invest' in community through, for example, community capacity building measures.

Another participant felt that the project resembled at times 'a political high wire'; it's a tense project.' The participant was referring to the multiple stakeholders in the project, with varying degrees of expectations and priorities. 'On one side you've got community who want to see this done right. On the other side, you've got people in government who just want the data now,' the participant explained. In one community, the participant felt the evaluation project was hard to get off the ground because of politics (personality and history driven) between two Aboriginal organisations. 'These politics are detrimental to the interests of the Aboriginal community. Gatekeepers can be either a help or hindrance to the community,' the participant added. Based on their experience in one community the participant felt that 'gaining community consent is easier said than done.'

Another participant explained the complexities in communities. 'There's mistrust of government and researchers,' they explained. 'They want to know who's evaluating, what's the outcome going to be, and what are the funding implications downstream?' The participant, an Aboriginal person, felt that too many small communities were 'isolationist in their thinking and that they need to break the cycle by opening their minds and engaging with other processes from other cultures and other ways of doing'. The participant also highlighted the particularly sensitive nature of the Aboriginal language and culture nests. 'It's very hard to get community agreement on the key question of how this should be done.'

One participant was keen to reflect on the myriad of challenges confronting remote communities, which they felt was important to discuss as it provided context to both OCHRE and its evaluation. The participant noted a lack of outreach services and the tyranny of distance that often stymied community progress, including through research and development. 'It's hard to build and sustain networks (including research and evaluation networks) when communities are 200, 300 or 500 kilometres apart,' the participant suggested. Small and isolated communities, it was suggested, are often encountering internal conflict because of lateral violence and competition for scarce resources. 'These communities often find themselves in a leadership vacuum because of isolation and the fact that there is so much mobility in and out of communities.'

# Practical tips moving forward

#### What the literature and case study teach us

Both the literature and case study point the fundamental importance of 'relationships of trust' in order to firstly, obtain community consent for research, and secondly, to sustain research activity which delivers tangible benefits for researchers and communities alike. The design and strategic intent of the OCHRE evaluation is in many ways unique and geared toward this principle of 'positive relationships' between public, research, and Aboriginal communities. It is difficult to locate another evaluation of its type and scale in Australia. Its uniqueness has a number of dimensions to it, including:

<sup>&</sup>lt;sup>9</sup> Based on the literature review which accompanies this case study

- a multitude of sites across remote, regional and urban settings
- its longitudinal form 10 years
- the diverse nature of initiatives involved (from Aboriginal languages to opportunity hubs to community decision-making models)
- the fact that it is government-sponsored and yet seeks to empower communities through community participatory research models and coproduction approaches, and
- that it seeks a convergence of Aboriginal community, public service, and research stakeholders and interests.

Consistent with OCHRE itself, the evaluation represents a fundamentally different way of doing business based on clearly articulated principles in Aboriginal research (AH&MRC, AIATSIS, NHMRC). However, while there may be clarity at the level of 'principle', what is not as clear is how this body of work is understood and translates at the level of 'practice'. As can be seen from the discussion of the Findings above, the kinds of paths (jointly stepped between public, research and Aboriginal communities) that are envisaged and aspired to in this project, have not been trodden before. In fact, the OCHRE evaluation is arguably akin to a 'greenfield' or perhaps a case of 'running against the grain', in so far as it seeks to recalibrate relationships— and overcome historical mistrust – between Aboriginal, public sector, and research sectors.

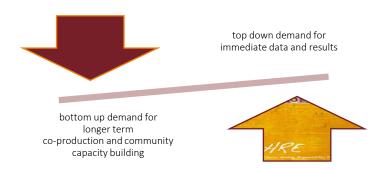
As earlier noted, one participant in this Case Study likened the approach to OCHRE's evaluation to a 'breath of fresh air'. Another participant felt that there needs to be a recognition that Aboriginal research done properly is a 'shared journey' where ideally 'reciprocal learning happens'. 'It takes time and is relational in nature,' the participant added. This experience is not unique to Aboriginal Australia. Research with First Nations people in Canada reveal similar demands for relationally driven and empowering research (which takes considerable time). This point perhaps best summed up through Castleden et al.'s (2012) rather poetic and poignant title to a journal article - 'I spent the first year drinking tea'. That is, Castleden and other researchers reported spending about 12 months in building trust and establishing relationships before data collection could even begin.

This paper also reveals considerable tensions and challenges on the ground when obtaining community consent. The terminology itself is problematic. While the word 'consent' is well established and known in research circles, it is seemingly less understood – both in terms of its intent and the processes involved – and holds little cultural meaning within Aboriginal communities. Participants in this Case Study created alternative messages with community so that the process could be better understood; including through the use of terms such as agreement', 'acknowledgement to work on Country', 'approval to continue the conversation' 'permission to work on Country', 'partnership', 'continuing conversations' and 'moving forward together'. This issue is more than one of semantics or nomenclature. It is perhaps illustrative of the considerable cultural shift that OCHRE aspires to. That is, a cultural shift:

- within government about the importance of community participatory research methods; and
- within community about the value and strategic importance of coproduced and co-owned robust and ethical research.

It should be borne in mind that these cultural shifts are overwhelmingly necessary given community apprehension toward research. As noted in Dreise (2017, p.10), 'research' can be a 'dirty' word in Indigenous communities, due primarily to an unfortunate history of it being 'done to' and without benefit to Indigenous communities. Concerns about research (and evaluation) extend to other First Nations peoples throughout the world who advocate for a 'decolonisation' of research, including in the United States, Canada, and New Zealand.

What also emerges from an analysis of this Case Study is that the OCHRE evaluation to date presents a tension between the demands of various stakeholders; the essence of which is illustrated and captured here:



Several participants noted an unreconciled demand for immediate data and results from some stakeholders on one hand, and a focus on relationships and shared learning on the other. Regardless of where one might sit across this continuum, from a pure research perspective it is important that data is presented at an appropriate and ethical point in time, which means that it is robust, enjoys integrity, and in this (OCHRE) case is co-produced and co-owned by community and researchers alike.

In terms of 'learnings' and alternatives that might emerge from the OCHRE evaluation, there are number of observations that can be made at this point in time. The first is, that parties may have underestimated the amount of time that it would take to work with community in understanding (let alone, obtaining) 'consent for research'. This underestimation has not only resulted in delayed timeframes, but also in terms of pressures on budget. A number of participants felt that the budget has limited the 'real on ground time' that SPRC and AANSW need to spend in the field.

What also emerges from this Case Study is the welcome development of investment in local Aboriginal researchers or research assistants. One participant felt that 'there is a lot of interest in this approach' and that 'it has merit in the community's eyes'. Another participant observed that having Aboriginal researchers in local communities in an ongoing capacity gave the community 'confidence'. This participant also noted the importance of Aboriginal researchers in community 'helping shift cynicism about research to one of empowerment'. While another participant noted that projects like OCHRE need Aboriginal researchers or research assistants on the ground to 'strategise, troubleshoot, and guide' throughout the course of research/evaluation projects.

One final observation to be made from this Case Study relates to the concept of *localism*. Aboriginal people and polity (as is said about mainstream politics) are intensely local. This fact requires greater appreciation from researchers and government agencies alike. As is shown in at least two OCHRE initiatives, the idea that a major regional centre (let alone, a capital city) can operate smaller communities via remote control is naïve. Equally, it would be unwise to think that a 'one-size-fits-all' approach to Aboriginal evaluation is going to work. There are both historical and contemporary dimensions to this phenomenon. Aboriginal communities are dynamic, mobile and far from homogenous. Any assumption that 'Aboriginal community' is a one-stop-entity that sits static in one place is deeply flawed.

### Seven practical tips for researchers, governments and communities

Against all of the aforementioned backdrop of literature and case study, the following seven tips have been developed by this author for stakeholders who are seeking to obtain consent and garner positive and effective relationships with Aboriginal communities in research and evaluation.

### 1. Get the language right

- Don't assume that academic terms are going to be readily understood, including the meaning of:
  - research
  - o evaluation, and
  - consent.
- Avoid jargon and academic speak (e.g. 'Chief Investigator)
- Use metaphors, visual aids, and 'brokers' who can talk effectively and sensitively with community.
- Clear-up things, don't dumb them down.

#### 2. Understand that precedes trust consent

- Be honest, transparent and upfront when discussing what the initiative is about before seeking consent.
- Empower community at every stage, including at the negotiation of research methods stage.
- Explain clearly and simply how the evaluation is intended to proceed – what is required of community and what support and resources will be provided to them to co-produced?
- 'Translational' research approaches are important.
- Highlight the benefits of research outcomes, but don't overstate them. There have been enough 'false dawns' in Aboriginal affairs.
- Recognise that there are legacies from government practices and experiences of research and evaluation that influence trust.
- Recognise that TIME is needed you cannot rush this, it took nearly 2 years in one community – you have to be prepared for this or you do more damage.

#### local 3. Invest in people and organisations

- Design your research in a way that invests in and builds local capacity.
- Local knowledge and networks are essential.
- 'Translational' research approaches are important and locally-based experience could add-value in this regard.
- Create Aboriginal employment opportunities within the project.
- Work with Aboriginal public sector employees and NGO employees to create intermediaries and brokers.

# 4. Customise locally

- Each community is different, they have their own identity, preferences, modes of operation, and decision-making processes
- The consent process needs local meaning and to be owned locally by community.
- Tailor information to local context so knowledge can be transferred.
- The mechanism of consent needs to have meaning at the local level.
- Each community has its own business to attend to, its own history and politics, so don't assume that agreements at regional levels will always transfer to local situations.

# 5. Invite the right people around the table

- The existence of Aboriginal agreed governance structures impact on the process.
- Who can speak on behalf of community needs to be sorted and can only be done by the communities.
- Who sits around the table will depend on context. For example, if the matter at hand relates to natural resource management, then land councils or native title bodies would be appropriate; if it relates to education then Aboriginal education consultative groups would be appropriate; and Aboriginal medical services in the case of health.
- If the research/evaluation relates to a 'whole of community' initiative, then Elders, land councils, and other community organisations should be included.

# 6. Share your journey

- Obtaining consent for research needs to be relationally-driven not transactionally-driven.
- It is a shared journey between researchers and community, including in some places Aboriginal agreed governance structures.
- It happens over time no speed researching.
- It is potentially more costly than other approaches in terms of field visits.

# Embrace complexity and flexibility

- Sometimes there will be tensions between community expectations and government expectations.
- Community people are busy with other more pressing things on their plate, so your evaluation may understandably not be their highest priority.
- The best laid plans will change as community develops understanding and has time to think through what consent means in their community.

# How this paper was developed

This paper has been developed using two principal methods – a literature review and a case study. An explanation of the methods is now provided.

#### Literature Review

The literature review has drawn upon multiple sources including journal articles, academic working papers, discussions papers, and grey literature. While the review draws upon academic research, every attempt has been made to produce a paper for multiple audiences including academia, government, and Aboriginal communities. As such, it has sought to adopt a 'translational research' approach and avoid jargon. The overarching aim of the literature review is to help clarify without 'dumbing down' the topic under investigation.

The review has been developed through a desktop search on the topic of obtaining community consent and associated challenges and tensions with regard to research and evaluation in Indigenous communities. The search has attempted to focus on social research in Aboriginal communities in New South Wales, but as Fitzpatrick *et al.* (2016) have recently discovered, there are few publications on 'how to' obtain community consent not only in Australia, but in other colonised nations such as New Zealand, the United States and Canada.

In undertaking the literature review, the author has sought out, collated, synthesised, and analysed research from peer-reviewed, published and grey literature from Australia, with an emphasis on NSW (where it is available), and from international sources should their findings prove relevant or potentially transferable to Australian contexts. The review also includes literature on the particular topic of research involving 'traditional owners' on country, and how it might differ from research involving Indigenous people who are residing off-country. This is a particularly important consideration given that certain public policies and programs are specifically designed for traditional owner interests (such as languages policy or land management policy), while other public services are more universal in their reach, such as education, transport or health.

Published material within this review has been sourced both online and from the author's library. Search engines such as the National Library of Australia, libraries at the Australian National University (ANU), Academia, and Google Scholar have been searched. In addition, a number of specific databases and journals have been explored, including (but not limited to):

- NHRMC
- AIATSIS
- Lowitja Institute
- CAEPR at ANU
- Closing the Gap Clearinghouse
- Evaluation Journal of Australasia
- Journal of Critical Indigenous Studies, and
- Australian Aboriginal Studies Journal.

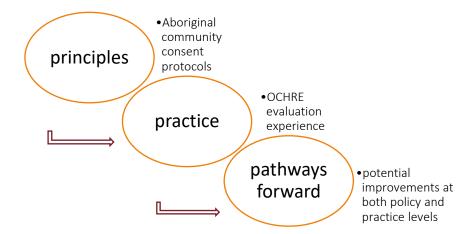
Search criteria for the literature review has included:

- Indigenous (and/or Aboriginal) research protocols and principles
- Informed consent in Indigenous research
- Permission to conduct research on 'country'
- Definitions of Indigenous 'community'
- Conducting research and evaluation in Indigenous contexts
- Tensions and obstacles in Indigenous research and evaluation
- Tensions between principles and practice in evaluation in Indigenous settings
- Successful case studies in Indigenous research and evaluation
- Indigenous community governance
- Indigenous community politics, and
- Indigenous community engagement.

## **Case Study**

With regard to the case study, a number of steps were taken in its development, including:

- Key background readings from sources such as AANSW, SPRC and other key bodies of published work on
   (i) OCHRE and (ii) Aboriginal research protocols and principles
- Interviews with key players involved in seeking community consent for the OCHRE evaluation
- Analysis of the studied phenomenon through the following conceptual framework:



The case study cites a number of principles and protocols that help guide and govern Aboriginal human research. It then reflects upon these from the point of view of practice on the ground, and the experiences of the key players in the field. It then discusses and analyses the differences between principles and practice, with a view to forming advice to help shape future pathways in Aboriginal community consent for research going forward.

As earlier noted, this Case Study has sought to document the experiences of researchers and AANSW employees involved in seeking or gaining community consent from Aboriginal communities involved in the implementation and evaluation of OCHRE. As such, the Study is guided by the following two-pronged, overarching research question:

How have key players gone about obtaining community consent for the evaluation of OCHRE in NSW and how can future endeavours in similar contexts improve?

As can be seen, the overarching research question is a 'how' question. Yin (2014) suggests that case study method is a highly appropriate approach when the research question commences with 'how' or 'why? Milliot (2014) finds that such approaches are appropriate when the studied phenomenon is complex (several actors, assignments, procedures, goals, etc.) and not clearly or sufficiently theorised. This OCHRE Case Study falls within that category.

A set of formal questions were posed, but the interviews took various courses and deviations based on what the participants felt compelled to talk about or share, and interesting points that emerged during the course of conversations. The set questions were:

- 1. How did you go about obtaining community consent for the OCHRE evaluation; i.e., what steps/strategies/approaches did you take?
- 2. What (if any) Aboriginal research principles or community protocols have you based your approach on?
- 3. What tensions and/or frustrations and/or challenges have you encountered along the way?
- 4. What changes would you like to see in this space (either at protocol/ethics level or practice level)?

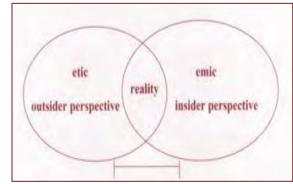
The interviews with participants were semi-structured. Each of the interviews was conducted on a one-on-one basis and were 30 to 90 minutes in duration. The researcher's notes were synthesised and summarised following the interviews. Because of the relatively small number of interviewees involved, the Case Study de-identifies so that contributors' 'frank and fearless' insights are preserved. The participants represent a broad and deep crosssection of talent and expertise working in three areas to support Aboriginal community to consider their consent for the evaluation:

- Public servants working directly with Aboriginal communities across urban, regional and remote settings;
- Academics who were members of the independent evaluation team responsible for obtaining Aboriginal community consent; and
- Public servants with a central office management and support function.

The participants were a mix of Aboriginal and non-Aboriginal researchers and public servants. A number of Aboriginal people interviewed were 'working on Country'.

Following the interviews and consistent with case study methodology identified by Zucker (2009), a process of 'theme mapping', 'typology building', and 'member checking' was undertaken. The analysis of the findings was based on the 'purpose, rationale, and research questions' identified at the outset of the Case Study. With regard to 'member checking', a draft version of this Case Study was provided to the interview participants for their review and comment.

Finally, with regard to method, both the case study and literature review have sought to strike a balance between emic (the researcher) and etic (the participants) perspectives in seeking to reach a closeas-possible 'reality' of the phenomenon under study (as illustrated right) 10. Together, the case study and literature review represent a 'mixed mode' of research. Such an approach can lead to greater validity of data collected. Bulsara<sup>11</sup> identifies a number of benefits of such approaches to social research:



- Variation in data collection leads to greater validity;
- Answers the (research) question from a number of perspectives;
- Ensures that there are no 'gaps' to the information / data collected;
- Ensures that pre-existing assumptions from the researcher are less likely; and
- When one methodology does not provide all the information required.

<sup>&</sup>lt;sup>10</sup> Emic and etic perspectives are terms used by social scientists and anthropologists, the former meaning 'insider's view' and etic meaning 'outside observer'. For more information about these perspectives, see (for example) https://medanth.wikispaces.com/Emic

 $<sup>^{11}\</sup> https://www.nd.edu.au/downloads/research/ihrr/using\_mixed\_methods\_approach\_to\_enhance\_and\_validate\_your\_research.pdf$ 

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# Appendix - Various guidelines on ethics and consent in Aboriginal research

#### **AIATSIS**

'Informed consent' is a key feature within a set of guidelines developed by the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS). AIATSIS's Guidelines for ethical research in Australian Indigenous studies developed in 2012 identifies the following fourteen principles of ethical research:

- 1. Recognition of the diversity and uniqueness of peoples, as well as of individuals, is essential.
- 2. The rights of Indigenous peoples to self-determination must be recognised.
- 3. The rights of Indigenous peoples to their intangible heritage must be recognised.
- 4. Rights in the traditional knowledge and traditional cultural expressions of Indigenous peoples must be respected, protected and maintained.
- 5. Indigenous knowledge, practices and innovations must be respected, protected and maintained.
- 6. Consultation, negotiation and free, prior and informed consent are the foundations for research with or about Indigenous peoples.
- Responsibility for consultation and negotiation is ongoing.
- Consultation and negotiation should achieve mutual understanding about the proposed research.
- 9. Negotiation should result in a formal agreement for the conduct of a research project.
- 10. Indigenous people have the right to full participation appropriate to their skills and experiences in research projects and processes.
- 11. Indigenous people involved in research, or who may be affected by research, should benefit from, and not be disadvantaged by, the research project.
- 12. Research outcomes should include specific results that respond to the needs and interests of Indigenous people.
- 13. Plans should be agreed for managing use of, and access to, research results.
- 14. Research projects should include appropriate mechanisms and procedures for reporting on ethical aspects of the research and complying with these guidelines.

#### **NHMRC**

The National Health and Medical Research Council (NHMRC) has identified a number of core values at the heart of Aboriginal health research. The NHMRC's Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research have been developed to assist researchers when developing proposals and undertaking research in Aboriginal and Torres Strait Islander health. The guidelines identify the following six core values (with spirit and integrity at the centre):



(Source: Keeping research on track: A guide for Aboriginal and Torres Strait Islander Peoples about health research ethics, NHMRC 2005)

In addition to these core values, the NHRMC has developed a guide for Indigenous communities on how they can help 'keep research on track'. The NHRMC identifies an eight step process as outlined below:

|   | The 8 steps research process                                      | earch on the right trac   |
|---|---|---|
|   | The o steps research process                                      | Researcher's cases  |
| 1 | Establishing relationships  | Contact and meet the Aboriginal Council members or appropriate Aboriginal organisation  Meet local key people Find out about our protocols  Contact and visit local Aboriginal organisations          |
| 2 | Conceptualisation—thinking and planning                           | Explaining the big research picture     Negotiation and decision making     Work with communities to fill out     ethics approval form to go to HREC  |
| 3 | Development and approval—<br>finalising the Research<br>Agreement | Finalise the Research Agreement Sign Research Agreement when everybody is happy Jointly develop the ethics application for approval. Do not start without ethics approval.                            |
| 4 | Data collection and management                                    | Training Aboriginal and Torres Strait Is lander peoples Working ethically with participants to collect data   |
| 5 | Analysis—working out what the data means                          | Look at the information that has been collected to see what it means Prepare the findings in a clear statement that everybody can understand Hold community meetings and get feedback on the analysis |
| 6 | Report writing  | Maintain constant relationships with communities/organisations when writing all reports     Acknowledge all local co-authors     Meet funding body's needs for report writing                         |
| 7 | Dissemination—sharing the findings or research results            | Present findings to community     Publish and broadcast the findings  |
| 8 | Learning from our experience                                      | Help the communities/organisations to work<br>out the effectiveness of their involvement at<br>each stage of the research process   |

(Source: Keeping research on track: A guide for Aboriginal and Torres Strait Islander Peoples about health research ethics, NHMRC 2005)

#### **NSW AH&MRC**

In New South Wales, the Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee has recently revised a set of key principles to guide research in Aboriginal health (September 2016). The purpose of the key principles document is to:

- guide researchers undertaking research into the health of Aboriginal people and assist them in the preparation of applications to the AH&MRC Ethics Committee; and
- guide AH&MRC Ethics Committee members in making decisions about applications for ethical approval of individual research projects.

#### The AH&MRC Ethics Committee assesses applications against the following criteria:

- a) Consistency with the National Statement on Ethical Conduct in Human Research (NHMRC, 2007) and Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (NHMRC, 2003); and
- b) The Ethics Committee will only approve a project where:
  - i. Net Benefits for Aboriginal people and communities: The research will advance scientific knowledge and result in a demonstrated net benefit for the health of Aboriginal people and communities.
  - ii. Aboriginal Community Control of Research: There is Aboriginal community control over all aspects of the proposed research including research design, ownership of data, data interpretation and publication of research findings.
  - iii. Cultural Sensitivity: The research will be conducted in a manner sensitive to the cultural principles of Aboriginal society and will recognise the historical aspects and impact of colonisation on Aboriginal people.
  - iv. Reimbursement of costs: Aboriginal communities and organisations will be reimbursed for all costs arising from their participation in the research process.
  - v. Enhancing Aboriginal skills and knowledge: The project will utilise available opportunities to enhance the skills and knowledge of Aboriginal people, communities and organisations that are participating in the project.

The AH&MRC Ethics Committee requires researchers to provide a written statement addressing the five criteria listed above. The following section provides further information to help researchers understand and address these criteria.

#### Other Guidelines (examples)

In addition to these guidelines and ethics processes operating at a state and national level, universities and other research institutions across NSW and Australia also have guidelines and criteria for ethical research at an institutional level. For example, the Behrendt Review of Indigenous higher education (Australian Government, 2012) provides the following case study of ethical Aboriginal research at Charles Sturt University:

Charles Sturt University has processes in place to guide ethical research including a university research code of conduct, an intellectual property policy and a Human Research Ethics Committee. These policies and processes address all research management and administration, including that relating to Aboriginal and Torres Strait Islander research. The university ensures senior Aboriginal and Torres Strait Islander representation on the ethics committee to drive accountability and culturally safe and ethical research practice relevant to Aboriginal and Torres Strait Islander research. The university is currently establishing an Indigenous Research Ethics Committee as a subcommittee of the Human Research Ethics Committee, and developing an Indigenous Research Strategy to provide an overarching framework for all Aboriginal and Torres Strait Islander research policies, protocols and procedures. (p.216)

Meanwhile, the Ninti One research alliance in the Northern Territory prescribes the following criteria for prior informed consent for Aboriginal research:

- 2.1 All applications for research must obtain the prior informed consent of the Aboriginal and Torres Strait Islander people with whom the research is going to engage. It is important to note that consent can be retracted at any time during the research project. Informed consent is ongoing. It is the responsibility of the researcher/s to keep Aboriginal and Torres Strait Islander people who are involved in and affected by the research updated on emerging research outcomes.
- 2.2 Ninti One actively encourages Aboriginal and Torres Strait Islander people to be involved in designing and developing projects. This iterative methodology allows scope for investing in local relationships and acknowledges that informed consent will take several meetings and cannot be granted at the first meeting, but only after the Aboriginal and Torres Strait Islander participants are happy with the research project and understand its implications.
- 2.3 Where the research project has been designed externally, the researcher/s should provide the communities and Aboriginal and Torres Strait Islander organisations involved with full details of the proposed project. This will assist applicants who wish to obtain a permit to enter Aboriginal or Torres Strait Islander land in order to conduct research in Aboriginal or Torres Strait Islander communities in seeking prior informed consent from Aboriginal or Torres Strait Islander people. The possibility of adapting the project to local interests should be explored once in the community. 12

The guidelines, principles and processes of bodies such as AIATSIS, NHMRC, AH&MRC, Ninti One, and universities such as Charles Sturt, are just some of the guidelines that exist nationally to assist Aboriginal-related research and evaluation.

 $<sup>^{12}\</sup> http://www.nintione.com.au/resource/Aboriginal-Research-Engagement-Protocol\_template-for-use.pdf$