HARC Scholarship

Project

Project title:

NZ Maori voices and the Aboriginal Australian Cultural Reference Group

Testing a pilot model to authentically represent Aboriginal community voices in health system design and delivery

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Canterbury Board of Health, Christchurch, New Zealand

Project funding body:
HARC, Sax Institute.

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1) Acknowledgements

I acknowledge the Hospital Alliance for Research Collaboration (HARC), Sax Institute for funding the authentic Aboriginal voice in health care design and delivery project undertaken in New Zealand in July 2016.

A warm thank you is extended to everyone in New Zealand who participated in this project who generously shared their knowledge and wisdom, which I have endeavoured to represent in this report.

I would also like to acknowledge and thank:

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- Canterbury District Health Board (Te Poari Hauora o Waitaha)
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- Te Whare Wānanga o Awanuiārangi
- The University of Sydney, School of Public Health.

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Thank you to everyone within the NSW Ministry of Health who contributed to this project including; Dr Andrew Milat (HARC mentor), Elizabeth Best (manager), Dr Stephanie Blows (workplace mentor), Cherie Butler (CRG program collaborator) and the many others who believed in the value of a project designed to gain authentic Aboriginal voices in health care design and delivery.

On a personal note I am fortunate to have the continued support of my partner Alison Birt who joined me on this project in New Zealand providing technical expertise with the filming of interviews, as well as a sounding board for this work.

Dedication

This report is dedicated to Gary and Arthur Burns, two young Aboriginal Wiradjuri brothers whose voices were silenced far too soon.

2) Executive Summary

As a first time visitor from Australia to New Zealand, there was an obvious presence of Maori culture within the country. This observation resonated with Maori people who were strong in their voice (see section 6 results) to express their beliefs about community, culture and recognition as well as the challenges faced by Maori people. Pākehā (New Zealanders of European descent) (Paulston & Kiesling 2005) people were also strong in their voice about respecting and embracing Maori culture, and not speaking for Maori people.

In Australia however, Aboriginal voices are all too often translated to fit within the standard dominant organisational language. This removes the authentic Aboriginal voice from those very processes supposedly designed to improve Aboriginal health outcomes. To be heard, Aboriginal people use a voice that reflects what they think the organisation wants to hear, rather than use words that actually express their own lived experience to better articulate what needs to be heard. This is known as 'Code Switching' (Gilies, Coupland & Coupland (eds.) 1991)

The NSW Ministry of Health has developed the Cultural Reference Group (CRG) to enable its Aboriginal-only membership to speak in their authentic voices and for the organisation to hear and use this information when considering cultural knowledge for its Aboriginal Maternal and Infant Health Service (AMIHS) evaluation.

In April 2016, I was one of three people who were successful in gaining a Sax Institute HARC Scholarship. The purpose of these scholarships is to undertake a project based on a challenge facing their agency. The HARC project commenced with a question raised in the initial scoping out of the AMIHS Evaluation Cultural Reference Group (CRG): what is Aboriginal cultural advice?

The HARC Project was hosted by the Canterbury District Health Board, Christchurch and took place over a period of fifteen days (7 July 2016 – 21 July 2016) on the North and South Islands of New Zealand. During this period, a range of Maori and Pākehā were interviewed to gain insight into health care models that have had success in the engagement with Maori populations in the design and delivery of health care in New Zealand.

Based on the themes that emerged through these interviews, the following principles were developed to facilitate a mutual understanding of perspectives that could be applied in Australia:

1) Be honest with your intention as to why you are there.

2) Ensure you are on their time and not on your own time.

3) 'Listen without prejudice' by hearing what has actually been said and not what you believe you have heard.

4) 'Reciprocity' - ensure you feedback what you have heard and what you have learnt.

5) Leave the door open for people to come back to you with further information.

6) Act on what you have learnt. You may not always like what you hear but you have a responsibility to authentically represent what you have heard.

7) Be yourself - Aboriginal people have the best radar for those who are not authentic to their cause.

These principles are not an organisational engagement 'tick a box' checklist; they are principles for people in organisations working on Aboriginal related activities (research, strategy, policy, projects, etc.). They are intended to be used as reflective principles applied to their own person to recognise themselves in what they are doing and why they are doing it.

To effect changes with Aboriginal heath service design and delivery (and Aboriginal health generally) there must be an honest acknowledgement by people who are not Aboriginal that they can never truly understand the issues Aboriginal Australians have faced nor the challenges that Aboriginal people face each day here in Australia.

People from the wider Australian community must stop believing they have permission to speak with authority on behalf of Aboriginal Australians, simply because they have undertaken research or have worked with Aboriginal communities for many years. Behaving in this way reduces the value and validity of authentic Aboriginal voices as it sends a very clear message that Aboriginal Australians cannot speak for themselves. In effect, authentic Aboriginal voices become a silent unheard minority.

In conclusion, when Aboriginal Australians speak in their authentic voices to share their knowledge and wisdom, "authentic listening" is one of the greatest gifts wider Australia can offer Aboriginal Australia (Benedict 2011).

3) Introduction

Australia and New Zealand are roughly 2,000 kilometres apart yet their cultures are vastly different. New Zealand has chosen to embrace their Maori heritage and hear their country's Maori voices (Orange 1987) and Australia has chosen not to embrace their Aboriginal heritage and so does not hear the voices of the country's first people(s) (Attwood 1967).

In Australia, Aboriginal voices are often translated to fit within the standard dominant organisational language**.** This removes the authentic Aboriginal voice from those very processes supposedly designed to improve Aboriginal health outcomes. To be heard, Aboriginal people use a voice that reflects what they think the organisation wants to hear, rather than use words that better articulate what needs to be heard. This is referred to in Aboriginal communities as code switching (Gilies, Coupland & Coupland 1991).

The NSW Ministry of Health is developing a model to hear authentic Aboriginal voices to gain important cultural knowledge(s) for its AMIHS evaluation. The model was developed in collaboration with the Centre for Aboriginal Health, Centre for Epidemiology and Evidence, and the Aboriginal Health & Medical Research Council of NSW.

The HARC project methodology took the NSW Ministry of Health, Aboriginal CRG model (the *CRG has been developed to enable its Aboriginal only membership to speak in their authentic voices and for the organisation to be able to hear these voices and act upon information provided as it relates to the AMIHS evaluation*) and compared it with similar health care models that have had success in the engagement with Maori populations in the design and delivery of health care in New Zealand.

The objective of the HARC project was to investigate methodologies currently used in New Zealand that may translate into a NSW Health context to successfully engage Aboriginal communities in NSW to ensure authentic Aboriginal voices are heard in health service policy design, delivery and research.

This HARC project is based on a qualitative research methodology using interviews and focus groups to gather data on the methods applied in New Zealand when designing health services for delivery to the Maori peoples.

This report shares my learning's from New Zealand with key findings, lessons learned and information to engage Aboriginal communities more effectively.

4) Setting the scene

In July 2016, I travelled to New Zealand to conduct research to inform the development and implementation of the CRG.

My purpose in New Zealand was to gather stories and translate these into strategies and actions to inform the development and implementation of the CRG. To achieve this, questions were prepared in Australia. They were then tested at the first interview along with the interview method of questions and answers in New Zealand with a senior Maori leader. Advice provided was; if you want to engage with Maori people to share their stories about their work and their experiences, start a conversation using your questions as a guide (1st Interview). Taking this advice, interviews were conducted in a less structured way (not question after question), to create the environment of a conversation during interviews and focus groups.

For all interviews, I travelled to where people were based and felt comfortable being interviewed, including other cities and towns outside of Christchurch. To open each interview, I introduced myself and my cultural background (NSW Wiradjuri man) and then shared some of my personal history of growing up in a single parent family in rural NSW, to then lead into the project about authentic Aboriginal voice. Following introductions, people were provided with a copy of the project description and a project consent form (see appendix A & B).

Participants were asked if their interview could be filmed to enable us to focus on having a conversation rather than me taking notes and possibly missing important points being raised. This would also enable interviews to be transcribed to text for analysis and, depending on the level of consent provided, video to be used for other related projects. Only one person did not want their interview recorded with everyone else giving permission to record their interview and use information gained for other project related purposes. The approach used for interviews and focus group demonstrated a level of trust had been created with everyone who participated in the project.

Following each interview, participants were thanked for their time and contributions to the project. Participants were also asked if they wanted a copy of their interview video following the completion of the project, to be made available on a secure password protected site such as the online video sharing tool “Vimeo”. Many participants expressed an interest in seeing a copy of their video interview.

5) Methods

The HARC authentic Aboriginal voice in health care design and delivery project (the HARC Project) was undertaken over 15 days in New Zealand from 7 July 2016 – 21 July 2016 and involved visits to four towns and cities (Wellington, Rotorua, Whakatane and Christchurch). Interviews and focus groups were conducted based on a set of pre-prepared interview questions, with permission sought from people to video record these for transcription (for qualitative analysis and for use in other project related activities).

All interviews and focus groups were conducted over 15 days in New Zealand from 7 July 2016 – 21 July 2016 as follows:

- 15 days on New Zealand's North and South Islands
- 4 towns and cities (Wellington, Rotorua, Whakatane and Christchurch)
- 16 interviews (average time per interview was 1 hour)
- 2 focus groups (90 minutes/second being 180 minutes)
- 26 people in total participated in the project
- Over 17 hours of interviews recorded on video – with signed consent to use in other work related this this project.

Interviews and focus groups resulted in over 17 hours of video footage that were transcribed to text which was then thematically analysed to inform the development of a coding book that was also informed by interview questions. Codes were entered into NVivo qualitative research coding software to identify and analyse key themes arising with scope for new codes to be created as new themes arose during the coding process.

A. Setting up the project

A literature review of Aboriginal cultural terminology, i.e. cultural safety and its meaning, identified New Zealand as leaders in this area. Other factors influencing this choice were New Zealand's close proximity and being colonised differently to Australia.

This made New Zealand a comparable choice to test the concept of authentic Aboriginal voice in health care design and delivery. Contact was then made with Dr Alistair Humphrey, Canterbury Medical Officer and Dr Ramon Pink (Te Aupouri), Canterbury Medical Officer, Canterbury Health in Christchurch to scope out project viability (http://www.cdhb.health.nz/Pages/default.aspx). To maximise the value of this visit, this project applied a snowball sampling technique to gain access to a diverse range of people for interview.

B. Development of and application of interview questions

Interview questions were developed to investigate factors that could influence the success of a CRG. These were developed from information arising during the development of the CRG, HARC project application and subsequent literature review of Aboriginal cultural terminology.

In total 15 questions were developed from the project question, literature review and other information gained during the development of the CRG. Furthermore, these were developed with an intention to seek feedback on their relevance to the project from the first interview with a widely respected Maori man. Based on feedback from this first interview, questions were not asked individually but were used as a guide to have a conversation with subsequent interviewees and focus group participants.

C. Arrangement of interviews

Prior to leaving Australia for New Zealand a small number of interviews were organised with a cross section of Maori and Pākehā people with an intention to access more community people/groups by referral through these networks.

D. The process of interviewing

All interviews took place at pre-arranged locations as requested by participants. Prior to interview, participants were provided with a Participant Information Statement that outlined the role, function and purpose of the project (see appendix 2). Participants were also provided with a consent form to sign (or not) with different levels of permission in relation the use of information shared, that included use of video (when shot) of other related projects (see appendix 4).

E. Interview demographics

Interview and focus group demographics are represented as follows:

Table 1

Gender	Maori	Pākehā	Total
Male	10		
Female	15	1	
Total	25	1	26

Table 2

Age range	Maori	Pākehā	Grand total
Under - 30	6		
30 - 39	3		
40 - 49	4		
Over 50	11	2	
Totals	24	2	26

Table 3

Employment/Community	Total
Health care sector	13
Higher education	2
Community people	10
Other employment	1
Total	26

Note: While Maori participants did share their tribe's names, these are not recorded in this report as findings contained do not seek to imply that these are the views or beliefs of any particular NZ Maori tribes.

6) Results

Fifty codes were exported for reporting and from these seven key themes were identified (table 4). For reference the highest coded node were 300 instances (voice below) and the lowest node being 12 (health status).

Table 4

Coded Theme	**Node definition (NVivo)**
Voice	Importance of understanding how strong people believe their Maori voice is represented in health care design and delivery
Culture	Gaining an understanding of Maori culture
Relationships	Importance of working with Maori communities
Challenges	Importance of understanding challenges in working on Maori issues
Workplace	Importance of recognising Maori in the workplace
Translation	Importance of feeding back information gained from communities back to communities in a way that is useful and relevant
Recognition	Importance of understanding the issues Maori people face

A. Voice

Voice as a theme was mentioned by 13 interviewees in three hundred instances. This is described as the "Importance of understanding how strong people believe their Maori voice is represented in health care design and delivery". A supporting theme was authentic voice that was described as "about being your real self" (in context, people speaking candidly). This theme was referred to in 168 instances by eight interviewees. Stories were also included and were defined as "when stories are important to communicate information". This theme was mentioned in 104 instances by 11 interviewees.

The importance of voice, authentic self and stories are illustrated by the following interview quotes;

- "We don't say things like; "with the Pākehā voice." Automatically to me, the Māori voice issue is already at a lower level than anything else." (2nd Focus Group)

- "We can highlight and articulate what the position is for our Indigenous and Aboriginal groups, the more I think that [we do that], there is a reflection that causes others to think about their culpability." (2nd interview)

- "It's a New Zealand thing. We're really good at asking the community's voice but they wouldn't do anything with it." (10th interview)

- "I believe that if we can uplift all of our people to work in a Māori world and a non-Māori world and understand what the non-Māori world is requiring of us, we can use our own value-based system to infiltrate that and change that." (3rd interview)

- "I think it some days it's really, really hard because you just want to give up." (1st focus group)

B. Culture

Culture as a theme was mentioned by 13 interviewees in 122 instances. Culture was defined in coding as "gaining an understanding of Maori culture" Incorporated as a supporting theme was Kaupapa Maori that was defined by instances where this term was mentioned by interviewees. This was mentioned by eight interviewees in 75 instances.

The importance of culture and Kaupapa[1] Maori are illustrated by the following interview quotes;

- "It was reinforced very much by our own people, who used to remind me that the first condition for good health is a healthy spirit." (1st interview)

- "That is the key to it isn't it? People do need to see their culture as valuable and their experience of their culture is valuable and they are valuable." (16th interview)

- "There is nothing that we can't overcome if we do it together as whānau, if the intent is true and the intent is not for your own personal self-gain." (3rd interview). [1]

- "We get some of our people who don't feel comfortable in the Maori, who don't know the Maori to know how it fits with them. But that comes down to the rest of us in supporting them through that journey." (7th interview)

[1] For a description of Kaupapa and Whanau see http://www.rangahau.co.nz/research-idea/27/

C. Relationships

Relationships as a theme was mentioned by 12 interviewees in 55 instances. Relationships was defined as the "Importance of working with Maori communities". This was mentioned by 12 interviewees in 168 instances. A supporting theme was building relationships, defined as "gaining an understanding of how relationships are built with communities" for example, go to Iwi[2] directly, work with stakeholders, hold community meetings. This was mentioned by 13 interviewees in 107 instances.

The importance of relationships is illustrated by the following interview quotes;

- "You've got to be a good listener, and you've got to have the whole engagement process as one, which is not conditional on time." (1st interview)
- "People are mindful of that at every level of government and governance, if it takes longer, it takes longer." (11th interview)
- You don't just walk up in a suit and tie and go, Gilda, listen to me I know what's good for you." Because you'd soon get told to bugger off. (6th interview)
- "Visitors are mostly not welcome because when they come they assume their business is a priority for and for the good of the Iwi". (13th interview)
- "Why mutuality's forgotten? Because I think many people don't think, but if you're going to have a good relationship, it's got to have two way benefits. Two way benefits need to be demonstrated." (1st interview)
- "A lot more can be done, there's a lot of tokenism from the government." (1st Focus Group)

D. Challenges

Challenges as a theme was mentioned by seven interviewees in 94 instances. This was described as "importance of understanding challenges in working on Maori issues". A supporting theme was colonisation. This was described as interviewees "references to being colonised and its effects on their world view" that was mentioned by 10 interviewees in 76 instances.

The importance of challenges is illustrated by the following interview quotes;

- "Maori take a great deal of risk when they put their trust in an unknown agency or professional that has never been in their lives before, he's sitting there and expecting them to reveal very personal details." (1st interview)
- "Often that we're speaking back to an institutional environment which has got lots, and lots of layers that are about protecting their own 'positionality', and so the question then becomes how do we get them to hear us." (2nd interview)
- "We've got to be skilful in both worlds. It's not a question of being good at one and ignoring the other, or being excellent at one and rejecting the other, it's not real." (1st interview)
- "Don't beat yourself up about it, because that achieves nothing as well. Understand the system created it, so the system can fix it." (6th interview)

[2] Iwi (Māori tribes)

E. Workplace

Workplace as a key theme was mentioned by 11 interviewees in 79 instances. Workplace was described as “the importance of recognising Maori in the workplace”. A supporting theme was workplace champions that was defined as “having people supporting Maori in the workplace, both Maori and Pākehā peoples”. This was mentioned by 11 interviewees in 50 instances.

The importance of recognising Maori in the workplace is illustrated by the following interview quotes;

- “Those who work in the academy represent our communities in a very institutionalised way.” (2nd interview)
- “I think vital to getting people to think, even subconsciously about their work and engaging with Maori.” (14th interview)
- “Also remember the status in the workplace mostly doesn't reflect the status in the community. This can be quite a disconnect and can impact on their capacity to participate.” (13th interview)
- “One of the things that was great for me was I was able to engage Māori staff.” (3rd interview)
- I think our general manager is unique in the fact that she does identify people in the organisation that she gives permission to say, "Just go. Just go and do it." (14th interview)

F. Translation

Translation as a theme was defined as “the importance of feeding back information gained from communities back to communities in a way that is useful and relevant” that was mentioned by 11 interviewees in 105 instances. The importance of feeding back information to communities from where it was obtained in a way that is useful and relevant is illustrated by the following interview quotes;

- “You don’t need to be an expert, actually, in the other person’s culture, but you do need to know that this person might have a different take on things.” (1st interview)
- “It’s hard; the nuances are often lost when you’ve got one culture talking to another.” (1st interview)
- “You can never be the other person. You can never have experienced what other people have experienced.” (16th interview)
- “We reshape their voice to match our policies and procedures.” (10th interview)
- “A lot more can be done, there’s a lot of tokenism from the government.” (1st Focus Group)

G. Recognition

Recognition as a theme was mentioned by 12 interviewees in 214 instances. Recognition was defined as the "importance of understanding the issues Maori people face". A supporting theme was racism that was defined as "where the word racism is used, in relation to Maori Pākehā beliefs about their experiences living in NZ". Nine interviews mentioned racism in 114 instances. Also mentioned was "treaty", that was defined as "recognition of Maori sovereign rights by Government", that was mentioned by 10 interviewees in 57 instances.

The importance of recognition is illustrated by the following interview quotes;

- "Just to acknowledge the group I suppose in terms of being those leaders and being wanting to take that step.'" (16th interview)

- "Deconstructing the impact of biased discrimination and colonisation, is very complex for patients." (10th interview)

- "I think that's basically where it is. Recognising that the culture that each party brings may be quite different, so we need to recognise the difference." (1st interview)

- "It's quite different when you have somebody who actually gives that permission, who actively supports it and promotes it and says, that's great. Get in there. Go for it". (14th interview)

- "You can just feel it's starting to grow here, in terms of recognition, and it's wonderful to hear Pākehā people standing up and saying, "Hey, we shouldn't be doing this," and really helpful when you have Pākehā people supporting what you're doing." (5th interview)

- "Ask any Australian to reach into their pocket and pull out Australian coins. They all go through the coins and you ask them what's that? It's a lyrebird, isn't it? Yes, it is a lyrebird. What about that coin there? That's an echidna, isn't it? I think it's the five-cent piece, I'm not sure. What's the one on there? That's a kangaroo. What are these? Ask them what they all are. They'll tell you. They are Australian animals. And you say, now pull out your most recent coin. Your two-dollar coin, pull it out, put it in the palm of your hand, and tell me what you see. Do you see an animal? And of course, it's an anonymous Aboriginal man. It's offensive. It would never happen anywhere in the world. Yet, a 21st century Australian cannot see that. They cannot see how offensive that would be." (11th interview)

7) Discussion

Maori are strong in being Maori as demonstrated by the findings presented in this report. Maori are strong in their Kaupapa, i.e. "*the philosophy and practice of being and acting Maori*" (Smith 1992) as reflected in many of the quotes contained in the results section of this HARC report. Clearly Maori are strong in their voice.

Whilst the key themes arising in this report (i.e. relationships and challenges) may influence Aboriginal health service design and delivery across wider Australia, it cannot be assumed that this will translate directly to Aboriginal Australian people. Critical to incorporating information gathered from Aboriginal peoples from around the world must come the realisation that organisations need to learn from, rather than directly transferring or applying that new knowledge. Simply put, one size does not fit all. Aboriginal peoples from around the world may share a common ancestry, but their experiences differ significantly. For example, unlike Maori, Aboriginal Australians are not strong in their voices.

In Australia Aboriginal people are a part of the Australian community yet treated differently, immediately recognisable by populist beliefs that ensure Aboriginal voices remain an almost silent minority. When Aboriginal viewpoints are sought, these voices are repackaged (all too often) within ubiquitous Aboriginal cultural terminology, that is open to wide interpretation depending on the situation with authentic Aboriginal voices being lost in translation (Freire 1970).

Fundamentally, the challenge is not for Aboriginal Australians to accept what is being 'culturally' designed and delivered for them, (again open to interpretation) rather, for organisations to listen authentically in order to hear what Aboriginal people are saying and to not repackage it into their organisational voices. The same is to be said for individuals working within these organisations.

As one New Zealand interviewee said, "We're really good at asking the community's voice but they wouldn't do anything with it." (10^{th} interview) Alternatively, as Aboriginal people in Australia commonly say, stop asking us the same questions every time you consult with us!

The HARC Project took the CRG model to the interviews and focus groups to create a space or an environment where people could feel safe to speak and be heard in their own unique authentic voices. Arising from the development and implementation of the HARC Project in New Zealand seven guiding principles were developed to engage Aboriginal people in the design and delivery of health care services:

1. Be honest with your intention as to why you are there

2. Ensure you are on their time and not on your own time

3. 'Listen without prejudice' by hearing what has actually been said and not what you believe you have heard

4. 'Reciprocity' ensure you feedback what you have heard and what you have learnt

5. Leave the door open for people to come back to you with further information

6. Act on what you have learnt. You may not always like what you hear but you have a responsibility to authentically represent what you have heard

7. Be yourself - Aboriginal people have the best radar for those who are not authentic to their cause.

These principles are conceptualised by an interviewee who said; “Maori take a great deal of risk when they put their trust in an unknown agency or professional that has never been in their lives before, he’s sitting there and expecting them to reveal very personal details” (1st interview). These principles are not an organisational engagement ‘tick a box’ checklist. Rather they are principles for organisational representatives to use in a reflective way, applying them to their own person to recognise in themselves what they are doing and why they are doing it.

It is also not sufficient to say that by having an Aboriginal person employed in the design and delivery our Aboriginal health related programs that we have done as much as we need to do. Programs do not work in isolation from the rest of the system and this thinking risks workplace isolation for the individual who is mostly misunderstood (voice) - “the nuances are often lost when you’ve got one culture talking to another” (1st NZ interview).

There is also the common occurrence whereby those who work within organisations represent our communities in an institutionalised way. This happens when “we reshape their [Aboriginal community] voice to match our [institutional] policies and procedures.” (10th interview). Whilst this may be unintentional, there remains a risk of Aboriginal voices not being able to be heard when they are being required to fit within a predetermined set of organisational requirements.

To affect any change in the design and delivery of Aboriginal health services (and Aboriginal health generally) there must be an honest acknowledgement by people who are not Aboriginal that they can never truly understand the issues Aboriginal Australians have faced nor the challenges that Aboriginal people face each day here in Australia.

People from the wider Australian community must stop believing they have permission to speak with authority on behalf of Aboriginal Australians, simply because they have undertaken research or have worked with Aboriginal communities for many years. Behaving in this way reduces the value and validity of authentic Aboriginal voices as it sends a very clear message that Aboriginal Australians cannot speak for themselves. In effect, authentic Aboriginal voices become a silent unheard minority (Sherwood 2010).

8) AMIHS Evaluation, HARC and the CRG

AMIHS evaluation:

The Aboriginal Maternal and Infant Health Service (AMIHS) is a targeted, community-based maternity service that aims to improve the health outcomes of Aboriginal women and women with Aboriginal partners during pregnancy and birth and to decrease maternal and perinatal morbidity and mortality. AMIHS midwives and Aboriginal Health Workers work collaboratively with other relevant health and social services to provide continuous, high quality and culturally safe antenatal and postnatal care.

AMIHS was implemented in seven program sites in 2001 and expanded in 2007 to over 30 programs. Currently there are over 40 AMIHS sites in NSW, delivering services to mothers of Aboriginal babies in over 80 locations in NSW. For further information, see;
http://www.health.nsw.gov.au/kidsfamilies/MCFhealth/priority/pages/AMIHS.aspx

An evaluation of AMIHS is being undertaken from 2016 to 2018. Health and Social Policy Branch are coordinating the evaluation, in collaboration with the Centre for Epidemiology and Evidence. An external consortium of evaluators Human Capital Alliance and Murawin have been contracted by the NSW Ministry of Health to undertake the evaluation.

The objectives of the AMIHS evaluation are to:

1. identify and describe the ways in which AMIHS is being implemented, at state and local levels;
2. explore client, staff and stakeholder experiences and perspectives of AMIHS;
3. investigate the extent to which AMIHS is reaching its target population(s);
4. investigate the impact of AMIHS on the health outcomes of Aboriginal babies and their mothers; and
5. investigate the costs of implementing AMIHS and, if feasible, undertake an economic evaluation of AMIHS.

During a meeting of the AMIHS Evaluation Advisory Committee there was agreement that greater Aboriginal membership should be included in all stages of the AMIHS evaluation project as per the Aboriginal Health and Medical Research Council of NSW (AH&MRC) guidelines for research in Aboriginal health.

The importance of Aboriginal input into each part of the evaluation was also voiced at consultations with Aboriginal Health Workers (AHW) working in AMIHS and the Aboriginal Community Controlled Sector (ACCHS). At a consultation with AHWs the need for 'grass roots' input was emphasised.

The Ministry agreed to strengthen the governance of the evaluation through the development of a specific Aboriginal Cultural Reference Group for the period of the AMIHS evaluation.

<u>HARC New Zealand:</u>

The HARC Project resulted directly from the development of the AMIHS CRG when the question was raised; what is Aboriginal cultural advice? A review of the literature made it clear that the best place to go to inform the answer to that question was New Zealand. The learning's from the HARC Project were incorporated into the development of the AMIHS CRG terms of reference.

Video clip sound bites containing information relevant CRG information were also prepared and shown to key stakeholders within the NSW Ministry of Health. Information contained validated the value of creating a CRG framework designed to enable its members to feel comfortable to speak and share information using authentic voices.

The first CRG meeting held on 15 August 2016 at the National Centre for Indigenous Excellence took the time to establish the group with a focus on enabling members to find their voice within the group and to understand their role and function. The development of voice will continue for the duration of the AMIHS CRG with both the evaluation and members benefiting. For further information about the governance structure of AMIHS and the CRG see Appendix 5, "Aboriginal Maternal and Infant Health Service Aboriginal Cultural Reference Group" draft Terms of Reference.

9) Where to from here – CRG

On 8 December 2016, the findings from the HARC Project was presented to the second meeting of the AMIHS CRG held at the NSW Ministry of Health, North Sydney. The seven principles contained in this report will be tested and built on throughout the life of the AMIHS CRG. This includes videos containing personal messages from Maori people to the CRG members. See example below:

- "Sort out your fella's core values, what is what for your people, what's going to be of benefit to you all because this is about your future and your children's and your grandchildren's future. It's a long term thing that's going to go on with us" (2nd Focus Group)

CRG members were also advised that Pākehā and Maori people(s) who participated in the HARC Project agreed to contribute further information if required for project related activities, including being contacted by the CRG to share their knowledge with the group. The CRG welcomed the continuation of the conversation with our New Zealand neighbours and so plans will be made to collaborate with them into the future, commencing with a video conference at the next CRG meeting in 2017.

10) Where to from here – Vladimir Williams, (NSW Wiradjuri)

The HARC Project to the author was a deep learning experience that further reinforced the value to your person, knowledge and culture by speaking in your authentic voice. It also provided an opportunity for an Aboriginal man working in government health policy to test the CRG engagement model in NZ with Maori and Pākehā people(s).

Information gained through the HARC Project will form part of an application for a Masters by Research to be undertaken in 2017 that too will likely inform how the CRG operates to provide authentic Aboriginal cultural advice to the evaluation of AMIHS. Incorporated into the research masters will be scoping out the viability of wider application of the CRG model across the NSW Health system to encourage Aboriginal Australians to speak in their authentic voices and for the system to hear these voices and act on information gained.

11) Conclusion

The seven principles contained in this HARC report are designed to facilitate individuals, organisations and their representatives to be their authentic selves when they are engage in conversation Aboriginal Australians without the need for worn-out Aboriginal cultural terminology.

In conclusion, when Aboriginal Australians speak in their authentic voices to share their knowledge and wisdom, "authentic listening" is one of the greatest gifts wider Australia can offer Aboriginal Australia (Benedict 2011).

12) Appendices

A. HARC Project Interview Questions

B. Participant Information Statement

C. Participant Consent Form (adapted from University of Sydney qualitative research template)

D. CRG Terms of Reference

E. CRG 1st Meting Communique (15 August 2016)

13) References

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Appendix A -

Health Service Provider Interview Questions

(Adapt as required for other interviews and focus groups)

1. So to start, may I ask where you are from?

2. May I ask who are your tribe, and something about your tribe?

3. Can I get you to share with me information about your role and what you do?

4. Can I get you to share with my, why you chose your line of work?

    a. Family
    b. Community
    c. Cultural
    d. Or something else?

5. **May I ask how closely do you work with Maori communities**

    a. Closely
    b. Some contact
    c. Little contact

6. **How do you build and maintain relationships with Maori communities?**

    a. Meetings in communities with community people
    b. Meetings with stakeholders
    c. Meeting in your office with stakeholders

7. **In your role can share some examples of how you work with Maori communities? Or to put it another way can you share a story about a project or other initiative?**

    a. What people do you work with?
    b. How do you choose the people to work with (identify people)?
    c. How do you invite people?
    d. How did you establish the group or community consultation processes?
    e. Do you follow a set of community protocols (if so can you share these with me?)

8. **Can you share the approaches you use to obtain information or advice? Or to put it another way, can you tell me how this works?**

    a. Is location important for meetings (if the answer is yes ask why and its value)
    b. Who do you work with?
    c. Why do you work with this group or community? (note for community referrals/contacts
    d. Why are they on the project (involved)
    e. How did they become involved in the project?

9. **Do you have some examples of where what is working well in your Maori, consultations community projects or community consultants?**

    a. What is specifically is working well
    b. What factors do you believe are contributing to this?

10. **Can you share some examples where you believe it could have been better?**

    a. Specifically, what could have worked better?
    b. What factors do you believe are contributing to this not working out as planned?

11. **How do you interpret what you hear from people and use it in your work?**

    a. How did you use the information?
    b. Did you have to modify it so you could use it
    c. What were the factors that influenced this?
        i. Budget
        ii. Political considerations
        iii. Language differences
        iv. Why did you feel you had to tweak information?
        v. The language was wrong – not presented in a way you could use it
        vi. The information didn't fit with the evidence
        vii. There was no evidence

12. **Do you feedback information to communities?**

    a. If you have feedback the final version to your stakeholders (communities) do you believe they understood the message?
    b. If so can you give some examples of how you knew they understood it?
    c.
    d. How do you feed this information back to communities (prompts; community sit down, email information out, invite people to the service?)
    e. How do you know that people have understood what you have shared with them?

13. **Is there anything you believe that I have missed in our conversation that you would like to share?**

14. **Following our sharing of our information and stories what advice would you give me starting up a CRG back in Australia?**

15. **As mentioned previously while I'm in New Zealand I want to engage with a diverse range of people to hear their stories, just as you have today, are there people who you could put me in touch with so I can continue the conversation?**

16. **Would you like a copy of the final report?**

17. **Thank you for sharing your experiences, stories and time today.**

Appendix B - Participant Information Statement

The Hospital Alliance Research Collaboration (HARC) Scholarship

Authentic Aboriginal Voices in Health Care Design and Delivery

Project Description for Participants

Project Title:

Testing a pilot methodology to authentically represent Aboriginal community voices in health system design and delivery.

Project Outline:

The Office of Kids and Families recognises the value of gaining authentic Aboriginal cultural advice to inform and support the Aboriginal Maternal and Infant Health Service evaluation as they have commissioned the development of the Aboriginal CRG. The purpose of the project is to test the pilot Aboriginal CRG methodology in an international context. The project will look at the governance model and proposed operations, including terms of reference of the group. It will explore whether a similar model for the provision of cultural advice in a government setting has been implemented in New Zealand. This country has been selected owing to its proximity to Australia and its similar characteristics of British colonisation that Maoris faced with regard to colonist history and the recognition of sovereignty and its impact on improving health and other social outcomes.

Unlike Australia, New Zealand Maoris have been successful in gaining sovereign recognition over their lands through the signing of the treaty of Waitangi (Māori: Tiriti of Waitangi) in 1840, and it has long been argued that this has been instrumental to improving Maori health and social outcomes. NZ as part of its broader cultural identity is recognised as a country with a strong Maori cultural narrative/identity. Central to this has likely been strong partnership between Maori communities and the wider NZ community. Central to this has likely been strong partnership between Maori communities and the wider NZ community. This project will consider models of community engagement relevant to the CRG that have been implemented in New Zealand. The learning's from this project will be used to further enable the successful implementation of the Aboriginal CRG.

In Australia, Aboriginal health research and Aboriginal voice are not mutually exclusive. The latter is often translated to fit within a standard organisational language. Such processes remove authentic Aboriginal voices from processes designed to improve their (our) health outcomes. To be heard, Aboriginal people align their (our) voice to fit within dominant organisational cultural beliefs, also known as "code switching". The NSW Ministry of Health has developed a methodology to hear authentic Aboriginal voices to gain important cultural knowledge(s) for its Aboriginal Maternal and Infant Health Service evaluation. This methodology has been developed in collaboration with the Centre for Aboriginal Health, Centre for Epidemiology and Evidence, and the Aboriginal Health & Medical Research Council of NSW.

The proposed project takes this methodology and tests its rigor using quantitative and qualitative methods with an international health service provider who has been successful in representing authentic Aboriginal voices in their provision of health research design and delivery. In addition, researching community engagement approaches with the Maori community in NZ may identify other ways of working that can be translated into the NSW Health context. Thus assisting Aboriginal Australians in providing an authentic voice in the design, implementation and evaluation of health services and policies for NSW Aboriginal mothers, children and families.

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Appendix C - Participant consent form

Priority Populations
Office of Kids and Families
NSW Ministry of Health

HARC Project Lead
Vladimir Williams, Analyst

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Web: http://www.health.nsw.gov.au/about/ministry/pages/default.aspx

Testing a pilot methodology to authentically represent Aboriginal community voices in health system design and delivery

PARTICIPANT CONSENT FORM

I, ... [PRINT NAME], agree to take part in this project.

In giving my consent I state that:

- ✓ I understand the purpose of the project, what I will be asked to do, and any risks/benefits involved.
- ✓ I have read the Project Description for Participants (1) and The Hospital Alliance for Research Collaboration, HARC Scholarships Information for applicants 2016 (2) and have been able to discuss my involvement in the project with the Project Lead if I wished to do so.
- ✓ The project leader has answered any questions that I had about the project and I am happy with the answers.
- ✓ I understand that being in this project is completely voluntary and I do not have to take part. My decision whether to be in the project will not affect my relationship with the project lead or anyone else at the NSW Ministry of Health, Office of Kids and Families.
- ✓ I understand that I can withdraw from the project at any time.
- ✓ I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the project. I also understand that I may refuse to answer any questions I don't wish to answer.
- ✓

- ✓ I understand that I may leave the focus group at any time if I do not wish to continue. I also understand that it will not be possible to withdraw my comments once the group has started as it is a group discussion.

- ✓ I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.

  I understand that the results of this project may be published, and that publications will not contain my name or any identifiable information about me, unless I agree otherwise.

  I consent to:

  - **Audio-recording** YES ☐ NO ☐
  - **Video-recording** YES ☐ NO ☐
  - **Photographs** YES ☐ NO ☐

  Do you give permission for your consenting information (above) that may identify you to be used for other purposes related to this project i.e. conference presentations?

  - YES ☐ NO ☐

  Please note, not giving permission will not affect your participation in this project.

  Would you like to receive feedback about the overall results of this project?

  YES ☐ **NO** ☐

  If you answered **YES**, please indicate your preferred form of feedback and address:

  ☐ Postal: _____

  _____

  ☐ Email: _____

  .....
  Signature

  ....
  PRINT name

  .....
  Date

Appendix D – CRG Draft Terms of Reference

MATERNITY CHILD YOUTH AND PAEDIATRICS

Formerly Office of Kids and Families

Aboriginal Maternal and Infant Health Service Evaluation
Aboriginal Cultural Reference Group (CRG)

TERMS OF REFERENCE (DRAFT)
To be read in conjunction with CRG operating principles

Context

The Aboriginal Maternal and Infant Health Service (AMIHS) was implemented in seven program sites in 2001 and expanded in 2007 to over 30 programs. Currently there are over 40 AMIHS sites in NSW, delivering services to mothers of Aboriginal babies in over 80 locations. An evaluation of AMIHS is currently being undertaken (2016 to 2018). The Maternity Child Youth and Paediatrics Unit, Health and Social Policy Branch are coordinating the evaluation, in collaboration with the Centre for Epidemiology and Evidence (CEE). External evaluators, Human Capital Alliance and Murawin, have been contracted to undertake the evaluation.

Role of the CRG

The purpose of the CRG is to provide Aboriginal cultural and community expertise to the AMIHS evaluation for the duration of the evaluation project. It is designed to be a safe place for its membership and others seeking its expertise, including the AMIHS evaluators, to discuss culturally sensitive issues that may arise during the evaluation

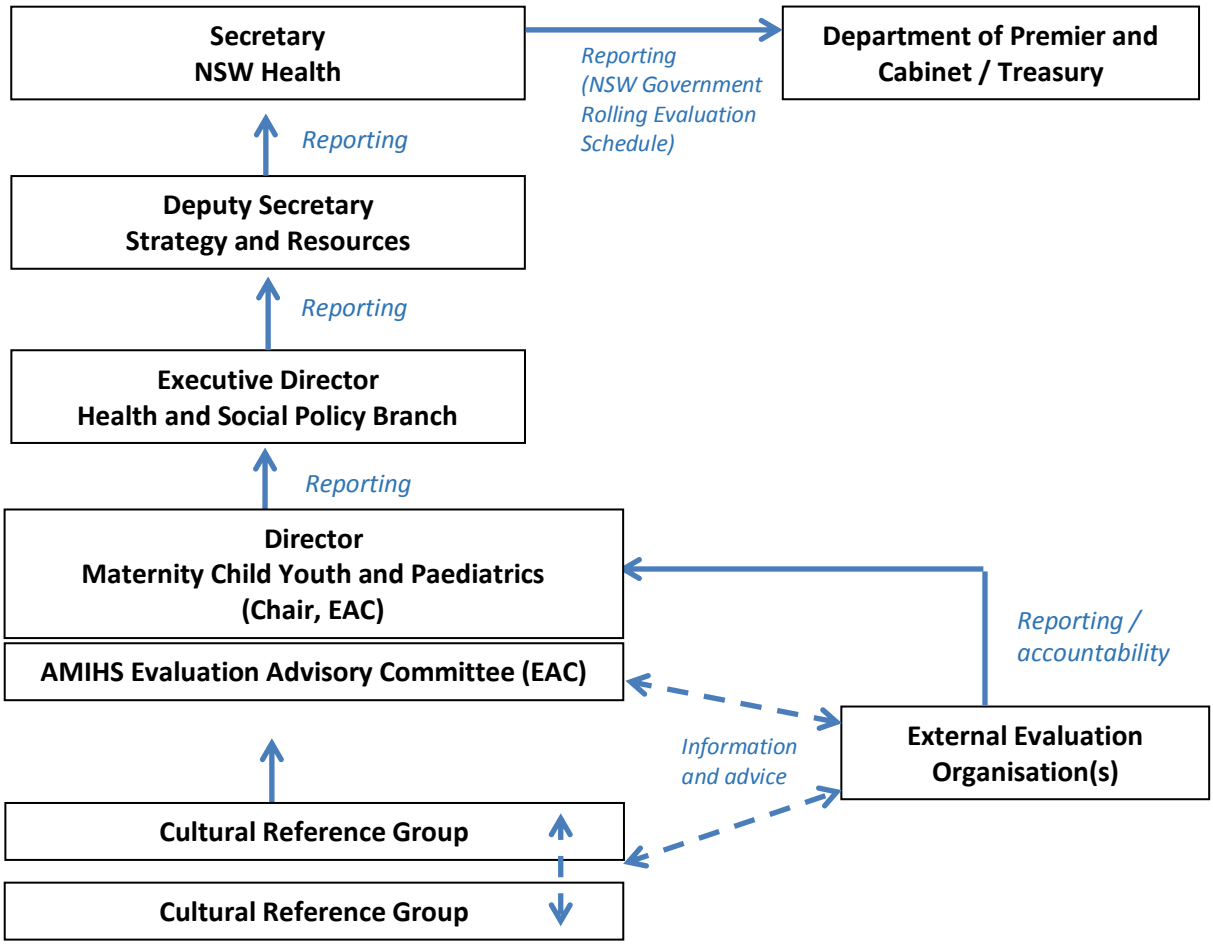
The CRG is one part of the governance structure for the AMIHS evaluation (refer 'Governance' section below). Other aspects of the governance structure provide organisational (including service) representation. The role of the CRG is to bring a range of community level perspectives to the evaluation. The specific functions of the CRG are:

- Provide advice on Aboriginal cultural protocols as they relate to working with Aboriginal communities
- Provide referral to suitable Aboriginal contacts to support the evaluators to engage and work effectively with Aboriginal communities
- Provide Aboriginal perspectives on the interpretation of data and findings from the evaluation
- Provide advice on relevant ways of communicating evaluation activities and findings to Aboriginal communities
- Review and provide advice on Aboriginal cultural terminology as it relates to the AMIHS evaluation
- Be a resource to Maternity, Child, Youth and Paediatrics to provide advice on issues that have relevance to AMIHS.
- Be a resource for other parts of the NSW Ministry of Health seeking Aboriginal cultural advice for their policy, programs and evaluations.

Governance

The CRG will be chaired by an Aboriginal person with relevant community and professional experience. The chair will be appointed by the Maternity Child Youth and Paediatrics Unit.

The following diagram illustrates the governance structure for the AMIHS evaluation:



Should a discrepancy arise between information provided by the CRG and the Advisory Committee to the evaluators, the Maternity, Child, Youth and Paediatrics Unit, where required, will facilitate a collaborative resolution process, review all information provided, and provide final advice to the evaluators.

Membership

The CRG has been designed exclusively to gain Aboriginal cultural and community perspectives to inform the evaluation of AMIHS. The only people who can provide this information are Aboriginal Australians and as such CRG membership is available only to Aboriginal Australians with this experience.

CRG members will be selected through an Expression of Interest (EOI) process with the exception of Chair who will be selected by the Maternity Child Youth and Paediatrics Unit. CRG members will be chosen to represent a broad range of Aboriginal cultural and community viewpoints, with where possible representatives from NSW metropolitan, rural and remote communities.

Group Support
Relevant training, support and development will be provided to CRG members to facilitate a level playing field among members and create an environment where all ideas are valued equally and are critically discussed and analysed. The Maternity Child Youth and Paediatrics Unit will engage an external facilitator to undertake this work with the CRG.

Remuneration and allowances
Group sitting fees will be paid to members who are not employed by the NSW Government. The Maternity Child Youth and Paediatrics Unit will also assist with travel arrangements and cover reasonable travel costs for members to attend face to face meetings.

Meetings
Up to four CRG meetings will be held each year that are to be rotated between metropolitan, rural and remote areas of NSW. Meetings may be held face-to-face or using teleconference and video conferencing options.

All agenda items are to be submitted to the Secretariat, using the CRG agenda item template at least 3 weeks prior to each CRG meeting.

Secretariat
A Maternal, Child, Youth and Paediatrics representative will be the Secretariat for the CRG, who will also attend CRG meetings. Consistent with the CRG membership requirements this representative must be an Aboriginal Australian.

Quorum Requirements
A minimum of four CRG members are required for the meeting to be recognised as an authorised meeting.

Proxy representation
CRG members are not permitted to nominate proxy representatives to attend CRG meetings in their place.

Out-of-session feedback
Any requests for CRG advice between meetings should be directed to the CRG Chair, who will use group email or teleconferencing to communicate requests to the CRG and facilitate feedback within an appropriate timeframe. The Chair will collate responses and provide feedback to those seeking a copy of this summarised communication to CRG members for their records.

Reporting and communication

At the end of each CRG meeting, CRG members will jointly develop a communique reflecting key outcomes of the meeting. The CRG Chair will provide the communique to the secretariat of the AMIHS Evaluation Advisory Committee. The CRG communique will be a standing item on the AMIHS Evaluation Advisory Committee agenda.

To inform meetings with relevant background evaluation information, the CRG will be provided with minutes of each AMIHS Evaluation Advisory Committee meeting. The CRG Chair will also provide an update at each meeting on how issues/ideas raised by the CRG are informing the evaluation.

Intellectual Property

New intellectual property generated by the CRG remains the property of the NSW Ministry of Health. Where information provided by the CRG is used (in internal/external documents, reports and publications) CRG members will be appropriately acknowledged, including co authorship where appropriate.

Chatham House Rule

For the CRG to be successful a level of discretion and trust is required from members and others involved with the CRG. For all CRG meetings unless stated otherwise, as being confidential the "Chatham House Rule" will be in effect. Application of this rule is designed to enable members and others attending CRG meetings to speak freely and discuss what may be at times challenging topics.

Subsequently members may speak about key themes arising from meetings, though must use their discretion to ensure they do not disclose information that may be contentious or identify individual's comments. The same rules apply to individuals/organisations seeking information from the CRG.

Confidentiality

The Chatham House Rule will not be in effect when members or others involved with the CRG have asked for information being presented or discussed to remain confidential.

Dispute Resolution

CRG members will seek to resolve issues arising during meetings, with provision for confidential issues to be raised directly with the CRG Chair. If issues raised are unable to be resolved through these processes, CRG members may raise these directly with the Chair of the AMIHS Evaluation Advisory Committee.

Appendix E – Inaugural CRG Meeting Communiqué

MATERNITY CHILD YOUTH AND PAEDIATRICS

Aboriginal Maternal and Infant Health Service Evaluation
Aboriginal CRG

COMMUNIQUE NUMBER 1

CRG Chair Report from the CRG meeting held 12 August 2016

Introduction

This is the first communique from the Cultural Reference Group (CRG) of the Aboriginal Maternal and Infant Health Service (AMIHS) evaluation. To introduce the CRG a set of background information is provided, followed by a report of key themes arising from its first meeting.

About the CRG

The purpose of the CRG is to provide Aboriginal cultural perspectives to the AMIHS evaluation for the duration of the evaluation project. In addition, the CRG will support the AMIHS Evaluation Advisory Committee and evaluators to ensure the evaluation enables Aboriginal Australians to authentically participate. The CRG has scope to meet (face to face) up to four times each calendar year until the end of 2018. Additional teleconference meetings will be held if urgent items require discussion between face to face meetings.

CRG Membership

To establish the CRG an expression of interest process was undertaken. Aboriginal Australians with professional, personal or family experience of an Aboriginal Maternal and Infant Health Service were invited to place an expression of interest with the Maternity, Child, Youth and Paediatrics Unit (Health and Social Policy Branch). A total of twenty-two nominations were received for CRG membership from across NSW.

To assess CRG nominations a panel consisting entirely of Aboriginal Australians was convened with representation from the Maternity Child Youth and Paediatrics Unit, Centre for Aboriginal Health, the Aboriginal Health & Medical Research Council of NSW, and an Aboriginal Community Controlled Health Service. Seven nominees were invited to become CRG members. There are eight Aboriginal Australians appointed the CRG including the Chair. The NSW Ministry of Health has one standing member (Aboriginal) on the CRG to provide secretariat support.

About CRG Members

CRG members are not organisational representatives, rather they are a group of NSW Aboriginal people who will come together to share their own unique experiences to inform the evaluation of the Aboriginal Maternal and Infant Health Service. CRG individuals will, therefore, represent themselves not any employing body.

The CRG is represented by the following people:

1.	Stevie Jai Kemp	Broken Hill
2.	Dorothy Cohen	Macksville
3.	Paula Craig (proxy)	Macksville
4.	Amy Creighton[3]	Tamworth
5.	Wendy Bunn	Engadine
6.	Pam Keed	Peak Hill
7.	Joanne Goulding	Narellan
8.	Michelle Dickson (chair)	
9.	Vladimir Williams (secretariat)	

Inaugural CRG Meeting

The inaugural meeting of the CRG took place in Sydney on 12 August 2016 at the National Centre for Indigenous Excellence (NCIE) Redfern.

Our first meeting was spent getting to know each other and building important relationships. We did some exciting work with Errol Benvie, a consultant who is working with us on the CRG journey.

Carol Vale and Lee Ridoutt from the evaluation team (HCA and Murawin), joined the group for part of the meeting and together we spoke about some parts of the evaluation framework. We look forward to our ongoing work with the evaluators.

Key points provided in future Communique will result from a group process that we will undertake at the end of each of our meetings. The CRG membership will review our meeting discussion points and select several items that we wish to share with readers of the Communique. We look forward to sharing our work with you.

Future CRG meetings

The next meeting is scheduled to be held in Sydney in December 2016. At this meeting, dates for 2017 CRG meetings will be planned. Meetings in 2017 will take place in a range of locations across NSW.

Michelle Dickson
CRG Chair

[3] Amy Creighton attended the CRG meeting on 12 August 2016. Ms Creighton recently advised that she can no longer be a member of the CRG. MCYP will seek another representative from the nominations received through the expression of interest process.