



COPYRIGHT AND USE OF THIS THESIS

This thesis must be used in accordance with the provisions of the Copyright Act 1968.

Reproduction of material protected by copyright may be an infringement of copyright and copyright owners may be entitled to take legal action against persons who infringe their copyright.

Section 51 (2) of the Copyright Act permits an authorized officer of a university library or archives to provide a copy (by communication or otherwise) of an unpublished thesis kept in the library or archives, to a person who satisfies the authorized officer that he or she requires the reproduction for the purposes of research or study.

The Copyright Act grants the creator of a work a number of moral rights, specifically the right of attribution, the right against false attribution and the right of integrity.

You may infringe the author's moral rights if you:

- fail to acknowledge the author of this thesis if you quote sections from the work
- attribute this thesis to another author
- subject this thesis to derogatory treatment which may prejudice the author's reputation

For further information contact the University's Director of Copyright Services

sydney.edu.au/copyright

**An investigation into how Aboriginal Medical
Services contribute to childhood immunisation**

Telphia-Leanne Joseph

31 March 2014

The University of Sydney

Acknowledgements

This work was supported by the following funding sources:

NHMRC Capacity Building Grant in Population Health: Building research capacity for health interventions to improve Aboriginal Health (2008-2012, APP457279)

NHMRC Centre of Research Excellence in Population Health Research: Immunisation in under studied and special risk populations: closing the gap in knowledge through a multidisciplinary approach (2012-2016, APP1031963).

The National Centre for Immunisation Research and Surveillance (NCIRS). NCIRS is supported by the Australian Government Department of Health and Ageing, the NSW Ministry of Health and The Children's Hospital at Westmead.

Many people helped me achieve this research in a vast array of ways.

The common thanks go out to supervisors but I was pretty blessed with some high powered personalities in Professor Sally Redman and Professor Sandy Thompson. I would like to give them an enormous thank you because I was in awe of their enthusiasm to take on this research, which gave me courage that it was a relevant subject and helped me run with it. I have buckets of thanks and affection for my primary supervisor (and work colleague) Associate Professor Julie Leask who supported me over the finish line. Julie was a fledgling supervisor when I started which I think worked in my favour. Julie was completely willing to learn about how best to support her students and I think she may have slept with her copy of Diane Walker and Alison Laycock's 'Supporting Indigenous Researchers – a practical guide' in the beginning. There was unbelievable patience, wisdom, late night calls and laughter from Julie.

Other staff from The National Centre for Immunisation Research that I would like to thank include: Rob Menzies, my manager who has guided me through the concepts of writing and assisted me in mad moments of panic over the evils of biostatistics. Rob's calmness and humour really helped me slash it down into bite size chunks. Also, Maria Chow for lessons

and computer time for Keypoint; Kerrie Wiley initially for coffees, pats on the back and referencing help, then for steering me through my emendations and most importantly for coming on a bike ride; Hal Willaby for reminding me that Excel was not out to get me; Brynley Hull for ACIR data, Brendon Kelaher for providing a template; and Peter McIntyre for his overall support. I also thank Heather Gidding for academic titbits via email and Sophie Couzos for advice from NACCHO. Thank you to Sue Campbell-Lloyd and Dennis Meijer from the NSW Ministry for Health, for the supply of data and their interest in this research.

To my beautiful, wonderful family, for seeing me as more than a shop assistant and for screaming in delight when it was finished.

To my friends who dragged me out for a blast on the bike, rang to check in or dumped gluten free biscuit's on my doorstep, darling Sallie Cairnduff thank you for dinners and calm words when one more track change may have sent me over the edge.

To Madeleine, Tom and The Whitehouse, who provided sanctuary and sensible words, preventing me from escaping on a plane.

Finally, I would especially like to thank all the AMS staff for their time and their welcome when visiting. I made friends, learnt how to make 'johnny cakes', was fed soup and reminded how bloody great these people and their organisations are.

Abstract

Objective

This study aimed to (1) describe the ways in which Aboriginal Medical Services (AMS's) contribute to immunisations for Aboriginal and Torres Strait Islander children aged five years or less under the National Childhood Immunisation Program (NCIP) and (2) evaluate how immunisation undertaken through an AMS is reported to the Australian Childhood Immunisation Register (ACIR). An AMS is an organisation whose main objective is providing a health service for Aboriginal and Torres Strait Islander communities. In NSW, an AMS may or may not be a member of the Aboriginal Health and Medical Research Council.

According to the Australian Childhood Immunisation Register (ACIR), less than 1% of all childhood vaccinations (equating to less than 10% of all Aboriginal children) are recorded as being delivered by an AMS. This is likely to be an under-estimate of the care provided. This study sought to determine to what extent AMS's contribute to the immunisation of Aboriginal children in their local areas.

Methods

This study investigated what activities and programs contribute to the health promotion, opportunity and service delivery of immunisation and how these delivered immunisations are submitted to ACIR.

A questionnaire aimed at AMS clinic staff was developed through consultation with the Aboriginal and Torres Strait Islander Immunisation Network, immunisation professionals, and interstate AMS's. Piloting with a small sample of AMS staff determined the appropriateness of questions and formatting. Questionnaires were posted, emailed or completed face-to-face.

All eligible AMS's in NSW were invited to participate. To be eligible, the AMS either provided an immunisation service or complimentary activity for Aboriginal children under 5 years of age.

Results

Of 46 AMS's in NSW in (year they were sampled), 41 were eligible. Of these, 22 completed questionnaires were returned (53% response rate); 20 of 22 provided immunisations under the National Immunisation Program (NIP) for adolescent and adults; and 18 under the National Childhood Immunisation Program.

The findings revealed that AMS's in NSW are taking active steps to achieve an improvement in coverage and timeliness of immunisations that occur under NCIP for Aboriginal Children. In addition, the observations revealed various systematic processes in some AMS's that directly contributed to up to 96% coverage of NCIP vaccines for regular clients. It also highlighted specific program implementation and community events that compliment immunisation through health promotion, reminders and follow up at different AMS's. There is likely to be under-recording of AMS-based immunisation provision on ACIR and concerns were also raised about recording error.

Conclusion

This study showed that the 'personality' and commitment of individual AMS's contributed significantly to the coverage rates of the children less than 5 years of age in the local areas of the AMS's that participated in this study. It is likely that the ACIR under-represents the true contribution of AMS to immunisation provision.

Table of Contents

Acknowledgements.....	2
Abstract.....	4
Objective.....	4
Methods.....	4
Results.....	5
Table of Contents.....	6
Introduction.....	8
Infectious Diseases.....	8
Vaccine preventable diseases today.....	11
(Adapted from the World Health Organization Web Site ¹⁹).....	12
Vaccines for Aboriginal and Torres Strait Islander peoples.....	12
National Immunisation Program.....	13
Aboriginal Health Services.....	15
Aboriginal Health Diversity.....	19
National Aboriginal Community Controlled Health Organisation.....	20
Aboriginal Medical Service and the Aboriginal Health Worker.....	21
Government Funded.....	21
This study.....	21
METHODS.....	24
Ethical considerations.....	24
Sample.....	24
Questionnaire Development.....	24
Recruitment and data collection.....	26

Data analysis	27
RESULTS.....	28
Survey participation	28
Respondent Aboriginal Medical Services Characteristics.....	29
Vaccine Fridges	30
Use of Patient Information Recall Systems.....	31
Reporting to the Australian Childhood Immunisation Register	32
Activities to Enhance Immunisation Coverage	33
Observations of immunisation contributions among Aboriginal Medical Services	34
Fishing on the Mission 2013 – a chance to yarn about new vaccines.....	35
Play Group - linking mums to immunisation service provision	36
Birthing Centre – continuity of care supporting timely immunisation.....	37
Vaccine fridge as whiteboard – a practical innovation for minimising temperature variations.....	38
Discussion.....	40
Immunisation provision	41
Recommendations	43
References	44
Appendices.....	47
Appendix 1 AMS Questionnaire.....	47
Appendix 2 Information Sheet.....	51
Appendix 3 Consent form	54
Appendix 4 Ethical Guidelines Considerations for Aboriginal and Torres Strait Islander Research.....	57

Introduction

Infectious Diseases

There has always been this battle. A need for pathogens, (bacteria, virus, fungi, protozoa or nematodes) to invade and replicate, then take up residence in the human body. More often than not, for the human body a symbiotic arrangement or immunity has built up so the host is no longer affected, creating what is called a 'commensal' relationship – one without harm.¹ As shown by the 'Human Microbiome Project' naturally flourishing bacteria, which is in abundance in all aspects of the body including blood, can prevent bacteria from getting a foothold.^{2,3} Unfortunately introduction to a pathogen does not always result in a commensal relationship.³ At best an immunological response can be activated to protect against pathogens which have entered the body (through broken skin, inhalation or by being ingested) either by providing a protective barrier, detection and elimination prior to replication or post replication.⁴ At worst, various introduced pathogens can kill and have the capacity to easily transfer infection to others. These transferable diseases are grouped under a broad heading of 'communicable' diseases.

Human existence has been shaped and tested by disease throughout its history and it is one of the significant contributors to the way human civilisation stands today. In the ancient world disease won wars, crumbled civilisations and prompted the change of religions when praying to one God during an epidemic was more practical than multiple gods.⁵ Prior to our understanding of what may cause, prevent or cure many known diseases, records were kept of extensive deaths that were attributed to the 'pestilence'.⁵ Cartwright and Biddiss provide a very detailed account of the effects of a plague in Athens in 430 BC which made its way into the city via a convoluted journey. Having started in Ethiopia (what is thought to be a 'highly malignant form of scarlet fever' or possibly 'typhus, small pox or measles') and crossing to Egypt, plague was taken by boat across the Mediterranean Sea to Athens. Athens, (led by Pericles) was currently at war with Sparta and ideally should have won due to Pericles' advanced and powerful navy. This 'pestilence' from Egypt caused many deaths, possibly up to two thirds of Pericles's navy, in a short period of time. Thinking that the

disease had run its course Pericles sent an armada to attack Sparta which had to return before attacking as another outbreak occurred. Pericles tried once again to attack Sparta, only resulting in a similar outcome and it is believed that he also contracted the infection and died during this aborted attack. While the Athenian empire was still in power the heavy loss on the naval manpower and civilians prevented the necessary attack on Sparta to maintain its position. Athens was eventually defeated by Sparta in 404 BC.

The tide of this destruction was averted when there was an understanding of disease pathways, improved sanitation and preventive medicine. One such advancement in the latter was variolation. This is the practice of breaking the skin by scratch or cut and introducing a pathogen to produce a reduced infection to provide protection from future infection.⁶ .

Variolation for small pox was used in China, India and Persia before becoming established in Britain, by way of Turkey, compliments of Lady Wortley Montague who learnt of the practice while joining her husband who was the British Ambassador in Constantinople. Lady Montague had her son inoculated during their time in Turkey and organised for her daughter to be inoculated upon their return to England in 1721.^{5,7}

This is over 200 years after Theophrastus Bombastus von Hohenhiem a student of the renowned army surgeon Ambroise Pare who invented the ligature among other things, learnt of the practice in Turkey in 1522 and brought it to the attention of Europe without success.⁸ In early eighteenth century England , in a very unethical way, prisoners from Newgate prison in London and orphan children were inoculated and then exposed to smallpox but did not become infected. Thus, convincing members of the Royal family, to use the Turkish practice for their own children.

The popularity of this practice was never great as 2-3% of cases still resulted in death compared to 20-30% from natural infection.⁷ Variolation came to America in 1721 with strong support from Benjamin Franklin. Even though many still had doubts of variolation, General Washington ordered all his troops to be inoculated in 1776 after an unsuccessful battle against British soldiers in Québec due to a smallpox outbreak amongst troops. Smallpox had not affected the British as they were already protected due to variolation.⁹ Variolation with smallpox became redundant when it became known that 'cowpox' - a

disease found in cows, which was commonly caught by milkmaids and farmers gave them a mild infection and provided immunity to reinfection and also protection to smallpox. A famous advancement in disease history is the well documented account of 'Dr Edward Jenner', who in 1796 infected a young boy with cowpox and then followed a few weeks later with small pox, proving its effectiveness.¹⁰

By the time the First Fleet arrived in Australia 1788, England and Europe was well accustomed to variolation and the rates of smallpox were greatly reduced. So when an outbreak in 1789 that affected a great many Aboriginal people Butlin observed that,

Most of the Aborigines were simply found dead, some victims were delivered to the medical officers for examination and treatment. That they were pronounced to be smallpox sufferers leaves little room for serious doubts.¹¹

Butlin also discusses an official report to Britain 'declaring that half the Aborigines between the Hawkesbury and Botany Bay died within two months.'¹¹ There is great debate regarding whether it was the First Fleet who brought such great disease down on the Aboriginal people or if it was already an 'Indigenous' disease, introduced by the French ships or due to established interaction between the Macassan sea cucumber fishermen who frequented Northern Australia for months at a time in the 1700's.¹²

It was not until 1803, that the practice of smallpox protection was made available in, Australia,¹³ when Governor King requested cow pox matter to be shipped to NSW. Other disease such as tuberculosis, whooping cough and measles were prominent offenders by the 1820's^{11, 12} and influenza, which created significant mortality in the white population in the late 1820's and 1838, must have caused ramifications in the 'black' population but it is undocumented.¹¹

This lack of documentation was common. Collection for Aboriginal health research was not a priority until prompted by health ministers in the early 1970 resulting in the 1st commissioned report by RL Smith *Aboriginal Statistics in Australia: a survey and a plan* in 1978¹⁴ with the Australian Human Rights Commission's 2008 Social Justice Report stating that Aboriginal people were 'first counted as Australian citizens in 1971'. Prior to this¹⁵ the Australian Constitution held that 'In reckoning the numbers of the people of the

Commonwealth, or of a State or other part of the Commonwealth, aboriginal natives shall not be counted'.¹⁶

Vaccine preventable diseases today

Many infectious diseases that historically created great mortality and morbidity worldwide have been prevented by the development of vaccines. The 2008 Atlas of Health stated that “3 million lives are saved each year” because of vaccines.¹⁷ Vaccines work by providing a weakened or killed version of the disease that stimulates the immune system and creates protection in humans without them developing symptoms of the disease. Vaccination does not just protect the person who receives the vaccine but if enough of the population becomes immunised (protected) then this can help protect individuals who are unable to be vaccinated. This is called ‘herd immunity’ which is vital for people with low immunity and/or those unable to be immunised, such as those receiving chemotherapy treatments or organ transplant patients.

The most effective way to provide vaccines is to deliver them as early as possible. Therefore many countries provide a childhood vaccination schedule that can start as early as a child’s first day, followed by a combination of vaccines, over the next five years. Most vaccines are for major infections that are found worldwide such as measles, tetanus or invasive pneumococcal disease, but some are region-specific and considered as travelling vaccines such as Yellow Fever or Typhoid.¹⁸ Vaccines continue to be developed either to provide different combinations of antigens (different types) such as pneumococcal disease or because science is still developing the vaccine.

Table 1 below shows all infectious diseases that can now be prevented by a vaccine and hence are called vaccine preventable disease (VPDs). Smallpox is still listed even though the World Health Organisation declared its eradication in 1980 after extensive worldwide vaccination programs.

Table 1 Current Vaccines Worldwide for Vaccine Preventable Diseases for humans only (2014)

(Adapted from the World Health Organization Web Site ¹⁹)

Vaccines Preventable Diseases		
Anthrax	Lyme Disease	Rubella (German Measles)
Diphtheria	Measles	Shingles (Herpes Zoster)
Hepatitis A	Meningococcal	Small Pox
Hepatitis B	Mumps	Tetanus
<i>Haemophilus influenzae type b (Hib)</i>	Pertussis	Tuberculosis
Human Papillomavirus (HPV)	Pneumococcal	Typhoid Fever
H1N1 (Swine flu)	Poliomyelitis	Varicella (Chicken Pox)
Influenza (Seasonal Flu)	Rabies	Yellow Fever
Japanese Encephalitis (JE)	Rotavirus	

Vaccines for Aboriginal and Torres Strait Islander peoples

With the arrival of the First Fleet and the subsequent colonisation by the British and other Europeans, Aboriginal people, who had little to no immunity against many of the newly introduced infectious diseases, fell heavily with many of the population dying.

Today, Aboriginal peoples are still affected by VPD's at a higher rate than non Aboriginal Australians even though Australia has a robust vaccine program. Poorer health, chronic diseases, difficulty in accessing health care services and basic housing (whether due to distance or discomfort) can all compromise vaccine timeliness, leaving children vulnerable to disease ²⁰

Table 2 shows the notification rates by age groups. Aboriginal people are affected by VPD's compared to non-Aboriginal Australians. It also highlights discrepancies between age groups most affected among Aboriginal peoples compared to non-Aboriginal peoples, and the age group most affected for that disease. For example in the 0-4 year old age group, Aboriginal children are affected by influenza up to 127 times more than non-Aboriginal children. As previously mentioned factors such as overcrowding or delayed vaccination can contribute significantly to disease prevalence.²¹

Table 2: Summary of combined notification or hospitalisation rates of vaccine preventable diseases in Australia, 2000 to 2002* Source: vaccines for our mob or VPD report22

Disease	Notification or hospitalisation rates — all ages [†]			Indigenous age group with peak incidence	
	Indigenous	Other [‡]	Incidence rate ratio	Age group	Notification or hospitalisation rate
Invasive Hib disease	1.2	0.1	9.7	0–4	10.0
Hepatitis A	9.1	3.1	2.9	0–4	37.1
Hepatitis B	7.2	1.6	4.4	15–24	14.1
Influenza [§]	49.3	17.1	2.9	0–4	127.3
Measles	0.2	0.4	0.6	---	---
Meningococcal disease	7.2	3.4	2.1	0–4	50.7
Pertussis	41.8	46.9	0.9	0–4	89.7
Pneumococcal disease	44.7	9.9	4.5	0–4	87.0

* Notifications (NSW, NT, SA and WA only) where the date of onset was between 1 January 2000 and 31 December 2002, except for pneumococcal disease, which is from 1 January 2001 to 31 December 2002.

† Notifications per 100 000 population (unless otherwise specified), age standardised to the Australian Bureau of Statistics Australian estimated population 2001.

‡ Includes records where Indigenous status was not stated.

§ Influenza data are hospitalisations (all States/Territories) where the month of separation was between 1 July 1999 and 30 June 2002.

National Immunisation Program

The Australian Government Department of Health (AGDH) provides funded vaccines under the National Immunisation Program (NIP), which includes the National Childhood Immunisation Program (NCIP). They also maintain the Australian Childhood Immunisation Register (ACIR) and provide current immunisation information such as immunisation rates or vaccine changes for health professionals. They also develop promotional material for both the general public and health professionals.

The AGDH under the advice of the Australian Technical Advisory Group on Immunisation (ATAGI) approves and purchases vaccines to be used in Australia. Vaccines are purchased for the:

- National Childhood Immunisation Program
 - Birth to 4 years of age
- School Based Programs
 - 10 to 15 years
- At risk groups
 - 6 months and over
 - 12 to 18 months
 - 4 years
 - 15 years and over
 - 50 years and over
 - Pregnant women
 - 65 years and over
 - Vaccines for Aboriginal and Torres Strait Islander people

A successful vaccination program has been established in Australia. There has been a continual decline in all childhood VPDs over the last 10 years with significant decreases in death rates after the introduction of vaccination.²³

To address the inequity, between Aboriginal people and other Australians, the AGDH has been proactive in tailoring a specific program that targets the Aboriginal community and puts in place strategies that help to improve vaccine coverage. In addition to this some local health areas participate in collaborative events with local ACCHS's to promote childhood vaccinations or deliver seasonal influenza vaccine. This can occur during NAIDOC week, Knockouts or when community health centres run outreach programs. These processes provide to initiate stronger ties between Communities and Public Health Units.²⁰

Table 3 displays vaccines exclusively for Aboriginal people in NSW under the NIP. Influenza vaccine is recommended Nationally for children aged 6 months and over with medical risks and for pregnant women and have been added to this table as a reminder that these groups are vulnerable in Aboriginal people.²²

Table 3 Vaccines Provided For Aboriginal People In NSW

6 months and over with medical risk conditions Aboriginal - 15 years and over Pregnant women	Influenza
Aboriginal - 50 years and over Aboriginal - 15-49 years with medical risk factor	Pneumococcal

Each State and Territory Department of Health is provided with its own budget from AGDH so that immunisation programs can be tailored to suit their demographic needs, such as ordering regionally specific vaccine. The New South Wales Ministry of Health (NSWMH) Immunisation Branch provides State-wide immunisation alerts (such as media releases for measles outbreaks as a result of travellers returning from overseas); implements school based programs; and provides information for the public and health professionals. During and after the commencement of this study's data collection, the New South Wales Ministry of Health funded 13 Aboriginal Immunisation Support Officer positions housed with PHU's (with aims to continue in 2015 post evaluation) to improve the timeliness of immunisations for Aboriginal children, contacting parents or guardians of children who are overdue and assisting immunisation providers to follow up with them. In NSW AHW are unable to give immunisations as this is against the regulations of vaccine service provision determined by the *Poisons and Therapeutic Goods Act 1966*.²⁴ This states that an AHW is unable to prepare or give any immunisations, under NSW Health legislation, regardless of a primary or a remote location.

Aboriginal Health Services

Aboriginal Medical Services have an important role in immunisation – both vaccine provision, promotion and other supportive activities. Since the aim of this thesis is to detail this role, the next section situates AMS within their historical context.

To truly understand the significance of the establishment of the first Aboriginal Medical Service in Australia ^{25 26} it is important to have some insight in to what prompted such an endeavour. The first Aboriginal Medical Service opened its doors in mid-1971. It was born from the fires of political unrest that were consuming the Aboriginal people at that time. One of the starting points for unrest came in 1965 when a busload of University of Sydney students belonging to the 'Student Action for Aborigines' travelled to rural NSW to draw attention to the plight of Aboriginal people. They wanted the wider Australian population to know about the poor standard of housing, health and education being experienced by the Aboriginal people ²⁷. Combine this with the newly acquired rights of the 1967 Referendum ²⁸ which now gave Aboriginal people 'permission' to move more freely throughout the state and move they did! To come and pound their feet and fists in protest for their 'rights' along the streets of Sydney!

This was a time of collective strength for the Aboriginal people and their collaborators such as the Communist Party of Australia and various Trade Unions who gave support and encouragement to move away from systemic racism, low wages and limited job opportunities if they chose to ²⁹.



<http://hdl.handle.net/1885/8925> Digital Collections Australian National University

Aboriginal people also wanted what was delivered up by Martin Luther King in his 'I have a dream', speech. As mentioned by Sol Bellear, they too wanted to embrace; *'one day this*

nation will rise up and live up to its creed, “we hold these truth’s to be self evident: that all men are created equal:’ ^{30, 31}

This time of flux was the start of more than one revolution. Australian ‘Black’ activism also walked side by side with a generational revolution that was taking place over Western countries. Hayden Keenan (producer of the ‘People of Interest’ documentary talking at the ASIO Through The Looking Glass Exhibition Damien Minton Gallery 22nd January 2014) discusses the casualness of the long haired younger generation in their flared jeans, tie dyed shirt sand thongs walking along side with their parents, aunties/uncles and grandfathers themselves clothed in starched Sunday best, long socks, polished shoes and ‘brilcreamed’ brush overs. Together they showed a solidification of the community. What may have severed many in the wider ‘white’ community was put aside for a stronger cause.(H Keenan opening address for his ‘ASIO - Through the Looking Glass Exhibition Damien Minton Gallery February 2014)



Courtesy of Hayden Keenan - Producer ‘People of Interest’ documentary and ‘ASIO Through The Looking Glass Exhibition’

‘Well ‘black power’ is about black people taking control of their own lives. I mean you can have the foot of the oppressor on your neck for a certain amount of time but eventually people are going to fight back’. (Kaye Belleair in *Black and White Australians*, 1976)³²

One of the ways the younger Aboriginal generation ‘fought back’ was by looking towards America and establishing ‘The Australian Black Panthers’. The American Panthers stood up against oppression and those who pushed inner city Black American communities into poverty and poor health. *“In Redfern the men took on the militant aspect while the women took control of social issues such as the breakfast program for children living in hardship around Redfern”*. (Hayden Keenan, personal communication, February 2014)



Denis Walker, Gary Foley and others The Australian Black Panther Movement

Courtesy Hayden Keenan

Mr W D Scott conducted a study into the Aboriginal population in Sydney in 1972 and the following year released his report ‘Problems and Needs of the Aboriginals of Sydney’.³³ He stated that 80% of Aboriginal people in Sydney had come from country areas and that 65% of the total Aboriginal population were living in the inner city and surrounding suburbs in

often overcrowded households with 25% of homes without running water or bathrooms and 15% sharing or without kitchens.³³

Understandably this provided opportunities for the rise of disease and ill health for this large Aboriginal population in the inner areas of Sydney living in crowded homes with poor facilities. Local doctors cost too much and Emergency Departments of local hospitals were the only way to access free medical attention during 'crisis' situations. Both local doctors and Emergency Departments were often avoided by the Aboriginal community due to lack of funds and fear of or experienced racism.³³

This led to a meeting in July 1971 that discussed how the community could comfortably gain medical attention. Some of the people who attended included Shirley Smith (Mum Shirl), Gordon Brisco, Dulcie Flowers, Dr Fred Hollows and Paul Coe a member of the Aboriginal Legal Service. The Aboriginal Legal Service had been set up in early 1971 from a shop front in Redfern by members of the community and volunteers such as lawyers and law students. It was decided by the meeting attendees that a medical clinic could be opened up in the same way. This clinic was also 'housed' from a shop and was manned by members of the community and volunteer medical staff such as Dr Fred Hollows and Dr Andrew Refshauge. With the newly set up 'Aboriginal Medical Service' Ms Shirley Smith acted as a field officer and would walk Redfern and physically bring people who were sick or in need of medical assistance to the AMS. Scott noted that within the year of the Redfern AMS opening, over 40% of the 'inner city Aboriginal peoples were using the service and the AMS was making a wide impact.'³³

It was from these simple beginnings of community action that gave the strength and longevity of Aboriginal Community Controlled Health that exists today. A more in-depth profile of today's New South Wales AMS shall be portrayed in the 'Observation' chapter.

Aboriginal Health Diversity

Today there are a variety of services that are funded to provide health services for Aboriginal and Torres Strait Islander people nationwide. There is also a variety of names associated with these services: Aboriginal Medical Service (AMS), Aboriginal Health Service, and Aboriginal Community Controlled Health Service. While the term AMS is used generically there are differences in the way that an AMS can be run or administered. These

services are moderated by a variety of stakeholders which vary within States and Territories. AMS can be accredited to show that their clinical care provision is in line with Australian healthcare standards. There has been an increase of AMS's who have applied for clinical accreditation through the Royal Australian College of General Practitioners (RACGP) for organisational accreditation through Quality Improvement Council (QIC) , International Organization for Standardisation Quality Management Systems (ISO), or the EQUIP Australian Council of Healthcare Standards.³⁴

National Aboriginal Community Controlled Health Organisation

National Aboriginal Community Controlled Health Organisation (NACCHO) was established in (year) as the national umbrella organisation for all Aboriginal Community Controlled Services (ACCHS). This was a revamp of the previous organisation the National Aboriginal Islander Health Organisation (NAIHO) that was established in the 1970's to provide direction and support for the newly opening ACCHS that were opening up across the nation. This name change also reflected the fact that the Torres Strait Islanders community had embarked on their own campaign for self-determination and wished to establish their own representative organisations.

NACCHO was established in part as a response to the National Aboriginal Health Strategy. It aimed to provide a health service with a holistic approach that is administered by its local Aboriginal community who have elected its Board of Management from within its local Aboriginal community. There are over 140 ACCHO in Australia with a high percentage providing a full clinical service. New South Wales has 49 AMS's that are under the auspices of the Aboriginal Health and Medical Research Council (in 2014). To be a member of NACCHO and its affiliates an ACCHS must be:

1. Initiated by a local Aboriginal community;
2. Based in a local Aboriginal community;
3. Governed by an Aboriginal body which is elected by the local Aboriginal community;
- &
4. Delivering a holistic and culturally appropriate health service to the Community which controls it.³⁵

Aboriginal Medical Service and the Aboriginal Health Worker

A significant aspect of this holistic service delivery of an ACCHS is the employment of Aboriginal Health Workers (AHW). The professional association for Aboriginal and Torres Strait Islander Health Workers describes their role as providing primary health care, immunisations, community health education, patient transport and interpretation. An AHW plays an integral part in health service provision by liaising between health professionals and the Aboriginal community.³⁶ They are often 'front line' and have a wealth of knowledge about their local community. They can often specialise in different areas such as otitis media, chronic diseases (diabetes or cardiovascular disease) or maternal and child health to name a few. The AHW can often play a vital part in organising individuals to come in for their immunisations. In the Northern Territory and northern parts of Queensland, South Australia and Western Australia AHW's play a vital role in immunisation service provision by assisting nurse immunisers rolling out seasonal and scheduled vaccines. The significance of the AHW in this role has helped to increase acceptability by the local community and the AHW often has a good understanding of their community and who are in need for vaccination and where to find them.^{37, 38}

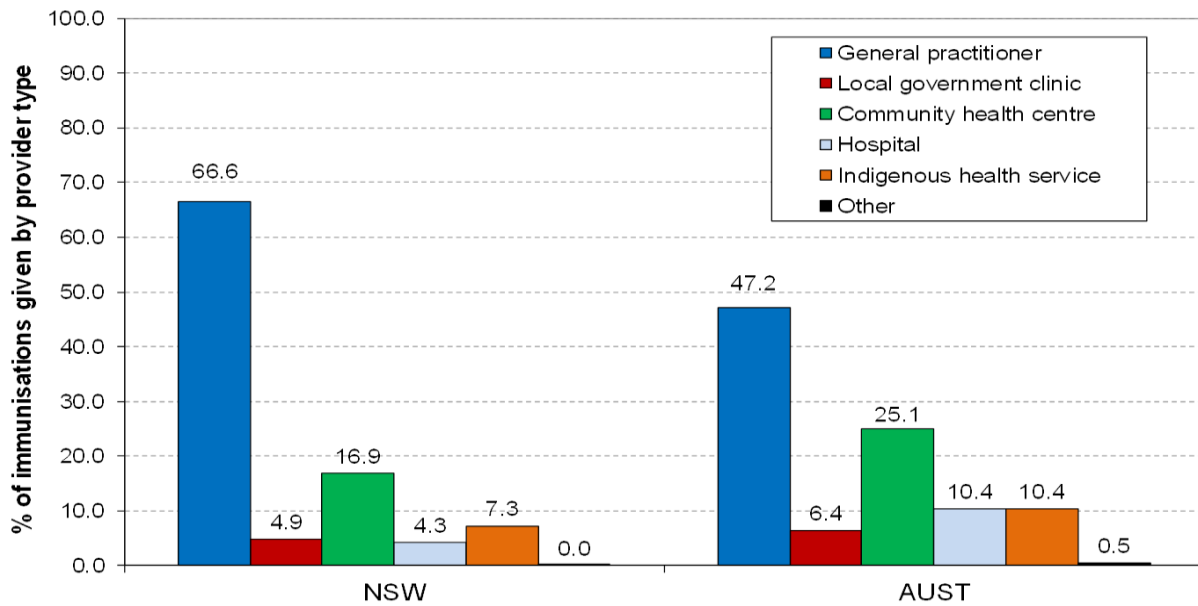
Government Funded

Aboriginal health services are often run by a State or Territory governments for isolated communities, the majority of these are found in remote Northern Territory and northern parts of Queensland. The majority of these services are under the jurisdiction of the State or Territory Departments of Health.

This study

Having provided an historical and contemporary background to the AMS's of NSW, the next section involves a study of how they contribute to the provision and promotion of immunisation. It aims to highlight and celebrate their unique roles in relation to immunisation of Aboriginal children in NSW.

Graph 1 Proportions of childhood immunisations on the ACIR (for Indigenous population only) given by various provider types - 2010



According to the ACIR in NSW, less than 8% of childhood vaccinations are recorded as delivered by an AMS. This is likely to be an under-estimate of the care provided; for example, vaccinations given at AMS’s may be reported under the provider number of the GP who is either employed or outsourced by an AMS. Secondly, it is evident that AMS’s contribute to immunisation promotion within their communities. For example, an AMS will transport patients to a local GP or public health nurse for immunisation. This activity needs to be more systematically documented to provide governments with a better picture of their contribution and to ensure resourcing is proportionate to their actual contribution to immunisation service delivery and promotion.

Therefore, this study aimed to describe the ways in which AMS’s contribute to Aboriginal childhood immunisation and evaluate how immunisation undertaken through an AMS is reported to ACIR.

The objectives of this study were to;

1. Quantify how many AMS’s are contributing to Indigenous childhood immunisation by documenting the AMS’s reporting to ACIR

2. Determine what and how many other immunisation supporting activities occur at AMS's including provider health education, reminder letters, transportation and/or a venue that will assist in the immunisation of Indigenous children.

Aboriginal Medical Services can vary considerably in budget, location, staff numbers and available resources greatly change the way that service provision is rolled out. This study gathered data from urban, rural and remote AMS's across NSW to provide for the first time a systematic and detailed picture of immunisation services that they provide.

METHODS

Ethical considerations

An essential aspect of this study was for it to consider the ethical principles set out in the Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research which is provided by the Australian Government National Health and Medical Research Council, Human Research Ethics Committee.³⁹ To this extent, I carefully considered how the study could reflect reciprocity, respect, equality, responsibility, survival and protection, and spirit and integrity. These values were built into the research design and consent process.

Ethical approval from a number of agencies was necessary including: University of Sydney and the NSW Aboriginal Health and Medical Research Council's Ethics Committee (AHMRCEC) which is independent to the Aboriginal Health and Medical Research Council. Approval was received once the development of the questionnaire, consent form and information sheet was completed and endorsed by AHMRCEC. An aspect of approval was to meet the five criteria set out by the AHMRCEC which can be found in the appendices.

Sample

When this study was first being formulated there was a plan to implement it nationally. After contacting affiliates of NACCHO in New South Wales, Queensland, South Australia and Victoria and starting the ethical approval process with these States it was decided to focus on NSW only. This enabled the project and necessary approvals and cost to remain manageable. NSW still offered urban, rural and remote locations and diversity in the way that an AMS was administered. In addition, restriction to NSW simplified the questionnaire since it did not need to accommodate the differences in items such as clinic staff titles, state and organisational policy procedures and differing use of the '*Poisons and Therapeutic Goods Act 1966*' between states and territories.

Questionnaire Development

Prior to deciding on the content of the questionnaire, I contacted colleagues, supervisors and project workers from state and territory NACCHO affiliates to ascertain if there was any information that they wished to gain from this research. This was a valuable step which provided direction and support for the research and insight into some of the administrative

aspects of the AMS that had not previously been considered, such as incomplete transition from a paper system to an electronic one for some AMS's.

The initial process of the questionnaire development was to write out every possible relevant question. I then presented questions back to supervisors at the National Centre for Immunisation Research & Surveillance, members of the National Aboriginal and Torres Strait Islander Immunisation Network (NATSIIN) and the National Immunisation Committee (NIC). The question list changed, with some being removed and new ones arising. It was quite challenging at this stage to stay focused on outcomes as different organisations had different agendas. So it was necessary to bring the project back to its initial focus: namely, ACIR reporting by AMS's and their support of immunisation activities. The final draft version had 50 items (questions) which were reduced to 36 items covering five domains which included:

1. Clinic capacity
2. Immunisation service provision
3. ACIR reporting
4. Collaboration and health promotion
5. Patient Information Recall Systems (PIRS) utilisation

Appendix 1 contains the final version. Once it was decided what information was desired, it was a case of trial and error to find the best response format for each question. A mixture of closed and open responses worked best. For 'closed' items responses, options were nominal (such as types of immunising staff, or patient information recall systems in use) dichotomous (such as 'yes/no' for whether standard procedures to check for immunisation coverage for children under five years of age occurred at the AMS or not) and ordinal (such as 'always/usually/occasionally/rarely' for ease of access to the internet). The questionnaire was developed using KEYPOINT software which provides templates and formatting options for surveys. To address face validity, a questionnaire containing 36 items was sent to six AMS's nationwide (NSW, QLD, TAS, VIC and WA) for pilot testing by their clinical staff and to avoid 'priming' too many NSW AMS's. Three AMS's agreed; 2 declined citing need for completion of ethics approval; and 1 declined citing lack of available time.

Minor updates to the questionnaire occurred at this stage including re-ordering of questions and some clarification of terminology. This process helped to address content validity of the questionnaire by attempting to ensure that all relevant questions were included.

Recruitment and data collection

The development of the consent form, which needed to be signed by the Chief Executive Officer(CEO) and returned, was a simple exercise as NACCHO provided a template (Appendix 2) which was adapted for the use of this study.

A letter was sent to the CEO along with an information sheet inviting their organisation to participate (Appendix 3). This one page (double sided) information sheet was developed so that individuals who were approached to participate in the study had a concise and engaging outline of the study process and expectations. A condensed version in the form of a 'postcard' (Appendix 4) was also developed and was mailed out to clinic staff at the same time an invitation letter was mailed to each CEO. Once CEO consent was obtained, the questionnaire was sent to each AMS. For non-respondents to the questionnaire, a follow-up phone call provided the option to answer the questions over the phone.

During an AMS visit unrelated to this study I had a chance meeting with a CEO and reminded them about the study. The CEO filled out the consent form directly and also introduced me to the clinic staff who made time to fill in the questionnaire straight away. It became clear that this method would provide information that would not have been collected by the questionnaire alone. Furthermore, the passive recruitment process rendered a very small response rate. Therefore, we decided that the remaining questionnaires would be completed via a site visit to the AMS's.

Phone calls were made to clinic staff and CEO's about potential visits and four 'road trips' were organised:

Northern NSW

Mid West NSW

North West NSW

Southern NSW

During the site visits it was possible to meet with either the CEO (gaining consent) or the clinic staff (questionnaire completion) even if both didn't eventuate at that time, it was possible to follow up at a later date. By visiting I was able to observe many aspects of the AMS on approach and while sitting in the waiting room. These observations shall be expanded in the results section. Once all four road trips were finalised and data had been collected and entered into the database, a final date was decided to no longer actively follow up on questionnaires so that data analysis could begin.

Data analysis

All questionnaires were entered into an Excel spread sheet. Data were entered under the randomly allocated code for each AMS. Due to small sample size it was decided to analyse the data and produce descriptive statistics using two way tables and frequency distributions rather than percentages.

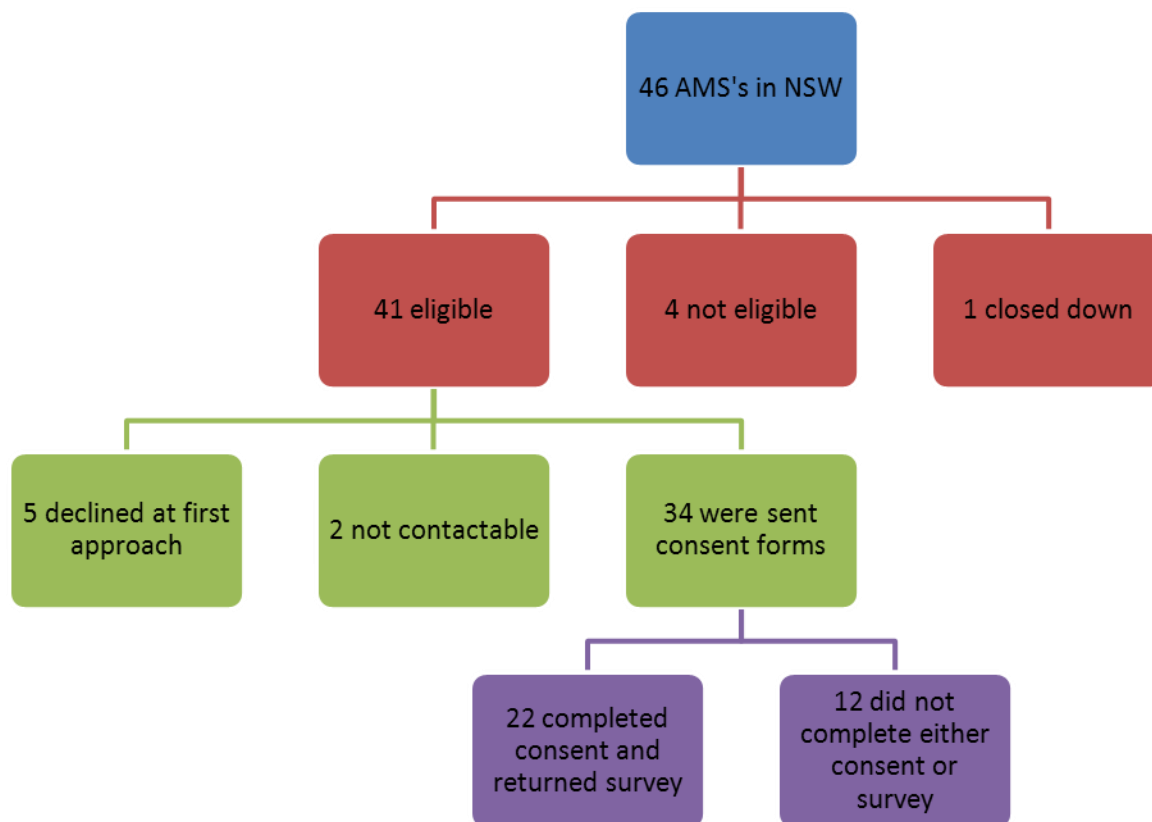
RESULTS

An important aim of this study was to identify and document all activities that occurred within NSW AMS which assisted in immunisation coverage of patients under five years of age. The following sections, describes the findings from the questionnaire and highlights some observations of the local context during face-to-face visits to AMS's.

Survey participation

A total of 46 AMS in NSW were invited to participate in the study. Figure 1 summarises the responses. One AMS closed down after the study started, 4 AMS's were not eligible due to a specific focus of the health service such as domestic violence, substance abuse or women's health. From the 41 eligible AMS 22 returned completed consent form and surveys giving an overall response rate of 53%. Of the remaining 19 eligible services that did not participate, reasons are summarised in Figure 1. Two services were not contactable and five declined to participate; and 6 CEOs had consented to participate but clinic staff were unable to complete and return the questionnaire. Reasons given generally involved staffing issues, such as time constraints or staff changes. Two of these services were visited during the 'road trips' so data gathered from observations still provided valuable input (once verbal consent was received) towards this study which can be found in the 'observation' chapter. Four AMS's that were visited during the 'road trips' had clinic staff complete the questionnaire and retained it within the AMS until they had received consent from their CEO which did not eventuate. Another 2 did not respond.

Figure 1 Aboriginal Medical Service participation in the study

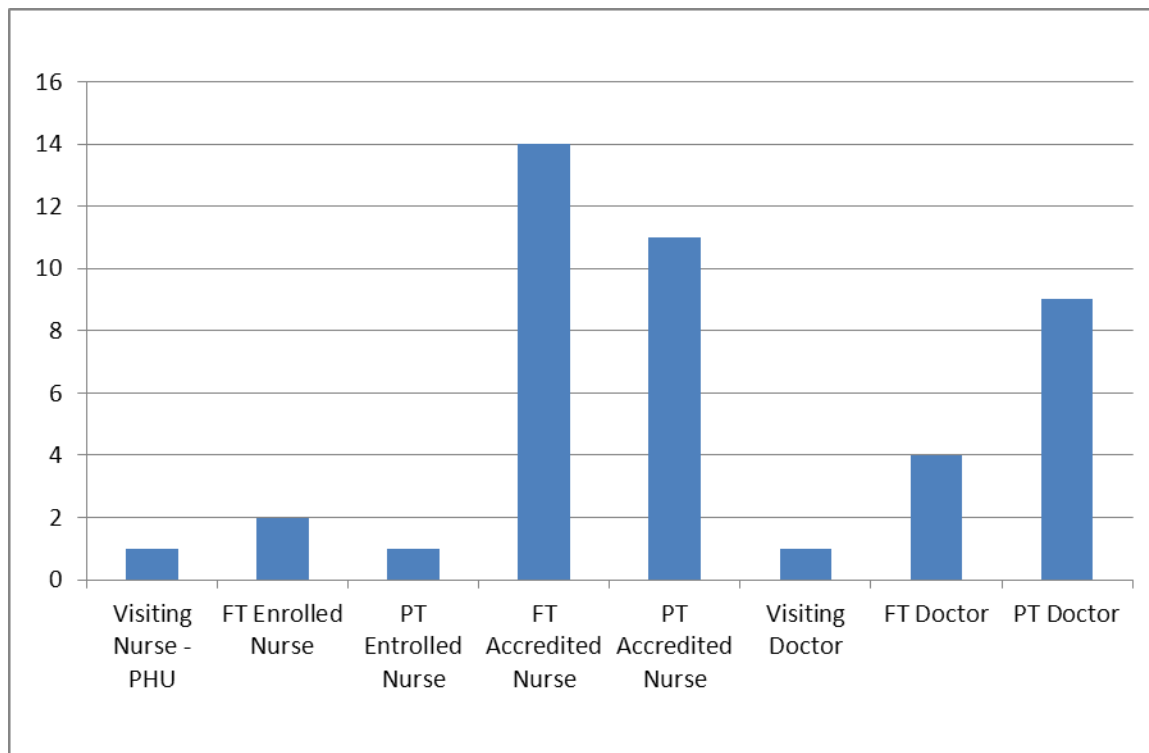


Respondent Aboriginal Medical Services Characteristics

Of the 22 AMS's that returned a completed questionnaire, 21 (95%) provided a clinical service that included immunisation provision for all ages of the local community. One of the 22 AMS's only provided seasonal flu, pneumococcal, adult pertussis and hepatitis B for patients 15 years and over, while 2 of the 22 provided no immunisation for any of their patients but did provide supporting activities.

Graph 1 below shows the number and types of professions that were employed or invited into the AMS to administer immunisations under the National Immunisation Schedule.

Graph1 Variation of Immunisation Staff Types working at Aboriginal Medical Services in 2013



The majority of AMS's had a combination of staff able to administer immunisations. For example an AMS may have 3 part-time doctors and one full-time accredited immunisation nurse plus 2 part-time accredited immunisation nurses. The number of such staff was usually a reflection of the size of the local Aboriginal community or an indication of how well resourced an AMS was.

Vaccine Fridges

Of the 18 AMS's that provided childhood immunisations 17 had a vaccine specific refrigerator while one AMS had a modified domestic refrigerator that was maintained by the resident Doctor. Each of the AMS's that housed a vaccine specific refrigerator reported robust vaccine fridge maintenance compliant with the 'National Vaccine Storage Guidelines – Strive For Five'⁴⁰ by recording daily temperatures of the refrigerator and by contacting their local PHU if they suspected any vaccine was compromised. A combination of clinic staff monitored the vaccine fridges daily, recording maximum and minimum temperatures. They included Aboriginal Health Worker, Clinic Nurse, Enrolled Nurse, Registered Nurse,

Nurse Manager, Project Manager, Child and Family Health Nurse and a visiting Public Health Nurse. These data were recorded either electronically or by paper each day.

Use of Patient Information Recall Systems

There are no uniform Patient information recall systems (PIRS) across NSW AMS's. The most consistently used PIRS was Medical Director used by 15 AMS, Communicare was used by 4 and Ferret by 3. A paper-based system was still used in combination with a PIRS system in 7 AMS and another 7 used two or more of the above. Of the 21 AMS's providing clinical services 14 would access the PIRS systematically to assess the immunisation status of children on presentation to the clinic.

The need to generate reports of immunisation status for patients differed and this often depended on patient numbers, staff availability and skill set. Reports were generated as required for 13 AMS's, monthly for 6 and weekly for 3. The reports would be accessed for a variety of reasons as seen in Table 5.

During the study participating staff were asked to access their PIRS and generate the number of patients under five years of age that attended the clinic in 2010 resulting in a total of 7079 children.

For privacy reasons we were unable to get the number of children eligible for the NICP at each AMS but 7079 is a very significant finding when compared with ABS data for the total NSW Aboriginal population under 5 years of age which is approximately 12,000 (Menzies, NCIRS unpublished data).

It is important to take into consideration that these 7079 children under 5 years of age are from just over half the number of AMS that were eligible to participate, suggesting that AMS's are providing much more immunisation for Aboriginal children than suggested by ACIR.

Table 5: Reasons for Report Generation at NSW Aboriginal Medical Services

Reason for Report Generation	Number of AMS's
Due or overdue	17

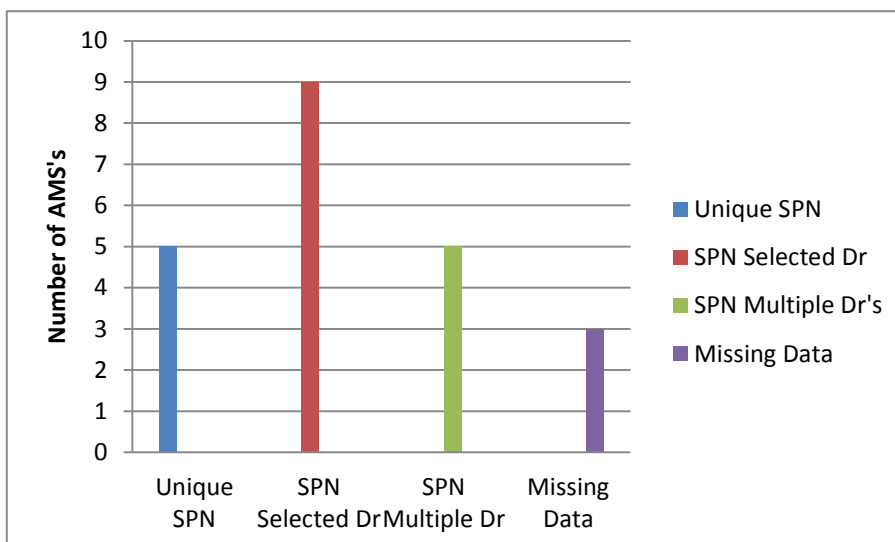
Vaccine orders	3
Data for ACIR reporting	3
Review of payment for ACIR	5
Review of acceptance letter for ACIR	1
Information for funding organisations	6
Other reasons not mentioned	1

Reporting to the Australian Childhood Immunisation Register

Once an immunisation for the NCIP occurs, data is sent to the ACIR. The method to transfer this data is through the ‘service provider’ number of a registered Doctor or a ‘unique service provider’ number that is allocated to an organisation such as an AMS.

This unique service provider number was owned by five out of 18 AMS while nine used the service provider number of a selected doctor working for the AMS. Five other AMS’s had multiple service provider numbers that could be used depending on which doctor was working the day the immunisation was given (Graph 2).

Graph 2: Comparison of Service Provider Number (SPN) Use for Reporting to ACIR



Locations of AMS's varied, with some residing in large regional or city centres while others were remote or very remote. Distance could determine the ability for an AMS to access a signal for the internet when they wished to access ACIR to check due or over-due Immunisation status or to report a delivered immunisation. Only 16 of the 22 AMS's, reported being able to access the internet immediately. Another 2 AMS's would wait 10-15 minutes and one often had to wait 1 or 2 hours.

Vaccines for children under the NCIP are all ordered from the New South Wales Vaccine Centre, with many AMS's receiving assistance from their local Public Health Unit who will order on their behalf. Respondents reported a total of 10337 vaccines ordered in 2010 and of these 6329 (61.2%) were reported as being administered.

Activities to Enhance Immunisation Coverage

An exciting aspect of many of the AMS was the activities that can complement the immunisation process and potentially decrease overdue schedules resulting in better coverage. For example 3 AMS's did not provide immunisations under the NCIP but they provided transport to the Public Health Unit for those less than 5 year of age. There was also transport provided for adult immunisation to the local hospital, Public Health Unit or Medical Centre. A transport service was provided by the AMS's for immunisation if needed by 19 AMS's which will be detailed in the observations section.

An important attribute of the AMS is its ability to be acquainted with a large proportion of its client base and to be an integral part of the community itself. It is this familiarity that allows for verbal reminders by clinic staff to parents of children who may be due for immunisations. The importance of immunisations were discussed with parents face to face in 19 AMS's and 15 combined this with mail out reminders while a further 18 AMS's provided verbal reminders either by phone or home visiting.

Three AMS's developed their own posters, 20 AMS's displayed posters that they received from state and territory Departments of Health, 15 displayed posters from their local Public Health Unit and 8 from the manufacturers of vaccines. One AMS displayed a poster from ACIR.

Observations of immunisation contributions among Aboriginal Medical Services

This section highlights the diverse ways that immunisation can be discussed, flagged and given amongst different AMS's. It describes simple and clever systems that staff had put in place to make their workplace more effective or they involved their patients so that immunisation coverage or timeliness was boosted. Visiting an AMS provided a greater insight to the day to day workings of the AMS.

An immediate observation was the diversity. There is no template (other than the boards) for staff, buildings or resources at each AMS and they generally reflected the local Aboriginal population by matching its service to size and local needs.

A major feature of importance was the Board, made up of individuals who have a strong connection to the local community and who have an understanding of the needs of the AMS and the local population. The Board was instrumental to the decision making of the AMS and members are elected by the community for terms of 2-3 years. The Board was also held in high esteem by AMS staff and I often noticed a healthy respect between the Board and the CEO.

The broad spectrum of services also reflect location. This ranged from small isolated AMS's that may cater to less than 200 people who are spread over 80 kilometres to the 3 urban based AMS's in Sydney that service the largest Aboriginal population in Australia of 46,900.⁴¹.

An AMS can provide a variety of programs and services such as;-

- Drug and Alcohol/Social and Emotional Welfare,
- Child and Family,
- Cardiovascular Health,
- Diabetes,
- Smoking Cessation
- Ear Health
- Clinic service
- Dental

The diversity of programs rolled out in an AMS is often determined by the skill set of employees and/or the population base. For example an AMS based in an area with a high prevalence of diabetes will adapt their programs to address this. Resources within an AMS can also be varied. Buildings (new, old or multiple), clinic rooms, specialist equipment or the number of pool cars are all dependent on funding. With funding often dependent on the ability of an employee with good administrative skills who also has the time to apply for extra funding for better resources. It is also often this person who will fill and submit the extensive application for 'Accreditation' as discussed in the AMS chapter. These staff members are important resources as well.

Staff numbers and skill sets were so varied that it was understandable that each AMS projected its own 'personality'. AMS's ranged from services that employed up to 60 people (part and full time) to a service that employed 2 people (CEO and a part time Doctor) with both residing in rural towns. Often there were recognizable 'champions' (CEO, Practice Manager, AHW or Nurse) who were enthusiastic and had very clear current expectations and future projections for the programs/services being provided by their AMS.

The following section features some programs, systems or events that are complimentary to the act of giving an immunisation. These features work adjacent to the clinical service to provide viable vaccine and opportunities for health promotion and reminders for immunisation. I gained verbal or written permission from each of the following AMS's to feature their exemplar program or event.

Fishing on the Mission 2013 – a chance to yarn about new vaccines

Murrin Bridge Aboriginal Health Service (MBAHS) is under the auspices of Griffith AMS and is located in a community of 150 people and 30 km away from the nearest town. During my visit, I was invited to attend a local fishing competition 'Fishing on the Mission 2013'.

The MBAHS in collaboration with Youth Services, the Local Land Council and Lachlan Land Services organized the fishing competition specifically for the teenagers but all ages joined in on the day. A BBQ was organized and there were prizes for various categories such as biggest and/or most fish caught for different age groups.

The day followed a very casual format but there was an opportunity to discuss items such as nutrition, various aspects of the children's schooling and Human Papillomavirus (HPV) vaccinations for the boys that was soon to be rolled out at the local High School. Some of the girls joined into the conversation (as they had already received one or more of the three doses) which led to some good natured teasing 'if we did it – we got it done, then you can too!' This event demonstrated that immunisation is a focus of MBAHS and that innovative ways can be used to remind the local community to care for themselves.

Play Group - linking mums to immunisation service provision

In Taree the AMS along with other local organisations collaborate in a playgroup for Aboriginal Mums and their children. The other organisations include Manning & Great Lakes Early Intervention, Burnside and Building Strong Foundations workers from the Public Health Unit. This playgroup meets weekly for 0-4 year olds on the premises of the local council run child care centre. They meet in a large play room, filled with toys and arts and crafts equipment that opens onto the outside play area. The two and half hours are started with a morning tea for everyone and then free play or crafts are set up for the children. After an hour the children generally go outside but on this occasion they were invited next door to share an activity with the childcare centre. While the children were being entertained with book reading and songs the others had an opportunity to raise any concerns from the last week.

The different professional staff on hand were able to assist in matters such as feeding, sleep problems, toilet training or any 'Centerlink' queries. The AMS staff also reminded mums if any immunisations are due and check each week for all patients at the AMS who are due? for immunisations. On this occasion AMS staff organized transportation for a mum and her child to the AMS after the playgroup for scheduled immunisations and the standard baby health checks.



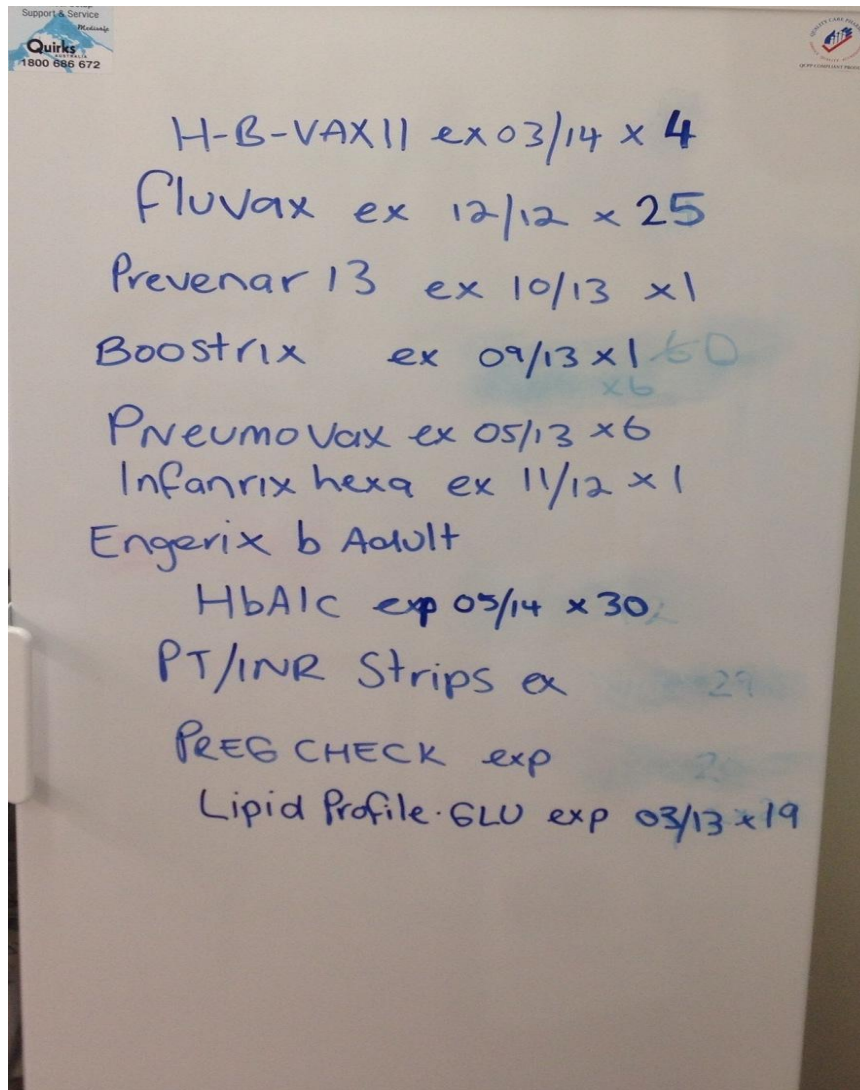
Birthing Centre – continuity of care supporting timely immunisation

The Orange Aboriginal Medical Service (OAMS) was the 1st Aboriginal Medical Service to annex a birthing program that included delivery as part of its service. The Murundhu dharaa birthing centre assisted in the successful birth of twelve babies all with healthy birth weight. Six mothers were existing patients of the OAMS and the other six were from the wider community. One woman travelled nearly 350 km and rented in the area, before and after her birth so that she could have her baby at Murundhu dharaa, after strong recommendation from her sister. The birthing program run by Murundh dharaa included prenatal home visits, midwifery care and delivery and postnatal home visits.

Murundh dharaa had a model to support the entire family throughout the pregnancy and this included assessing other members of the household when going on antenatal and postnatal home visits. If there were other children in the household they were checked to ensure that they had up-to-date immunisations and other adults were educated on seasonal influenza and pertussis (whooping cough) immunisation, which were given if applicable. A strong relationship was generally established between the mothers and their midwives and AHW's, which continued on during their postnatal care. The 1st visit postpartum was generally within 12 hours of delivery. The strength of this relationship between the clinic staff and mothers provided a strong platform to continue with follow-ups with the babies such as scheduled baby health checks and immunisations.

Vaccine fridge as whiteboard – a practical innovation for minimising temperature variations.

One AMS had a very simple but effective way to maintain the temperature of the vaccine accredited refrigerator they had. The refrigerator did not have a clear see-through door but the standard 'white goods' door. So rather than opening the door to see what vaccine was inside they used whiteboard markers and wrote the inventory on the door. The number of vaccines and their expiry dates were recorded. This allowed the fridge to be maintained at the recommended temperatures by reducing the need to open the door to check inside for the vaccine. This helped to stay in line with guidelines to keep vaccine fridges at an optimal temperature that is between +2°C and +8°C. It also easily enabled staff to see when vaccine needed to be replaced or reordered.



This section has described some examples of the various ways that AMS's support immunisation provision that go beyond administration of vaccines. It has also demonstrated that no two AMS's are alike and that a 'franchise' mentality cannot be associated with them when wishing to engage in research or evaluation.

Discussion

This research has established that Aboriginal Medical Services in New South Wales are actively engaging in clinical provision of childhood immunisations. They are complimenting this immunisation provision with collaborations (including transportation to another service provider), community engagement and innovative processes to improve and maintain immunisation coverage rates for children under five years of age within their communities. Furthermore, it is possible that the number of immunisations, given within an AMS is underestimated on ACIR.

The initial interest for this research developed during the consultation process of the National Indigenous Pneumococcal and Influenza Program (NIPIP) evaluation. This was conducted by the National Centre for Immunisation Research and Surveillance and extensive consultations were conducted with NACCHO, AMS's, state and territory Departments of Health and Divisions of General Practice. Although NIPIP was an adult program, while consulting with AMS's it was apparent that they were unique and each one visited had a story they wished to share.

I learnt about all immunisations programs being rolled out during these visits. The AMS's were engaging with their local communities, conducting immunisation clinics, designing innovated outreach programs and in-house programs to address due and overdue childhood immunisations. At a later date I was concerned that state and national data did not reflect the effort I had witnessed at the AMS level and this deserved some investigation. Too often there are reports, viewpoints or media items highlighting the inadequacies of Aboriginal people or organisations run by them. This study showcased the 'good' not the 'bad'.

There are some limitations to this study. First, the 53% return rate of the questionnaire limited how well the findings represented all AMS in NSW. However, those that responded represented a diverse range of locations and communities. The second limitation was the questionnaire. The information I gained from the site visits showed that some of the questions were inadequate to measure what was actually going on and that a preceding qualitative study would have informed a better questionnaire. For example, questions were asked about the existence of an accredited Nurse Immuniser and a doctor at each service.

However, only the latter included number of doctors and whether they were full or part-time. On observing the AMS it was clear that nursing numbers were significant as they were often the primary immunisers.

A second limitation of the survey was in the question about use of Service Provider Number. Once data were analysed, it was not clear whether the respondent considered a “Service Provision Number of a selected Doctor working at your service” as that being linked to the AMS or to the individual GP. Although pilot surveys were undertaken, cognitive interviews may have shown how this question could be interpreted in different ways. Nevertheless, while this limited data analysis, the research was still a valuable exercise and clearly showed that AMS’s Boards and Chief Executive Officers are constructing organisations and retaining skilled staff instrumental to effective service provision.

Immunisation provision

The study concludes that AMS are likely to be under-reported as providers of immunisation. Specifically, the study found that when a completed immunisation is reported to ACIR and a service provider number is required, 5 of the 22 AMS had unique service provider number allocated to the service and 14 AMS used the service provider numbers of doctors employed with their service. As noted above, a limitation is that the study could not identify whether those doctor provider numbers were AMS or individually linked. However, it was noted in informal discussions with seven nurses at different AMS experienced misrepresentation of immunisation provision in ACIR records. Two of these submitted with the unique AMS service provider number but ACIR data recorded that the immunisation had occurred as a Medicare General Practice. In one instance, one child, whose entire schedule was delivered under the AMS service provider number had their doses at 2 and 4 months of age recorded as given by a Medicare GP while at 6 months it was recorded as Aboriginal Medical Service. It was not clear why this was the case. Further investigation is needed to identify breakdown in data reporting. By not having correct data storage and reporting by ACIR, AMS’s are not being acknowledged for their true contribution which has the potential to lead to inadequate funding and support for these services.

A further finding, relates to the ability of AMS to intensively remind and follow-up on immunisations for children (reminder and recall). With respect to the use of PIRS to support

immunisation, of the 22 participating AMS, 17 were generating reports to address due or overdue immunisations so an assumption may be made that a good proportion of the non-participating AMS's may also be actively following up on overdue patients. An important element for accessing ACIR and PIRS when needed was the ability to access an internet signal. With only 6 of the 22 AMS's reporting not having immediate access this could compromise timely immunisations or inhibit follow-up. The roll-out of National Broadband Network may alleviate this problem in future.

The case studies showed that AMS extended standard clinical provision and adapted it to the local community by fitting in with local programs, proving promotion, and transport. These enabling activities were essential to the provision of timely and complete immunisation of children.

It was clear that the majority of AMS's had a strong focus on childhood immunisation. The combination of an AMS to adapt to its own local community and the knowledge of this community by the AHW's provided opportunities not often experienced by mainstream health organisations. Follow up of patients, innovated programs and service provision for, high numbers of Aboriginal children place an AMS in an integral position to provide, complete and improve immunisation coverage for Aboriginal children eligible for the National Childhood Immunisation Program.

Recommendations

In view of the findings of this study the following recommendations are suggested in order to address improved recognition of Aboriginal Medical Services immunisation service provision and their extra curriculum activities that support immunisation.

1. It is recommended that further research determine specifically the extent to which recording error or classification into “Medicare GP” is leading to significant under-representation of immunisations conducted at an AMS.
2. It may be useful for Medicare to provide a different mechanism for AMS’s to report to ACIR such as a forced choice field in ACIR that incorporates AMS or other.
3. That Federal and State or Territory funding/accounting bodies provide opportunities for AMS to report back their accompanying activities so that a full picture of immunisation service provision can be provided and they are afforded due recognition.
4. That the above information is filtered down to Medicare locals and state and territory Departments of Health so they are also aware of all activities that occur.
5. A defined funding pool is provided to enable professional updating opportunities for AMS immunisation staff. For example, the provision of scholarships to attend conferences or updates on immunisation.
6. A peer learning support meeting for immunisation staff that enables staff to meet across AMS types and allow for skill development such as presentation skills.
7. IT support is improved to enable data retrieval, particularly for smaller and remote and very remote AMS’s. This includes the ability for an AMS to have adequate internet access to ensure consistent ACIR logon.

References

1. Blaser MJ, Falkow S. What are the consequences of the disappearing human microbiota? *Nat Rev Micro*. 2009 12//print;7(12):887-94.
2. Grice EA, Kong HH, Renaud G, Young AC, Bouffard GG, Blakesley RW, et al. A diversity profile of the human skin microbiota. *Genome Research*. 2008 July 1, 2008;18(7):1043-50.
3. Kong HH. Skin microbiome: genomics-based insights into the diversity and role of skin microbes. *Trends in Molecular Medicine*. 2011 6//;17(6):320-8.
4. Brain M. How your immune system works: how stuff works; 2000 [31 March 2014]. Available from: <http://health.howstuffworks.com/human-body/systems/immune/immune-system.htm>.
5. Cartwright F, Biddiss M. *Disease and history*. 2nd ed ed. Gloucestershire: Sutton Publishing; 2000.
6. Fenner F. *History of Smallpox and its spread around the world* Geneva: The World Health Organisation; 1988 [cited 2014]. Available from: <http://whqlibdoc.who.int/smallpox/9241561106.pdf>.
7. Parish HJ. *A history of immunization*. Edinburgh: E&S Livingstone Ltd; 1965.
8. Kennedy M. *A brief history of disease, science and medicine: from the ice age to the genome project*. Rhode Island: The Writers' Collective; 2003.
9. The Army Heritage Centre Foundation. *A Deadly Scourge: Smallpox During the Revolutionary War*. Available from: <https://www.armyheritage.org/education-and-programs/educational-resources/education-materials-index/50-information/soldier-stories/282-smallpox>.
10. Riedel S. Edward Jenner and the history of smallpox and vaccination. . *Proceedings - Baylor University Medical Centre*. 2005;18(1):21-5.
11. Butlin NG. *Our original aggression: Aboriginal populations of southeastern Australia, 1788-1850* Sydney: Allen & Unwin; 1983.
12. Crosby AW. *Reveiw of Invisible Invaders; Smallpox and Other Disease in Aboriginal Australia 1788-1880* by Judy Campbell *Health and History*. 2002;4(2):125-7.
13. Curson PH. *Times of crisis: Epidemics in Sydney, 1788-1900*. Sydney: Sydney University Press 1985.
14. Jackson Pulver LH, M R. Ring, I. Waldon, J Etal *World Health Report (2010)Background Paper, 33) Indigenous Health Care Indigenous Health – Australia, Canada, Aotearoa New Zealand and the United States - Laying claim to a future that embraces health for us all*. *World Health Report: World Health Organization*, 2010.
15. Australian Human Rights Commission. *A statistical overview of Aboriginal and Torres Strait Islander peoples in Australia: Social Justice Report 2008* 2008. Available from: <https://www.humanrights.gov.au/publications/statistical-overview-aboriginal-and-torres-strait-islander-peoples-australia-social#Heading18>.
16. Australian Human Rights Commission. *Constitutional reform: Fact Sheet - Recognising Aboriginal & Torres Strait Islander people in the Constitution: Australian Human Rights Commission*. Available from: <https://www.humanrights.gov.au/publications/constitutional-reform-fact-sheet-recognising-aboriginal-torres-strait-islander-people>.

17. O'Donovan D. An atlas of health: mapping the challenges and causes of disease. London: Earthscan; 2008.
18. Travel Doctor. Vaccines Before Travel 2010. Available from: <http://www.traveldoctor.com.au/page/knowledge-hub/travel-health-fact-sheets/vaccines-before-travel>.
19. The World Health Organization. Vaccines and Diseases 2014. Available from: <http://www.who.int/immunization/diseases/en/>.
20. Menzies R, Joseph T. The National Indigenous Influenza and Pneumococcal Program Evaluation. 2004.
21. Menzies RS, RJ. Vaccine Preventable Diseases and Vaccination Policy for Indigenous Populations. Paediatrics Clinics of North America. 2009 56(6).
22. Menzies R, Joseph T, MacIntyre P. Vaccines for our Mob 2006. Canberra: Department of Health and Ageing; 2014.
23. National Centre for Immunisation Surveillance and Research. Vaccine Preventable Diseases in Australia, 2005 to 2007, Communicable Diseases Intelligence. In: Ageing DoHa, editor. Canberra: Australian Government; 2010.
24. NSW Department of Health. Poisons and Therapeutic Goods Act 1966: NSW Government; 1966. Available from: <http://www.legislation.nsw.gov.au/viewtop/inforce/act+31+1966+FIRST+0+N/>.
25. Aboriginal and Torres Strait Islander Commission Social Commission. Aboriginal and Torres Strait Islander Commission (1993) Annual Report 1992-93 Canberra: Australian Social Justice Commission; 1993. Available from: <http://www.austlii.edu.au/au/other/IndigLRes/1993/3/index.html>.
26. Marles E, Frame C, Royce M. The Aboriginal Medical Service Redfern Improving access to primary care for over 40 years. Australian Family Physician. 2012 6/01;41:433-6.
27. National Museum of Australia. Freedom Ride 1965 2008. Available from: http://indigenoustrights.net.au/civil_rights/freedom_ride_1965.
28. National Archives of Australia. The 1967 referendum – Fact sheet 150 Canberra: Australian Government; 2014. Available from: <http://www.naa.gov.au/collection/fact-sheets/fs150.aspx>.
29. Parker J. The History of the Communist Party's Support for Aboriginal Struggles Solidarity; 2009. Available from: <http://www.solidarity.net.au/aboriginal/the-history-of-the-communist-partys-support-for-aboriginal-struggles/>.
30. Belleair s. I Have a Dream Too of Basic Human Rights. The Sydney Morning Herald. 20013 13th August 2013.
31. King M. I Have a Dream America: Fox News; 1963. Available from: <http://www.foxnews.com/us/2013/08/27/transcript-martin-luther-king-jr-have-dream-speech/>.
32. Franklin M. Balck and White Australians; an Inter-Racial History 1788-1975. South Yarra: Heinemann Educational Australia; 1976.
33. Scott WD. Problems and needs of the Aboriginals in Sydney: A report to the Minister for Youth and Community Services New South Wales. Sydney: W.D. Scott & Co. Pty. Ltd. Management Consultants, 1973 Volume 1.
34. The National Aboriginal Community Controlled Health Organisation. Quality Health Standards Continuation Measure 2011-2015 Canberra: Commonwealth Department

- of Health and Ageing: OATSIH; 2012. Available from:
<http://www.naccho.org.au/promote-health/accreditation/#shash.1AknaJD8.dpuf>.
35. The National Aboriginal Community Controlled Health Organisation. Definitions Canberra: NACCHO Communication Network; 2012. Available from:
<http://www.naccho.org.au/Aboriginal-health/definitions/>.
 36. The Aboriginal and Torres Strait Islande Health Worker Association. What is an Aboriginal Health Worker/Health Practitioner Canberra: The Aboriginal and Torres Strait Islande Health Worker Association; 2012. Available from:
<http://www.natsihwa.org.au/what-health-worker>.
 37. Australian Human Rights Commission. Close the Gap - Progress and priorities report 2014 Canberra: Australian Government; 2014. Available from:
<https://www.humanrights.gov.au/publications/close-gap-progress-and-priorities-report-2014>
 38. Mitchell MH, LM. . The Aboriginal Health Worker. The Medical journal of Australia. 2006 May 2006;184(10).
 39. The National Health and Medical Research Council. Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research Canberra: Australian Government; 2003. Available from:
<http://www.nhmrc.gov.au/guidelines/publications/e52>.
 40. Department of Health and Ageing. National Vaccine Storage Guidelines - Strive for Five. 2nd ed. Canberra: Australian Government 2013.
 41. 4704.0 - The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, Oct 2010 [Internet]. Australian Government. 2010 [cited February 2014]. Available from:
<http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4704.0Main+Features1Oct%202010?OpenDocument>.

Appendices

Appendix 1 AMS Questionnaire

Aboriginal Medical Services and Aboriginal Childhood Immunisation



We would like to better understand how AMS's contribute to immunisation of children. This will provide data to recognise the actual contribution of AMS's to immunisation service provision and get better data on existing capacity. Please fill out this confidential short survey. You may need to consult your service records to answer some questions

Q1. Is your service any of the below? Tick all that apply

- clinically accredited in the process for clinical accreditation
 registered for GPPII registered for PIP

Q2. What is your position?

Q3. How long have you been in this position at this Service?

Q4. How many children under 5 years of age is on your 'patient information system'?

Q5. Is your service a member of the National Aboriginal Community Controlled Health Organisation or one of their State or Territory Peak Bodies?

- Yes No

Q6. Does your service provide a clinical service? If 'No' please go to Q11

- Yes No

Q7. Does your service provide immunisations for the National Immunisation Program (NIP) funded by the Immunise Australia Program?

- Yes No

Q8. Does your service have a 'vaccine' specific fridge? If 'Yes' please go to Q10

- Yes No

Q9. Has your service modified a 'normal' fridge that is compliant with 'strive for five' National Vaccine Storage Guidelines?

- Yes No Dont know

Q10. If you answered 'Yes' for Q8 or Q9 who is responsible to maintain this vaccine storage fridge? (ie Aboriginal Health Worker, Clinic Nurse, Clinic Manager)

Telphia Joseph | National Indigenous Immunisation Co-ordinator
The National Centre for Immunisation Research and Surveillance
t: (02) 9845 1424 | f: (02) 9845 1418 | e: "<mailto:TelphiaJ@chw.edu.au>" | w: "<http://www.ncirs.edu.au>"

**Aboriginal Medical Services
and Aboriginal childhood immunisation**

Q11. Does your service have a policy or process to systematically check children's immunisation status when they attend your service?

Yes No

Q12. Does your service provide or are they involved in any regular immunisation clinics? If 'No' please go to Q20

Yes No

Q13. Where does the immunisation clinic occur? Please tick all that apply

AMS/ACCHO Outreach site
 Local GP Public Health Unit

Q14. Where else might you immunise? Please tick all that apply

Community Events Home visits
 Other _____

Q15. Does your service have an accredited Nurse Immuniser?

Yes No

Q16. Does your service employ a doctor?

None
 Number of full time _____
 Number of part time _____

Q17. On average how many hours a week does your service have a doctor? (add together all the Dr's hours)

Q18. Does your service provide the following immunisations? Please tick all that apply.

Under 5 years olds 10-17 year olds 18 years and over

Q19. Who provides immunisations at your service? Please tick all that apply.

AHW Employed FT Enrolled Nurse Visiting Nurse Division of GP
 Employed FT Doctor Employed PT Enrolled Nurse Visiting Nurse Public Health
 Employed PT Doctor Employed FT Accredited Nurse
 Visiting Doctor Employed PT Accredited Nurse

**Telphia Joseph | National Indigenous Immunisation Co-ordinator
The National Centre for Immunisation Research and Surveillance**

t: (02) 9845 1424 | f: (02) 9845 1418 | e: <mailto:TelphiaJ@chw.edu.au> | w: <http://www.ncirs.edu.au/>

Page 2 of 5

**Aboriginal Medical Services
and Aboriginal childhood immunisation**

Q20. Does your service assist in the transportation of children for immunisation to any of the following? Please tick all that apply.

- To your AMS
- To a local GP or Medical Centre
- To a local Public Health Clinic
- To a local Hospital
- To an immunisation outreach service

Q21. Does your service do any of the following immunisation Health Promotion? Please tick all that apply.

- Talk to parents about importance of the childhood schedule
- Develop your own posters
- Put up delivered posters
- Mailout information/reminders about immunisation to parents
- Verbally remind parents that children are due for immunisation

Q22. Does your service display health promotional material from any of the following? Tick all that apply.

- State and Territory Department of Health
- Local Public Health Unit
- Vaccine manufacturer
- Other please specify _____

Q23. Does your service assist in any immunisation activity outside of your organisation and if so please explain? ie Knockout's or assist Public Health with their posters.

- No yes _____

Q24. How does your service order Childhood Schedule vaccines? Please tick all that apply.

- State and Territory Departments of Health
- Local pharmacy
- S100
- Other _____

Q25. Approximately how many vaccines did your service order in 2010 for the Childhood Schedule?

Q26. Approximately how many vaccines were used by your service in 2010 for the Childhood Schedule?

Telphia Joseph | National Indigenous Immunisation Co-ordinator
The National Centre for Immunisation Research and Surveillance
t: (02) 9845 1424 | f: (02) 9845 1418 | e: "<mailto:TelphiaJ@chw.edu.au>" | w: "<http://www.ncirs.edu.au/>

**Aboriginal Medical Services
and Aboriginal childhood immunisation**

Q27. What patient information system is used at your service? Tick all that apply.

- Paper based
- Communicare
- Ferret
- Medical Director
- Other _____

Q28. What information is recorded on this patient information record system? Please tick all that apply.

- Basic patient details
- Vaccine history
- Clinical information

Q29. Does your patient information system flag due or overdue immunisation when a patients details are accessed, ie by Dr or Nurse?

- Yes
- No

Q30. How easy is it for you to access overdue/due status on your information record system? Please tick one only.

- Can access data straight away
- May have to wait 10-15 minutes for data
- May have to wait hours for data

Q31. How often does your service generate regular immunisation reports for 0-7 year olds?

- Not at all
- Monthly
- Weekly
- As required

Q32. If your service is generating immunisation reports what are they used for? Please tick all that apply.

- Due/overdue status of patients
- Data for ACIR
- Review acceptance letters from ACIR
- Other _____
- Vaccine ordering
- Review payments from ACIR
- Information for reporting to funding organisations

Telphia Joseph | National Indigenous Immunisation Co-ordinator
The National Centre for Immunisation Research and Surveillance
t: (02) 9845 1424 | f: (02) 9845 1418 | e: "<mailto:TelphiaJ@chw.edu.au>" | w: "<http://www.ncirs.edu.au/>

Aboriginal Medical Services and Aboriginal childhood immunisation

Q34. When reporting to ACIR what does your service use?

- Unique Service Provision Number for your service*
- Service Provision Number of a selected Dr working at your service*
- Service Provision Number of more than one Dr working at your service*

Q33. Can your service access ACIR whenever you need to?

- Always*
- Usually*
- Occasionally*
- Rarely*

Q35. Can your service get the following data from ACIR?

- Vaccination status of individuals*
- Vaccination coverage of your client population*

Q36. Are you in contact with your local ACIR officers?

- Often ie, more than once a month*
- Sometimes*
- Seldom*
- Not sure, who they are?*

Q37. How do you report to ACIR?

- Electronically*
- By Post*

Thankyou for your assistance in completing this survey. A de-identified report of the results shall be forwarded to your organisation once all questionnaires have been collated and analysed.

Could you please post this survey back in the supplied return post stamped envelope. Or alternatively please post back to

Ms Telphia Joseph
NCIRS
The Children's Hospital Westmead
Locked Bag 4001
Westmead NSW 2145

Appendix 2 Information Sheet

INFORMATION SHEET

Study of Aboriginal Medical Services (AMS) Contribution to Childhood Immunisation

Page 1 of 2

Why this study

Currently the Australian Childhood Immunisation Register (ACIR) reports that nationally, 10% of Aboriginal and Torres Strait Islander children are immunised by AMS's. As this 10% does not reflect the true contribution by many AMS's we would like to gain a clearer understanding of the contributions that AMS's make towards the immunisation of Aboriginal children in NSW.

Purpose

The study aims to describe the range of ways in which AMS's contribute to Aboriginal immunisations under the childhood schedule and evaluate how immunisations undertaken through an AMS is reported to ACIR.

Methods

This proposed study shall be undertaken in two stages:

- Stage 1- a written questionnaire to be sent to all NSW AMS's to be Completed by a nominated clinic staff involved in immunisation.
- Stage 2- four selected AMS's to be follow up for face to face interviews with clinic staff.

What we would like from you?

It would be wonderful if your organisation could be involved in stage one of this study. If you could please complete this attached survey it will help us establish excellent state wide data.

Risks

There is no identified risk for you to participate in this study. Your participation is voluntary and if you choose not to fill out this survey you will not be affected in any way.



Inconveniences

Other than the 20 minutes it will take to fill out this survey there should not be any inconveniences.

Possible outcomes

Aboriginal Medical Services can vary considerably, budget, location, staff numbers and available resources greatly change the way that service provision is rolled out. By aiming to gather data from as many urban, rural and remote AMS's across NSW this will provide a stronger picture of immunisation service delivery nationally.

This study proposal has undergone the AH&MRC Ethics Committee and approval has been received from NACCHO and completion of this survey will imply consent.

Please contact the AH&MRC ethics committee on t) 02 9212 4777 if you have any concerns with this research process or Contact Telphia-Leanne Joseph on t) 02 9845 1424 or e) telphiaj@chw.edu.au for any other queries.



Appendix 3 Consent form

ABORIGINAL COMMUNITY ORGANISATION

Name of Aboriginal Community Organisation:

.....

Project: Survey of Aboriginal Medical Services to understand their contribution to immunisation

Principal Researcher: Telphia Joseph

Research Organisation: National Centre for Immunisation Research & Surveillance

This must be completed by the Chairperson or CEO of the Aboriginal community organisation.

I,can confirm that the
(insert name of Aboriginal organisation)
gives its consent to the above research project, subject to the following conditions:

1. We have the right to withdraw our consent and cease any further involvement in the research project at any time without any penalty and without giving any reasons.
2. The purpose of the research, as outlined in the attached brief, has been explained we have had the opportunity to ask questions about the project. We have received satisfactory answers to our questions and have been given adequate time to consider the appropriateness of the project.
3. We have been provided with the following information in writing:
 - The names of all people and organisations who are responsible for the security of data and who will have access to the data.
 - Details of the proposed storage and destruction of data.

4. The researcher will need to obtain additional consent from us if there are any changes to the project from the information provided under paragraphs [2][and [3] above.
5. Any information that any member of our staff provides or any personal details of our clients obtained in the course of this research, are confidential and any information that could identify individual participants will neither be used nor published.
6. Unless otherwise explicitly agreed, any information provided in the course of this research that identifies our organisation or the Aboriginal community which it serves will not be used nor published without our written permission.
7. The researcher will ensure there is continuing consultation with the community and our organisation during the course of the research. The research will not proceed until all required negotiation has occurred to our satisfaction.
8. The ethical provisions relating to the health of Aboriginal people, as set out in AH&MRC and NHMRC publications, will be complied with and the project will not proceed until the AH&MRC Ethics Committee has endorsed the project.
9. The researchers will obtain the written individual consent of all participants in the research.
10. We understand that if we have any complaints or questions concerning this research project we can contact the principal researcher mentioned above; the Chairperson or CEO, or the Chairperson of the AH&MRC Ethics Committee as follows:

The Chairperson
 AH&MRC Ethics Committee
 PO Box 1565
 Strawberry Hills NSW 2012
 Telephone: 9212 4777

 Signed on behalf of (insert name of Aboriginal organisation _____)

Signature

Position in the organisation (Board Chair or CEO)

Date

Witnessed by Date

As the Chief Researcher in the project, I acknowledge the conditions set out above

Name:

Signature..... Date

Witnessed by Date

Please Fax back to Telphia Joseph on 02 9845 1418

Appendix 4 Ethical Guidelines Considerations for Aboriginal and Torres Strait Islander Research

- Collaborative approach to project design with at least one Aboriginal group/organisation. It should also be noted that this necessitates budgeting to take account of appropriate payment for any assistance and understanding of individual workloads.

The relevance of the project was clarified with NACCHO in 2005 and all drafts were taken to the NATSIIN committee for feedback. An informal pilot process also occurred with AMS's in WA and Victoria to get feedback on the relevance of the questions.

I will provide regular updates on the study (with de-identified data) to AH&MRC ethics and also to AMS's via an existing Governance Committee. A short report shall also be sent out to all participating AMS's providing quantitative results from the questionnaire. It is important to the researcher that she is also able to receive feedback from individual AMS clinic staff and the AH&MRC during this study.

The researcher shall also continue to liaise with AH&MRC and individual AMS's under her capacity as the National Indigenous Immunisation Coordinator regarding issues such as expanded influenza program for Aboriginal people and human papillomavirus vaccine, school based program for boys.

The researcher is aware that the success of the study is dependent on the responses of AMS staff and is mindful of the demands and time constraints made on the employees working at AMS's. Therefore a time efficient questionnaire (15-20 minutes) will be developed with the opportunity for a follow-up phone call to assist in the completion of the form if needed.

Within the context of the questionnaire there are a limited number of questions that data may need to be generated (i.e. How many vaccines were used for the childhood schedule in 2009?) resulting in external time to the questionnaire being used.

Unfortunately there is not sufficient budget to compensate the time of participants but an intention to provide 4 Apple iTune gift cards to be used in a draw for all clinic staff that participated. This is yet to be finalised.

- Community resources used in the conduct of research should be appropriately costed and a process for reimbursement needs to be identified in the research application.

The main resource used is the physical time of the clinic staff participating in the questionnaire and face to face interviews.

- The Researchers must recognise the community's right to further information, and accept that changes to procedures or methods require further negotiations and consent. (The AHREC may also need to be approached for approval if any changes are proposed).

Changes have been discussed with the Governance Committee and AH&MRC were informed during an update report.

- Reciprocity

Early discussions with NACCHO helped to formulate the idea to investigate this issue more thoroughly. At all stages of the drafting of this proposal and identification of relevant research questions, NATSIIN participants from NACCHO Peak Bodies had the opportunity to drive the research process and helped to form the questionnaire. This study was generated because the researcher had concerns that AMS's were being under represented and not acknowledged correctly in any reporting mediums connected to immunisation coverage for Aboriginal children.

- Respect

The researcher's primary role as the National Indigenous Immunisation Coordinator involves collaborating with Aboriginal Community Controlled Health Organisations and their representing Peak Bodies. It is these respectful working relationships that have helped to keep issues such as 'Aboriginal Health Workers' as immunisers on the agenda of the National Immunisation Committee and the drafting of the 'Principals for use of data of identified Aboriginal children who are overdue for immunisation' that have been taken up in NSW, QLD, and the ACT. As the item of research is 'task processes' within the AMS setting, this was the focus of data collection and there shall be no identifiable data recorded of individual participants and the majority of AMS data collected has been de-identified except for the showcased items which the researcher received permission to write up.

- Equality

As the researcher works solely within the health setting she is very aware of the important role that the AMS plays to strive for equal health for Aboriginal people. It is this awareness that motivates the researcher to continually remind Public Health and General Practice Networks (GP) to increase their collaborations with AMS's. She also has a passion to encourage GP's to put in place respectful processes so that Aboriginal people have the opportunity to identify if they wish, thus increasing the ability for GP's to provide appropriate health care.

- Responsibility

Since the beginning of this research idea, representatives from Aboriginal Community Control Health have been involved. All participation in this research is confidential and it was made clear that no repercussion will occur for those who do not wish to participate. This is the only area of the research that any perceived 'harm' may occur – i.e., if a participant (clinic staff) does not wish to be involved then their CEO will not know of their decision as it will be confidential. Also the aim of this research is to promote and document how extensive the role is for AMS's in the immunisation of

Aboriginal children, all data collected shall be reported back in a de-identified quantitative format after the 'stage 1' of the research and then in a more comprehensive report after 'stage 2' which will also be de-identified.

- Survival and Protection

A singular aspect of this research is to support and promote the activities of the AMS towards immunisation coverage for Aboriginal children under the current National Immunisation Program. Immunisation has proven to be an effective and relatively cheap tool in the fight against poor health in Aboriginal people. Furthermore, studies by NACCHO have shown that Aboriginal people will utilise an AMS if it is accessible to them. All aspects of this collaboration/consultation process which occurred through NATSIIN have been done with support of and belief in the Community Controlled Health role. This study has been taken on because the researcher is involved emotionally, socially and professionally in her community and wishes to support immunisation as a contributor for better health in her community.