

# **Gaba Binggi (Good Needles): Developing an understanding of how two Aboriginal\* communities see and experience immunisation during pregnancy**

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**\*Hereafter interchangeable with First Nations.**

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Winunga-laa-nha ngay gomeroy marran dhiriya yumbuli, walay-gu ngay murri nhalay yaliwunga gurunga Warra-nha yilaadhu

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## Abstract

### Background

First Nation pregnant women experience five times the rate of admission to intensive care from influenza compared with non-First Nations women despite the influenza vaccine being found to be safe and effective in pregnancy. Preliminary coverage data already indicates a gap in immunisation coverage between First Nations women and others. To understand this gap this research explored stories around the experience of pregnancy and immunisation through the eyes of the participating communities and the researcher.

### Method

The study employed a community-based participatory action research (PAR) framework with decolonising methodologies. Based on the oral tradition of Murri culture, semi-structured interviews (talking listening and yarning) with Mums, family members and key stakeholders were undertaken. Twenty-five interviews were conducted along with two yarning circles. Interviews were recorded and notes taken. PAR phases of planning, action, observation and reflection were conducted.

### Results

Five main themes emerged from the data and recommendations for action: Special Bond & Celebrating Survival, “It connects family on so many levels, past and present and future”; Believe In Immunisation, “I don’t think I have ever seen anyone in our community refuse to get their child immunised”; Fear/Trust Balance, “Trust takes a long time to build but can be easily damaged”; Cultural Safety; and Ways Forward.

### Discussion

Gaba Binggi in the language of my people (Gomeri), and means good needles. This is how immunisation is seen, more than acceptance but a stronger sense of “good needles”. The past, present and future are inextricably connected and this needs to be embraced by health services. What has gone before impacts today and what we do today about immunisation in pregnancy speaks into the future.

### Conclusion

Pregnancy is deeply important to families and culture. The balance of fear and trust is integral in decisions about immunisation during pregnancy. Current services that provide immunisation to pregnant First Nations women must be designed to be culturally safe, flexible and empathetic to family and community issues. They must name and address racism in all its forms and further culturally safe research needs to be undertaken surrounding immunisation during pregnancy for/with/by First Nations peoples.

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## Terminology

Throughout this thesis the term First Nations is used to refer to Aboriginal and Torres Strait Islander peoples of Australia. This decision was made during the writing of the thesis. The project began using the terminology 'Aboriginal' and hence items in the Appendices reflect this.

The word Aboriginal is used when a name or person is directly quoted.

Non-First Nations is the word used for Non-Aboriginal.

The word Indigenous with a lower case is used when referring to other indigenous people of the world. Indigenous is capitalised when referring to First Nations people of Australia

Gomeri country is used to describe the cultural homelands where the research occurs.

## Chapter 1 Introduction

This chapter explores the context, issues and the setting for the work and is structured around the following sections:

- Introduction
- Influenza the disease and its impact on First Nations peoples
- Influenza and the risk in pregnancy
- Influenza and history
- Health disparities
- Influenza immunisation
- Other immunisations in pregnancy
- Health service delivery
- Cultural safety
- Significance of research
- First Nations peoples and Research

This research uses decolonising methodologies through qualitative research methods to explore with and for communities, and especially with Australian First Nations women, health issues during pregnancy, and immunisation during pregnancy.

The research occurs on the land of the Gomeroi nation which geographically overlaps the Hunter New England Local Health District of New South Wales (NSW), Australia. This Health District has more First Nations people than any other Health District in NSW and the First Nations population is younger than the non-First Nation population (HNELHD, Aboriginal Health Plan, 2014, P15). From 2006 to 2011, the First Nation population of Hunter New England increased 25% from 30,867 to 38,552. Almost half (49%) of the First Nations population within the Hunter New England Local Health District are aged 19 years or less, compared to 23% of the non-First Nation population aged 19 years or less and this highlights the importance of pregnancy and families. (Hunter New England Local Health District, 2014)



This research aimed to provide an insight into the following questions:

- How do First Nations women, in two First Nations communities in New South Wales, see and experience immunisation during pregnancy?
- What ways of talking about immunisation during pregnancy are more appropriate?
- What ways of pregnancy immunisation service delivery are more acceptable to First Nations women?



## **Influenza the disease and its impact on First Nations peoples**

### **Influenza and the risk in pregnancy**

The period of time encompassing pregnancy, childbirth and infancy is a special time for a mother and family. For many First Nations people, having children is one of the most important parts of life and has an added layer of celebrating survival and building the future. The family in First Nations communities is central to the social fabric and the survival of First Nations culture (Bourke & Bourke, 1995). However, pregnancy can be a time of increased risk. One of those risks is influenza.

Influenza is a contagious viral infection of the respiratory tract. The virus is continually changing so it is not unusual for new viruses to appear each year. The most common viruses currently circulating among people include: influenza A (H1N1) viruses, influenza A (H3N2) viruses, and influenza B viruses (NSW Health Communicable Diseases, 2016). The virus weakens the immune system, and causes, among other symptoms, high fever, body aches, fatigue and weakness, leaving people vulnerable to more serious infections. Severe cases can lead to life threatening illnesses such as pneumonia (Heymann, 2015).

Influenza infection is known to be a substantial cause of ill-health during pregnancy (Kourtis, Read, & Jamieson, 2014). The increased risk for severe disease because of influenza is thought to be connected with changes to the heart and lungs during pregnancy. Reports show that First Nations peoples, similar to other indigenous peoples, are approximately five times more likely than non-First Nations people to be hospitalised for the recent H1N1 influenza pandemic, and a similar proportion required intensive care treatment (Flint SM, 2010; La Ruche et al., 2009; Rudge & Massey, 2010). Other countries have also found higher risks of severe disease in indigenous people groups, for example the First Nations people of Canada (Charania & Tsuji, 2012).

### **Influenza and history**

Historically influenza pandemics have taken a large toll on First Nations Australians. The introduction of pathogens such as smallpox, tuberculosis and influenza, after 1788, caused high incidences of the diseases and high mortality in the years following the invasion (Dowling, 1997). In an environment of “unestablished immune responses and decreased immuno-efficiency” the diseases were uncontained and spread rapidly ([Dowling, 1997](#)).

### **Health disparities**

Health disparities are a common aspect of life for many First Nations Australians, particularly in rural and remote areas. Influenza has a greater impact on people with health disparities, including First Nations peoples, where in Australia, the risk of hospitalisation for influenza was at least doubled between 2003 and 2006 (Turnour, McIntyre, Menzies, & Chiu, 2008).

These disparities are related to crowded homes, excess co-morbidity, poor access to health care, communication difficulties with health professionals, reduced access to pharmaceuticals, and institutionalised racism (Aldrich, Zwi, & Short, 2007).

Currently there is a significant amount of research on the status of First Nations peoples' health. Much of the health challenge is linked intrinsically to First Nations peoples' ongoing social and economic disadvantage, which combines with the impact of institutional racism to negatively influence the health of First Nations peoples (Larson, Gillies, Howard, & Coffin, 2007). Immunisation is also seen as a matter of children's rights and about social justice (Durrheim & Cashman, 2010).

### **Influenza immunisation**

There continues to be a significant research agenda on the uptake of immunisation for First Nations children (Abbott et al, 2013)(Menzies & Andrews, 2014) and (Harris, 2014) related to the availability of data from the Australian Childhood Immunisation Register which records National Immunisation Program immunisations given to children up to age seven years. For those aged over seven years, including adults, there has been little data on uptake of vaccines to date, a deficit that will be addressed when an expanded register for all Australians is put in place by 2017 (National Centre for Immunisation Research and Surveillance, 2016).

This lack of adult vaccination coverage information to date sits in contrast to the burden of influenza and the potential effectiveness of the vaccine as a preventive measure. Much has been reported in recent years about the safety and effectiveness of influenza vaccination during pregnancy. In a summary of the evidence, Steinhoff et al (2014) report that influenza immunisation during pregnancy reduces risk and improves health across a number of areas. Maternal illness is reduced resulting in 40-50% decrease in hospitalisations for influenza; foetal outcomes such as preterm birth are improved (decreased by 10-20%); hospitalisation for influenza is reduced in infants up to six months of age by 40-63%; and it is reported that influenza immunisation during pregnancy potentially improves long-term adult outcomes for the infant (Steinhoff, MacDonald, Pfeifer, & Muglia, 2014).

In a very large retrospective study using linked safety data in the US, the vaccine outcomes of more than 74,000 women were considered by (Kharbanda et al., 2013) They found no observed risks for adverse obstetric events found to be associated with influenza immunisation; in fact there was a small reduced risk for gestational diabetes in the vaccinated group. In studies in the Netherlands (van der Maas, Godefrooij, Bondt, de Melker, & Kemmeren, 2016) and the US (Louik et al., 2013), and using international data (Moro, Tepper, Grohskopf, Vellozzi, & Broder, 2012) there were no

differences in adverse events between pregnant women vaccinated with the H1N1 pandemic influenza vaccine and those not vaccinated.

Providing immunisation during pregnancy is a very recent program in Australia and within such a short time frame already a gap in coverage exists. When this research began a 10% gap in coverage had already been reported between First Nations mothers and non-First Nations mothers in one NSW study (K Wiley personal communication, 11 October 2012). This coverage has remained low (O'Grady et al., 2015).

Given that immunisation is widely supported in First Nations communities, and is well accepted as a health initiative, this gap is an important concern. The gap may be an expression of the way the program has been developed and implemented in the past, where the voices and the understanding of First Nations people have not been at the centre; where culture does not appear to have been given due consideration (Bainbridge & McCalman, 2016).

### **Other immunisations in pregnancy**

A more recent program is the use of a pertussis (whooping cough) vaccine in pregnancy. Australian states and territories began funding dTpa (diphtheria-tetanus-pertussis) vaccination for pregnant women in 2015 (Beard, 2015). This program aims to protect the newborn through maternal vaccination. Research from 2013 found that First Nations women were more willing to have the vaccine (53%) than non-First Nations women (40%) in the postpartum period (Wiley et al., 2013). Yet later data from a larger study found a gap in coverage (R Andrews personal communication 30 April 2016). This suggests a need to change the systems of delivery.

### **Health service delivery**

Considerable health service delivery is modelled on what works in the non-First Nations world and little if any consideration is currently given to First Nations ways (Henry et al, 2004).

*What's happened is that the white man has set up his own health system....and we have to be a part of it and we have to educate ourselves about the system, and we see it breaking down...it's a white man's system designed for white, middle class people*

(Patterson B et al., 2014)

Most health care is directed to the person as an individual but that is not how many First Nations people see themselves. An example is that families are central in the lives of many First Nations communities. Elders, mothers, grandmothers, aunties, husbands, partners, cousins and other family members all have important and varying roles to play in health decisions. Gomeroi relationships are also based upon the groups to which a person belongs and not just the European style that is more based on individual relationships (Ash & Giacon, 2003).

*...they'll never understand it...it's about family...white people don't understand the role family plays*

(Patterson B et al., 2014)

However the offer of immunisation for pregnant women may only occur in the context of individual health care. Preventative measures to decrease this health inequity are not effective. The development, implementation and evaluation of programs targeting immunisation must also concentrate on providing such programs in a culturally safe context (Thackrah & Thompson, 2013).

### **Cultural safety**

Cultural safety is important. It enables First Nations voices to be at the centre of research and health care. Cultural safety in Australia is a process to better enable First Nation participation (Phillips, 2015). It requires the accumulation and application of First Nations knowledge of ways of knowing and being, to be imbedded in structural and systemic reforms (Mason, 2013).

As Anderson (1996) stated, and the NHMRC (2003) recorded, in First Nations health, research is important for improving health but this research must be connected to community, ethical, culturally safe and address real priorities (Anderson, 1996; National Health and Medical Research Council, 2003). However, the research process must be determined by the specific community. If it is not conducted appropriately, it can be detrimental to health.

Added to this, the use of a culturally safe research and evaluation framework is imperative. Obtaining information on participant's cultural heritage is necessary for evaluating impact and outcome measures. To understand the perspective of First Nations participants, information on cultural appropriateness, as part of the process of research and evaluation, must be collected (Coombes Y, 2010). Utilising this process it is expected that a specific culturally safe and appropriate delivery of an immunisation program for pregnant First Nations women would increase coverage and decrease mortality and morbidity from the disease.

### **Significance of research**

This thesis explored with First Nations communities, and especially with First Nations women, stories surrounding immunisation during pregnancy. This information was gathered by the Murri tradition of yarning with First Nations women, men and health providers in two communities in North West New South Wales. During the gathering of the stories, different ways of talking about immunisation during pregnancy and improving service delivery were explored.

Despite the fact that influenza vaccine is safe and effective in pregnancy, First Nation's pregnant women experience both a higher rate of admission to intensive care from influenza and a gap in

immunisation coverage compared to non-First Nations women. To better understand this gap and reasons behind lower immunisation coverage the research explored stories around the experience of pregnancy and immunisation through the eyes of the participating communities. There is a need to develop better understandings on how services are being delivered, so opportunities for First Nations mothers and their babies to be immunised and better protected are improved. The health of First Nations Australians is deemed to be a priority with the Close the Gap campaign a national initiative, it is time that this 'priority' becomes a real priority.

In Chapter 1 the significance of the research has been established. In chapter 2 decolonising methodologies will be outlined in relation to this research and my research journey will be considered as an element of decolonising research.

## Chapter 2 Decolonising methodologies

The invasion and subsequent colonisation of Australia effected First Nations people adversely. It is acknowledged that this has contributed to the transgenerational trauma, health disparities and disadvantage suffered by First Nations people today (Parker & Milroy, 2014). Some First Nations researchers have noted that past research practices have had a detrimental impact of First Nations people. To address health disparities today research needs to be decolonised. Research, must be mindful of this history and understand that to First Nations people the past, the present and the future are interconnected (Health & Council, 2003). This shift is necessary, as previous research has failed to bring about the change first Nations peoples want and need. This common thread connected First Nations peoples and was supported by literature that was explored in the context of this thesis.

Garry Creighton, a Gomeri Murri Elder's reply when asked about his views on research, articulates this: *They want to know all about us but they don't want to know us*

And by Juanita Sherwood (2001:28) in her declaration:

*I cringe at the texts that disregard and misrepresent my identity*

*I'm embittered by the data that confounds my notion of social justice*

*I weep at the reckless abuse of ignorance and power*

*I reject the consciousness of superiority and prejudice*

*I reflect on the despair of my brothers and sisters*

*I rejoice in the empowerment of my people's voices*

*I dance on the mother as she responds to our growth*

*I claim my inheritance of resisting oppression*

*I write my story to counter misbeliefs and encourage understanding*

*And I will my story to nurture a place for safety and respect of our cultures and our peoples*

(Sherwood, 2001)

Martin (2003) referred to these research practises as "terra nullius research" where First Nations people were dispossessed of knowledge with no recognition, reimbursement or respectful inclusion in research.

*In this research, we are present only as objects of curiosity and subjects of research. To be seen but not asked, heard nor respected. So the research has been undertaken in the same way Captain James Cook falsely claimed the eastern coast of the land to become known as Australia as terra nullius.*

(Martin & Mirraoopa, 2003)

In her book, *Decolonizing Methodologies*, Tuhiwai Smith, articulated how western research methodologies impacted significantly on indigenous people. (Smith, 1999) She provides a framework by which researchers can counter this. Tuhiwai Smith goes on to describe how some commentators talk about how specificities and methodologies are rooted in survival struggles. The indigenising of research methodologies gives a voice to those First Nations peoples being researched.

First Nations peoples' participation in every aspect of health research is increasingly recognised as a critical element of a successful research project (National Health and Medical Research Council, 2003). Even further decolonising can occur when the research is owned, conducted, interpreted and reported by Indigenous researchers and the communities. As stated in the National Health and Medical Research Council's *Values and Ethics: Guidelines for Conduct of Aboriginal and Torres Strait Islander Health Research*, (2003) First Nations researchers play an important role in obtaining accurate and culturally safe data for implementation of effective service delivery.

Further to this Lowitja O'Donoghue (1998) stated in her inaugural address to the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health

*Until very recently . . . research has been a very top down approach. For [First Nations] people, this has meant we have been amongst the most studied and researched people in the world . . . few if any tangible benefits have flowed to our people, as the research papers and the academic accolades have stacked up. Researchers have, by and large, defined the problems and sought solutions that they have seen as the correct, scientific way to go.*

Decolonising methodologies are further described as moving the research from problematizing First Nations people to a "focus on strengths, capacity and resilience" (Rigney, 2006; Zavala, 2013). The emphasis is placed on First Nations people being an integral part of the research process and the respect of First Nations ways of doing, being and knowing (Martin & Mirraoopa, 2003). While research outcomes are undoubtedly important, in many cases the process used is of greater importance.

Sherwood and Edwards (2006) argue that for First Nations health improvement to occur, a shift from the western dominant view of illness and disease must first occur (Sherwood & Edwards, 2006). The decolonising of research methodologies to view First Nations health in a more holistic way allows for the inclusion of First Nations voices. The inclusion of local First Nations people, researchers and communities from the beginning of the research is fundamental (Sherwood, 2013) as First Nations people have the expertise to address health needs, as 60,000 years and more of history attest.

As Anderson (1996) stated and NHMRC (2003) recorded, in First Nations health, research is important for improving health but this research must be connected to community, ethical, culturally safe and address real priorities (Anderson, 1996). Without respect for and the centring of First Nations voices, First Nations ownership and First Nations involvement the research remains “terra nullius” (Martin & Mirraboopa, 2003).

To alleviate these concerns community based participatory action research (PAR) (Wells, 2009; Cornwall, 1995; Miller, 2015) was preferred by both the community and the researcher. As a catalyst to decolonising the research PAR provides a process for First Nations people’s participation in research. This in turn leads to participation of community members, which leads to empowerment, increased control over one’s life and eventually improved health (Kowal, Anderson, & Bailie, 2005).

The PAR method’s key strength is the partnership between the researchers’ methodological expertise and the community and participants’ real world knowledge (Cargo et al., 2008). The research also continued the research cycles of the PAR approach taken in the development of more appropriate pandemic influenza control strategies. (Massey et al, 2011) and allowed me to build on the existing trust already established with the communities (Weiner & McDonald, 2013; Massey et al, 2012; Bergold & Thomas, 2012; Mooney- Somers & Maher, 2009).

### **First Nations peoples and Research**

Historically, research on First Nations peoples, and indigenous peoples in other countries, has often been deemed inappropriate as researchers sought to collect and interpret the data without providing benefits to the people or communities researched (Miller et al., 2015). I am acutely aware of the practice of researchers taking information from community members without reciprocating.

Generally, research has not been a positive experience for many First Nations’ communities.

Researchers have a responsibility to cause no harm, but traditional western forms of research have been a source of disempowerment for First Nations peoples due to inappropriate methods and practices (Sherwood, 2010).

The results of First Nations research have also been misused to harm First Nations communities.

Following the 2007 report of the Northern Territory Board of Inquiry into the Protection of Aboriginal Children from Sexual Abuse (‘Ampe akelyernemane meke mekarle’ “Little children are sacred’), the introduction of the Northern Territory Emergency Response (NTER) commonly referred to as The Intervention, occurred (Northern Territory Board of Inquiry into the Protection of Aboriginal Children from Sexual Abuse, 2007). The Intervention was developed quickly and without



consultation. Not only was there a lack of consultation but only selected findings, that were later found to be misleading, were used to justify the intervention.

A Health Impact Assessment was conducted by the Australian Indigenous Doctors' Association (AIDA) in 2010 and highlighted the damage to communities (O'Mara, 2010). The report highlighted that more harm than good occurred.

*Grandmothers spoke about the humiliation of going "back to the old days" when all decisions were made for them. Mothers spoke about the added burden of trying to buy family groceries using the BasicsCard, which can only be used in specified locations. Communities spoke about their hurt when their successful local programs were disregarded by the government. And men everywhere spoke about their despair at being labelled as paedophiles.*

Altman and Russell, (2012) in their evaluation of the NTER state "that the Intervention was developed quickly without comprehensive policy development based on evidence or consultation." (Altman & Russell, 2012) Their review of the evaluations "...are consistent with the view that they are both obfuscating mechanisms and techniques of governance designed to allay public concern and normalise the governance of marginalised [First Nations] Australian spaces."

This current research occurred within the shadow of The Intervention (Northern Territory Emergency Response), and the deficit approach taken by this culturally inappropriate response. Although conducted in the Northern Territory the results of this research and subsequent Intervention impacted all across Australia. This added to the necessity to conduct this research using culturally appropriate decolonising methodologies.

## My Research Journey

*We have faced adversity and genocide. This has been proven.  
We are a strong and proud people. This has been proven.  
We are the living proof, and knowing this will ensure our people and our stories of pride, of strength and of survival will live on.*

Amy Creighton, 2014

These facts underpin the construction of this thesis, and in the writing of this thesis I have spent significant time thinking of the appropriate words to use to ensure that what is written portrays the intended meaning. Words are used to inform our minds; to paint a picture of how we understand things to be. The words create language in a way that transfers knowledge and attitude from one person to another. It is our background and upbringing that informs our use of words and how we interpret the messages words provide. In the words of Ngarrindjeri Elder “language has a meaning, and meaning has a language” (S Gollan, personal communication, 2011).

Words are powerful. I see and feel the impact of words on the world around me; words of praise and respect, and words of biases, prejudices, and institutional racism. The impact of these words can be as powerful as any physical action. Dr. John Henrik Clarke, 1915 —1998 stated “To control a people you must first control what they think about themselves and how they regard their history and culture, and when your conqueror makes you ashamed of your culture and your history he needs no prison walls and no chains to hold you” (Gaffin, 2006).

The Gomeroi language has been sleeping. Cultural genocide has reduced the power of my use of my language to a few spoken words that have been passed on to me by my family. But these words live on; resurgence is occurring; a renewal and reclaiming of the vocal resonances that have echoed through countless centuries. The words and language are awakening, connecting back through generations. As with many of us I do not have the words of my language to write this thesis. Even if I did have, who could read it?

The research is therefore presented in English, to enable clear communication with the community, health services, and other interested people. Although at least 70 First Nations languages and dialects were spoken in the area what is now known as NSW, including Gomeroi, now much less is spoken. English is the best, but inadequate, option (NSW Department of Aboriginal Affairs, 2003) and (Horton, 1994). To illustrate this inadequacy, English includes the word “health”.

There is no one word for “health” in Gomeroi or many other First Nations languages. Research into First Nations well-being has been largely focused on non-First Nations understandings of health

(disease and treatment), rather than First Nations understandings of well-being (King, Smith, & Gracey, 2009). These understandings see wellbeing far more broadly, more than merely physical health or the absence of disease, but involving spirit, place, family and country. It is critical to the integrity of the research to ensure that First Nations ways of knowing, being and doing are respected (Lekoko, 2007).

Dominant culture words that describe us can also harm. The terms “aborigines”, “aboriginal”, “Aboriginal and Torres Strait islander”, “Indigenous” and other similar terms that are used by government policy to describe me, but do not define me. These words make my cultural identity invisible and are a form of cultural genocide.

This thesis is written in accordance with cultural protocol and based on research conducted on the lands of Gomeroi Murris. It is recorded in English, but in doing so it is grounded by my connection to country, culture and ancestors. It is written with respect, with truth and with a never ending belief that we are a sovereign people.

### **My story, so far ...**

*You was born in a small country town, only a few of us families lived on the fringes of the town there or further out the other way on the reserve (Tibberena). When I went in to have you I don't remember being segregated but I remember always being put on the veranda or in the corner.*

Gomerioi Murri Elder, Aunty Pearl Trindall, my Mum, 2013

I have always known who I am and where I sit in the context of my cultural identity. I was born the sixth of seven children to Gomerioi Murri Elders Joe and Pearl Trindall. I have a living history of knowing my Gomerioi Murri grandparents, aunts and uncles, brothers and sisters and was cradled from birth in their cultural strength and guidance. The old people, whose connection to culture, country and kinship provided me the foundation to undertake this research.

To be surrounded by cultural strength throughout my life has been my birthright. It nurtures me. This also defines who I am and where I sit. I am a Gomerioi Murri yinarr, a daughter, a granddaughter, a niece, a sister, a cousin, a wife, an aunty, a mother, and a grandmother. This allowed me a foundation of continuity to culture, providing a basis of pride and strength of spirit. In knowing this, it also brings with it cultural responsibilities to ensure this research is safe.



*Matriarch (Aunty) Pearl Trindall (nee Wallace) with daughter (me) Amy Creighton (nee Trindall) with my daughter Sarah with her daughters Rhiannah and Ellie*

*Mothers Day, 2015*

I have spent almost forty years working on country in positions relevant to the areas of the social determinants of health. The last twenty years have specifically been in First Nations health, encompassing positions such as Aboriginal Hospital Liaison Officer, Indigenous Health Coordinator, Academic, Lecturer, Aboriginal Antiracism Educator and Researcher. I see myself as an activist.

My worldview informs and shapes the way I undertake research. My connection to culture, country and community permeates my research. I am and have always been a Gomerioi Murri yinarr, and I am now a Gomerioi Murri yinarr involved in research.

The following poem was written by me one night, when I was struggling to bring clarity to what was happening in my life. The research journey and life events were taking its toll. I was feeling that my strength was being constantly drained from me and I needed to regain it. I began to write in a way that I had never written before. I found the use of poetic writing brought peace to me. The connection to the meaning of the words provided me a renewed sense of strength. The repetition and rhythm connected me back to the songs of my ancestors. It is written in the language of my people first as a mark of respect.

gomeri murri yinarr

gomeri murri yinarr naqaandi ngay qi-gi minya ngaya

guway-ga mauw-gi dhina ngaya-mayaa-y

dhurri-nhi ngaya qunnii-dhi

ganma-la-nha maaru gomeri-qu

naqaandi ngay qi-gi winunga-li, Dhalaa ngay yanaa-nhi winunga-li

miyay-dhi bubaa-gal qunii-dhi bubaa-gal

ngarra ngaya mubiirr walaybaa-ga

dhurri-nhi ngaya bubaa-dhi

ganma-la-nha maaru gomeri-qu

naqaandi ngay qi-gi winunga-li, dhalaa ngay yanaa-nhi winunga-li

miyay-dhi quniiqal qunii-dhi quniiqal

bawaa-dhi bawaagal walgen-dhi walqanqal

dhurri-nhi ngiyaningu maran-dhi

ganma-la-nha maaru gomeri-qu

naqaandi ngay qi-gi winunga-li, dhalaa ngay yanaa-nhi winunga-li

yaliwunga gayma-laa-nha qunungu wila-yaa-nha  
yugal dhina-qu qunungu-mayaa-y wila-yaa-nha ngay qawuqaa-qu  
dhurri-nhi ngaya gomeri-dhi  
ganma-la-nha maaru gomeri-qu  
ngaandi ngay qi-gi winunga-li, dhalaa ngay yanaa-nhi winunga-li

yaliwunga-mayaa-y qunungu dhiiyaan gayma-laa-nha  
dhuwi-qu maran winunga-laa-nha ngaya qunungu quwaa-laa-nha  
dhurri-nhi qunungu qunii-dhi  
ganma-la-nha maaru gomeri-qu  
ngaandi ganunga qi-gi ngay winunga-li, dhalaa ganunga yanaa-nhi ngay winunga-li

Amy Creighton 2016

(Gomeri translation Marc Sutherland 2016)

Gomeri Murri Yinarr

Who I am and what I am is Gomeri Murri yinarr  
The lines of my heritage are written in bloodstains  
Born from my mother  
Cradled in culture  
I know where I come from  
I know who I am

The daughter of fathers and the mother of fathers  
My birthright is sovereign engraved in our country  
Born from my father  
Cradled in culture  
I know where I come from  
I know who I am

A daughter of mothers and a mother of mothers  
Sister of sisters and aunty of aunts  
Born from our ancestors  
Cradled in culture  
I know where I come from  
I know who I am

Our circle of life has been turning forever  
The song lines of history alive in my mind  
Born from their heartache  
Cradled in culture  
I know where I come from  
I know who I am

The connections of kinship for over millennia  
The spirits of the old ones, I hear them say  
Born from our Mother  
Cradled in culture  
**They** know where I come from  
**They** know who I am

*Amy Creighton 2016*

I offer this information to position myself within the research.

In Chapter 2 decolonising methodologies were outlined and the importance of the use of these methodologies in relation to this research was provided. Chapter 3 will describe the methods, results and interpretation in the format of a manuscript for publication. Some parts will be similar in other chapters.



## **Chapter 3 Manuscript for publication**

### **Gaba Binggi (Good Needles): Developing an understanding of how two Aboriginal (hereafter inter changeable with First Nations) communities see and experience immunisation during pregnancy**

This chapter presents a manuscript for submission to a peer-reviewed journal (International Journal of Indigenous Health), providing the main findings for the study. The authors are: Amy R Creighton, Hunter New England Population Health, Peter D Massey, Hunter New England Population Health, and Julie Leask, University of Sydney. The paper's abstract is found at the beginning of this manuscript. The referencing is integrated into the manuscript for the purpose of reporting.

## Introduction

The period of time encompassing pregnancy, childbirth and infancy is a special time for a mother and family. For many First Nations people having children is one of the most important parts of life and has an added layer of celebrating survival and building the future. The First Nations family is central to the survival of First Nations culture. (Australian Institute Family Studies, 1995), but pregnancy can be a time of extra risks.

Influenza infection is a substantial cause of ill-health during pregnancy (Kourtis, 2014). The increased risk for severe disease attributed to Influenza is thought to be connected with changes to the heart and lungs during pregnancy. Reports show that First Nations peoples, similar to other Indigenous peoples, are approximately five times more likely than non-First Nations people to be hospitalised for the recent H1N1 influenza pandemic and a similar proportion required intensive care treatment (Kelly et al, 2009) (La Ruche et al, 2009) (Rudge & Massey, 2010) (Flint et al, 2010). Other countries have also found higher risks of severe disease as a result of influenza in Indigenous people groups, for example the Indigenous people of Canada (Charania & Tsui, 2012).

Currently there is a significant amount of research on the status of First Nations peoples' health which is linked intrinsically to First Nations peoples' ongoing social and economic disadvantage. Disadvantage also combines with the impact of institutional racism to negatively influence the health of First Nations peoples (Larson et al, 2007). There is also a growing research agenda on the uptake of immunisation for First Nations children (Abbott et al, 2013) (Menzies & Ross, 2014) (Harris et al, 2014) but there appears to be very little specifically focused with pregnant First Nations women (O'Grady, Dunbar et al, 2015).

Much has been reported in recent years about the safety and effectiveness of influenza vaccination during pregnancy. Evidence supports providing immunisation during pregnancy as it is safe and effective (Marshall et al, 2016). In a summary of the evidence Steinhoff et al (2014) reported that influenza immunisation during pregnancy reduces risk and improves health.

Providing immunisation during pregnancy is a very recent program in Australia and within such a short timeframe already a gap in coverage exists. There appears to be a 10% gap in coverage already reported between First Nations mothers and non-First Nations mothers in one state of Australia. This was apparent in an unpublished analysis of respondents to a larger NSW study in 2013 when this research began (K Wiley, personal communication, 11 November 2012). A more recent, as yet unpublished, mixed methods study indicates that the gap described by [O'Grady et al \(2015\)](#) continues (R Andrews 2015, personal communication, 27 April 2016).

Using decolonising methodologies this research explored with First Nations communities, and especially with First Nations women, stories surrounding immunisation during pregnancy. The information was gathered by the Murri tradition of yarning with First Nations women, men and health providers in two communities in North West New South Wales. During the gathering of the stories different ways of talking about immunisation during pregnancy and improving service delivery were also explored. This research used qualitative research methods to explore with and for First Nations communities, and especially with Australian First Nations women, health issues during pregnancy, and immunisation during pregnancy.

The research occurs on land of the Gomeroi nation which overlays the geographic boundaries of the Hunter New England Local Health District. This Health District has more First Nations people than any other Health District in New South Wales (NSW) and the First Nations population is younger than the non-First Nation population (Hunter New England Local Health District, 2014). From 2006 to 2011, Australian Bureau of Statistics data showed that the First Nation population of Hunter New England increased 25% from 30,867 to 38,552. Almost half (49%) of the First Nations population within the District is aged 19 years or less, compared to 23% of the non-First Nation population aged 19 years or less (Hunter New England Local Health District, 2014).

This research aimed to provide an insight into the following questions:

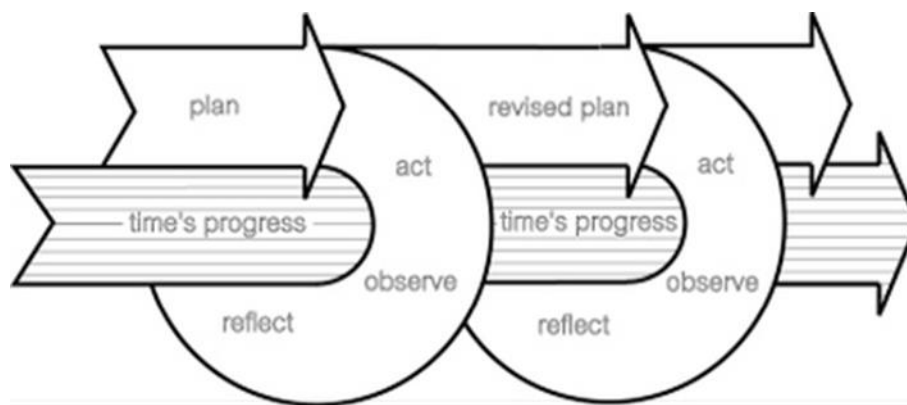
- How do First Nations women, in two First Nations communities in New South Wales, see and experience immunisation during pregnancy?
- What ways of talking about immunisation during pregnancy are more appropriate?
- What ways of pregnancy immunisation service delivery are more acceptable to First Nations women?

## **Methods**

Working within a community-based participatory action research (PAR) framework (Cargo & Mercer, 2008; Wells & Jones, 2009) and using decolonising methodologies (Smith, 1999 (Denzin, Lincoln, & Smith, 2008) this research continued the research cycles of the PAR approach taken in the development of more appropriate pandemic influenza control strategies (P. D. Massey et al., 2011) The pandemic influenza research was undertaken with First Nations communities in two locations in north west NSW, and this current research continued with these relationships and explored related issues in new cycles of research.

PAR method was preferred by the participating communities and the researchers because a key strength of PAR is the partnership between participants' real world knowledge and researchers' methodological expertise (Cargo & Mercer, 2008). PAR is also mostly a culturally acceptable method of research and allowed us to build on existing trust with the communities (Bergold & Thomas, 2012; P. Massey et al., 2012; Mooney-Somers & Maher, 2009; Weiner & McDonald, 2013)

Governance for the research was primarily through the Boards of the two First Nations Community Controlled Health Services, along with the Hunter New England Aboriginal Health Alliance, and relevant First Nations community services including the Aboriginal Mothers and Babies programs. A First Nations reference group was established with members from both communities. After these partnerships were further developed and maintained, the research went through the phases of PAR of planning, action, observation and reflection (Stringer, 1996; Stringer & Genat, 2004).



**Figure 1: A model of Participatory Action Research. Adapted 2015 by Adrian Miller from (Wadsworth, 1998)**

First Nations people's participation in research leads to participation of community members, which leads to empowerment, increased control over one's life and eventually improved health (Kowal, Anderson, & Bailie, 2005).

Through sharing the journey with First Nations, the two communities, and talking with key stakeholders, a detailed research plan was formed. I have extensive contacts with communities through family, friends and colleagues and am well known in the community for advocating for, and on behalf of, First Nations people. Conversations occurred with the First Nations Community Controlled Health Services, with the Aboriginal Mothers and Babies service and with Medicare Local First Nations health staff (now Primary Health Network). Written support was obtained from these services.

Information sessions and meetings occurred with Aboriginal interagency groups, Elders' groups and community groups in both locations. Community and government newsletters and community events were also utilised to further distribute information surrounding the research. This process was ongoing throughout the research. With approval from the communities, ethics applications were submitted to the Aboriginal Health and Medical Research Council (AH&MRC), University of Sydney and Hunter New England Health Human Research Ethics Committees. Approval was obtained from all parties.

A purposive sampling technique was used to recruit participants. Participants were drawn from existing networks within the First Nations communities in the two locations then expanded using the snowballing sampling approach. Twenty-five interviews were conducted across the two communities along with two small yarning circles of two to three people. The interviews lasted for about 45 minutes each and the small yarning circles went for about an hour. The participants included women who are not yet pregnant, pregnant women, recently-had-a-baby mums, mothers, grandmothers, aunties, partners and First Nations Health Workers.

The oral tradition of Murri storytelling was the basis of the data collection. In what is called in traditional qualitative research, 'semi-structured interviews and focus groups' is what we call talking and listening, or yarning with one or more people. The yarning explored issues that the participants found relevant to immunisation during pregnancy.

The interviews/yarns were recorded on a digital recording device and interview notes taken. One participant asked that the recording not be made and only notes taken, and this was respected.

A two-way education process between me and the participants occurred, an exchange of information from myself to participants and from participants to myself was ongoing throughout the research project. When issues were spoken of that needed action quickly, with the participant's permission, these were referred to the relevant health service. For example when some participants requested additional information regarding immunisation during pregnancy, in consultation with participants, appointments were organised with trusted health staff. Also as a result of the action process current information on immunisation during pregnancy was also distributed to the local AMSs.

Using a thematic analysis process the data were coded inductively (Minichiello, 2008). The researchers identified and defined themes and recurring ideas or concepts. A summary of the descriptions and interpretive accounts were discussed with participants. Further comments were received from the participants and these were incorporated into the findings.

The preliminary findings were also reported to the Hunter New England Health Area Aboriginal Health Forum (June 2015), encompassing First Nations Health workers and Managers working within the Hunter New England Health Service and the Aboriginal Health Alliance (October 2015) for comment and feedback. The complete set of stories, experiences and views of the participants were further reflected on. This reflection was done by myself and the research supervisors, and grounded within my community and my First Nations Elders and mentors.

## Results

Five main themes emerged from the data which informed recommendations for action. The themes cover aspects of the experience for the families

- Special bond & celebrating survival
- Believe in immunisation
- Fear/trust balance
- Cultural respect
- Ways forward.

### Special bond & celebrating survival

*It connects family on so many levels, past and present and future.*

Pregnancy was described as a “*special time*” by many of the participants. One young mum smiled widely when she said about pregnancy, “*I enjoy it, it was beautiful*” and another grandmother spoke of how “*precious children*” are. Highlighting the specialness of pregnancy is the sense of pain and loss for a number of the participants who carried stories of a previous pregnancy that did not work out. A pregnant Mum when speaking of her pregnancies said “*I lost one at 11 weeks and another at 6 weeks ...so what I went through made me appreciate it*”. But when the pregnancy works out there is a great sense of joy. Another pregnant mum commented that it has been “*ten years since we have had a baby, so [my] mum is super excited*”.

This specialness of pregnancy is also shared with partners, family and community. A pregnant mum on finding out about her pregnancy with her first child laughed, “*it was very exciting...we knew at 5 weeks, and they (family and close friends) knew at 5 weeks and 2 days...we couldn’t keep it a secret*”. And this from a yarning circle, pregnancy is special and “*family is number one priority*” in the lives of First Nation peoples. Pregnancy is central “*we always had babies around*” and everyone is involved and connected to the pregnancy, especially the aunts and nans who “*are really going to help enormously*”. The excitement of hearing of a new baby to bring into the family was spoken of with so much emotion “*when I told mum, she was crying*” said a first time pregnant mum.

A young Dad told of his feelings about the upcoming birth of his third child *"...just like a present when you're waiting for Christmas"* and added *"the more you talk to your baby, you grow a connection ... you don't feel disconnected"* with the pregnancy *"it changes your outlook... you don't live day to day"*.

All the participants expressed how all babies in all families are special. They also elaborated on how the pregnancy and birth surrounding a First Nations woman carries other layers and complexities. This concept of celebrating survival was best exemplified with one mum offering, *"all our kids have had their birthing ceremonies... when the babies were born"* and *"my mum and my aunties, and my grandmother, when she was alive, were all there."* Another older recent Mum spoke about *"growing up with cultural things like not getting my hair cut during that time... and I didn't dye it either"*.

Pregnancy brings with it a heightened sense of belonging and connection. A pregnant mum spoke of the conversations she was having with her family because of her pregnancy and explained *"it's nice to sit around with women who we know our families have sat also around together in previous generations"* brought with it a knowing of a continuation of cultural ways, *"our child will now get to do this"*.

Cultural survival was highlighted by a pregnant mum who said that when sitting and yarning with grandmothers, aunts and mothers *"baby will feel that too"* before birth. Further adding *"our child will grow up hearing the Gomeri songs and be a part of the tradition of weaving"* from before her birth. She added *"the connection and the feelings that has always been there"* with *"lots of yarning and connecting over stories is nice and therapeutic"*.

The special bond surrounding pregnancy and babies, and celebrating survival, are interconnected as both are dependent on each other.

### **Believe in immunisation**

*I don't think I have ever seen anyone in our community refuse to get their child immunised*

Because babies are special, immunisation is seen as important. Most participants described that they *"believe in immunisation"*. Some participants even described being a *"strong believer"* and one mum said about the influenza vaccine that *"I now know that the vaccine is good"*. An older woman Elder related *"I remember clearly what whooping cough and measles was like and I don't wish that on any child"*.

This belief in immunisation was more than just accepting it, but a stronger sense that the vaccines were really important even though they were not fully understood.

*“You want the best for your children...to have that bit of protection”* one mum said, and another *“I don’t know why people wouldn’t have their children immunised against those nasty diseases”*. In relation to influenza immunisation for the family a mum positively described her experience by saying *“always make sure my boy has it...now he hardly gets sick”*. Significantly an Elder said, *“I don’t have any problems with it (immunisation in pregnancy).”*

The research occurred during public discussion surrounded the introduction of The Social Services Legislation Amendment (No Jab, No Pay) Bill 2015 that stops parents who object to vaccination from claiming government family assistance payments. This policy was mentioned by a concerned community leader and mum, *“they think money motivates us, or exclusion... that is a weak structure. It just shows that they are not sincere about our health.”*

The belief in immunisation was sometimes revealed as a contradiction, with one participant promoting and encouraging family members and community to have the vaccine while being reluctant to have it herself. Only one participant expressed her concerns by deciding not to vaccinate, *“that doesn’t mean that I don’t agree with preventing disease”* and *“western medicine definitely has a place.”*

Health workers also believed in the safety of the vaccine in pregnancy and one stated that: *“there is a lot of research done beforehand...I don’t believe that they would be saying to have it if there was going to be any danger to the baby or the mum as well”*. But this information was not known by all. For example, a young mum spoke about the lack of information offered to her *“no one told me the information about it before”* and *“I don’t recall anyone offering me it (immunisation)”*.

Having immunisation was also seen as a normal part of health for children so will be as well during pregnancy. *“You just have babies and you get them immunised”*, said one mum showing how normalised immunisation is. One of the health workers interviewed emphasised this point by saying: *“I don’t think I have ever seen anyone in our community refuse to get their child immunised”*. For influenza specifically, the experience of influenza immunisation for some participants was positive and promoted *“next year I will be getting my family done”*.

### **Fear/Trust balance**

The participants spoke about balancing the level of fear around immunisation during pregnancy and trust in the vaccine and the health care providers who were giving the vaccine. This fear/trust balance was insightfully described by a participant, who is a grandmother and respected member of the community when she said:



*I always thought.... I guess I just trust that this will not harm the babies...I just trust it...I suppose a few things would go thru my head - is it safe? As I am aware that what goes through mum goes to the baby*

Fear of damage to the baby was very strong. One of the health workers reflected the fear in her words, *"it's that fear, it is always there, if I get vaccinated will it harm...?"* Others spoke about how they had received *"advice from mum and nan [that] said you would get sick from it [immunisation]"*. And the stories that are heard in community, *"the flu shot makes ya sick"* and *"getting that shot makes ya worse."* The depth of the fear was revealed by one mum who said, *"My head goes into a bit of spin because you can't even take a frigin Panadol but how come you can get all of these needles [during pregnancy]?"*

An older Mum related that *"when you're pregnant... you have this overwhelming desire to protect your baby at all costs but also don't want to hurt it"*. Before deciding to have the vaccination *"there was a lot of stuff I had to weigh-up ...even though I knew in my mind vaccination is a good thing,"* the Mum added. Another younger mum yarned about her reflections on the fear in this way, *"I thought you don't want anything in your body while you are pregnant but I am I learning a lot"*. One grandmother interviewed said that although she still didn't understand immunisation she *"advise[s] my grandchildren to have these immunisations"*.

As well as stories passed down, some of the fear was attributed to social media and the misrepresentation of facts. A first time mum spoke on the role social media plays now, *"you hear media stories that it leads to autism"* and *"you get a lot of stuff on social media"*. Also from an insightful health worker, *"just reading some of the posts about immunisation...I just think oh wow...there is so much crap that is on the internet and the stuff they link to vaccines...that's not credible and I think, if you're gonna run with that, then just keep going"*.

Fear due to experiences of racism and discriminatory government policies and practices was a major contributing factor. Racism and its impact were discussed by many of the participants and was emphasised by a participant stating *"there are big issues about not staying in hospital because of it."* Negative experiences with a health service and the *"expectation of doing what was expected"* also prompted one older mum to say *"If you could find an old lady to take me out bush to have my baby... that would be a viable option."* Another mother explained *"there's always that part of you that is a bit wary... stuff that happened with our people ... being experimented on and researched on."*

The trust /fear balance was further stressed by a mum who said about entering a health service facility *"I had fear around it... I had been dismissed and patronised by them... actually getting up and dressing myself and my child and going to an immunisation clinic was a massive thing for me, so I was often late or sometimes I sent my (non-First Nations) husband in to get my kids immunised"* and because of past stories added *"...because I didn't want 'em to die of measles or whooping cough"*.

Previous negative experiences with the health service also brought with it sustained strength, exemplified by a statement by an older mum who had recently had another baby: *"This [was] a learning experience...like a lesson... like them old fullas [men and women ancestors] are giving us a lesson"* and *"taught me to be an advocate for my kids...I found a voice"*. This mum found strength surrounding incidents that occurred when she was having her earlier children. This *"voice"* carried through to her recent pregnancy. The strength was spoken of as *"that energy of culture that comes, from the old people, and the land, it's everything, it just groups altogether when you need it."*

Trust in people was the strongest overriding influence and the importance of trust was spoken about by nearly all participants. Having trust in respected people in the family and community was integral to balancing the fear. Descriptions of the go-to people included being *"a strong black woman"* and *"people known"*. One mum said that she had *"spoken with other woman around town, and when I got there [clinic], there was all other mothers that I knew as well"*. This helped her trust.

Many women and their families had bad experiences with previous pregnancies or previous interaction with the health services. The need to have trust in the people providing health care was also a strong aspect of the stories. The importance of relationship underlined the trust in health workers when a mum said *"I listened because I knew them"*. One first time Mum on being given advice on her pregnancy by some health professionals *"always doubled checked"* and *"would always then go and check with someone I know [and trusted]."* And then when this Mum received advice and information from a known First Nations health worker she would believe her because *"I knew her and I trusted her"*. One participant summed this up by saying, *"you go to people you trust and not so much [to] services that you don't trust"*.

The people who were trusted were described as people who took time, a young mum said that *"I feel comfortable with them (health care providers), they took the time to sit down with me...they cared"*. Trust in the health workers and the health service *"was more than just about having some Aboriginal trimmings"* as one participant stated:

*Our people need to be able to relate to our service providers, you can have all the red black and yellow and Aboriginal design but unless they have that respect then I don't think you will gain anything...to utilise a service such as immunisation*

The First Nations health workers interviewed spoke about being careful who they took out to the community as “[Go to people can be a] springboard to non-First Nations people.” People in the community would normally trust who the health worker took out “they start trusting and allowing you in their lives, their families and their homes” and “it’s an honour when someone opens that door and allows you into their home.” But they “would lose respect from our people if we took someone out there who is very demanding....you can lose their trust straight away if you took someone out there like that”.

Trust takes a long time to build but can be easily damaged “the girls don’t have that trust in doctors” anymore due to the way people are treated, said one.

### **Cultural respect**

*[I am]...dedicating my time to educating my co-workers. I should be putting my time into my community and my people...*

For all of the participants, cultural respect, cultural appropriateness and cultural safety were significant issues in relation to health care. These issues impacted on the delivery of immunisation during pregnancy. At a yarning circle a community Elder, who was born in the Aboriginal section of a Hunter New England Health Service hospital, spoke about the lack of cultural respect and safety in health services being “big issues” in our community. This has led to new mums “not staying in hospital” due to the racism and as a result not receiving the care that the families require. The Elder went on to say that many families had “bad experiences at maternity, at many hospitals”, even with segregation still occurring with “Aboriginal mums always in one room” away from others, and that this “impacts the whole service because of the racism experienced by the families”. One participant summed this up by saying that “the cultural respect program, that message is not getting out there...”

Participants spoke about how cultural respect and safety can be enhanced in health services to enable immunisation to be safely given during pregnancy. Having an “Aboriginal worker can have a huge impact - if the other staff are disrespectful - to make a service safer.” Aboriginal health workers also are people who want to keep themselves and their community safe.... “not just in work hours”, so are seen as genuine. Being “genuine and caring” was described by a participant as needed attributes for non-First Nations health staff as well, someone who does “not just [pay] lip service [but] does what he says he is going to do...is real”.

A First Nations health worker highlighted the different ways of doing business. This worker commented on non-first nation's health services, *"... things were kept very superficial, and they talked a lot about boundaries and keeping things professional and not sharing personal information. Yet the paperwork [pregnant woman are required to complete] was often super personal stuff...so I soon learned that how health connected with community was very different to how I connected"*

There was also described a heavy burden on First Nations Health workers to try and change non-First Nations health staff at a cost by *"dedicating my time to educating my co-workers, I should [instead] be putting my time into my community and my people..."*

### **Ways forward**

Participants provided many suggestions and lots of advice on ways forward to enable greater uptake of influenza immunisation during pregnancy for First Nation families.

It was said that *"communication is just the biggest factor"*. To balance against the fear, the health providers *"need to talk more on their (First Nations) terms"*. For communicating information about immunisation in pregnancy, the health service, *"need[s] to look at visually...not just talking... [but show] this is what would happen to you"*.

The proof would make a good story to share so families can actually, *"see evidence of a woman who had the vaccination and everything is fine"*. The importance of lived experience with immunisation and pregnancy was also mentioned by an older Mum when she said that *"the theory is very different to the practical"* and this was reinforced by a first time Mum who said *"we informed parents here as part of my employment ... but since I've been a mum and been in the situation I tell my story as well... I'm like, I got it (immunisation during pregnancy) and I'm really good...it's got more meaning behind it now"*.

Communicating with all family members was seen as a key factor, *"talking with aunties, grandmothers"* and *"it doesn't cost ya nothing, just sitting down and yarning"*. And *"we know the power of the family and the power of the community"*, said a community leader.

Understanding the context was important in showing respect in communication, *"when working with an Aboriginal community you can't exclude Aboriginal issues...I am talking poverty, housing, employment, schooling...teenage pregnancy, sexual health"* which was voiced at a yarning circle.

Hearing personally from the health care providers is essential for families, *"I would want to speak with the medical person"*, and a safer way was described by a mum who said that *"I feel more comfortable to have one of my people sitting there"*. A Grandmother also said to *"have non-*

*Indigenous and an Indigenous person together". That way you "walk out feeling more comfortable, more relieved, better in yourself (if a First Nations person is there with you)".*

A community leader in health said that *"the posters are not the most important thing to us, it is about the community"*. Also another young Mum said that *"there is no point in just having the poster on the wall at the clinic. Medical people should be telling people that it's there.....That is where the gaps are because the health practitioners are not telling people stuff."* The lack of communication about influenza immunisation in pregnancy was clear when a young mum said that *"I don't recall anyone offering me it"*.

The potential impact of taking the time to really communicate was best articulated in these words:

*it's not about doing it because you have been told to do it, it's about understanding it, because when you understand it you have the power to pass it on, so the service may have spoke to one mum but guess who that mum has spoken to in the next couple of hours...20 mums and she is passing that on, you might not have that flash brochure...but the power and the time that you have put into her, she is putting that into her friends.*

A First Nations health worker said that some young mums say to *"come in here I don't understand what that doctor is saying to me" – "that's sad as they're just talking to her as though she has every idea of what is going on..."* Another First Nations health worker offered this advice from her experience, *"so how I talk to this patient is different to how I talk to that patient and that patient: it is about getting to know them as people"*.

Further advice was offered when a community leader in a yarning circle stated:

*for me, we respond to sharing stories because we are an empathetic, a caring people; we respond to a story, we respond to stories of people who have gone before us, but if go on a website and print out a fact sheet it is like a media release...it is not written so we can relate to it...*

For communicating with young mums it was suggested that *"Facebook is the key. If you want the communication you have to put it on the internet"*, because as one mum said, *"today's needs are different to tomorrow's and different to yesterday's"*.

Better support and training of existing First Nations health services was also seen as important. *"So a lot of education, especially with the AMIHS (the Aboriginal Maternal Infant Health Strategy) team, is maybe something they could look at, especially the young mums when they are seeing them during pregnancy"*. A few people suggested to *"utilise skills of AMIHS and early childhood workers, they [mums] like the AMIHS service because they don't have to go to the Dr and badger the Dr"*.

Along with that, being out in the community, away from the health service, was seen as really important when participants from a yarnning circle said to *“go where all the mums are and where they take the babies...get them while they [are] all together”*.

In relation to the focus of health services, a Mum said that a lot of funds and emphasis was on chronic disease *“but we should be targeting those mums-to-be and those young mums, they are the ones who are going to influence their child's health”*. This also underpins how health messages are passed on through the generations. What is done now speaks into the future.

## Discussion

Research “on” First Nations people has been occurring for a long time. This is best exemplified by a Gomeroi Elder when asked of his views on research, *“They want to know all about us but they don't want to know us”*. This current research attempted to address that inequity by following culturally safe research practices. The research process also occurred for an extended period of time, allowing for the cultural requirements of both the participants and myself to be respected.

Amongst almost all of the participants was a solid belief in immunisation. This was exemplified by the name given to the program Gaba Binggi meaning Good Needles in the language group of the two communities. Even without fully understanding how and why immunisation worked there was a strong sense that it was really important.

This research followed on from the pandemic influenza research that was undertaken with First Nations communities in NSW.(P. D. Massey et al., 2011) The continuation of research in a different but similar way provided a smoother journey for the participants and for me. A safe connection had already been established with the original researchers and I was able to build on these relationships. This previous trusted research relationship with health employees may have contributed to the strong belief in immunisation amongst most participants. The interviews were conducted during a period when the diphtheria-tetanus-pertussis vaccination in pregnancy was being introduced by Australian states and territories as a funded program (Beard, 2015). It became evident that further research needs to occur to capture information surrounding this and develop further understandings. The findings of this current study suggest a number of factors may be involved and require additional study.

It became evident during the research that the five themes that emerged were interconnected, analogically similar to the cultural connections of past, present and future. With respect to the past, the believing or “trust” in immunisation also carried a “fear” of harm to our babies and is extremely

complex and needs further unpacking. The layering of generations of oppression and genocide interwoven with wanting to “do what’s right for my baby” provided the environment for the research.

The compounded layers surrounding pregnancy for First Nations people are many, with immunisation during pregnancy adding an additional layer to this. All babies are special and First Nations babies are also proof of the survival and continuation of culture. The continuum of time highlighted that the past, the present and the future are intrinsically linked and pregnancy is central to this understanding.

It was interesting, however to note that the health service could also be seen as central to the continuum of time as well: a health service is a place where our culture continues, from the birthing of our babies to where our loved ones pass on to become our ancestors. Therefore the Health Service, in my reality, is a place of cultural significance. The Health Service however, is also a place where racism is evident and experienced. The complexity of this dichotomy was alive throughout the research with the fear/trust balance being the most multifaceted of the five themes.

The impact of discriminatory policies and practises against First Nations people were ever present in the conversations that occurred. Racism occurring in the health service was an underlying factor that became mentioned more often after the formal recording of the interviews had finished. The systemic nature of racism and the disadvantage this brings for First Nations people is well documented (Henry, Houston et al. 2004, Larson, Gillies et al. 2007, Paradies, Y et al, 2008). Studies in Australia, surrounding racism towards First Nations people found those who experience racism were more likely to have poorer mental health and have reduced access to public health, education, justice and reduced participation in community activities and festivals(Paradies & Cunningham, 2012). Safety issues around perceived and experienced repercussions from voicing concerns about this racism were regularly expressed. A report, *If not now, when?* outlined First Nations men’s experiences and impacts of racism in the Hunter New England Local Health district (Patterson B et al., 2014) where this research occurred as being “constant, pervasive and multidimensional”. Racism is a social determinant of health and until it is named and addressed consistently there is limited opportunity to effectively promote immunisation during pregnancy to First Nations people. Health Services must take this on board.

Balancing this was the value and importance of the “go-to-people”. This finding was similar in strength and understanding to the previous findings from the work on the influenza pandemic (P. D. Massey et al., 2011) that occurred prior to this research. The “go-to-people”, both first Nations and

non-First Nations who are trusted to navigate through the health service and decipher the information provided. Trust and fear was so intrinsically intertwined that the balance between the two is teetering constantly. Trust takes so long to build but can be destroyed quickly and the process must begin again, because there is no option.

## Limitations

Although this qualitative research project was conducted around a culturally safe framework there are still some limitations. First, the research occurred in two communities only. Both communities were located on Gomeri country but as we are a diverse people this may or may not be representative of all.

The recruitment process although culturally appropriate also has the potential to be “exclusive.” In an attempt to alleviate this, I spent considerable time meeting with numerous community organisations, including First Nations Medical Services, Elders groups, other relevant community groups and health committee meetings. A reference group was established with First Nations representatives from both communities involved. I attended many community events in both towns, engaging with community people, along with community people who were also employees. Information was also provided by phone and followed up electronically via emails if appropriate and information printed in community, non-government and government newsletters.

I am well known in both communities and related, biologically and culturally to a significant number of First Nations people on our country. I belong to a family that is recognised as advocates for social and cultural justice and I am seen as “*a strong black woman*”. I realised early in the interview process that some participants regarded me as an “*expert*”, particularly around the areas of health and cultural safety and were inhibited in their original responses. I quickly developed my way of yarning to focus more from the very beginning, indicating that there was no right or wrong response and that the participants’ opinion was, and would be, greatly valued.

The complexity of the topic, which encompassed so many other layers for First Nations people, could also be seen to create limitations. To understand health, we must understand the deeper spiritual, historical and cultural issues surrounding health for First Nations people, along with the physical, the social and the emotional wellbeing. So to discuss immunisation during pregnancy in isolation was not appropriate and many seemingly unconnected topics arose. Countless generations of connectedness, historical and current issues, ensured that all these topics are connected and worthwhile but could not be unpacked in-depth during this research.



One thing that became clearer through this research process was how the past, present and future are so interconnected. It has become common practice for some health services to Acknowledge Country and Elders past, present and future. I am an ancestor of future generations so we must speak into the future. The narrative of positive immunisation stories and culturally safe health services will be passed on so that the positive message of immunisation for pregnant woman is heard. We must speak into the future for change to occur.

## Conclusion

Using decolonising methodologies and qualitative methods to explore immunisation during pregnancy this research has affirmed that pregnancy is deeply important to families and culture and therefore health services, such as immunisation during pregnancy, must be developed with respectful partnerships. The balance of fear and trust was seen as integral in decisions by families about immunisation during pregnancy. The use of First Nations artwork and designs is important but appears to not be sufficient. It often attracts the eye but not the mind. It is the person who is trusted, who is the go-to-person whose message is believed.

Current services that provide immunisation to pregnant First Nations women must be designed to be culturally safe, flexible and empathetic to family and community issues. For a new program or health service initiative to be effective the historical and current rhetoric surrounding First Nations people in this country must be listened to, heard, believed and taken into account. Racism is real and is evident; the impact must be acknowledged and acted upon in a respectful and inclusive process. A mandatory requirement for consistency in effectively addressing all racist incidents would provide a sound foundation to move forward together. Health Services must name and address racism in all its forms, and further culturally safe research needs to be undertaken surrounding immunisation during pregnancy for/with/by First Nations peoples. This research is only the beginning:

I remember my old Dad, a Gomerioi Elder while at a research meeting in 2000, being told by a non-First Nations man the results of his research. The story went something like this:

*“When my dad questioned the results as being inaccurate the researcher replied “I have been researching Aboriginal communities for 20 years I know what I’m talking about” to which my Dad, a 75 year old Elder at the time, replied, “I know what I’m talking about because I have been Gomerioi ALL my life.”*

Immunisation during pregnancy is safe and effective. There are many stories surrounding immunisation during pregnancy; and many more that are yet to be heard and listened to. The understanding of the lived, the historical and the vicariousness of experiences within First Nations communities must be fully understood. Culturally safe, decolonising research must continue. To effect change the terms 'cultural respect', 'cultural appropriateness' and 'cultural safety' have to be more than words. Commit the words to action and the messages of safe immunisation will then speak to the future.

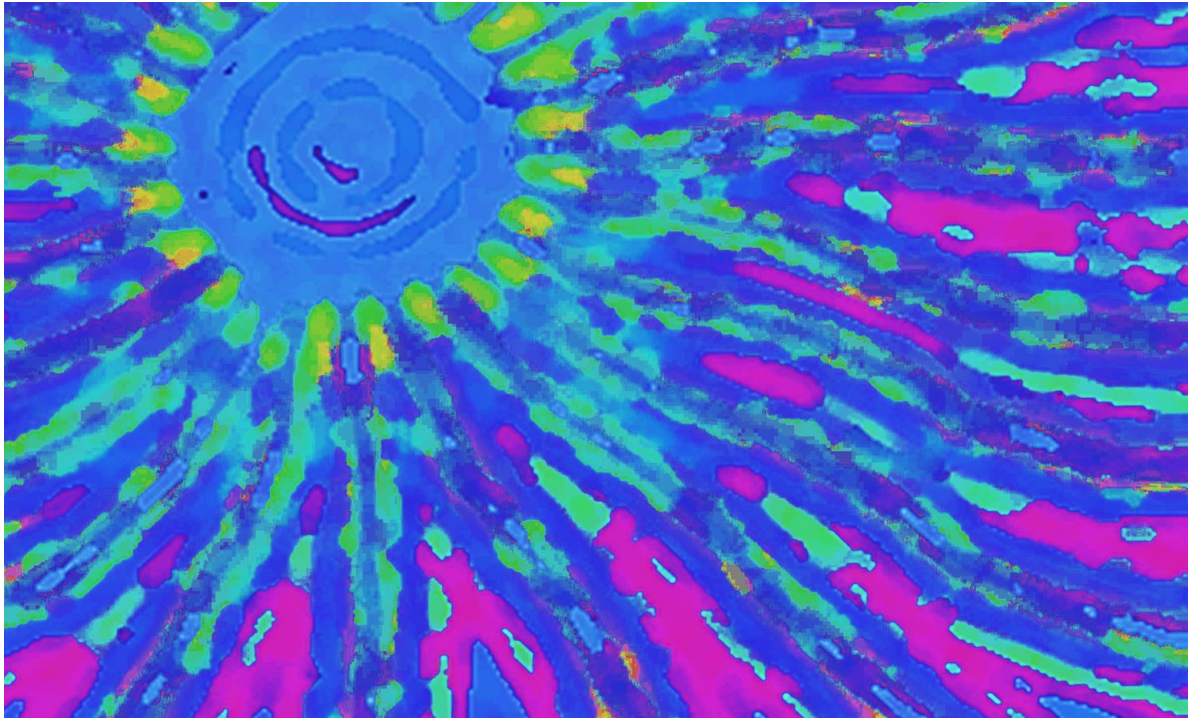
Chapter 3 was presented as a manuscript for publication. The chapter described the research project Gabba Binggi which included the results of 25 interviews, 2 focus groups and described the findings within 5 themes.

- Special bond & celebrating survival
- Believe in immunisation
- Fear/trust balance
- Cultural respect
- Ways forward.

Chapter 4 provides a visual representation of the research keeping in line with decolonising methodologies

## Chapter 4 Gaba Binggi – the story

This artwork was originally painted by me and then graphically manipulated on a computer program to achieve the end result. The act of combining the process of hand painting and digital methods is symbolic of the interconnectedness of the past, present and the future.



Meaning of the colours used:

Dark blue: Viruses

Light blue: Immunisation

Blue within circle: Immunisation during pregnancy for First Nations women

Green and yellow: First Nations people

Pink: Research and researchers

I have chosen not to relate my interpretation of my artwork. I have given you the meaning of the colours. Your world view will inform your interpretation.

Look at the artwork and understand your worldview.

The story is there.

## Chapter 5 Recommendations

In view of the findings of this study the following ways forward are recommended:

1. Further culturally safe research needs to be undertaken surrounding immunisation during pregnancy for/with/by First Nations peoples.
  - Immunisation and pregnancy is a complex space with many layers of understanding and experience. The current study has revealed important aspects of these layers but not the complete understanding. Ongoing research must be conducted in a way that respects culture, respects First Nations ways and is led by First Nations people.
  
2. Current services that provide immunisation to pregnant First Nations women would be improved by developing stronger links with First Nations communities to enhance communication and understanding.
  - Communication has been described as key but much of the communication in the past has been more of a one-way model without First Nations voices and views heard and included.
  - Facebook and other social media platforms should be considered for enhancing two way communications with communities.
  - The content of communications could link to notions of past present and future, celebrating survival of culture in talking about pregnancy and the importance of vaccination.
  - Technical information and jargon is not central to understanding the importance of vaccination. There could be more emphasis on pictures and stories to convey this.
  - Ensure that trust is put as the first priority, governing the actions and decisions of health services in the ways immunisation programs are chosen and delivered.
  
3. Current services that provide immunisation to pregnant First Nations women must name and address racism in all its forms. Unless addressed, racism will always be a barrier to higher vaccination rates in antenatal care services.
  - Addressing racism must go past just talking about it but actually changing ways and processes in the health service to carve out space for First Nations peoples to be fully included.

4. Current services that provide immunisation to pregnant First Nations women should ensure that First Nations health workers participate in services for First Nations women and families.
  - Having First Nations health workers can not only provide a safer space for families, these important workers can enhance service delivery through improved communication and enabling access to services that may have been inaccessible for First Nations families.
  - First Nations workers need to be well supported in their roles as cultural brokers between western and First Nations ways of seeing and understanding health. That support needs to include opportunities to connect with other health workers, understanding of the importance of time taken with community, and in relation to vaccination, ensure that workers are up to date with recommendations and well informed in a way that is accessible to them.
  
5. Current services that provide immunisation to pregnant First Nations women must be designed to be flexible and empathetic to family and community issues.
  - Services that are rigid and designed for the specialist staff and not designed for the community they serve will always deliver a gap in immunisation coverage.
  - Ensure that health services recommend the vaccine to all First Nations women
  - Education of staff on the greater burden of disease born by First Nations women.

I am a descendant of Elders and an ancestor of future generations. I am accountable to all, past, present and future.

Also accountable for the past, present and future are the people providing health services to our peoples.

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## Appendices

### Appendix 1 Information flyer

#### Gaba Binggi (Good Needles)

**Would you like to better understand how Aboriginal communities see and experience immunisation during pregnancy?**

We would like to discuss with you your experiences and thoughts about immunisation during pregnancy.

We would like to talk to Aboriginal people who are 18 yrs or over and live in the communities of Inverell and Tamworth who:

Are pregnant

Have had a baby in the last 3 year

Have a family member who has had a baby in the last 3 years

Is an Aboriginal health professional

This would involve a discussion with Amy Creighton

The project will help find better ways of providing the services so they are more culturally safe and respectful.

This project is voluntary. If you would like an information sheet, please contact

Amy Creighton

Mobile: 0447062476

Landline 0267648039

Email: [Amy.Creighton@hnehealth.nsw.gov.au](mailto:Amy.Creighton@hnehealth.nsw.gov.au)

**This project is supported by Armujan AMS and Tamworth AMS  
It has ethical approval from the Aboriginal Health and Medical Research Council (AH&MRC) Ethics  
committee 1018/14  
Hunter New England Health Committee Ethics**

## Appendix 2 Information sheet for community

### Participant Information Statement for Community

#### **Gaba Binggi (Good Needles) Developing an understanding on how two Aboriginal communities see and experience immunisation during pregnancy**

28<sup>th</sup> April 2014

#### **Researcher:**

Amy Creighton

#### **What is the study about?**

This research project will look at how two Aboriginal communities in Tamworth and Inverell feel about immunisation during pregnancy. This project is supported by Armujan AMS and Tamworth AMS.

#### **Who is doing the research?**

Amy Creighton will include this research in her Masters of Philosophy Degree with the consent of the communities taking part. This research is being supervised by Dr Peter Massey, Hunter New England Population Health and Dr Julie Leask, University of Sydney and will have an Aboriginal reference group to oversee the research.

#### **Why is the research being done?**

The influenza vaccine (Flu shot) is safe and effective in pregnancy but vaccination rates for Aboriginal women have been reported to be low.

One way to improve immunisation services to Aboriginal woman when they are pregnant is to find better ways of providing the services so they are more culturally safe and respectful. With your and other community members input, we are hoping to find these better ways. and your words will help us to do this.

#### **Who can take part in the research?**

We want to talk with Aboriginal people, 18 yrs or over, who live in the communities of Inverell and Tamworth, and who:

Have had a baby in the last 3 years,

Have a family member, who has had a baby in the last 3 years,

Is an Aboriginal health professional.

#### **Giving your permission to be part of the research?**

Taking part in this research is your choice. If you don't want to be involved you will not be affected in any way and this will not affect your care or access to services. If you do decide to take part, you may change your mind at any time without giving a reason.

#### **What would you be asked to do as part of the research project?**

You will be asked to take part in a discussion with us and maybe other Aboriginal people from your community for about an hour or two. Or you may talk with the researchers by yourself if you prefer. Some of the things we will talk about are your experiences around pregnancy and around immunisation. We will write down the issues which come up during the discussions and these will be what we write up into our final paper. The researcher, Amy will be in contact with you throughout the study to make sure the information recorded is what you want to say. You can contact Amy at any time to change or take out anything you have had recorded.

**What are the risks and benefits of participating?**

Talking about your experience with pregnancy for some people may bring back good memories but may also bring back some bad ones as well. If this happens the researchers will be able to provide you with some emotional support or refer you to a health service that can help you.

The benefits of participating are that your words will help provide ideas to help make it safer for our people when one of our family is having a baby.

**How will your privacy be protected?**

Any information that you give through this study that can identify you, will remain confidential, unless you want to be identified. Your name will not be used nor any information shared with anyone other than the research team. You can ask for copies of the information at any stage by contacting us.

**What happens with the results?**

First the Inverell and Tamworth Aboriginal communities will hear a summary of what the research found. The communities will be asked what they think of this information. Then the information will go back to the Aboriginal Health Partnership and the project Reference Group, and may be reported in papers in health journals and at health conferences. Names and anything that identifies people will be removed from in any reports coming from the project unless you specifically want to be identified. You can withdraw or amend information you provide to the researcher at any time.

**What do you need to do to take part?**

If there is anything you do not understand or you have any questions, Amy will be happy to talk with you. If you would like to take part, please sign the consent form and give this to Amy. You can change your mind at any time either in writing (see attached) or by telling Amy, mobile: 0447062476 landline; 0267 648039 amy.creighton@hnehealth.nsw.gov.au) or the Supervisor (Peter Massey mobile: 0429 688 106 landline 0267 64800 peter.massey@hnehealth.nsw.gov.au) or a member of the reference group.

**Complaints about this research**

If you have any complaints please contact  
Dr Nicole Gerrand,  
Manager Research Ethics and Governance,  
Hunter New England Health,  
Locked Bag 1, New Lambton NSW 2305,  
Phone: (02) 49214950,  
Email hnehrec@hnehealth.nsw.gov.au  
and quote the reference number 14/03/19/4.06.

or

The Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee  
Postal Address: PO Box 1565  
Strawberry Hills NSW 2012  
Phone: 02 9212 4777  
Fax: 02 9212 7211  
Email: [ahmrc@ahmrc.org.au](mailto:ahmrc@ahmrc.org.au)

## Information sheet for health workers

### Participant Information Statement for Health Professionals

#### **Gaba Binggi (Good Needles) Developing an understanding on how two Aboriginal communities see and experience immunisation during pregnancy**

28<sup>th</sup> April 2014

#### **Researcher:**

Amy Creighton

#### **What is the study about?**

This research project will look at how two Aboriginal communities in Tamworth and Inverell feel about immunisation during pregnancy. This project is supported by Armujan AMS and Tamworth AMS.

#### **Who is doing the research?**

Amy Creighton will include this research in her Masters of Philosophy Degree with the consent of the communities taking part. This research is being supervised by Dr Peter Massey, Hunter New England Population Health and Dr Julie Leask, University of Sydney and will have an Aboriginal reference group to oversee the research.

#### **Why is the research being done?**

The influenza vaccine (Flu shot) is safe and effective in pregnancy but vaccination rates for Aboriginal women have been reported to be low.

One way to improve immunisation services to Aboriginal woman when they are pregnant is to find better ways of providing the services so they are more culturally safe and respectful. With your and other community members input, we are hoping to find these better ways, and your words will help us to do this.

#### **Who can take part in the research?**

We want to talk with Aboriginal people, 18 yrs or over, who live in the communities of Inverell and Tamworth, and who:

- Have had a baby in the last 3 years,
- Have a family member, who has had a baby in the last 3 years,
- Is an Aboriginal health professional.

#### **Giving your permission to be part of the research?**

Taking part in this research is your choice. If you don't want to be involved you will not be affected in any way and this will not affect your care or access to services. If you do decide to take part, you may change your mind at any time without giving a reason.

#### **What would you be asked to do as part of the research project?**

You will be asked to take part in a discussion with us and maybe other Aboriginal people from your community for about an hour or two. Or you may talk with the researchers by yourself if you prefer. Some of the things we will talk about are your experiences around pregnancy and around immunisation. We will write down the issues which come up during the discussions and these will be what we write up into our final paper. The researcher, Amy will be in contact with you throughout



the study to make sure the information recorded is what you want to say. You can contact Amy at any time to change or take out anything you have had recorded.

### **What are the risks and benefits of participating?**

Talking about your experience with pregnancy for some people may bring back good memories but may also bring back some bad ones as well. If this happens the researchers will be able to provide you with some emotional support or refer you to a health service that can help you.

The benefits of participating are that your words will help provide ideas to help make it safer for our people when one of our family is having a baby.

### **How will your privacy be protected?**

Any information that you give through this study that can identify you, will remain confidential, unless you want to be identified. Your name will not be used nor can any information shared with anyone other than the research team. You ask for copies of the information at any stage by contacting us.

### **What happens with the results?**

First the Inverell and Tamworth Aboriginal communities will hear a summary of what the research found. The communities will be asked what they think of this information. Then the information will go back to the Aboriginal Health Partnership and the project Reference Group, and may be reported in papers in health journals and at health conferences. Names and anything that identifies people will be removed from in any reports coming from the project unless you specifically want to be identified. You can withdraw or amend information you provide to the researcher at any time.

### **What do you need to do to take part?**

If there is anything you do not understand or you have any questions, Amy will be happy to talk with you. If you would like to take part, please sign the consent form and give this to Amy. You can change your mind at any time either in writing (see attached) or by telling Amy, mobile: 0447062476 landline; 0267 648039 amy.creighton@hnehealth.nsw.gov.au) or the Supervisor (Peter Massey mobile: 0429 688 106 landline 0267 64800 peter.massey@hnehealth.nsw.gov.au) or a member of the reference group.

### **Complaints about this research**

If you have any complaints please contact  
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or

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Strawberry Hills NSW 2012  
Phone: 02 9212 4777  
Fax: 02 9212 7211  
Email: [ahmrc@ahmrc.org.au](mailto:ahmrc@ahmrc.org.au)

## Appendix 3 Consent forms



### Consent Form for Research Project

**Gaba Binggi (Good Needles): Developing an understanding of how two Aboriginal communities see and experience immunisation during pregnancy.**

28<sup>th</sup> February 2014

**Research Team:**

Amy Creighton (Researcher)

Dr Peter Massey (Supervisor) Program Manager Clinical Nurse Consultant, Population Health

Dr Julie Leask (Supervisor) Associate Professor, School of Public Health, University of Sydney

**Consent Statement:**

- I agree to participate in the above research project and give my consent freely.
- I have received the Participant Information Statement and have had the opportunity to ask questions.
- I understand the purpose of the research and my involvement in it.
- I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing. Withdrawal may be written or verbal to the researcher (Amy Creighton) or the supervisor (Peter Massey) or a member of the reference group. This will not affect any services that I receive.
- I understand that my personal information will remain confidential to the researchers unless I otherwise choose.
- I understand that if I have any complaints or questions concerning this research project I can contact the researchers, the Chairperson or CEO of the local Aboriginal Community Controlled Health Service; Hunter New England Health Service Human Research Ethics Committee, telephone 4921 4950, or the Chairperson of the Aboriginal Health & Medical Research Council Ethics Committee, telephone 9212 4777.

Print Name: .....

Signature: ..... Date: ...../...../.....

Researchers Signature: ..... Date: ...../...../.....

## Appendix 4 Interview guide

Gaba Binggi (Good Needles) Developing an understanding on how two Aboriginal communities see and experience immunisation during pregnancy

### Questions

1. Pregnancy can be a very exciting time especially for the woman, how do you feel about being pregnant or one of your family members expecting a baby?
2. Have you or any of your family ever had the flu? How did you or they feel/cope?
3. How do you feel about vaccinations, such as baby needles or the flu vaccine that you can have each year?
4. Would you be worried about having a vaccination while you were pregnant?
5. What would make you want or not want to have a vaccination while you were pregnant?
6. In relation to being pregnant, can you tell me about services that you attend or don't attend?
7. Tell me about what an ideal health service that you might go to for a vaccination looks like and what is important about it.

### prompts:

Why do or don't you attend these health services?

Tell me about what an ideal health service that you might go to for vaccination looks like and what is important about it?

## Appendix 5 Development Article

Article as a co-author that formed part of the development of the project.

Citation: O'Grady KA, Dunbar M, Medlin LG, Hall KK, Toombs M, Meiklejohn J, McHugh L, Massey PD, Creighton A, Andrews RM. Uptake of influenza vaccination in pregnancy amongst Australian Aboriginal and Torres Strait Islander women: a mixed-methods pilot study. *BMC Research Notes*. 2015;8:169.

O'Grady et al. *BMC Research Notes* (2015) 8:169  
DOI 10.1186/s13104-015-1147-3



RESEARCH ARTICLE

Open Access

### Uptake of influenza vaccination in pregnancy amongst Australian Aboriginal and Torres Strait Islander women: a mixed-methods pilot study

Kerry-Ann F O'Grady<sup>1\*</sup>, Melissa Dunbar<sup>1</sup>, Linda G Medlin<sup>1</sup>, Kerry K Hall<sup>1</sup>, Maree Toombs<sup>2</sup>, Judith Meiklejohn<sup>3</sup>, Lisa McHugh<sup>4,5,6</sup>, Peter D Massey<sup>7</sup>, Amy Creighton<sup>7</sup> and Ross M Andrews<sup>3</sup>

#### Abstract

**Background:** Influenza infection during pregnancy causes significant morbidity and mortality. Immunisation against influenza is recommended during pregnancy in several countries however, there are limited data on vaccine uptake, and the determinants of vaccination, in pregnant Australian Aboriginal and/or Torres Strait Islander women. This study aimed to collect pilot data on vaccine uptake and attitudes towards, and perceptions of, maternal influenza vaccination in this population in order to inform the development of larger studies.

**Methods:** A mixed-methods study comprised of a cross-sectional survey and yarning circles (focus groups) amongst Aboriginal and Torres Strait Islander women attending two primary health care services. The women were between 28 weeks gestation and less than 16 weeks post-birth. These data were supplemented by data collected in an ongoing national Australian study of maternal influenza vaccination. Aboriginal research officers collected community data and data from the yarning circles which were based on a narrative enquiry framework. Descriptive statistics were used to analyse quantitative data and thematic analyses were applied to qualitative data.

**Results:** Quantitative data were available for 53 women and seven of these women participated in the yarning circles. The proportion of women who reported receipt of an influenza vaccine during their pregnancy was 9/53. Less than half of the participants (21/53) reported they had been offered the vaccine in pregnancy. Forty-three percent reported they would get a vaccine if they became pregnant again. Qualitative data suggested perceived benefits to themselves and their infants were important factors in the decision to be vaccinated but there was insufficient information available to women to make that choice.

**Conclusions:** The rates of influenza immunisation may continue to remain low for Aboriginal and/or Torres Strait Islander women during pregnancy. Access to services and recommendations by a health care worker may be factors in the lower rates. Our findings support the need for larger studies directed at monitoring and understanding the determinants of maternal influenza vaccine uptake during pregnancy in Australian Aboriginal and Torres Strait Islander women. This research will best be achieved using methods that account for the social and cultural contexts of Aboriginal and Torres Strait Islander communities in Australia.

**Keywords:** Influenza, Vaccine, Pregnancy, Aboriginal and Torres Strait Islander Australian, Determinants, Uptake

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