

PERSONAL VIEW

Developing research in partnership with Aboriginal communities – strategies for improving recruitment and retention

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Submitted: 8 June 2012; Revised: 2 October 2012, Accepted: 8 November 2012 Published: 2 April 2013

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Rural and Remote Health 13: 2255. (Online) 2013

Available: <http://www.rrh.org.au>

ABSTRACT

Context: Australian Aboriginal communities in urban, rural and remote areas are continuing to suffer high rates of perinatal mortality and morbidity that will impact on the future health of the community. It has been well documented that Aboriginal women have extreme distrust of mainstream pregnancy-related health care and suggested that late entry into antenatal care is as high as 50% in the Aboriginal population. Although medical and midwifery staff have long discussed strategies to improve uptake of antenatal health care for Aboriginal women, researchers in many areas have found the recruitment of Aboriginal people into scientific studies almost impossible. This article seeks to share the strategies that have been developed over a period of time by the authors that have proved useful for recruitment and retention into research. It is anticipated that these strategies would also apply for health practitioners in maintaining their patients for clinical care management.



Issue: Although each research location (regional, rural and remote) has had to spend time determining what approach is best for meeting the research outcomes, many of these suggestions become applicable to clinicians seeking to develop better connections with Aboriginal patients in their clinics. With the management of ongoing chronic health conditions for Aboriginal people a priority in 'Closing the Gap', a number of these suggestions could easily be implemented by clinicians. Remembering that each community has specific needs that must be addressed, priorities for assistance for that community will be easily identifiable after community consultation (eg transport, or ability to access medical testing). Opportunities for the use of new social media (eg Facebook) as communication tools for researchers and clinicians will have increasing applicability as further software updates are created.

Lessons learnt: With open and trusting dialogues between researchers, clinicians and Aboriginal communities, we can go a long way towards understanding the needs of individual communities and working in partnerships to close the gap.

Key words: Aboriginal health, antenatal care, Australia, Facebook, Indigenous health, maternal and child health, recruitment, retention, social media.

Context

Australian Aboriginal communities in urban, rural and remote areas are continuing to suffer high rates of perinatal mortality and morbidity that will impact on the future health of the community. While many health issues are non-obstetric in nature, their impact on the burden of health in the mother is particularly important for managing antenatal care of the individual pregnant patient. General health issues include diabetes, maternal obesity, hypertensive disorders and anaemia, all of which occur at higher rates than in the non-Aboriginal Australian population. Sadly, although other colonised countries (Canada, New Zealand and the USA) have begun to improve the quality of health enjoyed by their Indigenous populations, this is not the case in Australia. There is approximately 17 years difference in life expectancy between Aboriginal and non-Aboriginal people, and although the life expectancy for non-Aboriginal people continues to increase, for Aboriginal people it remains relatively unchanged, leading to a greater divide¹. Rates of kidney disease, heart disease, stroke and Type 2 diabetes are particularly high in indigenous Australians, with those over 35 years being 10 times more likely to have kidney failure than non-Indigenous Australians^{2,3}. Aboriginal women are 10 times more likely to die of diabetes than non-Aboriginal women and Aboriginal men 7 times more likely to die of diabetes than non-Aboriginal men⁴. Between 1999 and 2003, diabetes was responsible for >8% of deaths of Indigenous people living in

Queensland, Western Australia, South Australia and the Northern Territory. Diabetes and kidney disease are significant risk factors for heart disease, hypertension and a shortened lifespan.

Importantly, data suggest that for both Type 2 diabetes and kidney disease the problems begin before birth. Increasingly research is showing that the health of the unborn baby can affect its future health as an adult. For a long healthy life it is essential to begin life in a healthy state.

Additionally, it has been well documented that Aboriginal women have extreme distrust of mainstream pregnancy-related health care⁵⁻⁷. It has been reported that many women attending pregnancy-related care, experience feelings of vulnerability, fear and isolation from their communities. For Aboriginal women many aspects of their care are frightening, yet they may benefit from this care as they are at increased risks of poor pregnancy outcomes compared with non-Aboriginal women^{8,9}. The discomfort with mainstream health services has led to difficulties with timely and regular antenatal care and routine serological screening in pregnancy in all Aboriginal communities.

The World Health Organization suggests that at least four antenatal visits are optimum for effective maternal health care¹⁰. Late entry into antenatal care (>20 weeks gestation) increases the rate of stillbirths from 5.9 to 9.2 per 1000 births¹¹. Women from



non-English speaking backgrounds and Aboriginal women are the two groups most likely to enter antenatal care late. It has been suggested that late entry into antenatal care is as high as 50% in the Aboriginal population¹². Only 76.8% Aboriginal women compared to 92.9% of non-Aboriginal women access four antenatal visits⁹. Other factors related to late antenatal care entry are reduced maternal age, increased parity and a history of smoking¹².

The socio-demographic profile of mothers varies with rurality; generally, with increasing rurality we see higher percentages of Aboriginal mothers, increased numbers of teenage mothers, increased numbers of single mothers, fewer private patients, and increased parity^{13,14}. Each of these characteristics has been linked with poorer fetal and maternal outcomes, and therefore antenatal care is of greater importance¹³.

In rural locations late entry to antenatal care is often due to limited access to services. The distribution of services is far from even, so that access to appropriate antenatal care is limited in many communities. It has been found that, on average, Aboriginal women did not attend antenatal care until 18 weeks gestation while non-Aboriginal women attended before 15 weeks gestation¹⁵. This may well be due to accessibility of antenatal services to Aboriginal communities and appropriateness of care with regard to cultural needs of Aboriginal women.

A number of issues that impact on health outcomes also adversely affect educational opportunities for Aboriginal people, so that universities have reduced numbers of Aboriginal students, staff and researchers. To date, development of research investigating long-term chronic diseases in Aboriginal people have been largely epidemiological. Many of the larger research institutes have staff and higher degree research students who have limited knowledge of Aboriginal cultural and community practices. With these issues in mind (ie reduced numbers of Aboriginal researchers, and organisations with limited understanding of Aboriginal traditions), development of rigorous studies to determine the underlying mechanisms of poor birth outcomes and long-term chronic disease have been extremely limited.

An NHMRC funded study (The *Gomeri gaaynggal* program – 2008) looking at developing an understanding of the mechanisms for premature and low birthweight deliveries, and early diagnostics and detection of kidney disease *in utero*, to improve the health of Aboriginal communities, has been underway in regional, rural and remote locations of NSW since 2009. This study recruits Aboriginal women in early pregnancy and monitors both their own and their infant's health at each trimester of pregnancy through hormone, immune, renal, environmental, psychosocial and ultrasound assessments. In 2012 it was awarded additional NHMRC funds to maintain the pregnancy cohort of participants and their infants into a longitudinal study for a further two years to focus on the early detection, diagnosis and prevention of diabetes and kidney disease in Aboriginal communities.

The *Gomeri gaaynggal* program has been in development since 2006, and has developed a research presence alongside local communities and health service providers to deliver a technically challenging study across pregnancy and the post-natal period. In addition, the *Gomeri gaaynggal* team is working in partnership with the Aboriginal community and healthcare providers to deliver an ArtsHealth program that seeks to improve health literacy by using results obtained from research in health education surrounding pregnancy and early childhood. Likewise it is hoped that through engagement in the *Gomeri gaaynggal* ArtsHealth program will encourage Aboriginal women to seek earlier and more regular antenatal care.

At our rural centre we have had an enduring ArtsHealth program running. This program runs in our studio and crèche room, and mothers attend, learn art skills from one of our local Elders (body sculpture, painting, ceramics) and have a variety of health professionals visit. These visits are held over a cuppa and informal discussions that relate to their particular aspects of health. It could be cooking with the dietitian, exercise 'zumba' with the physiotherapists, or designing oral healthcare brochures with the oral health team etc.

Issue

Medical and midwifery staff have long discussed strategies to improve uptake of antenatal health care for Aboriginal



women, but researchers in many areas have still found recruitment of Aboriginal people into scientific studies almost impossible. This article seeks to share the strategies developed over a period of time by the authors that have proved useful for recruitment and retention into research and other antenatal programs (ArtsHealth). It is anticipated that these strategies would also apply for health practitioners in maintaining their patients for clinical care management.

Lessons learnt

Lessons applicable to all areas

In 2002, NHMRC released a roadmap that made community consultation prior to research mandatory¹⁶. Prior to *Gomeri gaaynggal* study start, the authors spent two years in their location talking with the Aboriginal people of the community. While the authors own preconceived ideas suggested that discussions should only be held with health service personnel, the Aboriginal way of 'doing business' suggested otherwise. The term 'community consultation' encapsulates this process. Despite beginning a health research project, consultation occurred across multiple levels of the community. Discussions took place with Elders, local prison staff, employment organisations, men's groups, women's groups, in schools, with education staff, housing department staff, young mum's groups, DOCS, Centrelink, Aboriginal Medical Service, local artists and anyone the Aboriginal community felt the research team should listen to. At the time, the frustration to begin the research study was paramount, and we often had little or no idea why we needed to meet with some of these organisations and people. More importantly, we were spending precious salary funds from the grant on 'talking'. However, what we realised after 6–12 months was that our project ideas had expanded as our team gained further insights to community health issues. In addition, as time went on, instead of discussions looking at the politics of research in Aboriginal communities, there had been a subtle shift in dialogue to a collaborative 'when are we starting?'

It was essential to learn to sell our research ideas as well as ourselves – not easy and not the usual way of scientists doing science research. This development of community trust has been an integral part of the success of this study. Trust between the

researchers and the community has had to occur at all levels: research team and participants, their families, Elders, other community members. As with developing trust in any process, time is essential. An integral part of this was to ensure that staffing was predominantly Aboriginal. An ongoing supportive mentored environment was provided, with as many opportunities as possible to develop research skills and capacity in new Aboriginal staff members. Community members needed to know that they could contact an individual in the research team and have their concerns listened to and, more importantly, managed. Communication has had to maintain a committed and caring approach throughout the lifespan of the study. The priority of the investigators to employ Aboriginal staff has been critical and ensured that open communication has occurred between community members and researchers and vice versa. Although mistakes have certainly occurred, the development of long-term friendships between researchers and community members has ensured that these can be discussed openly and overcome.

A crucial approach for beginning the community consultation process included early contact with Elders of the community of interest. Elders have large family connections, and their advice on who needs to be approached and in what priority is vital. In addition, the Elders love to yarn in their day-to-day lives, and play a role in spreading the message a researcher or clinician might be trying to get out to a community. The author's research team developed many relationships with other community members through the delivery of many presentations at organisations that have links to health, such as Division of General Practice, Community Health Services Aboriginal Maternal Infant Health Strategy, Aboriginal Medical Services, TAFE and the Aboriginal Education Consultative group. These forums give all staff a chance to further develop their public speaking techniques and to engage in open discussions about the mechanics of a research study, such as when it would be best to recruit a participant in their clinic, or how would they design an information brochure. This kind of discussion shows a willingness to ensure that the organisation's own staff don't have their clinics interrupted by research work, and go a long way to developing a partnership approach to research.



As the authors' research program has expanded to other locations, it has become clear that each Aboriginal community has specific needs and that the research design and daily management needs to cater for this to ensure the success of any program. Key strategies that have worked in each location are shown (Table 1).

Regional lessons

In our regional research setting, the Aboriginal community is approximately 2% and widely dispersed through a population of approximately a half a million people¹⁷. Research participants need to attend a tertiary hospital to undergo sample collections, have a scan, and have any of their other routine antenatal care occur on the same visit. For participants this is often a fairly daunting experience. The general mistrust of hospitals and medical procedures among Aboriginal people can make this a long and stressful visit. In addition, the simple act of even getting to the hospital can be fraught with an inability to access transport and increased expense. To help with expense, participants are offered parking vouchers or a pick up service where possible. Unfortunately, as with all hospital procedures, there are often delays throughout the visit, so meal vouchers for the in-hospital coffee shops are offered to assist with a meal or morning tea and to minimise the expense while at the hospital. Aboriginal research staff spend most of the day with participants, to explain procedures, act as a support person when needed, introduce participants to health service staff and to minimise the discomfort that Aboriginal people may feel in a hospital setting.

Rural lessons

In our rural research location, parking at the hospital is generally not an issue; however, transport to the hospital is, as public transport is limited. Transportation can only be arranged if an appointment can be confirmed, so the research team works to remind and confirm with participants the time/day of appointments. When participants consented to be involved in study, each participant gave a minimum of three contact people. Aboriginal people often have family commitments away from home and move regularly, and it has proved very useful to be able to contact a participant via a family friend or other family member.

In addition, all of our ArtsHealth attendees are linked to our Facebook page. Obviously, participants have the choice to become 'friends'; however, we are yet to be refused. It must be noted that a large number of our ArtsHealth attendees are both ArtsHealth and research participants. The uses for social media for researchers is a newly developing area and one that needs new guidelines for ethics committees to follow. We have found that many of the dual ArtsHealth attendees and research participants who are connected to our Facebook would 'Inbox' us, to request transport for an ultrasound appointment or to find out about next sample collection. For those who don't know how to use Facebook, 'inboxing' is just like sending an email and will only go to the participant. It should be noted, however, that any discussion with a participant about their involvement in the research study is done through a private 'inbox' message that is only seen by the participant and not by others visiting either the participant's or the *Gomerioi gaaynggal* page. We had been contacting participants via text messages and were finding we often wouldn't hear back from participants about their transport or other needs. With the advent of many of the newer mobile phone contracts, Facebook has become a 'free' part of their mobile service contract. In this way, Facebook became a way for participants to contact us without it adding to their mobile phone expenses. Facebook is also available even if you lose your phone, as had been an issue in a few cases. This seems such a small thing, but it has markedly increased our compliance with sample collection from participants to almost 100% in the last 12 months. With this improving, we have moved on to suggesting that new research participants 'request friendship' with the *Gomerioi gaaynggal* page. Of course, this is completely voluntary and is at the impetus of the participant. All communication with individuals is through the 'inbox' mechanism, and we continue to phone or text those who don't request a Facebook connection. We have found that new research participants then have the opportunity to see updates about the ArtsHealth program and therefore become better connected with a community education program. With participant contact organised, arranging transportation on the day has been a very easy step. Of course, with increasing remoteness, internet access becomes a difficulty; however, all centres in our program have had the capacity to readily access Facebook.



Table 1: Summary of key strategies, many of which could be utilised in clinical care situations, for improved recruitment and retention of Aboriginal participants into a pregnancy research study

Areas	Essential lessons learnt
All	<ul style="list-style-type: none"> • Community consultation at all levels of community • Support from the Elders is essential • Trust between researchers and community takes time • Aboriginal staff are critical • Engagement of researchers in community projects helps build trust – eg ArtsHealth program, Elders workshops • Creating whole-of-community events to promote project – eg hosting events on significant community days, art exhibitions, concerts • Work in partnership with other community organisations • Develop flexible strategies for engagement that work for the community involved • Use of social media such as Facebook to remain connected with participants
Regional	<ul style="list-style-type: none"> • Use of food and transport vouchers to reduce cost for families • Aboriginal staff to liaise with patients and hospital staff • Aboriginal staff to support patients at hospital visit
Rural	<ul style="list-style-type: none"> • Appointment reminders using text, Facebook, or call in • Transportation arranged • Improve local access to health services such as ultrasounds, pathology sample collections by research staff
Remote	<ul style="list-style-type: none"> • Program initiated by local AMS • Involvement of local AMS staff

AMS, Aboriginal Medical Service.

In the rural setting of the *Gomeroi gaaynggal* program, improving health services has been an ongoing commitment by our research team. The local rural community members struggle to gain appointments in radiology services due to a short supply of appropriately trained clinical staff, and often need to access services more than 100 km away. For our rural research team this has meant locating radiology staff, purchasing the appropriate ultrasound equipment, and running a clinic specifically for Aboriginal women. While research participants have priority at this clinic, a number of appointments are set aside for non-research participants for each clinic. In addition, all Aboriginal research staff have obtained their qualifications in phlebotomy, so that participants and other patients can have any research or routine antenatal samples collected while attending clinics. This program and its participants are all connected to our Facebook page where we regularly update what is on, new artworks or who is visiting the centre each week. Through

participants' Facebook comments, we have had a number of new participants and growing community support.

Lesson from our remote town

The remote town we work in has a population of about 7000 people, with approximately 30% of the community being Aboriginal¹⁸. In such a small community trust is absolutely essential, as the grapevine can spread a poor message very quickly. We were lucky to be invited to work with the community by the local Aboriginal Medical Service (AMS) staff. Working in partnership with the local AMS has had many rewards for the research team and for AMS staff alike. The research team has been physically placed to share office space at the AMS and thus develop ongoing partnerships from the very beginning of project in this community. Aboriginal research staff work with AMS clinical staff to recruit participants into their routine antenatal care and to participate in the research project. The staff of both



the AMS and the research team wear uniforms carrying logos of both the AMS and the research project to show the community the partnership between the organisations. The AMS staff assist with transportation of participants to appointments that become dual appointments for both normal clinical and research needs.

In addition, from the very beginning of our study time in our remote centre, we ran our ArtsHealth program. The community ArtsHealth program provides a non-threatening informal way for potential participants to meet staff and ask questions without pressure. The confidence from developing new skills, selling artworks and meeting a variety of health professionals has increased the community trust for the research team with potential participants. All of our staff are local women, so the community has seen that we are putting money into the community, not just taking research data away. This notion of giving back and building capacity of local Aboriginal people is a priority for the team. Although it is early days in this location, the local AMS staff have already stated that they are seeing more women attending antenatal care at an earlier point in their pregnancy.

We have introduced our staff, AMS staff and participants in our remote centre to our Facebook page as well. This has meant that Aboriginal women are connected through their artwork on our site and can support each other in their development of skills. It has encouraged staff to tell participants and other staff of their training achievements and to promote a feeling of community pride. It has also meant that staff in different locations can get an idea of what each centre is doing and ways to improve on it, use the same idea or develop a new way appropriate for their centre.

Conclusions

Although each research location has had to spend time determining what approach is best for meeting the research outcomes, many of these suggestions are applicable to clinicians seeking to develop better connections with Aboriginal patients in their clinics. With the management of ongoing chronic health conditions for Aboriginal people a

priority in 'Closing the Gap', a number of these suggestions could be easily implemented by clinicians. New social media, such as Facebook, can be utilised in a manner that can build trust, establish and maintain contact at less cost for participants, researchers and clinicians. The use of these forms of social media will have more applicability as further updates are created. Remembering that each community has specific needs that must be addressed, priorities for assistance for that community will be easily identifiable after community consultation and include transport and the ability to access a medical test. With open and trusting dialogues between researchers, clinicians and Aboriginal communities we can go a long way towards understanding individual community needs and working in partnerships to close the gap.

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