

Practical challenges of conducting research into rheumatic fever in remote Aboriginal communities

Malcolm I McDonald, Norma Bengler, Alex Brown, Bart J Currie and Jonathan R Carapetis

Aboriginal people in remote communities of Australia's Northern Territory have alarmingly high rates of acute rheumatic fever,¹ and efforts to tackle the problem have met with limited success.² It is also apparent that the epidemiology of acute rheumatic fever in these communities differs from that typically seen in temperate climates. Symptomatic streptococcal pharyngitis is relatively rare, whereas pyoderma is common. A direct link with streptococcal skin infection is hypothesised, but has yet to be proven.³ A community-based study to investigate a possible causal relationship between streptococcal skin infection and acute rheumatic fever was proposed. The protocol required that research teams visit households in selected Aboriginal communities on a monthly basis to collect data on household size and living conditions, as well as information on sore throats, skin sores and episodes of acute rheumatic fever.

We present here a perspective on an individual Aboriginal health research project, with its flaws and strengths. It is not a comprehensive review of approaches to Aboriginal health research.

Community consultation and consent

Approval for the study by the Human Research Ethics Committee of Northern Territory Department of Health and Community Services and Menzies School of Health Research was received in mid 2003. Community consultation was then planned by Aboriginal members of the research team who had the benefit of extensive family connections across the region. The senior Aboriginal researcher, based in Darwin, had been involved in acute rheumatic fever and healthy skin research in the Top End for 13 years; she was widely known and respected, and had a great deal of experience with the process of community consultation.

The research team first met with members of community councils and traditional landowners, then health boards, health centre staff, community women's centres and senior staff at the schools. Community members indicated that the most influential people were often older women ("the nannas"), who belonged to none of these groups, and the team was advised to respectfully seek their counsel. It was good advice and did much to pave the way for community acceptance. During this process, non-resident researchers spent time staying in each community and participating in local activities. Once community consent was obtained, potential research officers were approached at each study site; they were usually practising or retired Aboriginal health workers who had worked with the research team on previous projects. Upon recruitment, additional training was arranged in Darwin for community-based researchers.

Collective approval by community leaders was followed by family consultation and consent.⁴ Gaining household and individual consent required engagement with families over several months. For many people, English was their third or fourth language and information was conveyed by Aboriginal research officers in the local language with the assistance of flip-charts. Providing information is a long way from ensuring understanding,⁵ and understanding was not accepted as accomplished after just one or two visits. Although Aboriginal and non-Aboriginal

ABSTRACT

- Before embarking on an epidemiological study of acute rheumatic fever in remote Aboriginal communities, researchers engaged in the processes of community consultation, consent and household enrolment.
- Community expectations and time constraints are not necessarily those of the funding bodies, and a considerable investment of time and local engagement was required before the project proceeded with local support.
- The remoteness of the communities, harsh climate and limited infrastructure made working conditions difficult. Nevertheless, the study was completed and the results are being returned to the local councils and households. The research team continues to maintain its relationship with each study community.

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people may have different concepts of illness and causality,⁶ particularly with respect to the role of invisible outside forces, research objectives were framed in a way that attempted to embrace apparently contrasting world views. It was generally agreed that the causative forces — Group A β -haemolytic streptococci — were unseen and sinister, and they were depicted as particularly ugly creatures by the Aboriginal artist on the flip-charts.

Individual informed consent was not always regarded as paramount. On at least three occasions, senior household members protested when their authority, as given to collective consent, was seen to be undermined when researchers approached family members for individual consent. Possibly because of past experiences with outside bureaucracy, requests to sign forms for individual consent were often met with suspicion.

The consultation process required sustained commitment and constant re-evaluation of expectations. In the first two communities, the governing bodies and households agreed to go ahead with the study after 6 months. Difficulties with logistics and maintaining community support were subsequently encountered at one of the sites and, after a year, the study was withdrawn by mutual agreement. The research team then started afresh with a third community and, wiser for the experience, negotiated community and household consent in about 3 months.

It was clear that the consent process was not finished once people agreed to take part and signed the consent form. Consent was re-negotiated at each monthly household visit. Mostly, it was non-verbal. Study personnel waited outside on the roadway; if the head of the household came out to greet the researchers and accept the previous month's results, consent was mutually implied. Other family members would then appear. It was expected that the research team would also address general health concerns of household members as they were raised, and people requiring medical treatment were transported back to the health centre.

1 Aboriginal health research and what it means to me

My name is Norma Benger Chidanpee. I have a diverse background; my mother's people come from Wadeye and Woodcupuldia in the Daly River region. My father's country is around Barrow Creek in Central Australia. My childhood languages were from the Ngunkikurrunku group, Marathiel and Murinpatha. English was my third language.

I would like to tell you about my work in Aboriginal health research and how it affects me personally. I joined Menzies School of Health Research (MSHR) in Darwin 13 years ago. Before that I worked as a teacher's aid, teaching arts and crafts to school kids to help promote Aboriginal culture and knowledge. Then an Aboriginal researcher from MSHR approached me to use art as a way of translating biomedical knowledge. My first project was with the team researching acute rheumatic fever and, with several colleagues, we developed educational booklets for patients and families plus an educational video. They were used in Aboriginal communities and hospitals right across northern Australia for more than a decade, and a survey conducted in 2005 indicated that they were still regarded by health centres as the most valuable educational tools available.¹ However, we thought they were becoming a little tired and outdated, so we made a new version, in DVD format, in 2005, with the support of the Australian Rotary Health Research Fund. Again, this has been distributed across northern Australia with funds provided by the National Heart Foundation.

I also worked with the Adult Aboriginal Mortality Project. This brought home to me the impact of early death statistics. It was a really sad time because every one of my family was a statistic. There was no real distinction between my work and sorry business. The sadness went on for a long time.

Another project was "Healthy skin". It was the first project that I worked on from its inception — from the feasibility stage to getting the program up and running and seeing the benefits research can bring. I learned how to ask research questions and understand hypotheses. I got a taste for research and research methods in action. This prompted me to enrol in a Master of Education course; my project is entitled "What is the best method to transfer medical knowledge to Aboriginal peoples?"

Community consultation is family business for me. I approach it using specific protocols and the order is important.² First off, I contact the land councils to obtain permits for the research team to enter Aboriginal land. Sometimes family members ask why I need a permit; I tell them it is because I am out on work business, on project work, and I would like to do the right thing. I then contact

community councils, health staff, families, and key strong community people. These networks come from being in a family with cultural ties across the Northern Territory. In one community, my work has reconnected me with family members I had not seen for years. It was a happy time in some ways but sad in others, seeing four generations in the same house with the same health problems after all this time. Why is it still like this? I know my role as a successful researcher depends on all of my life experiences and family connections.

From seeing the work we've done, I think you've got to stick around for a long time to get an idea of research questions and see how the answers fit into the scheme of things. For me, it's not about getting a PhD; it's about finding my place. I've carved out my niche. Working in research has given me the opportunity to travel the world representing my people and MSHR. I have also been a co-author on more than a dozen scientific papers. My art has always played a key role and still does.

The most recent acute rheumatic fever project was the most exciting — seeing it actually being a successful intervention, with disease rates going down, awareness going up, people getting employment, long-term increases in health infrastructure, and my people getting attention. They are getting what they need, and they are no longer alone in the world with their disease.

My work would not be possible without the support of my husband, children and huge family.

Correspondence: norma.benger@menzies.edu.au

1 Benger N, McDonald M. Evaluation of a rheumatic heart disease video as an educational tool in Aboriginal communities of Northern and Central Australia. *NT Commun Dis Bull* 2005; 12: 30-31.

2 Benger N, McDonald M. Streptococcal research in Indigenous communities: approaching community consultation and consent. Proceedings of the XVIth Lancefield International Symposium on streptococci and streptococcal diseases; 2005; Palm Cove, QLD. ♦



Norma Benger Chidanpee

Community expectations and research agendas

The concept of research is not new to many Aboriginal people, who have experience of non-Aboriginal people visiting communities to collect data, only to disappear without perceived benefit.⁷ Many adults knew about rheumatic heart disease and its terrible effects on family members, but did not welcome outside interference in personal and family activities unless there was a real benefit for their children. The expectation was that local people would participate in all phases of the project, that results would be returned to the community and individual families in a timely manner, and that there would be a tangible gain for all concerned.

Funding bodies require research agendas with timeframes. However, researchers' timeframes were not the prime concern of study participants. Community activities took precedence. When funerals occurred — and sadly, that was often — the whole community was involved, and other activities, including household visits, were suspended for that day. One community requested that, when there

was a funeral, outsiders should stay away for a week out of respect. This meant that almost a third of the monthly visits had to be cancelled.

The research team was also expected to provide specialist services in the health centre, and clinics were conducted each month. In addition, when there was a medical emergency, researchers often found that they had to drop everything and provide health centre staff with assistance.

Logistics

The Northern Territory is a vast area. Most Top End regions have a mean daily maximum temperature of 32°C–35°C and a mean annual rainfall of 1300–1500 cm, 85% falling in the months December to March. Many communities are truly remote. As roads in the region are mainly unsealed and impassable during the wet season, air transport was critical. Regular flights were scheduled, although they were less dependable in the wet season because of tropical



storms. Twin-engine aircraft were usually available, but not always. Over the study period, there were many rough trips, and researchers experienced one emergency landing with mechanical failure and two “near misses” due to dingoes and flocks of galahs on the landing strip. On-site transport was always problematic because vehicles were at a premium and fuel supplies were not assured. Community health centres, the health board or local schools often made vehicles available.

Household visits

The best time of day to visit households was late morning, just after families had returned from visiting the store, or in the hour before sunset, as families gathered for the evening meal. With few exceptions, researchers were made to feel welcome. It was invariably hot and dusty in the dry season and hot and sticky in the wet season. Activities were conducted outdoors, on verandas or under nearby trees and, when there was a breeze, datasheets and materials would often get blown about, despite efforts to keep them under control. Outside tables and chairs were few, and researchers got down on their knees to swab younger children. Collecting specimens could become quite chaotic, especially with large families and numerous young children, frequently accompanied by curious but unhelpful family pets.

These Aboriginal communities also have highly mobile populations. Up to half of each community leaves town and returns to “country” during the months of June and July to camp and hunt on traditional lands. “Ceremony” is an important event in September and October when adolescents are taken into the countryside by elders for instruction and initiation. A household may leave the community for a month or more because of family business, with relatives moving into the house during their absence.

When throat and skin sore swabs were transported back to the health centre they were inoculated onto culture plates, often using patient trolleys as makeshift laboratory benches. Some haste was required, otherwise tiny ants would invade the culture plates. Materials were then packed up and taken to the airfield for the flight to Darwin. There was always concern that they would be accidentally left in the sun on an airport tarmac somewhere. Fortunately, every specimen arrived in Darwin intact.

Study conclusion

Data collection and laboratory work are now complete and papers are being prepared for publication. The senior Aboriginal researcher (Box 1) is supervising the process of returning study findings to the communities and individual households. Proposed publications have been discussed with community leaders and meetings held to examine how the results can be translated into improved delivery of health services. Darwin-based members of the research team visit each community on a regular basis and will continue to do so for the foreseeable future.

This research project was part of a long-term collaborative approach involving Top End Aboriginal communities and researchers to tackle the problem of rheumatic heart disease. Community involvement and consent required careful planning, mutual respect, patience and persistence. Long-term relationships between researchers, community leaders and individual households are crucial. Providing information alone does not make people informed, and consent is not a single event, it is an ongoing process.

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Competing interests

None identified.

Author details

Malcolm I McDonald, FRACP, FRCPA, Research Scholar¹

Norma Bengler, BFineArts, DipHealthPromotion, Senior Indigenous Researcher¹

Alex Brown, BMed, MPH, Senior Research Fellow, Alice Springs Campus¹

Bart J Currie, FRACP, DTM&H, Director, Tropical and Emerging Infectious Diseases Division¹

Jonathan R Carapetis, PhD, FRACP, Director, Centre for International Child Health²

¹ Menzies School of Health Research, Charles Darwin University, Darwin, NT.

² University of Melbourne Department of Paediatrics, Royal Children's Hospital, and Murdoch Childrens Research Institute, Melbourne, VIC.

Correspondence: malcolm@menzies.edu.au

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