

# 'We want you to be our mother': Research to improve Aboriginal child health

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Surely we don't need any more research? Surely we know what to do to improve Aboriginal health? Surely we know the best environments for healthy child development? In this article I provide a rationale for Aboriginal child health research, give a history of my own personal journey in Aboriginal child health from the 1970s to 2011, give examples of our research and its application to improve outcomes and how we have provided the environment to build the careers of Aboriginal researchers; and finally, end with several recommendations.

The aims of the Telethon Institute for Child Health Research (TICHR) are fourfold:

1. To conduct high quality research;
2. To apply research findings (not only our own) to improve the health and well being of children, adolescents and families;
3. To teach the next generation of health researchers; and
4. To be an advocate for children, for research and for social justice.

We do all this by working in groups across themes of major childhood diseases and problems, including all areas from genes and cells, to children and families, to population-wide influences. Hence we have basic, clinical and population sciences all working together to investigate causal pathways, discover better treatments and to apply new knowledge wherever we can. We provide an enhancing research environment with excellent research support – including access to data, data management and analysis, bioinformatics, consumer and community participation and encourage a culture of communication both internally and to the external world (for example, media training).

National and international collaborations are essential for any research, particularly in Australia where we have small sample sizes and are a long way from conferences and other research environments. Perth is said to be isolated, but every day in our Institute people are working with other researchers from many different countries and parts of Australia (from Papua New Guinea to New York City; from Kununurra to Cairns). Such collaborations are increasingly exciting and useful for our increasing group of Aboriginal scholars.

**Rationale for Aboriginal research**

The very disparate circumstances facing Aboriginal Australians compared with non-Aboriginal Australia highlight the need to 'close the gap.' [1] The most recent estimates from the Australian Bureau of Statistics (ABS) indicate that an Aboriginal male born in the period 2005-2007 could be expected to live to 67.2 years, approximately 11.5 years less than a non-Indigenous male at that time. In the same period, an Indigenous female could be expected to live to 72.9 years, which is almost 10 years less than a non-Indigenous woman. [2]

The gap is huge; when we merge these high death rates in young adults with the population pyramids (Figure 1) which show the relative youth of the Indigenous population, 50% aged less than twenty years, it is clear how this impacts on the human capability of Aboriginal society generally. [3]

For example, this demographic pattern means that for every Aboriginal child there are only 1.19 adults, in comparison with nearly three adults for each non-Aboriginal child. If the adults are also sick or

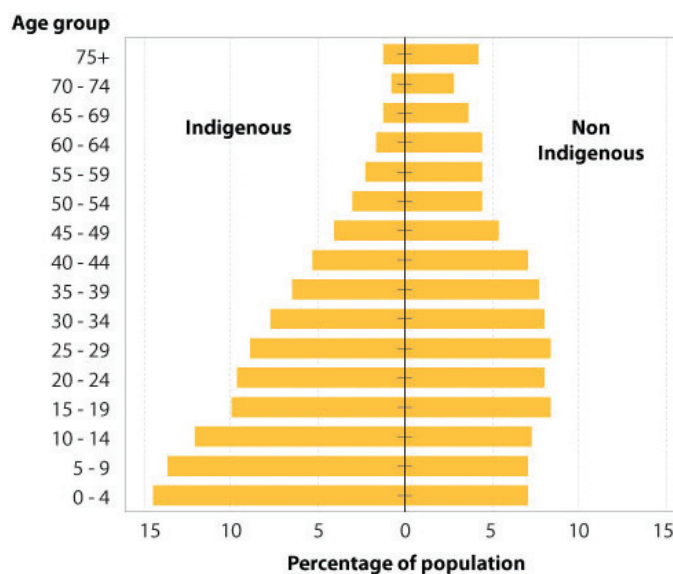


Figure 1. Population pyramid demonstrating the relative youth of Australia's Indigenous population, 2009. [4]

compromised, the environment that they can provide for the care and welfare of their children is limited, as is their capacity to participate in the work force, in education or use services effectively. This is important for us to understand as if our policies and practices are developed from non-Aboriginal constructs and assumptions, then we, as health professionals, will continue to fail our Aboriginal brothers and sisters.

Figure 2 illustrates the very clear pathways from colonisation to today's problems in health, such as infections, cardiovascular disease and diabetes and in social areas, such as domestic violence, child maltreatment and substance abuse.

Anyone providing services in health, education, child protection, housing or justice must appreciate these pathways. To ignore them

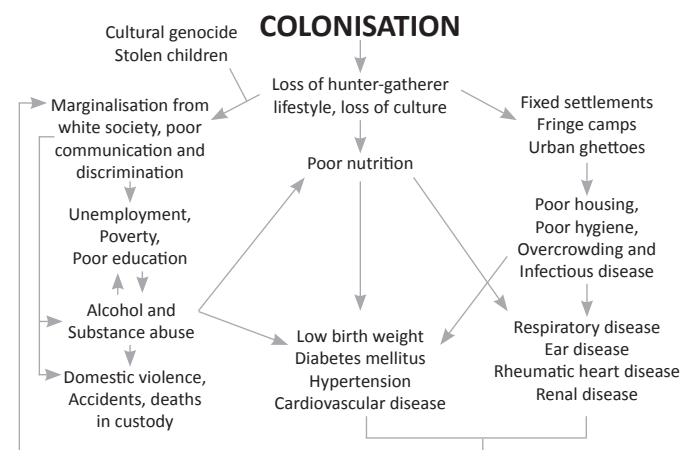


Figure 2. Flow diagram showing the relationship between colonisation and health today. [5]

and focus on the end of the pathways to provide crisis care will never result in reductions in these problems and could actually increase them. For example, by providing renal dialysis in remote locations we will keep people alive for longer, but will never reduce the incidence of renal disease. And by ignoring the cultural, social, emotional and environmental pathways to this range of problems, our solutions will not only be too late – they will be focused on singular factors and hence, will again be less effective.

Thus the rationale for continued research to improve health and wellbeing is that whilst we have done some useful research (particularly in vaccines and other population-based interventions), we have failed hugely to implement effective services to improve outcomes for Aboriginal people. This is not only in health services – with the gap in mortality but one measure – but in all other social and welfare services. The considerable waste of money, time and people in delivering ineffective services should be our biggest shame. [6] So, the answers to my initial questions are clear: we do know what to do, but we do not know how to do it. We appear to have ignored the very people with whom we need to work most closely – the Aboriginal people themselves.

### History of Aboriginal health research in Western Australia

I commenced working in Aboriginal health in the early 1970s by joining the Aboriginal Advancement Council in East Perth, working in the paediatric Aboriginal Clinic. I also conducted two state-wide surveys to look at living conditions and health status outside of the metropolitan area. This started me on a road to work in epidemiology and public health, as I realised that prevention of disease in children was the best way for me to practise medicine.

I trained overseas in the UK and USA and returned to Western Australia (WA) in the late 1970s to establish the first Australian group in perinatal and paediatric epidemiology and preventive medicine. This involved creating population disease data collections and linking them together to identify Aboriginal status – in those days neither birth records nor death certificates had Indigenous identification. To obtain death and disease rates for Aboriginal mothers and children, we expanded the Midwives Notifications of Births to include race and other variables and produced Australia's first comparative Maternal and Child Health (MCH) statistics. At the same time, in 1984, we appointed our first Aboriginal health researchers, Gloria Walley and Patricia Morich, and developed a dedicated team to work on the Aboriginal MCH data.

In the 1990s we all moved in to the new Institute for Child Health Research, which I established on the campus of the Princess Margaret Hospital for Children. This decade signalled two major changes in our work – we started working directly with Aboriginal communities (rather than just looking at their data, but of course we continued to do that too); and we, with the guidance of our Aboriginal partners, developed acceptable cultural research practices. [7] With a group of Aboriginal women in the Eastern Goldfields and with National Health and Medical Research Council (NHMRC) funding, we set up a MCH model service run by Aboriginal health workers. Ngunyitji Tjitji Pirni, which means 'mothers and grandmothers working together' in Wongai, is still going seventeen years later as an incorporated organisation with many of the clients now working in the service themselves to deliver more acceptable care.

The first project in Australia with an Aboriginal chief investigator (Indigenous medical graduate Dr. Sandra Eades, a Nyoongar woman) was also conducted in the 1990s, called Bibbulung Gnarneep ('solid kid' in Nyoongar). It was an urban cohort study investigating the major influences on pathways from birth to a range of health outcomes. [8] From this decade we had started on a road to develop Aboriginal researchers to run their own agenda, become research leaders and to work more effectively with us on projects that they developed and with methods they knew were respectful and acceptable. Dr. Eades was the first Aboriginal medical graduate in Australia to be awarded a PhD, in 2004.

In the 1990s, Dr. Eades and I went to local Aboriginal leaders with Ted Wilkes (Head of Perth Aboriginal Health Service) and asked them the question: 'We are a research institute and not a service provider; here is what we have done and are doing now – what do you want us to be?' They responded, 'We want you to be our mother.' Mothers, they explained to me, give birth to their children, give them all the love, nurturing, advice and capacity/education to prepare them for life and then let them go (but are always there for them). This was a clear call – help us get research skills and 'know-how' (how to win grants, write papers, translate findings, advocate with data and so on) and then relinquish the responsibility and capacity to us. Hence, Kulunga was born, a joint venture between our Institute and the Aboriginal-controlled health organisations in WA. Kulunga's aims were to grow Aboriginal research capacity, conduct the most important, relevant and culturally appropriate research with Aboriginal partners and assist them to translate this to improve outcomes. Specifically, Kulunga's vision is to:

- Develop a network which enables Aboriginal people to conduct research and training, which will form the basis for improvement in health and whole life expectations for Aboriginal children and families in Western Australia.
- Kulunga respects the right of Aboriginal people to control research activities in keeping with the principle of Aboriginal self-determination.

It has been a fabulous, if challenging, path.

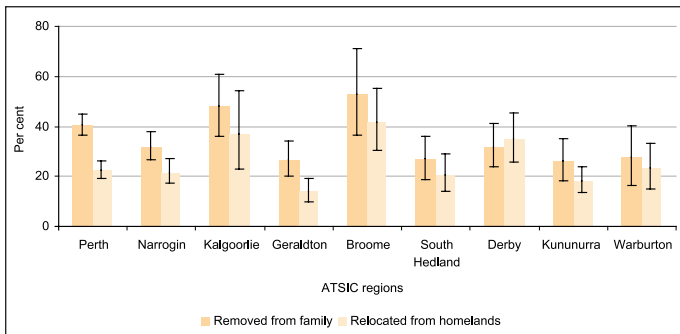
Throughout the 2000s our Aboriginal research agenda in TICHR has expanded enormously, as have the numbers and capacity of our Aboriginal researchers. Aboriginal research projects have been conducted in a range of areas, including mental health, child development, education, infectious diseases (particularly otitis media), birth defects such as neural tube defects and fetal alcohol syndrome, and interventions such as swimming pools in remote communities, early parenting programs and surveys to influence policy and practice.

The first workshop to develop an NHMRC roadmap for Aboriginal health was run out of TICHR and resulted in more support from the NHMRC for Aboriginal research and researchers nationally. [9] We were awarded the first Aboriginal NHMRC capacity building grant with all of our ten team investigators being Aboriginal. They were Cheryl Kickett-Tucker, Ted Wilkes, Helen Milroy, Jan Hammill, Dawn Bessarab, Daniel McAullay, Juli Coffin, Dr. Ngaire Brown, Dr. Sandra Eades and Dr. Michael Wright, who met with Sir Richard Doll on the first day of the grant.

All of these investigators now have their PhDs (except Professor Ted Wilkes whose work on high level national committees has precluded him working full time in research). All have now gone on to post-doctoral fellowships and research and are winning grants as Chief Investigators. One such grant, awarded in 2010, is our Centre for Research Excellence (again NHMRC) which asks two simple questions: 'Why do services fail Aboriginal people?'; and 'What works and why?' Of the ten Chief Investigators, eight are post-doctoral Aboriginal researchers dedicated to answering these questions using a range of different approaches. These include cultural competency, community engagement and community participation action research – powerful and empowering methods to fully engage the people for whom the services are meant. Much of this work comes up against racism, bureaucratic silos and inertia, vested interests, apathy and sheer ignorance by mainstream providers of the Aboriginal population and their circumstances.

Whilst I could give many examples of our research, space limits me to a few. One project conducted by us was the WA Aboriginal Child Health Survey (WAACHS) – the most comprehensive survey of Aboriginal child and youth health, education and family circumstances ever done in Australia. [10-13]

For those who deny that the 'stolen generation' actually occurred, Figure 3 shows the extent of forced removals in today's WA families.



**Figure 3.** Percentage of Western Australian children living in a household affected by forced separation or relocation 2000-2001. [14]

The results of the WAACHS demonstrated that children with a primary carer who was forcibly separated from their natural family as part of government policy were more likely to:

- Be at higher risk of clinically significant emotional symptoms (30.7 percent; CI: 24.9%–37.1%) than children looked after by primary carers who were not forcibly separated (20.7 percent; CI: 18.4%–23.1%);
- Be at higher risk of clinically significant conduct problems (41.5 percent; CI: 35.0%–48.4%) than children looked after by primary carers who were not forcibly separated (31.8 percent; CI: 29.3%–34.4%); and
- Have a higher mean conduct problems score (3.24; CI: 2.89–3.59) than children looked after by primary carers who were not forcibly separated (2.65; CI: 2.51–2.79); [15]
- Thus, showing inter-generational impact.

The four volumes of the WAACHS have been influential across all Australian states and territories in terms of policy and approaches to prevention of child and youth problems.

Our swimming pool studies in two remote WA communities were carried out over six years and demonstrated dramatic improvements in health (skin infections, ear disease and antibiotic usage), school attendance and self-esteem. [16,17] This has resulted in swimming pools being built in many more communities around Australia with similar impacts on health status.

Finally, there are several recommendations that I would suggest to those who want to influence this important area in Australia. All of us, as medically trained people, should be across these issues even if not directly involved with Aboriginal people because it is totally

## References

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unacceptable that a wealthy and capable nation like Australia has such an unacceptable gap in health and well being outcomes within its society.

## Recommendations

1. **Develop a Reconciliation Action Plan for your organisation:** this should be a living and changing document to acknowledge Aboriginal Australia, partner with Aboriginal people and fulfil our collective responsibilities to our nation's first people.
2. **Employ Aboriginal people wherever possible:** it might even be worth having a policy to engage in this way as we do for gender balance and to avoid discrimination. Some states in the USA measure racism by collecting data to see whether the employment of certain racial groups matches their proportions in the populations of those areas. We could do the same here – some organisations such as Australia Post have had an Aboriginal employment policy for years with success all over the nation.
3. **Build Aboriginal capacity:** so many Aboriginal projects and programs are set up to fail because they do not help/train/support Aboriginal people to develop the range of skills needed to succeed in a tough dominant culture with many harsh features and barriers to success. Our experience in building an Aboriginal health research capacity has been a two-way process with many of us learning better ways of doing our research and viewing pathways to health and disease in more holistic ways. Health and welfare services should be full of competent and confident Aboriginal people, fully trained to tackle the complex issues which face them.
4. **We need to change our focus from researching the pathways into poor outcomes, to researching success:** that is, why so many Aboriginal children in high risk situations do so well is more helpful to know than why so many of them do so poorly? If we want to make a positive difference then knowing success pathways is the way to go.
5. **Advocate for Aboriginal people:** do this with them, with respect and do not give up. Having data is very powerful for advocacy because if collected and analysed well it cannot really be ignored.
6. **We must work with Aboriginal people** to ensure that services of all kinds are culturally acceptable, that staff are culturally trained and competent; and that they are aware of the very negative effects of racism on use and effectiveness of services and how real and powerful they are on individual and collective self esteem.

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