

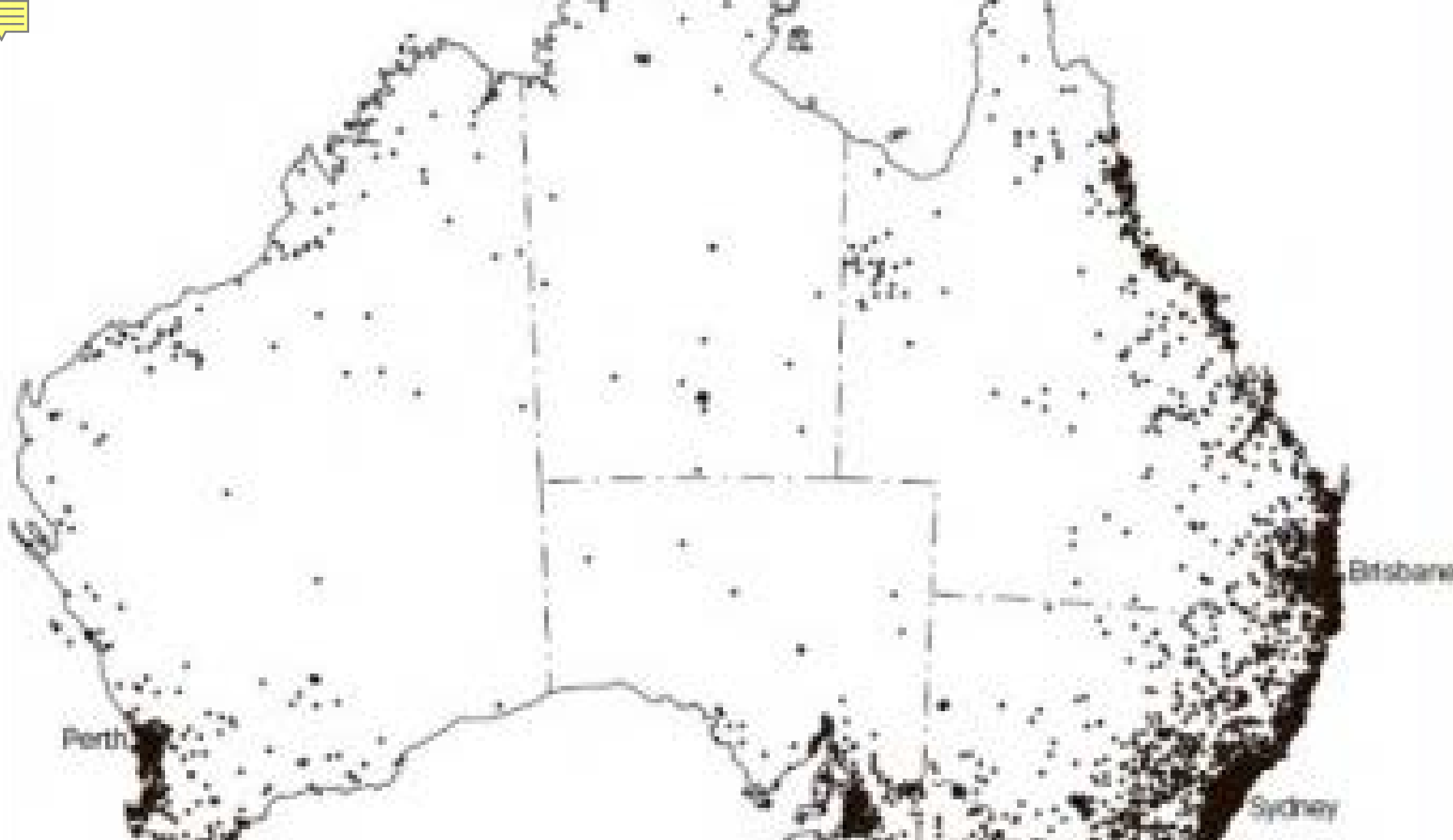
Practice Considerations for Aboriginal Palliative Care

What is Palliative Care?

Palliative Care is the care that an individual may require when they face a life threatening illness with the complications of the illness. The care is administered to provide pain relief and to improve the quality of life that remains for the patient and their families.

The most notable palliative care treats the troubling symptoms to make the most of the time remaining for the patient and to maintain the comfort and quality of life for the patient, which may also include support for the family even after the passing has occurred.

Aboriginal Palliative Care also takes into consideration the connection to the land even though they are not physically roaming in the land but remains spiritually and mentally connected.



Distribution of Aboriginal people in Australia

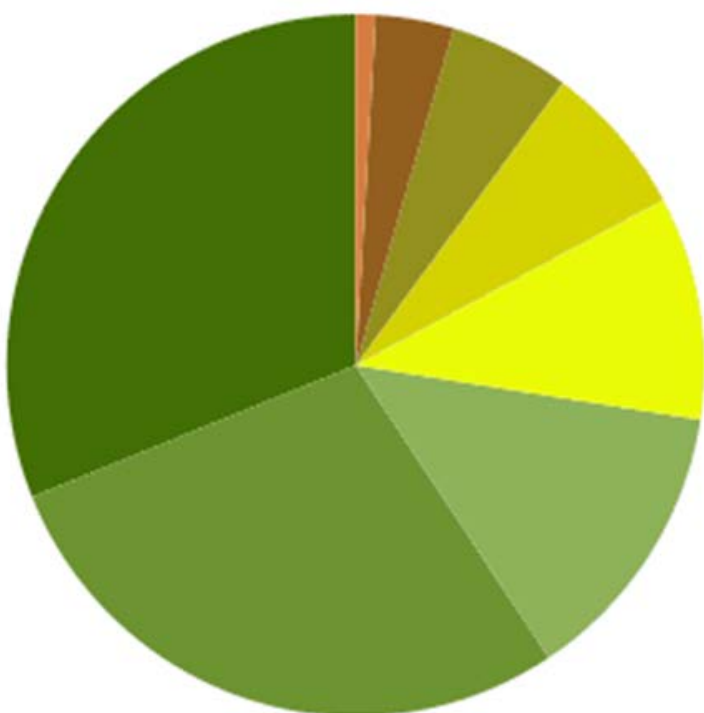
Shows the need for services with majority of distribution on East Coast, around the Sydney area (2006)

Picture from: <http://www.naccho.org.au/about-us/naccho-history/>

 1 dot = 1,000 people

Aboriginals in Australia

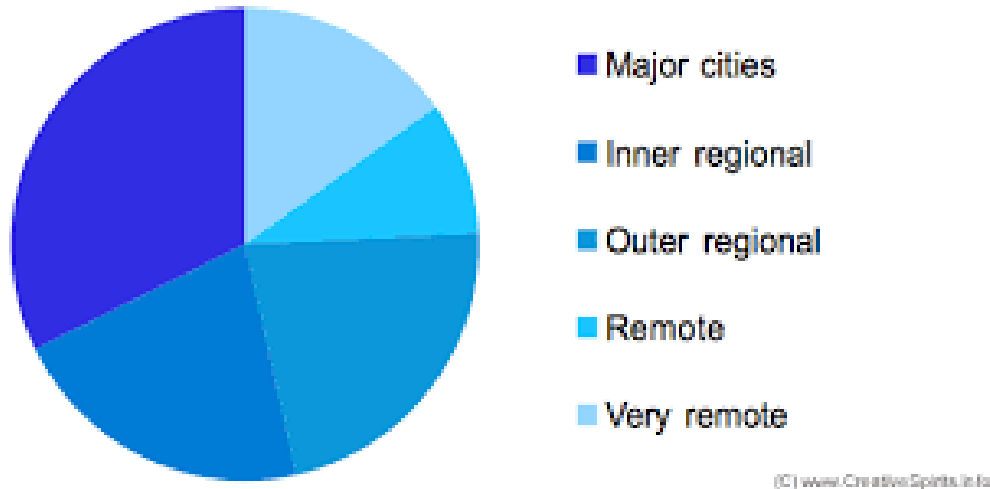
New South Wales have the highest percentage of Aboriginals in Australia (32%), while Northern Territory have the highest proportion of Aboriginals (29.8%) (ABS, 2011).



- New South Wales
- Queensland
- Western Australia
- Northern Territory
- Victoria
- South Australia
- Tasmania
- Australian Capital Territory

(C) www.CreativeSpirits.info

Aboriginal Health



Aboriginal populations in urban areas are expecting to grow by 2.6% annually.

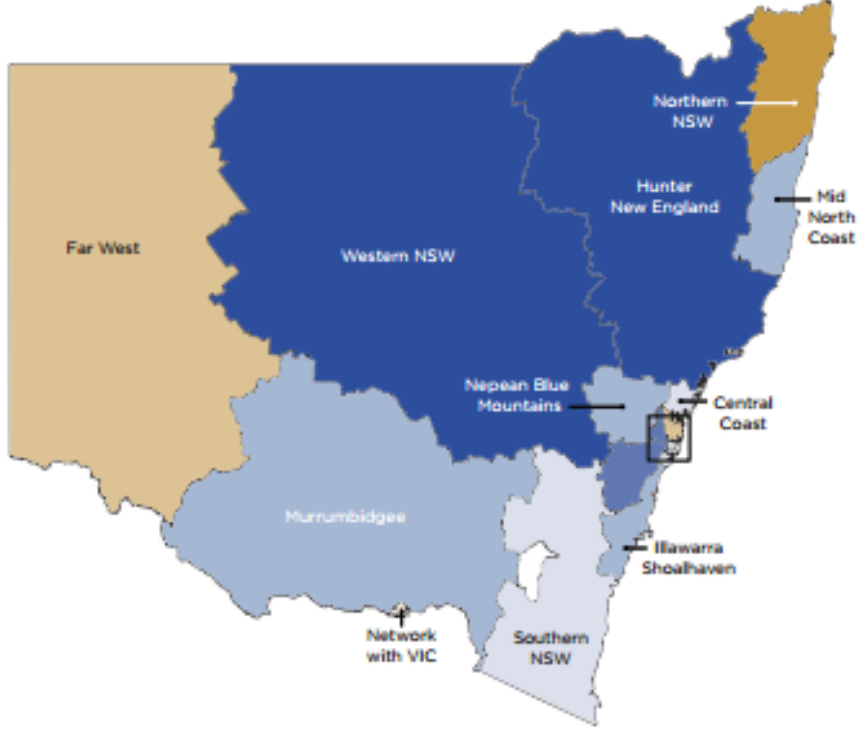
75% of the Aboriginal population live in major cities and non-remote areas.

‘Aboriginal health is not just the physical wellbeing of an individual, but refers to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their community.’
(NACCHO, 2006)

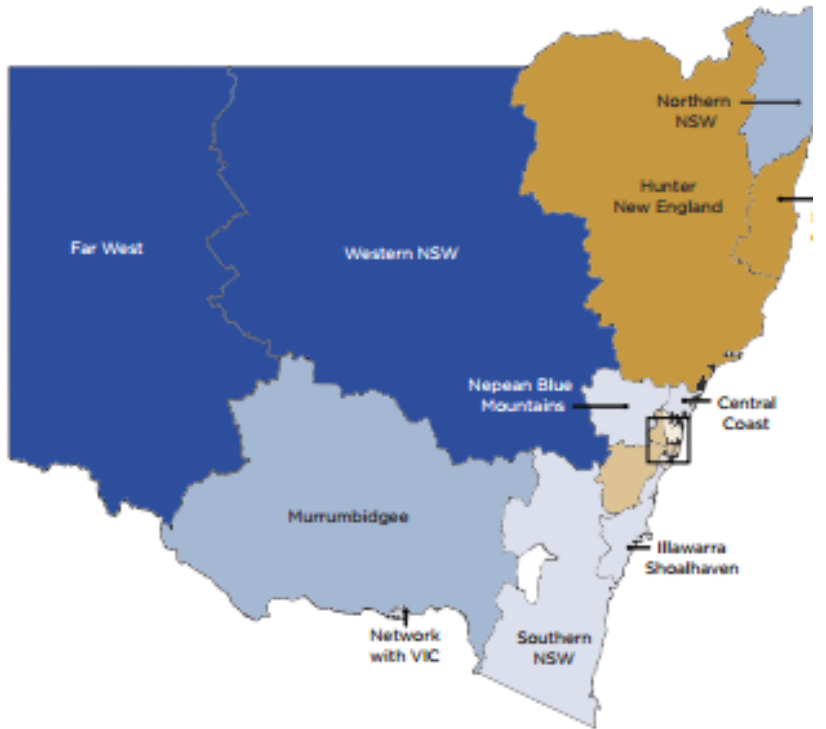
Picture from:

<http://www.creativespirits.info/aboriginalculture/people/aboriginal-population-in-australia>

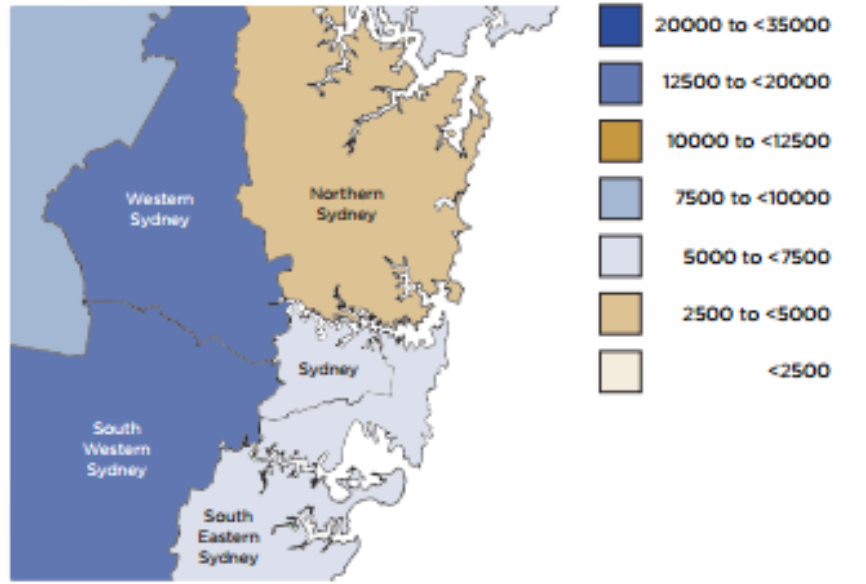
Total Aboriginal Population by Local Health District 2011



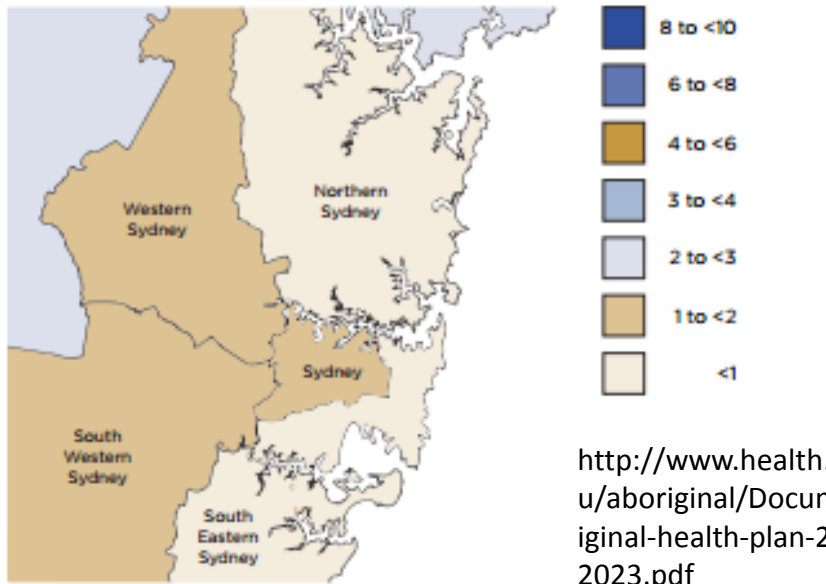
Per cent Aboriginal Population by Local Health District 2011



Greater Sydney Metropolitan area



Greater Sydney Metropolitan area



Participation Rates I

Indigenous Australian populations have one of the lowest Palliative Care participation rates, some issues are listed below:

Loss of cultural identity: Various long standing traditions may not be respected or allowed by 'Western' health care services, losing the connection to land (eg. end of life practices).

Trust/Safety: Past events (eg. Stolen Generation, forced relocation) has reduced the trust to a 'white person' providing care and whether if they are being treated differently because of their culture.

Education/Knowledge: Low participation rates in education result to a lack of knowledge on available services and the belief that Palliative Care is a costly service (where it isn't compared to doctor visits). Unaware that Palliative Care can be given at home and not just in a hospital setting.

Participation Rates II

Place of 'finishing up': the desire to pass away in the spiritual home for a traditional house death in order to be continually connected to the land as strong ties have already been formed. This can cause further distress on relatives and community members as well as the patient if this request is not met.

Taken away from home: loss of family and community support, as they have to relocate in order to be emotional and psychological support for the patient. May have financial issues with accommodation in unknown areas leading to safety issues.

Lack of understanding: awareness of the cultural beliefs of the patient and miscommunication. The patient may request traditional practices to be utilised (traditional healers, traditional food, etc.)

Miscommunication/Misunderstanding: technical terms may be hard to comprehend for them, as English would not be the primary spoken language but may be the third or fourth spoken language

Aboriginal Palliative Care

Different patients from different cultural groups have different cultural beliefs, practices, perspectives, requirements and priorities which must be considered by the volunteer carer.

The three main key themes are:

- Valuing Differences
- Avoiding Assumptions
- Communication



Valuing Differences

Cultural safety, the practice that supports and respects the cultures of an individual to ensure their wellbeing.

Even though these different practices may seem weird for us, it may be normal for Aboriginal people to engage in the behaviours they exhibit.

Carers and volunteers must understand that Aboriginals have different practices and beliefs, as these are the most vital aspect of the Aboriginal community.

The most important aspect of palliative care is to provide the best quality of care possible to make the most of what remains for the patient.



Avoiding Assumptions

Many assumptions and stereotypes have been given to Aboriginal Australians, where they can offend (leading to conflict and distrust) while undermining the validity and importance of service being provided.

Asking for clarification on information provided by the patient, or questions regarding the care is normal as it may be a new experience for both parties involved.

Remember, the most important aspect of palliative care is to provide quality care for what remains of the individual.

Communication

Experts believe that up to 90% of communication is non-verbal and may include facial expressions, eye contact, body movement, hand gestures or signs.

The choice of words used by the carer can also give the wrong impression, cause offense to or degrade the patient and family members, as the strong words such as 'death' or 'dying' are considered as highly offensive words.

English would not be the first language for the majority of the Aboriginal population, and carers may not understand the needs of the patient.





Aboriginal Health Workers (AHWs)

Aboriginal Health Workers (AHWs) can greatly assist in promoting and encourage Aboriginals to use the care and support services provided. Some rural AHWs have indicated they are overworked, under-resourced and un-supported.

An issue raised by Aboriginals' who have considered being employed as an AHW was the limited information and broad spectrum provided in the job description.

A basic knowledge of medical terminology would be essential in conveying the diagnosis and treatment terms to the patient in simpler terms that everyone can understand.

With the input of various local Aboriginal communities, various policies can be modified to establish culturally safe policies and procedures.

AHW in NSW Health

NSW Health have defined an Aboriginal Health Worker as *'provides flexible, holistic and culturally sensitive health services to Aboriginal clients and the community to achieve better health outcomes and better access to health services for Aboriginal people.'* (NSW Health, 2014) and must qualify for Cert III in Aboriginal Primary Health Care.

From January 9th, 2014, NSW Health have categorised AHWs into four categories:

1. Community Health Worker: assists in improving health to Aboriginal communities
2. Hospital Liaison Officer: non-clinical role to provide support and liaison between patient and carer in a health care setting
3. Principal Aboriginal Health Worker: provides services in Aboriginal community after tertiary qualifications
4. Aboriginal Health Practitioner: provides direct clinical services and hold a Cert IV Aboriginal Primary Health Care (Practice) qualification



Post-death Issues

Several issues were outlined by the Indigenous population after the passing of a close family member:

Trained Counsellors: Early access to trained Indigenous counsellors who understand the local issues and can provide adequate support for all individuals.

Loss of tradition: After 'passing away', are the cultural practices being conducted in a manner similar to traditional methods.

Financial Pressures: May delay funeral to ensure everyone can attend. Cost of attending a funeral for a family or community member (including funeral costs, transport/accommodation to attend the funeral, purchasing formal clothing for occasion, food costs etc.) Funerals were sometimes funded by community funds or pooling resources from families.

Practice Considerations

Many issues have been highlighted which has prevented the Indigenous population from utilising the care that is freely accessible. The main issues that can be resolved are listed below which will increase the participation rates:

- Respect beliefs and cultures
- Ensure confidentiality of all information provided, builds trust
- Keep promises that can actually be kept
- Avoid miscommunication to degrade or insult Aboriginals
- Use plain English, medical terms may not be understood and require more explanation and time to understand
- Do not assume all prior assumptions are true, ask for clarification if required
- Be flexible with patients, differing beliefs require different methods of care
- Goal is to provide **QUALITY** care, patient must be happy and comfortable

Reference List

- Providing culturally appropriate palliative care to Indigenous Australians Resource Kit
- Cultural Considerations: Providing end of life care for Aboriginal peoples and Torres Strait Islander peoples *Program of Experience in the Palliative Approach (PEPA)*
- National Aboriginal Community Controlled Health Organisation (NACCHO) (2014). Retrieved 16/03/2015 from: <http://www.naccho.org.au/aboriginal-health/definitions/>
- NSW Health (2014). Definition of an Aboriginal Health Worker. Retrieved 23/03/2015 from: http://www0.health.nsw.gov.au/policies/ib/2014/pdf/IB2014_001.pdf

Journal Articles:

- McGrath, P. (2010). The living model: an Australian model for Aboriginal palliative care service delivery with international implications. *Journal article*.
- Sullivan, K., Johnston, L., Colyer, C., Beale, J., Willis, J., Harrison, J., & Welsh, K. (2003). National indigenous palliative care needs study. *Report prepared for the Australian Government Department of Health and Ageing, Canberra*.
- McGrath, P. D., Patton, M. A. S., Ogilvie, K. F., Rayner, R. D., McGrath, Z.M., and Holewa, H.A. (2007). The case for Aboriginal Health Workers in palliative care. *Australian Health Review*, 31(3), 430-439.