



Engaging Aboriginal and Torres Strait Islander people in guideline development – Case studies

Three exemplar case studies are highlighted in this attachment to reflect different approaches used by guideline developers to engage Aboriginal and Torres Strait Islander people in guideline development.

Contents

1. Consensus-based clinical guideline for the management of volatile substance use in Australia.....	2
2. Pregnancy Care Guidelines	3
3. Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) Indigenous Guidelines	4

1. Consensus-based clinical guideline for the management of volatile substance use in Australia

This case study highlights how strong leadership and representation shaped the development of NHMRC's [Consensus-based clinical guideline for the management of volatile substance use in Australia \(2011\)](#).

Guideline owner

These guidelines were released by NHMRC in 2011, to provide systematically developed, usable clinical practice guidelines for metropolitan, rural and remote communities, including outstations.

Leadership

Dr Tamara Mackean, a descendant of the Waljen People of Western Australia, from Flinders University chaired a sixteen-member multi-disciplinary committee to develop the guideline.

Expert, professional and community representation

Other committee members were professionals with expert knowledge and experience including representatives from Aboriginal organisations in community, and hospitals delivering services to people in the Northern Territory and Victoria; clinical specialists, researchers and consumer advocates.

Committee members were drawn from a list of professional organisations that were asked to nominate a representative:

- The Council for Aboriginal Alcohol Program Services
- The Royal Australasian College of Physicians
- The Royal Australian and New Zealand College of Psychiatrists
- Central Australia Youth Link-Up Service
- Drug and Alcohol Office, Government of Western Australia
- Consumer groups including Health Issues Centre, Consumer Health Forum
- Harm Reduction Victoria.

Research questions

The guideline development group used the PIPOH formula (Population, Interventions, Professionals, Outcomes and Healthcare settings), which included search criteria such as Aboriginal health worker, *Ngangkari* (traditional healers from Central Australia)*, cultural continuity, Aboriginal health care services, outstations and remote communities.

Public consultation process

Consultation involved both a targeted and public process. This involved subject matter experts (ethics and cultural, legal, the Therapeutic Goods Administration, and the Chief Health Officer of the Northern Territory); over targeted notification of 300 national stakeholders and print advertisements run nationally.

Intended Users

Doctors, nurses, Aboriginal health workers, *Ngangkari*, AOD workers and allied health professionals including mental health workers.

Dissemination

The guideline developed group created an implementation plan for OATSIH, which detailed awareness and local adaptation strategies including the development and distribution of educational materials; organising interactive educational workshops with local health workers; engaging opinion leaders to promote key messages; and using audit and feedback to monitor practice.

** (from [Ngaanyaatjarra Pitjantjatjara Yankunytjatjara Women's Council](#)) 'For thousands of years the Ngangkari have nurtured the physical, emotional and social wellbeing of their people. These traditional healers are esteemed for their unique ability to protect and heal both individuals and communities from harm...Ngangkari say western and Anangu practitioners have different but equally valuable skills and knowledge...[NPY's Ngangkari program] works in communities in the region, hospitals, nursing homes, jails, hostels and health services in regional centres.'*
(*Ngaanyaatjarra Pitjantjatjara Yankunytjatjara Women's Council 2019*)

2. Pregnancy Care Guidelines

This case study highlights how an expert working group was established to engage clinical and community perspectives from Aboriginal and Torres Strait Islander women.

Guideline owner

The [Pregnancy Care Guidelines](#) (2018) were developed by the Australian Government Department of Health.

Terms of reference

The terms of reference for the expert advisory committee (EAC) included specific reference to consultation with advisory groups and national and international literature on the health needs of Aboriginal and Torres Strait Islander pregnant women and their families.

Cultural expertise, professional and community representation

A multidisciplinary expert advisory working group, which provided advice to the EAC, was established and co-chaired by Dr Jenny Hunt (Public Health Medical Officer, Aboriginal Health and Medical Research Council) and Dr Marilyn Clarke (Obstetrician and gynaecologist). The working group was made up of a range of health professionals with antenatal expertise, a consumer representative and a methodology expert. These included representatives from:

- Aboriginal Health and Medical Research Council
- Working Group for Aboriginal and Torres Strait Islander Women's Antenatal Care
- Queensland Aboriginal and Islander Health Council
- Kulunga Research Network
- Aboriginal Health Council of South Australia
- Central Australian Aboriginal Congress
- Victorian Aboriginal Community Health Organisation
- Tasmanian Aboriginal Centre
- National Aboriginal Community Controlled Health Organisation.

Members of the working group for Aboriginal and Torres Strait Islander Women were nominated by relevant organisations. Members of the Working Group were nominated by relevant organisations. The co-chairs of the EAC provided final approval of the membership of both working groups.

Role of the working group

The working group provided advice and guidance throughout the guideline development process and ensured that:

- discussion about cultural safety was included
- specific characteristics or risk factors relevant to Aboriginal and Torres Strait Islander women were identified
- wording and expression of all recommendations was inclusive of the needs and experiences of Aboriginal and Torres Strait Islander women
- relevant Aboriginal and Torres Strait Islander stakeholders were consulted
- implementation issues relevant to Aboriginal and Torres Strait Islander women and/or those providing antenatal care were articulated.

Intended users

The intended audience included Aboriginal and Torres Strait Islander health practitioners and Aboriginal and Torres Strait Islander health workers. Additionally, the guidelines outlined optimising care for Aboriginal and Torres Strait Islander women, as well as other groups with specific needs.

3. Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) Indigenous Guidelines

[The Kidney Health Australia – Caring for Australasians with Renal Impairment \(KHA-CARI\) Indigenous Guidelines](#)

This case study demonstrates how partnering with Aboriginal and Torres Strait Islander people can ensure guidelines reflect appropriate and relevant care and health outcomes.

The KHA-CARI guidelines group which involves health experts, service providers and peak bodies, is developing best practice guidelines for the ‘management of chronic kidney disease among Aboriginal and Torres Strait Islander Peoples and Māori’ to improve processes and outcomes of care. The guideline development project will run alongside the development of an Indigenous program to educate, support and advocate for Indigenous Australians affected by kidney disease.

Methodology

There are three strategies outlined for the development of these guidelines:

1. Establish a panel of Aboriginal and Torres Strait Islander health clinicians
2. Undertake local site consultations with Aboriginal and Torres Strait Islander consumers and services
3. Consult with Aboriginal and Torres Strait Islander health peak bodies.

Leadership

The convenors of the Australian guideline group are Dr Jacqui Hughes and Dr Richard Phoon. The guideline group members include Dr Odette Gibson, Dr Janet Kelly, Dr Liz Rix, Dr William Majoni, and Dr Shilpa Jesudason. The project will be led by an Aboriginal and/or Torres Strait Islander project officer.

Engagement

Engagement with Aboriginal and Torres Strait Islander communities is occurring as a new component of CARI’s existing consultation methodology. To ensure effective engagement consultations are being held across a variety of locations nationally. This ensures that the guidelines are culturally appropriate and reflect community preferences for care.

The engagement process will use KHA’s established partnerships with stakeholders in Indigenous health, as well as its own infrastructure to support community consultations. Engagement will be based on local community pathways and processes, with facilitators and meeting logistics being identified by local community contacts. Participants in the engagement process will have an opportunity to evaluate it. Consultation with peak bodies will also be undertaken.

Project panel

The project panel will be made up of representatives of metropolitan, rural and remote regions with a high chronic disease prevalence; and local site engagement fora – involving workshops – will be targeted, using KHA’s community partners, or other networks maintained by partner organisations.

Timeframe

The project will take approximately four years from the initial guideline group face-to-face meeting to the dissemination of guidelines and associated materials.

For updates on the consultation process please see: <https://kidney.org.au/yarning-kidneys-consultations>.