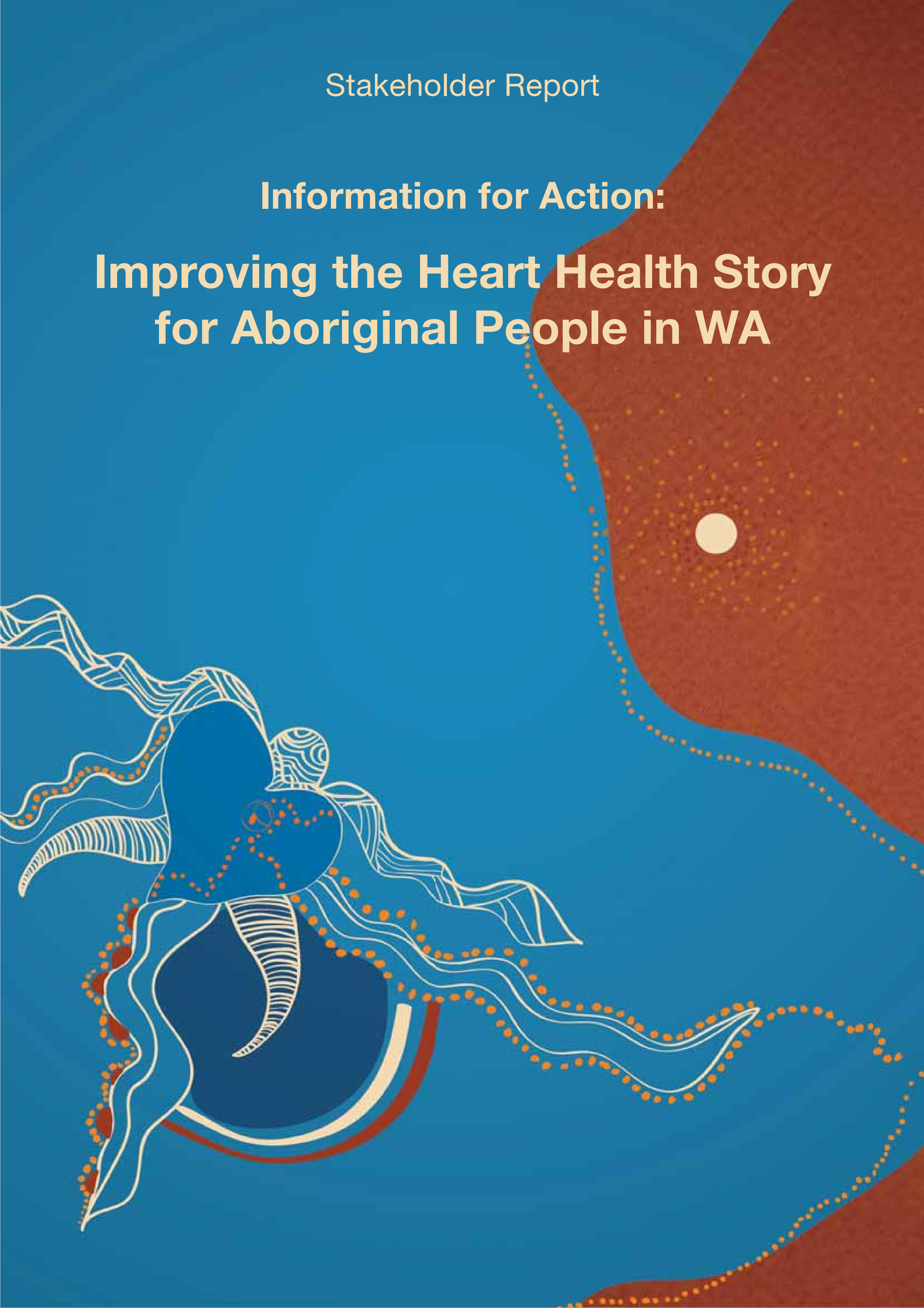
Stakeholder Report

# Information for Action:

# Improving the Heart Health Story for Aboriginal People in WA



## Acknowledgements

We acknowledge the traditional custodians of the land across Western Australia and their Elders past and present.

Members of the Heart Foundation in WA, in particular Lyn Dimer, Trevor Shilton and Julie Smith, have been an integral part of the BAHHWA project since its inception. We appreciate the constructive advice provided by the Cardiovascular Health Network of the WA Health Department, in particular Kim Goodman, Jacquie Garton-Smith, and Tony Mylius.

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## How this report should be cited:

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*these authors contributed equally to this work

## Use of the term 'Aboriginal'

Within Western Australia, the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of Western Australia. No disrespect is intended to our Torres Strait Islander colleagues and community.

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# Improving the Heart Health Story for Aboriginal People in WA

BAHHWA

Bettering Aboriginal Heart Health In Western Australia

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# Contents

# Executive Summary

This report primarily draws on research looking at disparities between Aboriginal and non-Aboriginal Western Australians in cardiovascular health and health care, conducted with funding from three research grants, the most recent known as the *Bettering Aboriginal Heart Health in WA* project. The methods used have included interviews, reviews of hospital records, analyses of linked hospital and mortality data, and literature reviews. Part I of the report primarily comprises summaries of the studies along with Key Findings and Recommendations arising from the research, while Part II details ‘Strategies for Action’ incorporating input from stakeholders and other strategic documents.

## Key findings

### Occurrence of heart attacks, heart failure and atrial fibrillation

The incidence of heart attacks as well as the frequencies of first-ever hospitalisation for heart failure and atrial fibrillation (AF) are much higher in Aboriginal people than non-Aboriginal people aged less than 65 years, with the disparities compared to non-Aboriginal people particularly high in early adulthood and among women. Disparities are greatest for heart attack and heart failure. Co-morbidities are significantly more common among Aboriginal patients; the presence of other illnesses (e.g., diabetes, chronic kidney disease, chronic obstructive pulmonary disease, rheumatic heart disease) means that managing disease is more difficult because of case complexity.

### Factors contributing to heart disease

Access to education, employment and health care influences people’s behaviours and lifestyle. Improving the circumstances in which people live, work and play are important for both preventing and treating heart disease. In addition, actions to target modifiable risk factors, for example smoking, will contribute significantly to reducing heart disease rates in Aboriginal people. Our research showed that although Aboriginal Health Workers (AHWs) have knowledge of the health risks of smoking, many have poor knowledge of quitting methods and often feel uncomfortable suggesting quitting to patients. Many Aboriginal people are fatalistic about their risk of heart disease and don’t realise that their risk can be reduced substantially by addressing many modifiable factors.

### Outcomes after heart attacks, heart failure and atrial fibrillation

Aboriginal people are twice as likely to be readmitted or die within two years of having a heart attack (once factors like age, other illnesses and rural location have been taken into account). Similarly, Aboriginal patients admitted with AF have a higher likelihood of death after 1 year than non-Aboriginal AF patients, after adjustment for these factors. In the case of heart failure, younger Aboriginal patients are twice as likely to die within the first year of their first hospitalisation. The much greater occurrence of comorbidities has a large impact on poorer Aboriginal outcomes.

### Aboriginal heart patients in hospital

Complex patient and service factors cause delays in accessing and receiving prompt, effective hospital treatment. Competing cultural, family and personal responsibilities as well as logistical challenges (like great distances and transport) can cause delays in accessing treatment. Limited understanding among staff of Aboriginal culture and communication styles and consequent miscommunication can reinforce perceptions of discrimination, meaning that Aboriginal people feel unwelcome and unsafe in hospital. This in turn affects patient behaviour and attitudes to treatment. Aboriginal patients with heart disease are 2.4 times more likely to discharge against medical advice, even after other contributing risk factors (like youth, alcohol/drug problems and male gender) have been taken into consideration. Employing Aboriginal health professionals has a positive effect on heath care for Aboriginal heart patients.

Among patients hospitalised in rural Western Australia for ischaemic heart disease, factors such as older age, the presence of comorbidities and lack of private health insurance (but not Aboriginal status *per se*) are associated with missing out on receiving coronary angiograms, when other factors are taken into account. However, these risk factors are much more common in Aboriginal people, who are therefore disproportionately affected. Among patients who have heart attacks in the Perth metro area, older Aboriginal patients are less likely than older non-Aboriginal patients to receive an angiogram, although for younger patients there is no difference in the likelihood of Aboriginal and non-Aboriginal people having an angiogram once other factors are taken into account. State-wide, receipt of evidence-based medicines at hospital discharge is equally likely in Aboriginal and non-Aboriginal heart attack and unstable angina patients, once other factors are considered.

### Ongoing care

Positive educational messages, explanations of medications and family support are central to the ongoing treatment of Aboriginal patients with existing heart disease. Evidence has shown that cardiac rehabilitation reduces risk factors and can prevent recurrence. 'System' deficiencies—particularly poor communications between services—impair continuity of care and contribute to many of the instances in which Aboriginal patients with heart disease fail to receive cardiac rehabilitation. Aboriginal patients report that media messages about Aboriginal heart health are negative and off-putting, making them less motivated to be involved in rehabilitation programs; additionally they often feel out-of-place at cardiac rehabilitation, partly because they tend to be younger than other patients. Often non-Aboriginal health professionals lack understanding about these factors and the need to be more encouraging and flexible to support better patient outcomes.

## Strategies for Action

To improve Aboriginal heart health we need to: (1) reduce the number of new cases of heart disease and cases occurring at a young age (primary prevention), and (2) improve treatment of Aboriginal patients with existing heart disease (secondary prevention). Strategies need to be implemented at three levels simultaneously: the individual-family-community level; the organisational level (services); and the government/policy level. Many of the recommendations made below are illustrated in the report through the use of case studies.

## Recommendations

### Reduce the high incidence of premature heart disease

- Implement policies across sectors to reduce disadvantage and barriers to healthy lifestyle
- Work with communities to make healthy choices easy choices
- Conduct heart health screens for risk factors, treatment and follow-up from early adolescence with appropriate advice and follow-up of findings
- Encourage businesses and Aboriginal community organisations to focus on healthy work/organisational environments, healthy life choices and screening
- Develop social marketing (i) to raise awareness and understanding of heart disease as having many modifiable risk factors, and (ii) to overcome feelings of powerlessness to change anything (fatalism). Work with Aboriginal community organisations and Aboriginal media to disseminate positive messages and facilitate normalisation of healthy choices.
- Encourage businesses/community organisations to support Aboriginal reconciliation and development where feasible by providing health programs for Aboriginal staff and community members

- Use opportunities presented by a 'teachable moment' following a cardiac event for engaging family and community members in reducing their own risks

**Address clinical, social and logistical complexity**

- Enhance multi-disciplinary health professional training around the State to recognise and manage heart disease appropriately, including through access to appropriate advice and guidelines
- Build the diversity and cultural understanding of the multi-disciplinary health workforce to prevent and manage chronic disease
- Boost numbers of Aboriginal health professionals and provide training and support for their role in patient care
- Enhance access to specialist advice and support to primary care and hospital clinical staff, particularly in rural areas
- Produce clinical guidelines and pathways that are relevant to the region where patients live and which take account of complex health and social issues
- Address financial barriers to uptake of cardiac assessment and management
- Recognise the importance of and address social and emotional wellbeing as well as conventional risk factors
- Consider both patient and family in the approach to care
- Develop/enhance culturally appropriate secondary prevention/cardiac rehabilitation services for all people, regardless of where they live
- Ensure mechanisms exist locally and within health care services to provide social and logistical support for Aboriginal patients in need

**Enhance inadequate systems**

- Promote primary health care as the central co-ordinating service for primary and secondary prevention of heart disease
- Establish seamless, high-quality health information processes and electronic patient information record systems to optimise flow of information within and between health service providers, particularly between primary care and hospital services
- Develop co-ordinated and supported cardiac care pathways across the state, including appropriate transfer system for patients between hospitals and between hospital and community
- Strengthen the inpatient experience and discharge processes for Aboriginal cardiac patients
- Establish mechanisms to ensure cultural security for patients, including ways in which family members can assist and support affected people during their patient journey
- Employ appropriate staffing to ensure communication between Aboriginal patients and staff, in particular Aboriginal health professionals and interpreters
- Strengthen organisational structures to incorporate Aboriginal health professionals as integral part of the clinical team
- Employ dedicated hospital-based staff to co-ordinate between hospital and primary care

## Conclusions

Aboriginal people experience both illness and death from heart disease at higher rates and at a much earlier average age than non-Aboriginal people. Many are further disadvantaged by living in rural and remote areas distant from centres of health service provision. The data underscore the urgency to direct efforts ‘upstream’ towards primary prevention and earlier, community-based detection and intervention. There is a need for more holistic and culturally appropriate approaches to health service delivery. Access to high quality primary health care, incorporating improved integration (e.g., multidisciplinary teams) and continuity (linkages between primary and specialist/hospital care) is vital. In addition to in-patient clinical excellence, the hospital system must address the need for augmented discharge processes for Aboriginal patients, strengthened Aboriginal Health Liaison Officer programs and up-to-date information technology solutions to ensure continuity of care and optimal outcomes.

We have high quality information to inform progress in this context. Knowledge translation is paramount, and we must consciously regard data as the basis for directing our efforts for improvement in the health of Aboriginal people. To deliver the best possible outcomes, efforts need to be sustainable and founded on partnerships incorporating the broader Aboriginal community as well as linking organisations. We hope that the strategies proposed in this *Information for Action* Report will serve to inspire actions to make a difference to the health of Aboriginal Western Australians.

# Introduction

In Australia, Aboriginal people are overrepresented in all markers of health and social disadvantage. Cardiovascular diseases (CVD) are the most common causes of death in the Aboriginal population and the main contributor to the profound life-expectancy gap between Aboriginal and non-Aboriginal populations. Aboriginal Australians are more likely to die from coronary heart disease, stroke and other cardiovascular conditions, are more likely to be hospitalised, and suffer adverse outcomes more frequently than their non-Aboriginal counterparts. The age-standardised rates of death from CVD among Aboriginal males and females are, respectively, 2.8 times and 2.4 times those of their non-Aboriginal counterparts. Hospitalisations for CVD are 1.4 times more frequent than among non-Aboriginal Australians. Of most concern, these disparities are greatest among younger individuals.

Research is still needed to tease out the nature of disparities in cardiovascular health and health care, and to understand the best ways to translate this information into action to close the gaps. Prompted by this need for more research to inform effective actions, a group of Western Australian health researchers commenced a broad-based research program in 2007, funded by a series of grants:

- *Beating Longer, Beating Stronger* (funding 2007–2008: State Health Research Advisory Council [SHRAC], WA Department of Health)
- *The Management of Coronary Heart Disease in the Indigenous population in WA: From Information to Action* project (funding 2007–2011: National Health and Medical Research Council [NHMRC])
- *Bettering Aboriginal Heart Health in WA* (BAHHWA) (funding 2012–2014: NHMRC)

The research initially centred on coronary heart disease, with statistical analysis of state-wide WA data, to determine the occurrence, comorbidities and outcomes for Aboriginal people, including age, sex, and geographic distributions. The team is now also studying other heart conditions such as heart failure and abnormalities of heart rhythm (dysrhythmias). Key heart conditions covered in this report are briefly explained in boxes in the relevant sections (See Boxes 4, 5, 6 and 7).

Qualitative research was undertaken on the experiences of both the Aboriginal people affected by these illnesses and the health professionals involved in their care. This research aimed to understand the barriers and enablers of quality care provision and to promote optimal models of care. These original research projects were supplemented with critical reviews of published literature, resulting in stand-alone publications on the topics of interest.

The BAHHWA project has had significant input from a number of key partnerships, including with the Heart Foundation, and the Cardiovascular Health Network and Aboriginal Health Division of the WA Department of Health. Table 1 shows the key people involved. More details on the researchers involved in the publications summarised in this Report are provided in Appendix 1.

*Use of the term 'Aboriginal'*

Within Western Australia, the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of Western Australia. No disrespect is intended to our Torres Strait Islander colleagues and community.

**Table 1. The BAHHWA research and knowledge translation team**

| Western Australian Centre for Rural Health | School of Population Health UWA | Other UWA | Heart Foundation (WA) | Clinical/Policy |
|---|---|---|---|---|
| Prof Sandra Thompson | Dr Frank Sanfilippo | Prof Dawn Bessarab[1] | Ms Lyn Dimer | Clin Prof Peter Thompson[3] |
| Dr Judith Katzenellenbogen | E-Prof Michael Hobbs | Dr Angela Durey[2] | Mr Trevor Shilton | Prof Joe Hung[3] |
| Ms Emma Haynes | Prof Matthew Knuiman | | | Dr Marianne Wood[4,5] |
| Dr Derrick Lopez | Dr Tom Briffa | | | Ms Kim Goodman[6] |
| Dr Tiew-Hwa Teng | Assoc Prof Liz Geelhoed | | | Assoc Prof Andrew Maiorana[4,7] |
| Mr John Woods | Dr Pam Bradshaw | | | Prof Patricia Davidson[8,9] |
| Dr Kaniz Gausia | | | | Dr Ben Scalley[10] |
| Dr Sandy Hamilton | | | | |
| Dr Shaouli Shahid | | | | |

1. UWA Centre for Aboriginal Medical & Dental Health, 2. UWA School of Dentistry, 3. Sir Charles Gairdner Hospital, 4. Royal Perth Hospital, 5. Aboriginal Health Council of Western Australia, 6. Health Network, WA Department of Health, 7. Curtin University, 8. Johns Hopkins University, Baltimore, USA, 9. University of Technology Sydney, 10. WA Department of Health

## Purpose of this Report

The BAHHWA project has produced an important body of work concerning heart disease among Aboriginal Western Australians. In this Report we present a range of these results, aiming to influence the policy and organisational factors that impact on Aboriginal heart health. By providing epidemiological and service information about Aboriginal inequities in disease occurrence, care and outcomes, this Report has a focus on initiating and supporting health system change. Health care providers, the organisations they work in, and policy makers all have a significant role in improving Aboriginal health outcomes. We hope this Report will be useful to clinicians (doctors, nurses, Aboriginal health professionals, health promotion staff, allied health practitioners), those in policy and planning (politicians, peak interest groups, health service managers) and those providing education and training (universities, professional bodies, Aboriginal training organisations).

## Structure of the Report

This Report is in two parts. *Part I* reports primarily on the BAHHWA research, much of which has already been published, though we have also drawn on research done by others to provide a more complete picture of the story. For example, acknowledging the significance of social, historical, economic and cultural factors, we have included an initial section sourced from external research titled 'Opportunities for health', to provide a context for the origins of heart disease in Aboriginal people. The structure of Part I is based on the *Heart Disease Story* (see Figure 1), which reflects the complex links between socio-economic factors, opportunities that influence lifestyle choices critical for health (e.g., diet, physical activity, and smoking), biological determinants of heart disease, health service provision and outcomes. While Figure 1 presents this as a linear process, we recognise that the links shown are neither inevitable nor necessarily linear for an individual; for example, some people may go through some stages more than once.

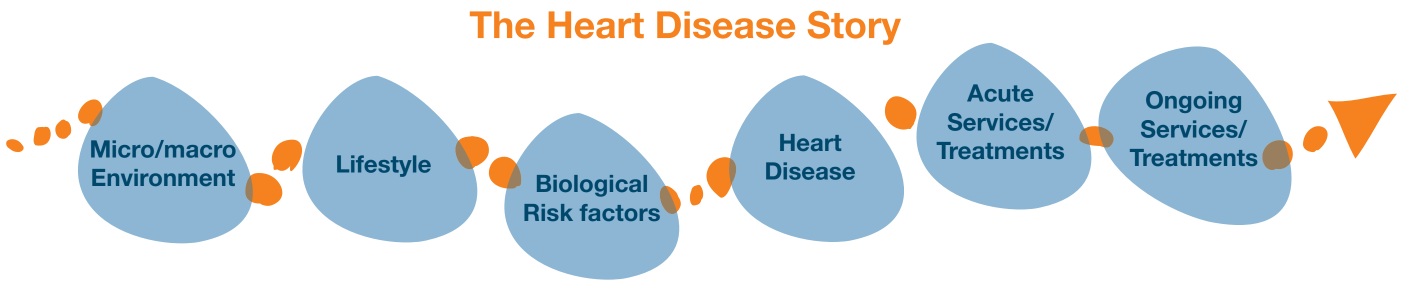


**Figure 1. The Heart Disease Story**

In *Part II* of this Report we look in detail at what can be done to address the heart health challenges identified by the research in *Part I*. Recommendations at community, organisational and policy level are discussed. This reflects the inter-sectoral and intercultural partnership approach needed to implement strategies for action and the importance of taking structural, social, historical, economic and cultural factors into account.

## How to read this Report

We aimed to make this Report accessible to a diverse audience.

The patterns on top of the pages and pages numbers have been colour-coded.

| Section | Colour | Page number |
|---|---|---|
| Executive Summary<br>Introduction | ▨ | Fawn |
| Part I | ▨ | Blue |
| Part II | ▨ | Brown |
| Conclusion, Appendices and References | ▨ | Yellow |

**Key Messages** are highlighted at the start of each section. In **Part I**, **Recommendations** arising from the research are highlighted at the end of each section.

Throughout the report, supplementary information is provided in **Boxes** labelled according to type of content:

- **Medical Descriptions** (for non-medically-trained readers) of the key conditions reported on
- **Case Studies** of success stories in improving Aboriginal Heart Health
- **Workshop Suggestions** for approaches to improving Aboriginal Heart Health
- **Approaches to Practice** offer suggestions to specific issues

The following resources are provided at the back of the Report:

- Summary of Medication Access Schemes for Indigenous Australians
- Consumer Rights statement
- List of toolkits, useful websites and other helpful resources
- Glossary of technical terms used in the Report
- References

## How did we do the research?

The research program components used a variety of methods. These are summarised in Table 2. More details about the methods used are shown in Box 1. There is a further discussion of data quality in Appendix 2: Shortcomings in Aboriginal health data.

**Table 2. Research methods used**

| | RESEARCH METHODS | | | | |
|---|---|---|---|---|---|
| | **Literature Review** | **Written questionnaire** | **Qualitative research** | **Linked data analysis** | **Review of clinical notes** |
| **Lifestyle:** | | | | | |
| Smoking & Quitting | ✓ | | ✓ | | |
| **Cardiac events:** | | | | | |
| Heart attacks | | | | ✓ | |
| Atrial Fibrillation | ✓ | | | ✓ | |
| Heart Failure | ✓ | | | ✓ | |
| **Acute Services/ treatments:** | | | | | |
| Hospital transfers | | | | ✓ | |
| Coronary investigations | | | | ✓ | |
| Coronary interventions | | | | ✓ | |
| Evidence-based drugs | | | | ✓ | ✓ |
| Hospital experience | ✓ | | ✓ | | |
| DAMA* | | | | ✓ | |
| **Ongoing services/ treatments:** | | | | | |
| Cardiac Rehabilitation | | ✓ | ✓ | | |
| Readmissions | | | | ✓ | |
| **Knowledge translation** | | | ✓ | | |

*DAMA = Discharges against medical advice

N.B. This table does not include our critique of policies

Before starting each element of the research program, the investigators team which included Aboriginal people made sure it was culturally appropriate and that there would be close collaboration with—and feedback to—Aboriginal stakeholders. The following steps were taken:

- Aboriginal research team members provided important feedback on the steps proposed to ensure the research was culturally appropriate
- There was close engagement with the Aboriginal Health Unit of the Heart Foundation, both in WA and nationally, including joint workshops, sharing of resources and partnership development (see also Part II)
- The research was approved by the WA Aboriginal Health Ethics Committee (WAAHEC) as well as other Human Research Ethics committees (multiple approvals)
- A BAHHWA Knowledge Translation Reference Group, made up of relevant Aboriginal and non-Aboriginal health professionals with extensive experience in Aboriginal health and health advocates, was involved in the development of this Report, through regular meetings and individual correspondence and contact (see also Part II)

BACKGROUND

**Box 1**

## Research methods used

Part of the research focused on learning about the experiences and opinions of Aboriginal people who have used health services because they were affected by heart disease. The researchers interviewed Aboriginal people and the health professionals who looked after them in hospital or during post-discharge care (e.g., rehabilitation programs). Some people were interviewed one-on-one, others were involved in focus group discussions, while some completed questionnaires.

Meanwhile, other members of the research team analysed data on heart disease in WA, comparing Aboriginal with non-Aboriginal people. They explored the frequencies of illnesses such as heart attacks and heart failure, tests and treatments performed in hospital for these, and outcomes like recurrence and death. The researchers used whole-of-WA data over several years that are routinely collected by hospitals and government agencies. The de-identified data from these different sources were linked together by the WA Data Linkage Unit. (See Box 2 and Appendix 2 for more detail.)

Other studies already published on heart disease in Aboriginal people also provided important information. The research team carefully checked databases for existing research relevant to certain aspects of heart disease in Australian Aboriginal people and similar topics. They then put together overviews of these topics, each containing a list of all the research papers and a summary of what had been discovered.

Refer to Table 2 for an outline of methods used for different sub-studies.

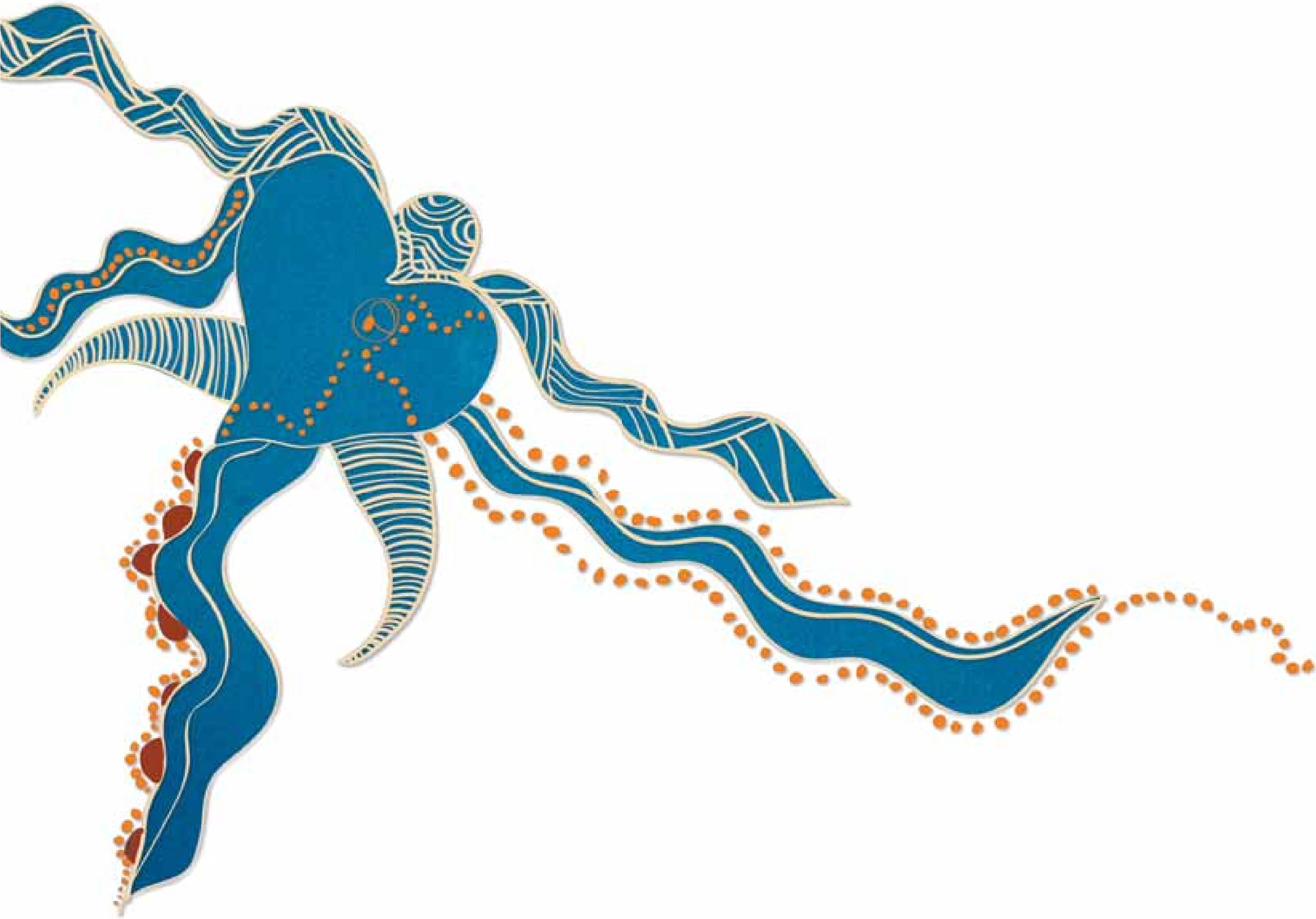
BACKGROUND
Box 2

## Linked Data for Health Research

Health information is routinely collected from different sources by governments and other agencies to provide statistics on how many people are admitted to hospitals (hospital data), die from different causes (mortality data), get diagnosed with cancer (cancer register), have babies (maternal and child data base) and attend emergency departments (ED data). Usually these datasets ‘stand alone’ and are analysed separately. Often, even within one of these datasets (e.g., hospital admissions), researchers cannot determine which records belong to the same person. This limits the type and usefulness of information that can be derived.

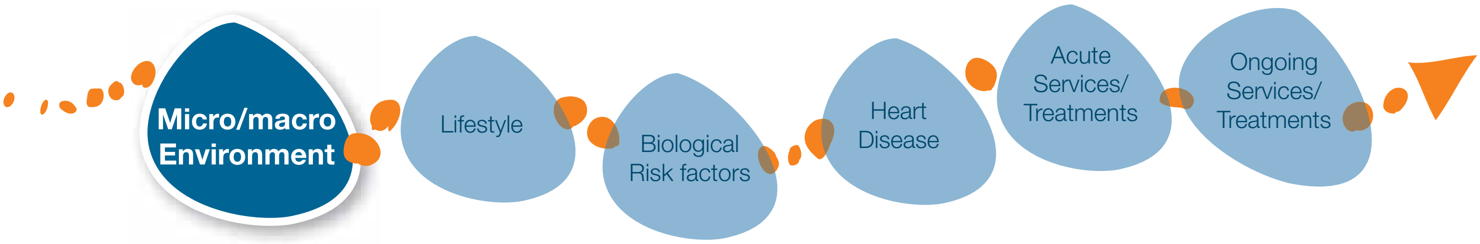
Western Australia has the infrastructure to link the records belonging to a single person within a source and from different sources. This is like creating a ‘book of life’ that follows a person from birth through their health-related events, providing profiles of people, their health service use and health outcomes. The researcher obtains these data in anonymous form, so confidentiality is ensured. This is a very useful facility that has produced much useful research making an impact on policy and practice. The Lowtija Institute promotes more use of linked data to provide useful information for Aboriginal health.[1]

# **Part I:**
# Research



# Health, Cardiovascular Disease and Life Opportunities

# 1



## Factors associated with the development of CVD in Aboriginal populations

As with all populations, CVD in Aboriginal people is the result of exposure at an individual or group level to many inter-related risk factors. These factors are generally experienced at much higher levels—and in more complex combinations—among Aboriginal people than in the non-Aboriginal population.[2]

### Key Findings

Many Aboriginal people, historically and currently, experience severe socio-economic inequities.

These inequities result in a higher risk of serious illnesses.

Inequities experienced by Aboriginal people can affect their health long before they become overtly unwell.

Access to education, employment and health care influences people's behaviours and lifestyle choices.

There is great diversity in the Aboriginal population with respect to language, culture, socio-economic status and family cohesion. Despite the strong kinship-based resilience in Aboriginal culture, many Aboriginal Australians continue to experience significant social disadvantage. When compared with the non-Aboriginal population as a whole, Aboriginal Australians are more likely to live in housing with poor sanitation and environmental conditions, to experience high levels of stress and social dysfunction, to experience adverse life events and illness throughout the life-course (particularly in childhood), to have poor educational attainment and income or be unemployed, and to live in rural and remote regions (isolated from necessary services). They are also less likely to receive evidence-based health care. These are all important contributors, both directly and indirectly, to excess levels of physical, emotional and social ill health. It is therefore not surprising that Aboriginal people are more likely than non-Aboriginal Australians to exhibit many of the documented risk factors for cardiovascular conditions.[3]

Societal and historical factors also impact significantly on the health of Aboriginal people. 'The loss of culture, land and identity, perpetuation of covert and overt racism, the impact of premature death, perpetual grieving and the lack of opportunity have long been highlighted by Indigenous individuals and organisations as fundamental causes of ill health'.[2] Family and community responsibilities are important elements of the social structure of Indigenous communities. For some Aboriginal people this connection to family and community is supportive, for others it can place demands on them that mean they are more at risk than others of being unable to commence or sustain healthy lifestyles.[2] (See Figure 12 in Part I, Section 7 for examples of the range of patient and service factors that BAHHWA research identified as contributing to delays in Aboriginal cardiac patients from northern WA accessing the acute care they need).

The relationship between social and environmental factors impacting on health, individual attributes including lifestyle, physiological risk factors and heart disease is summarised in Figure 2. Non-modifiable factors with which people are born (e.g. age, sex) form the base of the pyramid. The social and environmental factors (green level) influence Aboriginal people's opportunities to make healthy lifestyle choices (e. g. diet, smoking, activity). Unhealthy lifestyles in turn manifest in physiological CVD risk factors (e.g., high blood pressure, atherosclerosis) which ultimately cause heart disease and lower life expectancy.

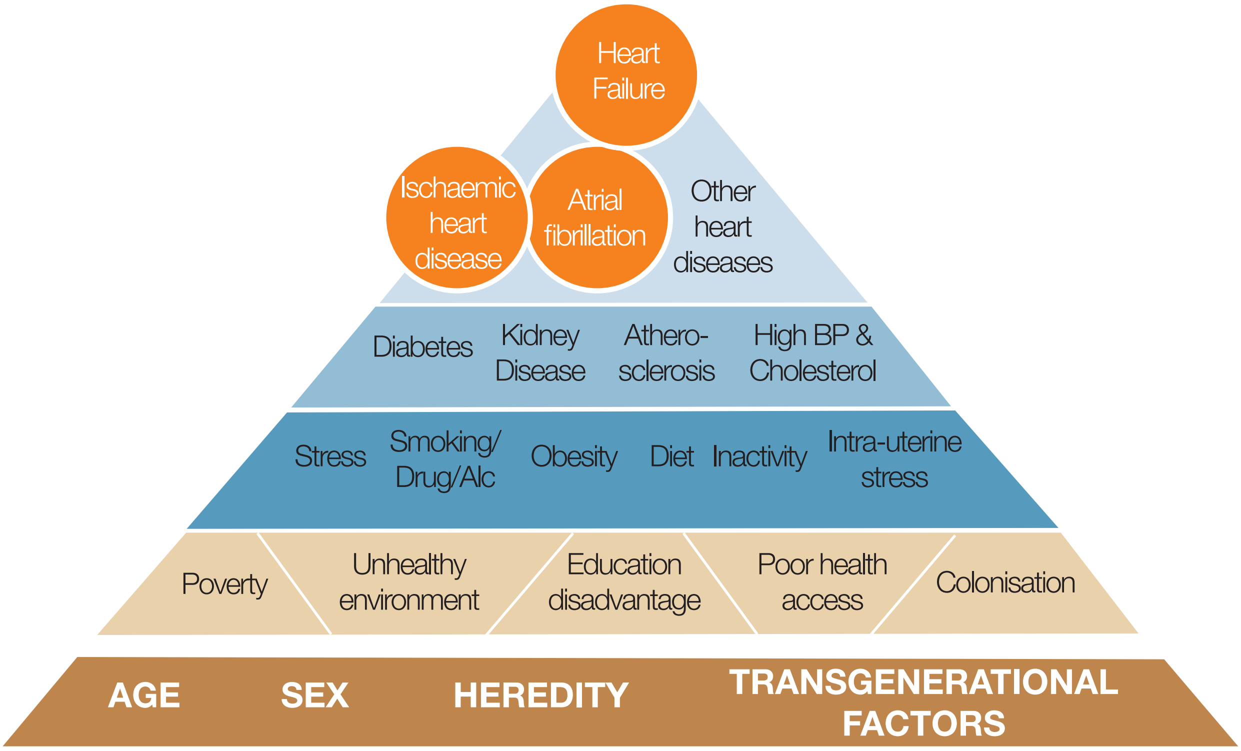


**Figure 2. Pyramid of Aboriginal heart disease**

Katzenellenbogen JM, Teng TH, Lopez D et al. Science Lands in Parliament seminar (2013)[4]

The 'Heart Disease Story' used to structure this Report reflects a simplified version of this description of the relationship between broader social factors and individual disease.

## Creating opportunities for health

As discussed, the environmental and social conditions in which people are born, grow up, live, work and age can be considered to provide opportunities for health. They influence the extent to which people have the physical, social and personal resources to:

- identify and achieve personal goals
- satisfy needs of daily living
- cope with the environment[5]

In this way, the capacity to make healthy choices is modified by social forces and social context.

While the current project does not include research specifically related to these factors, we include this section to draw attention to broader structural, social, economic and cultural factors affecting Aboriginal heart health. This is particularly important in the context of the holistic view of Aboriginal health, which incorporates the physical, social, emotional and cultural wellbeing of individuals and their communities.

> *The holistic view of health of Indigenous Australians is evident in their capacity to sustain self and community in the face of a historically hostile and imposed culture. Unique protective factors contained within Indigenous cultures and communities have been sources of strength and healing when the effects of colonisation and what many regard as oppressive legislation have resulted in loss, grief and trauma. That is, culture and spirituality are ongoing sources of strength and social and emotional wellbeing.*[6]

Family connections, culture and belonging, as well as notions of identity and history, are therefore important determinants of health. The cultural determinants of health approach originates from and promotes a strength-based perspective, ‘acknowledging that stronger connections to culture and country build stronger individual and collective identities, a sense of self-esteem, resilience, and improved outcomes across the other determinants of health including education, economic stability and community (see Figure 3).

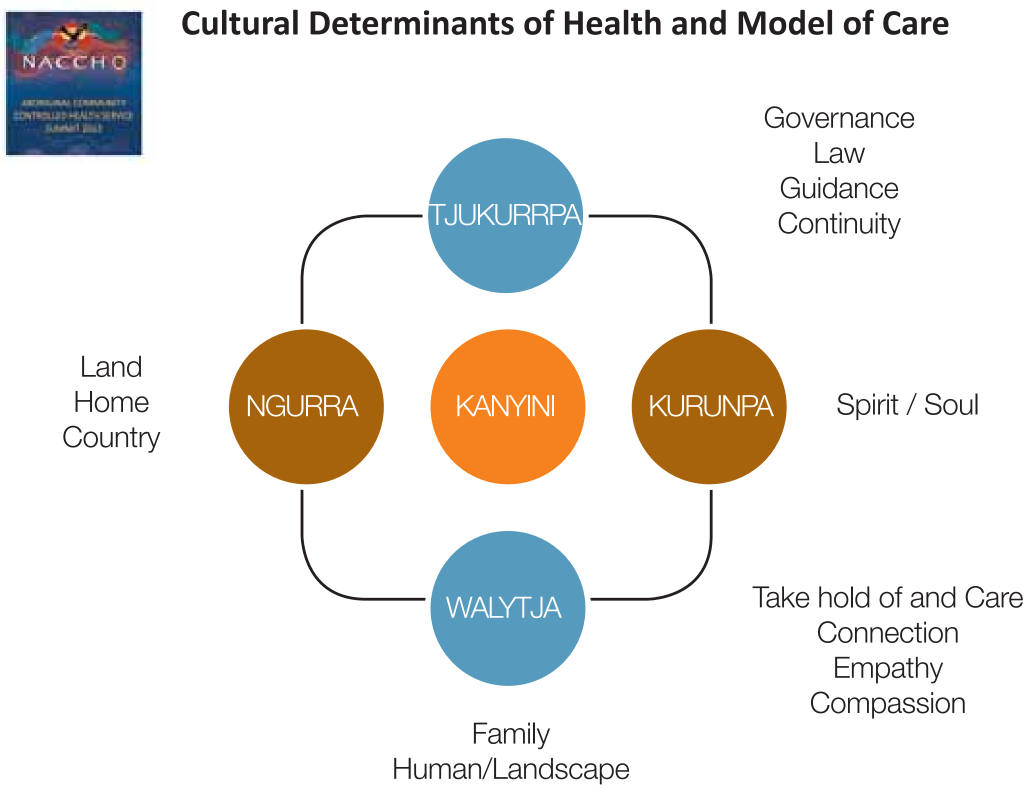
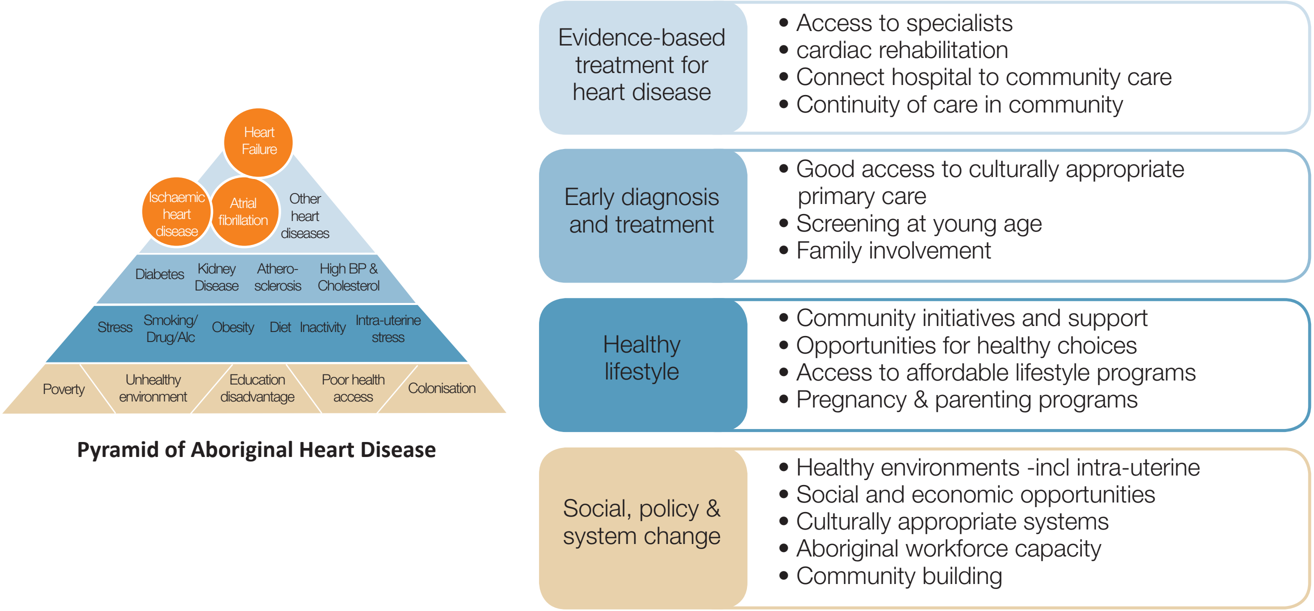


**Figure 3. Cultural Determinants of Health and Model of Care**

Brown N. NACCHO Aboriginal health: Culture is an important determinant of health (2013)

http://nacchocommunique.com/2013/11/08/naccho-aboriginal-health-culture-is-an-important-determinant-of-health-professor-ngiare-brown-at-naccho-summit/

The cultural determinants of health and wellbeing may be seen as 'cutting across individual, internal, external and collective factors. This approach recognises that there are many drivers of ill-health that lie outside the direct responsibility of the health sector and which therefore require a collaborative, inter-sectoral approach' (Ngaire Brown, 2013, http://nacchocommunique.com/2013/11/page/3/). Consequently, actions at many levels and across all sectors of administration (e.g., housing, transport, education and employment as well as health *per se*) are needed to improve Aboriginal health. Figure 4 portrays the types of actions that are needed to address the various levels at which Aboriginal opportunities for health operate and can be influenced.



**Pyramid of Aboriginal Heart Disease**

| | |
|---|---|
| Evidence-based treatment for heart disease | • Access to specialists<br>• cardiac rehabilitation<br>• Connect hospital to community care<br>• Continuity of care in community |
| Early diagnosis and treatment | • Good access to culturally appropriate primary care<br>• Screening at young age<br>• Family involvement |
| Healthy lifestyle | • Community initiatives and support<br>• Opportunities for healthy choices<br>• Access to affordable lifestyle programs<br>• Pregnancy & parenting programs |
| Social, policy & system change | • Healthy environments -incl intra-uterine<br>• Social and economic opportunities<br>• Culturally appropriate systems<br>• Aboriginal workforce capacity<br>• Community building |

**Building Blocks of Solutions**

**Figure 4. Building blocks of solutions to address pyramid of Aboriginal heart disease**

Katzenellenbogen JM, Teng TH, Lopez D et al. Science Lands in Parliament seminar (2013)[4]

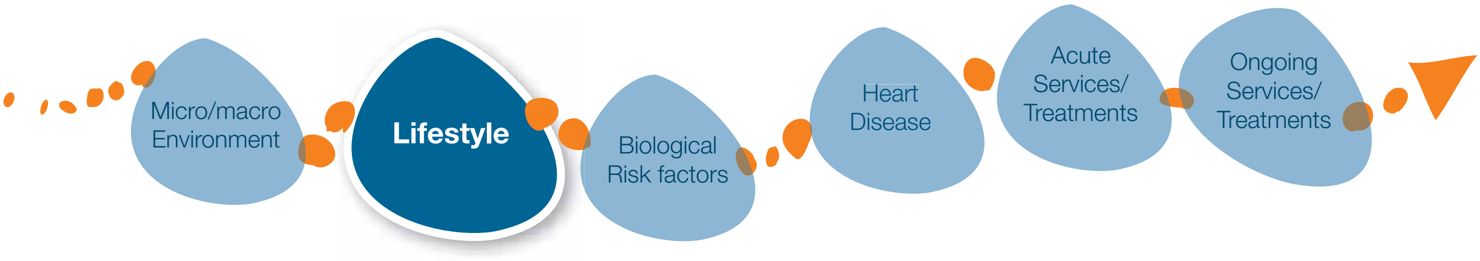
An approach to reducing the higher risk of disease among disempowered, disadvantaged groups requires simultaneously:

- reducing social inequality through policy initiatives
- providing infrastructure that facilitates healthy ways of living
- building the resilience of individuals and communities through information, skills development and social capital building[7]
- inter-sectoral government collaboration

That is, action needs to happen at three levels: the individual-family-community level, the health service organisational level, and at a broad-based government/policy level. Part II of this Report continues this discussion, and gives details of actions at these three levels, as well as resources to support these actions and a series of 'good news' case studies.

# Lowering Risks: Smoking and Quitting

2



## Context

There is no single cause for heart disease; rather, there are many risk factors that increase the chance of its development. While some risk factors such as family history, gender and age cannot be modified, other risk factors can. These modifiable risk factors include unhealthy behaviours such as tobacco exposure (active and passive smoking, chewing tobacco), physical inactivity, unhealthy diets, and harmful use of alcohol, as well as medical conditions such as hypertension (high blood pressure), high cholesterol, obesity, and diabetes. Depression, social isolation and lack of support also impart a higher risk of heart disease. Stress and poverty influence many aspects of life and can underpin many high-risk behaviours. They also impact on how people perceive their ability to have control over their lives.

## Key Findings

Smoking contributes significantly to high heart disease rates in Aboriginal people.

Although Aboriginal Health Workers have knowledge of the health risks of smoking, many have poor knowledge of quitting methods and often feel uncomfortable suggesting quitting to patients.

Cessation programs targeting Aboriginal people have to be carefully designed and implemented, with consideration given to community consultation and preferences, cultural safety (setting and mode of delivery), logistical barriers to participation, and embedding programs in a holistic philosophy of health and culture.

Smoking was included in our research as an example of a lifestyle choice strongly associated with poor health, particularly in people who start smoking at a young age and smoke heavily. It is well known that smokers are more likely to develop coronary heart disease and many other health problems, such as other disorders of the circulation (stroke, blocked arteries in the legs), lung problems (chronic obstructive pulmonary disease [commonly known as emphysema]) and many common types of cancer (such as cancers of the lungs and throat). Stopping tobacco use can reduce the risk of cardiovascular disease significantly, no matter how long a person has smoked.

Proportionally smoking rates are higher in the Aboriginal community[8] and this is one of the many reasons that Aboriginal people have a shorter life expectancy. As discussed in the previous section, lifestyle choices like smoking are influenced by access to education, health services and socioeconomic disadvantage. Lack of awareness of the health effects of smoking and the normalisation of smoking in some communities are other factors.

It can be very difficult to stop smoking, so people often need help to quit. Programs that help people to quit smoking can be aimed at three different levels:

1. the individual smoker
2. the individual's family and community
3. the whole society (through government policies).

Quit methods aimed at individual smokers usually involve counselling by a health professional (either face-to-face or via telephone, e.g., 'QuitLine') and/or by drug therapy (nicotine replacement therapy [NRT]) administered orally or by skin patch. For the best chance of quitting, a combination of counselling and NRT is more effective than either alone.[9] Others may just quit without extra support, but this is uncommon.

## How was the research done?

The researchers wanted to find out what other studies had previously been done on interventions to help Indigenous people quit smoking. This was done in order to understand better what works and what doesn't. Internet databases were searched for relevant journal articles from Australia, New Zealand, United States and Canada.[8]

In another study, the research focused on the important role of Aboriginal Health Workers (AHWs) in helping people to quit smoking.[10] Not much is known about the beliefs and practices of AHWs in this important part of their work. Some Health Workers are smokers themselves, and this might affect their practice. The researchers interviewed 36 AHWs by telephone to find out more about their knowledge and practices of smoking and methods of quitting.

## What did the research find out?

The literature review identified several key factors critical to the design and implementation of smoking cessation programs in Aboriginal people. These important characteristics included:

- engaging in community consultation and ensuring community ownership of programs,
- conducting interventions in culturally safe, community-based settings,
- embedding programs within the community's philosophy of health and culture,
- recruiting multidisciplinary teams to deliver programs, including both Indigenous and non-Indigenous personnel,
- requiring non-Indigenous team members to have undergone cultural sensitivity training,
- tailoring programs and resources to reflect community needs and preferences,
- considering and addressing environmental and logistical factors, such as transport, that may impact people's ability to participate in programs.

The AHW study showed that the health workers generally had a reasonably good knowledge of the health risks of smoking. However, many of the AHWs did not have good knowledge of quitting methods. Also, some AHWs told researchers they were uncomfortable with bringing up the issue of quitting with patients who smoke. They gave several reasons for this. They said that telling other people what to do can be difficult in Aboriginal culture (e.g., 'They would tell you "where to go" … it's up to them … they know the dangers.')[10] Also, the AHWs who themselves smoked said they felt like hypocrites if they advised someone else to quit (e.g., 'I'm a smoker. If I can't quit, how can I tell anyone [else to quit]?')[10]

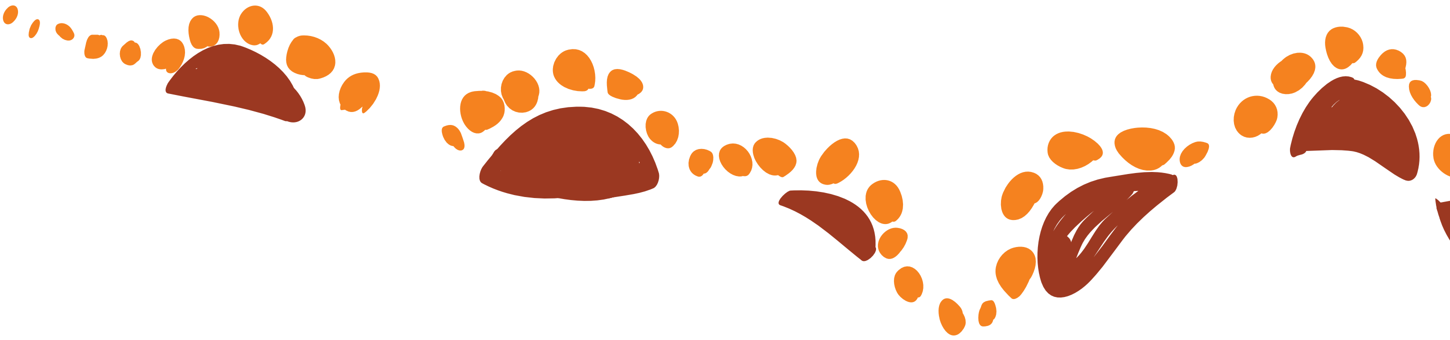
Recently instituted nationwide programs to reduce smoking levels in Indigenous communities have been informed by research of the type mentioned in this section. (See Box 3 ‘Smoking reduction and Closing the Gap’ page 20).

## Recommendations

Smoking cessation:

- Institute programs that increase the knowledge and skills of Aboriginal health professionals (particularly AHWs) in promoting smoking cessation.
- Develop adequately funded, culturally appropriate interventions for health professionals who are smokers.

See Part II - Section 2 gives practical suggestions about developing and delivering community based programs and services; Section 3 includes suggestions about required organisational changes and Section 4 includes Policy recommendations to support these actions.



CASE STUDY

**Box 3**

## Smoking Reduction and Closing The Gap

In recognition of the importance of reducing smoking levels for closing the gap in life expectancy (https://www.humanrights.gov.au/close-gap-indigenous-health-campaign), the Federal Government has funded a national *Tackling Indigenous Smoking* program from 2010 onwards, to raise awareness, provide education and challenge Indigenous community norms in relation to smoking and other chronic disease risk factors.

Dr Tom Calma AO, respected human rights and social justice campaigner and Kungarakan (NT) Elder, was appointed to oversee the implementation of the program. The program is nationwide in scope but localised in implementation. Its approach is team-based and multifaceted. For each of 57 regions involved in the program, the team responsible for implementing the program comprises a Regional Tobacco Coordinator and up to three Tobacco Action Workers who work with Indigenous communities, as well as two Healthy Lifestyle Workers who complement the anti-smoking initiatives by promoting physical activity and healthy eating habits.

The program is collaborative (often involving the local Aboriginal Medical Service as well as community members), highly flexible, innovative and tailored to the different needs of each community.

Dr Calma has commented that:

> ‘*One of the really good things is that once a community has come up with an action plan to combat smoking, we can provide them with $110,000 a year to implement the program without them having to jump through any more hoops. This new way of doing business involves a recognition that combating smoking is not just a responsibility of government; it’s an opportunity for Aboriginal and Torres Strait Islander people as individuals to get involved and to take ownership of issues at the local level. Everywhere I go now people are thanking me for doing something about smoking. We’re raising awareness and we’re getting a lot of support*.’

(http://www.lowitja.org.au/editorial-tom-calma)

Examples of local programs include:

- the Tharawal Aboriginal Corporation Aboriginal Medical Service (NSW), where weekly community workshops have been conducted, with community kitchen and garden projects established
- the Miwatj Project (NT), in which the team collaborated with Skinnyfish Music and community members to produce six smoking cessation advertisements that were posted on YouTube (www.youtube.com/watch?v=H2k83EL3a5M), uploaded onto mobile phones and ‘blue toothed’ across the region and beyond to promote the messages

To date, these programs have not been evaluated at a national level. However, there is encouraging evidence that smoking among Indigenous Australians has diminished in recent years. According to surveys conducted by the Australian Bureau of Statistics, in the period 2002 to 2012-3, the proportion of current daily smokers (of those aged 15 years and over) fell from 51% to 43% in males and 47% to 39% in females. The target is to achieve by 2018 the same levels of smoking among Aboriginal and Torres Strait Islander populations as currently exists in the non-Indigenous population (about 13%).

http://www.lowitja.org.au/editorial-tom-calma
http://blogs.crikey.com.au/croakey/2013/04/09/an-update-on-efforts-to-reduce-indigenous-smoking-rates/
http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/39E15DC7E770A144CA257C2F00145A66?opendocument

# First-ever Heart Attack: Rates and Outcomes

# 3

## Context

Cardiovascular disease is the leading contributor to the Aboriginal burden of disease, accounting for 17% of total burden and being 4.6 times more frequent (per capita) in Aboriginal than in non-Aboriginal people.[11]

Despite the many reports highlighting the disparities in cardiovascular health, detailed study of the epidemiology of ischaemic heart disease (IHD) in Aboriginal people is limited.

## How was the research done?

Using linked records from WA over a five year period (2000-2004), the researchers calculated how often first-ever heart attacks occurred in Aboriginal people aged 25-74 years compared with others, and also compared the outcomes.[12] In making these comparisons, other factors that contribute to the risk of heart attack, such as older age and gender, were taken into account. Comparisons were also made between people living in rural areas and metropolitan Perth.[13] A related part of the research followed-up the records of people for two years after their first heart attack.[14]

## Key Findings

Aboriginal people are much more likely than non-Aboriginal people to have heart attacks or to die of heart disease.

The disparity in heart attack rates between Aboriginal and non-Aboriginal people is greatest in the younger age groups, with Aboriginal people tending to have heart attacks at a younger age than others.

Aboriginal people have twice the risk of readmission or death within the first two years of a heart attack (once factors like age and co-existing conditions have been taken into account).

## What did the research find out?

### 1. Risk of having a heart attack

Aboriginal people tended to have heart attacks at a younger age than others, as shown by the different shape of the Aboriginal and non-Aboriginal age pyramids in Figure 5. The average age at the time of first heart attack was 50 years among Aboriginal and 64 years among non-Aboriginal people. Women accounted for a higher percentage of Aboriginal cases than of non-Aboriginal cases.

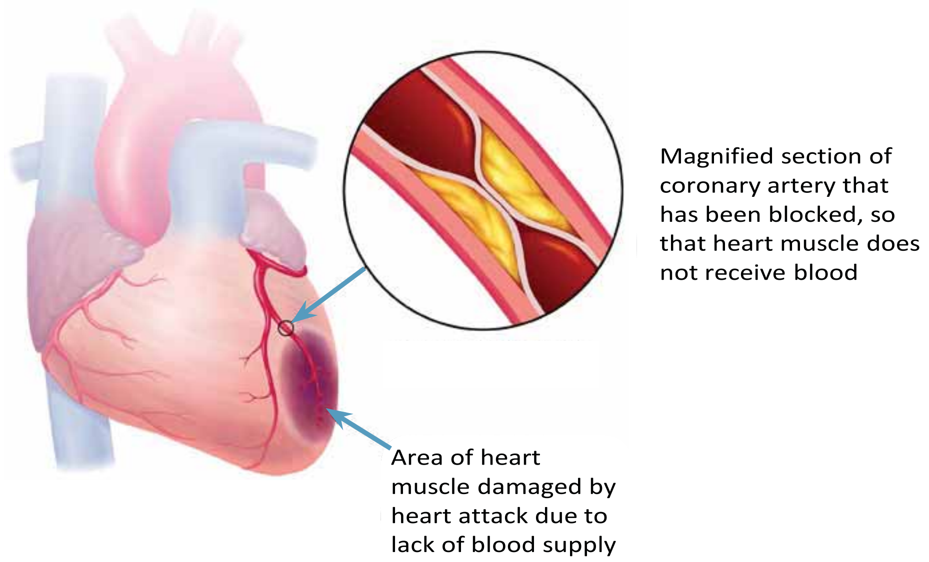
**Box 4**

MEDICAL DESCRIPTION

## Coronary Heart Disease (Ischaemic Heart Disease)

The heart muscle needs its own constant oxygenated blood supply so that it can pump blood to all parts of the body without stopping. Blood for the heart muscle flows through blood vessels located on the outside surface of the heart, known as coronary arteries. In *coronary heart disease*, areas of narrowing known as plaque develop over the years, due to gradual injury to the lining of these arteries causing the build-up of cholesterol, calcium and scar tissue. This narrowing of the arteries reduces the blood supply to the heart muscle. Consequently, this condition is also called *ischaemic heart disease*: ischaemia means insufficient blood supply to body tissues.

If the plaque cracks suddenly, blood clotting can occur and block the narrowed arteries, cutting off blood supply to part of the heart. A heart attack (*myocardial infarction*) occurs if part of the heart muscle is injured when this happens. A heart attack can sometimes be fatal, either because the damage to the heart muscle is so severe that the heart can no longer pump sufficiently to maintain life, or because the heart develops an abnormal rhythm that stops it from beating effectively (dysrhythmia). Even if someone survives a heart attack, the heart muscle can be permanently damaged to the point where it cannot pump properly any more, in which case *heart failure* develops (see also Box 5, Section 4).



Source of graphic:
Web-based resource: Teaching patients about cardiovascular events (2014)
http://sites.psu.edu/nurseswithheartabouthearts/category/all-about-the-heart/

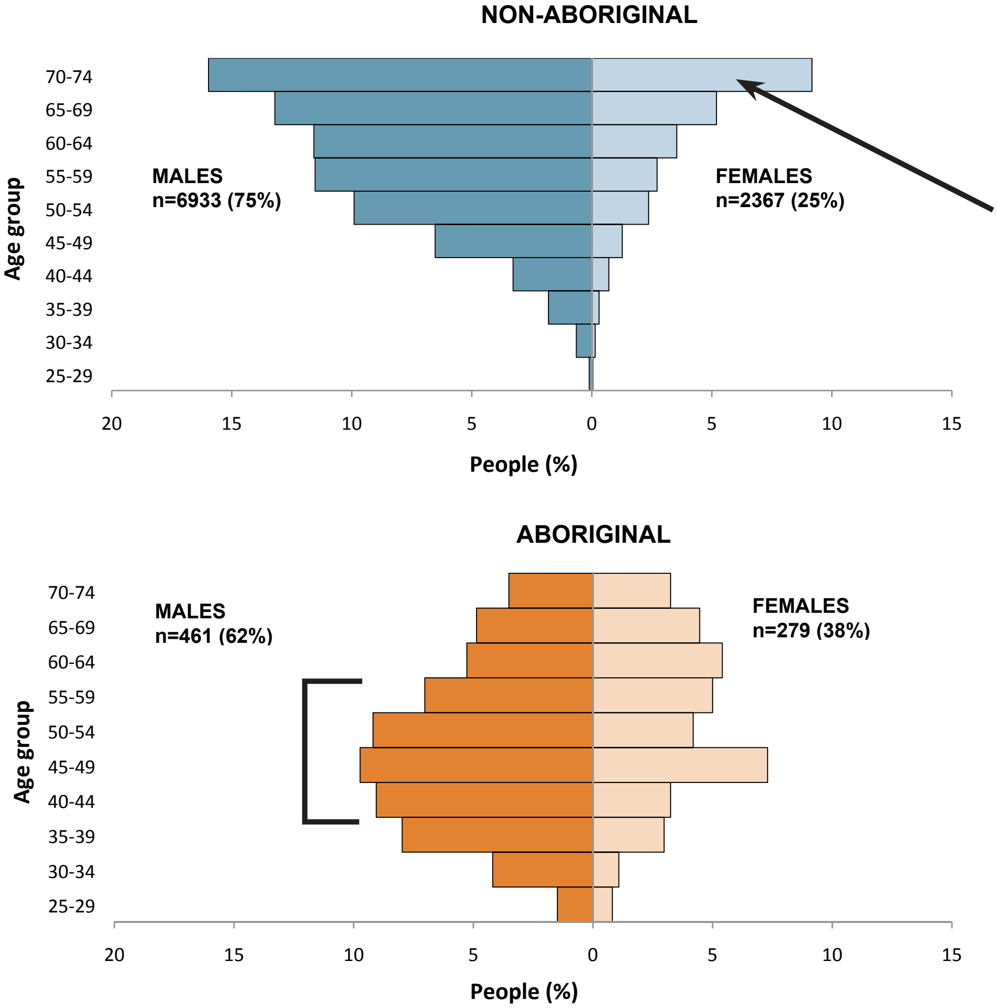


**Figure 5. Age and sex distribution of Aboriginal and non-Aboriginal first heart attack cases aged 25-74 years**

Katzenellenbogen JM, Sanfilippo FM, Hobbs MST et al. Heart Lung Circ (2010)[12]

## Interpretation

Each horizontal bar is the percentage of people in an age group. Oldest on top.

**Non-Aboriginal cases**

- Oldest age groups have the highest percentage of cases
- 25% of non-Aboriginal cases are women (light shading)

**Aboriginal cases**

- 7% of cases were Aboriginal
- Ages 35 to 54 years have the highest percentage cases, especially men (see black bracket)
- 38% of Aboriginal cases are women (light shading)

Aboriginal cases are YOUNGER and a higher percentage are women compared with non-Aboriginal cases

Aboriginal people are at substantially greater risk of having a heart attack than non-Aboriginal people (Figure 6). The disparity in risk of heart attack was greatest in the younger age groups. In fact, Aboriginal men 25-34 years were about 16 times more likely to have a heart attack than non-Aboriginal men in the same age group. This disproportion was even greater for Aboriginal women than men (Figure 6). Generally, Aboriginal people living in rural areas did not have higher heart attack rates than those living in the Perth metropolitan area.[13]

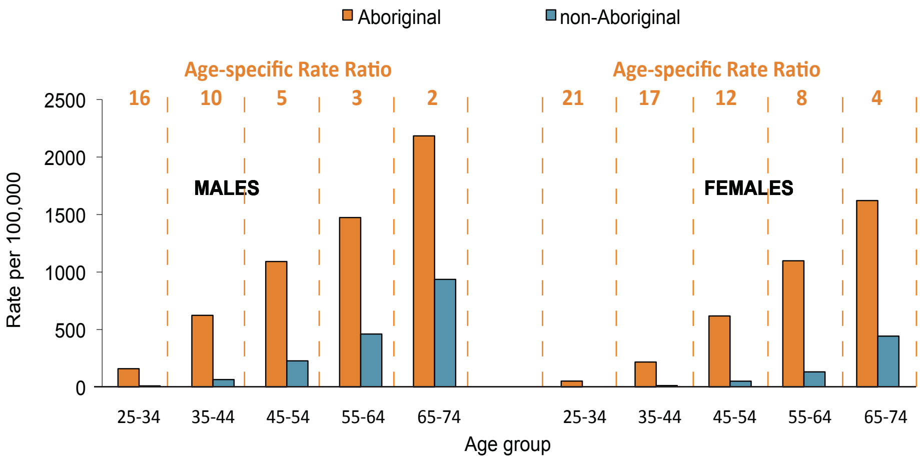


**Figure 6. Heart attack rates, WA 2000-2004 by Aboriginality, age and sex**

Katzenellenbogen JM, Sanfilippo FM, Hobbs MST et al. Heart Lung Circ (2010)[12]

## Interpretation

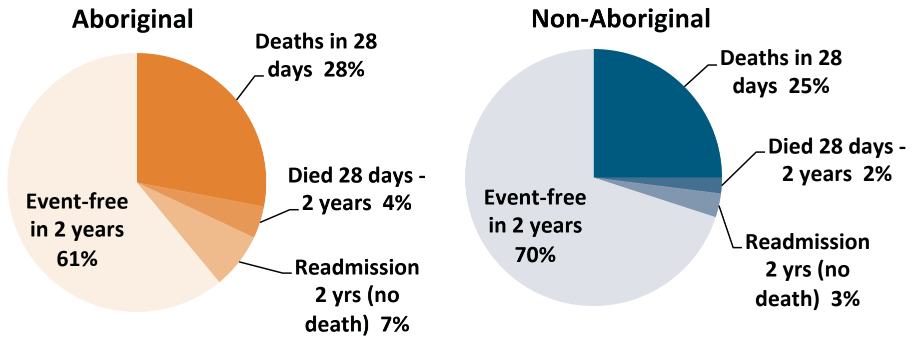
Vertical bars show heart attack rates for each age group.

The ratios in the highlighted text (orange) reflect the Aboriginal divided by the non-Aboriginal rates for each age group. This indicates how many times greater the Aboriginal rate is than the non-Aboriginal rate in each age group.

- Aboriginal rates are higher in every age group for both men and women
- In the 25-34 year age group, Aboriginal rates are 16 times higher for males and 21 times higher for females.
- Rate ratios go down with age (2 to 4 times higher in 65-74 year age group)

## 2. Risk of recurrence or death after heart attack

Figure 7 shows that Aboriginal people were less likely than non-Aboriginal people to be event-free (i.e., not to have had another heart attack or have died from CVD) two years after their first heart attack (61% versus 70%). When factors like their younger age and more remote location had been taken into account, Aboriginal men and women were more than twice as likely as others to have another heart attack admission or to die of heart disease within two years. A large part of these differences was related to Aboriginal people being much more likely to have other chronic illnesses such as diabetes and kidney disease. Aboriginal people without other major chronic conditions fared only marginally worse than non-Aboriginal people in terms of survival.



## Interpretation

A higher proportion of non-Aboriginal (70%) than Aboriginal (61%) people with heart attacks were event-free (no readmission or death) after two years.

Note: This comparative graph does not take into account differences in age, location and other illnesses.

**Figure 7. Two-year outcomes after heart attack WA 2000-2004**

Katzenellenbogen JM, Sanfilippo FM, Hobbs MST et al. Heart Lung Circ (2010)[12]

Katzenellenbogen JM, Sanfilippo FM, Hobbs MST et al. Eur J Prev Cardiol (2012)[14]

## Recommendations

Primary prevention strategies are needed to reduce the incidence of heart attacks:

- Promote co-operation across different sectors to reduce socioeconomic, environmental and cultural barriers to uptake of healthy lifestyle choices and messages
- Partner with Aboriginal consumers,* Aboriginal Community Controlled Health Organisations and communities to facilitate uptake of health messages
- Disseminate positive messages emphasising what Aboriginal people can do to reduce their risk of heart attack
- Institute systematic as well as opportunistic risk factor screening and treatment for Aboriginal people from young ages

Secondary prevention is needed to reduce the severity and recurrence of heart attack and to reduce deaths:

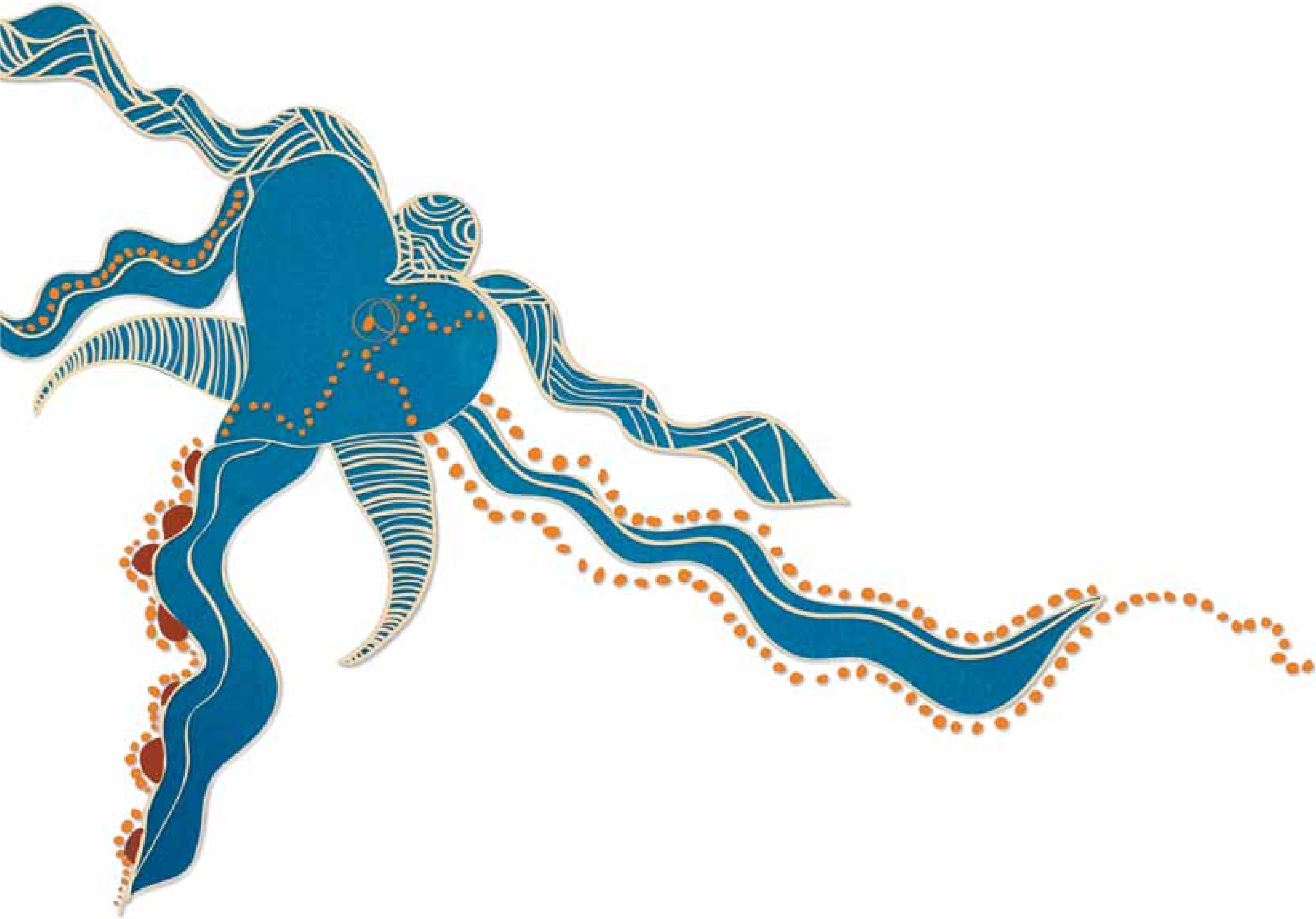
- Improve infrastructure to facilitate speedy access to hospital
- Adhere to evidence-based guidelines for assessment and management during admission
- Promote comprehensive post-discharge planning, including improved communication between GPs and specialists, and adherence to evidence-based guidelines
- Improve availability of and increased referral to culturally appropriate cardiac rehabilitation services post-discharge

*see (i) Appendix 4: Health service expectations: a matter of patient and consumer rights

(ii) National Safety and Quality Health Service: *Standard 2—Partnering with Consumers*

http://www.safetyandquality.gov.au/wp-content/uploads/2012/01/NSQHS-Standards-Fact-Sheet-Standard-2.pdf)

See Part II - Section 2 gives practical suggestions about developing and delivering community based programs and services; Section 3 includes suggestions about required organisational changes and Section 4 includes Policy recommendations to support these actions.



# First-ever Heart Failure Hospitalisations: Rates and Outcomes

# 4

## Key Findings

Aboriginal people are 3-5 times more likely than other Australians to have heart failure.

First hospitalisations for heart failure occur at much younger ages among Aboriginal people.

Younger Aboriginal heart failure patients are twice as likely to die from heart failure within the first year after their first hospitalisation.

## Context

Heart failure occurs as a result of other diseases of the circulatory system, so is considered a complication of these other conditions. Although much research has been done on the underlying diseases likely to cause heart failure in Aboriginal people, not much is known about heart failure itself in this population. The Australian Institute of Health and Welfare (AIHW: http://www.aihw.gov.au/) reports that Aboriginal people are almost twice as likely to have heart failure compared with other Australians, with hospital admission rates for heart failure being three times higher.[15] It appears that Aboriginal people are more than twice as likely as other Australians to die from heart failure.[16] However, the figures for Aboriginal people with heart failure may be an underestimate—heart failure is generally not a well-reported diagnosis and Aboriginal people are undercounted in the health system because Aboriginal status is not well recorded.[17,18]

Proper treatment can improve and prolong the lives of people with heart failure, so it is important to understand as much as possible about this condition: how often it occurs in Aboriginal communities, what is causing it, and how well health services are looking after people who have the condition. Although there is research already available showing clearly that Aboriginal people are more likely to have problems with heart failure, more work is needed.

## How was the research done?

There were four research studies for this component of the heart disease story.

1. First, researchers attempted to find everything that had already been published about heart failure in Aboriginal Australians. They made a thorough search of journal articles and government reports.[19]

2. Using linked data from Western Australian hospital and death records from 2000 to 2009, researchers calculated how often first-ever hospitalisations for heart failure occurred in the Aboriginal compared with the non-Aboriginal population. Mortality rates within 30 days and 1 year following first heart failure hospitalisation were also compared, taking into account differences between Aboriginal and non-Aboriginal people with respect to age, sex, comorbidities, type of hospital, where people lived and what procedures they received. Comparisons of conditions that might contribute to heart failure (e.g., high blood pressure, previous heart attack, diabetes) in Aboriginal and non-Aboriginal people were also made.[20]

3. Using the same dataset as above, researchers compared trends over 10 years between Aboriginal and non-Aboriginal heart failure patients in relation to risk factors for heart failure and mortality.
4. Comparisons of patterns of readmissions to hospitals over three years between Aboriginal and non-Aboriginal heart failure patients following their first heart failure hospitalisation.[21]

**Box 5**

MEDICAL DESCRIPTION

### Heart failure

Heart failure (HF) is a complex condition resulting from the inability of the heart to fill with or eject blood adequately. It does not mean the heart has stopped working completely, but rather that the heart muscle does not pump sufficiently to meet the needs of the body. Common causes of HF include heart attacks, high blood pressure, rheumatic heart disease and other disorders of the heart valves, heavy alcohol use and chronic obstructive pulmonary disease. Heart failure can cause fatigue, shortness of breath and a decreased exercise capacity and is associated with episodic or chronic fluid retention (e.g., swollen ankles). The symptoms and signs of heart failure are non-specific in some cases, making diagnosis difficult.

This cartoon of heart failure shows that the heart has to work harder because of the impairment in the 'pump mechanism'.

Treatments for HF include medications that reduce the load on the heart muscle (e.g., ACE Inhibitors and beta-blockers) or remove excess fluid (diuretics). Lifestyle changes are also recommended, including gentle physical activity balanced with adequate rest, quitting smoking, dietary changes, and restriction of alcohol. The underlying cause is treated when possible, e.g., medications to reduce high blood pressure, procedures to open blocked coronary arteries, or surgical repair of damaged heart valves. In extreme cases, a heart transplant may be recommended.

Text adapted from:
http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Congestive_heart_failure_%28CHF%29

Source of image: GloShiv Web Services.Web-based cartoon (Managing Heart Failure)
http://findmedicalsolutions.com/blog/congestive-heart-failure/

## What did the research find out?

Very few journal articles have been published on this topic. One study of Aboriginal people living in a Central Australian community found that 5 per cent of the adults had heart failure, which is much higher than in Australia generally. About two thirds of these had never been diagnosed before.[22] This suggests that there may be many Aboriginal people who have heart failure that has never been diagnosed. Studies focussing on other conditions (for example, heart attack) have found that a much higher proportion of Aboriginal patients had heart failure as a comorbidity compared with other patients.[14,23] Another study measured the distribution of specialist services for heart failure around Australia and demonstrated that Australians in rural and remote areas had poorer access to these specialised services.[24] This would particularly affect Aboriginal people, because many live in rural and remote areas.

Our research using hospital records[20] found that:

- Aboriginal people were more likely than non-Aboriginal people to have a first heart failure hospitalisation (3 times in men, about 5 times in women).
- Compared with other people, heart failure was found to occur at a younger average age in Aboriginal people (mean age 54 years vs 71 years). The disparity in rates was greater in young people and in women (Figure 8).
- Risk factors for HF including heart attack, high blood pressure, rheumatic heart disease, chronic kidney disease and renal failure, and chronic lung disease were significantly more common in Aboriginal than non-Aboriginal heart failure patients.
- The presence of high blood pressure and heart attacks, as the top contributors to heart failure, increased by a larger extent in Aboriginal patients with heart failure between 2000 and 2009.
- The presence of diabetes and chronic kidney disease were two times higher in Aboriginal patients at all time periods between 2000 and 2009.
- After adjustment for various related factors, there was no difference in early 30-day mortality between Aboriginal and non-Aboriginal patients.
- However, mortality within a year of hospitalisation was twice as high in younger (under 55 years) Aboriginal people but not in older patients (55 years and over).
- During the 3-year follow-up after first heart failure hospitalisation, a higher percentage of Aboriginal patients were readmitted for heart failure. The majority of these were emergency presentations.
- The time to readmission was shorter in Aboriginal HF patients and readmissions were more frequent but shorter than in non-Aboriginal patients (especially in people under 55 years).

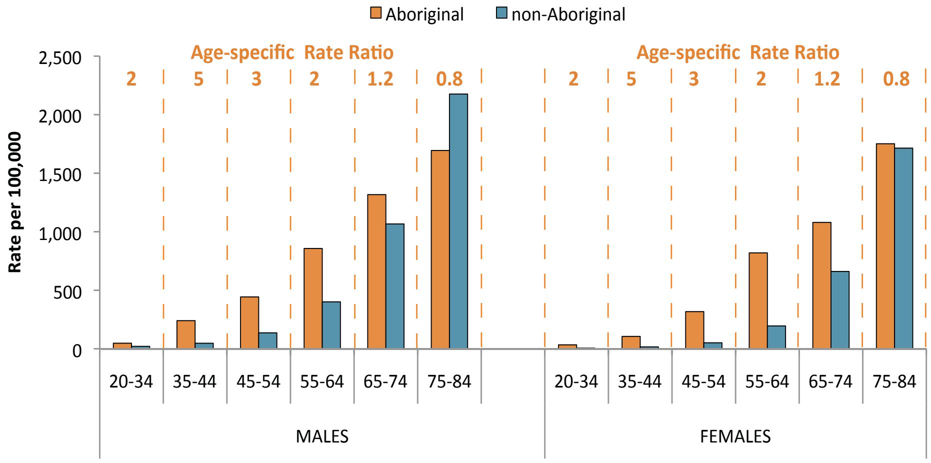


**Figure 8. Age-specific rates of first heart failure hospitalisation, WA 2000-09**

Teng TH, Katzenellenbogen JM, Thompson SC et al. Int J Cardiol (2014)[20]

## Interpretation

The ratios in the highlighted text (orange) reflect the Aboriginal divided by the non-Aboriginal rates for each age group

- Aboriginal rates are higher in every age group
- In the 20-39 year age group, Aboriginal rates are 12 times higher for males and 23 times higher for females.
- Rate ratios go down with age (1.5 and 2 times higher for Aboriginal people in the 70-84 year age group)

## Recommendations

Primary prevention of heart failure:

- Screen and aggressively treat risk factors and other chronic conditions underlying heart failure among Aboriginal people
- Reduce socioeconomic and cultural barriers to uptake of health messages and treatments through co-operation across the different sectors of government and partnering with Aboriginal consumers, services and communities

Secondary prevention of heart failure:

- Implement clear, evidence-based guidelines particularly for patients with multiple chronic health problems, and audit the implementation of guidelines
- Improve systems to support management of Aboriginal patients with heart failure in hospital and in the community: access to specialists, culturally appropriate care (including interpreters), cardiac rehabilitation services, discharge planning and follow-up care[25]
- Stress benefits and importance of evidence-based medications to service providers and patients

See Part II - Section 2 gives practical suggestions about developing and delivering community based programs and services; Section 3 includes suggestions about required organisational changes and Section 4 includes Policy recommendations to support these actions.

# First-ever Hospitalisations for Atrial Fibrillation: Rates and Outcomes

5

## Context

Atrial fibrillation (AF) is the most common serious sustained disturbance of heart rhythm (see Box 6). Heart failure (HF) and stroke are common complications of AF, with 15-20% of strokes being attributed to AF. AF is further associated with stroke recurrence and severity. It is also associated with a 50-90% increase in mortality risk and significant physical disability. In developed countries the prevalence of AF is increasing due to an increase in incidence as well as an ageing population. There is little information regarding AF among Indigenous populations in developed countries, despite documented high rates of predisposing factors and implications for poor outcomes. This is also true in Australia where AF has not been studied in detail in the Aboriginal population.

## Key Findings

In younger age groups, Aboriginal people are much more likely than non-Aboriginal people to be admitted with AF, but are more likely to have another condition as the main reason for these admissions.

Aboriginal people admitted with AF are more likely than others to have co-existing heart failure, diabetes or kidney disease, and are at higher risk of stroke.

After taking into account factors such as age, other illnesses and rural location, Aboriginal patients admitted with AF have a higher likelihood of death after 1 year than non-Aboriginal AF patients.

## How was the research done?

A similar methodology was used as for the heart failure research (Section 4). Using linked data from Western Australian hospital and death records from 2000 to 2009, researchers calculated how often first-ever hospitalisations for AF occurred in the Aboriginal compared with the non-Aboriginal population. Comparisons of conditions that might contribute to AF (e.g., high blood pressure, previous heart attack, diabetes) in Aboriginal and non-Aboriginal people were also made, and the risk of stroke in non-rheumatic patients was also assessed. Mortality rates within 30 days and 1 year following first AF hospitalisation were compared, taking into account differences between Aboriginal and non-Aboriginal people with respect to age, sex, comorbidities, type of hospital, where people lived and what procedures they received.

## What did the research find out?

Our research using hospital records found that:

- Rates of first-ever hospitalisation for AF (as a main or co-diagnosis) were higher in Aboriginal people at all ages less than 65 years but similar at older ages (Figure 9).

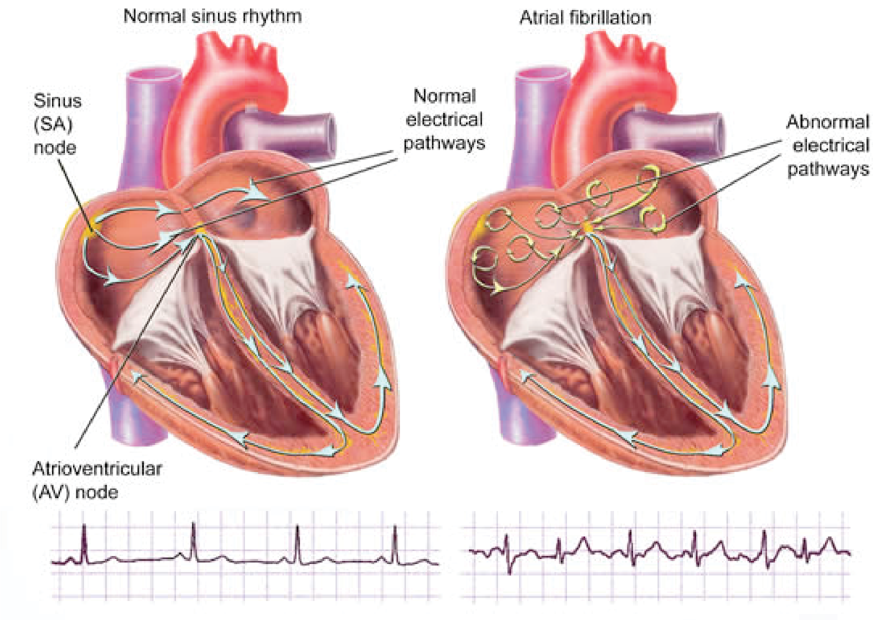
**Box 6**

MEDICAL DESCRIPTION

## Atrial Fibrillation

*Atrial fibrillation* (AF) is a type of disturbance of heart rhythm (*dysrhythmia*). The heart's pumping action is regulated by its internal electrical circuitry. Normally, the heart beat is initiated by a regular impulse arising in the heart's natural 'pacemaker' (the *sino-atrial [SA] node*), which is located within the right atrium, one of the heart's upper chambers. The electrical impulse spreads progressively from the node to all parts of the heart, and in doing so, causes the heart muscle to contract in a coordinated fashion.

In AF, a chaotic electrical circuit within the atria overrides the normal pacemaker function. As a result, the atria quiver ('fibrillate') rather than contract effectively. Furthermore, the electrical impulse is conducted in an irregular fashion to the lower heart chambers (ventricles) responsible for most of the heart's pumping action. This results in an irregular—and usually rapid—heartbeat.



Also, within the non-contracting atrial chambers, blood tends to stagnate and can form clots. In these circumstances, the heart can eject fragments of clot (emboli) into the circulation. These emboli can block arteries, resulting in complications such as stroke (from brain embolism) or gangrene (limb embolism).

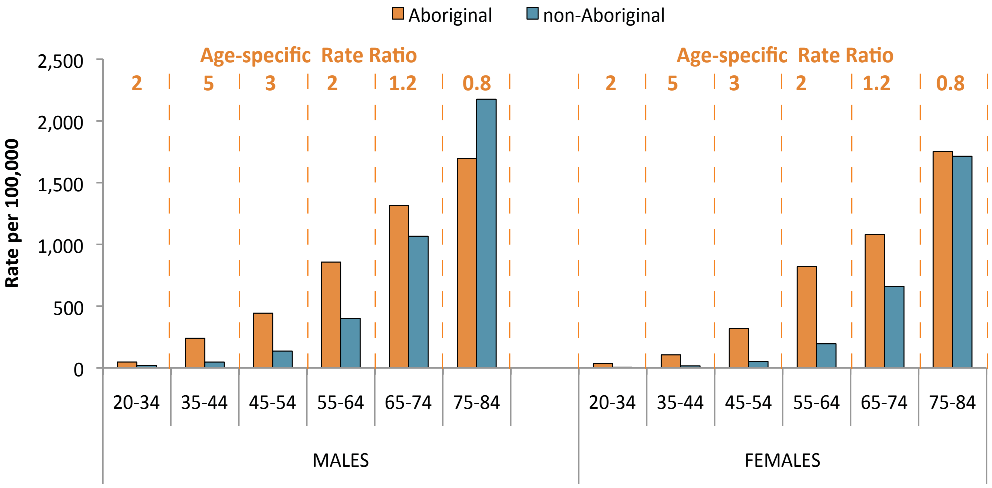
Most cases of AF result from strain or injury of the atrial tissue due to cardiovascular disorders such as *myocardial infarction*, *hypertension* or *rheumatic heart disease*. However, there are many other causes, including major surgery, alcohol intoxication, or an overactive thyroid gland. In some instances, no cause can be found.

Symptoms of AF include palpitations and lightheadness, in some cases along with symptoms of *heart failure* or *ischaemia*. However, *AF quite often occurs with no overt symptoms*. It can be a self-limiting, short term condition or may be chronic (sustained in the long-term).

The management of AF includes (i) identifying and, if possible, treating the underlying cause/s; (ii) reversal of the abnormal rhythm by an electric shock (cardioversion) in cases where the underlying cause can be reversed; (iii) long-term slowing of the heart rate with medications if a return to normal 'sinus' rhythm is unrealistic; and (iv) anticoagulant medication to prevent the formation of blood clots.

Source of images: http://www.drholdright.co.uk

- Aboriginal patients were more likely to have AF as a secondary diagnosis (showing that they were more likely to have another condition as the main reason for admission), with differences being most marked in the <55 year age group.
- Aboriginal patients had higher comorbidity prevalence of heart failure, diabetes and chronic kidney disease.
- Aboriginal AF patients had a higher predicted risk of stroke across all age groups.
- First-ever AF hospitalisation rates were 3.6 (males) and 6.4 (females) times higher in Aboriginal people between 20 and 54 years of age.
- Rates were similar in Aboriginal and non-Aboriginal males aged 55-84 years, while rates among Aboriginal females in this age group were almost twice those in non-Aboriginal women.
- After considering a range of factors like comorbidities, where people lived and hospital type, 30-day mortality was similar between Aboriginal and non-Aboriginal patients.
- After adjusting for multiple factors, 1-year mortality in 30-day survivors was significantly higher by 58% in Aboriginal versus non-Aboriginal patients.



**Interpretation**

The ratios in the highlighted text (orange) reflect the Aboriginal divided by the non-Aboriginal rates for each age group

**Figure 9: Age-specific rates of first-ever hospitalisation rates for AF, by Aboriginal status, sex and age group: WA 2000-09**

Katzenellenbogen JM, Teng TH, Lopez D et al. Heart (2015)[26]

## Recommendations

Primary prevention of AF:

- Prevent and treat the conditions that lead to AF (e.g., IHD, high blood pressure, heart failure) among Aboriginal people (see Sections 3 and 4)

Secondary prevention of AF and stroke:

- Screen for abnormal heart rhythm; show Aboriginal patients how to check their pulse for heart rhythm
- Implement clear, evidence-based guidelines for AF and underlying conditions
- Improve systems to support management of Aboriginal patients with AF: access to specialists, culturally appropriate care (including interpreters), cardiac rehabilitation services, discharge planning and follow-up care
- Stress benefits and importance of evidence-based medications to service providers and patients: blood thinning medication should be prescribed/provided to prevent stroke

See Part II - Section 2 gives practical suggestions about developing and delivering community based programs and services; Section 3 includes suggestions about required organisational changes and Section 4 includes Policy recommendations to support these actions.

# Rheumatic Heart Disease: Prevalence in Heart Failure, Stroke and Atrial Fibrillation

# 6

## Context

Although acute rheumatic fever (ARF) and its long-term consequence rheumatic heart disease (RHD) are now uncommon in industrialised countries, RHD remains the most common form of paediatric heart disease in the world. This is because of its high prevalence in developing countries where it is often the most common cause of cardiac mortality in children and adults aged less than 40 years (see Box 7 for explanation of ARF and RHD).

The prevalence of RHD remains high among Aboriginal people, resulting in substantial rates of surgical procedures for heart valve repair and death among young adults. While the BAHHWA project has not had a focus on RHD, there is a strong relationship between RHD and other conditions that the project investigated. Below we provide data on RHD as a comorbidity in three conditions studied in adults: heart failure, atrial fibrillation and stroke.

## Key Findings

Aboriginal people in parts of Australia have one of the highest rates of RHD in the world.

RHD is common among Aboriginal patients hospitalised with cardiovascular complications.

Differentials in the prevalence of RHD between Aboriginal and non-Aboriginal cardiovascular patients is highest at younger ages, particularly in stroke and atrial fibrillation. This contributes to case complexity.

## How was the research done?

Using linked records from WA over a number of years, patients with first-ever (incident) cases of hospitalised heart failure[20] and atrial fibrillation[27] were identified. Using similar data sources, first-ever and existing (prevalent) cases of stroke were identified.[28] For all these patients, hospital records from 10-20 years prior were reviewed to see if they had ever been admitted to hospital for rheumatic heart disease. The analysis identified what percentage of Aboriginal and non-Aboriginal adult patients had RHD as a comorbidity or a precursor to their other cardiovascular problem.

## What did the research find out?

**1. History of RHD in first-ever (incident) heart failure and atrial fibrillation patients**

One in 5 (20%) Aboriginal heart failure patients aged 20-54 years had a history of RHD, significantly higher than non-Aboriginal patients (14%). The difference between Aboriginal and non-Aboriginal patients was not significant in the 55-84 year group. (Figure 10)

The difference in the percentage of RHD among Aboriginal and non-Aboriginal atrial fibrillation patients was significant in both broad age groups, with the higher percentage in Aboriginal patients being most marked in the 20-54 year age group.

MEDICAL DESCRIPTION
**Box 7**

## Acute Rheumatic Fever and Rheumatic Heart Disease

*Acute Rheumatic fever ARF* is an illness caused by the body's inflammatory response to infection with Streptococcal bacteria that are often found in skin sores and sore throats. ARF is typically manifested by fever, joint pains, and sometimes a skin rash. Most importantly, it can cause inflammation of the heart, often resulting in permanent damage to the heart valves. It usually occurs in children aged 5 to 14 years, although people can have recurrent episodes well into their forties. Although anyone can get ARF, it is strongly associated with poverty and living in overcrowded conditions. As it can be prevented with prompt antibiotic treatment for the infection, it is also associated with diminished access to health services. For these reasons, ARF has become very uncommon in developed countries but remains common among disadvantaged communities in these countries.

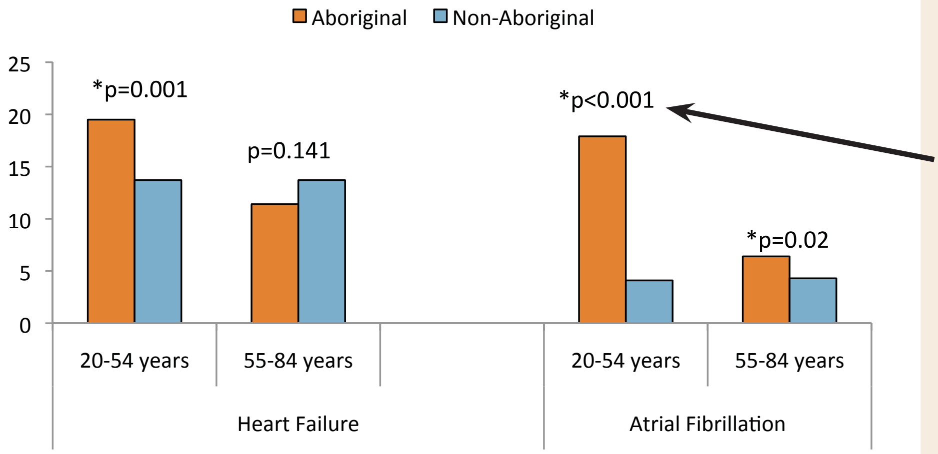
*Rheumatic heart disease* (RHD) is a long-term condition caused by permanent damage to one or more of the heart valves following ARF. When damaged by scarring due to ARF, the heart valve(s) may become narrowed and thereby obstruct the flow of blood and/or fail to close properly, allowing abnormal backward flow of blood within the heart. This can lead to heart failure and sometimes the need for cardiac surgery to repair or replace the heart valves. It can also lead to formation of clots within the heart that may break off and lodge in the vessels in the brain, resulting in stroke.

Because RHD is a complication of ARF, the best way of preventing RHD is to prevent episodes of ARF. People who have had ARF need regular penicillin injections to prevent recurrences and consequent heart complications.

People with RHD require regular check-ups, tests and medications. Those who have had replacement of a heart valve may require anti-coagulant (i.e., clot-reducing) medications and regular blood tests to ensure the anti-coagulant medications are at the correct level in the blood.

A national RHD register has been established to collect RHD information and assist in monitoring RHD, its management and outcomes. It has been designed with the ultimate aim of helping jurisdictions improve detection and management of ARF/RHD.

Source: compiled from RHD Australia website http://www.rhdaustralia.org.au



### Interpretation

- P-values help to determine the statistical significance of results. A small p-value indicates that results are less likely to be due to chance and thus reflect real differences. The p-values with asterisks (*) show which Aboriginal vs non-Aboriginal comparisons identified significant differences.
- The higher percentage of RHD in Aboriginal patients was most marked in the younger age group for both HF and AF (very small p-values).

**Figure 10. Percentage of rheumatic heart disease in (i) patients with heart failure and (ii) patients with atrial fibrillation, by broad age group and Aboriginal status: WA 2000-2009**

Teng TH, Katzenellenbogen JM, Thompson SC et al. Int J Cardiol (2014)[20]
Katzenellenbogen JM, Teng TH, Lopez D et al. Heart (2015)[26]

## 2. History of RHD in prevalent stroke patients

For both Aboriginal and non-Aboriginal patients with new or existing stroke, a history of RHD reduced with age. Almost one in four Aboriginal stroke patients aged 20-34 years had a history of RHD. In all age groups except the oldest, a greater proportion of Aboriginal than non-Aboriginal stroke patients had a history of RHD. The differential was highest in the youngest age group, and as shown in Figure 11, diminished in the older population.

Neither the Aboriginal to non-Aboriginal overall (crude) ratio (2.7) nor the age-standardised ratios (2.5) capture the changing differentials with age. Note that although the percentage of RHD seems higher in the younger cases, the actual number of cases with RHD as a comorbidity at older ages is actually higher than at younger ages, because the frequency of cases increases markedly with age for both Aboriginal and non-Aboriginal patients.

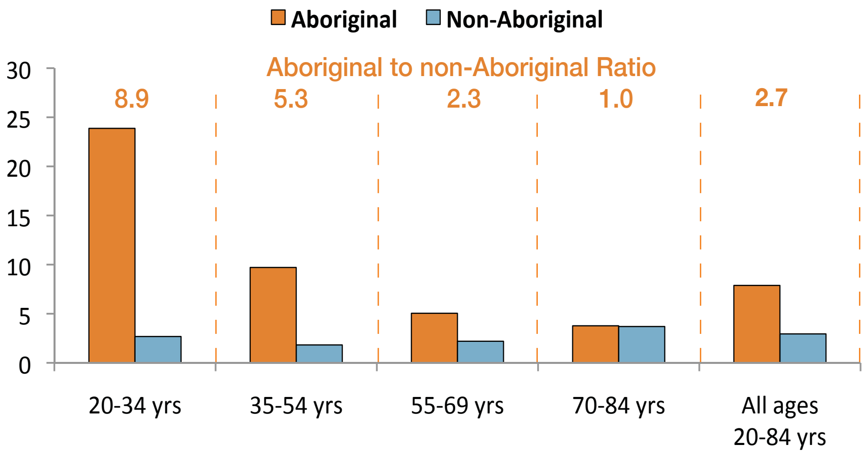


**Figure 11. Percentage of prevalent stroke patients with a history of rheumatic heart disease, by age group and Aboriginal status**

Katzenellenbogen JM, Knuiman M, Sanfilippo F et al. Int J Stroke (2014)[29]

## Interpretation

The ratios in the highlighted text (orange) reflect the Aboriginal divided by the non-Aboriginal percentage of RHD.

- Over all age groups combined, Aboriginal patients were 2.7 times more likely to have a history of RHD compared to non-Aboriginal patients
- In the 20-34 years age group, a history of RHD was 8.9 times more common in Aboriginal patients
- In the oldest age group, there was no difference between the two patient groups.

## Recommendations

Primary prevention of ARF/RHD

- Improve socioeconomic and environmental conditions contributing to overcrowding and untreated skin sores/sore throats, through co-operation across the different government sectors

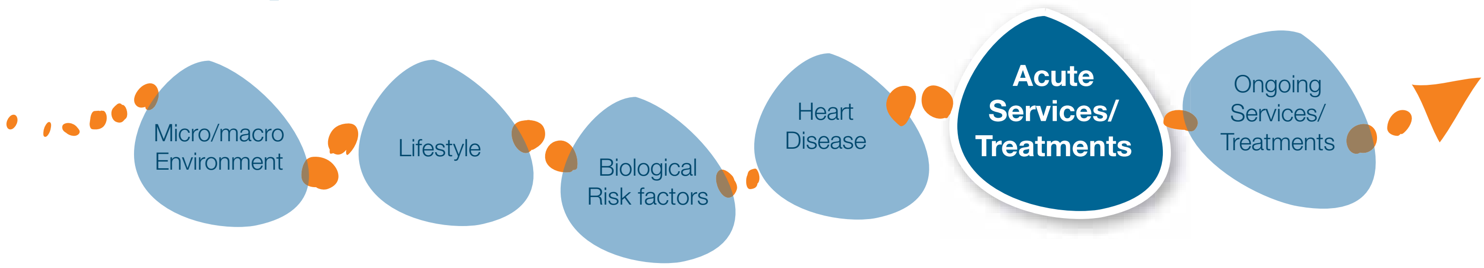
Secondary prevention of RHD

- Improve systems for detection, prompt treatment and scrupulous follow-up of ARF cases
- Improve access to and adherence to medical/surgical treatments and ongoing follow-up through culturally appropriate health education, systems and infrastructure
- Disseminate guidelines for complex management of Aboriginal cardiac and stroke patients with a comorbidity of RHD

See Part II - Section 2 gives practical suggestions about developing and delivering community based programs and services; Section 3 includes suggestions about required organisational changes and Section 4 includes Policy recommendations to support these actions.

# Going to Hospital: Aboriginal Patient Perspectives

# 7



## Context

Sometimes, heart disease can only be treated in hospital. Hospitalisation can be a difficult experience for anyone, but can be particularly hard for Aboriginal people, especially if they have had to travel a long way from their home ('Country') to hospital, have no family nearby, are not familiar with the medical system, and if they usually speak a language other than English. For many Aboriginal people Country is the place from which they draw spiritual and physical strength, so being away from Country when unwell is very stressful.

## Key Findings

Complex patient and service factors cause delays in accessing and receiving prompt, effective hospital treatment.

Health professionals often have limited understanding of the complex factors influencing Aboriginal health.

Health issues are often given a low priority among Aboriginal people due to competing cultural, family and personal responsibilities. This causes delays in accessing treatment.

Aboriginal people often feel unwelcome and unsafe in hospital because the hospital system may conflict with their culture and life circumstances.

Cultural miscommunication with staff reinforces perceptions of discrimination. This affects patient behaviour in hospital and attitudes to treatment. Employing AHWs in hospital has a positive effect on health care.

## How was the research done?

Part of the research reported here looked at what the experience of being in hospital was like for Aboriginal people in WA. It also examined how well the hospital system looked after Aboriginal patients, and how this could be improved. To get the most complete picture possible, the researchers used a number of methods, including talking to Aboriginal hospital patients and to health professionals working in hospitals,[30,31] as well as reviewing other literature.[31,32] Also, they looked at the experience of an Aboriginal Health Worker working on a hospital cardiac ward for six months to see what difference it would make for the Aboriginal patients.[33] The research was conducted in 2008-09, with results helping to inform decisions about how *Closing the Gap* funding could be used.

## What did the research find out?

Looking at work done by other researchers over the years, it was clear that problems with hospital care of Aboriginal people are a contributing factor for their poor health, even though there are many other causes for this. Aboriginal clients in hospital may face discrimination because of the way the hospital system works. For example, most hospitals are not set up to deal with people who have limited English language skills or who lack familiarity with medical terminology (both of which are needed for informed consent), with people who don't have a fixed address because they move between houses, and with people who have travelled from the bush to be in a city hospital and have no family support nearby. This is made worse by the small numbers of Aboriginal people being employed in hospitals as health professionals. Because of these problems, Aboriginal clients often feel unwelcome and unsafe in hospitals. They may be less likely to understand, trust or follow the health advice given by hospital staff, and more likely to leave the hospital before the doctors say they're ready to be discharged (See Part I, Section 9). They may delay going to a doctor or hospital when their health deteriorates. Aboriginal people are often blamed for these problems although the problem may be with the system, regardless of the underlying reasons. Figure 12 summarises our research into patient and service factors that contribute to delays in Aboriginal cardiac patients from northern WA accessing the acute care they need.

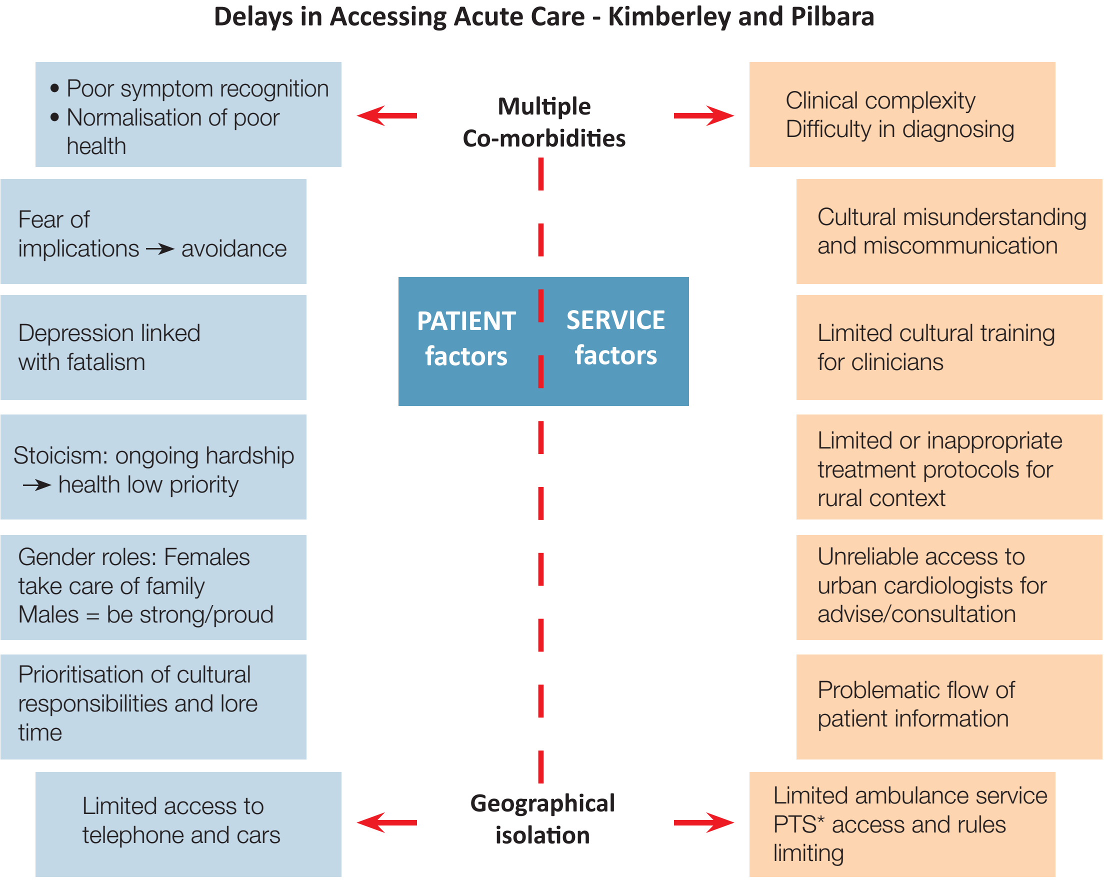


**Figure 12. Patient and service factors underlying delays in accessing acute care after a heart event in the northern regions of Western Australia**

*PTS=Patient Transport Service

Taylor KP, Katzenellenbogen JM, Sanfilippo FM et al. Rural Medicine Australia Conference (2012)[34]

If a client doesn't follow the health provider's instructions about treatment, they may be called 'non-compliant', when in fact this may occur because of a system problem. Poor communication by the health provider may result in instructions not being understood. Inaccurate recording by staff of patient contact details may mean discharge letters with follow-up care instructions don't reach the primary care provider, contributing to the patient not being helped to attend follow-up appointments. Limited/unreliable mail delivery systems also mean that patients miss out on appointment reminders.

Our research showed that employing AHWs in hospital had a positive effect on health care, as Aboriginal people felt safer and were less likely to self-discharge from hospital against medical advice. As one of the many tasks undertaken by the AHW (Figure 13), an important role was to 'yarn' with patients and to help explain what was being done for their care and make them less anxious. Yarning is having a conversation with Aboriginal people that respects Aboriginal culture and involves the telling of stories.[35] The AHW was also able to educate other staff members about Aboriginal culture so that they were better skilled to look after Aboriginal patients. However, many expectations were placed on the AHW that made her job very demanding—and often the description of her role was unclear.

We wrote articles about how these improvements could be made, in journals that are read by nurses and specialist doctors. Both of these types of health professionals play very important roles in the care of hospital patients. We participated in national forum discussions that contributed to policy change, including changes implemented through *Closing the Gap* funding (see South Metropolitan Health Service good news story [Box 12]).

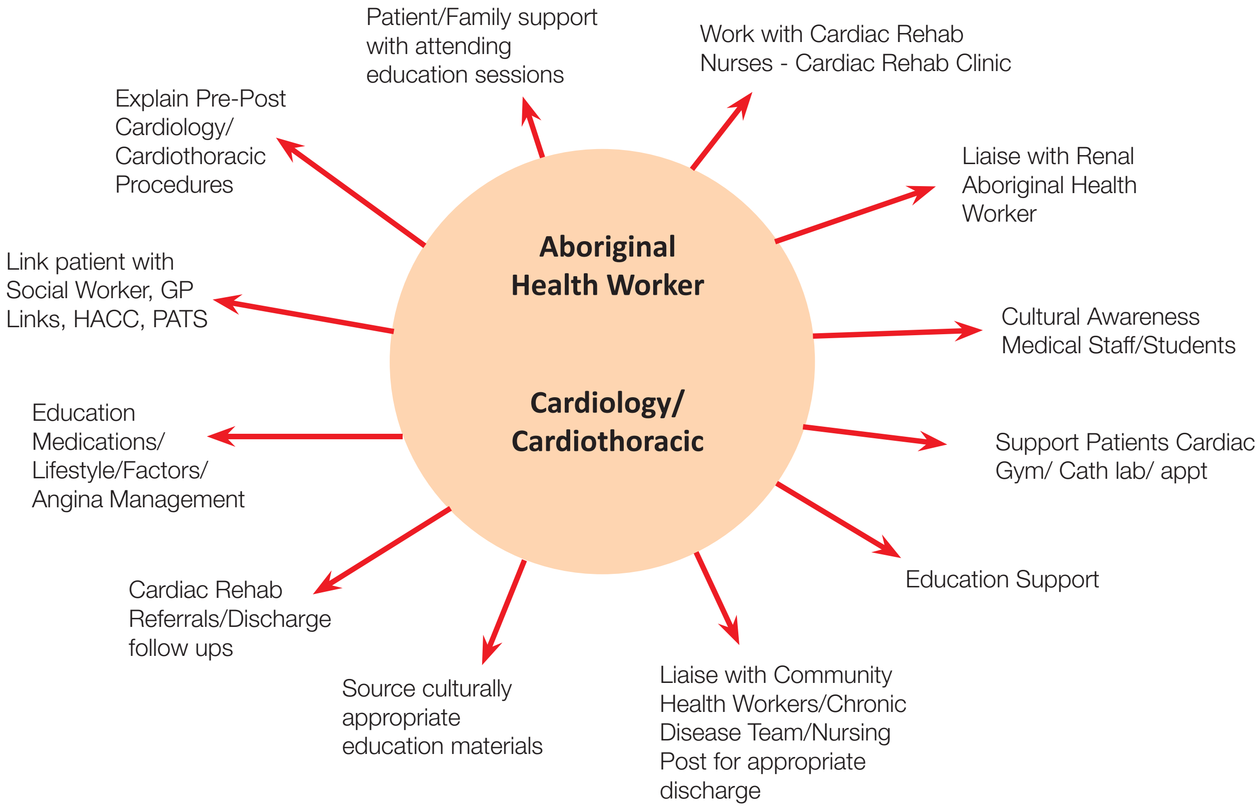


**Figure 13: Cardiology Aboriginal Health Worker defines responsibilities**

HACC=Home and Community Care, PATS=Patient Assistance Transport Scheme

Taylor KP, Thompson SC, Smith J et al. Exploring the impact of an Aboriginal Health Worker on hospitalised Aboriginal experiences: lessons from cardiology. *Aust Health Rev* (2009)[33]

## Recommendations

Hospitals need to make the following changes to practice:

- Improve infrastructure and organisation to address social and logistical needs (including transport and accommodation) of Aboriginal patients
- Increase the number of Aboriginal health professionals in hospitals
- Adhere to guidelines for hospital systems to respect Aboriginal culture, including availability of interpreters and ensuring informed consent is obtained
- Enhance training of health professionals in how to care for Aboriginal people
- Improve discharge processes and referral for follow-up
- Increase the involvement of Aboriginal people and communities in determining how the hospital is run; partnering with consumers*

*see Appendix 4:

(i) Health service expectations: a matter of patient and consumer rights

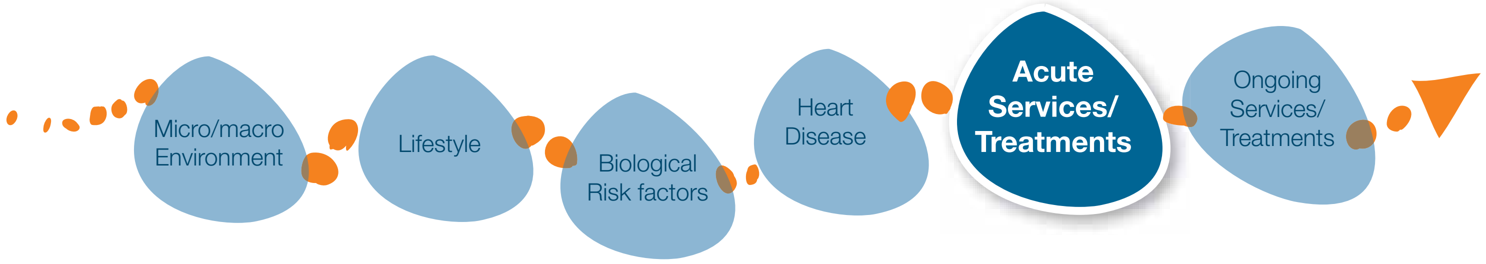
(ii) National Safety and Quality Health Service: Standard 2—Partnering with Consumers

(http://www.safetyandquality.gov.au/wp-content/uploads/2012/01/NSQHS-Standards-Fact-Sheet-Standard-2.pdf)

See Part II - Section 2 gives practical suggestions about developing and delivering community based programs and services; Section 3 includes suggestions about required organisational changes and Section 4 includes Policy recommendations to support these actions.

# Hospital Care: Receiving Treatment

# 8



## Context

Some of the disparity in heart health between Aboriginal and non-Aboriginal may be due to differences in the health care they receive. Factors influencing the types of services received include the patient's age, the presence of other illnesses, the remoteness of the patient's location from appropriate medical care and the location of the hospital admitted to, as well as whether the patient is Aboriginal or not.

A coronary angiogram is a specialised procedure used to diagnose blockages of coronary arteries. It involves x-ray imaging of dye injected directly into the arteries through a long catheter, performed by a skilled operator—usually a cardiologist. It is often followed by a procedure to unblock the artery. Angiograms are a key part of the diagnostic protocol for managing heart attacks and other coronary heart disease. In Western Australia, rural patients mostly need to be transferred to Perth for these diagnostic procedures.

## Key Findings

Among patients hospitalised for ischaemic heart disease, being Aboriginal is not associated with missing out on receiving angiograms or evidence-based discharge medicines, when other factors are considered.

However, some important risk factors for not being transferred to a metropolitan hospital for specialist care or receiving angiograms are those that more commonly occur in Aboriginal people, e.g., having comorbidities or not having private health insurance, suggesting that these are issues on which attention needs to be focused.

Among heart attack patients in the Perth metro area, older Aboriginal patients are less likely than older non-Aboriginal patients to receive an angiogram, but younger patients are as likely to receive angiogram regardless of whether or not they are Aboriginal, once other factors are taken into account.

Four classes of medication have been shown to be effective in reducing future heart attacks and deaths in heart attack and angina patients, and are recommended for all patients if not contraindicated. In order to maximise their effectiveness for 'secondary' prevention following a heart attack, these medications are usually prescribed for the rest of a patient's life.

In this section we describe three studies using linked data that looked at factors associated with the delivery of different types of health service:

1. the transfer from rural to city hospitals of rural patients with emergency admissions for ischaemic heart disease (of which heart attack is a subset and was studied on its own);
2. the receipt of diagnostic procedures (i.e., angiogram) following emergency IHD/heart attack admission;
3. the prescription of drugs to prevent future events (secondary prevention) following admission for heart attack or unstable angina.

## How was the research done?

The first two studies used administrative hospital and death information to identify people who had survived for at least 28 days following an emergency hospital admission for ischaemic heart disease. Rural hospital admissions were analysed separately (Study 1) from metropolitan hospital admissions (Study 2) because rural hospitals need to transfer their patients to metropolitan hospitals to receive diagnostic angiograms. An analysis was done to determine if Aboriginal patients were more or less likely to be transferred or receive angiograms. The subgroup of patients who had a heart attack was also looked at separately.

The third study compared Aboriginal with non-Aboriginal people who had been admitted to hospital for acute coronary syndrome (heart attack or unstable angina), to find out if they were prescribed appropriate medications to prevent further heart problems when they were discharged.[36] The types of medications were beta-blockers, ACE inhibitors/angiotensin receptor blockers, aspirin and statins (see Table 3). Receipt of at least three of these four medication types was considered as receiving appropriate 'evidence-based' therapy. The research used routine hospital data as well as clinical information collected from medical notes, discharge summaries and drug charts. The researchers determined which demographic, clinical and health service factors were associated with receiving evidence-based secondary prevention drugs at discharge.

We know that older age is a major reason for becoming ill, receiving health services and having poor health outcomes. Because Aboriginal patients are much younger on average than non-Aboriginal patients, we need to make sure that any research takes into consideration this difference in age between the two groups. However, age is not the only determining factor. We used statistical techniques to take into account numerous other factors such as presence of other diseases (comorbidities), whether patients are male or female and level of education.

**Table 3. Evidence-based medicines for long term use in ischaemic heart disease**

| Medication Class | Mechanism of Action | Demonstrated Benefits in Ischaemic Heart Disease | Other Cardiovascular Disorders Treated by this Drug |
|---|---|---|---|
| **Beta-Blockers** | Reduce the oxygen requirements of heart muscle | • Reduce blood pressure<br>• Reduce angina symptoms<br>• Reduce the risk of future heart attacks and deaths | • Hypertension (high blood pressure)<br>• Heart failure |
| **ACE Inhibitors** | Inhibit hormones that constrict blood vessels, thereby reducing load on heart muscle | • Reduce blood pressure<br>• Reduce the risk of future heart attacks and deaths, particularly in those who have already had a heart attack, have diabetes, or whose heart muscle is not contracting properly | • Hypertension (high blood pressure)<br>• Heart failure |
| **Angiotensin Receptor Blockers** | Similar to ACE inhibitors (generally used in patients who develop side effects of ACE inhibitors) | • Similar to ACE inhibitors | • Hypertension (high blood pressure)<br>• Heart failure |
| **Statins** | Cholesterol lowering | • Reduce the risk of future heart attacks and deaths | |
| **Aspirin and other anti-thrombotic agents (e.g., clopidogrel)** | Reduce blood clot (thrombus) formation by inhibiting the function of platelets (that contribute to clotting) | • Reduce the risk of future heart attacks and deaths | • Stroke prevention in people at high risk of stroke, e.g., in atrial fibrillation |

## What did the research find out?

### Transfers of rural patients to metropolitan hospitals

Almost 1 in 5 of the 1,947 patients admitted to Perth hospitals from rural WA after having emergency admissions for heart attack were Aboriginal. Similar percentages of Aboriginal (76.2%) and non-Aboriginal (74.8%) patients were transferred to metro hospitals at some time in the 28-days following their event. The high proportion of transfers among heart attack patients reflects the urgency of specialist care for these patients. When other demographic, hospital and comorbidity variables are considered, there was no significant difference in the proportions of Aboriginal and non-Aboriginal patients transferred from rural hospitals.

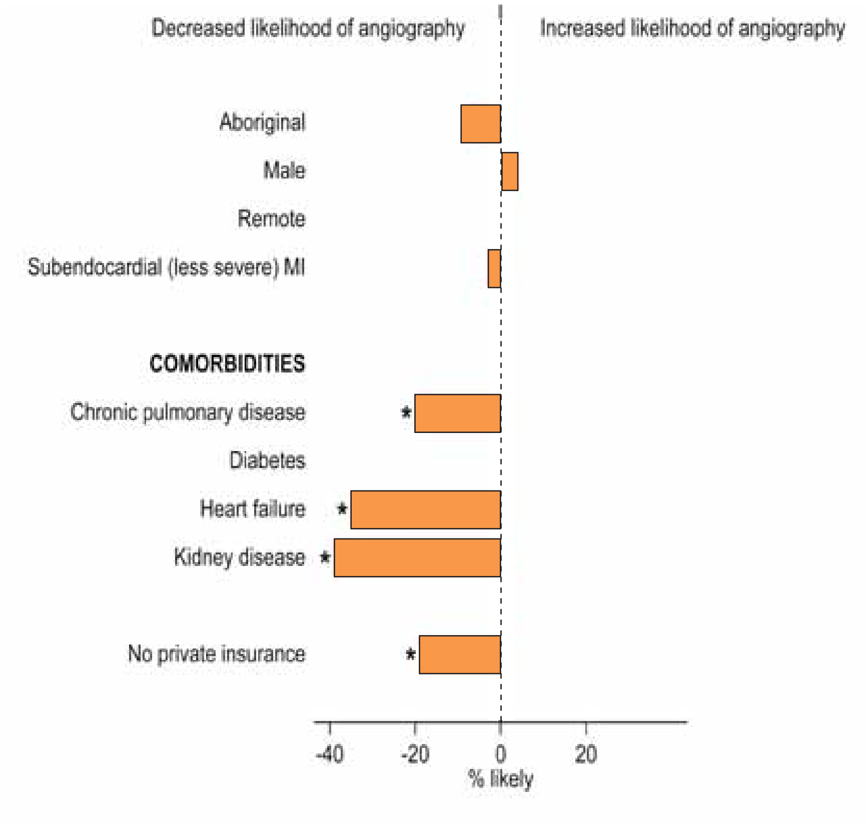
### Receipt of angiograms in heart attack patients

A range of factors that influence whether or not *rural* heart attack patients received angiograms is shown in Figure 14. The length and direction of the bars show, as percentages, how much more or less likely categories of patients are to receive angiograms, taking into account all the other factors we were able to measure. The stars indicate whether results are statistically significant.

When we take all characteristics into account, younger people were significantly more likely to receive an angiogram, while those who had heart failure, kidney disease, chronic lung disease or who had no private insurance were less likely to receive an angiogram. Aboriginal people were not less likely to receive an angiogram once all the other variables were considered (Figure 14).

Thus, it is not Aboriginal status alone that determines whether rural heart attack patients receive an angiogram. However, Aboriginal people tend to have many of the characteristics that are associated with not being transferred to metro hospitals (coronary procedures are only performed in metro hospitals) and not receiving angiograms—for example, high levels of chronic conditions and low levels of private insurance. On the other hand, younger age favours their being transferred and receiving angiograms in metropolitan hospitals.

The analysis of metro heart attack patients' receipt of angiograms found that, when all factors were considered, older Aboriginal patients were less likely to receive angiograms than older non-Aboriginal patients. However, younger Aboriginal metro patients were just as likely to receive angiograms as younger non-Aboriginal metro patients.[37]



## Interpretation

This graph shows the extent to which the variables studied increased (right side) or decreased (left) the likelihood of receiving an angiogram, once all the other variables were taken into account. The asterisks indicate those factors with a significant relationship with angiography.

- People with chronic pulmonary disease, heart failure and kidney disease were 21%, 38% and 40% LESS likely, respectively, to receive angiograms
- People without private health insurance were 20% less likely to receive angiograms
- Aboriginal people were about as likely to receive angiograms, once all other variables were taken into account.

**Figure 14. Characteristics that impact on the likelihood of receiving angiograms among (emergency) heart attack and angina patients admitted to rural hospitals in WA**

Lopez D, Katzenellenbogen JM, Sanfilippo FM et al. BMC Cardiovasc Disord (2014)[38]

(* shows statistical significance)

### Receipt of evidence-based medicines by heart attack and angina patients at discharge from hospital

Aspirin (to inhibit formation of blood clots) was the most commonly prescribed discharge drug, followed by statins (used to reduce cholesterol) (Figure 15). Without taking other factors into account, Aboriginal and non-Aboriginal people had similar likelihoods of being prescribed all the cardiac drugs except beta-blockers (which are often not recommended for certain patients with lung disease).

After other characteristics were taken into account, being an Aboriginal person did not influence whether or not at least three out of four evidence-based medications were received (Figure 16). Notably, however, a higher proportion of Aboriginal compared with non-Aboriginal patients (11% vs 7%) had none of the drugs prescribed .

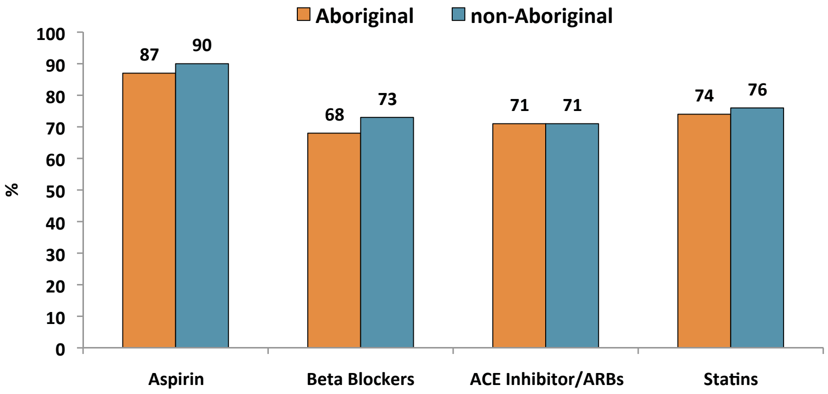
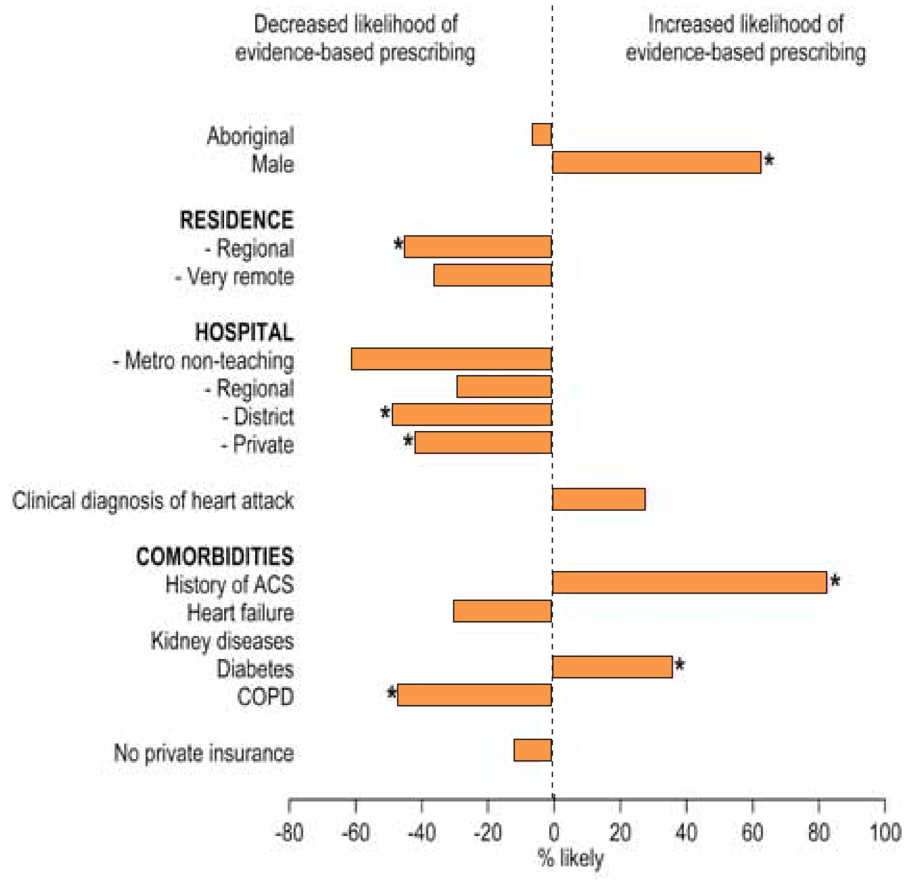


**Figure 15. Percentage of patients receiving different drugs**

Gausia K, Katzenellenbogen JM, Sanfilippo FM et al. Intern Med J (2014)[36]



## Interpretation

This graph shows the extent to which the variables studied increased (right side) or decreased (left) the likelihood of receiving evidence-based medicines (EBM), once all the other variables were taken into account. The stars indicate variables with significant relationships with EBM.

Aboriginal people were equally likely to receive EBM once all other variables were taken into account.

- Men were 63% more likely to receive EBM than women
- People with chronic pulmonary disease were 47% LESS likely, but diabetics and people with a previous ACS admission 83% MORE likely to receive EBM
- People living in regional areas were 45% less likely to receive EBM
- Patients attending non-teaching (including private) hospitals were less likely to receive EBM

**Figure 16. Characteristics that impact on the likelihood of receiving Evidence-Based Medicines (EBM) among heart attack and angina patients admitted to hospitals in WA**

Gausia K, Katzenellenbogen JM, Sanfilippo FM et al. Intern Med J (2014)[36]

(* shows statistical significance)

## Recommendations

Transfers

- Develop and implement consistent state-wide guidelines, protocols and processes for the management of acute events
- Co-ordinate and integrate patient transfers state-wide, including the trial of central referral coordination.
- Monitor whether private health insurance reduces the likelihood of evidence-adherent access to angiograms and other interventions
- Reduce barriers to receiving angiograms and interventions experienced by people without private insurance

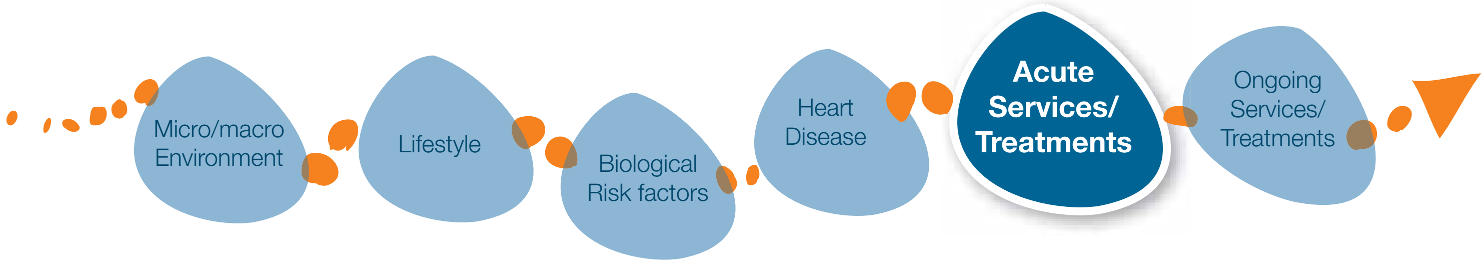
Discharge medicines

- Improve the level of prescription of guideline-recommended drugs at discharge (particularly in rural settings) through increased training and support of hospital doctors
- Improve recording of prescribed medications by doctors in non-teaching hospitals, including private hospitals. Ensure that hospital doctors and pharmacists are familiar with the range of mechanisms whereby Aboriginal patients can access free medications in the community (including Closing The Gap funding) and that they prescribe accordingly on discharge (see Appendix 3)
- Improve medication adherence through patient education and use of Home Medicine Reviews, particularly in rural and remote areas where there are fewer pharmacists
- Develop culturally appropriate resources (regarding access to drugs, side effects, importance of lifelong adherence) and train staff, supported by interpreter services, to communicate key messages effectively to patients and their families about taking prescribed medicines

See Part II - Section 2 gives practical suggestions about developing and delivering community based programs and services; Section 3 includes suggestions about required organisational changes and Section 4 includes Policy recommendations to support these actions

# Hospital Care: Discharge Against Medical Advice

# 9



## Context

Sometimes people who have been admitted to hospital leave before the doctors or other staff authorise their discharge, or even after being told by staff that they are not well enough yet to leave. People who discharge themselves against medical advice (DAMA) often end up needing to go back to hospital. They are also at higher risk of becoming sick or dying than if they have followed the advice of hospital staff.

Not all types of people are equally likely to discharge themselves from hospital against the advice of staff. It is more common for young adults (especially men), people who drink a lot of alcohol, those with mental health problems and people who are living in conditions of disadvantage or poverty. It was already known that Aboriginal people are more likely than other people in Australia to leave hospital in this way.[39]

## Key findings

The strong independent predictors of DAMA among patients with ischaemic heart disease are admission to a rural hospital while living in a rural area, being male, being young and having a history of alcohol or mental health admission.

Aboriginal people are 8 times more likely than others with IHD to discharge from hospital against medical advice. There are many factors that explain why this is the case. After these factors are taken into account, Aboriginal heart patients still discharge themselves at more than double the rate of non-Aboriginal patients.

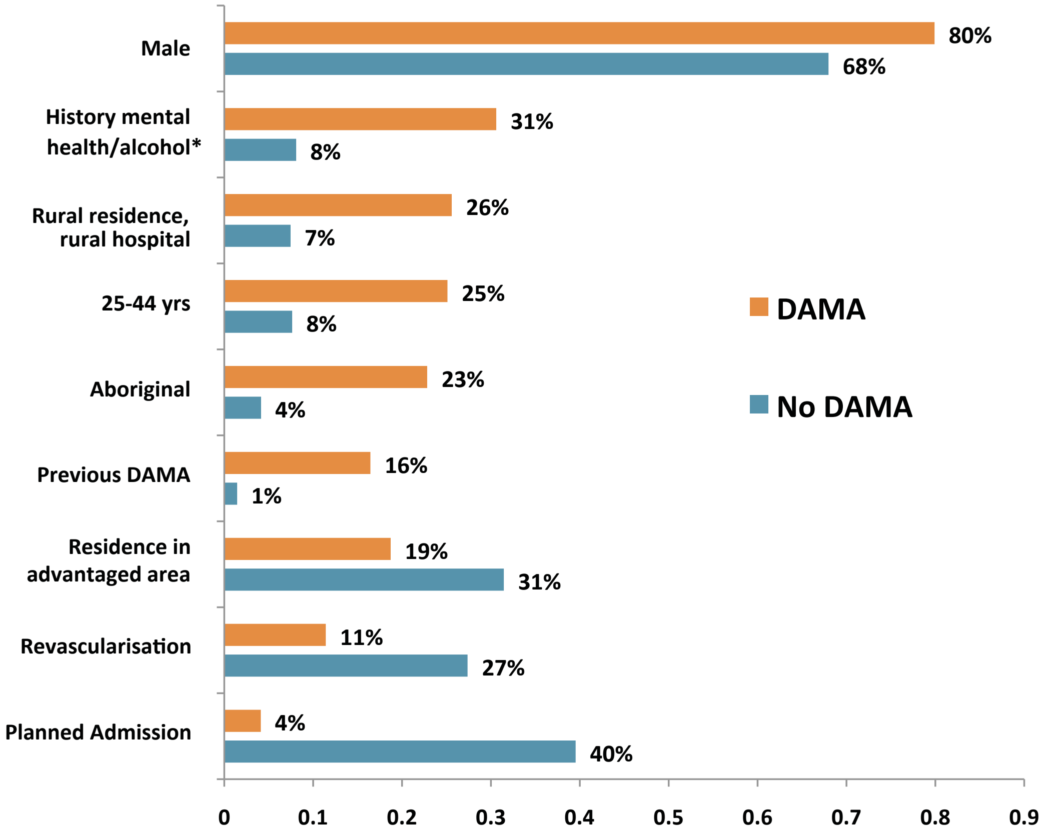
## How was the research done?

Using linked anonymous hospital data, the researchers studied people who were admitted to WA hospitals with ischaemic heart disease (IHD) for the first time between 2000 and 2008 and who then went on to discharge themselves against medical advice.[40]

## What did the research find out?

Although DAMA was relatively rare in these IHD patients (less than 1% of patients), the researchers showed that Aboriginal people were eight times more likely than others with IHD to discharge themselves from hospital. So, for example, almost a quarter (23%) of the 224 patients who discharged themselves were Aboriginal (Figure 17) even though Aboriginal patients made up only 4% of all the patients. However, there were other factors that at least partly explain why this is the case: being younger on average, being more likely to have an emergency admission, and being less likely to undergo a procedure such as a stent.

Based on other studies, the researchers suggested that this may be partly due to the anxiety and negative feelings many Aboriginal people have about being in hospital. Much of the time, hospital systems still aren't very well set up to deal with the needs of Aboriginal people and their families. Cultural misunderstanding and poor communication (or, in the case of language barriers, no communication) between hospital staff and Aboriginal patients remain problems that influence Aboriginal patients' experience of hospital. Hospital culture and systems need to change to improve cultural security for Aboriginal patients and their families.



## Interpretation

**Over-representation among DAMA:**

- Males
- Patients with history of alcohol or mental health admissions
- Rural patients in rural hospitals
- Younger (25-44 years)
- Aboriginal
- Previous DAMA

**Under-representation among DAMA:**

- Residence in an advantaged area
- Receipt of revascularisation surgery
- Planned admissions

* History mental health/alcohol: Admission for mental health or alcohol-related disorder in the previous 5 years.

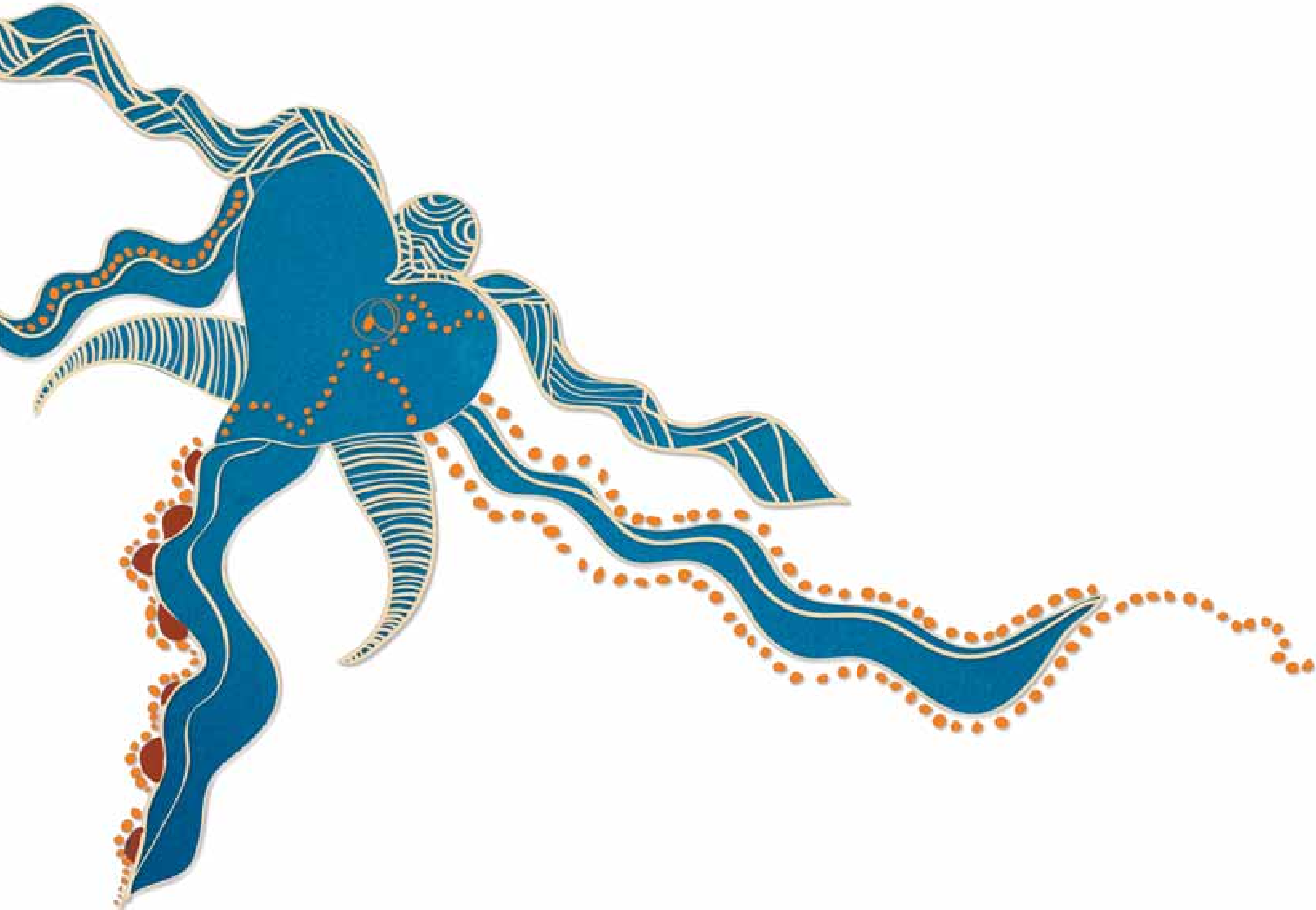
**Figure 17. Comparison of the characteristics of IHD patients which were significantly over- or underrepresented in patients who discharged against medical advice (DAMA), WA 2000-2008**

Katzenellenbogen JM, Sanfilippo FM, Hobbs MS et al. BMC Health Serv Res (2013)[40]

## Recommendations

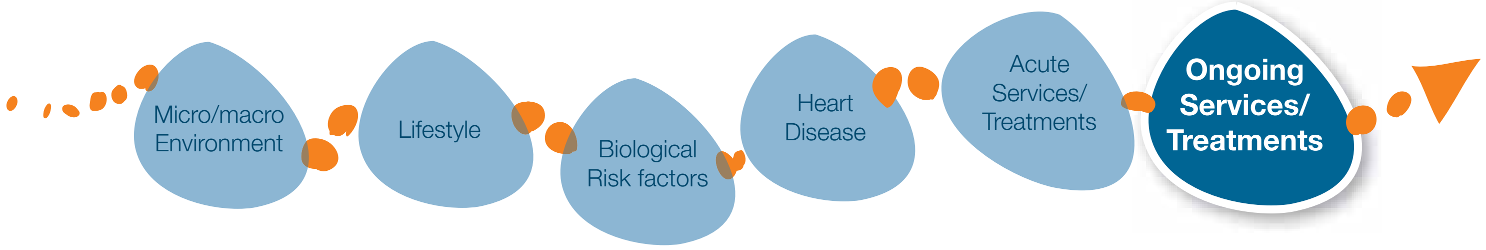
- Change hospital culture and systems so that Aboriginal experiences and attitudes towards hospitalisation are improved*
- Improve access to culturally safe services and to Aboriginal health professionals so that Aboriginal patients feel more comfortable in the hospital environment, have an advocate to talk to, and so that staff are more informed about Aboriginal patients' needs
- Improve early recognition of patient discomfort and develop strategies to address this before DAMA occurs
- Screen and deal with alcohol/drug/tobacco dependency with protocols for evaluation of risks and proactive interventions to reduce risk of DAMA
- Train staff (particularly in rural hospitals where workforce is less specialised and more transient) in the special needs of Aboriginal patients and the importance of not stereotyping or discriminating by race
- Put in place protocols to follow up patients after DAMA
- Include DAMA as a hospital KPI, in order to ensure hospitals take responsibility for providing appropriate care

*see Appendix 4: Health service expectations: a matter of patient and consumer rights



# Ongoing Cardiac Care

10



## Context

There are many ways of helping people with heart disease to get back to as normal a life as possible and to reduce the chances of developing further heart problems. This 'secondary prevention' includes lifestyle interventions (e.g., improved nutrition, increased physical activity, quitting smoking) and prescription of evidence-based medications (along with education on why the medications are important and how to use them properly).

Cardiac rehabilitation is an organised program of care delivered by an expert team of health professionals for a person with heart disease, aimed at reducing the person's likelihood of further heart disease or death. Cardiac rehabilitation programs usually feature a comprehensive approach to secondary prevention tailored to individual needs, including an exercise program along with education about lifestyle and medications. Cardiac rehabilitation is most often recommended for people who have recently had a heart attack; it improves health and reduces the chance of having another heart attack or dying. However, cardiac rehabilitation is also helpful for people with other heart diseases such as heart failure.

Unfortunately, services for secondary prevention are not always adequate. In fact, most people who need cardiac rehabilitation aren't getting it. Many people who should be in a program never actually start one, while others start a program but drop out and don't finish it. Around Australia, Aboriginal people are even less likely than others to get proper cardiac rehabilitation, but the reasons for this are not clear.

## Key Findings

Aboriginal heart disease patients requiring secondary prevention have a strong preference for attending an Aboriginal Medical Service rather than a mainstream practice. They express a need for positive educational messages presented in an understandable way.

There are critical systems-related barriers to Aboriginal heart patients' participation in Cardiac Rehabilitation: poor communications between services impair continuity of care, accounting for many of the failures to refer Aboriginal heart patients for cardiac rehabilitation. Incompatibility of Health Information Systems used by different providers compounds the poor communications.

Aboriginal heart disease patients are often reluctant to engage in cardiac rehabilitation programs because of negative media messages about Aboriginal heart health and because they feel out-of-place, partly because they tend to be younger than the non-Aboriginal people. Practical barriers to participation include costs of attending, transport difficulties, and inflexible schedules that conflict with other personal priorities

Many non-Aboriginal health professionals are unfamiliar with Aboriginal cardiac rehabilitation guidelines, and lack understanding about why Aboriginal people do not attend rehabilitation programs.

Several years ago, the Commonwealth Government published national guidelines on the best approaches to providing cardiac rehabilitation for Aboriginal and Torres Strait Islander people.[41] However, several years later, there was little information on how well these guidelines were being followed.[42]

## How was the research done?

The research group studied cardiac rehabilitation services for Aboriginal people. The main aim of this research was to provide information to help plan better cardiac rehabilitation services for Aboriginal people in WA. To get a complete picture of cardiac rehabilitation services for Aboriginal people, the researchers talked with two different groups of people. They interviewed health professionals working in cardiac rehabilitation: some were from public hospitals or 'mainstream' health centres and some worked in Aboriginal Medical Services.[43,44] They also interviewed Aboriginal people with heart disease; some of these had been involved in cardiac rehabilitation and some had not.[45]

Subsequently, a study was done to investigate how well secondary prevention for ischaemic heart disease was being implemented for the clients of a regional Aboriginal Medical Service (AMS), and to identify ways of improving secondary prevention in this context.[46] The study involved an audit of secondary prevention, based on medical records of 94 clients of the Service with known IHD, as well as focus group discussions with both AMS staff and a small number of the clients who had IHD.

More recently, based on experience in a metropolitan AMS, the Heart Foundation has produced a report that estimates the costs of establishing a CR service for Aboriginal people.[47]

## What did the research find out?

### (i) Interviews with health professionals about Cardiac Rehabilitation services[43,44]

The researchers' aim was to identify barriers to implementing the national Guidelines for CR among Aboriginal people.[41] They were conscious that these barriers are by no means limited to patient-related issues (such as transportation difficulties and competing life pressures). Accordingly, they specifically enquired about health care 'systems-related' barriers.

Many of the non-Aboriginal health professionals were mystified as to why Aboriginal people don't attend cardiac rehabilitation, and were not aware of the barriers that stop Aboriginal clients from attending. Notably, many of the health professionals were not aware of the Aboriginal Cardiac Rehabilitation Guidelines and few had access to Aboriginal health staff to assist them in implementing more culturally secure services. However, others were able to identify where some of the problems lay:

- Barriers could often be attributed to shortcomings in 'delivery system' design that result in poor communication across the health care sector:
  - Data collection processes were inconsistent and often insufficient—most importantly, those for accurately recording and storing information on whether or not a client identified as Aboriginal.
  - The systems that link cardiac rehabilitation facilities with hospitals and specialist clinics often didn't work very well. Aboriginal clients often got 'lost in the system' after being discharged from hospital because the chain of communication breaks down. For this reason, they often didn't get referred for cardiac rehabilitation when they needed it.
  - Services lacked a dedicated coordinator who could streamline referrals by liaising between providers

- There were barriers arising from the health information systems in use:
    - Multiple information technology (IT) platforms were in use, and these were often incompatible, resulting in poor linkages between different services. In some instances, incompatible IT systems were used by doctors and other staff within the same service. In consequence, vital information was often missed.
    - Data entry features of hospital IT systems were often insufficient: it was not possible to record salient personal and clinical details.
    - In remote areas, the IT systems generally lacked adequate data storage capacity.
- Furthermore, there was insufficient involvement of the Aboriginal community and integration of Aboriginal staff in CR programs:
    - Usually, the Aboriginal community had not been involved in setting up or delivering the rehabilitation program.
    - There was often no training for staff about Aboriginal culture or the particular needs of Aboriginal people, or even if training was provided, the staff were unaware of or had difficulties attending the training.
    - There were not enough AHWs involved in cardiac rehabilitation teams. Many of the facilities had no Aboriginal people on the staff. AHWs are important for maintaining relationships with Aboriginal clients and their families, and also in helping other staff to learn about Aboriginal culture.
    - AHWs were not always well supported in their jobs.

It was not all bad news, however. Some of the cardiac rehabilitation programs provided by Aboriginal Medical Services were quite innovative and did not have these problems.

### (ii) Auditing and improving cardiac secondary prevention in a regional AMS[46]

The audit found that there was substantial room for improvement in secondary prevention practices for heart disease clients of the AMS. For example, only 14% had been provided with the recommended Chronic Disease Management Plan, and only about half were receiving important evidence-based medications such as statins and aspirin (see Table 3, Section 8).

The focus group discussions highlighted the importance of culturally appropriate strategies for secondary prevention:

- Clients expressed a strong preference for attending the AMS locally rather than a mainstream service in Perth, and were enthusiastic about developing a formal CR program within the AMS
- Clients and staff identified the importance of positive educational messages presented in an understandable way, and of supportive family environments for adopting healthy lifestyle changes
- Systemic factors, such as inadequate referral and follow-up practices after discharge from metropolitan hospitals and prolonged waiting times at the AMS, caused dissatisfaction

### (iii) Interviews with Aboriginal heart patients about Cardiac Rehabilitation services[45]

The Aboriginal patients with heart disease explained the reasons why they don't participate in cardiac rehabilitation programs. They were able to point out some of the ways that a cardiac rehabilitation program could be made more suitable for Aboriginal clients.

Some of the things that made it difficult to attend cardiac rehabilitation were:

- other commitments were prioritised, particularly those to do with family
- not enough transport to and from cardiac rehabilitation
- costs of attending
- not set up for Aboriginal people, so they felt uncomfortable there
- inflexibility of program and appointments

They also said that media messages about Aboriginal heart health were negative and off-putting, making them less motivated to be involved in rehabilitation programs. Also, because Aboriginal people with heart problems tend to be much younger than the non-Aboriginal people at cardiac rehabilitation, the younger ones said they felt out-of-place with mainly old people who were attending.

### (iv) Approximation of set up costs of Cardiac Rehabilitation programs[47]

A 2012 position paper from the National Heart Foundation (WA), 'Eliminating disparities in hospital cardiovascular care of Aboriginal people in Western Australia' included approximation of costings for the paper's recommended actions.[47] Recommendation 3 was to 'Provide culturally appropriate cardiac rehabilitation and follow-up care and foster strong links between hospitals, Aboriginal community controlled agencies and/or general practice'.

Costings in this advocacy document were based on the Derbarl Yerrigan Cardiac Rehabilitation Trial and were intended to give future potential funders an approximation of set up and running costs (in 2008) as constructive advice for budgeting. It was hoped this would enable adaptation and replication of the program at other sites (more detail in Box 8 Case Study).

CASE STUDY
**Box 8**

## 'Heart Health for our People by Our People' at Derbarl Yerrigan Health Service

*Heart Health* is a culturally appropriate cardiac rehabilitation program for Aboriginal people, centred on education (formal and informal, involving yarning and lots of imagery), physical activity and support for behaviour change, conducted in a socially supportive environment within an Aboriginal Medical Service (AMS). The program embraces Aboriginal culture and ways of working to provide a culturally secure 'hub' around which improved health awareness can be achieved and broader health promoting activities can be facilitated. Key success factors include:

- Social support, for example a quote from participant: 'I like the lectures, friendliness, regular blood pressure and sugar checks and support the professionals give us. Getting together and sharing with others who have the same problems is very helpful.'
- Small, informal group discussions ('yarning')
- Sometimes separate sessions for women, depending on topic discussed
- Sometimes one-on-one sessions are held
- Education by demonstration: record blood sugar level pre- and post-exercise to show decrease
- Imagery to explain medical concepts and depict real discussion by all participants e.g. food labelling session conducted with food labels of real foods/snacks etc.
- Culturally appropriate written resources using simplified language, removing medical jargon and having Aboriginal images/artwork/photos
- Healthy morning tea and lunches provided to encourage uptake via experience, also to engage people in a social gathering

This program has identified some common drug adherence issues, including:

- sharing medication
- taking medications every second day or taking half a tablet to cut costs
- using Anginine tablets beyond the expiry date

Involvement in Heart Health has enabled these problems to be identified and addressed.

Many of the referrals to the program have been via word of mouth. Once community members attend and find the program is supportive and enabling, they tell their families and friends. The Heart Health environment has provided an opportunity to engage participants in a wide range of health issues, meaning that health is being addressed holistically. For instance, topics addressed to date—at the request of participants—have been as diverse as incontinence, optometry and dental health. Besides psychosocial support, the program has also invited people from Centrelink, Advocare and St Johns to come and talk to the group. It provides cultural safety and security by up skilling and training Aboriginal health professionals employed by the Medical Service to provide ongoing continuity of care.

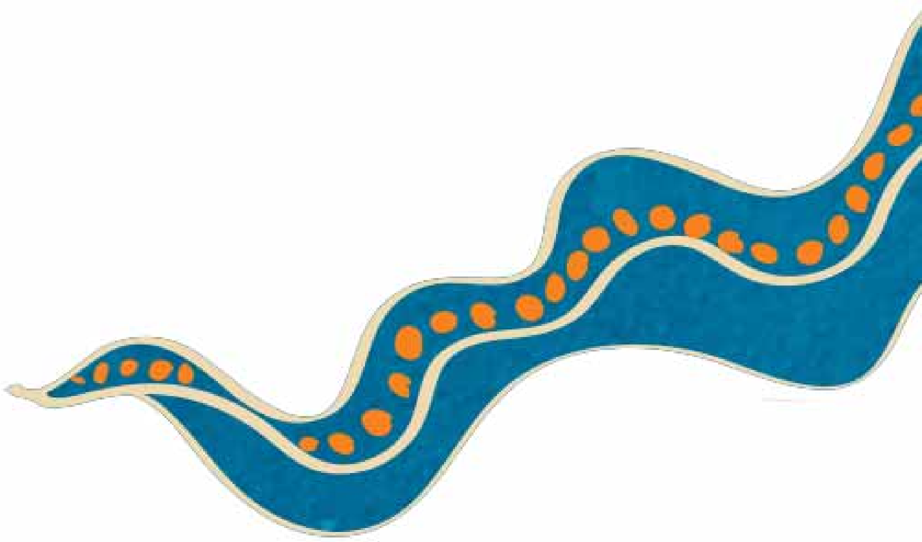
From: Dimer L, Dowling T, Jones J, Cheetham C, Thomas T, Smith J, McManus A, Maiorana A. Australian Health Review 2013:37(1); 79-82.[48]

http://www.derbarlyerrigan.com.au/index.php/programs/heart-health

## Recommendations

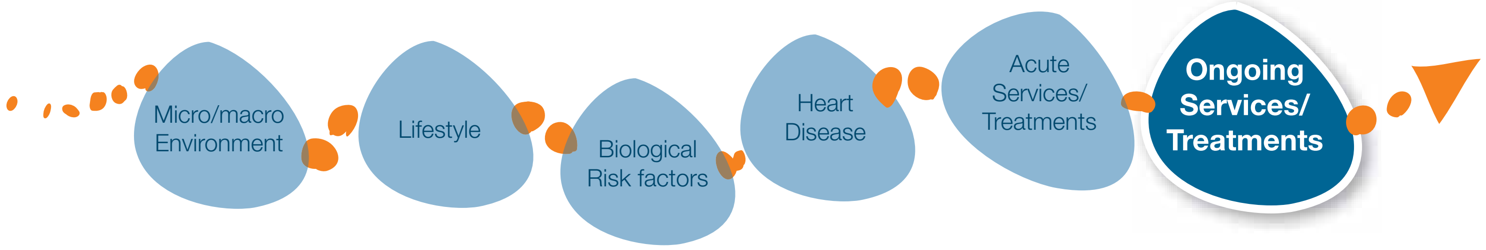
- Take into account the specific cultural needs and preferences of Aboriginal patients when planning/delivering secondary prevention interventions.
- Develop culturally secure cardiac rehabilitation programs.
- Use the comprehensive set of resources (for cultural competency, patient information sheets, materials for health professionals and managers) provided in the Federal Government Guidelines 'Strengthening cardiac rehabilitation and secondary prevention for Aboriginal and Torres Strait Islander Peoples'.[41]
- Implement strong referral systems between hospitals and primary care, incorporating a dedicated co-ordinator where possible.
- Promote mutually compatible, user-friendly Health Information Systems that support data sharing between different services and providers.
- Develop and sustain partnerships between organisations (e.g., mainstream and Aboriginal Community Controlled Health Services), incorporating elements of CR and secondary prevention into existing activities or building on existing networks within the community.

See Part II - Section 2 gives practical suggestions about developing and delivering community based programs and services; Section 3 includes suggestions about required organisational changes and Section 4 includes Policy recommendations to support these actions.



# Addressing Disparities in Cardiac and other Health Care for Aboriginal People

# 11



## Context

Members of the team have been involved in writing articles that comment on processes required to make a difference to Aboriginal health in a range of settings. Six of these are summarised here.

1. **‘Beyond the rhetoric: how can non-government organisations contribute to reducing health disparities for Aboriginal and Torres Strait Islander people?’[49]**

The article highlights six ways in which the Heart Foundation in WA, with Aboriginal employees and the Aboriginal community became more proactive in reducing Aboriginal health disparities.

1. **Governance**: appointment of Aboriginal board members; formation of senior working groups/committees dedicated to Aboriginal health programs; commitment to keeping Aboriginal health on the mainstream agenda
2. **Advocacy focus**: strong and persistent internal advocacy; supporting *Closing the Gap* initiatives; production of the report, ‘*Heart, stroke and blood vessel disease: a time for action in Western Australia*’ (2008); representation to politicians/government
3. **Targeted Aboriginal resources**: e.g., ‘*My Heart, My Family, Our Culture*’, a set of resource packages for Aboriginal consumers and health professionals developed to raise awareness of heart disease risk factors and symptoms.
4. **Building workforce capacity**: e.g., employment of Aboriginal staff and education through state-wide videoconferences
5. **Program innovation**: establishing a cardiac rehab program in an urban Aboriginal medical service
6. **Research and Evaluation**: involvement with Aboriginal health research and evaluation (for example, the BAHHWA research reported in this publication)

2. **‘Time to bring down the twin towers in poor Aboriginal hospital care: addressing institutional racism and misunderstandings in communication’[31]**

This paper challenged hospital doctors to reflect on their practice by identifying how cross-cultural misunderstandings undermine the quality of care provided for Aboriginal patients in hospital and offers suggestions for improving practice. It also explores the concept of institutional racism and challenges doctors to reflect on their role in perpetuating power imbalances. The authors argue that doctors and healthcare providers need to do more than just deliver evidence-based interventions, by critically reflecting on their own attitudes to and practices with Aboriginal Australians and working collectively to effect systemic change which creates a more inclusive and safe environment for all people accessing healthcare.

### 3. ‘Reducing health disparities of Indigenous Australians: time to change focus’[30]

The effects of ‘White’ Anglo-Australian cultural dominance in health service delivery were explored through interviews with non-Indigenous medical practitioners with extensive experience in Indigenous health. Racism emerged as a key issue: Indigenous knowledge, beliefs and values are often under appreciated by the dominant western biomedical model in policy and practice.  This research challenges Health providers to critically reflect on the ways in which policies and practices promote or compromise Indigenous health and wellbeing.

### 4. ‘Owning solutions: a collaborative model to improve quality in hospital care for Aboriginal Australians’[32]

This paper proposes a collaborative model of care to improve health service delivery by building capacity in Aboriginal and non-Aboriginal personnel. The model incorporates recruiting more Aboriginal health professionals, increasing knowledge and skills to establish good relationships between non-Aboriginal care providers and Aboriginal patients and their families, delivering quality care that is respectful of culture, and improving Aboriginal health outcomes. A key element of model design, implementation and evaluation is critical reflection on barriers and facilitators to providing respectful and culturally safe quality care at systemic, interpersonal and patient/family-centred levels. Nurses can play a central role in addressing the current state of inequity and are pivotal as change agents within the proposed model.

### 5. ‘Closing the (service) gap: exploring partnerships between Aboriginal and mainstream health services’[50]

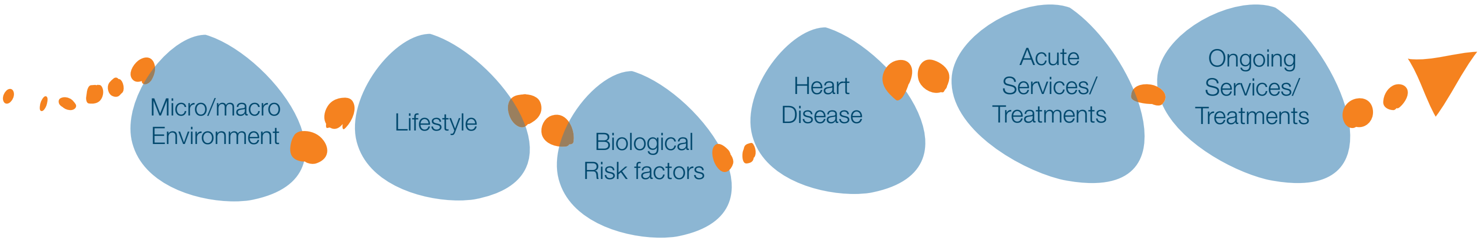
Partnerships between health services have been recognised as beneficial for broadening service capacity and effective use of resources. Partnerships between Aboriginal and mainstream services, in particular, offer multiple benefits for improving the cultural and clinical capacity of health service delivery. Yet many challenges face these arrangements, including tensions stemming from historical and current race relations, different ways of working and ongoing Aboriginal disadvantage. A literature review was undertaken to identify the factors that challenge and enhance partnerships.  Indicators of best practice included workshopping tensions early, leadership, building partnerships based on community-identified needs, and paying careful attention to power sharing. Other factors that enhance partnerships include encouraging reflective staff practices and provision of opportunities to build relationships of trust with partners over time without the pressures of unrealistic and imposed funding cycles.

### 6. ‘Examining the potential contribution of social theory to developing and supporting Australian Indigenous-mainstream health service partnerships’[51]

A literature review identified a range of social theories useful in guiding Aboriginal and mainstream partnerships, including: power relations, reflexivity, dialogical theory, borders, and strangeness. These theoretical concepts indicate the complexity of building and maintaining partnerships and stress the importance of understanding the factors that can strengthen or derail their effectiveness. Rather than viewing partnerships as merely arrangements between entities, they are better seen as essentially dependent on relationships occurring in an intercultural space that is complex, dynamic and subject to changes in power relations.

# Part I Conclusion

# 12



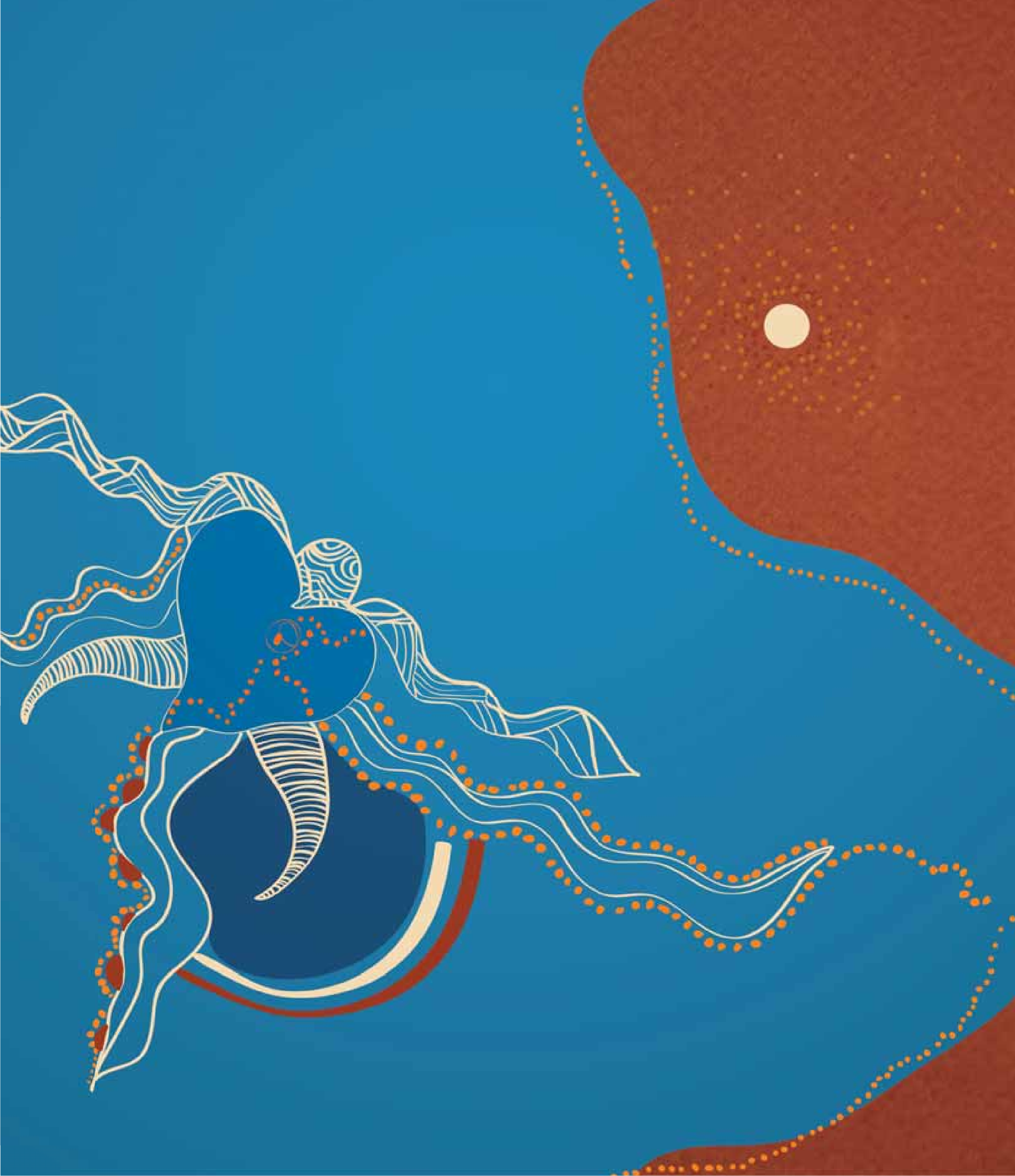
This part of the Report has described a wide range of research undertaken to expand our understanding of the Heart Disease story for Aboriginal people in WA.  The main body of research focussed on the part of the story in which people have serious heart events that take them to hospital. We have shown how the risks of these events are much higher among Aboriginal people, with other conditions (e.g., diabetes, kidney disease and lung disease) often complicating their recovery and influencing the kind of care they receive and their outcomes.

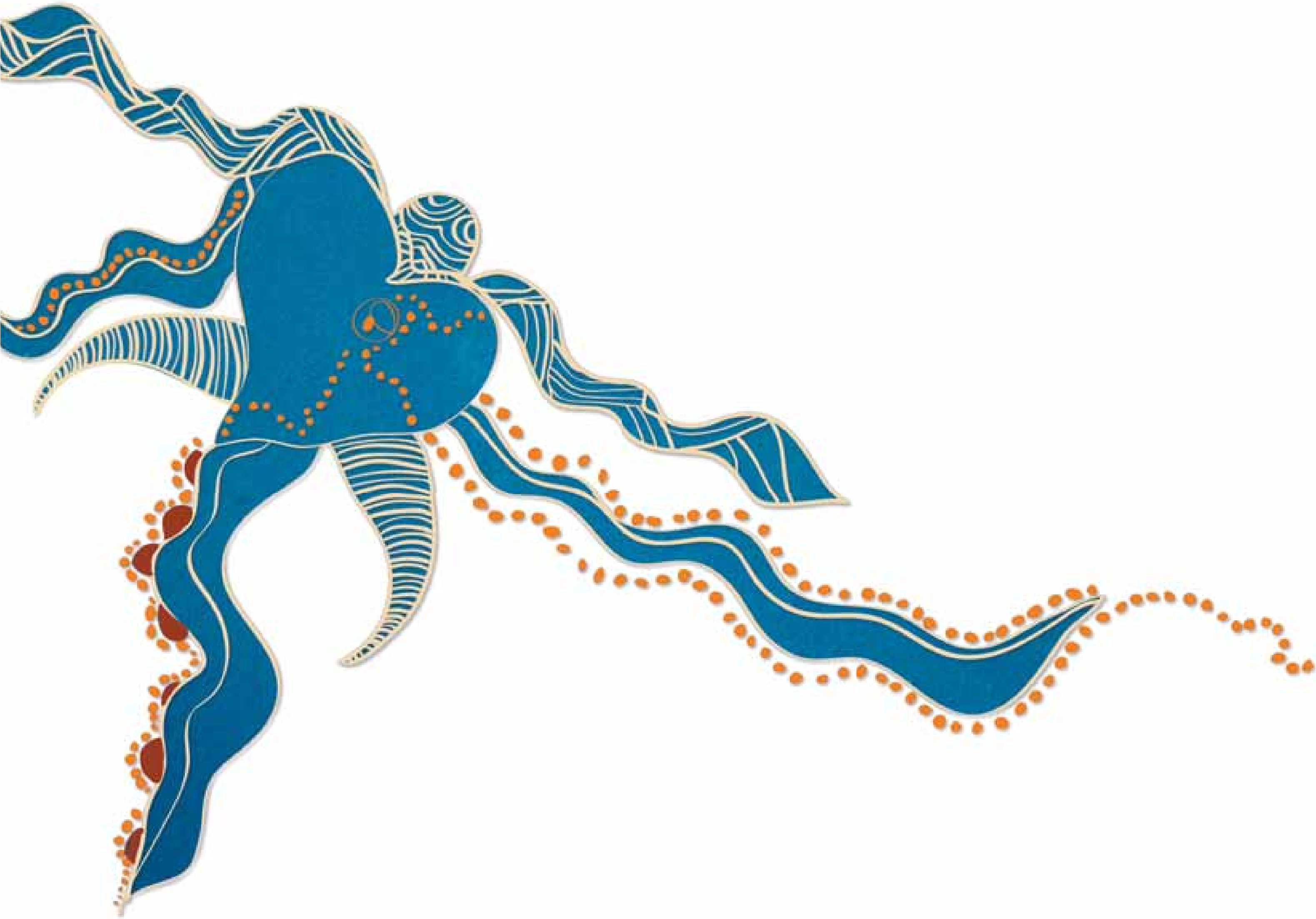
Many system challenges remain to ensure that the journey of Aboriginal people before, during and after hospital can be a positive one. The hospital environment, its information system, clinical practice and staffing are often not culturally safe and not considerate of the needs of Aboriginal patients and their families. These same issues also hinder referral back to community services and interfere with Aboriginal patients' participation in cardiac rehabilitation.

Aboriginal patients are often discharged into stressful environments in which health choices are difficult. These include lifestyle choices like smoking, diet and exercise as well as regular medical check-ups and medication review. Improved discharge processes and support for healthy choices in the community are a priority to ensure secondary prevention is successful.

Part II of this Report is dedicated towards outlining actions that can be taken to improve the cardiac health of Aboriginal people in WA, and, indeed, throughout Australia.

# Part II:
## Strategies for Action





# Introduction

1

In Part I of this Report we summarised the BAHHWA research and other information related to Aboriginal heart health. In Part II we address the question of what can be done to respond to the issues raised by this research, and report on recommended strategies for action that were developed through a variety of consultations. These strategies give more detail to the recommendations given at the end of each section in Part I.

## Principles for changing the Aboriginal heart health story

As discussed previously, social, economic and environmental factors remain major determinants of health throughout life. These need to be considered when making policy and planning programs and services.

A healthy lifestyle, including regular exercise, smoking cessation, reduced stress and a healthy diet, lowers the chances of developing cardiovascular disease. Similarly, following the occurrence of symptoms or diagnosis of heart problems, there are effective preventive actions including early assessment by a GP, good follow-up care, timely communication between primary care and hospital providers, and appropriate referral for other cardiac rehabilitation including dietary advice.

However, putting strategies into action is complex and challenging. Changing health behaviour is much more complicated than simply giving people information, just as changing healthcare practices is more complicated than producing clinical guidelines. The manner in which information is communicated, the context and the supports for patient change are all important, as reflected in the VicHealth best-practice principles for promoting health in Aboriginal communities (see Box 9). These principles are a useful guide for planning and implementing services and programs. They are most achievable when there are strong intercultural partnerships and co-operation across different government sectors, business and the community.

**Box 9**

APPROACHES TO PRACTICE

### Best Practice Principles to Promote Health in Aboriginal Communities

- take account of historical, social, economic and cultural contexts
- use an approach that is owned and driven by the community, and builds on strengths to address priorities identified by them
- be flexible and allow for innovation
- be accountable, in particular, build in monitoring and evaluation systems and use interventions that have been shown to work
- develop comprehensive and diverse strategies to address social, economic and environmental disadvantages impacting on health
- ensure sustainable funding, program design and governance
- use a strengths-based perspective to build and sustain social networks, community skills, capacity, confidence and optimism
- ensure early prevention and treatment with timely and appropriate care

From Life is Health is Life (VicHealth, 2011)[52] http://www.vichealth.vic.gov.au/lifeishealthislife

To improve the Aboriginal heart health story, effective intercultural relationships between organisations and individuals need to be developed and strengthened and trust built. Differences within and between organisations include factors such as:

- the complex and diverse needs of individuals and communities
- different models of care
- differences in funding and reporting between mainstream and Aboriginal Community Controlled Health Services
- organisational capacity for change

All of these factors require integrated strategies, partnerships and good governance in order to provide effective care. Intercultural partnerships are integral to promoting individual, family and community health. The case study below shows how a policy to encourage partnerships between mainstream and Aboriginal services was implemented in Victoria. The policy resulted in substantial sharing of resources and joint planning between organisations that had often not worked collaboratively before.

CASE STUDY

**Box 10**

## Policy support for health promoting partnerships

The value of working in partnership is well recognised, and as a policy direction has in some cases successfully driven practice. Here we describe an example of how this was achieved through the Aboriginal Health Promotion and Chronic Care partnership (AHPACC) program, funded by the Victorian Health Department.

AHPACC supports Aboriginal Community-Controlled Health Organisations (ACCHOs) and mainstream community health services to work in partnership to develop and deliver local services and programs addressing the high prevalence of chronic disease within Aboriginal communities.

The AHPACC funding model recognises that when funding is directed only toward service delivery, staff are often inadequately supported, and services and programs may not reflect the needs of the local community. Consequently, the funding model specifies that agencies can only use 50% of their funding for direct services, and requires the remaining funds to be used for activities such as working in partnership, community engagement, workforce development, organisational change and looking at new ways to deliver programs. These additional activities are monitored and supported through the use of a CQI Tool (http://www.health.vic.gov.au/aboriginalhealth/programs/partnership_program) that must have senior management endorsement within all AHPACC partnership organisations.

An example of an outcome from this policy is the resource produced by one of the AHPACC partnerships for mainstream partner organisations, ‘Improving employment opportunities for Aboriginal workers in mainstream community health services: an Aboriginal Readiness Checklist’.[53] This resource guides organisations to improve their readiness and ability to recruit and retain Aboriginal staff. It also includes resources to ensure that direct-care staff and administrators have appropriate skills, knowledge and attitudes. The resource includes case studies of practices that are proven to be effective. In addition it provides examples of organisation policies, administrative procedures and management practices that support access to culturally appropriate services and competent personnel.

Continued page 67

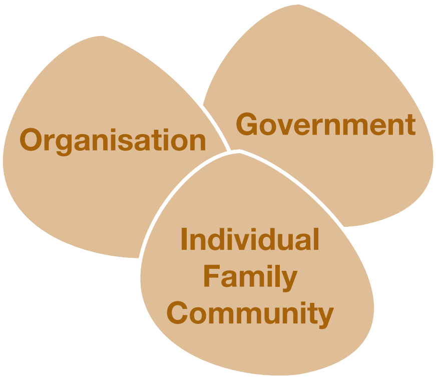
CASE STUDY
**Box 10** cont.

By changing the nature of the funding contract with these organisations, the policy encouraged innovation, workforce development initiatives and co-operation between organisations.

'Northern AHPACC Consortium Partners, Improving employment opportunities for Aboriginal workers in mainstream community health services: Aboriginal Readiness Checklist Project Report',19 September 2012, available from: http://docs.health.vic.gov.au/docs/doc/Northern-AHPACC-Consortium-Partners-Aboriginal-Readiness-Checklist-Project-Report

http://docs.health.vic.gov.au/docs/doc/AHPACC-Guidelines-and-Strategic-Directions-June-2013

## Structure of this Report according to levels of action



Not only do strategies to improve Aboriginal health need to incorporate intercultural principles, they also need action to happen at three levels simultaneously: the individual-family-community level; the organisational level (e.g., health services); and at the government/policy level (Figure 18).

We have structured Part II of the Report according to these three levels. Thus Section 2 reviews actions at the individual-family-community level. Subsequent sections look at the organisational actions to support health workers in delivering programs and services according to the Section 2 recommendations (Section 3), and the necessary government/policy level support (Section 4).

While the strategies for action are given here according to the levels that implement the actions, it is important to ensure that actions at different levels are integrated and all aligned to improve Aboriginal health. 'Good news stories' and case studies are presented throughout the Report as a guide to successful actions. Also, in Appendix 5, we include resources to help translate recommendations to practice.

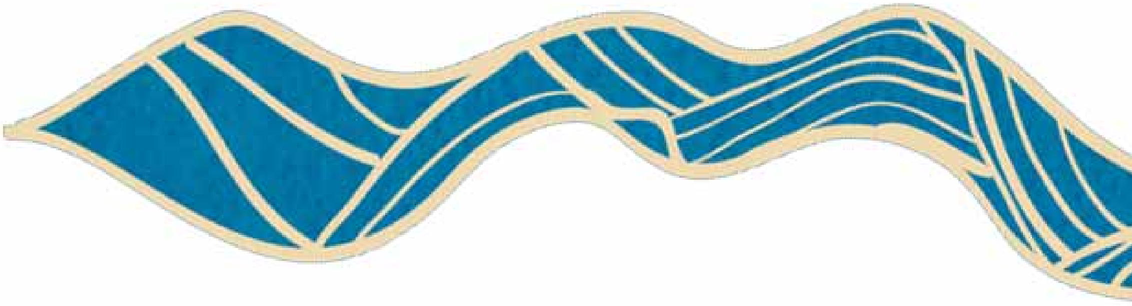
## How the actions were developed

An 'Information for Action' workshop was held in November 2013, initiated by the BAHHWA group. Representatives from diverse sectors, including research, policy, and health service provision, came together with representatives of Aboriginal health organisations and the Aboriginal community to discuss ideas and share their knowledge and experience. Their responses were organised into a framework that reflects the multi-level approach needed to implement strategies for action, that is, the three-level approach shown above (Figure 18). Many of the workshop participants subsequently joined the 'Information for Action' Reference Group and have continued to have input into these recommended actions.

In addition to the 'Information for Action' workshop, we have drawn on other sources, including recommendations made by the authors of the research reported on in Part I. Policy level strategies discussed here are informed by the work of a Victorian Aboriginal health partnership project (AHPACC), and recommendations from a national consultation process, the 'Better Cardiac Care for Aboriginal and Torres Strait Islander People' forum, an initiative of the Australian Health Ministers' Advisory Council (AHMAC).

The work of the AHMAC 'Better Cardiac Care' forum occurred concurrently with the development of the BAHHWA 'Information for Action' Report. The AHMAC forum undertook extensive expert consultation in 2013-2014, but only considered gaps in cardiac care for Aboriginal people that were within the remit of the health system. Through this process, participants identified priority areas for intervention and corresponding strategies, aligned with current national and relevant international guidelines of best practice. They also drew on previously implemented, successful or promising programs of care. The AHMAC work also emphasises the importance of integrating actions across all levels, recognising the needs and capacities of individuals and families as well as differences between health service providers. The 'Better Cardiac Care' forum priorities are expressed as policy level actions; consequently, they have been included in the Government Level section of this Report.

In setting policy direction, in particular where it influences resourcing, 'Better Cardiac Care for Aboriginal and Torres Strait Islander People' will significantly contribute to the successful programs and organisational changes described in the first two sections of Part II of this Report.



CASE STUDY
Box 11

## Getting Started, Leading By Example and the Power of Ripples

Kathy* was an experienced communicator and educator working for an Aboriginal organisation. Her job involved a lot of travel and liaising with Aboriginal primary health care services for the purposes of training, support and encouragement to improve health service delivery, including management.  For many years, she had been unhappy with being overweight.

Kathy's brother was a diabetic who, following a foot injury, developed an ulcer that became infected, eventually resulting in foot amputation. Kathy was deeply affected by this, being aware of her own risk factors: lack of regular physical activity and being overweight, as well as the family history. She was conscious that her New Year's resolutions for each of the last 3 years had been to 'lose 20 kg … exercise more'. She was also experiencing problems with aching joints and difficulty getting up out of chairs. Reflecting on this, she realised that if she genuinely wanted to exercise more and lose weight, she would need to make a commitment and act upon it immediately.

She sought a sustainable lifestyle change rather than a short term 'diet'. Her strategy for eating was to focus on the 'Great Australian Diet' she had read about: a variety of fresh and unrefined foods, predominantly plant-based (grains, fruits, vegetables, nuts and legumes) with the addition of lean meat. This strategy was simple and readily achievable even when she was travelling. She committed to walking every morning and night; if the weather was bad she used a cross trainer or gym. She had a frank conversation with her partner (who also had many chronic disease risk factors) about how important this change was to her, and sought his help and support. His previous resistance to walking with Kathy had made it difficult for her to exercise, but hearing her concerns and aware of what had occurred to her brother, he agreed to exercise with her, although not every day.

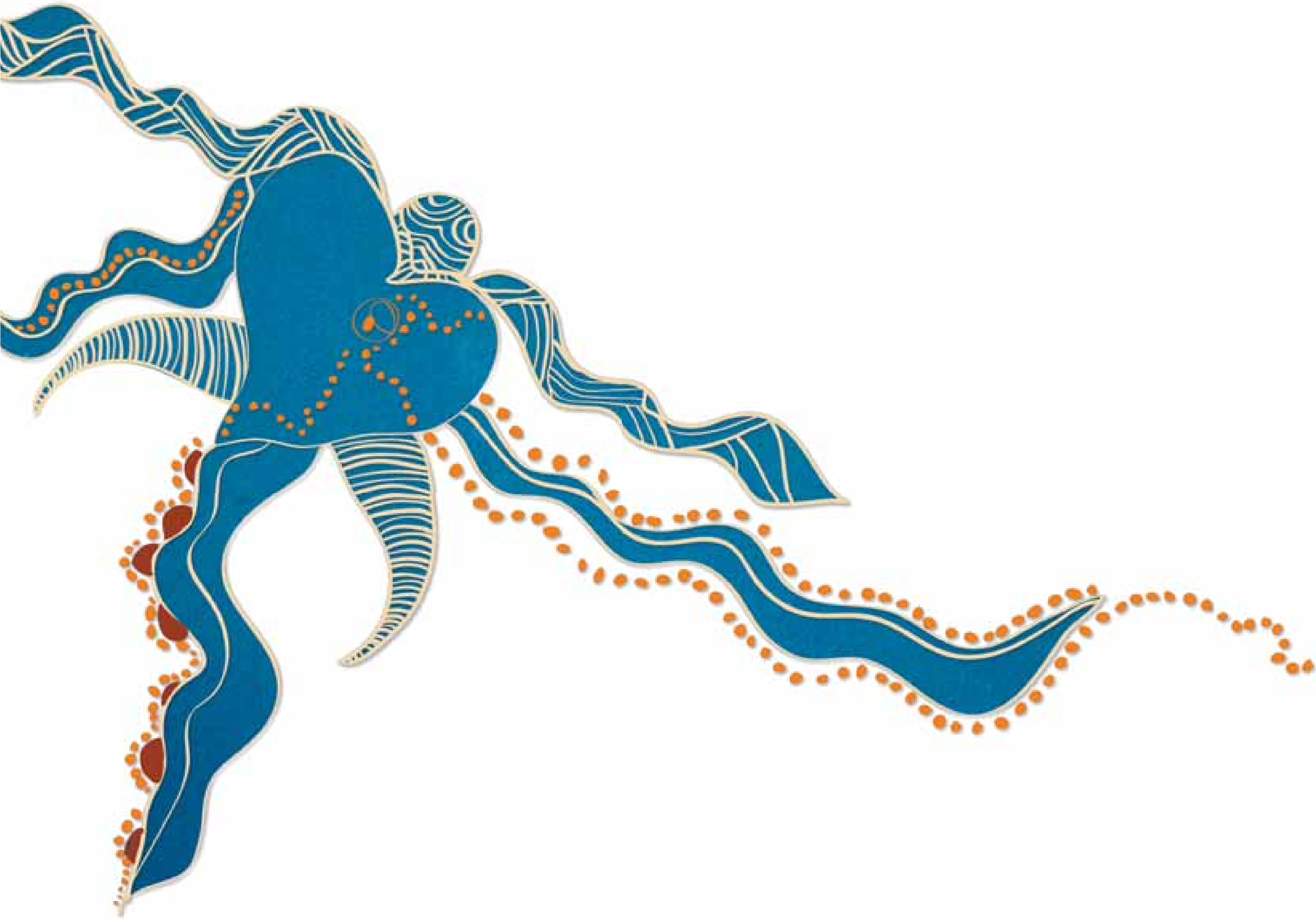
Kathy managed to maintain the lifestyle changes to which she had committed. She stopped drinking alcohol regularly, saving it for special occasions only, and avoided drinks containing sugar and calories, instead drinking diet cola or soda water with lime. She lost 10 kg over several months, and, as her figure and fitness improved, this became obvious to others around her. The old aches and pains she had been feeling, one of her main reasons for not exercising, lessened.

Her work colleagues, both Aboriginal and non-Aboriginal, couldn't help but notice the change in Kathy as the kilograms were progressively shed. She was open about sharing her new lifestyle strategy when anyone asked, but there was no sense of her pushing it down others' throats or of being a health promotion zealot. Co-workers sometimes came with her on lunchtime walks. Her organisation even started to have the occasional walking meeting, and put more emphasis on healthy catering. Kathy's relatives were also aware of her success and made changes in their own lives. Her partner regularly responded to her requests to walk the dogs with her. His fitness improved so he was no longer puffing just getting up off the couch as he had done before. Without her having imposed lifestyle changes on anyone (other than her partner), the benefits of the changes she had made became obvious, not only to Kathy's siblings, work colleagues and friends, but also to the much wider group of people that she interacted with through her work and all the travel this involved.

Kathy was feeling better physically, and her new sense of wellbeing reinforced the value of—and her commitment to—a healthier lifestyle. She enjoyed looking and feeling better, had a greater sense of control in her life, and appreciated the support from her partner and additional opportunities for communication with him.

Kathy's changes have served as a source of inspiration for others, and in turn, their changes have influenced those around them.  That's a ripple to be proud of.

Source: Anonymous account told to a BAHHWA researcher (*not her real name)



# Individual-Family-Community Strategies for Action

2

In this section, we draw on practical examples and suggestions, primarily those discussed at the 'Information for Action' workshop, about how health professionals can encourage people to take a more active role in their health. These recommendations address the difficulty of putting 'prevention' messages into action. For example, some people are less likely to engage in health promotion and are less health conscious than others, or do not seek health advice or utilise services because they do not want others to know that they are unwell.

## Key messages

- Ensure effective community engagement to develop appropriate ways of promoting health.
- Consider delivery (where, how, with whom) as well as content when delivering health messages.
- Organisations must provide adequate funding and logistical support to people delivering health services.

Heart health promotion should occur throughout life, and include pregnant women and children. Starting early in life is particular important with Aboriginal people because heart disease generally affects them when they are much younger than other Australians. This requires substantially more collaboration between sectors.

The key considerations for successful health promotion and services with individuals, families and communities that emerged from participants' responses include:

a. Community engagement

b. Location of program/project/service

c. Presentation of messages

d. Content of messages

These considerations for good practice in health promotion and care require good organisational support to overcome practical challenges. They are discussed in more detail below.

## a. Community engagement

Engaging and consulting with the community is fundamental, from the early stages of program development through to its evaluation. Consultation facilitates implementation and leads to community ownership and involvement. By this means, health providers understand better what works—and what does not—in health promotion and care. Health providers are thereby up-skilled, and the programs they deliver benefit from community support. Community ownership of programs builds community capacity, improves community awareness of health promotion and increases confidence in passing on information to others. Establishing good relationships with families and the community assists in disseminating information about programs and messages through word of mouth, in particular when 'champions' (often elders) who help disseminate information are identified. A good example of this is the District Aboriginal Health Action Groups (DAHAGs) in the Perth South Metro area, which played a key role in facilitating changes to services and programs. (See case study [Box 12])

CASE STUDY
**Box 12**

## South Metropolitan Health Service Community Engagement Process

The Public Health Unit at the South Metropolitan Health Service (SMHS) was able to enhance its engagement with the Aboriginal community by promoting the active involvement of Aboriginal people in their healthcare, with funding from the Council of Australian Governments' (COAG) *Closing the Gap* initiative. Despite a national legacy of mistrust and broken promises about improving healthcare to Aboriginal people, the SMHS team's innovative approach to engaging the community focused on strengthening existing relationships and building the community's trust. A transparent communication process where information was shared, reviewed, fed back and discussed at meetings with a view to improving practice facilitated this process—an approach that continues today. The team's vision also included the Aboriginal community leading the process of change and working in partnership with mainstream services and organisations including hospital services, local government and non-government organisations.

Each of the five districts in the SMHS area formed a District Aboriginal Health Action Group (DAHAG) consisting of community representatives nominated from the Aboriginal community and representatives from health services and agencies. DAHAG meetings were held quarterly, chaired by an Aboriginal representative elected by the community. The goal of DAHAGs was for health services, government and other stakeholders to commit to working in partnership with Aboriginal organisations and communities, to avoid tokenism and instead to move beyond talk to action. This required health providers to actively build relationships with community members, listen to their health concerns and act on appropriate recommendations to effect change.

Evaluation findings indicated that the community engagement process was effective and added value to improving the participation and involvement of Aboriginal people in decisions about their health care. There was very strong evidence that the community engagement process was driven and owned by the Aboriginal community, that the focus on community needs facilitated greater Aboriginal representation and involvement in decision-making about Aboriginal health care, and that the process built trust. The development of trust involved community representatives shifting from an initial position of distrust (based on previous experiences of being involved in consultations where nothing changed) to one of surprise that this community engagement process was making a difference by not being tokenistic, an attribute that has motivated members to continue their involvement. There was also strong evidence that DAHAGs were an effective forum for Aboriginal people to articulate their needs around health care, for the Aboriginal community and health service providers to discuss ways to improve Aboriginal health care, and to raise service providers' awareness of Aboriginal culture and the need to provide respectful and culturally safe health care. DAHAGs provided an opportunity for health service providers to have access, meet and talk with the local Aboriginal community about their health issues and to establish and build trust and strong partnerships to improve Aboriginal health outcomes.

Source: Bessarab D, Durey A, Christou A, Katzenellenbogen J, Taylor K (2014) Evaluation of the South Metropolitan Health Service Community Engagement Process. Perth: Curtin University.[54]

Community engagement is important in both primary and secondary prevention. The experience of a cardiac event can be an opportunity to educate the individual, his or her family and the broader community. Health professionals need to include family members in the patient's care so that knowledge of risk factors, early intervention and treatment needed by the patient can be shared with others in the family, who can both support healthy behaviours in the patient and reduce their own risks at the same time.

## b. Location

Choosing a location for health services and programs that is familiar, comfortable, and culturally safe for Aboriginal people makes a big difference to an individual's capacity to listen and absorb information. It is important that there is collaboration between the community and health services to identify and promote appropriate locations preferred by the community, ensuring community-owned and community-driven outreach programs. This does not necessarily require initiating community events or programs from scratch; in some cases it may be a matter of building on existing successful programs or existing community events, such as men's camps and sports days. Offering multiple services from one accessible, convenient location has been effective, as demonstrated by people coming as a result of word of mouth from others already participating. The significance of social interaction in promoting health messages and behavioural change should not be underestimated.

The 'Heart Health' program developed by the Perth-based Aboriginal Medical Service (AMS) Derbarl Yerrigan Health Service (DYHS) is a good example of how providing a service in a new, culturally appropriate environment can improve participation in cardiac rehabilitation. Previously, the only cardiac rehabilitation program provided by Royal Perth Hospital (RPH) was on-site at the hospital. Through a joint initiative with the Heart Foundation, a program was developed at DYHS, which is located a short distance from RPH. It was a 'game changer', using a family-centred approach based on partnership between a range of services/agencies. The project has led to family members becoming more aware of cardiac symptoms and this is known to have been translated into action. One example was when an individual complained to his family of cardiac symptoms, and an informed relative (who had attended a heart health education session) immediately took him to the hospital nearby. Further, when the patient was discharged from hospital, support was available from the community as well as from 'outsiders' such as health professionals (See Part I, Box 8).

**Box 13**

WORKSHOP SUGGESTIONS

### Factors to consider when selecting location of a program

- Select location where it is possible to offer food, childcare facilities, and transport/support to and from the location
- Ensure that events are welcoming, informal and fun and an opportunity to catch up with family and friends, making it more likely that people will come back
- Promote events that are jointly organised by health services and community organisations
- Organise outdoor activities (such as walks around the park): this allows easy interaction and can be an ice-breaker
- Improve access to recreation facilities including gyms or other exercise facilities
- Select facilities that are smoke-free zones and promote healthy eating, e.g., no chocolate/soft drink vending machines (including in schools and prisons)
- Encourage participants to bring along family members and friends

CASE STUDY
**Box 14**

## Aboriginal Lay Educators as Community Role Models for Cardiovascular Health Education

In the past few decades, despite large amounts of research and numerous health promotion campaigns, the cardiovascular health of Aboriginal Australians is still a major health issue. Clearly, it is important to identify and overcome the barriers that reduce the impact of Aboriginal cardiovascular disease (CVD) prevention programs. Dr Julie Owen, an Aboriginal woman, undertook her own PhD research in the South-West of WA to identify some of these barriers to inform and develop an alternative, culturally sensitive method of delivering CVD health messages to Aboriginal people.[55]

From previous research, the importance of *who* delivers health messages and *where* they are delivered is very clear. Health professionals based in formal settings using technical medical jargon may alienate Aboriginal people and not communicate messages effectively. On the other hand, trusted peers, elders and friends within a social network are generally more able to 'educate, motivate and advocate' about heart health. The role of the Aboriginal Health Worker (AHW) is pivotal: AHWs are the interface between the western medical model and the Aboriginal community. However, the dual identity of an AHW (as a health professional and a community member) can actually be a barrier in some situations—family and community ties can actually hinder the AHW's professional responsibilities.

The research involved setting up CVD education programs in three regional South-West towns with large Aboriginal communities, where there were AHWs who had completed a Heart Foundation specialised training course in CVD. Unfortunately, the AHWs were not generally able to translate this knowledge into practice or programs, due to heavy workloads, clinical demands and frequent resistance from the community (including antagonism between groups). A lack of confidence by some AHWs in organising findings and presenting messages was a barrier, with some feeling that they lacked credibility (e.g., if they were smokers who had to deliver a 'quit' smoking message).

A novel alternative strategy proposed by the researcher was to enlist and train respected community members as 'lay educators' from each town. The people recruited were carefully selected for personal experience of CVD and characteristics such as community-mindedness, self-confidence, willingness to maintain confidentiality, tact, a good sense of humour and ability to seek advice when needed. The people selected were trained in behaviours and healthy lifestyle for cardiovascular health at a 2-day retreat, which included lots of input and support from AHWs.

The second part of the strategy was to 'market' the lifestyle and behaviour messages by adopting the traditional way of passing on information in Aboriginal communities: small, informal, cohesive gatherings of people in familiar surroundings (in this case, 'HeartAware parties' in private homes). These included heart-healthy food for participants, DVDs, flyers and games, with AHWs as 'mentors'. As well as cultural sensitivity to size and location of meetings, another critical element for success was flexibility. An uncomplicated process to postpone and reschedule the gatherings at short notice was deemed important by the target group.

A number of HeartAware parties were held successfully and the program received strong support from the community. Evaluation of the program by the researcher showed that participants at the meetings acquired and retained important information about beneficial behaviours and lifestyles. The lay educators gained confidence in influencing the health of community, while health workers felt positive in their 'mentor' roles. Furthermore, it was clear that the messages from the

Continued page 75

CASE STUDY **Box 14** Cont.

HeartAware parties had been spread to other community members by word-of-mouth. As an unexpected benefit, the model was informally adopted by community members: a group of grandmothers was able to set up similar meetings to share messages on youth alcohol consumption. The success of this process was partly due to the process of 'action research', in which both the researcher and the participants collaborate to generate knowledge and actions.

Source: Owen J. Development of a culturally sensitive program delivering cardiovascular health education to indigenous Australians in South-West towns of Western Australia, with lay educators as community role models (unpublished PhD thesis). Perth, The University of Western Australia; 2006[55]

## c. Presentation of messages

It is important that health professionals are flexible in how they deliver health-related information and work together with Aboriginal communities to achieve this. This collaboration is important for developing understanding in the Aboriginal context about effective communication, building trust, and shared learning. Messages considered to be most effective are those that (i) are community-owned and delivered, using Aboriginal people rather than non-Aboriginal health professionals as educators where possible, and (ii) have early and ongoing support from community leaders. Getting young people involved can be a way to build capacity and increase confidence. Children can be involved in promoting health in their families. Similarly, trans-generational approaches to promoting health in children (involving parents and grandparents) can be effective, in particularly those involving a variety of modes of delivery such as the arts or multimedia. All health consumers have a right to high quality information (See Appendix 4: Australian Charter of Healthcare Rights).

Information needs to be practical, personal, and empowering. For example, blood pressure and heart beat checks (there is an app for measuring heart rhythm) can be used as opportunities for education. Information that is delivered in a way that encourages questions, is non-threatening and is enjoyable is more likely to leave them feeling they have learnt something that they value. Finally, visual recognition of the materials is crucial. Brochures, flags, pamphlets, magnets and T-shirts identifiable as Aboriginal-specific are all recommended. Many of these suggestions can be developed by investigating existing resources and building on creative approaches. Suggestions and resources can be found on the internet or through Aboriginal health networks. See also the list of resources in Appendix 5 of this Report.

CASE STUDY
**Box 15**

## The Western Desert Kidney Health Project

This project (http://westerndesertkidney.org.au) is an excellent example of an Aboriginal health promotion project incorporating the principles of community engagement, culturally appropriate message presentation and thoughtfulness about location.

Cardiovascular disease is often associated with kidney problems and diabetes, particularly among Aboriginal people from remote communities. Both kidney disease and diabetes can begin early in life; they are often present even in the children from these communities. The high risk of developing kidney disease and diabetes in these communities is partly due to lack of access to fresh foods, loss of traditional healthy lifestyles, and limited exposure to important public health messages that the general Australian population take for granted.

The Western Desert Kidney Health Project, launched in 2010, is a prevention program designed to reduce the impact of these conditions in ten remote WA Aboriginal communities. The project is led by a senior Wongutha woman, who is a medical practitioner in the community and involves a multidisciplinary team of Aboriginal and non-Aboriginal health professionals, artists and community development workers. There has been close consultation with the communities through every stage of project development.

The team travels to each of the communities in two specially fitted ‘Healthy Lifestyle’ trucks. Health professionals in the mobile clinic truck offer testing for kidney disease and diabetes to everyone in the community. They use ‘point-of-care’ machines that give instant results, so that the clinical team can discuss the results straightaway with every person who has been tested, and arrange follow-up if a problem is detected. Also, the leaders of the team review the medical test results of the community overall and discuss these at a community meeting.

Artists travel to each community in their own truck, along with the clinical team. They assist people from the communities to develop their own stories about illness and health, using the local people’s own language, images and visual media (e.g., sand painting). The visit ends with a small community event in which the new artistic creations are celebrated in a way that integrates stories of local Aboriginal culture with health knowledge. This promotes culturally appropriate understanding about healthy living and how to build people’s skills and achieve change at a community level. (An example of a practical outcome is the establishment of gardens to grow fresh food.)

Also, the team advocates on behalf of the community to government agencies and community organisations. Furthermore, they publicise the project using the media and by writing articles for health research journals.

There is already evidence from a pilot study that the project can succeed, both in engaging the community and in improving health status. People from the communities have enthusiastically engaged in the creation of art works and celebrated the community events. Furthermore, some people have been able to lose weight or reduce their blood pressure or cholesterol.

Source: Jeffries-Stokes C, Stokes A, McDonald L, Stokes S, Daly J. A complex Aboriginal health project and the challenges for evaluation. Aust N Z J Public Health. Jun 2011;35(3):204-206[56]

Also:
http://westerndesertkidney.org.au

http://www.abc.net.au/local/stories/2010/10/08/3033576.htm

**Box 16** WORKSHOP SUGGESTIONS

## Different means of communicating messages

***Arts,* for example:**

- Hip hop—gives a different approach that is fun, engages young people so they own the message and gives them hope for the future, thereby building capacity and confidence
- Use a performer, e.g., a clown, so learning is fun; can also act as an ice-breaker when getting people to talk and share stories
- Participant-created performances are both educative and develop participant skills and confidence

***Multimedia,* for example:**

- Video clips (especially if generated by Aboriginal person, e.g., Mary G).
- Web-based, for example children can use Photoshop to both learn and apply messages
- Animation or pictures, perhaps as a phone application
- Apps or SMS messages to remind people about appointments, medications, and support lifestyle changes

***Interactive,* for example:**

- A cookbook that modifies traditional recipes
- A book of Aboriginal games
- A culturally appropriate game targeting Aboriginal children (e.g., the SNAP into life project* (http://www.snapintolife.com.au/)
- Walking groups
- ‘Yarning it up’ (group discussion and support) programs are effective, for example, even a person who is still smoking and wanting to give up can talk about harm minimisation such as only smoking outside to avoid exposing their children to tobacco smoke
- Hands-on fun activities/community events to promote health, for example at sporting carnivals
- Using relevant imagery to chart progress, e.g. recording number of steps walked as distance covered if walking the Canning stock route

*SNAP: smoking, nutrition, alcohol and physical activity

## d. Content of messages

Health-promoting message content can support both primary and secondary prevention, encouraging people to attend to health issues early to prevent illness or slow its progression. To optimise meaning and relevance, health messages need to be developed and reviewed regularly (and improved if necessary) in collaboration with communities.

**Box 17**

WORKSHOP SUGGESTIONS

### Developing message content

- Personalise and simplify the key health promotion message for each individual
- Address a range of comorbidities rather than just focusing on heart disease alone
- Present messages clearly and provide other opportunities to further explain or discuss the messages
- Include messages that increase practical knowledge and skills (e.g., the cost of accessing health care and budgeting)
- Embed health messages in ways that are practical, and age- and skills-appropriate. For example, primary school children can have toothbrushes and toothpaste in the classroom to learn about oral health; a men's shed can offer men support; walking groups can bring women and/or men together in a health promoting activity
- Try to use positive messages rather than negative messages that can generate fear/anxiety

These examples of strategies for promoting health require good organisational support, as they can present challenges to staffing and logistics. The next section documents how organisations can support health workers in delivering programs and services.

CASE STUDY
**Box 18**

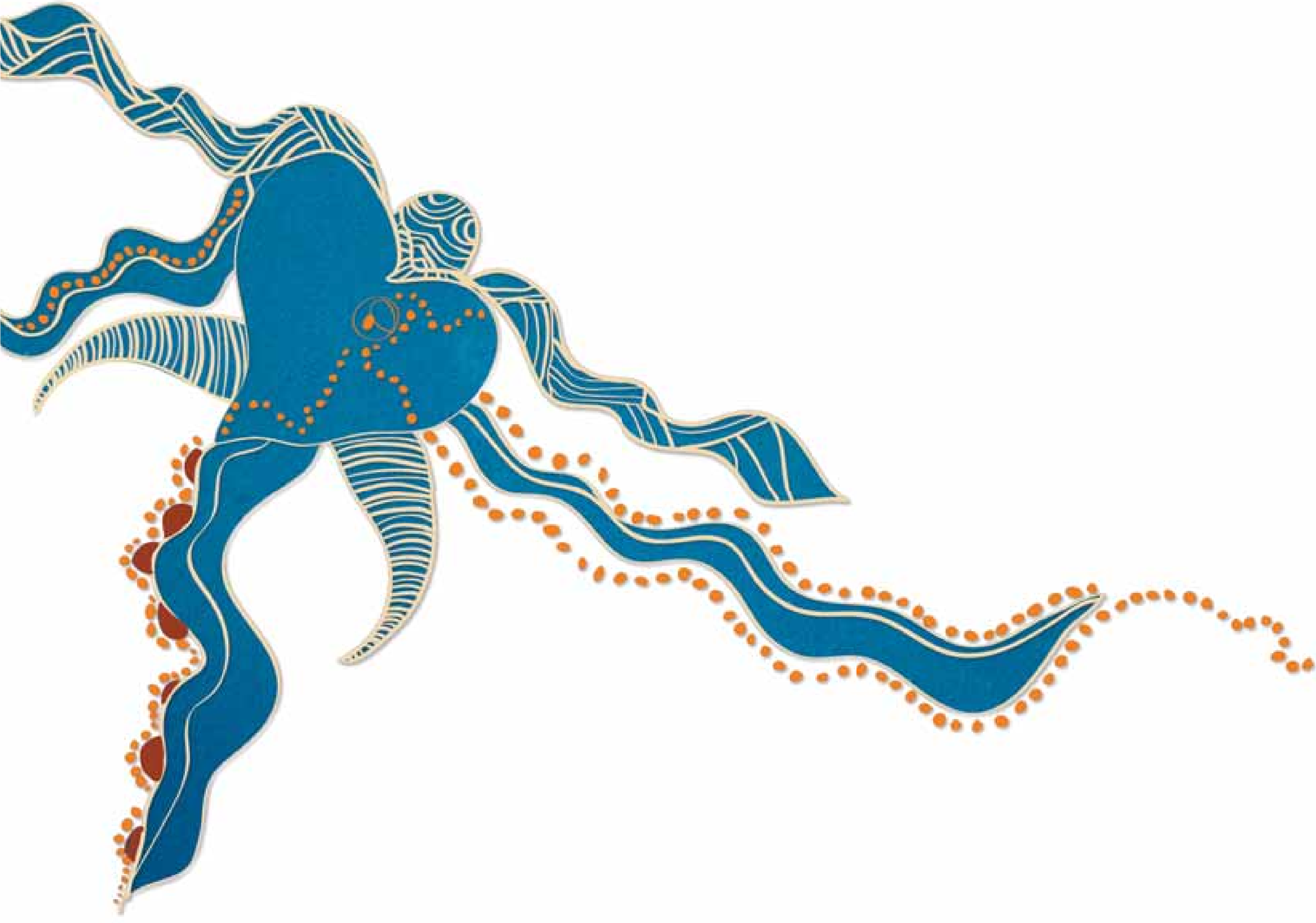
## Group-based physical activity

The Aboriginal Healthy Women's project, implemented by the Women's Health & Family Services, was first funded in 2008 by the Department of Health, Western Australia (WA). This project operated in different community settings in Perth, WA. The main aim of the project was to increase Aboriginal women's participation in physical activity thereby promoting physical and mental health and well-being. This was achieved by providing Aboriginal women with opportunities to:

- learn new skills
- participate in physical activity sessions based on women's preferences in safe and culturally appropriate environments
- link to mainstream services
- advocate on behalf of Aboriginal clients groups, and
- seek alternative arrangements to continue/sustain the program activities past the funding period.

A physical activity program comprising a series of exercise classes in two community-based settings in the southern part of Perth was evaluated in 2011. In the Aboriginal Healthy Women's project, staff members used a community development approach and recognised the need for flexible programs. This not only helped the program better address participants' needs, but also allowed staff members and participants to establish a trusting relationship. This trust further provided participants with a supportive environment, and helped them to feel comfortable, empowered and confident. Additionally, the use of group-based activities provided participants with a sense of community and gave participants additional peer support. Most groups comprised women of a mixed age range, and participants often brought their children and friends into the classes. One of these groups originally had classes in a local recreation centre but they requested that the local Council assist by providing access to a community hall. The Council responded positively and the women now have their own space for the exercise classes after hours.

Source: Shahid S, Deas K (2011). Evaluation of Aboriginal Healthy Lifestyle Program: Creating opportunities for women to improve their own, their families and their communities. A report prepared for Women's Health and Family Services, Perth[57]



# Organisational Level Actions

3

To deliver services and programs in the ways described in the previous section, health professionals require organisational support. Key organisational strategies for improved care for Aboriginal people include:

**a.** Reconciliation Action Plan to outline the organisation's vision for reconciliation through meaningful yet practical plans to develop relationships, show respect and increase opportunities for Aboriginal people (http://www.reconciliation.org.au/raphub/about/)

**b.** High quality, respectful, culturally appropriate care, including guidelines, staff training, and involvement of Aboriginal community representatives

**c.** Better communication and linkages between health services to improve the discharge or referral follow-up processes that take into account the challenges facing the Aboriginal patient journey

**d.** Aboriginal professional involvement in healthcare and resources to support their professional development

**e.** Audit, evaluation and research of health programs and services

Points b-e are discussed in more detail below.

### Key messages

- Organisations must support the delivery of appropriate care, programs and services through policies, guidelines, staff training, employing Aboriginal staff and undertaking community engagement and intercultural partnerships.
- Better health service linkages are needed to improve transitions, for example discharge from hospital to primary care and referral to other agencies.
- Aboriginal staff must be employed and appropriately supported throughout organisations.
- Quality improvement processes (audits, research and evaluation) are needed to ensure accountability and effectiveness in putting supportive strategies into place.
- Organisational actions require adequate staffing as well as logistical and financial/resourcing, which must be supported by policy level action.

## b. Culturally appropriate programs and services

High quality, respectful, culturally appropriate care, includes guidelines for the system of care (e.g., in the hospital), staff training, and involvement of Aboriginal community representatives in the way the programs and services are delivered. Fundamental to the success of services and programs is engagement with Aboriginal people through intercultural partnerships, working together from the outset on planning and development. In order for staff to have the necessary skills and confidence to engage in community partnerships, and to deliver culturally appropriate care (culturally safe care) cultural awareness/safety training is essential (see Glossary for definitions of these terms).

Many non-Aboriginal people are apprehensive about working with or initiating programs for Aboriginal people because they lack knowledge and skills in this area and do not want to offend. This can interfere with engagement between health professionals and Aboriginal people. Organisational support in terms of opportunities for education and training is important to ensure health professionals increase their confidence to deliver high quality care that is non-discriminatory and respectful of cultural differences. These programs need to focus on health providers expanding their understanding of the broader social and historic factors that undermine Aboriginal health.

Evidence suggests that by reflecting on and questioning their own biases and assumptions about Aboriginal people, health providers will be less likely to impose them in practice. Training in this area needs to be flexible, and offered frequently. This is required to allow for workforce turnover and individual staff development that takes into account different levels of awareness and receptivity (i.e., people aren't always ready to 'hear' this training, and it may need to be repeated). This will also help ensure that workplaces are more likely to be non-discriminatory and culturally safe, which is important in retaining Aboriginal staff. Box 19 lists questions for reflective practice to improve communication, avoid misunderstanding and achieve culturally safe healthcare.[31]

## c. Communication between services, including referrals to specialists, and between services and clients

Improving communication between different health services was a significant theme from the workshop. Good communication is essential between services (including referrals to specialists), as well as between services and clients, particularly when people are dealing with many complex health issues. Health professionals need institutional support to make this happen.

For example, there are many situations where patients need to be or can be referred to private sector GPs and specialist practices that are prepared to bulk bill Aboriginal patients. When there are transport difficulties or waiting lists for public hospital/out-patient investigations it may be more convenient or clinically appropriate to refer to private practitioners. However, there is a need to formalise partnerships which will enable this to occur. Without a formalised agreement on protocols for Aboriginal clients, policies (e.g., circumstances in which a public patient will be allowed into a private clinic/service) may not be applied consistently. The patient may also need to be reassured beforehand and at the time that there will be no costs to them, particularly as they may witness other patients being told about charges or paying gap fees. It is important to recognise a person's anxiety and reluctance to use a service that they can't afford to pay for. GPs at some AMSs may be able to provide advice on this issue.

Box 19

APPROACHES TO PRACTICE

## Questions for reflective practice to improve communication avoid misunderstanding and achieve culturally safe healthcare

- Have you attended training about local Aboriginal culture and belief systems? Do you check what training other staff in your team have attended?
- Do you model cultural respect towards Aboriginal people and those of other cultures?
- Does your organisation have a Reconciliation Action Plan? Do you know what is in it? How have you contributed to its development and implementation?
- Do you see patients who are Aboriginal Australians?
- What are the income, education and power differentials between you and an Aboriginal patient? How might this affect your interactions?
- Do you have an Aboriginal person in your healthcare team? How well is your Aboriginal team member treated? Are they included in team meetings, and not exclusively expected to work with Aboriginal staff? What support mechanisms are in place to assist them in their work?
- Is your hospital welcoming and safe to Aboriginal people who attend for care? Can they find their way around easily? Have you asked Aboriginal patients what they think?
- How well do you engage the Aboriginal patient and their wider family in decision-making in relation to their care and subsequent management?
- How do you talk with Aboriginal patients and family members? Do you know what community they are from? Are you sure they understand you and what you are saying? What are you doing to check that they do? How often have you used an Aboriginal interpreter to assist communication?
- Do you treat the whole person or just the body part? Do you ask about the major concerns of your Aboriginal clients and their life circumstances as part of caring for them? What mechanisms for psychosocial support are in place for Aboriginal patients and their family members?
- Do you ensure that when patients are discharged they will receive good follow up care—how? What healthcare resources are available in their home community?
- After discharge, how do Aboriginal patients get home and how long does it take? What about their family members who supported them?
- Does your system for communicating with primary care providers work for Aboriginal clients, not just those seeing urban GPs? How often do you ring the primary healthcare service to provide information and reinforce messages about the need for follow-up care of Aboriginal clients?
- If the system is not working adequately for Aboriginal patients, are you constructively engaged in systems reform?
- Are you part of the problem or part of the solution to poor Aboriginal health outcomes?

Western Australian Centre for Rural Health: online Aboriginal Cultural Orientation self-directed learning package: http://lms.cucrh.uwa.edu.au/login/index.php

And having this knowledge and understanding is not enough on its own—using that knowledge to inform their practice is integral to health providers improving the care of Aboriginal people and their health outcomes (Box 20 gives some examples).

**Box 20**

WORKSHOP SUGGESTIONS

## Ways Organisations Can Support Culturally Appropriate Care

- Add Aboriginal art/artefacts/symbols to make a friendlier environment, for example, a map of Aboriginal language groups at a cardiac gym got a lot of positive comments from Aboriginal participants and staff.
- Make services more flexible (e.g., offer some 'drop-in' rather than at fixed appointments, and services available out of working hours). The hospital policy of discharging patients because of a single missed outpatients appointment disadvantages those people who have transport problems, personal barriers to attending appointments, or are difficult to contact because they frequently move house.
- Increase collaboration between hospital management, health providers and Aboriginal people on issues/practices/rules in the hospital, for example as is happening with the South Metro District Aboriginal Health Action Groups (DAHAGs) (see Box 12)
- Reduce the factors that make it difficult or unpleasant for Aboriginal people to benefit fully from their hospital stay, e.g., cultural misunderstanding and poor communication between hospital staff and Aboriginal patients. (See Part I, Section 9 'Discharge against Medical Advice' for more detail.) This includes being aware of language barriers, and difficulties in understanding terminology.
- Have a genuine interest in patient care, including anticipating physical and/or emotional discomfort in Aboriginal patients, and actively and sensitively enquire about this. Delay in responding to symptoms or failure to recognise them is likely to occur precisely because of communication problems and cultural misunderstandings. Address Aboriginal patients' cultural, social and emotional needs in practical ways to minimise discomfort.
- Ensure that reminder calls/texts to patients' mobile phones show caller identity (e.g., 'FHOP' appears on Fremantle Hospital SMS messages). When the display shows as 'Blocked number', some patients may be reluctant to answer due to suspicion or fear. (It is important to note that many Aboriginal people have had unpleasant past experiences dealing with institutions).
- Ensure staff are aware of issues involved in discharge to remote communities. For example, some patients are unlikely to have a conventional street or postal address (and therefore it is better to ask, 'What is the best way to contact you?', rather than, 'What is your address?') Similarly, where health services are limited, asking: 'Who is your GP?' may result in 'nil-GP' being recorded on discharge notes with serious implications for post-discharge care (see Case study Incorrect Entry of 'Nil-GP' in Hospital Records Box 27).

**Box 21**

WORKSHOP SUGGESTIONS

## Ways to Improve Communication Between Health Services

- Determine and record the Aboriginal status of all clients. This ensures that they have access to Aboriginal-specific health subsidies such as *Closing the Gap* medicines and that organisations can do appropriate monitoring and planning.

- Accurately record the name of every patient's GP on the clinical records or hospital discharge summary. This ensures that the GP and/or community nurse gets a summary promptly, and that primary care follow-up is immediate and more likely to be effective. ('Nil GP' on a hospital record is not acceptable). Clerical staff and clinicians may need to be trained how to ask this simple question as some patients don't relate to the term 'GP' or only know first names. If the patient can't remember at the time of admission, this should be flagged and checked at a time when they are less anxious or unwell, or the family should be asked (See Box 27).

- Ensure continuity of care where possible. When doctors in training rotate through hospitals this can be difficult. Aboriginal professionals can assist by being a constant in the hospital environment.

- Develop better referral mechanisms, particularly focusing on communication between primary and hospital/specialist care, i.e., both to arrange hospitalisation and also following discharge.  Changing the language and mindset for staff to take responsibility for 'transfer of care' rather than 'discharge' will encourage hospital providers to consider beyond the walls of the hospital.

- Aboriginal health professionals can assist in liaising between health services and ensuring follow-up procedures are put in place, including with families and Aboriginal health workers in other services.

- Patient Journey Mapping tools: The tools developed by the Managing Two Worlds Together project in South Australia help document and map entire patient journeys from home to hospital to home, involving multiple services. This can help in planning and evaluate services, auditing, justifying costs, identification of areas for improvement, and staff training. The tools and examples are available from: http://www.flinders.edu.au/medicine/sites/health-care-management/mtwt

- Use the HealthInfoNet yarning place to develop and disseminate strategies: (http://www.healthinfonet.ecu.edu.au) HeartInfoNetwork (http://www.yarning.org.au/group/5).

- Some hospitals have no '*Closing the Gap*' (CtG) medications available or patients have to wait 3-4 hours for the hospital to dispense medicines. The situation is worse on weekends when the local AMS is shut and patients cannot get their CtG medicines and blister packs through the AMS. Although patients can leave with a script, they may then have to pay for medicines. GP Liaison doctors at the tertiary hospitals may be able to suggest the best way to deal with this difficult situation (see Appendix 3 for more detail).

WORKSHOP SUGGESTIONS

**Box 22**

## Ways to Improve Communication Between Health Providers and Patients

- Take time to hear patients' concerns and allow them to ask questions. Become comfortable with pauses and silence.
- Be genuinely interested in the person as patients are sensitive to this. Understand the person, where they come from and their family context and concerns.
- Address issues related to discharge planning and understanding of medications by hospital patients and families, prior to discharge. This means health providers need to know how to give clear instructions to patients and check patients have understood. Involve family members if the patient desires. Using telephone or Skype to involve family members from a geographically distant place has been helpful. Encourage questions from the client/relative, and ask for feedback on whether the message has been communicated adequately.
- Provide medical records to patients in a user-friendly format and advise them to carry these records when they visit a health service.
- Encourage patients to register for the Personally Controlled Electronic Health Record (PCEHR) scheme. This is an online summary of the patient's health information that allows doctors, hospitals and other health care providers to view and share important details that can help patients get more integrated care.
- Use direct one-on-one communication when contacting a patient, e.g., phone/text/visit.
- Follow up clients actively over time, for example, with periodic follow-up calls.

CASE STUDY

**Box 23**

## Initiatives of an Aboriginal Health Liaison Officer—Systems Change for Heart Health

Aboriginal Health Liaison Officers (AHLOs) make a critical contribution to ensuring that Aboriginal people have equitable access to health care by helping Aboriginal patients negotiate the complexities of the hospital system, facilitating communication between health service providers and Aboriginal patients, and promoting cultural awareness. However, in many cases, their input may not be integrated as well as it could be within a hospital's organisational system.

An AHLO working in the Cardiology department of a Perth teaching hospital took a proactive approach to improving the effectiveness of the AHLO role at a system level. AHLOs in her hospital had previously been poorly resourced and supported (e.g., a predecessor was not even provided with desk space) perhaps because of the importance of their role being underestimated. Also, the scope of AHLOs' contribution was restricted by their lack of access to the hospital's electronic databases.

The AHLO understood the necessity of embedding her practice more formally within the hospital's existing organisational practices, thereby being able to contribute more fully to improving the care of Aboriginal patients. Notably, she recognised possibilities for AHLOs using existing hospital information computer systems for improving the care of Aboriginal patients. Hospital databases contain detailed patient (address, GP, next of kin) and clinical (diagnoses, medicines, out-patient appointments, past admissions) information. From this information, issues such as a history of missing appointments, mistakes due to communication lapses, and patients discharging against medical advice (see DAMA – Part 1, Section 9) can be identified, and 'high-risk' patients who need extra support can receive the care they need. She realised that, given access to the databases, AHLOs' understanding of the needs of individual clients could be improved, their patient follow-up tasks simplified, and communications with health professionals in and outside the hospital enhanced. This would ensure better integration of the care of hospitalised Aboriginal patients. She also recognised that better recording of Aboriginal patient-specific data would make evaluating the AHLO role easier.

Consequently, the AHLO lobbied for access to the databases and offered suggestions on how additional information items (e.g., on cardiac rehabilitation referrals and attendances) could be added to enhance patient care.

She also instigated other initiatives to enhance the AHLO role, e.g.:

- adding AHLOs' own progress notes to patients' admission records (the result of access to hospital databases)
- training of hospital pharmacists to deal with the special dispensing issues of remote AMSs, eg geographical locations of remote areas and logistical challenges
- creation of an information resource for Aboriginal patients on the role of hospital social workers
- accessing and/or developing resource folders for health professionals, e.g., AMS contacts, maps to assist with discharge, discharge medications, geographical locations and logistics involved in returning patients home
- starting the discharge process on admission, from the first meeting discussing the health service they will return to, and occasionally including three way link ups with those services

Continued page 88

CASE STUDY

**Box 23** Cont.

- distribution of out-patient appointment follow-up reminders and discharge summaries to multiple health services, nursing posts and PATS (as patients are often transient for cultural, family and other reasons)

After much persistence, and with assistance from allies among the hospital staff, she was able to realise most of what she had set out to achieve, and to establish this expanded AHLO role formally for her successors in the job. The benefit of creating culturally appropriate systems is the potential for them to continue to be implemented despite staff changes. However, they are also dependent on staff being adequately trained, resourced and supported.

'If we're going to make a difference for our mob, we have to be part of the system.'

Source: unpublished interviews with an Aboriginal Health Liaison Officer working in Cardiology.

## d. Aboriginal Workforce

The limited number of Aboriginal staff working within hospital and mainstream primary health care services and programs is often a barrier to Aboriginal participation. The importance of having Aboriginal health staff in services with Aboriginal clients is well recognised. Challenges with achieving this include securing funds for positions as well as in recruiting, supporting and retaining Aboriginal health staff.

There are strong arguments for having dedicated positions for Aboriginal staff.  Examples of specific Aboriginal positions in health care include coordinators to tackle smoking, health workers and liaison officers.  There are many benefits to having Aboriginal people working in a range of clinical disciplines such as doctors, nurses, pharmacists, dieticians and physiotherapists. In addition, involving more Aboriginal people in non-clinical roles in the health system, such as interpreters, administrators and receptionists, not only increases the Aboriginal workforce, but can help to increases the cultural security of an organisation. These roles need to be integrated, ensuring that Aboriginal and non-Aboriginal employees work together as valued members of the health service team. This is also important as some Aboriginal clients may prefer a non-Aboriginal service provider. Finally, health services need to work in partnership with the community to educate and train community members to deliver programs to ensure continuity when staff members are unavailable, as well as building community capacity. Figure 19 outlines steps that organisations need to take to support Aboriginal Heath Professionals.

It is important that supporting Aboriginal patients is not seen solely as the responsibility of Aboriginal health professionals. A strong inclusive culture, in which knowledge is exchanged and two-way learning occurs, will help optimise Aboriginal patient outcomes.

| | |
|---|---|
| **System support** | • Review potentially discriminatory practices<br>• Cultural governance<br>• Increase profile of Aboriginal staff and their services |
| **Preparation** | • Clear role expectations/definitions<br>• Job orientation/training |
| **Facilities** | • Specific work spaces/desk/storage<br>• Space for private discussions with patients |
| **Career Development** | • Ongoing mentoring/supervision<br>• Opportunities for upskilling and job progression |
| **Peer support** | • Opportunities to work with other Aboriginal and non-Aboriginal staff in the organisation<br>• Enable development of links with community agencies which work outside of hospital setting |

**Figure 19: Steps organisations can take to support Aboriginal Heath Professionals**

CASE STUDY
**Box 24**

## South Metropolitan Health Service Aboriginal Health Liaison Officer Program

A key recommendation, following an extensive Community consultation process by the Public Health Unit at the South Metropolitan Health Service (SMHS), was the urgent need to increase access to culturally suitable hospital care for Aboriginal people in the region. As part of the Council of Australian Governments (COAG) National Partnership Agreement on *Closing the Gap* in Indigenous Health Outcomes, SMHS implemented the Aboriginal Health Liaison Officer (AHLO) program in seven hospitals in 2010 across the South Metropolitan region (now funded under the WA Footprints to Better Health Strategy).

The AHLO program employed Aboriginal health professionals in the hospital system to improve the cultural capacity of hospitals by providing a liaison role to support the Aboriginal patient journey from admission through to discharge planning and community referral. Key findings from evaluation of the program were (i) that AHLOs were able to demonstrate their skills and experience, where providing support and education to patients was a rewarding experience, and they felt valued and satisfied in their role; (ii) AHLOs were allocated sufficient time to engage with community and to participate in meetings with each other; (iii) they supported non-Aboriginal staff to increase their understanding of Aboriginal experiences and implement care practices respectful of cultural differences; (iv) AHLOs also learnt about hospital settings and the health system, and this two-way learning experience led to strong relationships between the AHLOs and the rest of the health care team.

These findings contributed to AHLOs feeling safe in their workplace and able to be proud advocates for Aboriginal culture. Findings also showed that health care teams' knowledge about the program resulted in improved patient linkages to the program and an increased awareness of culturally appropriate care and accountability to provide that care. Good organisational support and ongoing community engagement have been major elements in the program's success. Similar programs are delivered throughout Western Australia by Area Health Services and the Aboriginal community controlled sector.

Source: Taylor K, Brankovich J, Katzenellenbogen JM, Crowe S, Durey A, Bessarab D. Evaluation of the South Metropolitan Aboriginal Health Liaison Officer Program. Aboriginal Health Education and Research Unit, Curtin University; Perth 2014.58

## e. Audit, research and evaluation

Many interventions and service models to improve Aboriginal health care have been proposed. Once they have been introduced, it is important to review to what extent they have been implemented by health services and how effective they have been. Reviews can focus exclusively on Aboriginal-specific programs and services, or in other instances may include a comparison with non-Aboriginal patients in mainstream settings. Short- and long-term evaluations of programs are recommended to determine their effectiveness. Clinical audits are often considered as a first step in quality improvement and may be a part of accreditation processes. They can involve reviews of patient records and documentation of adverse events. Feeding back the results from these audits can help organisations to improve their processes and programs by setting goals as a team on how to improve. Repeated Plan-Do-Study-Act (PDSA) cycles underpin quality improvement in clinical care. Data from audits and other evaluation exercises can be published as research, for the benefit of other organisations. Additionally, organisations can initiate or participate in research into other aspects of Aboriginal health, such as epidemiological studies or clinical trials.

Some Aboriginal people are frustrated when they participate in health program/service evaluation or research but do not see the findings translated into benefit, in terms of improved health care. This highlights again the importance of ensuring that all such exercises are undertaken with a strong commitment to knowledge translation, capacity building and sustained effort to ensure that findings influence policy and practice. It is also important to recognise that change takes time (indeed often far too much time), but that the information from research is an important step in increasing knowledge about the need for improvements. In all research on Aboriginal health, Aboriginal people need to be engaged in the design and implementation. Developing intercultural partnerships to ensure Aboriginal people are part of the research team helps to create a greater understanding of the issues and potential solutions.

**Box 25**

WORKSHOP SUGGESTIONS

## Useful outcome measures when planning research/evaluation

### Measures to evaluate organisational effectiveness include:

- recruitment and retention of Aboriginal staff
- implementation of recommended changes to clinical practice, administrative processes and health programs (with formal documentation such as 'milestones' reports)
- cost-effectiveness data
- trends in numbers of people attending (and returning regularly to) programs and services
- participant feedback and follow up of non-participants to identify barriers of care
- sustainability of programs (e.g., at 3 years)
- long-term impact of programs on health outcomes and community engagement

### Measures to evaluate effective care for individuals/community include:

- improvements in patients' ability to recognise symptoms
- improvements in medication adherence
- increased referrals from relatives
- reductions in hospital readmissions
- increases in booked rather than emergency admissions
- increased use of primary care for ongoing management
- improvements in health outcomes
- improvements in other related outcomes, e.g., employment, training, housing

### Systematic and strategic reporting and documentation of program/service implementation:

- baseline and interim evaluation, including formal Key Performance Indicator (KPI) measures where appropriate
- qualitative appraisal of participant experiences (e.g., videos of program activities, participant interviews)
- quantitative evaluation of health outcomes, with reference to evidence-based guidelines where available
- regular audits as part of Plan-Do-Study-Act cycle

CASE STUDY
**Box 26**

## Acute Coronary Syndrome Audit at regional hospital

In 2011-2012, BAHHWA collaborated with a team of researchers at a busy regional hospital to investigate potential treatment differences between Aboriginal and non-Aboriginal patients. An audit was designed to measure disparities among those who presented with Acute Coronary Syndrome (ACS) at the Emergency Department, and was conducted by a public health registrar in the context of a supervised physician-training placement. In developing the study, members of the regional health service were consulted, including the Medical and Emergency Department Directors. The audit results suggested a number of deficiencies in the way ACS was managed for both Aboriginal and non-Aboriginal patients, and suggested that Aboriginal patients tended to receive fewer interventions. The results were provided to the WA Country Health Service and presented to hospital management. From the outset, the audit team concentrated on how best to maximise uptake of recommendations, rather than merely on exposing institutional failures. Dissemination of the audit findings and resulting advocacy had to be timed and directed appropriately). It was important to tailor ‘actionable’ messages to different audiences. The public health registrar leading the audit was sensitive to context when presenting findings to various stakeholders: he sought permission before presenting the findings to external agencies, and took care not to disclose the identity of the health service and to adopt a no fault quality assurance approach.

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The audit has prompted a number of changes within the hospital, including increased access to exercise stress tests and the employment of a highly experienced general physician to visit the hospital four times a year in order to train staff in the treatment and management of Aboriginal clients. The audit has also influenced modification of state-wide ACS pathway for the WA Country Health Service (WACHS). (The higher incidence of ACS and comorbidities at younger ages in Aboriginal people may mean that Aboriginal status needs to be a consideration in the guidelines for ACS presentations.)

Besides prompting a number of practical changes, the audit has been a positive demonstration of the way small-scale knowledge translation (KT) interventions can be implemented and how they can act as a precedent for further change within institutions. There is a concern that recommended evidence-based actions to address Aboriginal heart health disparities have not been effectively translated into practice. As a result, in-depth interviews with the audit team were examined using an equity-oriented framework[59] by BAHHWA researchers to explore barriers and enablers and identify effective ways to improve knowledge translation.

The audit resulted in a collaborative process being established, with improved communication channels and new working relationships between stakeholders, making the possibility of further internal audits of quality of care indicators more likely.

Continued page 93

CASE STUDY

**Box 26** Cont.

A follow-up audit will investigate whether there have been any changes between 2011-2012 and 2013-14 in the quality of care provided for patients with ACS, and whether differences still exist between Aboriginal and non-Aboriginal populations. Undertaking audits such as this can provide valuable insight into mechanisms that contribute to the effective uptake of evidence by clinicians, policy-makers, and health service managers.

Sources:

Scalley B, Katzenellenbogen J, Gilles M, Thompson S. Management of Acute Coronary Syndrome in a Regional Hospital 2011-2012: Unpublished report to WACHS. Perth: WA Department of Health; 2013[60]

Haynes E, Hohnen H, Katzenellenbogen JM, Scalley, BD, Thompson SC. (under review) Knowledge Translation lessons from a regional hospital's audit of Aboriginal patients presenting with Acute Coronary Syndrome.[61]

## Conclusion

The actions suggested for organisations in this section may improve Aboriginal healthcare. However, they require staffing, logistical and resource support. Resourcing is therefore a crucial issue, requiring government and policy level action, either to provide additional funding or to promote and support the redistribution of existing funds. In particular, inter-agency, intra-government and agency-government collaboration needs to be supported at a policy level. Some of the actions required of governments and policy makers are described in the next section.

CASE STUDY
**Box 27**

## Incorrect Entry of ‘Nil GP’ in Hospital Records

Following a patient’s discharge from hospital, continuity of care through communication with their general practitioner (GP) is critically important: a hospital discharge summary should contain correct and complete information on a patient’s condition (particularly, lists of all the major diagnoses and of all current medications and their doses) and be sent promptly to the correct GP/practice. High quality handover following an admission has become even more important in light of the trend towards early discharge after an acute event (e.g., a heart attack), with the responsibility for ‘post-acute’ care being shifted increasingly to the primary care sector.

Unfortunately, discharge summaries often are not received by the patient’s usual GP or practice, resulting in patients not receiving the medications and referrals they need. Frequently, this is because the GP/practice is never correctly identified and recorded during the admission. A doctor with extensive experience as a GP caring for Aboriginal people—and who also works at a major teaching hospital—was very familiar with instances of poor communication between hospitals and GPs about discharged patients. She discovered through tracking audits at the hospital that, in many cases, the GP Details box in the hospital medical notes recorded ‘Nil GP’ even when the patient did in fact have a GP, and that this error was more common for Aboriginal patients. There were several reasons for this: (i)the importance of the GP details wasn’t fully appreciated by hospital staff (ii) collection of this information was generally left to clerical staff in the Emergency Department (ED), who often had difficulties obtaining the correct GP details from patients because of their acute illness; (iii) patients did not identify with an individual named GP and this was misinterpreted by the clerical staff as having no identified general practice; (iv) hospital staff were unfamiliar with the names of the Aboriginal Medical Services and (v) hospital policy made it more convenient to enter ‘Nil GP’ as a default rather than ‘GP Unknown’ when the GP details were uncertain, because the latter entry would be recognised as inadequate and create a problem for hospital KPIs—and more work for someone to follow up.

The doctor had approached hospital clinicians about the problem repeatedly over a period of several years, but her concerns had generally been met with indifference. However, she was eventually able to raise the issue with staff from the hospital Quality and Customer Service Unit, who immediately appreciated its importance, and who quickly instituted a hospital-wide audit of ‘Nil GP’ admissions. This one-day audit of every patient in the hospital found that nearly 10% of patients had ‘Nil GP’ recorded and that in more than half of these cases, this entry was wrong; these patients actually did have a current GP.

Informally, the audit process itself opened the eyes of hospital staff to the magnitude of the problem; many ward staff were quite shocked to discover how often the ‘Nil GP’ had been incorrectly recorded for their own patients. The hospital administration responded to the audit by making substantial systems changes: meetings of the hospital’s senior staff were held to discuss the problem; workshops were held regularly for the ED staff on the clinical importance of correctly identifying the GP/practice and other important patient details (e.g., current address and next of kin); and there is now no penalty for entering a ‘GP unknown’ record and thereby less incentive to enter the ‘Nil GP’ default. Also, the doctor who instigated the audit process has been able to teach hospital staff how to elicit the correct details of a patient’s GP more carefully and in a culturally-appropriate manner.

The doctor attributed the success of instigating the changes to recognition that it was a ‘systems’ problem so that no individual needed to feel personal blame. Also, the process was facilitated by the engaging a diverse range of senior hospital management personnel (including administration, quality and safety, clinical, clerical, medical records) who—as a group—were empowered to introduce systems changes.

Source: unpublished interview with a Perth GP

# Government/Policy Changes

4

## Key messages

Policy development is a complex process, especially in Australia's political system and public/private healthcare mix.

Important policy directions include earlier, locally-based interventions, guideline-based care, and ongoing community-based primary health care for risk management.

Aboriginal heart health is underpinned by the policies of multiple sectors, including health (including mental health and drug and alcohol sectors), housing, education, environment, infrastructure/roads, finance, workforce, sports, culture, welfare, justice and business.

There are many barriers to effective implementation of Aboriginal health policies, in particular short-term funding of programs, narrow output KPI focus, vertical program delivery, service fragmentation, urban-centric models of care, antipathy and poor relationships between different parts of the health service sector such as ACCHS and mainstream providers.

Evidence-based research and knowledge exchange/translation can have an important influence on health policy in Australia.

Policy development and implementation requires collaborative action, with participation of Aboriginal consumers, researchers and other stakeholders.

As discussed earlier, recommended actions to address Aboriginal health inequity require changes in standard ways of doing business, and sometimes considerable reconfiguration of resourcing. Governments, political parties and health services make policies (high-level plans or courses of action) intended to direct the decisions and actions of others. In this section, we cover public policy, that is, decisions and actions taken by governments to address heart health in Aboriginal Australians. Policy is an important influence on funding and resourcing decisions. Research should lead to informed action and policy change; understanding how to influence policy and providing direction to policy makers is essential, and complementary to research.

Public policy in Australia is complex. Because of the federal structure, health policy is developed at national/federal, state/territory and local government levels. The complex division of responsibility for funding and health service provision between these three levels of government creates duplication and overlap of services, poor integration of services and shifting of costs (when agencies find ways to get others to pay some of the costs of services). The mix between private and public funding and service provision adds complexity, with many services and people falling between the cracks. The inequalities in health among Australians, particularly the gap between Aboriginal and non-Aboriginal Australians, is an important issue that governments have to deal with to achieve comprehensive, integrated and effective Aboriginal health policy.

Many groups—like consumers, interest groups and researchers—try to influence decisions although it is politicians and other key decision makers that actually make the policies. As advocates for Aboriginal health, it is useful to know how policies are developed. Figure 20 illustrates a model of the Australian Policy Cycle. The model proposes 8 stages (in practice, not always sequential) as follows:

1. The cycle starts with the *identification of the issue or problem* that requires intervention/policy.
2. The *policy analysis* step involves generating and researching different policy options and their potential feasibility and consequences.
3. *Policy instruments* are the means or type of action (for example, laws or funded programs) by which the problem will be addressed.
4. This is followed by *consultation* with a range of stakeholders that will be affected by the new policy, so that their views and input can be obtained.
5. To ensure that any new proposed policy is aligned with other government policies, initiatives and commitments, there must be *coordination* between any new initiative and other programs.
6. At this stage, a *decision is made* from among the different policy options.
7. The next phase is one of *implementing the policy* at the practical level.
8. An important but often overlooked step is that of *monitoring and evaluating* the implementation and outcomes of the policy.[62]

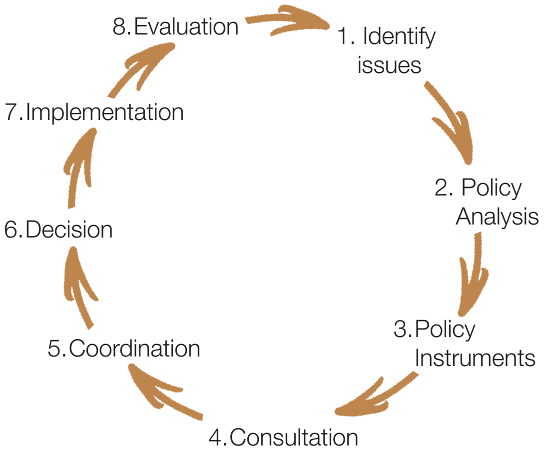


**Figure 20. Australian Policy Cycle**

Source: Adapted from: Bridgman and Davis 1998[63]

## a. Informing Policy Change: Barriers and Facilitators to Aboriginal Heart Health

Many governments have articulated the need and intention to improve the health of Aboriginal people; indeed the Closing the Gap initiative aims to do exactly that. However, whatever the intent is behind a policy, there may be underlying system issues and principles that can facilitate or obstruct the aims of a policy. Table 4 lists key issues identified by workshop participants and the BAHHWA team that can make or break initiatives to improve Aboriginal heart health.

Specific policies, procedures and funding mechanisms need to be developed to remove barriers such as: short-term funding cycles; poorly integrated/fragmented services; narrow Key Performance Indicators (KPIs) that focus on outputs, not outcomes; urban-centric systems of care which do not adequately cater for rural patients; and hospital discharge without adequate transition to care in the community. The need for accountability for public funds invested in health remains important although bureaucratic reporting should not overburden organisations at the expense of service provision.

Sustainability of initiatives requires longer-term funding with support from both sides of parliament. Mechanisms need to be put in place that encourage more collaboration between organisations, including partnerships between Aboriginal and mainstream organisations. Services need better integration to ensure comprehensive, patient-centred service delivery. Ongoing review of services (through audits and rigorous evaluation) needs to be incorporated into service structure and delivery. Government initiatives need to strengthen the primary health care sector, while ensuring that hospital systems work effectively with primary and rural health care. There needs to be a greater focus on promotion of multidisciplinary care to support patients, as they often have multiple health conditions requiring attention.

**Table 4. Barriers and facilitators to addressing heart disease in Aboriginal Western Australians**

| BARRIERS | FACILITATORS |
|---|---|
| Short-term and siloed funding cycles<br>• Loss of valuable experience, waste of momentum<br>• Undermining of Aboriginal workforce<br>• Poor continuity of services | Sustainable, politically bipartisan initiatives<br>• Longer-term funding<br>• Building on experience of what works<br>• Consultation on nature of initiatives |
| Fragmented efforts, stand-alone services<br>• Patients falling through cracks<br>• Duplication<br>• Skill gaps | Partnerships and collaboration between organisations<br>• Joint planning; sharing of service components<br>• Exchange of skills and knowledge, networking<br>• Shared resources & lists of programs<br>• Start small and build on successes<br>• Good electronic patient information record systems so information can be shared between providers<br>• Partnerships between specialist mainstream and Aboriginal services add value two-way |
| Vertical service delivery (by 'body part')<br>• Insufficient time to troubleshoot<br>• No resources for case management | Comprehensive patient-centred approach<br>• 'One-stop shop' where possible, go beyond core business<br>• System and service integration to recognise common risk factors and multi-morbidity<br>• Enhanced realistic protocols of care for high-risk patients (e.g., complex illness; substance withdrawal) that are deliverable for health providers working in rural and remote as well as urban settings |
| Narrow focus of services and accountability indicators<br>• KPI emphasis on outputs, not on what works<br>• Lack of evaluation of process and outcomes<br>• Research not valued | Reviews of 'what works'<br>• Continuous quality improvement approach (audits and feedback) to improve systems and teams<br>• Researchers part of service partnership<br>• Funding of partnership research<br>• Collaboration between researchers and policy makers |
| Disconnect between primary care and hospital care<br>• Emphasis on reducing bed-days, with inadequate discharge planning<br>• Primary/community care often poorly accessed resulting in preventable hospitalisations<br>• Poor transition to community care | Strong Primary Health Care sector<br>• Effective communication between hospital and primary care<br>• Well planned and supported transitions between hospital and community<br>• Multidisciplinary teams to support patients with multi-morbidities and complex circumstances |
| Urban-centric systems of care<br>• Gap in care between rural and urban<br>• Rural systems often fail to deal with complex logistics and needs<br>• Workforce turnover, lack of experienced staff, bureaucratic barriers to sourcing recruitment and impeding retention | Systems that take into account needs of rural population<br>• Mapping critical pathways in patient care<br>• State-wide co-ordinated logistics network for transport and bed availability/allocation<br>• Infrastructure and allowances for family support & cultural understanding, including translation |

## b. ‘Better cardiac care’ forum: a policy think-tank instigated by AHMAC

Some of these barriers and enablers have been addressed by the ‘Better Cardiac Care for Aboriginal and Torres Strait Islander People Forum’, instigated by the Australian Health Ministers’ Advisory Council (AHMAC) in 2014. The forum undertook an extensive expert consultation and evaluation of the critical gaps in cardiac care for Aboriginal and Torres Strait Islander people. This directive can be considered as contributing mainly to Step 1 in the policy cycle shown in Figure 20 (identifying issues), although also contributing to Steps 2-4 (policy analysis, policy instruments, consultation).

The aim of the forum was to identify priority areas and strategies for intervention that are aligned with current national and relevant international guidelines of best practice for cardiac care and chronic disease. They drew on successful or promising programs of care previously implemented, which were selected according to the population level impact, strength of evidence, feasibility of implementation and ability to monitor for impact.

The priority areas give rise to supporting actions that health services may need to implement to ensure that the priority areas are effectively addressed. These are similar to the strategies discussed in Sections 2 and 3 of Part II of this Report. That is, the AHMAC Forum, like the authors of this Report, recognised the necessity of undertaking actions integrated across all levels of influence on health service provision. This takes into account the varying and complex needs and capacities of individuals and families as well as the diversity among providers.

The five priority policy areas identified by the Forum, and the recommended actions arising from each of these, are:

### 1. Early cardiovascular risk assessment and management

All Aboriginal and Torres Strait Islander people aged 18 years and over without known cardiac disease should receive a cardiovascular risk assessment each year, and receive appropriate management and follow-up of identified risk factors and lifestyle modification advice according to absolute cardiovascular risk stratification.

### 2. Timely diagnosis of ischaemic heart disease and heart failure

Aboriginal and Torres Strait Islander people suspected to have ischaemic heart disease or heart failure should receive the appropriate initial diagnostic service (stress testing or elective angiography for ischaemic heart disease and echocardiography for heart failure) as close to the patient’s home as possible, and within acceptable timeframes according to the level of risk and the patient’s condition.

### 3. Guideline-based therapy for acute coronary syndrome

All Aboriginal and Torres Strait Islander people with acute coronary syndrome should receive guideline-based therapy. This includes evidence-based drugs as well as interventions/procedures (e.g., stents or bypass surgery) that reduce blockage of coronary arteries.

### 4. Optimisation of health status and ongoing preventive care

All Aboriginal and Torres Strait Islander people with cardiac conditions should receive ongoing guideline-based primary health care and specialist physician follow-up to prevent further illness and optimise health status, including active referral to allied and multidisciplinary health services for community-based cardiac rehabilitation services and ongoing risk factor management.

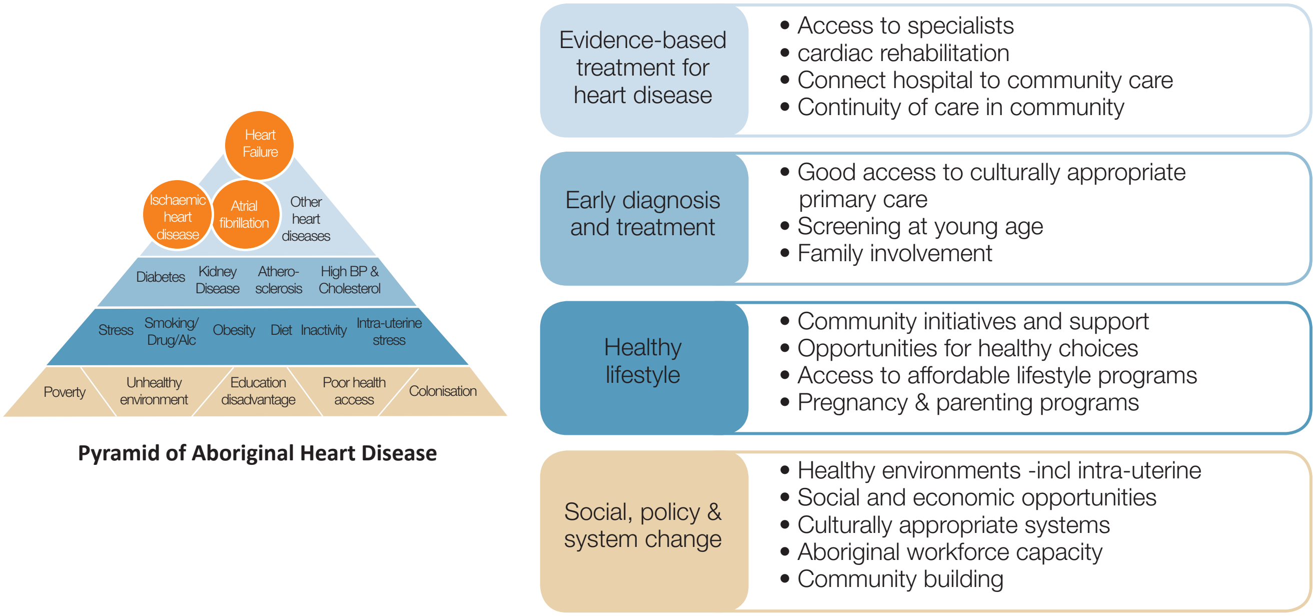
### 5. Diagnosis, notification and follow-up of rheumatic heart disease

All Aboriginal and Torres Strait Islander people suspected to have acute rheumatic fever or rheumatic heart disease should receive an echocardiogram as early as possible and new cases should be automatically referred to a central register, to facilitate tracking of patients and ensure ongoing preventive care.

The AHMAC Forum focussed on policy-level actions and is therefore seen as central to this section of the *Information For Action* Report. In setting policy direction, in particular where it leads to funding, the outcomes from the forum will significantly contribute to the successful programs and organisational changes described in previous sections.

## c. Building Blocks of Solutions for Aboriginal Heart Health

There is correspondence between the recommendations from the AHMAC forum and the model of causes of and solutions to Aboriginal heart health presented in Part I of this Report (Figure 21 below). However, it is important to note that the suggested health sector policy primarily impacts on the upper blue layers (healthy lifestyle, early diagnosis/treatment and evidence-based treatments) but that the greatest impact on heart health can be made by addressing the social determinants of health (green, bottom layer) through policies covering multiple sectors, including housing, education, environment, infrastructure/roads, finance, workforce, sports, culture, welfare, justice and business. The South Australian government's Health in All Policies (HiAP) strategy, with its focus on improving health and wellbeing through sectors other than health, is a good example of the work needed to bridge the gap between theory and practice (http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/ health+reform/health+in+all+policies). The Aboriginal community itself—through various community organisations, forums and structures—must be consulted and be a major player in community development and health awareness. The wider Australian population can play a part through becoming more culturally respectful and acknowledging the contribution of Aboriginal people to Australia, thereby reducing marginalisation/alienation from the mainstream.



**Pyramid of Aboriginal Heart Disease**

| | |
|---|---|
| Evidence-based treatment for heart disease | • Access to specialists<br>• cardiac rehabilitation<br>• Connect hospital to community care<br>• Continuity of care in community |
| Early diagnosis and treatment | • Good access to culturally appropriate primary care<br>• Screening at young age<br>• Family involvement |
| Healthy lifestyle | • Community initiatives and support<br>• Opportunities for healthy choices<br>• Access to affordable lifestyle programs<br>• Pregnancy & parenting programs |
| Social, policy & system change | • Healthy environments -incl intra-uterine<br>• Social and economic opportunities<br>• Culturally appropriate systems<br>• Aboriginal workforce capacity<br>• Community building |

**Building Blocks of Solutions**

**Figure 21. Pyramid of Aboriginal heart disease and building blocks of solutions**[4]

## d. Information for Action: Where to with BAHHWA Research?

Political decision-making is usually driven by ideological, economic and practical concerns rather than evidence for change.[62,64] Thus, research-based evidence, such as that provided in this Report, is only one input, among many, in policy decision-making. The concept of knowledge translation and exchange has been promoted as a means of increasing the application of scientific evidence in policymaking.[64,65]

A range of strategies for increasing knowledge translation has been suggested, emphasising an appreciation of context and promotion of partnerships between policymakers, researchers, advocates and the public/community.

This Report is one of the ways that the BAHHWA project hopes to disseminate research results, exchange information and indirectly influence actions taken at community/patient, organisational and policy level.

# Conclusion

*Everything has been said before, but since nobody listens*
*we have to keep going back and beginning all over again.*

**André Gide, (Nobel Laureate)**

The information presented in this Report is based on many sources. Its substantial and diverse research component presents a picture of what was occurring in Aboriginal heart health at the time the data were collected. Although all research has limitations, our quantitative results enhance understanding of the frequency, causes and outcomes of disease as well as the patterns of health service utilisation, allowing comparisons across different groups. The qualitative data add the rich insights needed to understand diverse perspectives and issues.

The data from this Report, and elsewhere, clearly indicate not only that cardiovascular disease is the biggest killer of Aboriginal people, but also that Aboriginal people are experiencing both illness and death from heart disease at a much earlier age than non-Aboriginal people. It matters little which particular cardiovascular condition we consider—heart attacks, atrial fibrillation, heart failure, stroke—the common pattern pertains.

Furthermore, the Report highlights that people living in rural and remote areas are generally more disadvantaged than those in urban areas in terms of service access. In this regard, many Aboriginal people suffer from a ‘double whammy’—the overlay of living at a distance from urban centres (where primary and specialist services are concentrated) along with the cluster of disadvantages arising from discrimination that has been perpetuated over time, lack of material resources, exposure to high risk environments and the ensuing burden of grief and trauma, along with limited education and health literacy.

A key message arising from these observations is the urgency to direct efforts ‘upstream’ towards primary prevention, as well as the need for earlier, community-based detection and intervention, recognising that these are every bit as important in extending people’s lives in good health as are acute/hospital-based care. This is a hard message to get across but an important one to make, time and time again.

> *‘By the time you get into a coronary care unit, it’s too late; you’ve damaged your heart. If we could have got you 10 years ago, stopped you smoking, got you to exercise a bit and controlled your diabetes, maybe you wouldn’t have ended up in coronary care. But politically you can’t prove that. I can’t employ 5 AHWs and say they’ve prevented 30 heart attacks; you can’t measure that … but I can employ 5 nurses in the hospital and say we treated 30 heart attacks, aren’t we good? … So politically, it’s easier to spend the money in a tertiary centre because you can say, “Look at all these patients I treated!”’*
>
> (Participant in health care worker study, tertiary hospital)[33]

Another important message is that a seamless, integrated health care system with linkages between primary, tertiary and follow-up care has not been achieved, despite this being given attention as a necessity in many policy documents. There is little point in developing endless strategies and models of care while glaring inadequacies in the fundamentals of the system, such as patient information systems and co-ordinated pathways, have not been addressed.

The data underscore the importance of more holistic approaches to addressing health problems. To ensure that Aboriginal patients receive the best possible health management and advice, access to high quality primary health care is imperative. Improved integration and continuity of care are likewise important: the role of multidisciplinary teams must be enhanced and—where practicable—'one-stop shop' service provision is recommended. This is particularly important for some Aboriginal people who may not have the financial means, health literacy or experience to navigate their way through the complex health service environment. Specialist care is also important in modern diagnosis and management. Outreach clinics, videoconferencing and telephone support providing good communication and timely support for patients and primary health care providers are necessary for better integrated care with specialist input. Almost all of these changes will improve care provision for other population groups who experience similar challenges and also want holistic care.

Critically, there is much that can be done to overcome the many barriers that Aboriginal people encounter in accessing good health care. Part II of the Report has provided examples of progress in improving services and of special initiatives developed to improve access and acceptability. They demonstrate the efforts of talented and committed individuals, who nevertheless almost always function as part of dedicated groups, strategizing, planning and working together. Substantial change rarely occurs as the result of single person or initiative. In order to deliver the best possible outcomes, efforts need to be sustainable and founded on partnerships incorporating the broader Aboriginal community as well as linking organisations. This Report encourages readers, including health care providers, to think carefully about the ways in which—both as individuals and by working with others at an organisational and societal level—they can help reduce Aboriginal cardiovascular (and other health) disparities. There is no quick fix, but small changes can ultimately effect sizable improvements, and through the exchange of knowledge, successful approaches developed in one place can inform the efforts of people elsewhere. We hope that the practical strategies proposed in our workshops will serve as inspiration to others in this regard.

We must consciously regard data as the basis for directing our efforts for improvement in the health of Aboriginal people. We have more than enough high quality information to inform the development of interventions at individual, community, organisational and policy levels. It is important in this work that we go beyond rhetoric to look at data to ascertain what is happening and to assess progress. Ongoing monitoring and evaluation will help to inform our progress and refine our approaches into the future.

We thank the many people—Aboriginal and non-Aboriginal—who generously shared their wisdom and experience, particularly in regard to what has worked and what has failed. By exchanging knowledge in this manner, we can be catalysts for improvements in health care. Research generates information that helps build our understanding, but the information in itself is not enough to effect change without a commitment that it be used to educate individuals and to guide program and policy development. Change generally requires evidence and/or political will to catalyse action; we certainly encourage a tight nexus between the two. This report brings together the information from research to identify priority areas for action.

We will take forward the partnerships developed in our research to implement the ideas and address the issues discussed in this Report. The establishment of the Poche Centre at the University of Western Australia through the generous donation of Greg and Kay Poche provides an opportunity to build on the momentum achieved through this Report. Join us in working towards making a difference to Aboriginal heart health in WA.

# Appendices

# Appendix 1:

## Contributing Researchers

| | |
|---|---|
| **CHIEF INVESTIGATORS** | |
| *Professor Sandra Thompson*<br>Chief Investigator A/Project Leader | Director<br>Western Australian Centre for Rural Health (WACRH)<br>The University of Western Australia |
| *Dr Judith Katzenellenbogen*<br>Chief Investigator B | Senior Research Fellow<br>Western Australian Centre for Rural Health (WACRH)<br>The University of Western Australia |
| *Emeritus Professor Michael Hobbs*<br>Chief Investigator C | Emeritus Professor/Senior Honorary Research Fellow<br>School of Population Health<br>The University of Western Australia |
| *Dr Frank Sanfilippo*<br>Chief Investigator D | Senior Research Fellow<br>School of Population Health<br>The University of Western Australia |
| *Associate Professor Elizabeth Geelhoed*<br>Chief Investigator E | Head of School<br>School of Population Health<br>The University of Western Australia |
| *Professor Dawn Bessarab*<br>Chief Investigator F | Director<br>Centre for Aboriginal Medical and Dental Health (CAMDH)<br>The University of Western Australia |
| *Clinical Professor Peter Thompson*<br>Chief Investigator G | Deputy Director, Harry Perkins Institute of Medical Research<br>Clinical Professor, School of Medicine and Pharmacology<br>The University of Western Australia |
| *Dr Angela Durey*<br>Chief Investigator H | Senior Research Fellow<br>School of Dentistry/Oral Health Centre of Western Australia<br>The University of Western Australia |
| **ASSOCIATE INVESTIGATORS** | |
| *Dr Pamela Bradshaw* | Research Fellow<br>School of Population Health<br>The University of Western Australia |
| *Professor Patricia Davidson* | Dean<br>School of Nursing<br>Johns Hopkins University |
| *Ms Lyn Dimer* | Manager<br>Aboriginal Health<br>Heart Foundation Australia (WA Division) |

| | |
|---|---|
| *Professor Joe Hung* | Professor of Cardiology<br>School of Medicine and Pharmacology (QEII Medical Centre Unit)<br>The University of Western Australia |
| *Professor Matthew Knuiman* | Teaching and research biostatistician/epidemiologist<br>School of Population Health<br>The University of Western Australia |
| *Associate Professor Andrew Maiorana* | Associate Professor<br>School of Physiotherapy and Exercise Science<br>Curtin University |
| *Mr Trevor Shilton* | Director<br>Cardiovascular Health<br>Heart Foundation Australia |
| *Mr Peter Somerford* | Principal Epidemiologist<br>Epidemiology Branch<br>WA Department of Health |
| *Dr Tiew-Hwa Teng* | Research Fellow<br>Western Australian Centre for Rural Health (WACRH)<br>The University of Western Australia |
| **OTHER RESEARCH COLLABORATORS** | |
| *Ms Emma Haynes* | Research Fellow<br>Western Australian Centre for Rural Health (WACRH)<br>The University of Western Australia |
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| *Dr Kaniz Gausia* | Senior Research Fellow<br>Western Australian Centre for Rural Health (WACRH)<br>The University of Western Australia |
| *Dr Shaouli Shahid* | Research Fellow<br>Western Australian Centre for Rural Health (WACRH)<br>The University of Western Australia |
| *Dr Sandy Hamilton* | Research Fellow<br>Western Australian Centre for Rural Health (WACRH)<br>The University of Western Australia |
| *Dr Tom Briffa* | Senior Research Fellow<br>School of Population Health<br>The University of Western Australia |
| *Ms Kate Taylor* | Project Manager<br>Aboriginal & Torres Strait Islander Health Curriculum Framework<br>Curtin University |

| | |
|---|---|
| *Associate Professor Tim Leahy* | Associate Professor<br>Aboriginal Health Curriculum<br>University of Notre Dame Australia (Fremantle campus) |
| *Dr Michelle DiGiacomo* | Senior Research Fellow<br>Faculty of Health<br>University of Technology, Sydney |
| *Dr Marianne Wood* | Public Health Medical Officer<br>Aboriginal Health Council of Western Australia<br>Liaison GP (Aboriginal), Royal Perth Hospital |
| *Ms Kim Goodman* | Development Officer<br>Cardiovascular Health Network<br>Department of Health, Western Australia |
| *Dr Ben Scalley* | Public Health Registrar<br>Department of Health, Western Australia |
| *Mr John Woods* | Research Assistant<br>Western Australian Centre for Rural Health (WACRH)<br>The University of Western Australia |

# Appendix 2:

## Shortcomings in Aboriginal health data

Governments make every effort to provide accurate information on major health problems for the whole state/territory or country, and routinely collect data from health services. The information from this is used for policy and planning. Inevitably there are some problems with the quality of information that health services such as hospitals provide. Important clinical information is also not recorded in these ‘administrative’ data, so they are limited in what they can tell us. Often the information provided tells us about numbers of occasions of service (e.g., admissions) but not about numbers of people, because the anonymous information cannot tell one person from another.

When undertaking research regarding health inequity in Aboriginal populations there are additional problems that reduce the accuracy of the data. These include the undercounts of Aboriginal people in these sources because not all Aboriginal people’s records show that they are Aboriginal. Thus, Aboriginal people are under-identified in routinely available information. Also, because Aboriginal people make up only 3% of the population in WA, the numbers of Aboriginal patients are small, statistically speaking, and thus statistical methods may not be able to give conclusive results. Information can also be collected in an inappropriate way (e.g., tests/questionnaires may not be validated for Aboriginal people) and people may not accurately recall information so that results may not be accurate.

The BAHHWA researchers have used data linkage methods (Box 2) to evaluate the quality of administrative information related to Aboriginal heart health. This research helps with conducting studies and interpreting study findings from other projects.

Four articles were written on challenges that the shortcomings of administrative data present to methods for studying Aboriginal health:

1. **A literature review on the quality of Aboriginal identification in linked administrative health data in Australia[17]**

**Findings:**

Poor identification of Aboriginal status in administrative health datasets has different effects for different diseases. This problem generally results in under-estimation of Aboriginal health indicators, but may perversely overestimate Aboriginal rates and differentials in the setting of stigma-associated conditions such as sexually transmitted and blood-borne virus infections. There is also under-counting of Aboriginal people in Census surveys, resulting in population denominator undercounts in Aboriginal health research. Under-identification of Aboriginal status can be substantially reduced through data linkage, but ultimately the information should be better collected and recorded.

2. **Analysis of linked hospital and death data to determine how much under-counting of Aboriginal cardiovascular patients there is in hospital and death data[18]**

**Findings:**

Linking hospital and death records increased the identification of Aboriginal patients in routinely collected information. Under-identification was highest in metropolitan and high socio-economic areas, and in older people. Death records, if unlinked, would under-estimate Aboriginal deaths by up to 25%.

### 3. Analysis of linked hospital and death data to determine by how much first-ever heart attack rates are under-estimated when existing cases are not removed from population figures used in the calculation[66]

**Findings:**

The under-estimation of rates (caused by not removing existing cases from the population denominator) increased with age, was higher for men than women, and substantially greater for Aboriginal than non-Aboriginal people. However, this underestimation had little impact on the relative difference in Aboriginal and non-Aboriginal rates. The method used to correct the problem, while more accurate, is difficult to apply and would add only modestly to our understanding of differentials in rates.

### 4. Analysis of linked hospital data to evaluate the accuracy of identifying diabetes in Aboriginal and non-Aboriginal heart patients[67]

**Findings:**

The accuracy of identifying diabetes in heart patients is improved in linked health data by using at least 10 years of hospitalisation history. Use of this method would reduce errors when measuring time trends in diabetes occurrence in heart patients. Measures are as reliable in Aboriginal as non-Aboriginal patients.

## Recommendations

- Encourage the use of linked data to investigate Aboriginal health, while recognising that this does not replace prospectively collected clinical data
- Establish systems to improve identification of Aboriginal status in health records
- Use linked data to improve accuracy of Aboriginal identification in routinely collected health information—provide a range of results using different methods of identifying Aboriginal people—no single method is best
- Use linked data to improve accuracy of identifying chronic diseases (e.g., diabetes) in routinely collected health information
- Adjust for age and also calculate separate rates for younger (<55 years) and older age groups when analysing differences in rates between Aboriginal and non-Aboriginal people. This is recommended because the age profile is so different between the Aboriginal and non-Aboriginal people

# Appendix 3:

## Summary of Medication Access Schemes for Indigenous Australians

1. The government subsidises a large number of important medications for **all Australians, under the Pharmaceutical Benefits Scheme (PBS)**

2. **The list of medications subsidised under the PBS Scheme is longer for Indigenous people,** with the inclusion of medications such as anti-fungal medications and ear-drops (on the basis of greater need).

3. The costs of medications may be **further reduced for Indigenous clients attending general practices who have signed up to the *Closing the Gap*** (CTG) **and Practice Incentive Program Indigenous Health Incentive (PIP-IHI) Schemes.**

4. **Aboriginal Community Controlled Health Services** can apply for **additional funds under Quality Use of Medicines Maximised (QUMAX) to pay for dosage administration aids** (e.g., W**ebster packs)** (capped amount).

5. There are **special arrangements for medications supplied in remote areas** (**s100 Scheme). There are also schemes for Indigenous clients in specific remote locations e.g., the Kimberley Standard drug list (not detailed here)** http://www.kamsc.org.au/resources/ksdl.html

6. **Hospitals have no consistent way of charging for medications dispensed through their out-patient pharmacies.** Generally, they charge the usual PBS co-payment but some do not charge this to Indigenous clients, especially those from remote areas. PBS quantities (generally 1 month's supply) are usually provided by public hospitals.

A more comprehensive resource on ***Schemes to Improve Aboriginal People's Access To Pharmaceuticals*** has recently been compiled by the BAHHWA group.

It can be downloaded free of charge from: http://www.wacrh.uwa.edu.au/images/publications/Indigenousaccesstomedicines112014.docx

The *Pharmaceutical Society of Australia* has recently published a ***Guide to providing pharmacy services to Aboriginal and Torres Strait Islander people.***

This document can be downloaded free of charge from:

http://www.psa.org.au/wp-content/uploads/Guide-to-providing-pharmacy-services-to-Aboriginal-and-Torres-Strait-Islander-people-2014.pdf

# Appendix 4:

## Health Service Expectations: A Matter of Patient and Consumer Rights

The Australian Commission on Safety and Quality in Health Care is a government agency that coordinates national improvements in safety and quality in health care across Australia, aiming to support healthcare professionals, organisations and policy makers who work with patients and carers.

The Australian Charter of Healthcare Rights describes the rights of consumers using the Australian health system. These rights were developed to ensure that the health care provided is of high quality and safe.

**What can I expect from the Australian health system?**

| MY RIGHTS | WHAT THIS MEANS |
|---|---|
| **Access**<br>I have a right to health care. | I can access services to address my healthcare needs. |
| **Safety**<br>I have a right to receive safe and high quality care. | I receive safe and high quality health services, provided with professional care, skill and competence. |
| **Respect**<br>I have a right to be shown respect, dignity and consideration. | The care provided shows respect to me and my culture, beliefs, values and personal characteristics. |
| **Communication**<br>I have a right to be informed about services, treatment, options and costs in a clear and open way. | I receive open, timely and appropriate communication about my health care in a way I can understand. |
| **Participation**<br>I have a right to be included in decisions and choices about my care. | I may join in making decisions and choices about my care and about health service planning. |
| **Privacy**<br>I have a right to privacy and confidentiality of my personal information. | My personal privacy is maintained and proper handling of my personal health and other information is assured. |
| **Comment**<br>I have a right to comment on my care and to have my concerns addressed. | I can comment on or complain about my care and have my concerns dealt with properly and promptly. |

**The Health Consumers' Council (Western Australia)**

Access to health services is a fundamental right. The Health Consumers' Council (HCC) is an independent (not-for-profit) community based organisation in WA, representing the consumers' voice in health policy, planning, research and service delivery. The HCC offers you the chance to have your say through a consumer representative.

The HCC Aboriginal Advocacy Program employs two Aboriginal staff members who travel the state to listen to Aboriginal people's experiences and views about accessing health services and to promote advocacy and consumer health rights.

**The Aboriginal Advocacy Program:**

- provides individual advocacy and support to Aboriginal consumers

- regularly hosts community forums

- works in partnership with health services in consumer evaluation of their service

- delivers training in Advocacy, Consumer Engagement and Complaints Management

Contact: laura.elkin@hconc.org.au Website: http://www.hconc.org.au/home/

### The National Safety and Quality Health Service (NSQHS) Standards

- The National Safety and Quality Health Service (NSQHS) Standards were developed by the Australian Commission on Safety and Quality in Health Care to drive the implementation of safety and quality systems and improve the quality of health care in Australia.
- Ten NSQHS Standards provide a nationally consistent statement about the level of care consumers can expect from health services. In September 2011, Health Ministers endorsed the NSQHS Standards and a national accreditation scheme. This has created a national safety and quality accreditation scheme for health service organisations.
- The website provides information about the National Healthcare Standards all of which hospitals must demonstrate for their accreditation. All emphasise partnering with consumers.
- Assessment against these Standards in the acute sector is driving changes in health service delivery and improving patient safety and the quality of care provided.
- In collaboration with the Aboriginal and Torres Strait Islander community, jurisdictions, health services and others, the Commission is working towards improving the safety of care provided to Aboriginal and Torres Strait Islander peoples in main stream health services.
- By determining the areas of greatest safety risk, the Commission hopes to develop resources to support main stream health services to implement culturally appropriate safety systems and quality services.

### Two standards have particular relevance to service provision:

#### Standard 2: Partnering with consumers

Aim: to ensure that health services are responsive to patient, carer and consumer input and needs.

This requires that:

- Governance structures are in place to form partnerships with consumers and carers
- Consumers and carers are supported by the health service organisation to actively participate in the improvement of the patient experience and patient health outcomes

- Consumers and carers receive information on the organisation’s performance and contribute to ongoing monitoring and evaluation of performance for continuous quality improvement

**Standard 4: Medication Safety**

Aim: to ensure competent clinicians safely prescribe, dispense and administer appropriate medicines to patients informed about their medicines.

This requires that:

- Health service organisations have mechanisms for the safe prescribing, dispensing, supplying, administering, storing, manufacturing and monitoring of medicines
- The clinical workforce accurately records patients’ medication history and this history is made available throughout the episode of care
- the clinical workforce is supported for the prescribing, dispensing, supplying, administering, storing, manufacturing and monitoring of medicines
- The clinician provides a complete list of patient’s medicines to the receiving clinician and patient when handing over care or changing medicines
- The clinical workforce informs the patients about their options, risks and responsibilities for an agreed medication management plan

http://www.safetyandquality.gov.au/our-work/clinical-care-standards/

# Appendix 5:

## Resources to improve Aboriginal Heart Health

1. Australian Indigenous Health*InfoNet*, an innovative Internet resource that aims to inform practice and policy in Indigenous health by making research and other knowledge readily accessible as an online clearinghouse. (http://www.healthinfonet.ecu.edu.au/). Among many other components, Health*InfoNet* includes a cardiovascular health resource (Heart*InfoNet*: http://www.healthinfonet.ecu.edu.au/chronic-conditions/cvd) that provides quality information and resources about how to prevent and manage cardiovascular disease among Indigenous peoples, and also supports an Indigenous cardiovascular 'yarning place' (called the Heart*InfoNetwork*) by providing electronic services that encourage information sharing and collaboration among the full range of health professionals and others involved in Indigenous cardiovascular health.

2. The Centre for Excellence in Indigenous Tobacco Control (CEITC) has developed a number of downloadable resources aimed at Aboriginal Health Workers to assist them in developing and running Tobacco cessation programs through their health service. See CEITC publications and resources page http://www.ceitc.org.au/ceitc-publications-and-resources for the *'Talkin' Up Good Air*' resource kit, *'What do we know about'* and *'Top Tips'* series of fact sheets, *'Smoking Matters'* and '*Clearing the air on passive smoking*' brochures. Some of these resources are also available in hard copy.

3. *Life is health is life: Taking action to close the gap: Victorian Aboriginal evidence-based health promotion resource* (Kelly, M., 2011) available from: http://www.vichealth.vic.gov.au/lifeishealthislife

   This evidence-based health promotion resource provides information and guidance for action to improve Aboriginal health and life expectancy. It brings together stories of promising health promotion practice from across Victoria and a review of the scientific literature. It provides the evidence for effective interventions that can be used in health promotion planning. The purpose is to provide the best available information to guide service and program planning. This resource is designed for people who work in community and women's health services, Aboriginal community controlled health services and local government. It will also be useful to others who are working to close the gap.

4. *Live Longer! Community health action pack: a practical guide to health promotion planning with Aboriginal and Torres Strait Islander communities* (2011) Department of Health and Ageing (DoHA) available from: http://livelonger.health.gov.au/files/2011/11/BL_001_11_FINAL_LOW-RES_WEB-FILE.pdf

   This Community health action pack can be used by anyone who wants to run a health promotion project to improve Aboriginal and Torres Strait Islander peoples' health and wellbeing. The pack is designed to enable flexibility so that communities and organisations can use it to suit their own needs. It includes templates, examples, checklists and tips to help with planning a health promotion project.

5. *AHPACC resource*

   Northern AHPACC Consortium Partners, 2012, 'Improving employment opportunities for Aboriginal workers in mainstream community health services: Aboriginal Readiness Checklist Project Report 19 September 2012, available from http://docs.health.vic.gov.au/docs/doc/Northern-AHPACC-Consortium-Partners-Aboriginal-Readiness-Checklist-Project-Report

6. *Department of Health, Western Australia. Cardiovascular rehabilitation and secondary prevention pathway principles for Western Australia. Perth: Health Strategy and Networks, Department of Health, Western Australia; 2014.*

   http://www.healthnetworks.health.wa.gov.au/docs/1405_CRSP_Pathway_Principles_WA.pdf

   Although not specific for Aboriginal people, this document provides useful information applicable to all Western Australians.

7. *Position Paper: Eliminating disparities in hospital cardiovascular care of Aboriginal people in Western Australia (National Heart Foundation WA; 2012)*

   Available on request from the Heart Foundation (WA): 1300 36 27 87

8. *Culturally and clinically appropriate health information to help Aboriginal and Torres Strait Islander peoples*

   Heart Foundation resources available to download or preview at www.heartfoundation.org.au or phone 1300 36 27 87 to order

   *My Heart My Family Our Culture – information package on CV Risk Factors*

   *Living Every Day with Heart Failure*

   http://www.heartfoundation.org.au/information-for-professionals/aboriginal-health/Pages/default.aspx

9. Ilton MK, Walsh WF, Brown AD, Tideman PA, Zeitz CJ, Wilson J. A framework for overcoming disparities in management of acute coronary syndromes in the Australian Aboriginal and Torres Strait Islander population. A consensus statement from the National Heart Foundation of Australia. Med J Aust. 2014; 200 (11):639-43

   doi:10.5694/mja12.11175 (Open Access, with links to Appendices)

   https://www.mja.com.au/journal/2014/200/11

10. Heart Research Centre: ‘Preparing for the cardiac blues’: Resources for patients and health professionals to support emotional adjustment after an acute cardiac event.

    http://www.heartresearchcentre.org/about-our-research/current-studies/cardiac-blues/

11. *SNAP into Life* is an interactive and culturally appropriate game for players 7 years and up. The game has been developed and trialled in Kimberley schools with Aboriginal children and their families, with the input from the Kimberley Aboriginal community and local health and education professionals. The game—loosely based on Monopoly and Snakes & Ladders—covers basic health education topics including our bodies, mental health, environmental health and road safety, and aims to develop awareness of lifestyle health risk factors such as: Smoking, Nutrition, Alcohol, and Physical activity (SNAP). The *SNAP into life* project was funded by Healthway, the Alcohol Education and Rehabilitation Foundation (AERF), the Kimberley Division of General Practice, and the Kimberley Aboriginal Medical Services Council (KAMSC).

    http://www.snapintolife.com.au/

12. Patient Journey Mapping tools: The tools developed by the Managing Two Worlds Together project in South Australia help document and map entire patient journeys from home to hospital to home, involving multiple services. This can help in planning and evaluate services, auditing, justifying costs, identification of areas for improvement, and staff training. The tools and examples are available from

    http://www.flinders.edu.au/medicine/sites/health-care-management/mtwt

# Glossary:

## some important terms explained

This Glossary draws upon several sources, including definitions used in the 'Better Cardiac Care for Aboriginal and Torres Strait Islander People: Post-Forum Report' (May 2014),[68] but includes many modifications

**Acute coronary syndrome:** an overall term used for sudden reduced blood flow to a portion of heart muscle due to (incomplete or complete) blockage of a coronary artery. ACS is classified as either **unstable angina** (no evidence of permanent damage to heart muscle) or acute **myocardial infarction** (evidence of heart muscle damage)

**Age-standardised rates:** a summary rate used to account for the difference in the age of populations in order to make a valid comparison of rates

**Aboriginal Community Controlled Health Service (ACCHS):** A service that provides primary healthcare, run by and for local Aboriginal communities to improve access and health outcomes. They can also have a significant role in supporting mainstream delivery of effective health care to Aboriginal people. Alternatively called an Aboriginal Community Controlled Health Organisation (ACCHO)

**Aboriginal health workforce:** The Aboriginal health workforce can be part of a registered or un-registered profession and be employed in a range of job roles often involving liaising between other health professionals and Aboriginal patients and their families, providing information and advocacy. While a large majority are employed in ACCHSs or the Government health sector, many also work within mainstream non-government services. This term also refers to Aboriginal people who have graduate professional skills in traditional clinical roles e.g. doctors, midwives, nurses, physiotherapist.

**Aboriginal health professionals, Aboriginal Health Workers and Aboriginal Health Liaison Officers** are commonly used titles and vary across Australia and may or may not describe specialty or level of training. Since 2012 Aboriginal Health Practitioner is a registered profession with a protected title and an increasing number of the Aboriginal health workforce are registered as such in WA.

**Aboriginal Medical Service (AMS):** A health service funded principally to provide services to Aboriginal and Torres Strait Islander people, either run by a community board or by a state/territory government.

**Angina:** A sensation of pain or discomfort (often described as 'pressure', 'squeezing' or 'tightness') due to inadequate blood flow to heart muscle, usually caused by narrowing or spasm of a coronary artery. Angina is usually felt in the chest, but can also be felt in the jaw, neck, back, shoulders or arms, or a combination of these.

**Antiplatelet therapy**: Medicines (such as aspirin) that reduce blood cells sticking together to form a blood clot.

**Arrhythmia**: see **dysrhythmia**

**Atherosclerosis:** A process in which fatty and fibre like deposits ('plaques') build up on the inner walls of arteries that can then cause blockages. It is the main underlying condition in heart attack, angina, stroke and peripheral vascular disease.

**Audit:** A planned, formal, documented evaluation by qualified personnel to determine whether a program has been implemented effectively and according to agreed procedures

**Capacity building:** An approach to the development of people or communities that focusses on enhancing the skills, competencies and abilities they need to achieve their goals

**Cardiac event:** Any severe or acute cardiovascular condition including acute myocardial infarction, unstable angina or cardiac death.

**Cardiac rehabilitation:** Cardiac rehabilitation (cardiac rehab) is a professionally supervised program to help people recover from heart attacks, heart surgery and coronary procedures such as stenting and angioplasty. Cardiac rehab programs usually provide education and counselling services to help heart patients increase physical fitness, reduce cardiac symptoms, keep taking their medications, improve health (e.g., change in diet and stress reduction) and reduce the risk of future heart problems, including heart attack.

**Cardiac rehabilitation program**: Describes all measures used to help people with heart disease return to an active and satisfying life and to prevent recurrence of cardiac events.

**Care plan:** An agreement between a consumer and health professional (and/or social services) to help manage day to day health. It can be a written document or something recorded in patient notes.

**Carers**: People who provide unpaid care and support to family members and friends who have a disease, disability, mental illness, chronic condition, terminal illness or general frailty. Carers include parents and guardians caring for children.

**Chronic:** persisting over a long period

**Clinical pathway:** A clinical pathway explicitly states the goals and key elements of care based on clinical guidelines, best available evidence and patient expectations by facilitating communication, coordinating roles and sequencing activities of the multidisciplinary care team, patients and their carers; by documenting, monitoring and evaluating variances; and by providing the necessary resources and outcomes.

**Clinician:** A healthcare provider, trained as a health professional. Clinicians include registered and non-registered practitioners, or a team of health professionals, who spend the majority of their time providing direct clinical care.

**Community development:** A process where community members come together to generate solutions to common problems and take collective action.

**Community engagement:** A planned process by which an individual or organisation builds a long-term relationship with a community to understand and address issues affecting the well-being of community members

**Comorbidity**: the presence of one or more additional disorders (or diseases) co-occurring with a primary (main) disorder

**Contraindication**: A symptom, condition or factor that serves as a reason to withhold a particular treatment or procedure because it may be harmful to the patient. For example, unstable coronary heart disease would typically be a considered a contraindication to having elective surgery for a non-life-threatening condition (e.g., a hip replacement).

**Coronary angiography/angiogram:** A procedure in which a special X ray of the heart's arteries (the coronary arteries) is taken to see if they are narrowed or blocked.

**Coronary heart disease:** Caused by a slow build up of fatty deposits on the inner wall of the blood vessels that supply the heart muscle with blood (the coronary arteries). These fatty deposits gradually clog the arteries and reduce the flow of blood to the heart.

**Coronary arteries:** The blood vessels that supply heart muscle, so called because they encompass the surface of the heart in the pattern of a crown.

**Coronary revascularisation:** Procedures used to restore good blood supply to the heart, for example, coronary angioplasty, which involves inserting a catheter with a balloon into a narrowed coronary artery and coronary artery bypass graft surgery.

**Cultural awareness**: In the context of healthcare for Aboriginal people, cultural awareness means general or basic knowledge of Aboriginal culture, customs and values, without this knowledge necessarily leading to any specific action or practice

**Cultural safety:** Knowledge of Aboriginal culture, customs and values that **informally** influences an individual's practice or an organisation's guidelines

**Cultural security:** Knowledge of Aboriginal culture and customs and values that is **formally incorporated into the design, delivery and evaluation of services**, thereby directly linking understanding with organisational policies and guidelines

**Demographic characteristics:** These characteristics describe the composition of a population in terms of age and sex distribution, socio-economic variables (e.g., education, income, employment status), ethnicity, religion, marital status, household composition and religion.

**Dysrhythmia**: any of a group of conditions in which the electrical activity of the heart is irregular or is faster or slower than normal (irregular heartbeat).

**Electrocardiogram (ECG):** A test that records the electrical activity of the heart, commonly used to detect abnormal heart rhythms (**dysrhythmias**) and to identify evidence of myocardial damage (such as **myocardial infarction**).

**Evaluation:** A systematic and rigorous assessment of the design, implementation, improvement, or outcomes of a program.

**Fibrinolysis:** The breakdown of fibrin, the principal component of blood clots. This term is sometimes used in place of **thrombolysis** ('clot busting').

**Health promotion:** The process of enabling people to increase control over their health and its determinants, and thereby improve their health.

**Health service:** A separately constituted health service is responsible for the clinical governance, administration and financial management of a service unit(s) providing health care. A service unit involves a grouping of clinicians and others working in a systematic way to deliver health care to patients and can be in any location or setting, including pharmacies, clinics, outpatient facilities, hospitals, patients' homes, community settings, practices and clinicians' rooms.

**Health service provider**: A person or organisation providing a health service, such as a private/self-employed doctor (GP/specialist), dentist, or allied health practitioner or a hospital or clinic.

**Heart attack:** A common lay term for **myocardial infarction**. This condition is often confused with—but does **not** mean the same thing as—**cardiac arrest**, a condition in which the heart stops beating completely.

**Hospital:** A licensed facility providing healthcare services to patients for short periods of acute and subacute illness, injury or recovery.

**Hypertension (high blood pressure)**: A **chronic** condition in which the blood pressure in the arteries is elevated, resulting in an increased risk of health problems such as **stroke**, **ischaemic heart disease** and kidney disease.

**Incidence**: A measure of new cases of a health condition in the population per population at risk in a given time period. It is a measure of risk of the condition in the population.

**Intercultural:** something that occurs between people of different cultures, e.g., between Aboriginal and non-Aboriginal people

**Intersectoral**: Based on the recognition that health is determined by a complex network of factors, an intersectoral approach to health policy refers to the inclusion of government sectors beyond the health sector alone (e.g., education, transport, employment) in the design and implementation of public policies to improve health.

**Ischaemia** (spelled **ischemia** in American publications): when there is not enough blood flow to part of the body. **Ischaemic** (or **ischemic**) **heart disease** (IHD) and **coronary heart disease** (CHD) both mean the same thing—a common condition in which not enough blood flows to the heart muscle because of narrowed arteries. This is the underlying cause of **angina** and **myocardial infarction** (**heart attack**).

**Key performance indicator**: a type of performance measurement used to evaluate the critical success factors of an organisation or of a particular activity in which it engages.

**Knowledge translation**: The activities involved in moving research results into the hands of people and organisations who can put them to practical use.

**Linked data:** The electronic linking of information belonging to a particular person or persons from different data sources do that case histories and outcomes can be determined, e.g., linking a person's birth, hospital, maternity and death records.

**Medication:** A chemical substance given with the intention of preventing, curing, controlling or alleviating disease, or otherwise improving the physical or mental welfare of people. Prescription, non-prescription and complementary medicines, irrespective of their administration route, are included.

**Model of care**: An overall design for providing a particular type of health care service, shaped by theory, evidence and defined standards.

**Mortality rate**:  Death rate from all causes or due to a specific cause (often in a population)

**Myocardium:** heart muscle

**MSOAP:** The Commonwealth Medical Specialist Outreach Assistance Program funded specialists to undertake outreach services in rural areas to improve the access of rural and remote communities to medical specialists. Various funding streams have now been consolidated under the Rural Health Outreach Fund.

**Myocardial infarction:** A potentially life threatening emergency that occurs when heart muscle is damaged by lack of oxygen. The usual cause is a sudden blockage of a coronary artery by a blood clot, which in turn is typically due to rupture of an atherosclerotic plaque. The common lay term for this condition is a **heart attack**.

**Non–ST elevation myocardial infarction (NSTEMI):** A type of heart attack (myocardial infarction) identified by what is seen on the electrocardiogram. In a NSTEMI, the artery is only partly blocked, so only part of the heart muscle being supplied by that artery is affected.

**Non–ST segment elevation acute coronary syndrome (NSTEACS):** A condition where patients have acute chest pain but do not have ST segment elevation in their electrocardiogram. NSTEACS is further divided into unstable angina and non–ST elevation myocardial infarction.

**Percutaneous coronary intervention (PCI):** A procedure that opens blocked or narrowed coronary arteries. A thin, flexible tube with a balloon or other device on the end is threaded through a blood vessel to the narrowed or blocked coronary artery. Once in place, the balloon is inflated to compress the plaque against the wall of the artery. This restores blood flow through the artery. During the procedure, the doctor may put a small mesh tube called a 'stent' in the artery.

**Policy**: A course or principle of action adopted or proposed by an organisation or individual

**Prevalence**: The proportion of a population found to have a condition (typically a disease or a risk factor such as smoking or seat-belt use) at a specific point or period in time

**Primary care**: The day-to-day health care given by a health care provider in the community, who usually acts as the first contact and main point of continuing care for patients within a health care system, and coordinates other specialist care that the patient may need.

**Primary Prevention:** Measures aimed at healthy people (before they become ill) to promote good health or provide specific protection of target group against disease or injury—aims to minimise the number of new cases (incidence) of a disease or condition.

**Reperfusion:** The restoration of blood flow to an organ or tissue.

**Rheumatic heart disease:** is permanent damage to the heart (particularly the heart valves) following rheumatic fever.

**Risk factor:** Any variable (e.g., smoking, abnormal blood lipids, elevated blood pressure, diabetes) that is associated with a greater risk of a health disorder or other unwanted health condition or event.

**Risk stratification**: Categorisation of people according to their level of risk of a developing a particular health problem in the future. This is calculated based on the presence of risk factors for the health problem.

**Rural Health Outreach Fund**: Commonwealth-supported program funding specialists to undertake outreach services in rural areas to improve the access of rural and remote communities to medical specialists.

**Secondary prevention:** Treatment to manage existing disease and risk factors to prevent recurrence of acute events and to prevent complications of an existing condition. Aims to minimise morbidity and reduce mortality.

**Sector (of government)**: Department of government responsible for particular portfolio e.g., health, education, housing, agriculture

**Social determinants of health**: The conditions of advantage or disadvantage in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, and are largely responsible for health inequities, i.e., the unfair and avoidable differences in health status seen within and between countries.

**Specialists:** In the context of cardiac conditions, specialist physicians with appropriate expertise include both general physicians and cardiologists. For patients being considered for surgery, specialist cardiothoracic surgical review is required.

**ST segment elevation myocardial infarction (STEMI):** A type of heart attack (myocardial infarction) identified by what is seen on the electrocardiogram. In an STEMI, the artery supplying blood to an area of the heart muscle is completely blocked.

**Statins:** A group of cholesterol lowering medicines that reduces the risk of heart attack or stroke.

**Strengths-based approach**: Policies, practice methods, and strategies that identify and draw upon the strengths of individuals and communities, and thereby shift away from a 'deficit' approach, which emphasizes problems and pathology

**Stroke**: An injury to part of the brain caused by sudden disruption to brain circulation, usually because of either blockage or leakage of blood from an artery

**Thrombolysis:** The breakdown of blood clots blocking an artery by medical treatment, colloquially referred to as 'clot busting'.

**Troponin:** A heart muscle protein, which, when present in the bloodstream above a defined concentration, is suggestive of myocardial damage. Testing of troponin in the blood at the bedside or sent to laboratories is a key diagnostic test for myocardial infarction.

**Unstable angina:** A form of angina usually attributed to new blockage of a coronary artery by a blood clot. It is manifested by sudden onset or worsening of angina. Unstable angina is a medical emergency: although it is defined by the absence of evidence of **myocardial infarction** after appropriate investigation (i.e., no sign of heart muscle injury on ECG or blood tests), it is part of a continuum with myocardial infarction and can rapidly evolve to become an infarction.

**Vertical service delivery**: Health service delivery in which facilities or programs selectively target specific diseases, risks and populations, and are not integrated with the broader health system.

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## Cover illustration

About the artist: Lennie Smith is a Yawuru man born in Port Hedland after his family was relocated to the Pilbara area from their traditional Kimberley country some three generations ago. Yawuru people have a long history of association with the coastal landscape, seascape and marine life. Lennie was privileged to benefit from the continuity of these strong cultural connections to the Saltwater country and relates to his traditional lands as a source of identity.

The design: The goorlil (marine turtle) continues to play a fundamental cultural, customary and totemic role in Lennie's life as a Yawuru man. The goorlil brings life, returning to the shoreline to nest and perpetuate the cycle of life from time immemorial. The iconic shape of the goorlil's shell also provided the opportunity for Lennie to connect the design with the intent of this publication as a resource pathway to improve heart health for his kin. The uniqueness of Lennie's design lies in the stylistic arrangements that seek to merge the goorlil's cultural representations of life and hope, with his own experiences of family loss due to heart failure.

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