

# Aboriginal Chronic Disease Care Pathways Community Report

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December 2016

## About the Artwork

The artwork on the front cover is by artists and sisters Lorraine Brown and Narelle Thomas, east coast Saltwater people. The painting is titled 'Dealing with our sickness knowledge – change of life.' The painting is inspired by the following words which relate to the challenges and necessity of dealing with illness.

*When we know we're sick.  
We must deal with it.  
We must change our ways.  
It's hard but we must try.*

# Key Messages



- ❖ **There are unacceptable rates of preventable chronic disease amongst Aboriginal people in the Illawarra and Shoalhaven regions.**

*Within the Illawarra Shoalhaven Local Health District Aboriginal people have twice the rate of potentially preventable hospitalisations for chronic disease compared to non-Aboriginal people; The Illawarra Shoalhaven Local Health District is amongst the Local Health Districts with the highest proportion of unplanned readmissions within 28 days for Aboriginal people.*

- ❖ **There is a need to strengthen the supports offered to chronically ill Aboriginal people while in hospital and in the post-discharge period.**
- ❖ **Addressing health literacy is a major gap in current supports.**
- ❖ **Aboriginal targeted chronic disease management programs should be more widely promoted and enhanced.**
- ❖ **There is a need for a more collaborative approach to service delivery which meets the complex needs of Aboriginal people with chronic conditions.**
- ❖ **There is a need for a comprehensive strategy to address Aboriginal health workforce needs.**
- ❖ **Better linkages between health and social services in the region are needed to address the underlying social and cultural determinants of Aboriginal health, including support for Aboriginal Community Controlled services which address the ongoing impact of the stolen generation and provide a cultural approach to wellbeing.**

# About this Community Report



The Aboriginal Chronic Disease Care Pathways Research Project was commissioned by the Illawarra Shoalhaven Local Health District and conducted by a team of Aboriginal and non-Aboriginal researchers from the University of Wollongong over an 18 month period in 2014-15. This Community Report is a shortened version of the main report. It highlights key information from the research. More detailed information can be found in the main report.

## *This community report:*

- ❖ Prioritises Aboriginal voices.
- ❖ Explores the ways in which Aboriginal people with chronic disease experience the health system in the Illawarra and Shoalhaven regions.
- ❖ Documents the perspectives, concerns and recommendations of Aboriginal people, health service providers, managers and those working in the health system.
- ❖ Reports on the effectiveness of Aboriginal chronic disease management programs.
- ❖ Provides feedback to the Illawarra Shoalhaven Local Health District to inform planning and policy development relevant to chronic care services.
- ❖ Draws attention to the complexity of the health care system and identifies some of the barriers and enablers to achieving change and improvement.
- ❖ Recommends directions for future policy and service improvements.

## *What do we mean by 'chronic disease'?*

- ❖ The term 'chronic disease' includes a group of diseases that tend to be long lasting and have persistent effects. They are different from acute diseases, which have a quick onset and are often brief, intense and/or severe.
- ❖ Chronic disease often has complex causes and multiple risk factors; gradual onset often with no symptoms; and involves functional impairment and/or disability.
- ❖ Chronic disease includes: diseases of the circulatory system including heart disease; cancers; endocrine and metabolic diseases; diseases of the respiratory, digestive, genitourinary and nervous systems; and mental and behavioural disorders.
- ❖ In this research we focused on people with one or more of the following conditions:
  - Cardiovascular disease
  - Diabetes
  - Kidney disease
  - Respiratory disease

# *Why is this study important?*



## *We know that:*

- ❖ Aboriginal Australians experience chronic diseases at much higher rates than other Australians.
- ❖ Hospitalisation rates for Aboriginal people with chronic conditions has increased significantly over the last 10 years, in 2012-2013 rates were nearly five times higher than for non-Indigenous Australians.
- ❖ There are many barriers related to inequitable access to health systems, including stigma and discrimination that contribute to poor health outcomes and increase the risk factors for chronic illnesses.
- ❖ There are underlying factors that impact on Aboriginal people's chronic disease management such as social and economic determinants in addition to biological and behavioural factors.

## *But we know little about:*

- ❖ The impact of chronic conditions on Aboriginal people, their families and communities.
- ❖ How Aboriginal people are managing their chronic disease.
- ❖ How Aboriginal people experience the health system.
- ❖ Whether patient journeys of Aboriginal people in the Illawarra and Shoalhaven are similar to those of Indigenous people in other parts of Australia.

## *The key questions we asked in this research were:*

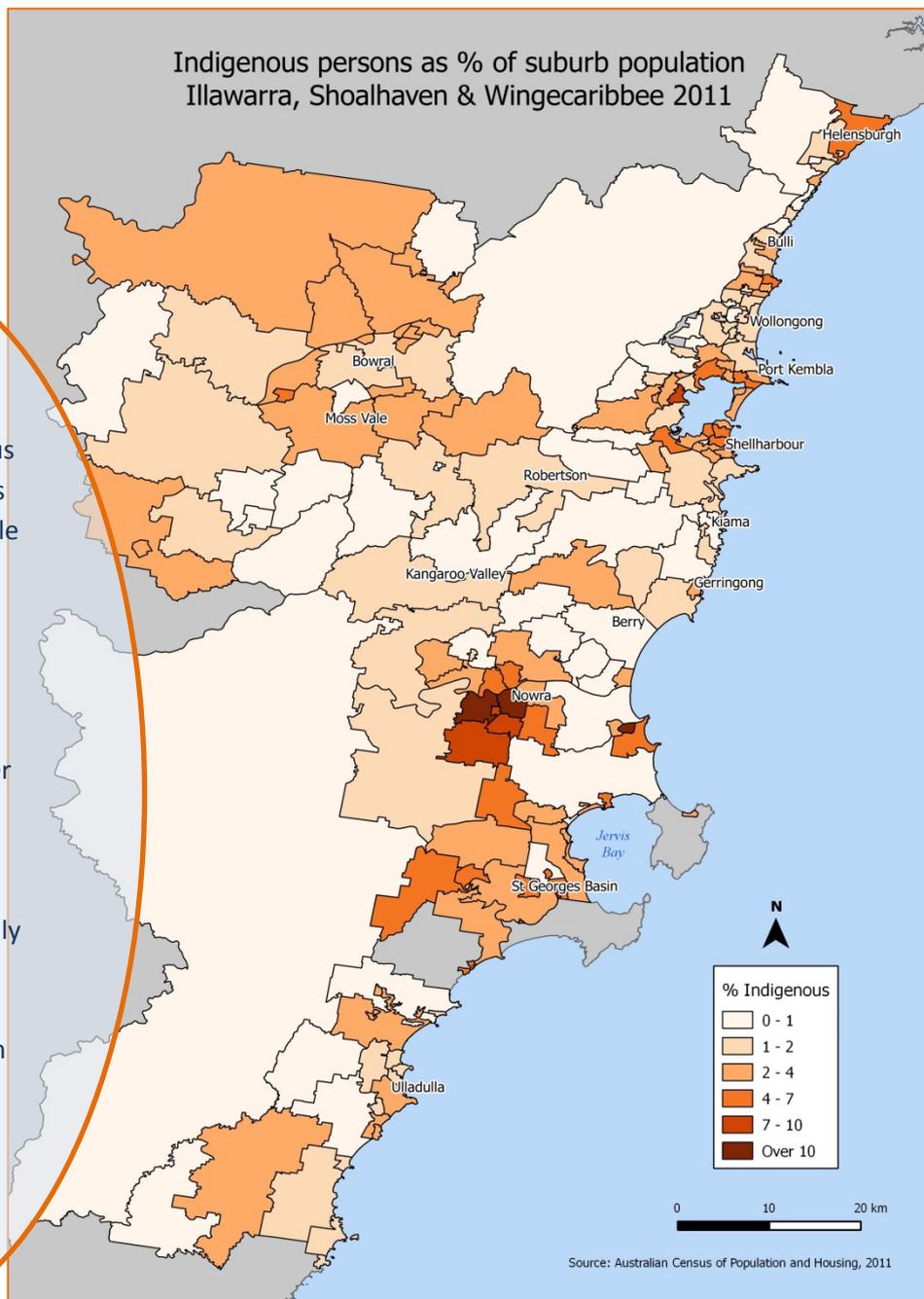
- ❖ What are the factors that impact on Aboriginal people's experience of chronic disease and its management in the Illawarra and Shoalhaven?
- ❖ How do the patient journeys of Aboriginal people in the Illawarra and Shoalhaven regions compare with what we know from other research?
- ❖ How are Aboriginal chronic disease programs designed and how do they function in the Illawarra and Shoalhaven?
- ❖ How effective are the services, programs and supports available to Aboriginal people to assist in their management of chronic disease following discharge from hospital?
- ❖ What are strengths and weaknesses of current chronic disease management approaches for Aboriginal people?
- ❖ What lessons can be learnt to inform future Aboriginal health research?

# Where was the research done?



The research was undertaken in the **Illawarra and Shoalhaven regions** where there are approximately 10,763 Aboriginal people, or 2.9% of the total population. Sixty per cent of Aboriginal residents, (6,445 people) live in the Illawarra region; while 40% (4,318 people) live in the Shoalhaven.

Based on the 2011 Census information the locations in which Aboriginal people within the **Illawarra and Shoalhaven** live are also areas where there are high levels of social disadvantage, high unemployment and lower incomes. The Aboriginal population is a 'young' population but children and young people typically experience poorer educational outcomes, significantly worse health outcomes and poorer access to services



SOURCE: ABS 2011 Census Data Statistics by Local Government Areas

# How was the research done?



Our research was guided by an Indigenous research approach and underlined by the principles of self-determination, social justice and Indigenous protocols. We used qualitative research methods that involved us talking directly to Aboriginal people and the people who provide their health services. Our discussions focused on the way in which Aboriginal people experience and make meaning of their journey through the health system.

## *There were 4 main components of the research*

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**1.** To describe the extent and type of chronic disease in the Aboriginal population in the Illawarra and Shoalhaven regions,



We reviewed what has already been written on chronic disease in journal articles, books and reports to describe chronic disease in the Aboriginal population within the two regions.

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**2.** To document formal chronic disease management models of care for Aboriginal patients across NSW.



We investigated the regions' Aboriginal chronic disease programs and interviewed program managers.

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**3.** To explore and document Aboriginal people's experiences of chronic disease management,



We interviewed 22 Aboriginal people recently discharged from hospital and held four focus group discussions with 27 Aboriginal people in the community to understand more about how they are managing living with chronic disease and using local health services.

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**4.** To identify the strengths and weaknesses of current chronic disease management for Aboriginal people,



We interviewed health professionals, service providers (including four Aboriginal people) and nine managers (including three Aboriginal people) of Aboriginal chronic disease management programs working in health to understand more about the services they provide to Aboriginal clients.

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A total of 56 Aboriginal people (64 %) participated in the research.

# What did we find out?



The findings from the different groups who participated in this research provided the basis for our recommendations for where improvements in health service delivery could be made.



## 1. Broad factors impacting on Aboriginal people's experience

It is now well accepted by researchers and others that having good health depends on more than just your individual behaviour, biology or having good genes. There are a broad range of factors known as the 'social determinants of health' that also impact on a person's health. The social, environmental and economic factors that contribute to better health include having good education, employment, adequate housing and having 'social capital', that is, the social connections that help some people and families increase their wealth.

The social and economic disadvantage which Aboriginal people face in all of these areas has been linked to the high rates of chronic disease in Aboriginal communities. This means that in order for Aboriginal people to have better health, we also need to address the inequities in education, housing, employment and other areas.

In addition to these social and economic factors, Aboriginal researchers have argued that cultural determinants, such as stronger connections to culture and strong identity, self-esteem and resilience, also play an important part in good health.

*Cultural Determinants originate from and promote 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 safety. (Brown 2014)*

Some of the common themes which emerged our discussions with Aboriginal community members were: Aboriginal identity, education, stolen generation and intergenerational trauma, community connectivity, and the issue of trust or distrust in seeking help.

**Key Message** - Better linkages between health and social services in the region are needed to address the underlying social determinants of health.

**Recommendation 1**- Support action on the social and cultural determinants of health



## 2. Patient journeys of Aboriginal people in the Illawarra and Shoalhaven

### *Attitudes to health, illness and medicines*

Most of what has been written about Aboriginal people and chronic diseases is based on research done in the remote parts of Australia. There is much less research on how Aboriginal people living in urban and inner regional areas experience living with and managing chronic disease and accessing health services.

In our research we found that there was not just one way Aboriginal people from the Illawarra and Shoalhaven experience the chronic disease management or the health system; rather there is a great deal of diversity in Aboriginal people's experiences. This is not surprising given the Illawarra and Shoalhaven, includes Aboriginal people from many different local communities and Indigenous cultural backgrounds.

*...no one has really ever explained what that disease is, what chronic disease to me is all about*

We found a wide variation in how people understood chronic disease. While some had a good understanding and knew how to manage home, others were unsure. Many found it very difficult to adjust their lives to having to manage a chronic disease, to take regular medications or make the lifestyle modifications that their doctors insisted on.

*At the hospital they told me that I'd had severe dehydration, gastroenteritis and I'd had renal failure. So my body had started breaking down after the three or so days. Yeah. Because I was at home I was drinking (water), but I wasn't - totally wasn't drinking enough. But I wasn't eating either, couldn't eat, because every time I got up I'd have trouble. Yeah...*

Despite this diversity, there some consistent themes emerged about how Aboriginal people manage their chronic conditions and how they experience the health system. Individual responsibility for health was a common theme, such as how their lifestyle choices such as smoking had contributed to their health condition.

**Key Message** - Addressing health literacy is a major gap in current supports

**Recommendation 2** - Explore options for improving health literacy

## *Personal stories, family and Aboriginal identity*

Aboriginal community members generously shared much personal information and often drew on their own life histories to explain and illustrate how and why they managed their condition in a particular way.

- ❖ Aboriginal people involved in the research showed a deep and profound understanding of the importance of good health in their lives and the lives of their family and community
- ❖ Aboriginal identity frequently arose in discussions about personal and family history and people's interactions with health services.
- ❖ A number of people spoke about the impact of the stolen generation on their health.

## *Hospital and discharge experience*

People had both good and bad things to say about being in hospital.

- ✓ Many people described their treatment by hospital staff to be kind and helpful
- ✓ Many people spoke of the positive support they received from nurses and Aboriginal Hospital Liaison Officers.
- ✗ But while the Aboriginal Hospital Liaison Officers position was seen as valuable it was also under-resourced, under-acknowledged with unrealistic expectations from the health service and the Aboriginal community.
- ✓ There was widespread support for increasing the Aboriginal workforce across all areas of the health system.

Most of the people, however, found being in hospital a negative experience:

- ✗ Feelings of isolation, confusion and restrictions because of the physical hospital environment
- ✗ There was a lack of understanding by hospital staff of the importance of family to Aboriginal people particularly when they were ill.
- ✗ There were frequent complaints about poor communication between doctors and patients
- ✗ Many people were unhappy about the way their visitors were treated in hospital and the unwillingness of the hospital to accommodate large number of visitors

*I felt like climbing the flaming walls...I'd be very, very reluctant to go back in. It was the most shocking experience*

People did not generally explain these poor hospital experiences in terms of racism, but rather they felt that the hospital system dealt the same poor treatment to everyone.

There are number different types of services and programs available to Aboriginal people to assist in their management of chronic disease following discharge from hospital in the Illawarra and Shoalhaven regions. However, people described their experience of being **discharge from hospital** to home in largely negative terms:

- ✘ People described being left confused and overwhelmed when they returned home from hospital
- ✘ People were concerned about the lack of, particularly written, information provided about how to manage their condition when they returned home
- ✓ Those who did receive information about their health, however, reported becoming more actively engaged in their health

*had to change my diet, change my way of doing things - watching my sugar levels, but I've got a book here that will give you a rough idea...*

The information provided by the diabetes education enabled some people to be more actively engaged in their health, for example by recording their sugar levels.

The 48 Hour Follow-Up program is the Illawarra Shoalhaven Local Health District's key mechanism for post discharge support. The program generally works well but there are a few areas which could be improved:

- ✘ People may be unprepared for the 'cold call' from the 48 Hour Follow-Up team,
- ✘ There is lack of knowledge about the 48 Hour Follow-Up program amongst service providers

### *Access to health services in the community*

Research which has been done in different settings across Australia, tells us that Aboriginal people with chronic diseases continue to face significant challenges in accessing health services. Our research explored the main issues which have been shown to influence access to health services: **transport, cost of health care** and **appropriateness of care**.

- ✓ Overall, the Aboriginal people we spoke to were satisfied with the care they received by health care practitioners in the community.
- ✓ Transport issues were largely alleviated for those people attending local Aboriginal chronic disease management programs which provided transport.
- ✘ Travel to Sydney for hospital treatment or specialist appointments was often tiring and stressful particularly for people from the Shoalhaven.

- ✘ Many people found the inflexibility of specialist appointment times added to their difficulties.
- ✘ The cost of care was consistently raised as a barrier to accessing medical specialists.
- ✘ Aboriginal people were affected by systemic health care problems, such as long waiting times in busy acute care settings.
- ✘ The recognition of Aboriginality by health care professionals and services and the need to repeatedly provide evidence of Aboriginality was often problematic, particularly in relation to access to Closing the Gap benefits.
- ✘ Some people were not satisfied with what they viewed as health care providers 'double dipping' through the Closing the Gap program.

**Key Message** - There is a need to strengthen the supports offered to chronically ill Aboriginal people while in hospital and the post-discharge period.

**Recommendation 3** - Improve hospital and discharge experience



### 3. Review of Aboriginal chronic disease programs

Our review of guidelines for Aboriginal chronic disease programs focused on three themes: service design, operations and cultural capability.

- ❖ Government, non-government and Aboriginal community controlled organisations had different approaches to designing services for the Aboriginal community.
- ❖ The Aboriginal Care Coordination Supplementary Scheme was an important strategy for ensuring specialist support for chronic disease management.
- ❖ The service provision relied heavily on the frontline staff to build and sustain relationships with stakeholders; however the fundamental human rights premise of self-determination was not enabled through their governance structures.
- ❖ The non-government sector should aim to improve its cultural governance if it continues to deliver health services to the Aboriginal community.

*Everyone says, 'But why should Aboriginals have their own health services and everything and that there?' But to me, some of the - the way some of the doctors and some of the people are and that there, that is why we need them, because they do not pass judgment on us...Yes, yeah. I'm proud of my heritage.*

**Key Message** - Aboriginal targeted chronic disease management programs should be more widely promoted and enhanced.

**Recommendation 4** - Enhance Aboriginal chronic disease management programs



## 4. Effectiveness of health services for chronic disease management

### *What's working well?*

#### **1. Targeted Programs**

There are a number of Aboriginal specific programs targeting chronic disease management, operated both by mainstream organisations and Aboriginal organisations. Overall programs were very well regarded by Aboriginal people. We found that the local Aboriginal communities benefit from having a range of different programs to meet the diverse needs of the population.

#### **2. Care in the community**

Aboriginal people were generally positive about the health care they received from Aboriginal and non-Aboriginal health services and practitioners in the community. Many Aboriginal people chose to use and were strongly supportive of the Aboriginal Community Controlled Health Services. Others were very satisfied with the care they received from their general practitioners. However, some were not satisfied and many people reported that they did not have a written care plans from their general practitioner.

#### **3. Closing the Gap assistance**

People who were able to access programs funded under the Closing the Gap strategy benefitted from subsidised medicines; many stated that they would not be able to afford or would stop taking their medications for diabetes or other chronic illness, if it were not for the scheme. Others received assistance in accessing specialist care or medical equipment.

### *What could be improved?*

Service providers and Aboriginal people made useful suggestions about how services and programs could be improved.

- ❖ Hospital and discharge experience
- ❖ Improved information about benefits available under the Closing the Gap program
- ❖ Promotion of the 48 Hour Follow-Up Program
- ❖ Improved uptake of General Practitioner care plans
- ❖ A stronger role for Aboriginal Community Controlled Health Services

### *Where are the gaps in support?*

- ❖ Health literacy
- ❖ Workforce development
- ❖ Greater connectivity of health and social services

**Key Message** - There is a need for a more collaborative approach to service delivery which meets the complex needs of Aboriginal people with chronic conditions.

**Recommendation 5** - Develop a more collaborative approach to service delivery

*Where you get people with bad attitudes about us as Aboriginal people which we do suffer and we've had people say, 'Oh I won't treat them, they're Aboriginal.' Because if you're going to be a nurse, you're there for everybody. Not pick and choose patients which made it worse and this is a young fella that we have to drag him to hospital to get tended to and then when you get the wrong attitude, they don't want to go. It's always next time, next time.*

**Key Message** - There is a need for a comprehensive strategy to address Aboriginal health workforce.

**Recommendation 6** - Address health workforce needs



## 5. Lessons learnt in undertaking the research

In conducting this project the research team learnt valuable lessons about Aboriginal health research. The qualitative methods used proved highly appropriate to achieve the overall aim the study. The interviews and focus groups used semi-structured questions but were flexible enough to allow the opportunity for all people to have a yarn, tell their stories, express their strong support for what was working, to complain about what was not working and to make valuable suggestions for what needed to change.

*Mate, you're the first one that I remember that's actually come over and asked us how do we handle it, you know*

The researchers were encouraged to and share the research findings. People believed sharing information from this research would be helpful to Aboriginal people in the Illawarra and Shoalhaven as well as to other communities.

# Recommendations



This project has resulted in identifying a number of recommendations for Illawarra Shoalhaven Local Health District for how improvements might be achieved at three levels: individual, family and community level, organisational level and systems level.



## 1: Support action on the social and cultural determinants of health

### Support action on social determinants of health by:

- ❖ Acknowledging and supporting actions for improving the underlying social determinants of health, including support for regional Aboriginal education, housing, justice, employment and welfare initiatives.
- ❖ Improving the connection between services which meet the complex needs of Aboriginal people with chronic conditions, including better linkages between health and social services

### Support action on cultural determinants of health by:

- ❖ Strengthening and resourcing the network of Aboriginal community controlled service organisations delivering primary care, advocacy, referral and gender specific programs.
- ❖ Developing a transparent mechanism for ongoing consultation with the diverse range of Aboriginal community stakeholders for decision making about health policies and service delivery.



## 2: Explore options for improving health literacy

### Address health literacy at the individual, family and community levels by:

- ❖ Providing a supportive environment for behavioural change.
- ❖ Resourcing outreach activities which employ a range of strategies and flexible approaches, including informal 'yarn ups' and information sharing which bring Aboriginal people together in a culturally safe environment, workshops to deliver health messages and campaigns.
- ❖ Expanding the uptake of existing culturally appropriate educational resources for chronic disease prevention and management (e.g. Aboriginal Health and Medical Research council resources, Heart Foundation).
- ❖ Promoting the use of new technologies (for example, the NSW Healthy Get Healthy Information and Coaching Service) and supporting upskilling to increase access.



### 3: Improve the hospital and discharge experience

#### Improve the hospital experience of Aboriginal people by:

- ❖ Acknowledging the priority which Aboriginal people place on family support while in hospital.
- ❖ Providing physical spaces within the Wollongong, Shellharbour and Shoalhaven hospitals for the use of Aboriginal hospital liaison officers, patients, their families and visitors.
- ❖ Ensuring that frontline hospital staffs receive specific training in cross cultural communication.

#### Improve the discharge experience of Aboriginal people by:

- ❖ Providing sufficient medication prior to the post discharge GP appointment.
- ❖ Making the Doctor's appointment for clients prior to discharge.
- ❖ Ensuring that there is an appropriate level of support and safety available to Aboriginal patients at discharge (including available family/friend support, transport, and ability to cope at home).
- ❖ Providing clear written information about how to manage their chronic conditions following discharge.
- ❖ Promoting the 48 Hour Follow-Up program widely across health services in the Illawarra and Shoalhaven and in the Aboriginal community.
- ❖ Providing Aboriginal Health Worker home visits following discharge to ensure ability to cope at home.



### 4: Enhance Aboriginal chronic disease management programs

#### Enhance the Aunty Jean's program by:

- ❖ Ensuring the program is widely promoted as catering for the individual needs of Aboriginal people with mild to severe chronic conditions at all levels of fitness.
- ❖ Increasing the inclusivity of all chronic care programs by providing flexible delivery options (for example on weekends and after hours).



## 5: Develop a more collaborative approach to service delivery

### Develop a more collaborative approach to service delivery for Aboriginal people with chronic conditions by:

- ❖ Providing a centralised online resource of available health services and programs, including service description, eligibility, location etc.
- ❖ Developing formal agreements with organisations providing Aboriginal chronic disease management programs to ensure transparency and ongoing commitment and role clarification.
- ❖ Negotiating with General Practitioners and their representative organisations to ensure that a written Management Plan or Team Care arrangement is implemented, discussed and regularly reviewed for all Aboriginal clients.
- ❖ Promoting the need to address Aboriginal people with co-morbidities, particularly mental illness.
- ❖ Developing stronger pathways to cardiac rehabilitation engagement by providing a flexible service in the community.



## 6: Address Aboriginal health workforce needs

### Address the need to improve and expand the Aboriginal health workforce by:

- ❖ Reviewing the role of the Aboriginal hospital liaison officers to achieve a clear, feasible, job description and ensure that the role is supported and understood by other health professionals and communicated to the Aboriginal community.
- ❖ Promoting employment of Aboriginal people across the Illawarra Shoalhaven Local Health District.
- ❖ Assisting non-Aboriginal staff to build relationships with Aboriginal communities to reduce the burden on the relatively few Aboriginal health workers, for example through a buddy system.
- ❖ Increasing the number of Respecting the Difference trainers to ensure that cultural training is implemented across the Illawarra Shoalhaven Local Health District workforce
- ❖ Supporting Aboriginal health workers to gain qualifications to deliver primary health care of screening and monitoring chronic disease in outreach settings.
- ❖ Building the capacity of the Aboriginal health workforce by supporting them to obtain professional qualifications.
- ❖ Engaging strategically with tertiary organisations for the recruitment, mentoring and training of Aboriginal health personnel by providing scholarships, internships, and placement experiences.

# Acknowledgements

We acknowledge the Aboriginal traditional owners of the Illawarra and Shoalhaven regions and pay our respects to elders past and present.

We are indebted to all of those who participated in the research for sharing their valuable time and knowledge. **In particular, we thank the Aboriginal community members, who informed this research by generously agreeing to share their stories, views and insights, at a time when they were managing chronic illnesses and often much more.** We also thank the health professionals and others for giving up their valuable time to talk to us.

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## *For further information see:*

Clapham K, Winch S, Senior K, Grootemaat P, Neal N, Marshall V, Manning C . (2016) Aboriginal Chronic Disease Care Pathways: Final Report. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.