

# Aboriginal Chronic Disease Care Pathways: Final Report

---



December 2016

**Kathleen Clapham**

**Scott Winch**

**Kate Senior**

**Pam Grootemaat**

**Nadia Neal**

**Virginia Marshall**

**Claire Manning**

**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.*

**Suggested citation for final report**

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.

## Table of Contents

<b>List of figures .....</b>	<b>IV</b>
<b>List of tables .....</b>	<b>IV</b>
<b>Terminology.....</b>	<b>V</b>
<b>Acknowledgements .....</b>	<b>VI</b>
<b>Abbreviations .....</b>	<b>VII</b>
<b>Objectives of the Report .....</b>	<b>VIII</b>
<b>Key messages.....</b>	<b>VIII</b>
<b>Executive summary.....</b>	<b>IX</b>
<b>1 Introduction .....</b>	<b>1</b>
1.1 Background.....	1
1.2 Aims and objectives of the research .....	1
1.3 Scope of the report.....	2
<b>2 Background and literature.....</b>	<b>3</b>
2.1 Key findings from the literature .....	4
2.1.1 Perspectives on chronic disease in the Australian Indigenous population .....	4
2.1.2 Trends in chronic disease .....	4
2.1.3 Indigenous experience of having and managing a chronic disease.....	5
2.2 Policy context .....	6
2.2.1 The national level .....	7
2.2.2 The state level .....	10
2.2.3 The Illawarra Shoalhaven Local Health District.....	13
2.3 The regional context.....	13
2.3.1 Hospitalisation due to chronic conditions .....	14
2.3.2 Potentially preventable hospitalisations.....	15
2.3.3 Unplanned hospital readmissions within 28 days .....	17
2.3.4 Services available to Aboriginal people with chronic condition .....	18
<b>3 Methods and Approach.....</b>	<b>21</b>
3.1 Addressing the aims and objectives of the research.....	21
3.2 Indigenous research approach .....	21
3.3 Data sources and data collection processes .....	21
3.4 Selection and recruitment of participants .....	22
3.4.1 Aboriginal client interviews.....	22
3.4.2 Focus group participants.....	23

3.4.3	Service providers .....	23
3.4.4	System stakeholders .....	24
3.4.5	Program managers .....	24
3.5	Program design review .....	24
3.6	Data analysis .....	24
3.7	Ethical issues and approvals .....	25
3.8	Governance.....	26
3.9	Strengths and limitations of the study .....	26
<b>4</b>	<b>Experiencing the system: Aboriginal perspectives .....</b>	<b>27</b>
4.1	Interviews with Aboriginal clients .....	27
4.2	Focus group discussions with Aboriginal community members .....	28
4.3	Key questions of interest .....	29
4.3.1	Understanding of their health condition .....	29
4.3.2	Recent hospital experience .....	31
4.3.3	Information and support from hospital staff .....	36
4.3.4	Managing their chronic disease at home.....	37
4.3.5	Accessing health care .....	43
4.3.6	Experiencing local health services and having a care plan .....	45
4.3.7	Experiencing Aboriginal Chronic Disease Group Programs .....	52
4.3.8	Aboriginal people’s suggestions for improvement .....	58
4.4	Section summary .....	61
<b>5</b>	<b>Experiencing the system: Service providers and system stakeholder perspectives .....</b>	<b>63</b>
5.1	Interviews with service providers.....	63
5.2	Interviews with system stakeholders .....	64
5.3	Key questions of interest.....	64
5.3.1	Providing support .....	65
5.3.2	Challenges in providing support.....	67
5.3.3	Referral.....	71
5.3.4	Understanding the needs of Aboriginal clients.....	72
5.3.5	Providing culturally appropriate health services .....	75
5.3.6	Suggestions for improvement.....	78
5.4	Section summary .....	79
<b>6</b>	<b>Aboriginal chronic disease program design review .....</b>	<b>82</b>
6.1	Participants .....	82
6.2	Key questions of interest .....	82
6.2.1	Program design .....	82

6.2.2	Program operations .....	84
6.2.3	Cultural Capability .....	86
6.3	Section summary .....	90
<b>7</b>	<b>Discussion .....</b>	<b>91</b>
7.1	Broad factors impacting on Aboriginal people’s experience .....	91
7.2	Patient journeys of Aboriginal people in the Illawarra and Shoalhaven.....	92
7.2.1	Attitudes to health, illness and medicines .....	92
7.2.2	Personal stories, family and Aboriginal identity .....	93
7.2.3	Hospital and discharge experience .....	94
7.2.4	Access to health services in the community .....	95
7.3	Aboriginal chronic disease programs .....	96
7.3.1	Design .....	96
7.3.2	Operations.....	97
7.3.3	Cultural Capability .....	98
7.3.4	Summing up.....	99
7.4	Effectiveness of health services for chronic disease management.....	99
7.4.1	What’s working well.....	99
7.4.2	What could be improved?.....	100
7.4.3	Where are the gaps in support?.....	102
7.5	Lessons learnt in undertaking the research .....	103
<b>8</b>	<b>Conclusions and Recommendations .....</b>	<b>105</b>
	<b>References.....</b>	<b>108</b>
	<b>Appendices .....</b>	<b>115</b>
	Appendix 1 Chronic disease programs and services in the Illawarra and Shoalhaven .....	116
	Appendix 2 Data collection tools .....	124
	Appendix 3 Ethical approvals and letters of support.....	131
	Appendix 4 Steering Committee membership.....	139

## List of figures

Figure 1	Aboriginal and non-Aboriginal Population compared .....	14
Figure 2	Cause of Hospitalisations by Aboriginality Illawarra Shoalhaven LHD 2013-14 (excluding non-chronic causes) .....	15
Figure 3	Cause of Hospitalisations by Aboriginality Illawarra Shoalhaven LHD 2013-14 (excluding non-chronic causes and dialysis) .....	15
Figure 4	Potentially preventable hospitalisations by Aboriginality, ISLHD, 2006-07 to 2014-15. .....	16
Figure 5	Potentially preventable hospitalisations by Aboriginality, all LHDs, 2001-02 to 2013- 14 .....	17

## List of tables

Table 1	Services and Programs .....	18
Table 2	Data collection .....	22
Table 3	Location of individual client interviews .....	27
Table 4	Individual Interview Participants (Clients) .....	28
Table 5	Location of focus group discussions .....	28
Table 6	Positive and negative hospital experiences .....	31
Table 7	Service Providers .....	63
Table 8	System stakeholders .....	64
Table 9	Programs Reviewed .....	82

## Terminology

In this document:

- The term 'Aboriginal' refers to the both Aboriginal and Torres Strait Islander people. This term is used interchangeably with 'Indigenous' or 'Indigenous Australians' in this report.
- The term 'health services' refers to public health services provided by the Illawarra Shoalhaven Local Health District.
- The term 'support services' refers to the social and welfare services available to assist people with a broader range of health related and social needs.
- The term 'other organisations' refers to relevant entities such as Non-Government Organisations, Aboriginal Community Controlled Health Organisations etc.
- The term 'Closing the Gap' refers to a government strategy that supports the Council of Australian Governments 2008 targets and timeframes to address Indigenous disadvantage in life expectancy, child mortality, access to early childhood education, educational achievement and employment outcomes.

## 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 whom we have referred to as stakeholders in this report for giving up their valuable time to talk to us.

A number of organisations must be acknowledged for the key role they played in facilitating the research. We are very grateful for the assistance of ISLHD Aboriginal Chronic Care Unit (Zane Rice, Eric Winch, Rebecca Dawson), Grand Pacific Health (Carolynne Leon), Illawarra Aboriginal Medical Service (Julie Booker), South Coast Medical Aboriginal Corporation (Craig Ardler), the Illawarra Koori Men's Support Group (Gerald Brown), Coomaditchie United Aboriginal Corporation (Lorraine Brown, Narelle Thomas), Waminda South Coast Women's Health and Welfare Aboriginal Corporation (Faye Worner).

We acknowledge that the research has been a collaborative effort between the investigators and the Steering Committee set up to guide and advise the research, and assist with the recruitment of participants. Members of the committee include Paul van den Dolder, Franca Facci, Zane Rice, Eric Winch and Pauline Brown. In particular, we acknowledge and thank Paul and Franca for their extensive support and valuable contribution to the project.

We also acknowledge the contribution of Leanne Drury and thank her for allowing us to draw from some of the interviews she undertook with health professionals for her University of Wollongong, Public Health Honours thesis (Drury 2014).

The research was funded by Illawarra Shoalhaven Local Health District. We acknowledge and thank the ISLHD Board for supporting this work.

## Abbreviations

ABS	Australian Bureau of Statistics
ACI	Agency for Clinical Innovation
ACCHS	Aboriginal Community Controlled Health Service
AHLO	Aboriginal Health Liaison Officer
AHMRC	Aboriginal Health and Medical Research Council of NSW
AHSRI	Australian Health Services Research Institute
AMS	Aboriginal Medical Service
ARC	Access and Referral Centre
ATSI	Aboriginal and Torres Strait Islander
CCAP	Chronic Care for Aboriginal People
CCSS	Care Coordination and Supplementary Services
CDMP	Chronic Disease Management Plan
CHI	Centre for Health Innovation
CHSD	Centre for Health Services Research
CKD	Chronic Kidney Disease
COAG	Council of Australian Governments
COPD	Chronic Obstructive Pulmonary Disease
CPAP	Continuous Positive Airway Pressure
CRCAH	Cooperative Research Centre for Aboriginal Health
CTG	Closing the Gap
CVD	Cardiovascular Disease
CNC	Clinical Nurse Consultant
DALYs	Disability Adjusted Life Years
eGFR	Estimated Glomerular Filtration Rate – to test kidney function
ESKD	End of Stage Kidney Disease
GP	General Practitioner
GPR	General Practitioner Registrar
GPH	Grand Pacific Health
GMS	Graduate Medical School
IAMS	Illawarra Aboriginal Medical Service
ICDP	Indigenous Chronic Disease Package
ICHP	Improving the Culture of Hospitals Project
IKMSG	Illawarra Koori Men’s Support Group
ISLHD	Illawarra Shoalhaven Local Health District
LHD	Local Health District
NACCHO	National Aboriginal Community Controlled Health Organisation
NAIDOC	National Aboriginal and Islanders Day of Observance Committee
NGO	Non-Government Organisation
NSW	New South Wales
PBS	Pharmaceutical Benefits Scheme
PIP	Practice Incentives Program
PHN	Primary Health Network
RN	Registered Nurse
SCMSAC	South Coast Medical Service Aboriginal Corporation

## Objectives of the Report

This 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 programs targeting Aboriginal chronic disease management.
- Provides feedback to the Illawarra Shoalhaven Local Health District (ISLHD) to inform planning and policy development relevant to chronic care services.
- Draws attention to the complexity of the health care system and identifies the some of the barriers and enablers to achieving change and improvement.
- Recommends directions for future policy and service improvements.

## 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.

## Executive summary

### 1. Introduction

Aboriginal Australians experience chronic diseases at much higher rates than other Australians, but little is known about the impact of chronic conditions on Aboriginal people, their families and communities, or how their chronic disease is being managed, particularly in urban communities. In September 2014 the Illawarra Shoalhaven Local Health District (ISLHD) commissioned an Aboriginal led research team at the University of Wollongong (UOW) to conduct the 'Aboriginal Chronic Disease Care Pathways Research Project'. The research was conducted over an 18 month period from September 2014 to March 2016.

The research focused on the services and programs available to Aboriginal people following their discharge from hospital and their experiences of those services. It examined the supports systems and identified gaps in services for Aboriginal chronic disease patients, with the aim of producing evidence that could contribute to the planning and delivery of effective, accessible, acceptable and appropriate services for Aboriginal people within the region.

### 2. Background and literature

The literature review which formed the first part of this research found that Indigenous Australians with chronic illness experience far worse health outcomes than non-Indigenous Australians. Over the past 10 years, there has been a significant increase in the hospitalisation rates for Aboriginal peoples with chronic conditions. In 2012-2013 hospitalisation rates for Indigenous Australians were nearly five times higher than for non-Indigenous Australians. Aboriginal Australians continue to confront a raft of 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. However, there is a lack of research which focuses on Aboriginal peoples' experience of living with and managing chronic disease, particularly people living in urban and inner regional areas.

### 3. Methods and approach

The aim of the research was to explore the factors that impact on Aboriginal people's experience of chronic conditions and its management in order to inform improvements in care planning across the care continuum. There were four key objectives which were addressed as follows:

- To describe the extent and type of chronic disease in the Aboriginal population in the Illawarra and Shoalhaven regions, we conducted a targeted review of the literature including peer reviewed journal articles, books and 'grey' literature (McMullen, Grootemaat et al. 2015).
- To document formal chronic disease management models of care for Aboriginal patients across NSW, we conducted a program design review, involving a desk review of published guidelines for Aboriginal chronic disease models of care and conducted interviews with the managers of programs operating in ISLHD;
- To explore and document Aboriginal people's experiences of chronic disease management, we conducted qualitative interviews and focus group discussions with Aboriginal people managing chronic illness in the community.

- To identify the strengths and weaknesses of current chronic disease management for Aboriginal people, we conducted qualitative interviews with service providers and systems stakeholders.

The overarching framework for this qualitative study was an Indigenous research approach, underlined by the principles of self-determination, social justice and Indigenous protocols (Henry, Dunbar et al. 2002), to provide insights into the way in which Aboriginal people experience and make meaning of their journey through the health system.

The research drew from a wide variety of sources, including a targeted literature review which incorporated a review of chronic disease management programs throughout Australia ((McMullen, Grootemaat et al. 2015). The research also incorporated a review of guidelines for the design and implementation of Aboriginal models of care. Individual interviews were undertaken with Aboriginal people with a chronic illness who had a recent hospital experience as well as service providers, program managers of Aboriginal Chronic Disease Management Programs (CDMSs) and systems stakeholders. Focus group discussions were undertaken with Aboriginal people in the community who were living with or caring for someone with a chronic illness. Aboriginal participants from a variety of settings and service providers from a broad range of health professionals, organisations and sectors participated. The study had a number of limitations which should be acknowledged. This was a qualitative study with a relatively small number of participants. Although the findings of qualitative studies are not able to be generalised to a larger population, many aspects of the study are transferable to other settings.

The table below summarises the qualitative data which was collected and analysed.

<b>Data collection method</b>	<b>No. of sessions/ models</b>	<b>No. of Participants</b>
Review of guidelines for Aboriginal models of care	8	
<b>Semi-structured interviews</b>	61	
Aboriginal clients <sup>1</sup> with a chronic condition and recent hospital experience		22
Health service providers from a broad range of organisations and professions		22
System stakeholders from key Illawarra and Shoalhaven organisations		8
Managers of Aboriginal Chronic Disease Management Programs		9
<b>Focus group discussions with Aboriginal community members</b>	4	27
<b>Total</b>		88

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

<sup>1</sup> Aboriginal interviewees are referred to as 'clients' to distinguish them from focus group participants.

## 4. Experiencing the system: Aboriginal perspectives

The following topics were discussed in the interviews and focus group discussions with Aboriginal participants:

- *Understanding of their health condition*
- *Recent hospital experience*
- *Information and support from hospital staff*
- *Managing their chronic disease at home*
- *Accessing health care*
- *Experiencing local health services and having a care plan*
- *Experiencing Aboriginal Chronic Disease Group Programs*
- *Suggestions for improvement*

## 5. Experiencing the system: Service providers and system stakeholder perspectives

The following topics were discussed with service providers and systems stakeholders:

- *Providing positive support*
- *Challenges in providing support*
- *Referral*
- *Understanding the needs of Aboriginal people with chronic illness*
- *Providing culturally appropriate health services*
- *Suggestions for improvement*

## 6. Aboriginal chronic disease program design review

The responses from the service providers to the questions asked in the individual interviews and focus groups are presented below under the following headings:

- *Program design*
- *Program operations*
- *Cultural capability*

## 7. Discussion

The findings from the multiple participant groups presented in chapters four, five and six of this report demonstrate that although there is wide variation in the views of the various participant groups, on any particular issue, a number of consistent themes emerge about how chronic disease is being managed by Aboriginal people and their carers and where improvements could be made. These findings are presented in this section around a number of key questions:

- What are the broad factors that impact on Aboriginal people's experience of chronic disease and its management?
- How do the patient journeys of Aboriginal people in the Illawarra and Shoalhaven regions compare with the literature?
- 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? And what

are strengths and weaknesses of current chronic disease management approaches for Aboriginal people?

- What lessons were learnt about Aboriginal health research?

### **7.1 Broad factors impacting on Aboriginal people's experience**

There is extensive evidence to support the view that health is determined by a broad range of social and economic determinants, in addition to any individual biological, behavioural or hereditary factors. Aboriginal people living in the Illawarra and Shoalhaven regions are concentrated in areas of high levels of social disadvantage, high unemployment, lower levels of educational attainment and lower incomes (Australian Bureau of Statistics 2006). Aboriginal researchers have also 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.

The findings from the interviews and focus groups with Aboriginal community members illustrates the diversity of ways in which Aboriginal people in the Illawarra and Shoalhaven experience 'the health system'; this is not surprising given the heterogeneity of Indigenous populations living in urban environments. Despite this diversity of experience, a number of common themes emerged from the data collected from Aboriginal community members including: the importance of Aboriginal identity; education; stolen generation and Intergenerational trauma; community connectivity; issues around the impact of smoking; and the importance of trust in decisions about help seeking.

### **7.2 Patient journeys of Aboriginal people in the Illawarra and Shoalhaven**

There are both similarities and differences in the recounting of patient journeys shared by Aboriginal people in the Illawarra and Shoalhaven, compared to those of Indigenous people in other parts of Australia.

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

- The participants in our study demonstrated a deep and profound understanding of good health in their lives and the lives of their family and community.

#### *Personal stories, family and Aboriginal identity*

- Aboriginal identity, personal and family history were discussed frequently in relation to their chronic condition and the interactions with health services.
- The ongoing impact of the stolen generation on the lives of the Aboriginal participants reinforces the need for the provision of holistic health care services.

#### *Hospital and discharge experience*

- Being in hospital was generally a negative experience for most Aboriginal participants.
- Family support is very important to Aboriginal participants and many were unhappy about the way their visitors were treated.
- The cultural competency of health professionals was questioned, with hospital staff ignoring or speaking across them, or speaking in technical terms that the Aboriginal participant could not grasp.
- Positive comments about hospital experiences were more likely to focus on the way the person was treated by hospital staff.

- The discharge experience of the Aboriginal participants was largely negative with many participants left confused and overwhelmed when they returned home from hospital.
- Participants frequently commented about the lack of information, particularly written information, provided in hospital about the management of their condition once they returned home.
- 48 Hour Follow-Up, ISLHD's key mechanism for post discharge support, generally works well, but participants may be unprepared for the 'cold call', and there is lack of knowledge about the program amongst service providers.

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

- The three main issues of access explored extensively in the present study were those related to transport, cost of health care and appropriateness of care.

### **7.3 Aboriginal chronic disease programs**

Three key themes emerged from the review of available guidelines for Aboriginal chronic disease programs, presented in chapter six, were: service design, operations and cultural capability.

There was a diversity of positions which the various sectors that included government, Non-Government Organisations (NGOs) and Aboriginal Community Controlled Health Services (ACCHS) applied 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.

Vertical integration of health is the preferred model of service design where different health is collaborative and aligns internally. This however the capacity to deliver holistic disciplines across non-health sectors and horizontal integration could be considered as a model for enabling a more holistic approach to Aboriginal health.

There is a level of duplication which occurs across the health sectors and a lack of strong identity on the roles of different providers as well as the role of Aboriginal health workers. This should be addressed collaboratively across all sectors. There needs to be a level of responsibility by the state and federal governments to also direct funding to the organisations which are best equipped to address the funding priorities.

An Aboriginal workforce is critical for the success of improving Aboriginal health. There has been and continues to be a skills shortage in Aboriginal health.

### **7.4 Effectiveness of health services for chronic disease management**

#### **7.4.1 What's working well?**

- *Targeted Programs*
- *Care in the community*
- *CTG assistance with medications*

#### **7.4.2 What could be improved?**

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

- *Hospital and discharge experience*
- *Improved information about CTG*
- *Promotion of the 48 Hour Follow-Up Program*
- *Improved uptake of GP care plans*
- *Advocate for a stronger role for ACCHS*
- *Systems improvement*

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

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

### **7.5 Lessons learnt in undertaking the research**

In conducting this project the research team learnt a number of valuable lessons both Aboriginal health research. Participants believed sharing information from this research would be helpful to Aboriginal people in the Illawarra and Shoalhaven as well as to other communities. The researchers were encouraged to and share research findings as they emerged.

## **8. Conclusions and Recommendations**

This study set out to explore the factors that impact on Aboriginal people's experience of chronic conditions and the management of those conditions post discharge within ISLHD. The purpose of the study was to improve planning across the care continuum. Addressing this complex area requires action at multiple levels; it also needs to take into account the diversity of the Aboriginal community within the two regions. Action taken at the individual, family and community level could help to empower Aboriginal people to take control of their chronic conditions, and thus contribute to reducing avoidable hospitalisations, patients leaving against medical advice or being readmitted for the same condition. However action at the organisational level is also needed. This includes improving organisational practices and procedures and the interpersonal and communications skills of health professionals. Ultimately, however, change at the systems level is essential to address the complex issues highlighted throughout this report. Systems level improvements include addressing workforce issues, particularly the urgent need to improve the cultural competence of ISLHD employees as well as the NGOs working in the sector. To ensure more effective, accessible, acceptable and appropriate services for Aboriginal people a systems approach needs to be informed by Aboriginal community views. The following are recommendations for how improvements might be achieved at each of these levels.

### **Recommendations**

That ISLHD:

- 1: Support action on the social and cultural determinants of health
- 2: Explore options for improving health literacy
- 3: Improve the hospital and patient discharge experience
- 4: Enhance Aboriginal chronic disease management programs
- 5: Develop a more collaborative approach to service delivery
- 6: Address Aboriginal health workforce needs

## **1 Introduction**

### **1.1 Background**

Aboriginal Australians are known to experience chronic diseases at much higher rates than other Australians within the population. However little is known about the impact of chronic conditions on Aboriginal people, their families and communities or about how chronic disease is being managed in the Aboriginal community. In September 2014 the Illawarra Shoalhaven Local Health District (ISLHD) commissioned an Aboriginal led research team at the University of Wollongong (UOW) to conduct the 'Aboriginal Chronic Disease Care Pathways Research Project'. The research was conducted over an 18 month period from September 2014 to March 2016.

### **1.2 Aims and objectives of the research**

The broad aim of the research was to explore the factors that impact on Aboriginal people's experience of chronic conditions and the management of those conditions within the ISLHD, in order to inform improvements in care planning across the care continuum. The research set out to focus on the services and programs available to Aboriginal people following their discharge from hospital and experiences of those services, examine current supports systems and identify gaps in services for Aboriginal chronic disease patients. The research was expected to produce evidence that would contribute to the planning and delivery of services which are effective, accessible, acceptable and appropriate to Aboriginal people within the region.

Four key objectives were formulated to achieve the broad aim:

- Describe the extent and type of chronic disease in the Aboriginal population in the Illawarra and Shoalhaven regions;
- Document formal chronic disease management models of care for Aboriginal patients across NSW;
- Explore and document Aboriginal people's experiences of chronic disease management; and
- Identify the strengths and weaknesses of current chronic disease management approaches for Aboriginal people.

The research was conducted by a team of Aboriginal and non-Aboriginal researchers at the UOW. Researchers from The Australian Health Services Research Institute (AHSRI) in the Faculty of Business, the Graduate School of Medicine (GSM) in the Faculty of Science, Medicine and Health and the Centre for Health Innovation (CHI) in the Faculty of Social Sciences, were advised by a Steering Committee which included key personnel from the Ambulatory and Primary Health Care Division within the ISLHD. The research team also worked closely with the ISLHD Aboriginal Chronic Care Unit, Illawarra Aboriginal Medical Service (IAMS), South Coast Medical Service Aboriginal Corporation (SCMSAC), the former Illawarra Shoalhaven Medicare Locals (ISML) (Australian Government Department of Health 2016), and other relevant stakeholders including Aboriginal community members and organisations.

### **1.3 Scope of the report**

This final report presents the results of the research. It consists of eight main sections.

Section 1 provides an introduction to the project, including the aims and objectives of the research and outlines the scope of the report.

Section 2 presents the key findings from the literature, a summary of the policy context relevant to Aboriginal chronic disease management and a detailed overview of chronic disease and the Aboriginal population within ISLHD.

Section 3 outlines the research methods and approach, incorporating details of the data sources, data collection processes and analysis. Information is also included about relevant ethical issues and the limitations of the research.

The results and key findings of the research focus on the multiple perspectives around chronic disease management. These are presented in three sections. Section 4 summarises the results with key findings from Aboriginal people with chronic conditions. Section 5 summarises the results with key findings from Aboriginal people with chronic conditions from service providers and system stakeholders. Section 6 draws together the results of the Aboriginal chronic disease program design review and the interviews with program managers. Each of these sections concludes with a brief overview of the key points.

Section 7 brings together the implications of the results and discusses the factors that impact on Aboriginal people's experience of chronic disease and its management in the ISLHD; their patient journeys and how they compare with what is known from the literature; the effectiveness of services, program and supports available to Aboriginal people post discharge from hospital, as well as the insights arising from the program design review and lessons learned about conducting Aboriginal health research.

Section 8 provides a brief conclusion and presents the key recommendations for ISLHD.

The report contains a list of references and four appendices, including an overview of chronic disease programs and services in the Illawarra and Shoalhaven and other supporting documents.

## 2 Background and literature

There is no standard definition of 'chronic disease'. The Australian Institute of Health and Welfare applies the term 'chronic disease' to a group of diseases that tend to be long lasting and have persistent effects. They differ from acute diseases, which have a quick onset and are often brief, intense and/or severe (Australian Institute of Health and Welfare 2016). The major disease groups that are classified as 'chronic' in the International Classification of Diseases (ICD-10) are: diseases of the circulatory system; cancers; endocrine and metabolic diseases; diseases of the respiratory, digestive, genitourinary and nervous systems; and mental and behavioural disorders (World Health Organisation 2010). Chronic disease is characteristically associated with: complex causality and multiple risk factors; gradual onset often with no symptoms; long lasting; the development of other chronic diseases and functional impairment or disability (Australian Institute of Health and Welfare 2011).

The disparities in life expectancy and the poorer health status of Indigenous Australians compared to other Australians is well documented (Vos, Barker et al. 2009, Australian Institute of Health and Welfare 2011), and has been the major focus of national, State and Territory health policies since 2008 (Council of Australian Governments 2008, Steering Committee for the Review of Government Service Provision 2011). Around 80% of the mortality gap between Indigenous peoples and other Australians aged 35-74 years is due to chronic disease. Indigenous people are also much more likely to experience a potentially preventable hospital episode for a chronic disease than other Australians (Australian Institute of Health and Welfare 2011). Non-communicable diseases have been identified as constituting over 70% of the health gap between Indigenous and non-Indigenous Australians; as measured in Disability Adjusted Life Years (DALYs) (Vos, Barker et al. 2009). The chronic diseases which are most prevalent in the health profile of Indigenous people are: heart disease, diabetes, diseases of the liver, chronic lower respiratory disease, cerebrovascular diseases and cancers.

Many chronic diseases share behavioural and biomedical risk factors; and modifying these can reduce an individual's risk of developing a chronic disease and result in large health gains, by reducing illness and rates of death. Aboriginal people experience much higher rates of the behavioural risk factors most associated with elevated chronic disease morbidity and mortality: tobacco smoking; physical inactivity; alcohol misuse; poor nutrition; and obesity (Australian Bureau of Statistics 2006, KPMG 2014). Indigenous Australians are less likely to utilise the health services available for the prevention, treatment and management of these conditions despite the higher rates of chronic illness (Council of Australian Governments 2008).

A broad range of factors are known to contribute to the higher burden of chronic disease in the Indigenous population, including lower socioeconomic status and other social determinants of health, and poorer access to health care for the prevention and early diagnosis of disease (Gracey and King 2009). Underlying these factors are the influences of historical dispossession, loss of language and connection to the land and waters, environmental deprivation, spiritual, emotional, and mental disconnectedness, and the experience of racism (King, Smith et al. 2009).

More recently, 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. The term 'cultural determinants of health' has been used to describe

a 'strength based perspective' that acknowledges the health implications of stronger Aboriginal people's connections to culture, their individual and collective identities, self-esteem, resilience, in addition to improved outcomes across the other determinants of health including education, economic stability and community safety (Brown 2014, The Lowitja Institute 2014).

## 2.1 Key findings from the literature

### 2.1.1 Perspectives on chronic disease in the Australian Indigenous population

The literature review which formed the first part of this research examined peer reviewed and grey literature sourced from Australia and relevant international papers (McMullen, Grootemaat et al. 2015). The review examined Australian and international material relevant to the research to address the following questions:

- What are the trends in chronic disease in Australian Indigenous peoples? How are these comparable to trends in non-Indigenous Australians?
- How do Indigenous people both in Australia and overseas experience having and managing a chronic disease and how do they experience the patient journey through a sometimes disorganised and confusing health system?
- What has been attempted or achieved to make chronic disease programs more inclusive of Indigenous views?

The literature review focused primarily on four chronic conditions: chronic cardiovascular disease, diabetes, chronic kidney disease and chronic respiratory diseases, and included studies of Indigenous people across urban, regional and remote locations. Key findings from the review are discussed below.

### 2.1.2 Trends in chronic disease

All data in this section is extracted from the Australian Institute of Health and Welfare (Australian Institute of Health and Welfare 2014) unless otherwise stated. Three chronic diseases, cardiovascular disease (CVD), diabetes and chronic kidney disease (CKD) acting alone or together, contribute considerably to illness, morbidity and premature mortality in the Australian Indigenous population; resulting in high usage of the health care system. The highest rates of hospitalisation for CVD, diabetes and CKD are for Indigenous people, those in the lowest socioeconomic group and people living in remote or very remote areas.

The trend data reveals that Indigenous Australians with chronic illness experience far worse health outcomes than non-Indigenous Australians. Over the past 10 years, there has been a significant increase in the hospitalisation rates for Aboriginal peoples with chronic conditions. In 2012-2013 hospitalisation rates for Indigenous Australians were nearly five times higher than for non-Indigenous Australians. Around 94 per cent of Indigenous Australians are hospitalised in public hospitals, in contrast to 60 per cent for non-Indigenous Australians. Hospitalisation of Indigenous people from chronic kidney disease (CKD) has increased by 17% and is twice as high as hospitalisations for cardiovascular disease (CVD); the latter is the largest contributor to the mortality of Indigenous Australians. Hospitalisations for Type 2 diabetes are four times higher than for non-Indigenous peoples. Similarly, the available data on hospitalisations due to respiratory diseases shows major inequities between Indigenous and non-Indigenous Australians, with the greatest ratio of mortality being in the 45-55 age group.

The trends in chronic disease for Indigenous people in NSW are similarly alarming. The statistics in NSW, reported by the Centre for Epidemiology and Evidence (2012) show the rate of hospitalisation of Aboriginal people to be significantly higher than non-Aboriginal Australians - 1.6 times higher for CVD, 2.7 times higher for diabetes, 3.9 times higher for COPD and 5 times more likely for CKD. The admission rates for Aboriginal people with preventable hospitalisations are 2.5 times higher and for chronic conditions are 3.2 times higher than non-Indigenous people in NSW (Centre for Epidemiology and Evidence 2012). The rates of chronic disease experienced by Aboriginal people in NSW and the increase in hospitalisations and readmissions require urgent attention.

### **2.1.3 Indigenous experience of having and managing a chronic disease**

Although quantitative data such as hospitalisation trends for Indigenous people suffering chronic disease reveals the extent of the problem, culturally sensitive qualitative research can provide a deeper understanding of how Indigenous people experience chronic illness and so generate culturally sensitive solutions. The poor health status of Indigenous Australians has been well described, and there is a growing body of literature about factors in the health system itself that contribute to poor health outcomes for Indigenous Australians. The literature review identified that Aboriginal Australians continue to confront a raft of barriers related to inequitable access to health systems, stigma and discrimination that contribute to poor health outcomes and an increase in risk factors for chronic illnesses.

At the global level, Indigenous peoples' experience of having and managing chronic disease is influenced by their shared colonial history of racial and cultural oppression, disempowerment and racial inequality. The historical and continuing impacts of colonisation have led, over generations, to increasing high rates of chronic disease which contributes to premature mortality (Gracey and King 2009). The World Health Organisation (WHO) supports the view that the social determinants of health influence a person's social and economic position and exerts a powerful influence on their lives. Issues such as poverty, education, racism, housing and employment have a significant influence on the health of Australia's Indigenous population. According to the substantial review of evidence by the WHO, there is a demonstrated link between socioeconomic determinants and mortality.

Overall there is a lack of research on Aboriginal peoples' experience of living with and managing chronic disease and much of it focuses on remote areas (Senior 2003a, Senior 2003b, Preston-Thomas, Cass et al. 2007, Burnette and Kickett 2009, Dwyer, Kelly et al. 2011, Kelly, Dwyer et al. 2011, Senior and Chenhall 2013). The scant literature on Indigenous Australians' experiences of living with a chronic diseases across a range of settings highlight that significant challenges persist in accessing culturally appropriate health services in urban as well as rural and remote regions of Australia. It is often assumed that Aboriginal people who live in urban areas have access to mainstream health care but evidence shows that Aboriginal people living in urban environments are less satisfied with their health care and experience systemic barriers to receiving treatment because of chronic disadvantage and cultural marginalisation (Houston 2004, Scrimgeour and Scrimgeour 2008).

Much of the information about chronic disease management for the Indigenous Australian population is found in the grey literature. The literature review (McMullen, Grootemaat et al. 2015) contains information about studies and projects in Indigenous chronic disease management across various parts of Australia. The table was collated from information

provided on the Australian Indigenous Health InfoNet (Australian Indigenous Health InfoNet 2015), which brings together information about studies, projects and educational material on many different areas of Indigenous health within Australia. InfoNet lists projects and studies, both current and completed, on chronic disease; which have been accessed for the purposes of this research.

It is difficult to ascertain the degree to which chronic disease programs have become more inclusive of Indigenous views, as a result of these initiatives, due to the lack of documentation of such programs. There have been some notable gains in specific areas of the NSW health system for Indigenous Australians including: 48 Hour Follow-Up program,<sup>2</sup> introduced under the Chronic Care for Aboriginal People (CCAP) program; increased employment of Aboriginal people within the health system; developing referral pathways with Aboriginal community controlled health services (ACCHSs) and working to improve Indigenous health outcomes through the Closing the Gap Strategy. The introduction and expansion of specific Aboriginal community health service models, such as the expansion of culturally appropriate models such as the Aunty Jean's Good Health Model (Aunty Jean's Program), in primary health service delivery, has contributed to improved health outcomes for Indigenous people (Curtis, Pegg et al. 2004, Williams, Curtis et al. 2004).

Aboriginal Community Controlled Health Services (ACCHS) have been integral to addressing barriers to health care for Indigenous people and communities in rural, remote and urban areas of Australia for over forty years. The current emphasis on increasing Indigenous access to mainstream services in urban areas is important, but unless it is complemented by strategies that recognise the unique needs and strengths of Indigenous communities, the limited evidence from the literature suggests the problems will continue.

## 2.2 Policy context

The wide gap in life expectancy between non-Indigenous Australians and Indigenous peoples has been widely recognised as a national issue for over a decade and efforts to address this problem through the Close the Gap Campaign first initiated by the Aboriginal and Torres Strait Islander Commissioner in 2005, have as yet, met with mixed results. The commitment by the Australian, State and Territory governments, to the Closing the Gap policy, in 2009, was a turning point in Aboriginal health. However, the Council of Australian Government's national policy response to date has failed to meet the reform targets (Australian Government 2015).

Unlike non-Indigenous Australians, who are living longer and represent an ageing population, Indigenous Australians are a predominantly youthful population with more than one-third of Indigenous people younger than 15 years of age (compared with one-fifth of non-Indigenous people) and only four percent of Indigenous people 65 years or over, compared with 14% of non-Indigenous people (Australian Bureau of Statistics 2012b). It can be expected that as the Indigenous population ages, addressing the needs of people with complex chronic conditions in this population will place an increasing burden on individuals, families and the health system.

---

<sup>2</sup> Note: This program is currently being evaluated. See <http://www.eih.health.nsw.gov.au/initiatives/48-hour-follow-up-evaluation>.

Addressing the unacceptable rates of chronic disease in the Australian Indigenous population was at the centre of Closing the Gap health policy initiatives. This in turn has led to an increased activity and priority strategies and action around the prevention and management of chronic illness at the regional level.

### **2.2.1 The national level**

At the national level, there have been various policy attempts to address improved health for Aboriginal people since the 1960s. A history of health planning and approaches in Australia confirms that between 1967 and 1995 the Commonwealth took little action to improve the health services for Aboriginal and Torres Strait Islander communities delivered through the mainstream health system (Australian Government 2013). The National Aboriginal Health Strategy, produced in 1989, was an early attempt to develop a national strategy underpinned by Indigenous understandings of the concepts of health and wellbeing, but was never fully implemented. The National Aboriginal Health Strategy Working Party defined Indigenous health as:

‘Not just the physical well-being of the individual but the social, emotional, and cultural well-being of the whole community. This is a whole-of-life view and it also included the cyclical concept of life-death-life’ (National Aboriginal Health Strategy Working Party 1989).

It was not until 2003 that the next major national policy initiative was launched. The National Strategic Framework for Aboriginal and Torres Strait Islander Health was intended to address contemporary approaches to primary health care, and other policy issues (National Aboriginal and Torres Strait Islander Health Council 2003). In addition, there have been numerous policy and framework documents developed and initiated by the Commonwealth Government to address the critical health problems affecting Indigenous Australians.

A milestone leading to the major change in national policy was the release of a report by Dr Tom Calma, the then Aboriginal and Torres Strait Islander Social Justice Commissioner (Aboriginal and Torres Strait Islander Social Justice Commissioner 2005). This report called on Australian Governments to commit to achieving health equality for Indigenous people and sparked the National Indigenous Health Equality Campaign which led to a formal launch of Close the Gap Campaign in Sydney in April 2007<sup>3</sup>. In March 2008, the Indigenous Health Equality Summit released a statement that committed the Australian Government to achieve equality of health status and life expectancy with Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians by 2030. In November 2008, the nation’s leaders committed to this policy in signing the National Indigenous Reform Agreement. COAG agreed to be accountable for the national policy delivery and appointed the COAG Reform Council to

---

<sup>3</sup> Please note that the term ‘Close the Gap’ is still used to refer to the Indigenous health campaign, a national movement led by the Australian and Torres Strait Islander Social Justice Commissioner, that aims to achieve health and life expectancy equality for Australia’s Aboriginal and Torres Strait Islander peoples. The much publicised figure of the gap in life expectancy of 17 years was later revised due to changes in the methods to calculate life expectancy by the Australian Bureau of Statistics. A more recent estimated life expectancy gap is 10.6 years lower for Aboriginal and Torres Strait Islander males (69.1 years) and 9.5 years lower for Aboriginal and Torres Strait Islander females (73.7 years), for the period 2010–2012. (AIHW 2014).

monitor progress and independently report on whether Australian governments were achieving their targets.<sup>4</sup>

The most recent policy initiative, the National Aboriginal and Torres Strait Islander Health Plan is underpinned by definitions and principles in planning and policy documents such as the social determinants of health, systemic racism, intergenerational trauma and Closing the Gap (Australian Government 2013). The implementation plan for the National Plan was recently released by the Australian Government Department of Health (Department of Health 2015). However the most recent report on the Closing the Gap initiative (Commonwealth of Australia Department of the Prime Minister and Cabinet 2016) highlights that there will be significant challenges in operationalising the Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan, which requires the work of the Primary Health Networks to achieve Aboriginal and Torres Strait Islander life expectancy equality by 2030.

### ***Chronic disease under Closing the Gap***

Improving chronic disease management and Follow-Up was one of three of the key aims of the Indigenous Chronic Disease Package (ICDP), the Australian Government's contribution to COAG National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes in 2008. (Council of Australian Governments 2008) The ICDP was progressively implemented from 1 July 2009 and the Indigenous Australians' Health Program, established in 2014, consolidated four existing funding streams including the Aboriginal and Torres Strait Islander Chronic Disease Fund which replaced the ICDP; while continuing with most of its original measures (KPMG 2014).

A national monitoring and evaluation of the ICDP was carried out between 2010 and 2016 and assessed the implementation and effectiveness of the ICDP in achieving its expected outcomes and likelihood of achieving longer term outcomes (Bailie, Griffin et al. 2013, KPMG 2014). It included a formative evaluation of sentinel sites and a more focussed evaluation of local measures and a national formative and summative evaluation. The formative evaluation of the sentinel sites for the ICDP conducted by the Menzies School of Health Research from early 2010 to mid-2013, found wide variation between sites in uptake of the various measures for improving chronic disease management and Follow-Up care.

In relation to improvements in chronic disease self-management, the authors found that a key opportunity for improvement requires models that enable effective self-management approaches (Bailie, Griffin et al. 2013). This research also found evidence that further work to achieve effective integration into the primary care or General Practice sector is needed (Bailie, Griffin et al. 2013). The final evaluation found that most components of the ICDP were successfully implemented against KPMGs Baseline (KPMG 2013a) and first monitoring (KPMG 2013b) and cited that effective collaboration between mainstream and Aboriginal and Torres Strait Islander health sectors was critical to address local implementation issues. The national Indigenous peak bodies were important in guiding the implementation. Indigenous community organisations welcomed the opportunity to develop their own, tailored 'grass roots' community strategies to address chronic disease risk factors and develop solutions.

---

<sup>4</sup> COAG subsequent adopted the use of the term 'Closing the Gap' to refers to government strategies that support the Council of Australian Governments 2008 targets.

The summary of the impacts of the ICDP upon the health system were:

- Primary health care organisations have increased capacity to provide appropriate services to Aboriginal and Torres Strait Islander people at risk of or with a chronic condition
- Some general practices are more attuned to the cultural needs and this remains a work in progress; 'there was a perception that cultural awareness training requirements within the ICDP were inadequate; the minimum training requirement was not sufficient'.
- Community organisations take a more integrated approach to preventive health and organisational leaders viewed integration as important'.
- Organisations have enhanced capacity and capability to develop and implement preventive health programs; and
- New and enhanced existing partnerships strengthened the local focus on preventive health.

Many of the impacts of the ICDP for Aboriginal and Torres Strait Islander people related to the prevention of chronic disease, which included; targeting the priority needs of Aboriginal and Torres Strait Islander people, changing ideas about the inevitability of chronic disease and individuals being better supported in their attempts to adopt healthier lifestyles. Organisations involved in the delivery of preventive health programs were cautious about suggesting that the ICDP had made definitive change and that Aboriginal and Torres Strait Islander people were making more use of services that lead to earlier identification of a chronic disease and improved assessment.

The approach taken by the ICDP to managing chronic disease was multi-faceted and included GPs applying best practice chronic disease management, a care coordination workforce to encourage greater use of health services and more culturally appropriate general practice.

The challenges identified for future policy consideration include:

- the difficulty in addressing the social determinants of health
- the capacity constraints of the care coordination workforce
- The relatively low use of the care coordination related MBS items being promoted through the Practice Incentives Program (PIP) Indigenous Health Incentive.

The evaluation recognizes the 'increasing levels of chronic disease necessitates a remodelling of modern health care systems, which are oriented to provide episodic rather than the integrated, patient centred care appropriate to chronic disease management. This type of system level change is by necessity incremental rather than transformative, and the ICDP can be viewed as an important step in that process'.

Considerations for the strengthening of chronic disease management include: to shape initiatives to directly incentivise patient outcomes, embed the key features of the ICDP, develop an integrated approach to build the capacity of individual's self-management such as chronic disease and recognise future planning through team based models of care.

### ***Funding initiatives to support improved management of chronic disease***

The Australian Government has introduced a number of funding initiatives to support improved management of chronic disease by GPs and allied health providers. These include: The enhanced primary care (EPC) programs, through which GP receive incentives to develop structured management plans for patients with chronic illnesses (GPMP) and team care arrangements (TCA) for multidisciplinary care of patients with complex needs; Medicare items for patients with team care arrangements to be funded for up to five occasions of service per year from private allied health services and, more recently, for group services; and Specific funding through the Practice Incentives Program (PIP) for practice systems and completing an 'annual cycle of care' for patients with diabetes and a series of planned visits for asthma (Harris and Zwar 2007).

The Closing the Gap PBS Co-payment Programme, implemented on 1 July 2010, was one of 14 measures in the Indigenous Chronic Disease Package (ICDP), and was established to reduce the cost of PBS medicines for eligible Aboriginal and Torres Strait Islander people living with, or at risk of, chronic disease. The Closing the Gap PBS Co-payment Programme is available to Aboriginal and/or Torres Strait Islander people of any age who present with an existing chronic disease or are at risk of chronic disease, and in the opinion of the prescriber:

- Would experience setbacks in the prevention or ongoing management of chronic disease if the person did not take the prescribed medicine; and
- Are unlikely to adhere to their medicines regimen without assistance through the program.

When obtaining PBS medicines at their local pharmacy, eligible general patients who would normally pay the full PBS co-payment (currently \$37.70 per item) pay the concessional rate (currently \$6.10 per item). Those who would normally pay the concessional price receive their PBS medicines without being required to pay a PBS co-payment (Australian Government Department of Health 2016).

#### **2.2.2 The state level**

The overall directions and strategies for health policy at the NSW state level are found within two documents: The NSW State Health Plan: Towards 2021 (NSW Government 2014a) and the NSW Rural Health Plan: Towards 2021 (NSW Government 2014b). At the NSW State level there are various health frameworks and policy documents guiding the delivery of health services for Aboriginal people in NSW. The NSW Aboriginal Health Plan 2013-2023 recognises the importance of the NSW Aboriginal Health Partnership between the NSW Government and the Aboriginal Health and Medical Research Council (AHMRC) of NSW, and the continued need for strong partnerships between NSW Local Health Districts (LHDs), Aboriginal Community Controlled Health Services (ACCHSs), Primary Health Networks, NSW government departments and not for profit organisations at the state and local level (NSW Ministry of Health 2012). Its key strategic directions include: partnerships; implementing what works and building the evidence; integrated planning and service delivery; strengthening Aboriginal workforce; providing culturally safe work environments; and strengthening performance.

There are a number of programs in NSW, some of which are described below, which have been developed to improve service delivery and health care for Aboriginal communities. Screening and Assessment is important in detecting chronic disease, given the known high burden of chronic disease in Aboriginal communities; where behaviour is linked to the onset and progression of these chronic diseases (NSW Department of Health 2010).

The NSW Integrated Care Strategy is one of the key priorities in the NSW State Health Plan: Towards 2021. This strategy involves moving from a hospital centred system focused on episodic and acute care to a system where care is connected across different health and social care providers. It emphasises preventative and, primary and community-based services to support people with long term conditions and necessarily involves working collaboratively with diverse organisations across sectors.

The Walgan Tilly Redesign Project was developed in New South Wales to address the disparities in health care and improve access to and utilisation of chronic care services for Aboriginal people in NSW. It specifically addressed four major diseases: heart disease, diabetes, chronic lung disease and kidney disease. The development of a model of care through the Walgan Tilly project is one of the key NSW responses, and commenced in 2007. There are eight fundamental elements essential to the model of care: Identification, Trust, Screening and assessment, clinical indicators, treatment, education, referral and Follow-Up. The Walgan Tilly findings consisted of six state-wide solutions:

- A model of care for Aboriginal people
- Greater Aboriginal cultural awareness and cultural sensitivity of services
- Integration of Aboriginal health and chronic disease mainstream services
- Justice Health linkages
- Improved access to primary care
- Improved data quality.

(NSW Department of Health 2010)

The Walgan Tilly model of care also requires the employment of Aboriginal health practitioners with Aboriginal Health Workers to ensure there is an integrated approach in implementing the roles and responsibilities under the NSW Aboriginal Employment Strategy.

One of the outcomes of the Walgan Tilly project was the 48 Hour Follow-Up program. This NSW wide program developed by the Chronic Care for Aboriginal People team at the Agency for Clinical Innovations (ACI) aimed to address gaps in health care and to improve access for Aboriginal people to chronic care services. The program involves following up, within two working days of discharge, Aboriginal people aged 15 years and older who are admitted to an acute care facility with a chronic disease. The Follow-Up is mostly carried out by telephone by a Chronic Care Worker, though home visiting is also an option. The program targets Aboriginal patients with selected chronic diseases (cardiovascular disease, diabetes, chronic renal and respiratory disease). Issues followed up include knowledge of and access to medications, transport and other issues around referrals and general well-being (NSW Agency for Clinical Innovation 2016).

The main goals of the project were:

- To develop practical steps and real solutions to improving access to chronic disease services for Aboriginal families and communities;
- To build working relationships between Aboriginal and chronic disease services; and

- To identify and share best practice in meeting the needs of Aboriginal people with chronic disease.

The program is currently being implemented across all Local Health Districts and over 50 facilities in NSW. The results of a preliminary evaluation conducted in 2010 by the NSW ACI, suggesting that the 48 hour telephone call may assist in reducing hospital readmission rates to 17%, led to enhancement funding for LHDs to deliver the program. The additional initiatives conducted under enhancement funding are currently being evaluated (NSW Agency for Clinical Innovation 2016). The implementation of this project was coordinated by the NSW Ministry of Health in collaboration with LHDs and stakeholders including local ACCHSs and General Practice NSW. The LHD Service Agreements include relevant indicators and strategic priorities to meet the objectives of the chronic care program (Gordon and Richards 2012 ).

The NSW CDMP, the Connecting Care Program is a chronic care program which was introduced in 2009; for people eligible in NSW aged over 16 years and who are in hospital or require support to manage their needs (NSW Health 2015). The Program aims to reduce the progression and complications of chronic disease, improve the quality of life of people with chronic diseases, to support carers and families. It also aims to reduce unplanned and avoidable admissions to hospitals and improve the health systems capacity to meet the needs of eligible Aboriginal people in NSW (Gordon and Richards 2012 ). In addition to programs there a range of rehabilitation services available for Aboriginal people.

The NSW Rehabilitation Model of Care describes six care settings which underpin service delivery: in-reach to acute care, inpatient subacute, day hospital, outpatients, home based and outreach rehabilitation. The Model outlines eight guiding principles and enablers for rehabilitation services. A patient may be considered ready for rehabilitation but not meet the admission criteria. 'Ready for rehabilitation' is focussed on the patient's needs and suitability for rehabilitation; and dependent on the care setting and capability of the service. 'Ready for rehabilitation' is based on the clinical judgement of doctors and health professionals and there are no agreed objective criteria for defining 'ready for rehabilitation' (NSW Health Rehabilitation Redesign Project 2015).

In 2011 the NSW Ministry of Health, Local Health Districts and other NSW Health Organisations introduced a mandatory training policy, entitled 'Respecting the Difference', which sets out cultural training requirements for all staff that equips staff to meet the particular needs of Aboriginal people. The training aims to deliver culturally competent and more respectful, responsive and culturally sensitive services for Aboriginal families and communities; guided by Respecting the Difference: An Aboriginal Cultural Training Framework for NSW Health. The evaluation of Respecting the Difference is due to be reviewed in 2016.

The NSW Ministry of Health Aboriginal Health Impact Statement guides policy and program design which may impact on Aboriginal people. It mandates that proper consultation should occur in the developmental phase and that potential effects on the policy on the Aboriginal community need to be identified. It also directs that any new policy or program should be aligns with broader policies and strategic direction and the resource implication should also be considered (Wheeler 2005).

At a broader level, the NSW Government has a plan for Aboriginal Affairs: Opportunity, choice, Healing, Responsibility, Empowerment (OCHRE) which includes an Aboriginal community

governance initiative known as Local Decision Making (LDM). LDM recognises the need for a localised and flexible place-based approach to service delivery in NSW Aboriginal communities. The overall coordination of LDM is through Aboriginal Affairs (NSW Government 2015).

### **2.2.3 The Illawarra Shoalhaven Local Health District**

The Illawarra Shoalhaven Local Health District was formed in January 2011. It extends from Helensburgh in the north to North Durras in the south, a coastal strip of around 205 kilometres. The ISLHD services a population of around 390,000 residents (NSW Government 2016). An important strategic document guiding the work of the ISLHD includes the Health Literacy Framework 2012-2015 which is underpinned by five key principles for becoming a health literate organisation and enables the health service to be responsive to patient, carer and consumer needs. The ISLHD Vision: 'Our Statement of Strategic Intent' outlines the commitment to achieve health outcomes; provide greater patient involvement and to deliver world-class health care.

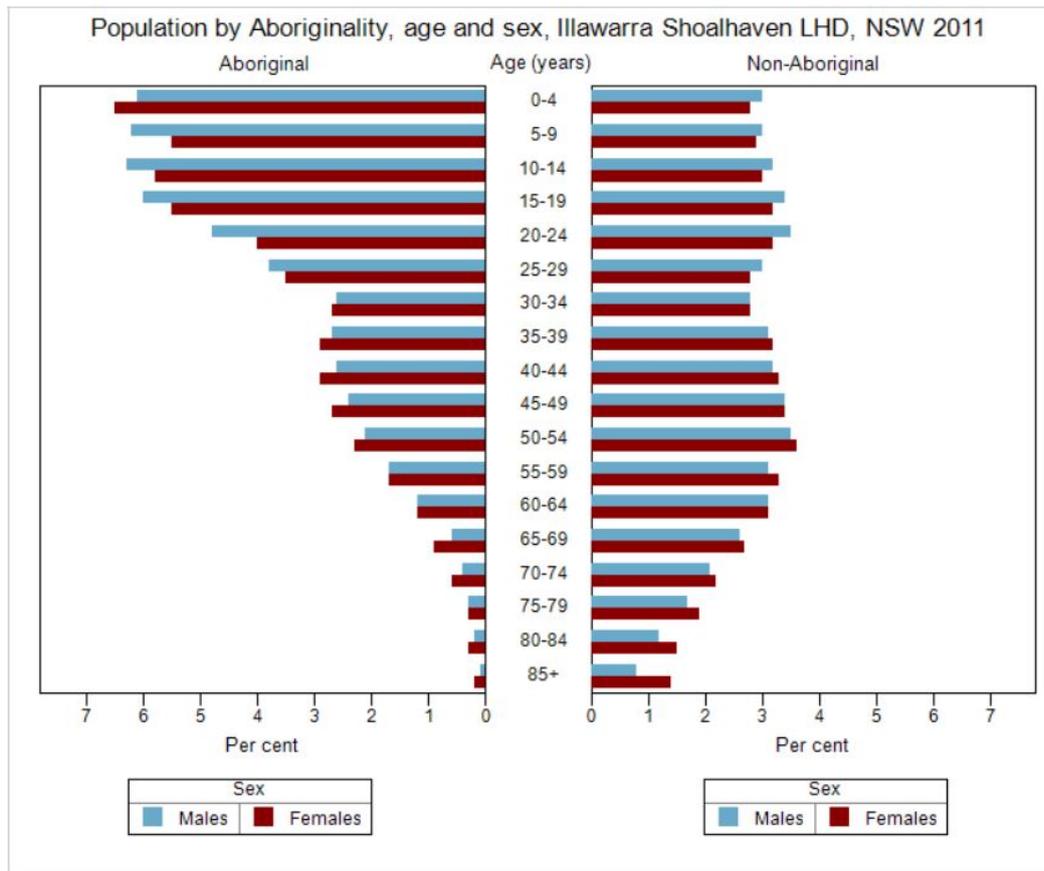
The strategic direction of the ISLHD aligns with the NSW Government policies and is described in the ISLHD Health Care Services Plan 2012 – 2022, Working Together Building Healthy Futures. Strategies include the reduction of potentially preventable hospitalisations for Aboriginal people, on improving access to health services for Aboriginal people with chronic disease and to develop new models of health care that better support Aboriginal people.

## **2.3 The regional context**

There are approximately 10,763 Aboriginal people in the Illawarra and Shoalhaven regions which encompass the Local Government Areas (LGAs) of Wollongong, Shellharbour, Kiama and Shoalhaven. This constitutes 2.9% of the total population. Sixty per cent of Aboriginal residents, around 6,445 people, live in the Illawarra region; while 40%, around 4,318 people, live in the Shoalhaven. The Socio-Economic Indexes for Areas (SEIFA) has been developed by the Australian Bureau of Statistics and enables statisticians to rank areas in Australia according to relative socio-economic advantage and disadvantage. The Indexes are based on information from the five-yearly Census (Australian Bureau of Statistics 2006). Based on the 2011 Census information and the SEIFA index, 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, lower incomes and where children and young people typically experience poorer educational outcomes as well as significantly worse health outcomes and poorer access to services (Besnard 2010).

Aboriginal and Torres Strait Islander communities are typically 'young' populations and this is also the case in the Illawarra and Shoalhaven regions. As illustrated in Figure 1 below, 37% of Aboriginal ISLHD residents are under 15 years of age, compared with 19% of non-Aboriginal residents. Persons aged 65 years and over comprised four percent of the Aboriginal population and 18% of the non-Aboriginal population.

**Figure 1 Aboriginal and non-Aboriginal Population compared**



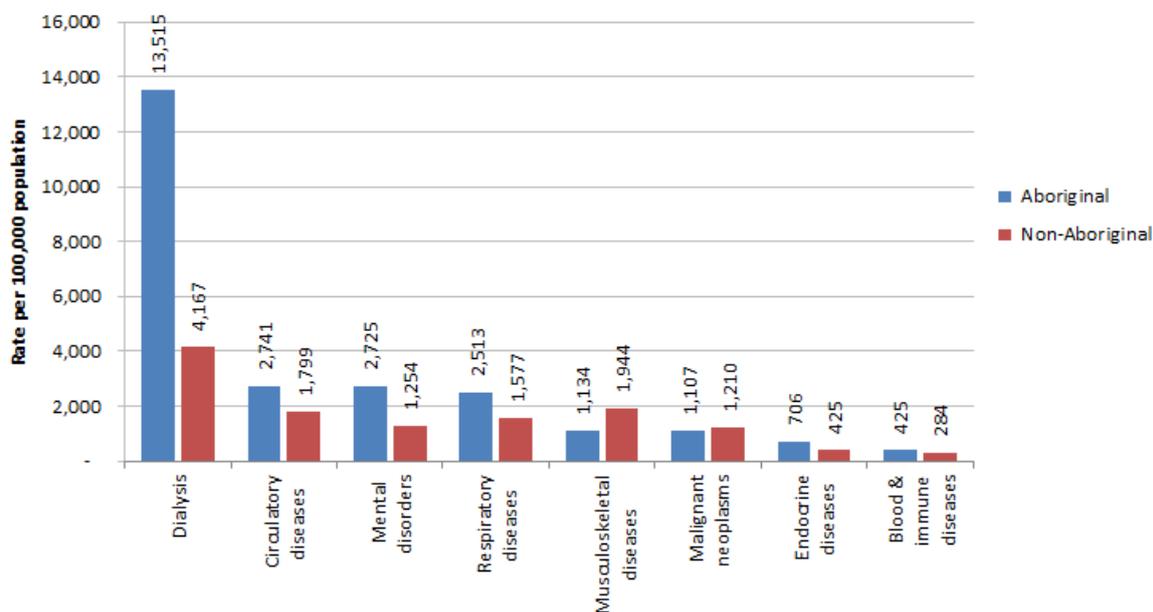
Source: Based on population estimates developed by Prometheus Information Pty (SAPHaRI). Centre for Epidemiology and Evidence, NSW Ministry of Health.

As with other parts of Australia, there are significant differences between Aboriginal and non-Aboriginal access to health services which are evident in the patterns of hospital admissions of Aboriginal compared to non-Aboriginal people in the Illawarra and Shoalhaven regions. The health status of regional Aboriginal people mirrors that of the broader national Indigenous population and is typified by high levels of chronic illness experienced at an earlier age.

### 2.3.1 Hospitalisation due to chronic conditions

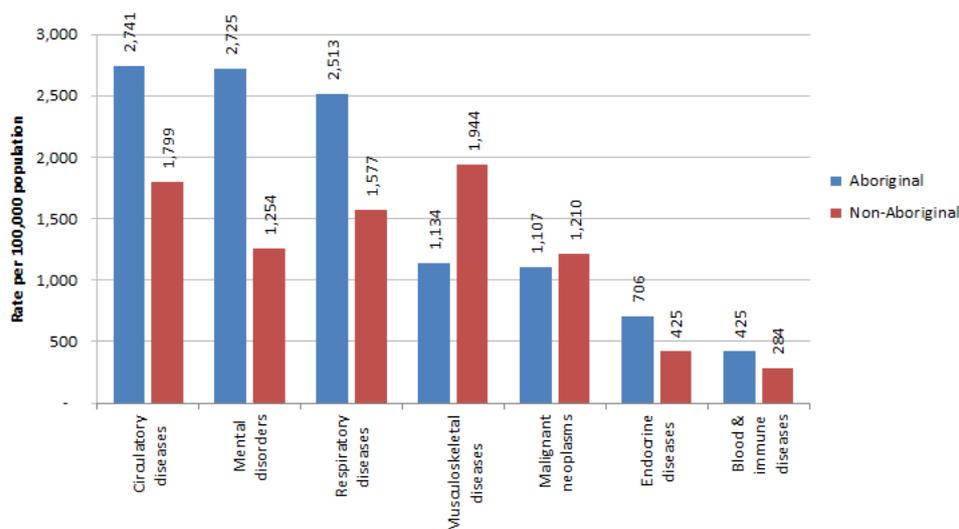
This section provides an overview of the patterns of hospitalisation due to chronic conditions. More detailed information is available from the NSW Health Statistics website (<http://www.health.nsw.gov.au/hsnsw/pages/default.aspx>). Figure 2 below shows that, for the period 2013-14, the leading causes of hospitalisation for chronic conditions for Aboriginal people in the Illawarra Shoalhaven LHD were dialysis, circulatory diseases, mental disorders, respiratory diseases, musculoskeletal diseases, malignant neoplasms, endocrine diseases and blood and immune diseases. Figure 3 illustrates the same causes but excludes dialysis.

**Figure 2 Cause of Hospitalisations by Aboriginality Illawarra Shoalhaven LHD 2013-14 (excluding non-chronic causes)**



Source: Centre for Epidemiology and Evidence. Health Statistics New South Wales. Sydney: NSW Ministry of Health. Available at: [www.healthstats.nsw.gov.au](http://www.healthstats.nsw.gov.au) Accessed 15 June 2016.

**Figure 3 Cause of Hospitalisations by Aboriginality Illawarra Shoalhaven LHD 2013-14 (excluding non-chronic causes and dialysis)**



Source: Centre for Epidemiology and Evidence. Health Statistics New South Wales. Sydney: NSW Ministry of Health. Available at: [www.healthstats.nsw.gov.au](http://www.healthstats.nsw.gov.au) Accessed 15 June 2016.

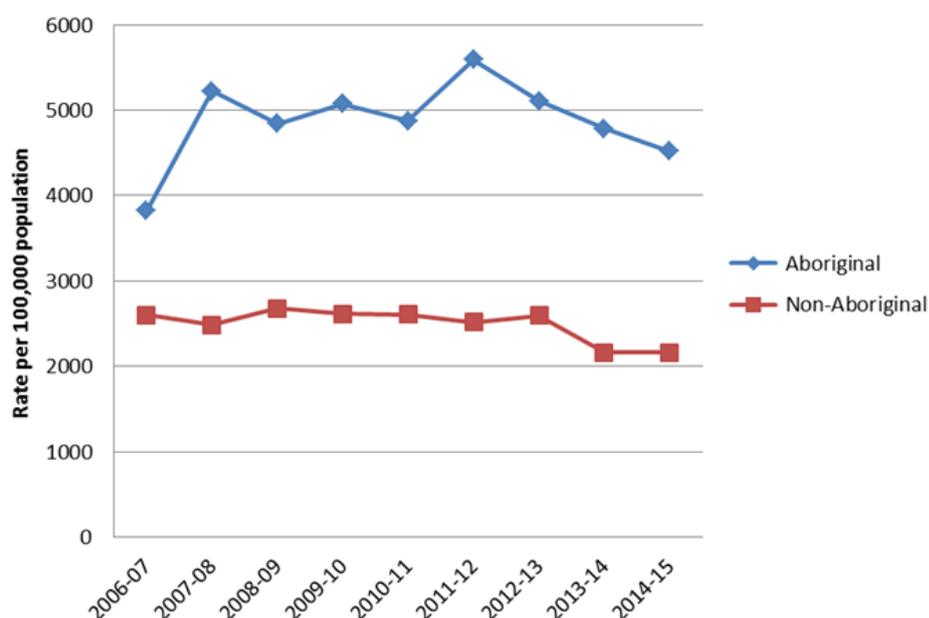
### 2.3.2 Potentially preventable hospitalisations

Potentially preventable hospitalisations are hospital admissions that could have been avoided by providing appropriate preventive care or early medical treatment in primary health-care

settings, including both acute and chronic conditions. Figure 4 below, shows that within the ISLHD Aboriginal people have a much higher rate of potentially preventable hospitalisations than non-Aboriginal people overall; in 2014-2015 this rate for Aboriginal people was more than double the rate recorded for non-Aboriginal people in the ISLHD. The rate of potentially preventable hospitalisations for chronic disease alone, for Aboriginal people, was also twice that of non-Aboriginal people. Moreover, the rate of increase in the potentially preventable hospitalisations for Aboriginal people has been much larger than for non-Aboriginal people within the ISLHD. The data in Figure 5 suggests that the increase in potentially preventable hospitalisations for chronic conditions, for Aboriginal people, is a state-wide problem.

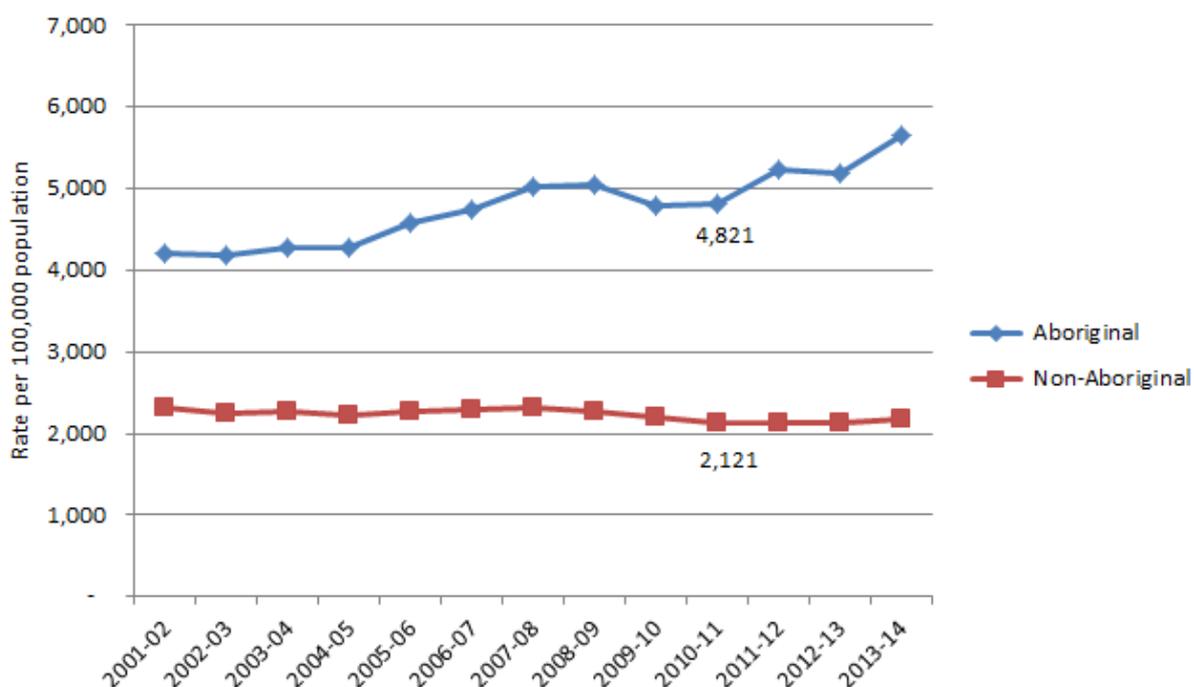
It should be noted that trend data needs to be interpreted with caution due to the under-reporting or identification of Aboriginal and Torres Strait Islander people in administrative data sets. This issue has been the focus of data quality improvements over the past ten years (Australian Institute of Health and Welfare 2005, Australian Institute of Health and Welfare 2010, Centre for Epidemiology and Evidence 2012).

**Figure 4 Potentially preventable hospitalisations by Aboriginality, ISLHD, 2006-07 to 2014-15**



Source: Centre for Epidemiology and Evidence. Health Statistics New South Wales. Sydney: NSW Ministry of Health. Available at: [www.healthstats.nsw.gov.au](http://www.healthstats.nsw.gov.au) Accessed 22 June 2016.

**Figure 5 Potentially preventable hospitalisations by Aboriginality, all LHDs, 2001-02 to 2013-14**



Source: Centre for Epidemiology and Evidence. Health Statistics New South Wales. Sydney: NSW Ministry of Health. Available at: [www.healthstats.nsw.gov.au](http://www.healthstats.nsw.gov.au) Accessed 15 June 2016.

### 2.3.3 Unplanned hospital readmissions within 28 days

An unplanned hospital readmission is defined as a readmission within 28 days of discharge from the first admission to the same facility, which was not planned. It is an indicator of the quality and continuity of care provided to patients while in hospital and in the weeks following discharge. (van Walvaren, Bennett et al. 2011) Unplanned readmissions within 28 days, and discharge against medical advice from inpatient care, are indicators of the quality of care provided to Aboriginal people while inpatients in hospital and are used as a measure of the cultural competence of the health service (Betancourt, Green et al. 2003).

In NSW in 2010–11, unplanned readmissions within 28 days occurred in 8.1% of all admissions for Aboriginal people, and 6.3% of all admissions for non-Aboriginal people. This difference was significant, with Aboriginal people 1.3 times more likely to have an unplanned readmission. There has been no significant change in the rate of unplanned admissions for Aboriginal people over the past 10 years, and no significant change in the difference in rates between Aboriginal and non-Aboriginal people (Centre for Epidemiology and Evidence 2012).

The higher proportion of unplanned hospital admissions within 28 days among Aboriginal people in 2010 resulted in 711 additional readmissions that needed to be avoided through appropriate out of hospital care and support in order for rates to be the same between Aboriginal and non-Aboriginal people.

The five Local Health Districts with the highest proportion of unplanned readmissions within 28 days for Aboriginal people were Southern NSW (13.2%), Mid North Coast (11.0%), Illawarra

Shoalhaven (9.8%), Western NSW (8.4%) and Sydney (8.3%).(Centre for Epidemiology and Evidence 2012)

### 2.3.4 Services available to Aboriginal people with chronic condition

There are a sizeable number and range of 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, the larger concentration of services programs in the Illawarra region provides relatively fewer health service choices available to residents in the Shoalhaven region.

The services can be broadly categorised into Indigenous specific health services and mainstream services; the latter includes diverse services that do not specifically target Aboriginal people and include fee for service private general practices and government-run services (Aboriginal Health & Medical Research Council 2015). It is important to note that there are important differences between these organisations which need to be taken into account when making comparisons between services.

Table 1 below lists some of the broad range of organisations, services and programs in the Illawarra and Shoalhaven regions involved in the treatment and management of chronic diseases and/or the provision of social and support services. Services and programs are delivered by a broad range of mainstream and Aboriginal organisations, including government, non-government organisations and private businesses. Most involve collaboration or referral networks of some sort and a small number of programs are delivered by a consortium of more than one organisation. The ISLHD is the largest provider of health services in the two regions. The list of services provided below therefore is by no means exhaustive; it represents the key services identified as important by either the Steering Committee for the research project or those referred to by participants in the research.

Further details of the Aboriginal specific service or program and the organisations that operate them are found in Appendix 1 of this report.

**Table 1 Services and Programs**

Name of organisation	Activities relevant to chronic disease	Aboriginal specific service or program <sup>5</sup>
ISLHD	Hospital admitted patients	
	Emergency Department	
	Social Work	Aboriginal Hospital Liaison Officers
	Cardiac Rehabilitation and Heart Failure Service	
	Respiratory Service	
	Renal Unit	
	Allied health Services	
	Illawarra Drug and Alcohol Service	Aboriginal drug and alcohol workers

<sup>5</sup> Note: The Programs in italics in Table 1 are included in the Program design review.

Name of organisation	Activities relevant to chronic disease	Aboriginal specific service or program <sup>5</sup>
	Health Promotion	Quit 4 New Life Program
	Cancer support team	
	Community Mental Health	Aboriginal mental health workers
	Ambulatory and Primary Health Care	Aboriginal Chronic Care Unit 48 Hour Follow-Up <i>Aunty Jeans Program</i> <i>Aqua program</i>
	ISLHD Diabetes Service	Outreach clinic to IAMS
<b>Medical specialists</b>	Medical Specialists (including Respiratory, Cardiovascular Renal, Endocrine, Ophthalmology)	
<b>Pharmacies</b>	Pharmacists	Closing the Gap –Pharmaceutical Benefits Scheme Co-payment Programme, Health Incentive under the Practice Incentives Programme (PIP)
<b>Private allied health services</b>	Allied health professionals (including physiotherapists, podiatrists)	Closing the Gap provision
<b>Private General Practice clinics</b>	General practitioners Practice nurses Allied health professionals Diagnostic services	Aboriginal health practitioners
<b>Grand Pacific Health</b>	Coordinating Care	<i>Care Coordination and Supplementary Services (CCSS)</i> Outreach health workers - Closing the Gap
<b>Heart Foundation</b>		<i>Koori Cook Off</i>
<b>Diabetes NSW</b>	Diabetes educators	Provision of diabetes education sessions to Aboriginal groups and organisations
<b>Illawarra Aboriginal Medical Service</b>		Aboriginal Community Controlled Health Service General practitioners Diabetes Educator <i>Chronic Disease Management program</i> <i>(Aboriginal Chronic Disease Worker)</i> Counselling and other services
<b>South Coast Aboriginal Medical Service Aboriginal Corporation</b>		Aboriginal Community Controlled Health Service Aboriginal Men’s Health Group <i>Care Coordination and Supplementary Services (CCSS)</i>
<b>Waminda: South Coast Women's Health and Welfare</b>		Aboriginal Community Controlled Health Service

Name of organisation	Activities relevant to chronic disease	Aboriginal specific service or program <sup>5</sup>
<b>Aboriginal Corporation</b>		Chronic Disease Management Program ( <i>Dead or Deadly</i> )
<b>Illawarra Koori Men's Support Group</b>		<i>IAMPHAT (Illawarra Aboriginal Men's Physical Health And Training)</i>
<b>Weja Aboriginal Home Care</b>		Aboriginal home care services
<b>Coomaditchie Hub</b>		Referral, advice and advocacy
<b>Illawarra Aboriginal Corporation and Keeping Place</b>		Aboriginal home care services Seniors packages for Aboriginal people
<b>Consortium (ISLHD, GPH, IAMS)</b>		<i>Koori Knock Out</i>

As discussed in the previous section on policy context, Aboriginal health programs and services have long been developed in order to address the specific cultural, political, social and health needs of the Aboriginal population. There are well established frameworks which provide guidance for organisations to be able to respond to the needs of their Aboriginal communities in an appropriate manner.

The NSW Ministry of Health have had numerous strategies over the past 20 years to address chronic disease within the Aboriginal community. As stated, these strategies aim to improve access for Aboriginal people by having a more culturally responsive health system and one which engages effectively with community and take a systems perspective to how Local Health Districts can meet the needs of Aboriginal people (Wheeler 2005). There have been various frameworks designed to guide Aboriginal chronic disease programs, including the NSW Aboriginal Chronic Disease Area Health Service Standards, Walgan Tilly, Audit and Best Practice Chronic Disease and the Aboriginal Health Impact Statement (Wheeler 2005, Gordon and Richards 2012 ).

However, while these frameworks exist, they are not always applied effectively within the government sector or considered in other health sectors. The Aboriginal health services and programs which have been developed to target chronic disease amongst Aboriginal people within the Illawarra and Shoalhaven regions are further explored in the program design review conducted as part of this research.

## **3 Methods and Approach**

### **3.1 Addressing the aims and objectives of the research**

The aim of the research was to explore the factors that impact on Aboriginal people's experience of chronic conditions and its management in order to inform improvements in care planning across the care continuum. There were four key objectives which were addressed as follows:

1. To describe the extent and type of chronic disease in the Aboriginal population in the Illawarra and Shoalhaven regions, we conducted a targeted review of the literature including peer reviewed journal articles, books and 'grey' literature (McMullen, Grootemaat et al. 2015).
2. To document formal chronic disease management models of care for Aboriginal patients across NSW, we conducted a program design review, involving a desk review of published guidelines for Aboriginal chronic disease models of care and conducted interviews with the managers of programs operating in the ISLHD;
3. To explore and document Aboriginal people's experiences of chronic disease management, we conducted qualitative interviews and focus group discussions with Aboriginal people managing chronic illness in the community.
4. To identify the strengths and weaknesses of current chronic disease management for Aboriginal people, we conducted qualitative interviews with service providers and systems stakeholder.

### **3.2 Indigenous research approach**

The overarching framework for the study was an Indigenous research approach, which is underlined by the principles of self-determination, social justice and Indigenous protocols and world views. This approach includes Aboriginal leadership and partnerships, ethical practice which is responsive to the priorities of local communities and is methodologically rigorous (Henry, Dunbar et al. 2002). Two of the chief investigators and the three project managers were Aboriginal people who provided leadership and input into the design and implementation of the research. A qualitative approach was regarded as most likely to yield rich descriptive data which provides insights into the way in which Aboriginal people in the region experience and make meaning of their journey through the health system.

### **3.3 Data sources and data collection processes**

The study commenced with the setting up of the research steering committee, consultation with local Aboriginal communities and the development of data collection instruments and ethical protocols. Initial research activities included conducting a literature review; conducting preliminary stakeholder consultation with service providers and mapping regional programs and services.

Information about Aboriginal experiences of the health system was sought from Aboriginal community members in two ways: individual interviews with Aboriginal people with a chronic illness who had recent hospital experience; and focus group discussions with Aboriginal people in the community who had experience of living with or caring for someone with a chronic illness. Similarly, we sought to obtain information from service providers, program managers

and system stakeholders from across a broad range of health professionals, organisations and sectors, in order to obtain a wide range of views.

Data was collected in two stages. Stage one, which took place throughout 2015, included interviews with program managers, service providers, system stakeholders and focus group discussions with Aboriginal community members. Stage two involved interviews with Aboriginal people with chronic condition; it commenced towards the end of 2015 and continued until mid-February 2016. A total of 56 participants (64%) in the research identified as Aboriginal people. Table 2 below summarises the qualitative data were collected and analysed for the study.

**Table 2 Data collection**

<b>Data collection method</b>	<b>No. of sessions/ models</b>	<b>No. of Participants</b>
Review of guidelines for Aboriginal models of care	8	
<b>Semi-structured interviews</b>	61	
Aboriginal clients <sup>6</sup> with a chronic condition and recent hospital experience		22
Health service providers from a broad range of organisations and professions		22
System stakeholders from key Illawarra and Shoalhaven organisations		8
Managers of Aboriginal Chronic Disease Management Programs		9
<b>Focus group discussions with Aboriginal community members</b>	4	27
<b>Total</b>		88

## 3.4 Selection and recruitment of participants

### 3.4.1 Aboriginal client interviews

The recruitment strategy for Aboriginal clients was intended to maximise the participation of Aboriginal people from a variety of settings, which go beyond the existing programs for people with chronic conditions. A number of changes were made to the method of recruitment and the conduct of the individual interviews with Aboriginal clients over the course of the study. The recruitment of clients for the individual interviews was originally intended to take place through the ARC team (Access and Referral Centre) 48 Hour Follow-Up Program. This method of recruitment, however, was not successful as it was found that few of the clients contacted expressed an interest in talking to a researcher and no interviews were able to be scheduled. This was likely due to the timing of the call so soon after discharge from hospital when clients were still quite ill.

On the advice of the Steering Committee ethical approval was sought to vary the method of recruitment. The research team subsequently sought assistance from the Grand Pacific Health (GPH) Aboriginal Closing the Gap Officer and the Manager of Aboriginal Health from the Chronic Care Unit within the Local Health District. The support and assistance from these two

<sup>6</sup> Aboriginal interviewees are referred to as 'clients' to distinguish them from focus group participants.

groups was crucial to the successful recruitment of Aboriginal people for stage two of the research. Most importantly they were able to draw on their existing professional relationships to make contact with the clients with one or more chronic conditions and who had been recently hospitalised. They were also able to explain the purpose of the research to prospective research participants, and invite them to have their contact details forwarded to an Aboriginal researcher who provided further information about the project and obtained formal consent for the interview.

### **3.4.2 Focus group participants**

Purposive sampling was used to select and recruit Aboriginal participants in the focus groups. In collaboration with the ISLHD, IAMS and GPH a recruitment strategy for the focus groups was developed to maximise the participation of a diverse range of Aboriginal people from a variety of settings, including those who are not currently participating in programs for Aboriginal people with chronic conditions, in both mixed and gender specific groups. Broad criterion for participation in the focus groups enabled the inclusion of Aboriginal people in the community who were living with, or caring for a person with a chronic condition(s), but who may or may not have been recently, or ever, hospitalised for their condition.

Researchers sought the assistance and advice of staff at organisations that had regular support groups. Coomaditchie United Aboriginal Corporation, the Illawarra Koori Men's Support Group (IKMSG), South Coast Medical Service Aboriginal Corporation (SCMSAC), Waminda South Coast Women's Health and Welfare Aboriginal Corporation (Waminda) and the Illawarra Aboriginal Medical Service (IAMS) agreed to assist with the focus groups. Additional focus groups were planned but not conducted due to recruitment problems. The focus groups were facilitated by Aboriginal members of the research team.

### **3.4.3 Service providers**

Service providers providing care and support to the local Aboriginal community were invited to undertake a face to face semi structured interview of 45 to 60 minutes. The purpose of the interview was to gain an understanding of the experience and perspectives of service providers about chronic disease management in the local Aboriginal population.

Service providers represented a range of health care professionals who are engaged in providing health services and health education for Aboriginal people managing a chronic illness across a range of providers such as community-controlled organisations, clinical consultants, hospitals, general practitioners, and specialist services.

Potential participants were identified by their professional involvement with services and support systems for Aboriginal people with chronic disease in the ISLHD. This was achieved by an initial scoping of services via internet and directory searches of publicly available information and with the assistance of the Steering Committee who were able to provide the research team the names and contact details of relevant service providers.

The interviews conducted were semi-structured and included questions on their experiences in managing Aboriginal people with a chronic illness, positive ways to support Aboriginal people manage their illness, the referral process for services, and the keys to achieving appropriate health services for Aboriginal people (See Appendix 2 for the interview schedule).

#### **3.4.4 System stakeholders**

In addition to program managers, service providers and Aboriginal users of health services, the researchers sought information from a number of key individuals experienced in the provision of health services to Aboriginal people within the local region. These people have been referred to as 'system stakeholders'.

The system stakeholder participants were drawn from a diverse range of health care professionals; the majority had direct experience in working with Aboriginal people with chronic conditions. The interviews provide information regarding the delivery of services and/or programs that are available to Aboriginal people following discharge from hospital; and assess the efficiency of current support systems and identify gaps in support for Aboriginal patients with chronic diseases.

Semi-structured interviews focused on the models of care in managing chronic disease with Aboriginal people, the systems in place for health care providers within the Illawarra and Shoalhaven and systems for Aboriginal people to self-manage their illness, perspectives on the integration of care, the barriers and facilitators in accessing care and specialist programs.

#### **3.4.5 Program managers**

Semi-structured interviews were conducted with key organisation informants, usually program managers, to provide insight into whether guidelines and programs meet the aims and objectives essential for the support of Aboriginal people managing chronic conditions. The interviews focused on the design, operations and cultural capability of programs and services. This included, for example, the operation of the programs; the cultural appropriateness of the services and programs; and to identify if they are effective, accessible, acceptable, and appropriate to Aboriginal people within the region. These were analysed using grounded theory to enable an inductive process for determining themes (Glaser and Strauss 1967). The findings from the qualitative research are compared to Aboriginal health program theory. This is aimed at ascertaining the strengths and gaps in the current design of Aboriginal chronic disease programs in the Illawarra and Shoalhaven as they occur across the various sectors. The questions, which can be found in Appendix 2, are based on realist review analysis methodology which investigates program design and outcomes (Pawson and Bellamy 2006).

### **3.5 Program design review**

Based on the understanding that improvements to the Aboriginal patient journey within the ISLHD requires a systems approach to improve the quality of services delivered to the Aboriginal community, a program design review was undertaken to understand how Aboriginal health programs are established within organisations based on Aboriginal health program theory. The fundamental question was 'are programs and services in the Illawarra and Shoalhaven developed and do they function in the way in which Aboriginal health program theory is intended to function to meet their intended outcomes' (Pawson, Greenhalgh et al. 2004).

### **3.6 Data analysis**

Qualitative data analysis is an ongoing, iterative process that begins in the early stages of data collection and continues throughout the study (Bradley, Curry et al. 2007). The analysis of the qualitative data was facilitated by the use of NVivo software (QSR International Pty Ltd 2012) to

generate nodes and identify patterns within and across the data. Individual interview and focus group transcripts were imported into NVivo, classified by source (for example, interview or focus group) and by case (for example individuals by gender, Aboriginality, region, chronic condition) and coded.

Auto coding was used to group answers to the specific interview questions asked of each participant group; further manual coding was employed to refine these categories. The focus groups were coded and analysed thematically. Interview transcripts were also coded thematically to allow for an inductive process of emergent concepts and ideas. Constant comparison was used to further refine, analyse and re-code according to the themes emerging.

Framework analysis was then employed to analyse the auto-coded interviews to provide systematic and visible stages to the analysis process (Ritchie and Spencer 1994). For the thematic analysis, emerging themes were identified separately in the first instance for each participant group to allow comparison across different groups; some of these themes were later combined for all or some participant groups.

For the program design review the semi-structured interviews were conducted with key organisation informants (program managers) and were analysed using grounded theory to enable an inductive process for determining themes (Glaser and Strauss 1967). The findings from the qualitative research were then compared to Aboriginal health program theory in order to ascertain the strengths and gaps in the current design of Aboriginal chronic disease programs in the Illawarra and Shoalhaven as they occur across the various sectors.

### **3.7 Ethical issues and approvals**

Each stage of the research was approved from the University of Wollongong Health and Medical Human Research Ethics Committee (HE14/474; HE15/059), the ISLHD Research Directorate and the Aboriginal Health and Medical Research Council of NSW (Ref:1060/14 1067/15).

The research was guided by the guidelines and principles developed for Aboriginal health research (National Health and Medical Research Council 2003, Aboriginal Health and Medical Research Council 2013) to ensure the research benefits Aboriginal communities in the spirit and integrity of those principles. In keeping with those principles we initiated and maintained regular communication with relevant Aboriginal communities in the region on the progress of the health research project. The project was approved by the IAMS, the SCMSAC and the Waminda: South Coast Women's Health and Welfare Aboriginal Corporation (Waminda), with letters of support provided from those organisations.

Cultural sensitivity has underpinned the project. A community report and final report will be disseminated to the community. The Aboriginal Research Team has ensured reciprocity at the broader community level in developing a dissemination plan at the outset to ensure that local Aboriginal communities and the ACCHSs received regular communications on the progress of the research. Training and support were provided for the Aboriginal researchers working on each stage of the research project.

All participants were provided with a written Participant Information Statement (PIS) and their written consent obtained. Participants were advised that they can withdraw their data from the

research project at any time by contacting any member of the research team. Some of the interviews were conducted by non-Aboriginal researchers however Aboriginal researchers were available to explain the PIS and answer any questions the participants might have to ensure full, prior and voluntary consent. Interview transcripts were returned to each of the participants to enable them to review the comments they had made and make any changes. The consent form for the focus groups included three optional boxes in which participants could indicate whether they wished to take part in a focus group, whether they agreed to have the focus group audio-recorded and whether they sought to review the transcript of the interview. The voluntary nature of their participation in the group, and their ability to withdraw at any time, was explained by the facilitator at the commencement of the group discussion. Participants in the individual interviews and focus groups were provided with vouchers to compensate for their time.

### **3.8 Governance**

A Steering Committee consisting of members of the research team and ISLHD personnel was formed in the early stages of the research to provide oversight and guidance throughout the research period. Six of the Steering Committee members were Aboriginal people (See Appendix 4). The Steering Committee played an important part in the research process by reviewing and providing input into data collection tools, identifying potential stakeholders for the interviews, assisting with the recruitment of service providers and identifying the processes for the recruitment of Aboriginal clients recently discharged from hospital. Committee members provided practical and ongoing feedback on direction of the data collection processes and reviewed draft reports.

### **3.9 Strengths and limitations of the study**

One of the strengths of the qualitative research design used in this study is that it enabled each of the key questions of interest to be examined in detail and in depth in addition to allowing for emerging themes to be identified and explored; participants were afforded ample opportunity to relay their personal experiences and insights, and to both raise concerns and express support for the health services they used. The flexibility of the qualitative design also allowed for comparison across the different participant groups. Although the study relied primarily on data from interviews and focus group discussions, the data collection took place in naturalistic settings, in the community, in health services, at meetings where people usually gather for a health program, and in peoples' homes. This provided a valuable opportunity for the research team to observe individuals and their interactions with others which provided important context for the interpretation of interviews and focus group data. The direct quotes from participants, used extensively throughout the report, are a powerful way of giving voice to individuals, in a way that is not possible in studies which rely on quantitative data.

The limitations of the study, as with any qualitative study, include that data were collected from a relatively small number of individual participants. Although the findings are not generalisable to a larger population, many aspects of the study area are transferable to other settings. The selection of participants was designed to reflect a broad range of experience, views and perspectives, rather than a representative sample. Also typically qualitative findings do not have the predictive power of larger quantitative studies.

## 4 Experiencing the system: Aboriginal perspectives

This section presents the results of the qualitative data collection. It is organised into three main sub-sections. Section 4.1 presents the findings from the individual interviews with Aboriginal clients<sup>7</sup> and the focus group discussions and is organised by presenting the findings around each of the key questions of interest. Section 4.2 presents the views of service providers and systems stakeholders. Section 4.3 provides a review of Aboriginal chronic disease programs and is based on the interviews with program managers. Summaries of the key findings are found at the end of each of the sub sections.

### 4.1 Interviews with Aboriginal clients

All of the Aboriginal client interviewees were with people who had more chronic condition and had been recently admitted to one of the major hospitals within the Local Health District (for any cause). A total of 29 Aboriginal community members initially agreed to be contacted by a researcher for an individual interview. Thirteen of these responded to an invitation from GPH and 16 people responded to an invitation from the Local Health District. From the initial respondents seven were unable to participate due to various reasons. The recruitment strategy resulted in 22 Aboriginal community members consenting to an individual interview. A single interview of up to one hour was conducted with the Aboriginal clients who consented. The interviews were either held face to face or by telephone. The locations included ACCHSs or the person's home when that was more convenient. Table 3 below summarises how the interviews were conducted.

**Table 3** Location of individual client interviews

Place of interview	Number of interviews
Face to face interview at clients home	9
Face to face visit at ACCHS	4
Phone interview	9
<b>Total interviews conducted</b>	<b>22</b>

Further details about the individual interviewees are provided in Table 4 Individual Interview Participants (Clients) below, which uses the following descriptive categories:

Region: Illawarra or Shoalhaven  
 Age groupings: 18-24; 25-34; 35-44; 45-54; 55-64; 65 and over  
 Aboriginal: Yes or no  
 Gender: Male or female  
 Chronic Condition 1: Respiratory, diabetes, CVD, renal, multiple conditions,  
 Other condition: Cancer, injury

<sup>7</sup> Aboriginal interviewees are referred to as 'clients' to distinguish them from focus group participants. Both clients and focus group participants are referred to more generally as 'Aboriginal community members'.

**Table 4 Individual Interview Participants (Clients)**

Region	Gender	Aboriginal or TSI	Age Group	Chronic Condition	Other condition	Recent hospitalisation
Illawarra	Female	Aboriginal	65 and over	Respiratory	Other chronic condition	Multiple visits last 12 months
Illawarra	Female	Aboriginal	55-64	Respiratory	Other chronic condition	Not specified
Illawarra	Female	Aboriginal	65 and over	Respiratory	Other chronic condition	Last 3 months
Illawarra	Female	Aboriginal	65 and over	Other condition	Not Applicable	Last 3 months
Illawarra	Female	Aboriginal	65 and over	Respiratory	Other chronic condition	Multiple visits last 6 months
Illawarra	Male	Aboriginal	65 and over	Diabetes	Other chronic condition	Last 6 months
Illawarra	Female	Aboriginal	65 and over	Respiratory	Injury	Last 3 months
Illawarra	Female	Aboriginal	65 and over	Diabetes	Cancer	Last 3 months
Illawarra	Female	Aboriginal	65 and over	Respiratory	Injury	Last 3 months
Illawarra	Male	Aboriginal	55-64	Diabetes	Other chronic condition	Last 6 months
Illawarra	Female	Aboriginal	65 and over	Diabetes	Not Applicable	Last 3 months
Shoalhaven	Male	Aboriginal	55-64	Diabetes	Injury	Last 3 months
Illawarra	Male	Aboriginal	55-64	CVD	Not Applicable	Last 36 months
Shoalhaven	Male	Aboriginal	55-64	Diabetes	Injury	Not specified
Illawarra	Male	Aboriginal	65 and over	Other condition	Not Applicable	Not specified
Shoalhaven	Male	Aboriginal	65 and over	CVD	Not Applicable	Last 6 months
Illawarra	Male	Aboriginal	65 and over	Renal	Respiratory - Asthma	Not specified
Shoalhaven	Male	Torres Strait Islander	65 and over	Renal	Diabetes	Last 3 months
Shoalhaven	Male	Aboriginal	55-64	Other condition	Injury	Last 3 months
Shoalhaven	Male	Aboriginal	55-64	CVD	Renal	Last 3 months
Shoalhaven	Male	Aboriginal	55-64	CVD	Not Applicable	Not specified
Shoalhaven	Female	Aboriginal	45-54	Respiratory	Not Applicable	Multiple visits last 12 months

## 4.2 Focus group discussions with Aboriginal community members

A total of 27 Aboriginal community members participated in four focus groups conducted in community settings across the Illawarra and Shoalhaven. These locations are shown in Table 5 below.

**Table 5 Location of focus group discussions**

Focus group	Region	Location	Type	No. of Participants
Focus group 1	Illawarra	Community setting	Mixed	6
Focus group 2	Shoalhaven	Community setting	Female	8
Focus group 3	Illawarra	Community setting	Male	8
Focus group 4	Shoalhaven	Community setting	Male	5
<b>Total</b>				<b>27</b>

### 4.3 Key questions of interest

The responses from the Aboriginal community members to the questions asked in the individual interviews and focus groups are presented below. The actual set of questions asked can be found in

Appendix 2. The responses from each of these two participant groups are discussed separately below under the following headings:

- Understanding of their health condition
- Recent hospital experience
- Information and support provided by hospital staff
- Managing their chronic disease
- Accessing care
- Experience of local health services
- Having a care plan
- Experience of Aboriginal Chronic Disease Programs
- Aboriginal people's suggestions for systems improvement

#### 4.3.1 Understanding of their health condition

##### *Findings from client interviews*

All of the clients interviewed had been diagnosed with one or more chronic condition and many had another condition or injury which required ongoing medical care (see Table 4 for details). For most, the diagnosis had occurred more than two years previously, with some suffering from chronic conditions for over 15-20 years.

There was considerable variation in the clients' level of understanding of their conditions. While some simply knew the name of the disease, others demonstrated a more detailed understanding of their condition/s and their prescribed medications, due to their long history of having the condition and the knowledge gained from continually questioning doctors and medical staff. Family history and their own research also contributed to their knowledge. Most of the clients were able to state when they were first diagnosed and many had no difficulty in naming the specific medications they were taking for their respective conditions.

Clients shared their understandings of illnesses in different ways. There were clients who responded by sharing information about their current regular medical appointments schedule while others provided their medical histories with details on complications or initial misdiagnoses. Lack of, or confusing medical information, was a concern for several clients especially those who were not able to provide a detailed understanding of their condition.

*Yeah, yeah because they were testing me for diabetic and the doctor said, 'No, we've found that you've got a bone disease, some chronic whatever - you're born with it. There's no cure for it.' Client 2*

*I was supposed to have a blockage in my heart and I never had one. That was a lot of rigmarole. Client 2*

One client stressed how they had to continually question doctors and obtain several opinions about their health condition, before getting a correct diagnosis,

*I don't think - a lot of doctors don't listen, when I told them the pain in my left side was different ... they should have investigated, but they didn't. But it's just luck that I persevered and got a third opinion. **Client 4***

Individual responsibility for health was a common theme, and clients talked regretfully about how their lifestyle choices such as smoking had contributed to their health condition. One recognised that not drinking enough water had contributed to his kidney problems.

*'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, 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..' **Client 20***

Family history was a strong theme in people's own search for meaning in their disease and was especially important for conditions such as diabetes and macular degeneration.

#### **Findings from focus group discussions<sup>8</sup>**

Participants in the focus groups also described having a wide range of illnesses and comorbidities. Some were unsure or confused about what illnesses they had, and many found it difficult to get information about their condition:

*Probably he's not sure what he's got, so tick all of them...*

*Like it took me ages to find out about this thing for my liver and that and yeah, like I had to find out through someone else that had done it. Doctors didn't refer me or anything. They ended up referring me after I asked them.*

But participants were aware of the grave implications of not fully understanding the seriousness of their conditions:

*That not wanting to go to hospital was a thing that caused his death because he wouldn't go ..So they're the things where they leave it too long because they think it's like all the other times and it's not. Sometimes it's severe and they don't realise how severe it is and that's the same like with the diabetes, hey.*

---

<sup>8</sup> All of the quotes in this section are from focus group clients.

### 4.3.2 Recent hospital experience

This section provides information gathered from Aboriginal clients about their recent hospital experience. The focus group questions did not include questions about individual hospital experience.

#### *Findings from client interviews*

Amongst the 22 Aboriginal clients interviewed, there was considerable variation both in the reasons for the hospitalisation and the number of times which they had been admitted over the past year. Similarly, clients' hospital experiences were quite diverse.

Most clients had both good and bad things to say about their hospital stay. Clients who spoke about the positive aspects of their stay almost invariably mentioned the way they were treated by the staff. Overall clients found doctors and nurses to be helpful and treated them kindly and with respect. Many also commented on the good relationships they had with their specialists. Some clients found that the hospital provided them with a chance to rest and at least one enjoyed the food. These positive and negative experiences of Aboriginal clients in the District hospitals are illustrated in Table 6 below.

**Table 6 Positive and negative hospital experiences**

Client	Positive comments	Negative comments
1	Went to hospital for a day due to an overdose. The people there were really good.	Confusion and extended waiting time around admission.
2	After the incident with the fire, 'I told them to move me, so they moved me, which is good.'  Didn't believe this was a race issue or neglectful treatment because she was an Aboriginal woman, just 'how it goes'.	It was normal to be left in the hallway for hours. Was moved out but then moved back in because there wasn't enough room. Felt scared. Staff didn't seem concerned. Admitted to a men's ward where one of the men smoked and nearly 'lit the room on fire' and 'I think that was wrong to put me in that ward'. 'That was scary, the person lighting their clothes up and they come in - they weren't really concerned. Anybody could have died'.
4	The specialist eventually accepted the large number of visitors.	Visits from family members were viewed as a problem by the hospital. 'When family come in they like to laugh and joke and carry on, and they tell you you've got to be quiet, 'cause they're other people around, but half the time the other patients get involved with you'. 'And if you're in hospital, and in the case of an emergency, you ring one family member, they ring someone else and by the time they get to the hospital you could have anything up to 30 or 40 family members there and close friends for support, to support each other, and the hospitals can't handle that, they don't know how to handle it, they don't like it some cases, but you can't turn them away, because we're all family'.

Client	Positive comments	Negative comments
5	Treated well during all hospital visits. Well know with all staff. Gets on well with specialist.	<p>We have wandering patients and when they put me in this floor with three other people there and I thought, well I know ... and (my daughter) nearly cried and said, 'What have they got you in here for?...It was the only bed they had. I know you got to cop that, I understand that but I just felt – I reckon if they keep you in a ward like that, say if I was in there two weeks, I reckon you'd end up feeling like the other patients. You'd feel old and you think you've got dementia and all that and I reckon they'd keep you in a ward like that, it's going to happen. In your mind I think it is'.</p> <p>'The last time I was in the hospital... there was an elderly person next to me and we were sharing the same toilet and shower thing and they got up, poor old soul, beautiful old person and they got up to go to the toilet and couldn't walk that far, they were really bad. So they put the person back in bed and they had to get the crisis team to come down and their legs were that swollen, they were just oozing, they were just oozing out of their legs and everything and I thought oh shit, I've been in the same bathroom.'</p>
6		'I felt like climbing the flaming walls...I'd be very, very reluctant to go back in. 'It was the most shocking experience.'
7	Resigned to her medical condition. 'There's really nothing they can do for it. What I've got - the medication I've got is, you know, is about it, you know.' Received information on medication, how to look after oneself and best thing to do. Not worried about it being female or male doctor or nurse.	'They are terrible places, just awful places. They are full of germs and bugs and all that sort of stuff. And if you've got a chest complaint you don't want to be around that, you know.'
8		Diabetes wasn't taken into account when they did the biopsy. She was left for many hours without eating.
9	Spent two weeks in hospital. Some of the procedures were 'horrific' - 'they've got a thing around your head and you can't take it off. It's more or less like a life support thing'. But was always treated with respect in hospital by the nurses and doctors and physios.	She was shifted into different rooms five times in one hospital stay.
t 10	Hospital staff treated me well	Circumstances meant had to leave before being seen by a doctor due to emergency priorities; long waits at Shoalhaven

Client	Positive comments	Negative comments
12		Was 'shattered' after hospital experience at both Wollongong and Shoalhaven. Didn't fix the problem he went in for; tested him for another issue 'when they found out that was all clear, they sent me home after four days of being there with no food, no nothing'. 'You feel like what's the point of going in there because they're not going to do nothing anyway. I just couldn't believe it.
13		'And they kept saying to me every day, you're gonna have – you're the second on the list, second on the list, and then when I come to the bed – the second one – there was no second one...Then I had to wait for four days, every day they were sort of saying that you're gonna be done... , and on the fifth day, on the fourth day – it was New Year's Eve, actually, and they were talking about how we're going to go get on the grog and all this and that, and they didn't even – I said when am I gonna get done? Well, sorry Mr X, you won't get done until the holiday break. I couldn't get done, and I had to wait for another four days... I wasn't gonna sit around, because I suffer with anxiety, and I never sat around. I told my sister and my wife and the nurses that I was gonna walk out if it wasn't gonna get done today, and it never happened so I walked out.
14		'When I was in hospital they didn't give me the full amount of insulin to get me back on track and all that...Now I'm only using half the amount of insulin that I should be'.
16	They were accommodating. I stayed there overnight and I didn't want to sleep in the bed so I was sleeping on the floor. That was all right; the nurses don't worry about that.	The nurses were tired and overworked. 'No one seemed to know what was going on. There was confusion. 'When you get tired you make mistakes. I felt like saying go and get some sleep'. 'The nurse said you're going home. And I said, "Well, I've got no-one to take me home until 5 o'clock," and then they had to come and - oh, they had to take the cannula out, and, yeah, somehow they got all confused'.
18		Found the food no good. Couldn't eat it.
19	Was treated with a lot of respect, nicely spoken to. Very happy with the staff.	
20	Was treated promptly. I went into hospital with, a gastroenteritis and dehydration and I had renal failure as well in amongst it. 'They put me straight in. Put me straight on a drip and put me into the hospital - into the emergency. Didn't mind being in hospital. 'It's	

Client	Positive comments	Negative comments
	relaxing, you know'. Nice and easy. A bit of nice different food'. Staff were fine. I get on with everyone. 'I had them cheering up and smiling and, yeah, yeah. So I give them a - I give them a cooee up. Yeah. And, because, that makes me a lot easier when I'm there. I'm not so bored and, yeah'.	
22	Gave me a good rest; nurses were really good to me	I was away from family; didn't have many visitors

Many of the negative comments about hospital experiences were centred on how clients felt about the institutional aspects of care, including the sense of confusion they felt in what they perceived as an alien environment, and the administrative and physical restrictions placed on patients admitted to hospital for an extended period of time. The negative comments, however, provide some insight into why some Aboriginal people may chose to leave hospital against medical advice (see for example Client 13 in the table above).

One client said that he preferred to sleep on the floor and the nurses accommodated this. Others felt very physically restricted and many clients said that they felt isolated in hospital. Clients also complained about the lack of nutrition in hospital food. These negative experiences made them question what they would do in the future as they were reluctant to return to hospital. Clients frequently expressed concern and unhappiness about being away from family, not having many visitors and not having their visitors accommodated in the way they would have liked. They attributed this to lack of understanding by decision makers within the hospital of the importance of family to Aboriginal people. Many complained of having to endure long periods of waiting, being left to wait in corridors, being moved from ward to ward or being put in wards which were unsuitable. Clients placed in dementia ward because 'there were not enough beds', were distressed, particularly because it restricted access. One client became anxious, felt embarrassed and intimidated and finally left hospital after being prepared for an angiogram which was subsequently postponed; he had a heart attack four days later.

A few clients expressed concerns for their safety and treatment, such as the woman accommodated in a male ward, having to endure patients smoking and causing a fire, or being left in a hallway due to the limited availability of beds. Clients were also concerned about their safety due to the nursing staff being visibly tired and overworked risking them 'just getting it wrong' or administering wrong medications. The risk of infection either from other patients or from air conditioning was mentioned by a few clients. Some clients who did not like being in hospital, and had some family support, preferred to receive medication and information on and how to look after their health and manage their illness at home.

On the whole clients did not attribute these disappointing or negative experiences to their being Aboriginal; most were of the view that this was 'it's just how it goes'. These clients often expressed feelings of resignation that things like being left on a trolley in a hallway for hours are just what it was like to be in hospital. They also accepted that there were good and bad nurses and doctors and that some have a bedside manner and some do not.

However there were a few notable exceptions to the satisfaction with their treatment by staff, particularly where clients felt they were not listened to by hospital staff and had to question and challenge the hospital staff. This is illustrated in the case of Client 3 who re-told described her most recent hospital experience as ‘disastrous’.

### Client 3 Hospital experiences

Client 3 has been a local resident for over 50 years and has been hospitalised many times. She The interview was the ‘first time I’ve been able to complain’. Client 3 had a good knowledge of her medication needs, and much of the confusion and errors had occurred during the hospital visit centred on these requirements. During the hospital visit there were three situations where medication requirements were badly handled by the hospital staff. Firstly, when she was admitted to hospital for a week when her regular doctor was away on vacation. She was on oxygen for the whole time, she usually used Ventolin twice a day was not given Ventolin until the end of her hospital stay. The second incident involved the medicine for another patient being left on the client’s table:

*One day there was two tablets sitting on my little table and the person diagonally across from me, I – it was – they were there for about an hour, but no-one come to tell me what ones to take, but the person across the room, said to me, ‘Where’s my tablets this morning?’ The staff member said, ‘Oh, I must get you your tablets.’ I said, ‘Well, what are those two tablets on my table for?’ They were the other person’s tablets ... I don't know what that other person had and I don't know what the tablets would have been if I would have taken it.*

The third incident happened the night of the previous medication mix up. She was told to take steroids (Prednisone) that they missed dispensing in the morning. When she questioned the timing of this medication as she knew that the medication might make it difficult for her to sleep and her specialist never prescribed them at night, the nurse dismissed her, telling her not to worry and that she would be given sleeping tablets if needed. Client 3 didn't take the tablets. She hid them and informed her daughter who made a complaint to the hospital:

*Oh, I couldn’t believe it. I didn’t take them, I put them in my tissue and the next morning my (daughter) visited and I said, ‘... have a look at these tablets and they’re a high dose and I was supposed to take them last night.’ Well, did they hit the roof, because (the client’s) partner is on the same medication all the time and they knew what they were. (The client) to the head nurse – whoever was there, was a doctor there – and did (my adult child) give them a dressing down ... and said, ‘Why would you want to give my parent this at night?’*

The hospital doctor continued to insist that she should take the medicines prescribed. But Client 3 argued they she would continue to do what her specialist had prescribed. It was only when the specialist's name was mentioned that the doctor backed down and supported the client’s decision not to take the medication. The final issue for this ‘disastrous’ stay involved a very long delay waiting in the ward for discharge to be finalised.

Client 3 did not put her negative hospital experience down to her being Aboriginal her non-Aboriginal husband had had a similar bad experiences with the local hospital.

### 4.3.3 Information and support from hospital staff

This section provides information gathered from Aboriginal clients about their information and support provided by hospital staff about how to manage their chronic condition at home. The focus group questions did not include questions about information received in hospital.

#### *Findings from the client interviews*

Six clients provided a response to our question about the information provided to them whilst in hospital about the management of their condition once they returned home; most of these were negative comments. Most clients commented on the lack of information provided in hospital, particularly written information which could improve their understanding of their condition. One client said that she was planning to go to the library to find out more about chronic disease:

*...no one has really ever explained what that disease is, what chronic disease to me is all about. Client 2*

Not all clients were dissatisfied with the information provided in hospital and there were a few neutral comments, but only one client strongly endorsed the information provided about their condition. This client was being treated for cancer in addition to having other chronic conditions. She expressed confidence in the information provided to her in hospital, she felt fully informed about her ongoing treatment for cancer and was well supported by a worker at the cancer clinic looked who after her and provided written information in the form of a useful booklet. When she was verbally told, 'it didn't really sink in...' but once she read the information

*...everything was 100% and it's clear so that you could understand it. And I thought to myself, maybe I shouldn't have read it, but in the same token, it was important for me to read it. Client 4*

Not all advice given to clients by hospital staff was well received; some clients were 'sick of being told about food and exercise' by doctors:

*Oh, matter of fact you've got diabetes, you've got to lose weight, blah, blah, blah. Oh, you're overweight... You hear that every day, if you go to the doctors, you know what I mean?...You're overweight, blah, blah, blah... And that pisses me off, to tell you the truth, sometimes. Client 11*

Nurses appear more likely than other hospital staff to provide clients with information in hospital about managing their condition at home. Some nurses took time to be sociable and some clients found it comforting being able to see an Aboriginal nurse working at the hospital. Nurses asked about whether clients needed help at home and connect clients to home care services:

*Well, they did, they offered doing those care plans with Aunty Jean and going to the doctors and seeing the nurses that – oh, God – there's a clinic down here that you can go and see a nurse for your diabetes and just heart checks and that. Client 22*

Very few clients said that they saw or received support or information from a social worker, even though a number of clients had requested to see one. One client was helped by a social worker after they made a formal complaint about the continual waiting they endured for a heart procedure.

Eight of the 13 clients who mentioned visits from an Aboriginal Hospital Liaison Officer (AHLO) said that they had seen an AHLO at their most recent visit. All but one of these clients was positive about the assistance offered, commenting on a high level of support and their assistance with special needs, such as transport. Clients who had multiple hospital visits found the AHLO especially helpful. One client said that she appreciated the AHLO's visit because her own Aboriginality was often questioned by other hospital staff; she noticed this in what they said and in their body language. The AHLO was 'wonderful' and they knew them from the medical centre and the most recent visit was 'really good' because it was easier on her family.

Five clients stated that they had not seen an AHLO at their most recent hospital visit. In most cases, the AHLO simply was not available. Only one client was not happy with the treatment provided by AHLO. This client believed it was important to have an Aboriginal medical worker to support Aboriginal patients, but she found that the support was not 'reliable'.

Only a few clients commented on their interactions with allied health workers. One found the information provided by the diabetes education far more useful than what he had learnt from the doctor. Having a book enabled him to be more actively engaged in his health and he was now recording his sugar levels at home and was able to explain the different readings that he had been recording:

*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...Client 6*

But another client who had seen a dietician in hospital was very dissatisfied because nothing changed in the food brought to her by the hospital despite being there for 2 weeks:

*'Well we'll give you this, we'll give you that...my menu never changed for those two weeks.... Client 9*

Physiotherapists were only mentioned in passing in relation to rehabilitation services received, but there was no mention of information or assistance in managing a condition.

#### **4.3.4 Managing their chronic disease at home**

This section reports on the way clients spoke about how they were managing their chronic disease at home. The major themes explored in the interviews were: managing lifestyle modification including the barriers to individual lifestyle change, managing through medication, other ways of managing chronic disease, and the support available to manage their condition.

##### ***Findings from client interviews***

###### **Managing lifestyle modification**

Promoting behavioural change is an important part of professional rhetoric about chronic disease management. Discussions with clients often highlighted the many challenges of achieving lifestyle modifications and health literacy. Clients in our study reported that health

professionals frequently told them to stop smoking, walk, and eat properly and often people spoke about how they had successfully changed their diets, by cutting out sugar, alcohol and junk foods, but they also talked about many barriers to achieving such a lifestyle change, such as the cost of buying nutritious food.

Not all clients accepted that there was a link between diet and exercise and health status, as is exemplified in the following account:

*They told me if I didn't change my lifestyle I was going to end up flaming dead. I find that quite amazing. I'm the eldest of four brothers and I'm still alive and kicking.*

**Client 11**

The information provided to clients about managing their chronic condition was extremely variable. Several clients were only given verbal information at the time of diagnosis, and commented that it was often difficult to take this information or ask questions about how to manage the condition at this stage due to the shock of the initial diagnosis. Other clients found that repeated education was necessary to process, understand and apply the information available about how to manage their condition. Others still struggled to manage their condition because they found the information they received about life style modification to be confusing and inconsistent:

*Client: Well they told me that diabetes is reversible. Well at least, one of the young nurses has, she's told me repeatedly that diabetes is reversible.*

*Facilitator: So what do you have to do to reverse it?*

*Client: I have no idea. Client 6*

*Useful (information) but I can't understand portions. I don't know what size portions they are. They just say portions. So I gave up on that. Client 14*

Some clients felt that they were being judged when health professionals described their lifestyles and health outcomes. As this person commented, a focus simply on an individual's weight failed to take in the whole person or the complex co-morbidities that they experienced:

*And that word, morbidly obese. That's the one thing, I don't like. I mean I know that I'm big. I mean they they're saying it in probably the right way, but you know..... go back and look at what is wrong with the whole person, like mental health and suggest things to people about that too. Client 11*

For some, the dislike of vegetables and fruit, or advice that was too discordant with their established eating patterns and beliefs, was a barrier to changing their diet:

*Someone said to me 'have a shake of kale and this' and I fucking hate kale. Do you know what I mean? Client 17*

Similarly, other people described the frustrations of being told to exercise, when their conditions made this impossible, or that the opportunities they had to be involved in exercise were limited by their inability to secure reliable transport:

*I joined the local bowls club to meet people, but only been once due to no license and car. **Client 6***

#### Managing through medication

In discussions about medication, some clients listed their medications and shared their experiences of medications working or not working. Clients commonly reported that they did not consider that their medications were helping and some complained that they had been given the wrong medicine. Some people were reluctant to take their medication because it made them feel ill. One client struggled with having to inject himself with insulin, and felt like,

*dropping the whole flaming lot, continuing on my merry reckless ways as I used to before I even took up insulin. **Client 1***

Other clients also found it difficult to adjust their lives around the medications prescribed, for example one client had had to carefully plan travel on trains because she was prescribed fluid tablets for her swollen foot but knew she'd be 'running to the loo' while on the train.

For clients dependent on many medications, successful management of their condition was dependent on a good relationship with their GP and pharmacist. Support included having prescription repeats kept at their regular pharmacy, the pharmacy delivering the medications to the client at home. Many clients felt that they were managing their health as well as they could and were aware of the need to be constantly monitoring their condition:

*My heart is pretty good, yeah. Haven't had asthma for a while. Pretty good with my asthma. I've got puffers and all that. My thyroids are good really. Sometimes they're down but that's normal. Blood pressure is pretty good when I go and get it all checked and my weight and all that, because Auntie Jean does all that. **Client 2***

#### Other ways of managing their chronic disease

Clients also managed their health by getting flu shots and regular check-ups. One client talked about their significant success in giving up smoking to assist in managing health issues. They talked about going 'cold turkey' and developing strategies to reduce the urge to smoke.

#### Support available to manage condition

Assistance from family was the major support for clients in managing their condition. Spouses and children were mostly commonly mentioned as sources of support, and some clients had become increasingly reliant on the goodwill of these family members:

*They'll take me if I need to go anywhere, they'll do the shopping, they'll do the washing, they do all that now. They never used to, but they do now that I've gotten worse. **Client 22***

Some spoke of the difficulties they had encountered in gaining more recognition and support for the family members caring for them. For example the client who talked about how Centrelink had refused a family member an application for the carer's allowance.

Others talked about the good support they obtained from specific and the ACCHS. Good support from these professionals was defined as providing lots of information and being helpful

with phone requests. They also provided information about new treatments suitable for their conditions. Support also included home care provision and transport options when required:

*Like you ring them up and ask them something and that there and they do it. It doesn't seem to be any trouble. **Client 1***

### **Findings from focus group discussions<sup>9</sup>**

Key themes arising in the area of managing their chronic disease that were discussed in the focus groups were: the importance of specific Aboriginal services, the difficulties of making behavioural change, the tendency to neglect one's own health and the importance of effective communication.

#### Aboriginal services

Focus group clients spoke enthusiastically about how specific Aboriginal services, organisations and groups had been critical in helping them to manage their health condition. Life style changes such as taking up exercise were often considered to be difficult to do alone, but far more possible in a convivial and supportive environment:

*We also had on the Thursday we do an exercise program and stuff like that. So it's getting us moving and not seizing up.*

The all Aboriginal groups were seen as being essential to provide on-going support and a safe place to discuss health concerns and worries. For example, male participants provided extensive feedback about the importance of the IKMSG, listing the moral support they received, the reassurance from being with other people in the same situation and being able to talk in a safe and trusting environment:

*We do every week here in this group here we get to talk about our dramas and things like that and there's no secrets between any of us here, we just don't start going out spreading rumours.*

*We support each other and we all talk to each other...That's why this group is great. I think everybody, not just health wise but mentally wise. Blokes have everyone to talk to and we all have our own dramas we can relate to one another.*

Focus group participants from Waminda also recounted how important it was for them to have a place to go and the support from the staff and other participants:

*Yeah, we've got our women's evening house, and when I go there I sit in with them, and get into those programs over there and you can stay there as long as you like if you need that break away.*

For some participants, however, actually being able to access these sorts of services was very difficult, and required complex re-structuring of daily commitments:

---

<sup>9</sup> All quotes in this section are from focus group participants.

*And I think that's a big thing with us. We've been trying to get into Auntie Jean's swimming for that long but the thing is we've always got jobs on that day. So we've got to make it so that we never get booked on a Wednesday. We keep saying it but we don't do it and we've got to start thinking about ourselves because of our age.*

### Behavioural change

Despite the acknowledgement of supports, participants talked extensively about the difficulties of changing one's behaviour, as one participant commented, this was akin to completely changing the way a person lives their life:

*It's hard to make a change, especially with eating habits and that. If you have diabetes and have been diagnosed with it, it's hard to kick all these things you've been living on all your life.*

Along with diet and exercise, giving up smoking was considered to be one of the greatest challenges in managing their chronic disease:

*Because they're a heavy smoker. Since they come out of the stroke, it's been really hard, because of their short-term memory makes it hard ... the thing is they loved smoking before the stroke.*

In some cases giving up smoking was made more difficult by the physical limitations of the person's condition, leading to being housebound and bored:

*Yeah. If they're sitting in the lounge room watching TV all day, its smoke after smoke. Yeah, it's no good.*

One participant was confronted with a complex family situation, having gained custody of his child, but this interfered with his ability to look after his own health:

*I've been putting off my treatment for my condition. There are bad side effects in the medication and I'm afraid it will affect caring for my child. I'll have to wait for treatment till my child is older.*

### Taking responsibility

Many people in the focus groups had first hand experiences of the serious consequences of poorly managed chronic disease, including limb amputations in the case of diabetes:

*I think the main thing that's happened, like we've seen things happen in our families that made us quite aware. My mum, my grandmother, and my auntie had a leg amputated from diabetes.*

*And we didn't know much about, eh, didn't know much about it. Now we know more about it.*

*I know with my father, he passed away, he stopped going to the doctor's and he had melanoma and a hernia and just things on top of each other and he ended up going into hospital, it was just too much to work on, and they had to give up on him. It cottoned on people like me because I don't go to the doctor myself and I thought,*

*well, I better get myself checked, so I go every couple of months, just to see how things are going.*

Some participants acknowledged, that despite these experiences, that they had a tendency to neglect their health and to ignore health issues and that these attitudes could lead to serious consequences.

*I went and got some hearing aids but I couldn't- Hadn't got used to them and they said, 'Well, you know that if you don't start wearing those hearing aids I'm going to remove your licence off you.*

*For 25 years I've been taking needles and really I do step overboard a bit, but the point is this, you shouldn't. With diabetes you don't play around with it. Because when you have a high day you know it.*

People talked about a reluctance to use health services and a sense of denial about their health condition:

*A lot of it is self-inflicted injury because of neglect of our sickness and neglect of what we have to do to make ourselves better. So that's another big part of the issue of us being crook.*

*I think we just keep going because they don't think oh it's not going to happen.*

*But that's the thing when you're Aboriginal, you know yourself, you don't go in unless you've got a broken leg or a broken arm or something.*

In some cases though, the barriers to personal responsibility are due to a range of social and structural influences, which leave the individual with no time to care for themselves:

*Well we get out of bed. We come to work every day but it's that leaving time out for ourselves for our own health around the work calendar. See that's our diary and that is chock-a-block but what we should do is not put anyone on that day; we should have that day for ourselves 'cause it's only an hour or two.*

*It's pretty hard when you're a battler and ill and have lots of kids running around ... you've got to feed them. You're not going to go to the health food store. You're going to buy what's cheap and quick.*

An important and often stated theme in the focus groups involved the effect of racism on an individuals' ability to take responsibility for their own health. In some cases, it appears that people found it difficult to counter stereotypes about Aboriginality and these contributed to their struggles with managing their condition:

*There's a lot of sadness too is our people put it down and not just because we're black but because we're Aboriginal and they put that as a perspective that we're a lazy race of people.*

*When I've sat down on the side of people and they're running my race of people down, it hurts inside my zone and I've got a lot of feelings for it and it's for the love of life of man and humanity. Get up and do something about it instead of running it down all the time day after day.*

Another important barrier to managing their condition was relationships with health professionals and lack of effective communication. Trust was a very important theme in people's discussions about their relationship with mainstream health professionals:

*I mean that took a while because we never had any trust in the medical centre years ago, we never accessed the medical centre at all.*

People's sense of trust was eroded when communication failed to be sensitive or meaningful, or where people struggled to get answers to their questions:

*Yeah, because before I come here I was struggling to get answers for anything because you were just going around in circles with the doctors with mine because they didn't know why I had a heart attack. There was no blockages, yet it killed off a third of the muscle of the heart and they still don't know why. So they're just treating it for now. That's all they can do.*

Despite acknowledging the structural and personal barriers that they encountered in managing their chronic disease, the focus group respondents talked about challenging these and the importance of being a good role model for future generations:

*If the kids get it from us then the kids will grow up with a better attitude towards those type of things if they learn early.*

#### **4.3.5 Accessing health care**

This section reports on the responses from Aboriginal clients who were asked in the interview about how they accessed care. Drawing from the academic literature (Scrimgeour and Scrimgeour 2008, Vicki-Ann Ware 2013 ) specific questions were asked about access to transport, and the cost of health and appropriateness of health care. Focus group participants were not asked specifically about how they accessed health care.

#### ***Findings from client interviews***

##### **Transport**

Transport was a concern for several, but not all of the clients interviewed. Twelve of the 22 clients said that they did not have difficulties in getting to services. Most of these clients drove their own vehicle, were driven by family members or were able to access some form of travel assistance. A few of the clients who were eligible for some form of travel assistance preferred not to do so because it was not practical for them to do so because of their chronic condition

Although the clients who used their own vehicle were not asked specifically about the amount they spent on petrol and maintenance, the distances travelled would have incurred a substantial cost. Within the Shoalhaven, for example, some clients had travel 45 minutes each way to see a GP and many clients had to travel to Sydney from the Shoalhaven (320-360 km

round trip) or Wollongong (170 km round trip). Even clients with their own vehicle said that they found it difficult to make early morning appointments in Sydney.

The most common forms of organised travel assistance were the use of vouchers from the Aboriginal Community Controlled Health Service, the Illawarra Aboriginal Corporation or the local Council, the ACCHS bus or having an Aboriginal health worker pick them up and also pick up medication. Other clients either walked or cycled to the local medical service.

One client who did experience transport problems which impacted on their ability to access health services had no licence, no car, no direct bus service and found taxis too expensive. Some assistance was available through an Aboriginal transport service but there were some restrictions if that service is not available. She was keen to get her licence but her doctors recommend not driving as she is a diabetic.

### Cost

There was some variation in the client responses to questions about cost as a barrier to accessing care. Ten of the 22 interviewees discussed the cost of medications. Most, but not all of these, said they struggled financially, with a number of clients living on disability pensions and another stating that money was an issue and he would only be able attend Aboriginal health programs if they were free.

The eight clients who were registered for the CTG subsidy for medicines indicated that they would find it difficult to purchase medications if they were not covered under this scheme; two clients said that they would stop taking their medication if CTG was taken away. One client said that he was unable to register with Closing the Gap because he had been 'blackballed' by the medical practice which included the pharmacy.

The cost of specialist care was frequently mentioned as a barrier to attending specialist appointments. This was somewhat alleviated for clients who said that they received a pensioner discount from their specialists, or for those who received financial support for specialist care under CCSS.

### Appropriateness

As with the questions related to cost there was variation in the answers to the question 'As an Aboriginal person, how appropriate have you found the mainstream health services? Only six of the 22 clients provided answers to this question. Some clients found services to be 'quite good' and only complained about the waiting period.

Those who responded negatively to this question, were either not satisfied with the level of cultural appropriateness, and thought that there could be improvement, or thought that communication was a problem. One added that he felt like 'a third class citizen' because he is on disability pension.

*people they get to train them half the time don't know anything about Aboriginals.*  
**Client 4**

Other clients felt that they received the same care as everyone else, good or bad:

*Worst time I've ever had and it wasn't just me, it was my husband too, but he was not Aboriginal. Client 3*

*Look, I don't care if they're Aboriginal or not, as long as I get the care that I need, that's all that matters. Client 4*

One client spoke at length about the need for greater cultural awareness amongst health professionals and thought that cultural awareness programs should be available to all health students whether at TAFE or university. She often took time to explain her personal history through stories to help health professionals who were treating her build a cultural understanding. From her experience she believed there needed to be more training in Aboriginal ways by Aboriginal people who have knowledge. Acknowledging that not all Aboriginal people know about culture, she felt there was a need for both qualifications and an understanding of culture.

#### **4.3.6 Experiencing local health services and having a care plan**

Both clients and focus group participants were asked about their use and experiences of local health services. There was considerable variation in the way both groups spoke about their experience. Many clients, for instance, never had any difficulties with health services, and found them very good, while others 'wouldn't have a clue' about where to go for services. The following section describes clients' use of the most frequently mentioned services and some of their experiences.

Both Aboriginal clients and focus group participants in the study were specifically asked about their experience of having a written chronic disease care or management plan from their GP to assist them in managing their chronic disease. A GP Management Plan is a plan which has been prepared by a GP, for a patient with one or more chronic conditions.<sup>10</sup> The plan typically outlines the goals, care and service upon which the doctor and patient agree. Management care plans for a patient with more or more chronic conditions requiring multidisciplinary care can combine the Management Plan with a Team Care Arrangement (TCA) in collaboration with other services. People with a chronic medical condition may be able to get Medicare benefits to cover allied health services that help manage their condition.

#### ***Findings from client interviews***

##### General Practitioners

Many clients spoke very favourably about their local private GP service. They rated the medical care highly and utilised the yearly check-ups as well as regular GP visits. But more importantly they felt that the GPs went to great lengths to support them. One client felt supported by a GP who phoned the hospital and advocated on his behalf when there was a problem:

*I mean what doctor would ring the hospital to find out how you are and ring and they put her straight through to me and I could talk to her while I was in hospital. Now not very many doctors these days do that. So that's part of why they are so special. I mean to me, they're my second family 'cause they have to be 'cause they look after me so well. Client 5*

---

<sup>10</sup> Also see <https://www.humanservices.gov.au/customer/services/medicare/chronic-disease-management-plan>

However some clients had bad experiences with local medical centres. One client made it clear that his concern was with what he called 'corporate' medical centres, rather than his GP. This client felt strongly that Aboriginal people in regional towns had limited choice in health care providers and did not think that the large medical centres offering various types of service in the same organisation were dangerous. This client said that he had lost any trust in the medical profession and that this had implications for his ability to manage his condition:

*Does it cause hardship? Oh yes. Financial hardship? Oh yes. Does it make it easy to communicate to a doctor? Oh no it makes it very hard because you're frightened that what you'll say you'll be misinterpreted. You're frightened that you'll be exonerated so you keep your mouth shut. **Client 10***

Other clients described their medical centres as 'fantastic' and recounted good experience with medical centre GPs:

*They have a lot of services. He's a good doctor but often 'packed out'. They're very compassionate towards Aboriginal people, they've got their care plans in place. **Client 13***

Others still were not always open to the advice they received from their GP:

*(I'm) sick of doctors. 'they tell me what I can't do'...Every time the doctors want me to have tests ... they say don't do this don't do that ... you're unfit ... I go surfing but get affected from my heart condition ... it stopped 6 weeks ago and they had to start my heart. **Client 21***

Only one client said that they were seen by an Aboriginal health worker in a GP clinic.

Poor experiences with large GP services were described by a few participants and some felt that these services were 'double dipping' in programs funded under the Closing the Gap strategy by forcing clients to purchase their medication at a particular pharmacy which was part of the corporation rather than allowing him to purchase at his local pharmacy 'and the difference is approximately 60 km return trip'. When he complained he was accused of threatening staff.

### Having a Care Plan

Care plans were not common amongst the clients interviewed, with only three of the clients saying that they had a written care plan from their GP or were in the process of developing one. These included a client, who experienced multiple chronic illnesses, including cancer, and had a plan which outlined her ongoing treatment for chemo, radiation, medication. A second client had a written plan from his GP and a third client had organised to do a care plan on next appointment with her GP. Her preferred option was to stay home next time and manage at home with support from Aboriginal Medical workers if possible.

There were varied understandings of what a care plan was, from the other clients. The clients who said they did not have a written care plan said that no one had discussed a care plan with

them; they were mainly managing on their own; they were unsure about what is happening for future treatment.

*No, no, they haven't done anything like that... Yeah, care - what is it ? - care plan.  
Client 2*

One client said that she left her care planning to their adult child who is a trained nurse. Another client responded that she had a written letter from specialist for managing hospital admission if she had concerns about respiratory problems. Another did not have a care plan but felt supported by the ACCHS. One client without a written plan thought that it was her responsibility to develop one:

*But I need help doing that, you know? And be positive, really positive about what I was saying. Work up to that. Work up to that plan. You know what I mean?  
Client 11*

#### Aboriginal Community Controlled Health Services

The great majority of clients who had accessed an Aboriginal Community Controlled Health Service spoke very positively and at length about their experiences<sup>11</sup>. Clients were particularly impressed with the way they were treated by the staff, and said that they felt comfortable, welcomed and respected:

*At the AMS they treat me really well. No complaints. Client 12*

*it gives so much help ...Anything that comes up that they think that is suitable for my conditions they let me know...Oh yeah, yes. They've been very helpful. Client 1*

*The staff are 'fantastic'. They're fantastic. They are absolutely fantastic and that...You feel like you're welcome and that there, you're not causing any trouble and that there if you want to go and see the doctors and if they can do anything and that, like when you walk in that there and that sometimes they will ask if you would like a drink of water or whatever and things and that, just different little things and that... Client 1*

The ACCHS provided a wide range of services such as: podiatry, optometry, drug and alcohol counselling, diabetes educator and a dental service. Clients were very satisfied that they could obtain help with managing their various health issues and chronic conditions at the same service. They also commented frequently on the importance of the practical assistance with transport, covering certain costs and generally providing a high level of personal support:

*They set me up with everything to get me in there, and get it done. They covered all my costs and like if I had any problems I only had to go and ask them and they'd have it sorted out for me in no time. If anything's wrong they can help. Client 19*

---

<sup>11</sup> Note: Aboriginal clients in these quotes usually refer to the Aboriginal Community Controlled Health Service as the 'AMS' (Aboriginal Medical Service)

*The doctor is 'really good', they provide transport and they are caring, they are just very good, they do their job and they do it well, you know, like really do, you know.*

**Client 7**

In addition to receiving good service clients believed the ACCHS was important because it valued and supported their Aboriginal identity. An important aspect of the ACCHSs is that clients did not feel judged:

*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. **Client 1***

Clients commented on the friendliness and the fact that they called the doctors by their first names. They also liked that that information is given face to face. A few compared Aboriginal services favourably to non-Aboriginal services where they found doctors to be unsupportive and did not seem to have time for clients. The following quote from client sums up the view of those who were not only positive but also very proud of the ACCHSs:

*Well to be perfectly honest I reckon like our medical centres, they're great. They are. I mean they would put mainstream to shame the way I'll say we look after our patients and look after people and get some of the mainstream staff in the ward and doctors to work in one of ours and see how they go and then see how it works and maybe impart some of that to them and make it good in their own surgeries type thing. **Client 5***

The only negative comment from an ACCHS client that that there was 'too much' service offered at the ACCHS:

*It's not so much the blood test, it's they go to do your sugar, they go do your blood pressure, they've got to do this, they've got to that, before you actually see the doctor.. I mean, if people are happy with it, that's fine...But...we're being guinea pigs for the government, we've got to account for every time we come to you guys, and we have to have this and that done, if I go to mainstream medical centres and that, they don't do all that. **Client 4***

Some clients knew of ACCHSs, through the hospital and through family members, but had not accessed the services themselves because they were satisfied with the care received at their local GP services:

*No, I didn't even think of it, because my husband, like, he had a very good job and everything and we just went to the doctors when we needed them, and there was no specific reason why I would have gone to another doctor. **Client 3***

Others alternated between the ACCHS where they see the doctors now and then and get their flu shots, and local GP services which were much closer to home in the southern Illawarra. Other clients accessed the Aboriginal workers at GPH. A small number of clients thought that it did not matter whether or not the service was an Aboriginal or mainstream service:

*Yeah, it doesn't really matter which one really as long as you get the help, really*  
**Client 2.**

The issue of proof of Aboriginality was raised in relation to the use of ACCHSs. The requirement to show proof of Aboriginality before using services differs from service to service:

*Can't go to the Aboriginal Medical Service ...because he has no proof of  
Aboriginality. No, you've got to be accredited to get medical services...Client 10*

But some participants some did not report being Aboriginal 'because that was my business'.

### Aboriginal Home Care

Eight clients spoke about Aboriginal home care services. The four clients who were currently using or had previously used these services and two others were in the process of organising home care. Clients accessed home care through a variety of means, including: a nurse at the hospital; the IAMS; or the Illawarra Aboriginal Corporation. All of the clients who used these services were very satisfied with the assistance they received, finding it very helpful:

*yeah, but I do have an Aboriginal worker come in and change my bed every  
week...She mops this floor and she hangs my washing...And she is just so good and  
I've had – she was off last week and I had another girl and they're lovely girls to  
do...It just takes the pressure off. Client 3*

One client expressed some concerns about the funding available for home care services. Another client said he had heard about home care but has not used it because he was 'a bit proud' and found it hard to accept help.

### ***Findings from focus group discussions<sup>12</sup>***

The discussion in the focus groups around peoples' experiences with health professionals and local health services was somewhat more free-flowing than in the individual client interviews. A number of different themes emerged which are discussed below.

Some of the positive experiences were around the use of GP services and the use of a health coach. As with the individual clients interviewed, several focus group participants shared how they had very good relationships with their GPs and felt they were supported well with their chronic disease requirements:

*If you've got a good doctor, not saying nothing against the AMS, I don't go there,  
but my doctor anytime - I'm going to see him in the morning - so anytime, it costs  
you nothing for ultrasounds and everything like that.*

Clients in the focus groups also described a range of care plan approaches that involved both medical and ongoing health (exercise and nutrition) options. But many participants did not have a care plan for their condition. Others confirmed they had a plan that had expired or

---

<sup>12</sup> All quotes in this section are from focus group participants.

needed to be reviewed. The most positive responses from focus group participants came from clients of Aboriginal chronic disease programs such as Waminda's Dead or Deadly, who found that the program helped them get them on track in managing their condition:

*When they come in the nurse does their blood pressure and their sugars and stuff like that to keep that on track as well.*

Another participant spoke positively about being able to access a health coach through the 'Get Healthy Program'<sup>13</sup> which had been recommended by her doctor. She:

*If I feel sad about something or if I'm just feeling down because I've eaten pasta or something, they don't judge or anything. I think the shortest time I've had is about 15 minutes and they just give me some ideas as to what exercises I can do or some different – I'm very picky with what I eat, so they give me some ideas to use what I like and make meals with that.*

However participant's experiences with specialist treatment were less consistent. Many focus group participants were very concerned about the costs related to specialist appointments and felt they might avoid seeing specialists in the future, due to the financial strain:

*We won't be seeing the specialists the way we are now. I had my gall bladder taken out. I said to the doctor everything was done in hospital, it cost nothing, they wanted us to come back in afterwards, and I had to pay \$150.*

There were also frustrations about making appointments with specialists with particular concerns around the inflexibility around re-scheduling of appointments. Participants acknowledged that from the medical services perspective that managing appointments was challenging, but felt that the services did not take patients' feelings and circumstances (e.g. stress and fear related to major surgery) into account around missed appointments.

*'cause I've cancelled two appointments or I think they only give you three. If you miss your appointments, you've got to go right back to scratch again and you got to go back and get a referral.*

It was also acknowledged that missing appointments also arises out of fear. Some focus group participants were very fearful of dealing with specialists because of their past experiences. In particular, they felt that their Aboriginal culture was not recognised or acknowledged and this had led them to avoid treatment:

*It's a reality for them because we've known people that it's happened to and I think that makes it a certain big issue about it too and our culture really – our culture itself is not really into the medical system ... that's a big change.*

*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.'*

---

<sup>13</sup> Get Healthy is a NSW Health funded program – See: <http://www.gethealthynsw.com.au/>

*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.*

Building relationships and trust with health professionals was important and the gender of a specialist was also mentioned as a concern for some:

*They're not used to men looking at her and she's gotten used to her doctor, her main doctor.*

The focus group participants also held different views about the support from programs funded under the Closing the Gap strategy. Some focus group participants spoke very favourably about the supports put in place:

*I think, to be honest, probably the last 12 months has been as good as it's ever going to get ... we can go and see a specialist now and pay for it ourselves with the Grand Pacific Health, and the staff goes, 'Oh no, you shouldn't be paying for that stuff' and organised for me to be taken to a specialist, and that's a big, big help for us.*

But the majority of participants expressed concerns and confusion about the CTG scheme, for example, in relation to who is entitled to assistance. They also spoke of the need to search for doctors who are part of the program and were unsure about whether the government had cut back on funding as financial support entitlements appeared to keep changing. For example, in terms of medical equipment, items that had formerly been low cost, now appeared to be too expensive:

*When I was going through sleep apnoea, I applied for a machine. It was going to cost about \$4,500. Because there's a shortage of them and the wait is so long they gave it to me for nothing. Four years later, it kept cutting out, I rang them up and told them, they looked at that, that's not even four years old. We've got to give you another free one under warranty. All the masks and anything that I need for it, Pacific Health buys for me.*

*Why with CTG ... because my wife is Aboriginal - why can't I get it for my wife because that would help us out as well.*

*It's just they – they didn't cut it out, the government cut it out. This is what I think.*

There were also a great many concerns expressed about the processes for accessing subsidised medication under CTG and the financial stress associated with medications for chronic illness, as not all medical expenses are covered under CTG. There were several not on PBS examples provided. Participants shared a range of costs for what appeared to be similar medications:

*If you go to a doctor and he's not your normal doctor and say you go to a hospital or something, they write out a script. When you go to your own chemist and say he hasn't put Close the Gap on here. If you've got your own chemist she knows. She*

*puts it down. If you went to a strange chemist, they don't put Close the Gap on there.*

*I know my brother was on some medications ... he doesn't get close the gap. He's got to pay \$6.50 ... they are really expensive and he's got to pay the full price for them.*

*I've got to pay \$59.90 with this stone that I've got in my kidney because they diagnosed me in the hospital and they gave me a script, something called Flomax. 30 tablets costs me \$59.90. I said, 'Why? Close the Gap, what's going on?'*

*The cost is - as you get older and you get sicker, the medical costs are bad.*

Finally, there were additional concerns about continually having to prove Aboriginality and entitlement to be on program:

*If I've got to go to a doctor and they don't believe me, they won't even sign a prescription form for Closing the Gap.*

*Yeah, but my drama is if you sign off for closing the gap with an Aboriginal person why do you need to sign it every year? 'Cause I say my skin colour is not going to have changed in 12 months. I'm always going to be a black fella no matter what and doctors and that come here and a lot of them say, 'You have to sign this paper saying that you're closing the gap'.*

#### **4.3.7 Experiencing Aboriginal Chronic Disease Group Programs**

The discussion of Aboriginal people's experience with the health system in the sections above has focused primarily on Aboriginal people's experiences of local health services, including hospitals, GPs, specialists and the clinical and support services offered by the IAMS (through its CDMP) and the SCMSAC (through CCSS which it jointly operates with GPH). This section describes in more detail the way clients in individual client interviews and focus groups discussed their experience in attending a number of the group programs targeting Aboriginal chronic disease. Individual interviewees and focus group discussions are discussed together in this section.

Most of the Aboriginal clients were aware of one or more of Aboriginal chronic disease programs operating in their area. Focus group clients were more likely than individual interview clients to have heard about or partaken in programs. Of the 22 interviewees, 12 knew of Aboriginal programs, 6 had not heard of them and the topic was not discussed in the remaining 4 interviews. The program most often referred to in both the interviews and the focus groups was the Aunty Jean's Program, followed by IAMPHAT, Dead or Deadly and the Aqua Program. A few clients also mentioned women's healing campus, the Get Healthy Program.

Despite knowing about the program and viewing them quite positively, only a small number of interviewees were currently attending a program. Many of the interviewees felt that a group program to help them manage their chronic disease would be too much for them due to their health condition, too stressful, or otherwise unsuitable for them. Some, including those in paid

employment, felt that there needed to be more flexibility in the delivery of programs. A small number of clients said that they had previous poor experiences and would not be interested in attending a program again. Overall, however, those who had participated in the chronic disease programs spoke very positively about their experiences. A brief description of each of the programs and links to further information and service delivery organisations can be found in Appendix 1.

#### Positive experience of programs

Clients were mostly positive about the programs they attended and discussed a number of aspects about the groups and the program that they valued. The two main themes that came through from discussions about the IMPHAT program were the positive benefits of the social support provided by the program and its assistance in helping participants manage their health. The social support aspect has potential for both mental health benefits, providing a safe environment for participants to discuss their issues and challenges, as well as physical health benefits. Participants also felt it was important that they were looked after physically as part of the program, received information about their health condition and enjoyed the physical activity component of the program.

Many of the participants enjoyed the exercise aspect of the Aunty Jean's program, although some found this aspect difficult. Other aspects viewed positively were the opportunity for social interaction and learning about a healthy lifestyle. Participants were also appreciative of being able to link in with other programs such the over 40's program.

Participants in the Dead or Deadly program stated that if the program wasn't there they would not have the resources to help them manage their health and were keen that the program should continue to run in the future.

#### Hearing about the program

Participants heard about the programs from a range of sources including health care workers, written material and family contacts. Information about the Aunty Jean's program came from nurses, the Aboriginal health services, and during a stay in hospital. One participant heard about both the Aboriginal Health Worker and the Aunty Jean's program while in hospital. Another participant had been given a pamphlet about the program, although it was not stated where she received the pamphlet. Many participants knew about the program through their close family connections. Access to the program was also facilitated when participants were informed about the program for example by the ACCHS or by a health professional such as the diabetes educator and provided with assistance to attend.

#### Flexible delivery

The flexible delivery of programs and the informal nature of the interactions were frequently mentioned by participants. The Dead or Deadly Program has been running for many years and as a result many participants have come to depend on the program for helping them manage their health. The different times and locations appear to be of benefit to allow participants to attend at times and locations more convenient to them. The program, for example runs on different days and at different locations, is open to anyone on one of the days and with transport being provided on most days. As one participant stated,

*(it) works good. It fits in with my schedule. Focus Group Participant*

### Help in managing their condition

In regards to the management of their health, group participants were very positive about the program. Participants noted that feel taken care of as part of the program. They appreciated that staff did not push them beyond their limits and made sure any problems they have are taken care of as part of the exercises:

*The balance - I think the balance is pretty right in because if someone comes in and they've got a crook back rather than struggle and get back and we're pretty lucky, we've got a young girl, she makes everyone feel part of the group. But that's just the way we've sort of trained her to do that sort of stuff, hey. **Focus group participant***

*Yeah, she knows. So we make everyone feel comfortable, we've got to do. (name) and (name) and they go we've got to take it easy, walk out here today. So they really understand where we're coming from, so yeah, it's important for us, eh. But if we didn't have them... **Focus group participant***

Participants valued finding answers to their health problems:

*Yeah, because before I come here I was struggling to get answers for anything because you were just going around in circles with the doctors with mine because they didn't know why I had a heart attack. **Focus group participant***

*didn't know much about it. Now we know more about it. **Focus group participant***

Focus group participants noted that if the Waminda Service wasn't available then they would not be involved in any program to support healthy lifestyles:

***Facilitator:** So if the Waminda service wasn't available, how would – how do you think you'd be coping with managing your health, your diet, your exercise plans?*

***Focus Group Participant** Probably wouldn't. Well, we'd be off. Only for the ladies here, with the support of the ladies and the organisation here we'd be bugged.*

### Supporting behavioural change

Participants in the IAMPCHAT program talked about how the group supported behaviour changes:

*With our food, we come out here and we try and eat healthy food and we've got a strict rule that we don't eat cakes or biscuits or anything. **Focus Group Participant***

One participant noted that coming to the group was better than getting help from formal health services as the program brought in outreach workers to their weekly meetings.

### Appreciating the benefits of physical exercise

Many of the participants appeared to enjoy the exercise and other activities of the program and noted its positive effects. Some valued the fact that they were within their capabilities. For example one participant said:

*The swimming and that, walking, just different exercises and that there. You can do them sitting down. **Participant 1***

Others, however, found the exercise programs challenging:

*And Aunty Jean's is a bit – it's a bit of a – stressful, because you've got to be exercising and skipping and running and all that sort of stuff, so you've got to burn the energies up and burn out all the calories that's not supposed to be there. **Participant 19***

A number of participants expressed the need for caution in overdoing it with exercise. One participant experience of the Aunty Jean's program was expressed as:

*Yeah, it's good, exercise and that. I can do as much as I can, but sometimes I'm bugged with my foot and I'll have a rest. They say, 'Don't overdo yourself. Have a rest when you want to.' **Participant 2***

*I can't do it yet. I'm trying to get back with them because I loved it, but I wouldn't push myself too overboard. I do as much as I can. **Participant 2***

Participants were positive about the physical activity aspect of the program and felt it was beneficial to them:

*But we also had on the Thursday we do an exercise program and stuff like that. So it's getting us moving and not seizing up. **Focus Group Participant***

### Social benefits

Many of the participants were positive about the social aspects of programs. This was an important attraction of the Aunty Jean's program where typical statements were:

*No. My sister goes to Aunty Jean... She's always trying to talk me into going... She goes. She loves it... The company, the exercises, the lunch, yeah. **Participant 15***

*Yeah, back on track. Get back to Auntie Jean's and get a bit more – do a lot more than – I go to my little bingos. That's my little outing. That's what me and Auntie do. But a bit more out with the women over 50s. I want to get more involved in that one and then Aunty Jean's, as I said. **Participant 2***

Participants were very positive about the program and the Waminda Centre; some participants had been coming to Waminda for more than ten years. Participants enthusiastically described the different activities as part of the Dead or Deadly program, including gym exercises, beach outings and camping trips:

*This is a good program with our little exercise gym here. Sometimes we go on trips, stay away, camps and outings on the day I've got no, if we're here, but other than that I can't think of any other program. **Focus Group Participant***

*Yeah, we've got our women's evening house, and when I go there I sit in with them, and get into those programs over there and you can stay there as long as you like if you need that break away. **Focus Group Participant***

The social aspects of the IKMSG supported the health education and training received in the IAMPCHAT program:

*Well, The men's group, they go fishing, so they have a lot of seafood, just look after their bodies, do a bit of walking and stuff like that, it sounds all right. **Participant 19***

#### Improved understanding of health and nutrition

Some participants also felt they had learned about health from programs and that this was something they would remember later. In response to questions about the nutritional advice provided by the Aunty Jean's program one participant stated that:

*I eat pretty good here. But, I mean, after the operation I think I would be on a diet, which is good. Like I like my salads and all that. I think it would be good for me and then I heal a lot better, faster... Yeah, yeah, they were telling, yeah, sandwiches, brown bread. I eat really good. I don't eat much bread really. **Participant 2***

Another participant made the important observation, that information was more effective if it was repeated over a series of visits:

*A lot of information. But it gets up there and then I might remember it later. **Participant 14***

#### Opportunities to share information with others

Participants in the IAMPCHAT program spoke at length about how they valued being able to talk with others about any challenges they may have as well as the social support. The following quotes are from the IKMSG focus group:

*That's why this group is great. I think everybody, not just health wise but mentally wise. Blokes have everyone to talk to and we all have our own dramas we can relate to one another. **Focus Group Participant***

*Another thing, the guys kind of like to ask each other, how are you going with your diabetes, how is the heart going or how is your knees or whatever, people are concerned about how each other is coping. So that's the thing. **Focus Group Participant***

#### Culturally safe environment - respect, trust and confidentiality

One of the important features about Aboriginal programs highlighted by many participants was the way they showed respect for others in the program. This was important to members of the IAMPHAT program group as outlined by one participant:

*One good thing about this group here, when anyone new comes or anything like that we form a circle and it goes - Every introduce themselves around and you get to know everyone in that respect. **Focus Group Participant***

A sense of camaraderie was also noted among participants. In particular group members supporting each other by having a sense of responsibility towards the group:

*That's a big thing for our group, what I say here, is 'One in, all in,' that's what I say all the time. So we all do it together and it's the only way to go with it. Because otherwise a couple blokes will come in and say 'No, I don't feel like doing it today.' **Focus Group Participant***

Participants in the IAMPHAT program particularly valued the confidentiality aspect of the group:

*And that's something I couldn't usually say outside the group, talk about it. **Focus Group Participant***

*and there's no secrets between any of us here, we just don't start going out spreading rumours. **Focus Group Participant***

They felt comfortable in the program environment and spoke about the health consequences that they had observed among family members, such as amputations due to diabetes, as reasons for coming to the program/group:

*we've seen things happen in our families that made us quite aware. My mum, my grandmother, and my auntie had a leg amputated from diabetes. **Focus Group Participant***

When asked about how participants heard about the men's group one participant indicated they knew about it through a family connection:

*My nephew works for them... My uncles and cousins and all the rest of the nephews and family... Yeah, all related. **Client 19***

#### Accessing programs

Where transport was available, such as a bus to attend the Aunty Jean's program, this facilitated attendance. The bus to the Aunty Jean's program in Nowra was sometimes combined with a trip to see the GP. Transport to the program was considered important for participants of the Dead or Deadly program, as one woman said:

*If they're willing to take that responsibility, on travelling for us, pick us up and bring us to our things, and get our – like (name deleted) said, our medical checks and everything. **Focus Group Participant***

Another client said that assistance from the AHLO helped her 'get organised' to attend a program.

### **Barriers to participation**

There were several barriers to participation in programs, including lack of awareness of programs, difficulties in getting started, distance, physical or health limitations, work commitments and personal preferences. Many participants cited lack of transport as an issue, despite the fact that most of the programs offer free.

Some participants just had trouble getting started, particularly programs such as aqua which involved physical activity. As one participant noted 'I've just kept putting it off.' Distance from the program location was an issue others, and participants living in rural areas, particularly in the Shoalhaven, found it more difficult to attend programs:

*I know there's a couple rang me and then I – oh, I've got to go into Nowra ... either you've got to go somewhere further away and you go, oh, jeez... if it's close and handy and easy, well, I'll see, and that's it. **Client 16***

*Because I don't live right in town where they are, it's a bit hard to get in there. **Client 22***

*I've thought about going to Aunty Jean's, but because I can't walk very far, I haven't been able to get there. I mean for all the sorts of things they do, because I know people that go there and I can't get there at the moment, but I have thought about it. **Client 22***

Many clients felt their health condition was a barrier to participation, often because their symptoms, such as fluid build-up for asthmatics, that were hard to manage and that made attendance and participation difficult. A lack of strength or ability was also a reason given for not participating. One client felt they wouldn't be able to attend an Aunty Jean's program:

*No, I've been really sick. I haven't been back. I rung them today and I haven't really been back... Sometimes they say, 'Go and walk.' But with your leg, how are you going to do that? **Client 2***

*No, I wouldn't be able to do it; I just wouldn't be able to do it... I'd love to be able to do them, but I know I can't. **Client 3***

*No, no, no. I tried Aunty Jean's but I just don't have the energy. Look, I'm flat out getting out the back. **Client 7***

### **4.3.8 Aboriginal people's suggestions for improvement**

The Aboriginal people we spoke to had many suggestions for how improvements could be made. These centred on a number of key themes which are summarised below under the following broad headings: health service delivery; health information and communication;

providing programs that support and connect the community; involving the Aboriginal community in decision making; and greater accountability for Aboriginal targeted funding.

### ***Health service delivery***

#### Greater flexibility

- Health services and programs need to be more flexible, to take into account the participants' circumstances. Some notable examples were: the availability of transport which made it very difficult for participants, particularly those from the Shoalhaven to attend specialist appointments in Sydney; and participants who were admitted to hospital on a weekend would like to be able to see an AHLO.

#### Greater respect for Aboriginal people in mainstream health services

- Aboriginal participants want to be treated with respect by health services; they do not want to be judged or to feel that they are 'creating trouble', for example when they ask for more information. They felt there needs should be accommodated when they have large number of family members visiting them in hospital.

#### Support Aboriginal families

- Health services need to be more sensitive to the needs of the family and to provide more family support, particularly when in hospital. Health care providers need to adapt to family support during appointments. For example, they need to find space and chairs to accommodate several family members.

#### Cultural awareness training for staff

- Cultural awareness programs should be mandatory for all trainee doctors, nurses, midwives etc. Cultural awareness should be provided by people who have knowledge in Aboriginal ways. Some Aboriginal people do not know everything about culture. There is a need for both qualifications and an understanding of Aboriginal culture.

#### More Aboriginal workers

- There is a need for more Aboriginal health professionals at all levels, particularly in hospitals settings, in both Aboriginal identified and mainstream positions.

#### Aboriginal Community Controlled Health Services as models for service delivery

- The ACCHSs in the Illawarra and Shoalhaven were held up as models for how participants do wish to be treated by the system, that is, with respect, care and competence.

### ***Health information and communication;***

#### Better access to information about how to manage their condition

- Several participants received insufficient or no information about their condition. Services need to be more strategic about when and where information is provided. It is important to give the right amount of information and follow-up with extra information if requested. Information needs to be in language that Aboriginal people can understand. Participants may need support to access information using new technologies.

#### Better communication with patients

- Participants complained about being 'talked over' by health practitioners, as if they were not there. Health care providers need to be much better at listening.

***Community education that encourages sharing of information***

- Acknowledging that people with chronic disease play an important role in the management of their own health, many participants recommended community education that encourages the sharing of information. There were various suggestions about the form that community education should take. Some participants thought that ongoing education workshops or discussions forums to share experiences would be helpful as ‘it’s good to yarn up about your problems.
- Others went further and some suggested education and media campaigns showing negative impacts graphically in real life films, such as those used in other health areas (e.g. drink driving deaths), could be helpful in building awareness of consequences of individuals not taking responsibility of their health).

***Fund existing culturally safe programs that support and connect the community***

- There was overwhelming support across participant groups for the small number of existing culturally safe programs that provide opportunities for Aboriginal people to communicate build awareness and encouraging others to take action (for example IAMPHAT and Dead or Deadly). Participants particularly valued the opportunity for frank and open discussion where they could talk openly and ask questions about their health issues in a safe, respectful and non-judgemental environment. They felt encouraged and supported by the Aboriginal leadership of elders and hearing the experiences of others made them realise they were not alone.
- Gender specific programs were seen as very valuable. Women who attended Dead or Deadly preferred to come to a female only group. Men at the IAMPHAT program expressed the view that they find they often feel that they lack support around them and have to do it themselves.

***Improve decision making and accountability for Aboriginal targeted programs***

- Participants thought that those making decisions about policies and service delivery should seek a broad range of Aboriginal community views in decision making, and not just seek the views of experts.

## 4.4 Section summary

Based on the interviews and focus group discussion undertaken with Aboriginal participants in the study, this section provided detailed information about how Aboriginal people experience the health system. This information was presented around eight key questions of interest. The findings of this enquiry are briefly summarised below:

### **Experiencing the system: Aboriginal perspectives**

#### **1. Understanding of their health condition**

- There was wide variation in the way participants understood their chronic condition.
- Individual responsibility for health and the role of lifestyle choices were significant considerations for Aboriginal people.

#### **2. Recent hospital experience**

- Positive experiences in hospital focused on the kind and helpful treatment by staff.
- Negative aspects of hospital stays were widely reported and included feelings of isolation, confusion and restrictions resulting from the physical hospital environment.

#### **3. Information and support from hospital staff**

- There is inadequate information provided to Aboriginal patients in hospital about how to manage their chronic condition at home.
- Communication between doctors and patients was often poor.
- Many patients had received positive support from nurses and Aboriginal Hospital Liaison Officers (AHLO).

#### **4. Managing their chronic disease at home**

- There was wide variation in the way participants manage their condition/s at home.
- Health literacy and lifestyle modifications were key challenges.
- The need for behaviour change was not always well communicated by health professionals and was frequently seen as judgemental and difficult to accommodate.
- The quality and accessibility of the information provided was extremely variable.
- Problems related to medication included the lack of knowledge of how the medicine helps, negative side-effects and difficulties of managing within daily routines.
- Enablers for managing a chronic disease included the provision of information both in person and by phone, family, doctors and the ACCHS.
- Barriers for managing chronic conditions include stereotyping and racism as well as relationships with health professionals and lack of effective communication.

#### **5. Accessing health care**

- Supports available through programs funded under the Closing the Gap (CTG) strategy and other Aboriginal services and programs have alleviated some problems associated with transport to access services and programs
- Transport remains a barrier to accessing mainstream services, hospitals and attends specialist appointments in Sydney, particularly for Shoalhaven residents.
- The costs involved in accessing medical services, including medicines and specialist services, were barriers, particularly for those on disability and other pensions.
- There was considerable variation in views about the cultural appropriateness of current health services.

## **6. Experiencing local health services and having a care plan**

- There was wide variation in the way participants described their experiences of using local health services for chronic disease management
- Services discussed included GPs, medical specialists, IAMS (CDMP), SCMSAC (CCSS is jointly operated with GPH).
- Medical care and support received at local GP services was generally highly regarded, and included yearly check-ups and regular visits.
- Many patients reported not having a GP care management plan.
- Having a GP care management plan improved access to support services, including through CTG.
- Overall experiences of Closing the Gap (CTG) funded programs varied, with participants reporting a lack knowledge about available support, inconsistent support and the burden of having to register on an annual basis.
- Attendance at Aboriginal Community Controlled Health Services (ACCHSs) was overwhelmingly positive experience
- Having to provide proof of Aboriginality was a problem for some who accessed services through CTG and some ACCHSs.

## **7. Experiencing Aboriginal Chronic Disease Group Programs**

- Most patients had heard of group-based Aboriginal chronic disease program, but many had not attended one.
- Aunty Jean's was the most well-known program and generally regarded positively with participants valuing the social, exercise component and appreciating the support and sensitivity of professionals such as nurses and diabetes educators.
- Gender specific programs provided a convivial and supportive environment.
- Availability of transport to and from the program was an important facilitator to ongoing participation.
- Reasons cited for choosing not to attend a program included, difficulties in getting started, lack of transport, work commitments, personal preferences, feelings that the program would not be beneficial or too stressful, and the physical limitations associated with their chronic health condition.
- Barriers to participation included lack of flexibility in program delivery.

## **8. Suggestions for systems improvement**

- Improve health service delivery through greater flexible delivery of health services; better health information and communication with patients; better support for families; cultural awareness for staff; more Aboriginal workers. ACCHS were models for service delivery.
- Better health information and communication; providing programs that support and connect the community.
- Community education that encourages sharing of information.
- Fund existing culturally safe programs that support and connect the community.
- Involve the Aboriginal community in decision making and greater accountability for Aboriginal targeted funding.

## 5 Experiencing the system: Service providers and system stakeholder perspectives

Information about managing and providing services within health system was sought from two participant groups: health care providers and a broader group of individuals whom we have referred to as system stakeholders'. The recruitment of service providers, program managers and systems stakeholders was designed to draw information from as broad as possible range of health professionals, organisations and sectors, within the timeframe and resources of the project.

In addition to those in a direct service provision relationship to clients, the study sought to obtain the views of experienced Aboriginal and non-Aboriginal professionals from a range of policy, research and health service organisations across the Illawarra and Shoalhaven. The eight system stakeholders invited to participate in the research were employed within the following organisations: UOW, GPH, ISLHD and the ACCHSs.

### 5.1 Interviews with service providers

The 22 service providers who agreed to participate in the research were selected from a broad range of organisations across the two regions, which included:

- ISLHD (See Table 7)
- Aboriginal Community Controlled Health Services (IAMS, SCMAC, Waminda)
- Private general practitioners
- Private health professionals
- Non-Government Organisations (Grand Pacific Health)

Of the 22 service providers interviewed, 18 were female (81.8%) and four were male (18.2%). Eighteen were from the Illawarra region, three from Shoalhaven and one from Illawarra and Shoalhaven. Two interviewees (9.1%) identified as Aboriginal and / or Torres Strait Islander. The majority (16, 72.7%) were from the ISLHD. Other organisations were private GP, the Australian Diabetes Council, IAMS, and GPH (GPH). Other characteristics of the services providers are presented in Table 7.

**Table 7 Service Providers**

Organisation / Division	Position
ISLHD / ARC 48 Hour Follow-Up	Nurse
ISLHD / ARC 48 Hour Follow-Up	Nurse
Aboriginal Community Controlled Health Service	GP
Aboriginal Community Controlled Health Service	GPR
Aboriginal Community Controlled Health Service	GP
Aboriginal Community Controlled Health Service	Diabetes Nurse Educator
ISLHD	Respiratory CNC
ISLHD	CNC
ISLHD / Renal Services	Nurse Practitioner Renal Services

Organisation / Division	Position
ISLHD / Illawarra Heart Health Centre	CNC
ISLHD	CNC Cardiac
ISLHD	CNC Chronic Kidney Disease
ISLHD / Heart failure	CNC
ISLHD / Social Work	AHLO
Private practice	GP
ISLHD / Social Work	AHLO
ISLHD / Podiatry Service	Podiatrist
ISLHD / Podiatry Service	Podiatrist
ISLHD / Podiatry Service	Podiatrist
Australian Diabetes Council	Diabetes Educator
ISLHD / Social Work	Social Worker
Illawarra Diabetes Service	Diabetes Educator

## 5.2 Interviews with system stakeholders

Of the eight systems stakeholders interviewed, five were female (62.5 %) and three were male (37.5%). Eighteen were from the Illawarra region, three from Shoalhaven and one from Illawarra and Shoalhaven. Two interviewees (9.1%) identified as Aboriginal and / or Torres Strait Islander. Three had positions based in the Illawarra (37.5%), two were based in the Shoalhaven (25%) and three worked across the Illawarra and Shoalhaven (37.5%). Other characteristics of the system stakeholder participants are presented in Table 8.

**Table 8** System stakeholders

Organisation	Position
University of Wollongong	Academic
ISLHD	Coordinator
NGO	Team leader
NGO	Manager
NGO	Manager
ISLHD	Project Officer
NGO	Manager
ISLHD	Manager

## 5.3 Key questions of interest

The service providers were drawn from a range of government and non-government organisations ACCHSs and private practice, and across various divisions within the ISLHD which treat people with chronic illnesses. They were experienced in a wide range of professional and clinical roles including Aboriginal health workers, registered nurses, nurse educator, clinical nurse consultants, doctors, allied health worker, senior health managers, podiatrists, respiratory CNC, diabetes educators, outreach workers, team leaders, chronic disease project managers, child and family health workers and social workers. Many had extensive experience as clinicians in Aboriginal health over many years, while others were less experienced. All service providers were aware of the high burden of chronic disease amongst the Aboriginal

population, and many were treating people for a range of illnesses including: renal disease, diabetes, ischemic heart disease, and respiratory diseases.

The majority system stakeholders interviewed had previous experience working with Aboriginal people experiencing chronic illness, some with substantial experience in coordinating Aboriginal programs and managing teams, including programs for women and youth. Only one mainstream manager had no previous direct experience with Aboriginal programs.

The responses from the service providers to the questions asked in the individual interviews and focus groups are presented below under the following headings:

- Providing positive support
- Difficulties in providing support
- Referral
- Understanding the needs of Aboriginal clients
- Providing culturally appropriate health services
- Suggestions for improvement

The actual set of questions asked can be found in Appendix 2.

### 5.3.1 Providing support

#### ***Findings from service provider interviews***

There were many ways in which positive support was provided.

For a private GP with a large Aboriginal clientele, this was done in a very comprehensive way; the key aspects were - establishing relationships; awareness of transport needs; flexibility; and networks:

*I think the key thing is the relationship with the person, and so being a long term GP in the town I think makes a very big difference. Because I had the opportunity to work in the community, in a clinic, and see folk in their own homes and know the much broader family, then I think establishing that relationship was a lot easier than, for example, if I'd been some distance, or I'd not had the opportunity to actually be in people's houses and know everyone, immunise their kids, look after pregnant mums, and that whole kind of whole life thing that you get to be able to do as a GP over time. So that's a huge advantage. The other couple of things which we have found important in our surgery is that we're very aware of the difficulties with private transport, with car ownership, with multitude of demands that family members have, such that turning up at an appointment time is jolly difficult. So we have a very flexible approach to appointments for Aboriginal patients, 'cause we're very mindful of that. So we make appointments, but we're also just very mindful if someone turns up, we'll just see them, and if they turn up an hour late we'll still see them, and if they don't turn up, we remind them until they see us, and that's fine, and we just build that into what we do, and that just makes a big difference, it just takes all of the tension out of the appointments and so on, and it means that we're able to maintain relationships quite well. And then I think the third thing is just the*

*network of who else are we going to get this person to see, and having a network of people that we think would be culturally appropriate or culturally aware so that we can build effective multidisciplinary teams for people. Service provider 15*

The approach of ACCHSs over many years is to put the Aboriginal health workers in a key position in patient care. Patients at the IAMS are first seen by the Aboriginal Health Worker who initiates an Aboriginal/Torres Strait Islander health assessment. If a chronic disease is detected a nurse will prepare a chronic disease management plan; the patient will then see a GP who signs off on the plan. Team care arrangements may then include allied health providers, diabetes educator nurse, optometrist, and the chronic care Aboriginal health worker.

Other perspectives which produced positive delivery and provided community support included delivering the Closing the Gap medications assistance, assisting Aboriginal people with the right information on Type 2 diabetes and foot care, cultural safety, ensuring system flexibility, making the connection to other services, respecting the contribution of Aboriginal Elders, and build the capacity of Aboriginal people.

The Aboriginal Hospital Liaison Officer position was identified as a positive and contributing factor to supporting Aboriginal patients and their families, both in the follow-up care with hospital, assisting GPs with care coordination for Aboriginal people, and by building networks and information sharing with other care professionals in attending seminars and conferences.

Other service providers emphasised the importance of the personal interaction:

*'yarning, listening, respecting family and making people feel comfortable'.*

Building rapport, trust and continuity with Aboriginal communities was acknowledged as a long term process; and should address the particular needs of cultural groups in program delivery, as well as Aboriginal men's and women's groups. It was expressed that Aboriginal Programs were vital:

*[c]ommunity who attended the health programs say they would be dead without it*

### **Findings from system stakeholders**

System stakeholders were able to draw on their broader experience to suggest ways in which positive delivery could be achieved. Some emphasised the importance of establishing a relationship with Aboriginal clients in care coordination and in organising a care plan.

Some participants acknowledged that was difficult to get Aboriginal people to come in and use services. One of the difficulties in service delivery is that people may be overwhelmed with having things pushed at them:

*I think sometimes...that we've overwhelmed people with a lot of it, they get tired of having the same thing pushed at them, tired of surveys and things like that. Maybe that's a reason, I don't know. Maybe we have to look at something different.*

**Systems Stakeholder 7**

Aboriginal organisations acknowledged that they were looking at more innovative ways of engaging people because of the reluctance of many Aboriginal people to access services:

*because we'll ask them, "Would you like a letter sent, would you like an SMS sent out?" A lot of them prefer the SMS. I mean, they're very transient, a lot of people. You can send a letter and they don't get it...We're now setting up in the waiting room a video, an ongoing video of health messages, health information that's going to continually run in the waiting rooms at Dapto and Wollongong. That's in the process of putting that up for people. Yeah, so in terms of communicating to people about the clinics and things like that, I mean, we've got a newsletter, a Facebook page, we've got posters and that up.*

**Systems stakeholder 7**

In this service, SMS messaging was used to connect with clients to remind them about their appointments and things like that. They also give clients portion control plates, diabetes booklets and magazines and are looking at a system of giving people who turn up for appointments incentives such as fruit and vegetable boxes.

One systems stakeholder spoke of past project in which the government had provided a mentor that supported the roles of the project coordinators:

*So they would ring up and suggest different ways and different things and they had some conferences specific for outreach workers. So we all got together fresh, new role and we were able to nut it out and say how did that work for you and what did you do for that, this is what I did and you'd gather information and gather notes about other ways to do things.. Those conferences were just priceless because we were all battling along and it was difficult to roll a position out with no structure.*

**Systems stakeholder 1**

Not all system stakeholders saw the need for special support for Aboriginal people. One hospital based manager without direct experience with Aboriginal service delivery, described the provision of health services to Aboriginal people as the same as for any client:

*how it works is patient that get admitted to the hospital with an acute (condition), whether it's an acute exacerbation of a chronic condition or it's a new acute illness, they're normally reviewed by the (named) CNC and then if they meet her criteria for the wellness program she refers them and yeah, so it's like a gentle exercise program, education, those types of activities. **Systems stakeholder 8***

### 5.3.2 Challenges in providing support

#### **Findings from service provider interviews**

The majority of those interviewed believed their role was about empowering Aboriginal people, and providing the necessary skills to educate Aboriginal people on the prevention of chronic disease and to provide Aboriginal communities with the information and knowledge to manage their chronic condition. It was noted by a number of participants that Aboriginal peoples 'long

history of disempowerment' and feelings of 'shame and powerlessness' impacts on self-managing their health issues and chronic disease.

Observations were made about the complexity of the Aboriginal family structure, which included the care responsibilities of grandparents for grandchildren whilst trying to manage their own chronic conditions, the need for flexibility in attending appointments because of deaths in the family, dealing with mental health issues (their own and others) and private and public transport availability (for example, a lack of car ownership or reliable vehicle, public transport connections and the availability of community transport).

The majority of service providers identified that Aboriginal clients often present with mental health and chronic disease; and 'often the mental health issues are major compared to their chronic health issues'. Noting that, 'managing a patient's diabetes or heart disease is a lower priority'.

But many services providers spoke of the difficulties of operating within the current systems. For example, the acknowledged the difficulties of navigating the complex health system:

*I know there's a whole pile of (services) out there, but I don't know all of them. I think probably navigating the health system is complex for anybody, especially people from non-English speaking background, especially for people from Aboriginal*

The lack of services, particularly in the Shoalhaven, was identified by a number of practitioners, one of whom described the service provision in the area as 'uniformly poor', but 'incrementally getting better'.

The only general practitioner interviewed noted that of the biggest challenges was the cost of specialist appointments:

*The main issue for our service is getting Aboriginal people to specialists when they really need to go ... its very costly. A client had an appointment that cost \$300 ... they don't eat for a week ... very bureaucratic to get all the costs. **Service provider 3***

Some service providers acknowledged the difficulty of offering best practice in chronic disease management, and of measuring its success:

*It's very difficult to know what you class as success in chronic disease management. If I look at good services it would be services that have good attendance and none of us are achieving that. I don't think there is a best practice model. There is fragmentation. There is no coordinated systematic approach to manage Aboriginal people. **Service provider 22***

Others noted the over emphasis on services meeting key performance indicators

*In all our models of care that we are providing in the services we are probably letting them down because we look to the key performance indicators. It's all about numbers. Continuity of care is the big thing. Successful programs are the ones that*

*health professional that are always there and always available. Medical services are too medical ... it's about getting them in and out. Service provider 20*

Further difficulties in delivering Aboriginal patient care were discharge issues, such as the lack of understanding from medical staff of Aboriginal patients complex needs of support, lack of attention to the readmission of Aboriginal patients to hospital, a transparent process to identify Aboriginal patients are discharged to an environment that is safe and has ongoing physical support structure (in rural or remote communities patients were discharged home where no phone contact was available, no running water or toilet facilities and outstanding house maintenance repairs) and the lack of direct communication from hospital staff with GPs on patient discharge to ensure treating GP can accommodate patient appointments, medication requirements and follow-up. The following comments from a GP illustrate the frustration which arose in GP practices as a result of this lack of communication:

*but no-one's contacting me to say, what's their management normally like? What's their blood pressure normally like? I'm going to send them home, do you think there's enough supports in place? Do you think you might be able to see them? So there's none of that communication. They just come home. There may well have been and a number of strategies put in place, but all I'll find out about is I'll get a discharge summary which states that we've directed the patients to their GP within a week, and that's an extreme frustration, because it would be really nice if I got a phone call on their in, really nice to get a phone call to know they were coming out, and then I could make sure there was an appointment available. I don't know of any GP practices that have got appointments within a week. Service Provider 15*

The role of Aboriginal Hospital Liaison Officer was also raised in our discussions with service providers in relation to challenges in providing support. Although service providers were positive about the importance of the AHLO, as previously discussed, they also noted the challenges inherent the position. The AHLOs interviewed supported this view. One AHLO described the role as very 'prescriptive', being in an acute setting, and posing numerous challenges in delivering service. Some of these were: the absence of handover to new AHLOs; cultural isolation within the system; cultural safety; opportunities to debrief with Aboriginal team members; potential for burn out; lack of resources to undertake the work required (for example, IT, phone and transport); heavy workload in dealing with health and non-health issues (for example, Centrelink, homelessness, psychosocial issues, health justice, criminal matters, deaths, health advocacy, linking clients with out-patient services and support). AHLOs spoke of difficulty arising from the need for hospital admissions staff to have to consistently confirm Aboriginality to initiate an immediate link to the AHLO and they were frustrated by the lack of flexibility in the system for the AHLO to address the social needs of Aboriginal people and the lack of access to systems, such as the My Aged Care System.

*When you have to do a psychosocial assessment for an Aboriginal person but their areas of need are Centrelink issues and it's creating high levels of stress and it could render them homeless. So during their admission you're working on Centrelink issues. Aboriginal people's issues are very complex. Service provider 14*

Other service providers were very positive about the importance of the AHLO. It was expressed as, 'managing the health journey for the Aboriginal client's expectations, for their family and

the medical requirement of managing chronic conditions'. The work of an AHLO was referred to as 'intense case management' that also supported Aboriginal client's multiple presentations, readmissions and 'end-of-life' stage. One example in a hospital referral to the AHLO was to assist with a patient refusing assessment and treatment, the AHLO engaged with the patient and identified underlying mental health issues. However it was recognized that the role is a very challenging one, as they had to deal with so many issues:

*When people leave the hospital they're not aware of the service and if they had that first contact with an AHLO in hospital then it would have a flow on effect. AHLOs have so much to do ... it's a work in progress. **Service provider 2***

The death of Aboriginal patients with chronic conditions was expressed by one participant as 'highly emotional and highly charged', where many family members attended. Further issues to be addressed for Aboriginal patients were the high number of Aboriginal people with chronic diseases presenting to the emergency department with other social issues such as housing.

### **Findings from system stakeholders**

There were a range of responses in relation to delivering government programs in primary health care for Aboriginal people, for example, Aboriginal programs that were launched without strategies and deliverables, the uncertainty of short-term funding on the continuity of Aboriginal programs and the continuous challenge of local transport connections within the Illawarra and Shoalhaven region and arranging clients to attend their appointments in the Sydney area.

From the perspective of an ACCHS, the main difficulty was the inflexibility of funding arrangements:

*We all know that Aboriginal people are a high rate of chronic disease patients. The government still keeps telling us, "Here's some money here, but you have to do this, this and this with it." They don't seem to make allowances for you to tailor make something, you know what I mean? **Systems stakeholder***

For example, in this service, mental health was the major problem within the service, but there was no flexibility in the funding arrangements to deal with it. Overall there needs to be a much stronger focus on the nexus between mental health and chronic disease.

System stakeholders also spoke of the difficulties which arise from 'quick fix' programs rolled out from the government with short term funding and unrealistic expectations. Such practices by government led to a loss of trust and engagement by community, and also fared badly for the Aboriginal health workers engaged to deliver programs:

*(the community) lost trust in a lot of organisations because they'd roll out to the community, bombard them with all these things, resources and information and it was just too much and it was gone in three months and they go just as they were starting to engage and feel there was a trust and confidentiality, just when that was developing, we'd be gone. The funding had stopped and so they'd say, "Oh, what happened to that? I was going to do that." **Systems stakeholder***

### 5.3.3 Referral

#### ***Findings from service provider interviews***

The referral process received a wide ranging level of responses, for example, in how effective or not the referral process works; the effectiveness of referral pathways; the networking of service providers within the health system and the availability of specialists for referral across the Illawarra and Shoalhaven regions.

The referral process for Aboriginal clients included a range of pathways;

The 48 Hour Follow-Up program, operated by the Access and Referral Centre (ARC) team at Port Kembla Hospital, the program involves a phone follow-up from a health professional to Aboriginal clients within 48 hours of their discharge from hospital. Follow-Up covers issues such as medications (knowledge of and access to), referrals (booked and transport arranged) and general wellbeing. This is to ensure appropriate links to GPs, ACCHSs, Specialists, or other services to provide care post discharge. The program works closely with the Aboriginal health worker from GPH:

*They 'all sort of know the health care workers' and that breaks down the barriers a bit. The AHWs also provide feedback to the 48 Hour Follow-Up person who has made the referral. **Service Provider 1***

One problem identified, however, is that 48 Hour Follow-Up is not widely known across the Illawarra and Shoalhaven. One private GP with a large Aboriginal clientele over many years had not heard of the program, while a manager of an ACCHS asked if the program was still operating.

Some participants were critical of services which were too 'in-house' and did not refer out, with detrimental effects on Aboriginal and other clients. Others however were hopeful that improvements were being made in referral practices in their organisation:

*We have business rules and referral pathways and we have tried to model towards best practice with evidence-based guidelines for Aboriginal health. Hopefully this will prevent complications in treating chronic disease. **Service provider 18***

Participants accessing the Chronic Disease Management Program at the IAMS have a wide availability of internal and external referral options to them. The IAMS, for example, participates in the Australian Government Practice Incentives Program (PIP) Indigenous Health Incentive, as well as providing bulk billing for GP services which may include a GP Management Plan and Team care arrangements. Other relevant services provided by the IAMS include Alcohol and Other Drugs, Social and Emotional Wellbeing, the Cancer Team, Family Support and Dental Services. A visiting psychologist from GPH also sees patients. Referrals can be made to medical specialist (e.g. endocrinologist), allied health (e.g. physiotherapy) and community programs (e.g. ISLHD's Aunty Jean's). A visiting psychologist from GPH also sees patients. Men's health checks are also conducted.

### ***Findings from the system stakeholders***

System stakeholders identified a number of issues around referral, including the need to individualise the referral process to individual circumstances, the lack of specialists in the service regions such as Nowra and long waiting lists, and the lack of AHLOs and resources to service Illawarra and other regional services across hospitals and other service providers:

One mainstream systems stakeholder was removed from the day to day business of referral:

*Oh, so normally that's done at ward level, so either the nursing staff do it or we do have a discharge planner or social worker, so, whatever the discharge planner tends to get involved in more complex. **Systems stakeholder***

Some noted that although the integrated-health care model is considered the model in service delivery that there are considerable gaps in the local experience of referral pathways. It is suggested that a framework around Aboriginal health within the local health district be adopted to build the capacity of Aboriginal health workers, to provide culturally appropriate health services and create mindfulness with the complex day-to-day experiences within Aboriginal families. The AHLO was seen as playing an important role in ensuring health service referrals after discharge from hospital.

Referrals from ACCHSs and the hospital facilitated connecting Aboriginal people with CTG funded programs. One manager noted that when the AHLO position was vacant there were significant decreases in the number of referrals from the hospital system to the CTG providers.

Improvements to the discharge follow-up were needed in helping Aboriginal community follow-up, for example, Aboriginal people were discharged with only 3 days medication, and the GP appointments were booked out for several weeks; problems with finding contacts in hospital was difficult.

It was identified that the need to explain to Aboriginal patients the process of discharge, planning and follow-up when they leave hospital, as well as communicating health information in a way that is not overwhelming and user-friendly. The Aboriginal Hospital Liaison Officer was regarded as very valuable in the care coordination of Aboriginal patients.

### **5.3.4 Understanding the needs of Aboriginal clients**

#### ***Findings from service provider interviews***

There were diverse views expressed about the 'needs' of Aboriginal people, by service providers. The majority of participants recognised that Aboriginal peoples have distinct or different needs to other groups, not only for their priority in chronic disease prevention and management but by their cultural heritage and identity, cultural responsibilities and history.

Others observed that the medical needs for chronic conditions are the same for Aboriginal and non-Aboriginal individuals, however the way practitioners 'handle the treatment of Aboriginal people is different'. Some noted that it was a 'mistake to generalise about Aboriginal people and that you need to work with the individual'. For example, Aboriginal people may access

ACCHSs (requires confirmation of Aboriginality and approval by the ACCHS Board) that many chose not to use these services, opting for private practice or medical centre.

A few recognised that although Aboriginal people share a strong focus on community, as health care providers they had to recognise the great diversity in the Aboriginal population. For example, the information provided to them needed to reflect their own lived experience, but this was not always the case; health information such as pamphlets, brochures made available about some chronic conditions reflected the realities of remote areas, more than the south coast of NSW:

*"in renal services we often use a lot of patient pamphlets and information ... But patients need different information along their sort of journey ... some of the materials that we have are targeted for Aboriginal people who are perhaps living in the Northern Territory and some of the remote communities ... I'm a bit reluctant to use some of those here and I've actually had some advice from some of the health workers about this information and they also felt it wasn't very proper because just the way people look - identify might not be exactly what's appropriate" **Service Provider 9***

There were views expressed on the high level in 'social stress' that many Aboriginal people live with on a daily basis, from balancing employment and cultural obligations such as 'taking time off for Sorry Business, Men's and Women's Business', managing the financial burden of being sick, caring for family with chronic conditions, affording medications, dealing with literacy issues (their own or others) and keeping appointments:

Service providers also recognized that Aboriginal people were sometimes fearful of diseases, such as diabetes, because of the strong family history of this disease:

*if a family member or loved one has diabetes they're fearful of it ... fearful of going onto insulin ... fearful they'll lose a leg ... it's about dispelling those myths. **Service provider 6***

### **Findings from system stakeholders**

Those system stakeholders who had extensive experience in working amongst Aboriginal communities acknowledged the many barriers to accessing care for chronic conditions, including the high costs of medical specialists; this led to Aboriginal people were being admitted to hospital with serious issues because they couldn't afford the specialist. They pointed to the need for improvement with cultural understanding of Aboriginal people's needs among medical practices and specialists' rooms.

Other significant barriers for Aboriginal people accessing care were a range of transport issues that included the lack of availability of local transport systems which connect the Illawarra and the Shoalhaven, the availability and high costs of transport to the Sydney region, the uncertainty in arriving to appointments, not having a licensed driver in the family group and long waiting times for specialist appointments in the South Coast, particularly the Shoalhaven. These comments were consistent with the comments made by Aboriginal community members in this study:

*For example, someone at Wreck Bay might have needed a referral to a specialist in Sydney. So Wreck Bay is 45 minutes from Nowra and then we're two and a half hours to Sydney from Nowra. So to get them there for a specialist visit was quite an exercise. So we'd get transport organised, get them to Sydney. We'd generally get them up there the night before if it was an early appointment and we'd allow for a family member to go. We'd put them in a motel, same with an operation from the Sydney Hospital. So those sort of things, that was one of the barriers, transport. The cost was another barrier. **Systems stakeholder***

Some non-Aboriginal participants noted that it was hard to understand the different politics between some Aboriginal groups, and understand the history between them and how to develop good working relationships in the health system. Aboriginal cultural awareness training was identified as very important to underpinning these relationships and to develop a common understanding that service providers may also feel challenged in their service role within Aboriginal communities.

Other needs identified included the particular issues around elderly Aboriginal people who, because of their past histories and difficult family backgrounds, had little trust in any medical services:

*So we had to go very gently with our elders and we had to make sure that they fully understood what the problems were and if they didn't comply, what the consequences would be. So generally we'd get some of the family members involved with consent and they would come into some appointments with us or we'd give them the information to get the person to the place they needed to be. **Systems stakeholder***

The issue of the hospital system not understanding the need for family visitors in hospital, which was raised by several Aboriginal participants, was reinforced by the experience of the system stakeholders, who suggested bringing family into the conversation was a way forward that met the needs of elderly Aboriginal clients:

*In the hospital system there was a lot of problems where they didn't understand that family come in. When the family come in that the whole family comes in. It becomes a family issue if someone's sick. So there was lots of things like that but it was particularly with the elderly that didn't trust and so we had to build up that rapport, and once things started to happen for them and they felt better, things changed and they were happy to engage with what they had to do from there on and comply and as long as they knew the situation in layman terms instead of going technical. A whole lot of technical information when you're sick, you can't take it in. So we found the best way was to bring the families in and generally someone younger that could take hold of the information and go with it. So yeah, that's sort of what we found. **Systems stakeholder***

System stakeholders also gave valuable insights into discharge planning:

*We need to be mindful of the type of language we use and how we explain the needs of individuals when they leave hospital around discharge, discharge planning ... information to take on board ... that's where AHLOs are very valuable. (System stakeholder 6)*

### **5.3.5 Providing culturally appropriate health services**

#### ***Findings from service provider interviews***

One of the main ways cultural appropriateness of health services is approached in mainstream services is through cultural awareness training. The mandatory 'Respecting the Difference' training is being rolled out throughout the staff of the ISLHD; however some service providers noted that not all staff had been trained due to the need to engage Aboriginal trainers to complete the training, while others commented on the inconsistent level of cultural awareness, particularly within the hospital system.

*Generally the cultural awareness of the staff is terrible. You can go to one ward in a hospital that is brilliant. The other one is absolutely terrible. They are terrible. Most referrals are made because a person looks Aboriginal. **Service provider 16***

Many participants viewed the high rate of success delivered from Aboriginal health programs such as Aunty Jean's as a 'brilliant chronic disease program' which provided individualised support, attendance flexibility and culturally appropriate environment to provide results. Non-Aboriginal staff commented on the invaluable links created by working with the ACCHS and being involved with the Aunty Jean's; which promoted other services available for Aboriginal clients and could provide access to the statistics on chronic disease in the regions. Developing relationships of trust with Aboriginal clients, Aboriginal health workers and community was mentioned often and the positive environment it facilitates:

*We're big on talking about integration of services but there is a big gap in referral pathways.*

A number of participants held the view that committed and ongoing funding for additional Aboriginal health workers is required to achieve success. In particular several commented on improved outcomes for Aboriginal health staff in the appointment of an Aboriginal identified director in the Local Health District such as creating Aboriginal career pathways, strategic Aboriginal health planning, in building the capacity of Aboriginal staff into the practice streams (increasing the number of clinicians) :

*The biggest turnaround was recognising that the health system needed Aboriginal health workers in Aboriginal health settings*

Aboriginal health workers related that their own identity as an Aboriginal person was the key to achieving successful outcomes for Aboriginal people. However many participants highlighted the stress of meeting those complex needs of each client required a higher expectation of performance from Aboriginal families and the client:

*I am an Aboriginal person first and foremost. I live in my community and whatever decisions, whatever I say, whether they're adverse or whether they're good, impacts on me emotionally, spiritually and physically ... it's very complex being an Aboriginal person ...*

Additional comments outlined ways of achieving success such as; ensuring networks are strengthened with Aboriginal and non-Aboriginal local health workers to achieve patient education on chronic disease management, increasing the number of Aboriginal CD health programs, improving communication from GPH and Aboriginal health workers, funding mobile outreach CD programs, ensuring gender-appropriate staff positions for men's or women's programs and services and the continuation of Closing the Gap funding for Aboriginal health.

A number of participants highlighted the complexity of Medicare billing and the time it takes to train staff in this system; noting that servicing chronic care is complex enough and the current system requires a review. To improve the success and coordination of Aboriginal appropriate health services it was the view that there was a need to have service agreements (MOUs) with NGOs and other service providers. The promotion of health prevention for Aboriginal youth on chronic disease education was a key to reducing adult chronic disease; and linking with the mum's and bubs groups and increasing dental services for youth.

#### ***Findings from system stakeholders***

System stakeholders recognised Aboriginal Health Workers from GPH as significant in helping Aboriginal patients with follow-up care after discharge from hospital, for instance with networking with hospital staff, connecting with specialists, providing information on Aboriginal community programs, accessing assistance with the cost of medications and hiring equipment to manage the patients chronic condition such as sleep apnoea.

The importance of providing culturally appropriate Aboriginal programs such as the ISLHD Aunty Jean's Chronic Care Programs in Ulladulla, the Fighting Fit Program were identified as empowering Aboriginal people to manage their chronic condition. Aunty Jean's Programs provided community members with support in exercise participation, nutrition. In Ulladulla Aunty Jean's program is the main referral for patient. In Nowra, SCMSAC and Waminda provide the CCSS program for Aboriginal people

Nurturing community trust in care providers was identified as important to building rapport and positive relationships to be accepted. In particular elderly Aboriginal people had difficulties with trusting the hospital system and medical services because of the lived experience, past histories and stories of Aboriginal family. It was noted that Aboriginal clients don't only have a single chronic disease but have a huge range of problems which compound the management of chronic diseases. Further it was seen as necessary to try to address most of these which also include the complexity of intergenerational trauma, depression, grief and loss.

There are various ways that Aboriginal community and their families are involved in services and programs. For example, the employment of an Aboriginal workforce within the health system facilitates a direct and positive connection to Aboriginal communities, where community members generally rely on 'word of mouth' to access or not to engage with health services. Aboriginal Liaison Workers generally live in the Illawarra and Shoalhaven communities

and have family members and extended families in service and program delivery and clients. Elders in the Aboriginal community are seen as positive ways to build connections within their communities and the health system. An observation was made on the demands on community:

*[w]hen working in mainstream my job doesn't end when I go home ...*

Comment was made that when a non-Aboriginal health worker has come from a hospital background and into the Aboriginal community and working with Aboriginal health workers that a knowledge gap exists in understanding Aboriginal culture.

The engagement of a Local Health District director of Aboriginal health was believed to provide strategic planning and address the significant gap in referral pathways. Noting that developing trust with the Aboriginal community from those disengaged from the local health district would be engaged in Aboriginal programs; building strong relationships with service providers out there, linking with Exercise Physiologists, Registered Nurses and psychologists, inviting specialists to Aboriginal programs and encouraging engagement with the primary health care system.

There was a consensus that the employment of Aboriginal people across the health system and services improves care coordination and enhances Aboriginal engagement into primary healthcare. In a number of programs, such as Aunty Jeans', Aboriginal individuals and Aboriginal health teams work with the rural doctors' network, with GPH across their services and with the ISLHD Aboriginal health team. However the heavy reliance on Aboriginal health workers in the community was also observed. Services and programs often relied on introduction to communities from Aboriginal health workers, but some recognized the need to build greater confidence in non-Aboriginal staff to build relationships, and thereby decrease the burden on the relatively few Aboriginal health workers. Others spoke positively about the introduction of the new role of Aboriginal health practitioner which they regarded as having a better career pathway and the need to build the capacity of these people, and thought that funding was needed to establish these positions within the system.

One manager of a key regional facility was not aware of any of the Aboriginal specific CDMPs that incorporate exercise, but was aware of a hospital based project around strengthening relationships between the hospital and non-government organisations. This project had developed a directory where hospital based clinicians could refer Aboriginal people and had received good feedback. There was a general lack of awareness of the processes by which Aboriginal people admitted as patients or through Emergency, identify as Aboriginal, was not sure if there if Aboriginal patients received any specific support and did not know about the AHLO position, because she did not get involved at that level. She was aware, however, that the hospital normally celebrates NAIDOC week:

*We've had some barbecues and cakes and those sorts of things.*  
**Systems stakeholder 8**

When asked about whether Aboriginal people have different needs in hospital, she responded:

*Yeah, I suppose it's just an awareness of the way they communicate and what's important to them. Like those sorts of cultural issues around in - families really*

*important and I suppose that's not just for patients, we need to be conscious of that for our Aboriginal workforce as well. So, yeah, things like the way you approach them and talk to them and those sorts of issues around lots of family, and often in acute hospitals staff don't cope with 100's of family [10.00] showing up at once and yeah. **Systems stakeholder***

This systems stakeholder offered some useful insights on the challenges associated with implementing the Respecting the Difference training which is mandatory for staff across the LHD, including the lack of Aboriginal people within the ISLHD workforce:

*So I mean we do have the Respecting the Difference training that's face to face training that all the staff has to do, although we do have issues trying to get people through it because there's just not enough people to deliver the training. **Systems stakeholder***

Her comments, however, also raise questions about the impact which the Respecting the Different training is having on frontline and management staff:

*I can't say that it changed the way we do anything differently. I mean we don't have a high incidence of did not attends for ED, so that's sort of a reasonable indication that they're being welcome and treated and, yeah. **Systems stakeholder***

### **5.3.6 Suggestions for improvement**

The system stakeholders made the following suggestions for health system improvement:

- Improving the referral pathways within the health service, particularly between hospital and service providers in the community
- greater flexibility in funding arrangements for Aboriginal chronic disease programs
- greater flexibility in client appointments (to link with transport issues and family obligations)
- increasing face to face outreach clinics
- increasing the number of Aboriginal AHLOs
- increase the number of Aboriginal health professionals in mainstream health settings
- better promotion of available services
- ongoing professional development for Aboriginal staff
- communicating the programs available and client pathways for access
- involving family members in building client rapport and support systems
- recognising and addressing racism within systems and service provision
- addressing the knowledge gaps in client understanding of chronic conditions
- creating partnership models with Aboriginal organisations
- inclusion of chronic conditions health prevention for Aboriginal youth
- review and improve the 48 Hour Follow-Up referral pathways

## 5.4 Section summary

Based on the semi-structured interviews conducted with service providers and system stakeholders, this section provided detailed information about how those in professional and service delivery positions perceive and experience health service delivery and the health system. The information obtained was presented around six key questions of interest. The findings of this enquiry are briefly summarised below:

### **Experiencing the system: service provider and system stakeholder perspectives**

#### **1. Providing positive support**

- Empowering Aboriginal people, educating about chronic disease prevention and providing the knowledge and skills to manage their chronic condition.
- ISLHD 48 Hour Follow-Up) involves a phone follow-up from a health professional to Aboriginal clients within 48 hours of their discharge from hospital to ensure appropriate links to GPs, ACCHSs, Specialists, or other services to provide care post discharge.
- ACCHSs provide holistic care, put Aboriginal health workers in key positions in patient care and provide GP Management plans and Team care arrangements.
- NGOs notably GPH, provide support through CCSS, funded under CTG. The CCSS program runs in conjunction with SCMSAC in the Shoalhaven, and assists with the cost of medications, medical equipment, information and connecting clients to services etc.
- Support provided by general practitioners (GPs) was not ascertained in this study, and varies across the regions. The only GP interviewed described a strategy that included establishing relationships, awareness of transport, being flexible and networking.
- Aboriginal workers employed across the health system were seen to improve care coordination and enhance Aboriginal engagement into primary healthcare.
- The Aboriginal Hospital Liaison Officer (AHLO) position was recognized as a key position. The AHLOs identity as an Aboriginal person was seen as central to their role, supporting their ability to achieve successful outcomes for their Aboriginal clients.
- System stakeholders acknowledged challenges in engaging Aboriginal people because of the reluctance of many people to access services. Positive delivery of health services included establishing a relationship with Aboriginal people in care coordination and organising care plans. More innovative ways of engaging people are needed.

#### **2. Challenges in providing support**

- Challenges in providing support related to complex health and social situations.
- Complex family structures demanded greater flexibility in service provision. Many Aboriginal chronic disease clients presented with major mental health conditions, so managing the chronic condition become a lower priority.
- Getting clients to access their services and attend appointments was challenging for many service providers
- Challenges related to the hospital discharge processes included the lack of understanding from medical staff about the complex support needs of Aboriginal patients and the lack of a transparent process to ensure that Aboriginal patients are discharged to a home environment that is safe and has ongoing support.

- Improving the direct communication between hospital staff and GPs on patient discharge is needed to ensure that the treating GP.
- Poor local transport connections when arranging for clients to attend specialist and hospital appointments in Sydney was a continuous challenge.
- There were numerous challenges related to the role of Aboriginal Hospital Liaison Officer in working to meet the complex needs of each client and the high expectations which Aboriginal families and clients placed upon them.

### **3. Referral**

- The referral process for Aboriginal clients included a range of pathways, including those initiated through the ISLHD 48 Hour Follow-Up program.
- The effectiveness of referral depended to a large extent on the effective networking of service providers within the health system and the availability of specialists for referral.
- Service Providers and systems stakeholders identified that 48 Hour Follow-Up is not widely known by services across the Illawarra and Shoalhaven regions.
- Issues related to discharge processes make it difficult for optimal Aboriginal community follow-up through 48 Hour Follow-Up. For example, only three days medication provided on discharge.
- Patients need better information about discharge and follow-up, and health information should be communicated in a way that is not overwhelming.
- ACCHSs have various internal and external referral options available.
- System stakeholders identified the need to individualise the referral process, the lack of specialists in the Shoalhaven and long waiting lists. Some were critical of corporate medical services which were said to be too 'in-house' and did not refer out.
- Gaps in the local experience of referral pathways were identified and systems stakeholders recommended a framework around Aboriginal health within the District be adopted to build the capacity of Aboriginal health workers and to raise awareness among service providers, of the complex day-to-day experiences of Aboriginal people.

### **4. Understanding the needs of Aboriginal clients**

- There was wide variation in amongst service providers understanding of the needs of Aboriginal people.
- Aboriginal people were generally regarded as a priority group for chronic disease prevention and management
- Most regarded Aboriginal people as having a distinct set of needs, due to their distinct cultural heritage and identity, cultural responsibilities and history.
- Aboriginal participants were sometimes fearful of diseases, such as diabetes, because of the strong family history of this disease.
- Some service providers were reluctant to generalise about Aboriginal people and preferred to 'work with the individual'.
- Others saw the medical needs of Aboriginal people with chronic conditions as the same, but the way practitioners handle the treatment of Aboriginal people as different.
- A few emphasised the diversity within the Aboriginal population and recommended that health information should reflect their own locally lived experience, and were critical of pamphlets and brochures which reflected the realities of remote areas

- System stakeholders emphasised the many barriers to accessing care for chronic conditions, including the high costs of medical specialists and thought medical specialists needed a better understanding of the needs of people on low incomes.
- Transport was regarded as a significant barrier which Aboriginal people faced in accessing care.

### **5. Providing culturally appropriate health services**

- Cultural awareness training is one of the main ways culturally appropriateness of health services is approached in mainstream services.
- The level cultural awareness training within ISLHD was commonly regarded as inconsistent, particularly within the hospital system.
- Some noted that not all ISLHD staff had been trained in the mandatory 'Respecting the Difference' training, due to the need to engage Aboriginal trainers.
- There was a need for committed and ongoing funding for Aboriginal health workers to achieve success in providing culturally appropriate services.
- Creating Aboriginal career pathways, strategic Aboriginal health planning and building the capacity of Aboriginal staff into the practice streams by increasing the number of Aboriginal clinicians, were all seen as important in this regard.
- There were expectations for improved provision of culturally appropriate health services through the appointment of an Aboriginal Director within ISLHD.
- Culturally appropriate health service delivery required: ensuring networks are strengthened with Aboriginal and non-Aboriginal local health workers; increasing the number of Aboriginal CD health programs; increasing the number of telehealth specialists to meet Aboriginal demand; funding mobile outreach CD programs; ensuring gender-appropriate staff positions for men's or women's programs and services; and the continuation of CTG funding for Aboriginal health.
- Nurturing community trust in care providers was important to building rapport and positive relationships to be accepted as a service provider by the Aboriginal community.
- Being sensitive to the care needs of elderly Aboriginal people was important; it is also necessary to address intergenerational trauma, depression, grief and loss.
- The employment of an Aboriginal workforce was also seen to facilitate a direct and positive connection to Aboriginal communities, where community members commonly rely on 'word of mouth' to access, or decide not to engage, with health services.
- Working with Aboriginal Elders is a positive way for services to build connections within their communities and the health system.

### **6. Suggestions for improvement**

Systems stakeholders stressed the need to address the knowledge gaps in patient understanding of chronic conditions. Suggestions for systems change included: improving referral pathways within the health service, particularly between hospital and service providers in the community and by creating partnership models with Aboriginal organisations within the two regions and increasing the number of face to face outreach clinics.

They also recommended greater flexibility in funding arrangements for Aboriginal chronic disease programs, increasing the number of Aboriginal AHLOs and Aboriginal health professionals in mainstream health settings and addressing racism within systems and service provision

## 6 Aboriginal chronic disease program design review

This section presents the findings from the program design review. The section draws information from two sources. Firstly, a review of guidelines available for the management of chronic disease, and secondly, the results of the semi-structured interviews undertaken with nine program managers from across six organisations in the Illawarra and/or Shoalhaven. Of the nine program managers interviewed, four were female (44.4 %) and five were male (55.5 %). Four were from the Illawarra region, two from Shoalhaven and three from Illawarra and Shoalhaven. Three program managers (33.3%) identified as Aboriginal and / or Torres Strait Islander.

### 6.1 Participants

**Table 9** Programs Reviewed

Name of Program	Organisation
ARC Team (48 Hour Follow-Up)	ISLHD
Koori Cook Off	Heart Foundation
Supplementary Service Program.	Grand Pacific Health
Manager Aboriginal Health, Chronic Care Unit	ISLHD
Ambulatory and Primary Health Care	ISLHD
Chronic Disease Programs	SCMAC
Dead or Deadly	Waminda
Chronic Disease Team Manager	ACCHs
Connecting Care (CCSS)	Grand Pacific Health

### 6.2 Key questions of interest

The responses from the service providers to the questions asked in the individual interviews and focus groups are presented below under the following headings:

- Program design
- Program operations
- Cultural Capability

The actual set of questions asked can be found in Appendix 2.

#### 6.2.1 Program design

Engaging the community was fundamental for most of the organisations in this review. The stages of engagement varied with some looking at involving community later in the process as a course of validation and approval while other organisations were directed by community when developing a service or program. The ongoing community engagement also varied for organisations outside of programs with some having program committees which included community members while others relied on other mechanisms such as Community Control of Organisations to provide overall input into the function of the service where programs existed.

*So usually events that are happening, we'll go out and hold a stall and get out and talk to communities. Our Outreach Worker and Project Officer, that's one of their main roles, are to get out in the community.*

Community engagement is a fundamental premise of creating culturally appropriate programs through ensuring programs reflected the needs of the local community. This engagement also enables community control of how programs are developed and delivered. This varied throughout the organisations with government and NGOs tending to have stronger control of programs and less empowerment of communities in the governance of programs.

*we always consult with our elders we're guided by the community needs. We follow protocols.*

All sites spoke of being appropriate for the local community though this was sometimes determined by the program managers or funding and reporting. Creating culturally safe programs was often not a priority of program design, though many had designs which inherently provided cultural safety such as having settings based approaches, facilitating access, having an Aboriginal workforce and culturally appropriate resources.

*it's just men gathering as well which is quite good for men's healing*

Elders are often a source of wisdom in communities through their deeper understanding of the history and determinants which impact on the disadvantage experienced by many Aboriginal people. Elders also have an excellent insight into solutions in communities in terms of priorities and how to facilitate access. Elders were part of the design of many of the programs with Aboriginal community control enabling better elder engagement which essentially exists through their representation on the boards of the organisations. Elders are often the primary target group as chronic disease and hospitalisations from chronic diseases largely occurs in this age group.

*it's also driven by a couple of elders that are really passionate about health and want to see improvements in men within our community and the health of our community, so having the elders involved in decision makings and driving things is probably one of the cultural factors as well.*

In terms of public health relevance, all programs typically focus on the high priority area chronic disease through prevention, early intervention and management. There is a particular focus on management through lifestyle modification such as exercise and nutrition, medication compliance, access to specialist treatment and education.

Health promotion is a focus of many programs using culturally relevant resources and activities to engage with target groups. Some programs have been designed at national and state levels and adapted locally while others have been developed locally. Educational resources were also developed locally in addition to researches developed at state and national level. By also being identifiable through visual brand that people within the organisation can identify under and people in the community and other organisations.

*They usually have to have one of the five chronic diseases, which is respiratory, renal, diabetes, cancer, cardiovascular*

### 6.2.2 Program operations

Funding was a large driver of organisation sustainability in the NGO and Community Controlled sector. NGO's largely targeted program developed to be responsive to funding opportunities. Aboriginal Community Control funding had a little more flexibility in terms of sustainable funding and reporting requirements. New funding arrangements allowed more local development of programs to be responsive to community. Governments have stable workforce and typically have allocations of program funding for their workforce. This means that funding is not an important driver of government programs.

*It's going to damage their reputation for being unable to deliver programs and may damage the ability of getting further funding.*

The costs of running programs was of important though the efficiencies existed at different levels largely based on funding sources and timeframes. Programs which had recurrent funding had stable and set budgets, while those with time limited funding often seek to maximise expenditure and outcomes in relation to their budget.

*You've got all this money here that you need to spend and if you don't spend it you'll have to give it back.' So then we started paying for it all.*

The flexibility in which a program is able to operate has variability across organisations and sectors. There is typically more flexibility in the ACCHSs where funding guidelines now enable more responsiveness to community needs. The flexibility for government is typically less responsive and operates in a more continuing quality improvement framework. Data was also a main driver for decision making for government.

*So we've, sort of, modified the program a little bit to, I guess, reflect community. We try to provide resources that are Aboriginal, as opposed to mainstream resources, where possible.*

The governance structures for the programs were significantly different across the three sectors. ACCHS has a distinct community governance structure where Aboriginal community members are elected to provide advice on the strategic direction of the organisation. The CEO of ACCHS is then responsible for the operations of the organisation. NGO's also typically having a board which governs the organisation. There is usually no Aboriginal representation on the board. In terms of operations there are managers who govern Aboriginal workers and programs but these are not identified positions. The Local Health District has a board which governs the strategic direction. There operational governance of Aboriginal health in chronic disease comes under the Manager of Aboriginal Chronic Disease. This is an identified position and enables an Aboriginal perspective to be embedded in governance of the program area.<sup>14</sup>

*We're certainly governed by our board which represents the community, we have a constitution which constitutes what we do, a strategic plan which outlines the philosophy and our values so we ensure that it rolls out from the top level down to*

<sup>14</sup> It should be noted that, at a strategic level, a new position of Director, Aboriginal Strategy for ISLHD was established in 2015.

*the programs and so once it gets – becomes a program that those things that identify*

Quality assurance was seen as a key function of most organisations. The process of plan-do-study-act allowed organisations to be able to modify programs to meet the needs of the community, funding bodies and clients. Quality assurance was seen to serve different purposes such as clinical and organisational governance as well as cultural governance through community engagement and direction.

*I mean, we look at our continual quality improvement and our own activities that we do within our teams and we review those as part of CQI. You know, the plan, do, study, act activities. But on the bigger picture, it's more so what we reflect against our national KPIs*

The service delivery to community is not always stated needs by the community but derived from data which demonstrate a need. Reporting allows an accurate collation of activity of services. There are however challenges in terms of not capturing all activity or sometimes other services capturing the same information where there is shared program delivery. Privacy can be an issue particularly across agencies where sensitive information may be requested or confidentiality potentially compromised. Data collection and reporting was of differing importance across the different agencies. The complexity of the tools used to collect data and how the data was analysed also varied across organisations. It was recognised though that data was important to justify an acquit program activity.

*But we need to record the activity, group, session that happened, and those sorts of things. It looks like they do nothing.*

Behaviour change was said to be complex particularly through learned behaviour and the need to modify behaviour from what had been often normalised behaviour. The lifestyle modification that was required through different phases of prevention, early intervention and management was engaged through different mechanisms. This included examples of education, skills development, empowerment, access to specialist services and case management. 'In most cases we're dealing with people that are probably on the way of the unhealthy lifestyles, they've lived it for a while and they are starting to go to hospital, starting to be overweight and things like that.'

The complex needs of Aboriginal clients were discussed by most organisations particularly in relation to the social determinants of health. This included such factors as the cost of accessing healthcare, transport, housing, social security, food security, drug and alcohol and mental health services, communicable diseases, domestic violence and the justice system.

*Our Outreach Workers, they assist clients with filling out forms, medical forms, housing forms or social types of forms they need help with. Getting into doctor's appointments, specialist appointments, any medical appointments.*

The empowerment of Aboriginal people through service delivery was described by organisations in different manners. The Aboriginal community controlled sector advocated empowerment as an essential component of how services were delivered to ensure Aboriginal

people engaging with their service were equipped with the tools and confidence to manage their disease.

*It empowers the men in the group to ask questions about their health care as well and they're more aware of what's going on with them and you still come up against men that are still a bit unsure about asking questions to their GP or anything like that, but after they've met their GP what they'll do is they'll come and ask me – he sent this, what does it mean - and that happens quite a bit, so they still come to that person they trust to get the knowledge off, but we don't have all the knowledge, it's then about supporting what to from there*

The ongoing self-management of chronic disease often requires significant lifestyle changes. It often required a case management approach by a number of health practitioners and often coordinated by an Aboriginal health worker. This critical role of coordinating care required regular and sustained monitoring of the health condition or conditions to be able to responsive to the health needs of the client. This role was more prevalent in ISLHD funded positions within some ACCHS and also in the NGO sector where there was a dedicated role for this need. The balance of providing absolute care and a client taking responsibility was discussed, where the complexities of coordinating specialists was done by the health worker but the day to day management of lifestyle and contacting the health worker was often taken on board by the client. Linking in with health programs was seen to be important to enable better health literacy and skills to manage their own health. Management plans from GPs also provided a framework for which the Aboriginal clients alongside their GP could target specific management requirements to improve health outcomes. Medication compliance was said to be an issue and part of the ongoing GP management plan.

*Well can you help with this or help with that,' so they don't just leave it and don't come back at all. I think they're more proactive in this program of looking after their own health.*

### **6.2.3 Cultural Capability**

The cultural capability of the organisations was discussed with all and with differing models and methods of gaining capability. ACCHS have an inherent role of cultural capability in how they are governed and operate. The boards are made up from the local Aboriginal community and understand the localised needs for their communities. A majority of the staff are Aboriginal people from the community and have strong family and community ties and again understand the complex needs of community. By providing holistic services, which is a unique position of ACCHS, also enable a more responsive approach to the needs of clients by wrapping appropriate services around their clients. The cultural capability of government and the NGO sector are more acquired through different mechanisms of training, having an Aboriginal workforce as well as introducing cultural relevant resources and practices.

*Like, that has its challenges as well because sometimes as a health worker you want to guide things one way but if the elders have a different view on things, that where we both need to come to an understanding and I don't want to be disrespectful*

Employment varies across the sectors with most of the employment occurring for Aboriginal staff in government and ACCHS. There were Aboriginal staff in some of the NGOs and a number

of positions and teams within government. The ACCHS sector had the largest Aboriginal workforce which were the predominant component of their workforce. There were employment targets for government as well as in the ACCHS sector. However there were no specific targets in the NGO sector. The NGO sector relied heavily on collaborations with other Aboriginal staff to deliver their programs. The workforce is usually derived from the local Aboriginal community.

*So with – the first thing we try to do is we’ve got a 70 – we’ve got over 90 staff here, we’ve got a minimum 70% target for Aboriginal staff so the first thing is to make sure that our staff understand the – what is culturally sensitive, what the community’s needs are and basically have a good knowledge of the historical – the effects of Aboriginal people and, but that’s the first thing and then we look at how to make the program sensitive to the needs of each community.*

Building workforce capacity was usually discussed at a grass roots level in terms of building a skilled Aboriginal workforce. This meant employing local Aboriginal community members and providing on the job training. Another model was providing training opportunities for Aboriginal people in the community to build their capacity to apply for jobs in Aboriginal health. The education and training provided by organisations occurred both externally through registered training organisations and the tertiary sector as well as internal training. The main qualifications for Aboriginal health workers were through the TAFE sector as well as short courses. The internal training was delivered through senior Aboriginal staff as well as non-Aboriginal staff who had specific skills and qualifications.

*So they’d go out and do that program with the organisations. But we try to build in as much as possible working with other organisations, developing their skills in being able to deliver that program in the future.*

Cross cultural training was provided through different mechanisms and programs by all sectors. The ISLHD has a mandatory training program for all staff called respecting the difference. Within the NGO sector there are no specific mandatory training programs. ACCHS also have no mandatory training but non-Aboriginal staff were given mentorship by other Aboriginal staff to provide guidance and awareness of working with Aboriginal people and communities.

The cultural safety of organisations was an important factor discussed by some participants. This was built through staff having cultural awareness and capability to deliver culturally safe services. Ongoing awareness of issues which impacted the community was an important process which services that had cultural awareness. This was enabled through community members being part of the workforce and also having advisory groups from the community. Cross cultural communication was an important skill for non-Aboriginal staff to have or acquire through training and experience. Having culturally appropriate resources and spaces was an important strategy for culturally capable services. The ISLHD undertook a review of spaces at some of their hospitals to ensure culturally safe spaces are available for the community. Having Aboriginal management was an important factor for many organisations to provide culturally appropriate leadership and governance. Organisations also spoke of policies which existed which were related to cultural capability.

*so in a space that's our own and it's also male friendly so that issue around if there's any men's business, men are quite open, like, historically we don't always talk about our issues, but like I've mentioned before over time I feel like men are opening up and that's because it's culturally and gender safe*

Having a partnership approach to service delivery was very important for organisations to be effective in meeting their client needs. Organisations with limited capacity to deliver Aboriginal specific services relied on partnerships with other organisations but also communities to have the capacity to deliver programs which utilised a broad skill base. Partnerships not only exist within health but across other sectors. This includes social services as well as education, research and community sectors. This approach enhances a service function and also brings in expertise to train and develop the organisations. It also allows for community to come together with holistic programs and events. Having an agreed position from all organisations can be a challenge. This can be at the program and service delivery level or at an organisational level where there are differing philosophical positions. There can also be tensions of competing for funding or organisations have collaborated to apply for funding.

*And, again, it's that – the great position we are in with the regional networks is, like I said, we've got really good partnerships with organisations - Aboriginal organisations, non-Aboriginal organisations – up and down the Far South Coast and Illawarra region so if we need to get information from, say, the community down in – on the Far South Coast we know who to speak to, we know how to get that information so it's not just us going - so we've got them partnerships that allow the information to get back to us to filter through both the Aboriginal and non-Aboriginal staff to make sure our services are culturally appropriate to that region.*

While program delivery is a major component of program delivery, coordinated care is another key aspect. By developing links across the health, social and community sectors an enhanced model of care is enabled. The continuity of care which is based on wrapping appropriate services around clients ensures a holistic approach to service delivery. There are multiple entry and exit points for clients with chronic diseases from primary and tertiary health and also the non-health sectors. Once engagement is made then services are able to either screen or have advice referred to their service. For the management of chronic disease which was referred from the tertiary sector the normal pathway was referring through 48 Hour Follow-Up and then into the Aboriginal Chronic Disease Coordinated Care program. This normally occurs through an email from ARC to the program. The responsible Aboriginal health worker then has to have a GP management plan before providing service and arranges this process. This program is responsible for ongoing engagement with GPs for ongoing management as well as linking into other specialist services and programs. With patient centred care services are able to ensure care is tailored to the need of the client. Engaging family and community was very important for the organisations involved in client management. The family provided support for clients while at home and community programs also supported programs to manage chronic disease. Some of the logistical requirements for coordinating care and referring onto other services included organising referral letters, paying for specialist fees and transport costs. Providing gender appropriate services can also be a consideration for coordinating care.

*So it can be from - God, there's a wide range. So we have the GP, the Care Coordinator, nurses at the AMS, if they're an AMS client, the health workers at the*

*AMS, social workers, dental - I've had that a lot. Housing, Centrelink, Corrective Services - I've had a few of those. Mental health workers, I have a few clients who I've worked with the mental health team as well, joint care in that area. And I also refer to the mental health team, because there's a lot of mental health issues out there. And OTs and physios and all the specialists in the, I've got a list of all the specialists. Various - and your x-ray and ultrasound departments and renal units and independent home care for equipment, medical supplies that to get equipment for clients. Pathology, all types of different health field out there, that we deal with.*

Enabling access for the Aboriginal community to health services and programs was an ongoing challenge for all services. The models employed to achieve this had many similarities but services still had their unique approach to engaging community. Social marketing was employed by all organisations. This was used with information resources, online information, social media and community promotion programs. Education resources were also developed to provide information around prevention, early intervention and management. Providing outreach services into the community including home visits was a model which enabled settings based approach to facilitating access to services. Multi-purpose programs which had a variety of health professionals providing outreach services enabled community to have a variety of health care options available in the community.

*And getting the staff in contact with those with the chronic conditions. I suppose the best way to put it is, we're the access point, we provide and direct - the staff can, to all the services that are out there.*

High rates of chronic disease and hospitalisation continue but still low attendance of programs. This was attributed by one organisation as the same people doing the same thing with little or no gain. Accessing unmet communities that aren't as visible has been an ongoing challenge where programs are typically targeted with identifiable groups and locations for the Aboriginal community. It was said that engaging with the hard to reach community members would enable services to be appropriately coordinated around individual needs. The expectations of community are also not also met and this can be around historical experiences or experiences which have occurred more recently. The community is hesitant to attend health service based programs which is why outreach models have been more effective. Most of the focus for programs delivered to the Aboriginal community was said to be based on illness rather than wellness. Also not engaging with community when designing programs and services can be a barrier for future engagement because of the lack of ownership

*So there's - breaks down a lot of things. But I think - what used to be a big barrier is the accessibility to services, just because you run a service doesn't mean that they're going to come to the service so that you're able to be flexible in providing that service and how you provide that service will determine what barriers are there.*

Offering transport was an important strategy for facilitating access to services. This not only addresses the costs aspect but also the motivation aspect where going around to people's home and collecting them promoted engagement. The settings based approach was discussed on many occasions which meant services are very entrenched in community settings. Soft entry programs also allowed engagement through working alongside other health professionals or non-health professionals to enable opportunistic engagement with Aboriginal clients who may not have been considering certain aspects of their health or need the support to address

certain health needs. The Aboriginal Coordinated Care Supplementary Services program was described as a great success for facilitating access to specialist services for Aboriginal clients with an Aboriginal chronic disease care plan from GPs. This coordination minimised the challenges for people to manage chronic diseases.

*That's the basic gist of where this program is running, its care coordination and getting clients seen to and decreasing hospital admittance.*

### 6.3 Section summary

This section focused on how Aboriginal chronic disease programs are designed and operate. It was based on a review of guidelines available for the management of chronic disease and semi-structured interviews undertaken with nine program managers from across six organisations in the Illawarra and/or Shoalhaven. The results are organised around three main themes: design, operations and cultural capability, and are briefly summarised below.

#### **Aboriginal chronic disease program design review**

##### **1. Design**

Engaging the community is a fundamental premise of creating culturally appropriate programs that reflect the needs of the community. Elders were part of the design of many of the programs with Aboriginal community control enabling better elder engagement which essentially exists through their representation on the boards of the organisations. All programs typically focus on the high priority area chronic disease through prevention, early intervention and management. Health promotion is a focus of many programs using culturally relevant resources and activities to engage with target groups.

##### **2. Operations**

Funding was a large driver of organisation sustainability in the NGO and Community Controlled sector. The flexibility in which a program is able to operate has variability across organisations and sectors. The service delivery to community is not always stated needs by the community but derived from data which demonstrate a need. The governance structures for the programs were significantly different across the three sectors. Quality assurance was seen to serve different purposes such as clinical and organisational governance as well as cultural governance through community engagement and direction. Behaviour change was said to be complex particularly through learned behaviour and the need to modify behaviour from what had been often normalised behaviour. It often required a case management approach by a number of health practitioners and often coordinated by an Aboriginal health worker. The complex needs of Aboriginal clients were discussed by most organisations particularly in relation to the social determinants of health.

##### **3. Cultural capability**

The cultural capability of the organisations was discussed with all and with differing models and methods of gaining capability. ACCHS have an inherent role of cultural capability in how they are governed and operate. The cultural capability of government and the NGO sector are acquired through different mechanisms of training, having an Aboriginal workforce as well as introducing cultural relevant resources and practices. Employment varies across the sectors with most of the employment occurring for Aboriginal staff in government and ACCHS. The

NGO sector relied heavily on collaborations with other Aboriginal staff to deliver their programs. Building workforce capacity was usually discussed at a grass roots level in terms of building a skilled Aboriginal workforce. Cross cultural communication was an important skill for non-Aboriginal staff to have or acquire through training and experience. Having culturally appropriate resources and spaces was an important strategy for culturally capable services. By developing links across the health, social and community sectors an enhanced model of care is enabled. High rates of chronic disease and hospitalisation continue but still low attendance of programs. The settings based approach was discussed on many occasions which meant services are very entrenched in community settings.

## 7 Discussion

The findings from the multiple participant groups presented in chapters four, five and six of this report demonstrate that although there is wide variation in the views of the various participant groups, on any particular issue, a number of consistent themes emerge about how chronic disease is being managed by Aboriginal people and their carers and where improvements could be made. The discussion in this section focuses around a number of key questions:

- What are the factors that impact on Aboriginal people's experience of chronic disease and its management?
- How do the patient journeys of Aboriginal people in the Illawarra and Shoalhaven regions compare with the literature?
- 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? And what are strengths and weaknesses of current chronic disease management approaches for Aboriginal people?
- What lessons were learnt about Aboriginal health research?

### 7.1 Broad factors impacting on Aboriginal people's experience

There is extensive evidence to support the view that health is determined by a broad range of social and economic determinants in addition to any individual biological, behavioural or hereditary factors. The social, environmental and economic factors that contribute to poorer health experienced by Aboriginal people include inequitable community social capital, education, employment and housing. (Carson, Dunbar et al. 2007, Commission on Social Determinants of Health 2008, Marmot 2011, Centre for Epidemiology and Evidence 2012). There are complex and powerful relationship between these broad underlying factors and health behaviours (Chin, Monroe et al. 2000), and the interrelationships among these factors contribute to individual and population health. Aboriginal researchers also argue that cultural determinants, such as stronger connections to culture and strong identity, self-esteem and resilience, play an important part in good health (Brown 2014, The Lowitja Institute 2014).

Aboriginal people living in the Illawarra and Shoalhaven regions form part of the majority of Indigenous Australians who live in 'urban' or 'inner regional' areas (Australian Bureau of Statistics 2006). The diversity in the Indigenous Australia, population is reflected in the Illawarra

and Shoalhaven regions. Demographically, Aboriginal people in the two regions are concentrated in areas of high levels of social disadvantage, high unemployment, and lower incomes. Within the ISLHD Aboriginal people have twice the rate of potentially preventable hospitalisations compared to non-Aboriginal people; ISLHD is amongst the LHDs with the highest proportion of unplanned readmissions within 28 days for Aboriginal people (Centre for Epidemiology and Evidence 2016).

There are a sizeable number and range of 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, the larger concentration of services programs in the Illawarra region provides relatively fewer health service choices available to residents in the Shoalhaven region.

## **7.2 Patient journeys of Aboriginal people in the Illawarra and Shoalhaven**

The literature review (McMullen, Grootemaat et al. 2015) identified the lack of research on Aboriginal peoples' experience of living with and managing their chronic disease (Scrimgeour and Scrimgeour 2008), a lack of documented Aboriginal programs and identified that most Aboriginal health research on chronic illness is based on remote areas of Australia (Senior 2003a, Senior 2003b, Preston-Thomas, Cass et al. 2007, Burnette and Kickett 2009, Lawrence, Dodd et al. 2009, Dwyer, Kelly et al. 2011, Kelly, Dwyer et al. 2011, Senior and Chenhall 2013). The literature on the Aboriginal patient journey tends to be dominated by studies which focus on the experience of Aboriginal people living in remote areas. The analysis of findings in the present study reveal both similarities and differences in the patient journeys of Aboriginal people in the Illawarra and Shoalhaven, compared to Indigenous people in other parts of Australia.

The findings from the interviews and focus groups with Aboriginal community members illustrates the diversity in the way in which Aboriginal people in the Illawarra and Shoalhaven experience 'the health system'; this is not surprising given the heterogeneity of Indigenous populations living in urban environments. However, again, a number of common themes emerged from the data collected from Aboriginal community members, notably the importance of Aboriginal identity, education, smoking, stolen generation and intergenerational trauma, community connectivity, and the issue of trust or distrust in seeking help.

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

Not surprisingly, much of what is written about Aboriginal people's experiences of living with and managing chronic disease, in remote areas, did not apply in our study, for example, the widespread sense of fatalism and the belief that little can be done to prevent ill health or feeling that attending a health facility or committing to a course of treatment may make things worse (Senior 2003a, Senior 2003b, Senior and Chenhall 2013).

However, like the participants in remote area studies, the participants in our study demonstrated a deep and profound understanding of good health in their lives and the lives of their family and community. This is consistent with the extensive reference throughout the Indigenous health literature, to the Aboriginal definition of health being a holistic view of health. This definition recognises the importance of the social, emotional, cultural and spiritual wellbeing of the community, as well as the physical wellbeing of the individual (National Aboriginal Health Strategy Working Party 1989), the close connection to the land and the

community-centred idea of the person which is shared by Indigenous peoples throughout Australia, and indeed globally (King, Smith et al. 2009).

### **7.2.2 Personal stories, family and Aboriginal identity**

In answering the researchers' questions about the experience or managing chronic illness, 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. The issue of Aboriginal identity frequently arose and was discussed in many ways, in relation to their personal and family history and in interactions with health services.

The importance of family in the patient journeys was a strong theme across the Aboriginal participants in the study. Participants spoke in many different ways about family in relation to their health. Not all of the participants had the support of family, some spoke regretfully about the estrangement of siblings, and their hopes for future reunion; others had relocated to the Illawarra or Shoalhaven to be close to family. Many participants relied heavily on assistance from family members to assist them with personal care, at home, with transport to attend health and medical services, financially and providing social and emotional support during periods of illness.

Many participants attributed their chronic illness to smoking or drinking. The topic of smoking was frequently mentioned by participants when talking about their own childhood. Many of those with respiratory conditions, talked about their long history of smoking, one from as early as the age of seven. Participants also talked about the difficulties of giving up smoking, but for many, smoking was a thing of the past.

The theme of education also arose in the interviews and focus group discussions. Participants were not asked directly about their level of education, but those who did talk about education in relation to the management of their chronic condition often did so in terms of the educational disadvantage they had experienced due to being brought up in difficult socio-economic circumstances. Some participants indicated that their level of literacy made it difficult for them to understand the health information they needed.

Another theme which frequently emerged was that of the ongoing impact of the stolen generation on the lives of the Aboriginal participants. It was clear from these discussions that the past trauma of this history, as well as, in a small number of interviews, the history of sexual abuse and other trauma continued to impact on their ability to manage their chronic illness. This reinforces the need for holistic health care services.

Despite the diversity within our participant group, issues around Aboriginality and Aboriginal identity emerged frequently in the course of the discussion of how participants managed their chronic illness. Many of the Aboriginal participants in our study found the issue of Aboriginality to be challenging in relation to health service use. Participants shared some of the personal histories related to Aboriginality, the experience of racism, and also spoke of their children's current struggles with having to deal with a lack of cultural understanding about Aboriginal people in the education system.

### **7.2.3 Hospital and discharge experience**

Being in hospital was generally a negative experience for most Aboriginal people, largely because of the strange environment and physical restrictions associated, but also because family support is very important and they were unhappy about the way their family and visitors were treated. Issues were also raised about the cultural competency of mainstream services. For example, the way Aboriginal people were sometimes ‘talked over’ by doctors and hospital administration staff.

It is interesting that interview participants did not usually attribute negative hospital experiences to racism because they felt that the health system dealt the same poor treatment to everyone in hospital. Focus group participants were more likely to attribute poor experiences to racism in the health system, and they often referred to past experiences or retold the stories of others. It is important to recognize that these stories and memories of racial inequality, which are told and retold, continue to influence people’s perceptions and explanations of health services, and that this negative narrative can and should be addressed through improved visible efforts to address both the quality of care and the cultural competency of staff.

Positive comments about hospital experiences were more likely to focus on the way the person was treated by hospital staff, and most participants spoke positively about the treatment they received in hospital particularly from nurses and the AHLOs, but also from doctors, nurses and allied health workers. There was widespread support, across all participant groups, for increasing the Aboriginal workforce across all areas of the health system. Key positions such as the AHLO position were found to be under-resourced, under-acknowledged with unrealistic expectations for the position, on the part of both the health system and the Aboriginal community.

There is limited discussion of discharge practices in the literature. However, many of the issues raised in previous studies, also apply to this study. Remote area studies by Lawrence et al. (2009) and Kelly et al. (2011), for example, highlight the problem of medication management following discharge, lack of consideration of patient needs, lack of suitable primary healthcare or specialist services in the patient’s home community and communication difficulties leading to misunderstanding about what is required of them in their return to community. Kelly et al. identified that a premature or uncoordinated discharge upset patients; who did not feel well enough to go home and lacked effective and coordinated follow-up care (Kelly, Dwyer et al. 2011). Lawrence et al. (2009) claim that there is an assumption that once people are discharged from hospital they will be under the care of their ‘usual GP’, but that some people may not have a usual GP is not seen as the problem of the hospital.

The discharge experience of the Aboriginal participants in our study was largely negative with many participants complaining that they were left confused and overwhelmed when they returned home from hospital. Participants frequently commented about the lack of information, particularly written information, provided in hospital about the management of their condition once they returned home.

One of the key mechanisms for following up Aboriginal people with chronic disease post discharge from hospital is the ISLHD 48 Hour Follow-Up, which allows for Aboriginal people to be referred to a CDMP for care coordination and self-management support in the community.

Although Aboriginal participants were not asked specifically about their experience with 48 Hour Follow-Up, interviews with service providers considered that the program generally works well, with nurses at the ARC team located at the Port Kembla hospital, phoning all Aboriginal participants from the hospital database identified as having a severe or moderate chronic disease, and providing telephone support to gauge how they are coping.

Although it appears that these calls are done sensitively and attempts to meet individual needs, there are a number of challenges with the program. One issue identified is that participants are not always given information about the 48 Hour Follow-Up phone call when there are in hospital, so they may be unprepared for the 'cold call' from the ARC team. Also, the number of types of services available is in a state of flux and so there is a constant need to update information. There appears to be a lack of knowledge about the program amongst service providers, suggesting the need for increasing the awareness of the program more broadly.

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

Barriers to health care have typically been classified as problems of availability, affordability, acceptability and appropriateness (Scrimgeour and Scrimgeour 2008). Lack of acknowledgment and respect for cultural factors, physical barriers and economic barriers or lack of awareness, can therefore restrict access to care (Vicki-Ann Ware 2013). All of the barriers to access for Aboriginal people, identified in the literature, apply to those people living in urban areas, but the acceptability and appropriateness of services are particularly relevant. The three main issues of access explored extensively in the present study were those related to transport, cost of health care and appropriateness of care.

Unlike Aboriginal people living in remote areas, participants in our study did not have to experience leaving home and travelling great distances to access treatment. However many of the factors affecting access and quality for Aboriginal people from remote area (Kelly, Dwyer et al. 2011), still apply. For example, travel to Sydney for hospital treatment or specialist appointments was often tiring and stressful for people with chronic conditions and the inflexibility of appointment times added to these difficulties. The geographical spread of the Aboriginal population in the Shoalhaven, including Wreck Bay and Jervis Bay, made access to services in the Shoalhaven particularly difficult. This problem was largely alleviated for those attending local Aboriginal CDMS where transport is provided.

As with remote living people, Aboriginal people with chronic or complex conditions in our study were also affected by systemic health care problems, such as long waiting times in busy specialist care settings. The cost of medical specialists was also consistently raised as an issue affecting access to services.

The Aboriginal people in our study did not experience the difficulties associated with English as a second, third or fourth language, but issues of communication were also often reported by the participants in our study. However, the issue of communication was frequently raised in relation to health professionals ignoring or 'speaking across' participants, or speaking in technical terms that the Aboriginal participant could not grasp.

Acceptable standards of health services for Aboriginal people living in urban areas have been also shown to relate to the idea of cultural safety. Scrimgeour and Scrimgeour note that Indigenous people in urban areas are less satisfied with their access to health care than

Indigenous people living in remote communities and experience systemic barriers to receiving treatment because of chronic disadvantage and cultural marginalisation (Scrimgeour and Scrimgeour 2008). The literature highlights that Aboriginal people living within urban areas are an ‘invisible minority’ and are exposed to discrimination and non-indigenous attitudes that they are not ‘real Aborigines’, contributing to the overall poorer health of Aboriginal people in urban areas (Scrimgeour and Scrimgeour 2008). As Fredericks (2004) observed,

*‘It is not easy for Aboriginal people in the city. Life in big cities presents Indigenous people with many factors and interactions that create self-doubt, identity confusion and anguish.’(Fredericks 2004)*

As with previous studies of Aboriginal people living with chronic disease in urban NSW (Jowsey 2011, Aspin, Brown et al. 2012), the Aboriginal participants in our study reported both positive and negative experiences of managing a chronic illness and their experiences of using health service was also quite variable. Overall, participants were satisfied with the care they received by health care practitioners in the community. One recurring theme however, was the difficulty around recognition of Aboriginality by health care professionals and services.

Aboriginal people without the requisite papers to prove their identity were sometimes denied access to CTG assistance and to some ACCHSs, despite their stated need. It is important this was not the case for ISLHD services or all ACCHSs. Participants, particularly those of the stolen generation, also spoke of continually having to ‘prove’ their Aboriginality, or of their Aboriginality being challenged by doctors or pharmacists, in relation to benefits under CTG. Many participants spoke strongly in support of the holistic services offered by the ACCHSs. For others, Aboriginality was irrelevant; it was seen as ‘nobody else’s business’ but their own, and they expressed a clear desire to choose the health services on the basis of their personal preference.

### **7.3 Aboriginal chronic disease programs**

Three key themes emerged from the review of available guidelines for Aboriginal chronic disease programs, presented in chapter six, were: service design, operations and cultural capability. These are discussed in further detail below.

#### **7.3.1 Design**

Some organisations are less bounded and governed by Aboriginal health program theories as Aboriginal health is only a component of their service activity. ACCHS are strongly embedded in Aboriginal health program theories though this may not be articulated with specific policies (Bell, Couzos et al. 2000). There are no specific Aboriginal chronic disease frameworks which apply to the NGO sector.

Community engagement underpins all culturally appropriate strategies to enable culturally appropriate services (Pyett, Waples-Crowe et al. 2008). The NSW health frameworks in Aboriginal health outline the role community should be given opportunities to provide input into the design of programs. This was not always the case with the organisations included in this study with varying amounts of opportunities for input from Aboriginal communities into service and program design. This was dictated through different factors such as the governance structures of organisations, funding sources, organisational priorities and workforce capabilities. The lack of community consultation which was apparent by some organisations in

the service and program design can lead to culturally unsafe programs and practices (Coffin 2007). The NSW Health Aboriginal health plan first priority is building trust through partnerships which typically occur at a staff level with community or at an executive level. There was less interaction on a regular basis between sectors at a management level. Decision making in the NGO sector was largely directed by non-Aboriginal people and reflected their funding responsibilities and the organisational charter. Elders were engaged to varying degrees and their important role as knowledge holders of community as well as their strong connections within community. The ongoing involvement in the direction of programs is an important mechanism for facilitating self-determination and engagement (Mikhailovich, Morrison et al. 2007).

The relevance of the programs which were delivered was derived from various factors. This included funding sources, organisational priorities, data and community direction. Programs delivered may not always be the right fit for Aboriginal communities and are limited in their reach and participation (McLennan and Khavarpour 2004).

### **7.3.2 Operations**

Governance in the health sector is usually seen through corporate, financial and clinical streams. Within Aboriginal health however cultural governance is also an important mechanism for de-colonising the health care sector from an illness perspective to a wellness and holistic perspective which reflects Aboriginal health perspectives (Sherwood and Edwards 2006). The main drivers for the different sectors come from different stakeholder responsibilities. The government sectors are very much driven by data and reporting as workforce and programs are typically embedded in recurrent funding models. Funding and service insecurities were apparent drivers on the ability to deliver in the NGO and ACCHS sectors. This translated to activities particularly in the NGO sector to reflect broader national and state priorities and funding. ACCHS however though still having ongoing concerns around sustainability the main driver in their strategic direction was based on community need and the flexibility in funding allowed the sector to be more responsive to community needs.

The sustainability of programs can be largely around funding but also requires a continuous quality improvement approach to ensure certain standards are being met and the organisation improves their operations to meet the needs of the community (Bailie, Si et al. 2008). The ACCHS sector spoke more prominently on continual quality improvement (CQI) as an integral component of their operations and responsibilities for continual accreditation. CQI was also spoken of in the government sector around reviewing program performance and activities to improve how they are delivered to the community.

Empowering community not only provides improved cultural governance and increased social capital but this also provides health benefits to individuals who are empowered (Campbell, Pyett et al. 2007). Empowerment is extremely important for individuals to self-managing chronic disease (Tsey, Wilson et al. 2007). Providing a supportive environment for Aboriginal people with chronic disease is extremely important. The lifestyle modification that is required often in a short or abrupt period can be daunting without the right knowledge and skills to be able to enact change (Rowley, Daniel et al. 2000). There are often complex needs for Aboriginal people and a holistic approach to service delivery should be a fundamental tenet of how services and programs are designed. This approach not only embodies health but other social determinants of health (Boddington and Räisänen 2009). ACCHS are best positioned to engage

a broad application of holistic health through their service design. All health services however relied on external relationships to wrap the appropriate services around clients which they engaged with complex needs.

### **7.3.3 Cultural Capability**

Having a strong Aboriginal workforce is instrumental for delivering a culturally competent and effective health program (Taylor, Thompson et al. 2009). The workforce composition of the organisations varied between strong Aboriginal workforces to non-Aboriginal people delivering Aboriginal programs. This also extended to the management levels of the organisation. The success of many of the programs came down to Aboriginal health workers who had trust and respect within the community. Organisations which had non-Aboriginal frontline staff described the challenges of working within the community.

Building an Aboriginal workforce capacity is extremely important for effective service delivery. Typically half of the Aboriginal workforce has qualifications at a certificate or diploma level yet less than 5% have a degree or higher level of qualification. Building this workforce capacity would not only enhance service delivery in Aboriginal health but also enable Aboriginal people to work across all professions in the health workforce (Sibthorpe, Becking et al. 1998). The Aboriginal health workers however had a diversity of roles across and within all health sectors. This ranged from clinical, chronic disease program coordination, health promotion and health advocacy.

Building cultural capability in the health sector has been addressed for a number of years through various cross cultural training strategies. The health benefits from having a culturally appropriate health sector will improve patient outcomes and improve early and sustained engagement with the sector (Durey 2010). Cultural capability is an inherent practice of ACCHS and government have well-articulated programs to build their capability. The NGO sector has a less structured approach to cultural capability which can impact on the acceptability of their services in the community.

A partnership approach is critical for ensuring health service is able to engage appropriately and effectively with all stakeholders. The way in which sectors engage with ACCHS and the Aboriginal community can be challenging where often a dispersion of power is needed to negotiate a shared position which is ultimately demands improved health and wellbeing outcomes for the Aboriginal community. These relationships often require trust and respect to build over time and to be demonstrated through meaningful actions and not just rhetoric (Taylor, Thompson et al. 2009). The relationships of the participating organisations in this study with ACCHS and the community varied and trust was stronger between different organisations. Some were articulated through formal organisational agreements while others relied heavily on personal relationships to sustain partnerships. These relationships are particularly important when coordinating care across agencies to ensure transfer and continuity of care is undertaken with the most appropriate model of care for the client (Bailie, Si et al. 2004).

Access by Aboriginal people to health services is a well-documented barrier to improving the health and wellbeing of the community. the rates of Aboriginal people accessing services which provide Medicare items was 39% less than non- Aboriginal people (Hayman, White et al. 2009). Factors include the real or perceived cost of services, the ability to travel to and from services, the cultural appropriateness of services and having the right service provision required for the

needs of the community (Scrimgeour and Scrimgeour 2008). The ability for all sectors to facilitate access to primary health and specialist services was an ongoing challenge which was at the core of service delivery strategies. All relied heavily on the Aboriginal community to facilitate community engagement. The burden of cost was also addressed through such programs as the CCSS and transport provision. Having a settings based approach where services are delivered within the community was also a strategy employed by all organisations. An Aboriginal workforce was considered an important model for facilitating access to health care for the Aboriginal community.

#### **7.3.4 Summing up**

There was a diversity of positions which the various sectors that included government, NGO and ACCHS applied 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 positioning of the service which is a standardised national strategy should be considered due to the limited cultural capability of the sector compared to other sectors. 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 NGO sector should aim to improve its cultural governance if it continues to deliver health services to the Aboriginal community. Mandatory cultural training should be enacted and cultural mentors could work in all sectors to build their cultural capability. This can also be achieved by creating Identified positions for roles which primarily work in Aboriginal health.

Vertical integration of health is the preferred model of service design where different health is collaborative and aligns internally. This however the capacity to deliver holistic disciplines across non-health sectors and horizontal integration could be considered as a model for enabling a more holistic approach to Aboriginal health.

There is a level of duplication which occurs across the health sectors and a lack of strong identity on the roles of different providers as well as the role of Aboriginal health workers. This should be addressed collaboratively across all sectors. There needs to be a level of responsibility by the state and federal governments to also direct funding to the organisations which are best equipped to address the funding priorities.

An Aboriginal workforce is critical for the success of improving Aboriginal health. There has been and continues to be a skills shortage in Aboriginal health. This can be attributed to the historical nature of building workforce capacity focusing on short courses and certificate or diploma level courses. A new level of competency needs to be developed within Aboriginal health. This should happen across sectors through supporting existing Aboriginal health workers and developing Aboriginal people who want to work in the sector and engaging with community, schools and higher education sectors. The Aboriginal workforce is also part of the local community and the potential multiplier effect from building capacity and social capital in Aboriginal staff will have flow on effects into the community.

## **7.4 Effectiveness of health services for chronic disease management**

### **7.4.1 What's working well**

#### *Targeted Programs*

Service providers acknowledged that the health system is complex and difficult to navigate; challenges included linking Aboriginal participants to the most appropriate service. Most service providers thought that the choice of service should be an individual decision and that it was important not to make assumptions about participants' preferences for an Aboriginal specific service. At the same time they recognized that the Aboriginal specific programs provided effective pathways to other services.

The District has a sizeable number culturally appropriate Aboriginal specific programs targeting chronic disease management, operated both by mainstream organisations and Aboriginal organisations. Overall programs were very well regarded by Aboriginal participants. The findings suggest that the local Aboriginal communities benefit from having a range of different programs to meet the diverse needs of the population. Some of the positive aspects of these programs mentioned by participants were:

- Providing information to assist people in making choices about their health
- Monitoring health and providing feedback
- Offering flexible arrangements and transport assistance
- Providing a culturally safe and supportive environment
- Including nutrition and exercise components
- Providing opportunities for program participants to share and learn from each other
- Availability of health professionals
- Having a social component and building trusting respectful relationships

#### *Care in the community*

Despite some variation in the way participants in our study described their health care experiences, Aboriginal participants were generally positive about the health care they received from Aboriginal and non-Aboriginal health services and practitioners in the community. Many Aboriginal participants chose to use and were strongly supportive of the ACCHSs. This positive support for ACCHS is supported by previous findings in the literature (Scrimgeour and Scrimgeour 2008, Jowsey 2011, Aspin, Brown et al. 2012, Vicki-Ann Ware 2013). Others were very satisfied with the care they received from their general practitioner. It should be noted however, that GP care plans were not widely reported by participants.

#### *CTG assistance with medications*

Participants who were able to access programs funded under the CTG strategy benefitted from subsidised medicines under the PBS Co-payment measure which was making a great deal of difference to their lives; many stated that they would not be able to afford, and would stop taking the medications for their diabetes or other chronic illness, if it were not for the scheme. CCSS has also had some success in assisting people to access specialist care, with more people accessing medical equipment.

### **7.4.2 What could be improved?**

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

### *Hospital and discharge experience*

Findings from the study strongly suggest that there is a gap in the supports offered to Aboriginal people while in hospital and in the post-discharge period. Aboriginal people place great importance on family, particularly when they are ill in hospital. This is not always well understood, or is disregarded, by busy hospital staff.

The hospital discharge experiences of Aboriginal participants were also largely negative with many participants left confused and overwhelmed when they returned home from hospital. A stay in hospital can offer an opportunity for health education, but our study found communication between doctors and patients was often poor and that inadequate written information was provided to Aboriginal patients about how to manage their chronic condition at home. This suggests that more emphasis should be placed on improving cross cultural communication skills, providing clear written information about health conditions and the importance of extended family relationships to Aboriginal people. This could be included in the mandatory cross cultural training of all ISLHD staff, particularly those working in frontline positions.

### *Improved information about CTG*

Despite the assistance offered to many through programs funded under the CTG strategy, there were inconsistencies about the program; participants expressed concerns and confusion about their entitlement, stated that they needed to search for doctors who are part of the program and were unsure about whether the program would continue or be subject to government funding cuts. Participants also complained about having to sign up every year for the scheme.

### *Promotion of the 48 Hour Follow-Up Program*

Service providers identified a number of areas for improvement of the 48 Hour Follow-Up Program. Although the program has been designed specifically to address the complex care needs of Aboriginal people following discharge, and there is a high level of cultural competency among staff, this is a need for broader dissemination about the program. This included a need to ensure that service providers are well informed and there is referral from the program to a wide range of health and social service options to meet the individual needs of Aboriginal people. There was a strong indication, however, that this problem had been recognised and was being addressed by the ISLHD, by strengthening the relationships between hospital and health services delivered in the community.

### *More widespread uptake of GP care plans*

Another clear area for improvement is to increase the number of Aboriginal chronic disease participants with GP care management plans. Many participants did not have a GP care plan for their chronic disease, and said that no one had discussed a care plan with them. These participants were managing for the present, but were unsure about what future treatment they might require.

### *Advocate for a stronger role for ACCHS*

ACCHSs play an important role in the health delivery system within the region. However, they face many challenges in their efforts to holistically meet their clients' health and social needs. For example, in addition to chronic diseases, mental health is a major problem amongst ACCHS participants, but there is little flexibility in the funding arrangements to enable the services to

deal adequately with these problems. ACCHSs need assistance to implement new ways of engaging people in their services, including through social media and new technologies.

#### *Systems improvement*

Aboriginal participants' suggestions for how health system improvements could be made centred on improved health service delivery; providing programs that support and connect the community; more flexibility in the delivery of programs and services; involving the Aboriginal community in decision making; and greater accountability for Aboriginal targeted funding.

Systems stakeholders made a number of suggestions for systems change included, improving referral pathways within the health service, particularly between hospital and service providers in the community and by creating partnership models with Aboriginal organisations within the two regions and increasing the number of face to face outreach clinics. They also recommended greater flexibility in funding arrangements for Aboriginal chronic disease programs, increasing the number of Aboriginal AHLOs and Aboriginal health professionals in mainstream health settings and addressing racism within systems and service provision.

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

#### *Health literacy*

Acknowledging that people with chronic disease play an important role in the management of their own health, participants, particularly those in focus group discussions, draw attention to the need for greater health literacy as a major gap in current support. There were various suggestions about the need for community education delivered in culturally appropriate ways, including ongoing education workshops discussions and forums to share experiences as 'it's good to yarn up about your problems'. Aboriginal system stakeholders made similar suggestions about the need for a flexible education program, tailored to individual needs, rather than the structured approach, such as an education session at particular intervals, as is the case in many programs.

#### *Workforce development*

The need to strengthen and support the Aboriginal health workforce across the District was consistently raised by study participants as a gap service provision. There are numerous ways which have been identified throughout this report, in which Aboriginal health workforce needs could be addressed. There is an urgent need to review the role of the AHLOs and to ensure that the role is supported and understood by other health professionals and communicated to the Aboriginal community. Supporting Aboriginal health workers to gain qualifications, including as Aboriginal health practitioners to deliver primary health care of screening and monitoring chronic disease in outreach settings; this is likely to have immediate to mid-term benefits for Aboriginal client care. Increasing the number of Respecting the Difference trainers to ensure that cultural training is implemented across the ISLHD workforce. Assisting non-Aboriginal staff to build relationships with Aboriginal communities could also reduce the burden on the relatively few Aboriginal health workers.

#### *Greater connectivity of health and social services*

Health service provision across the health services was frequently described by service providers and systems stakeholders as fragmented. Services were not necessarily located in areas of greatest need, that is, areas of socio-economic disadvantage where most Aboriginal people live. This was notable in the Shellharbour area, the northern Illawarra, as well as in the

Shoalhaven. Health service providers also noted that some large medical services kept business 'in house' and did not refer externally, limiting participant choice. There is considerable scope, therefore, for improved connection between services which meet the complex needs of Aboriginal people with chronic conditions, including better linkages between health and social services to address the underlying social determinants of health.

## 7.5 Lessons learnt in undertaking the research

In conducting this project the research team learnt valuable lessons about the research processes and the importance of the research to community.

The initial challenges in the recruitment of Aboriginal participants who had a recent hospital episode were overcome by a more flexible approach to recruitment and seeking the support of the Steering Committee. Two important issues were identified: firstly, the importance of timing in making the initial approach to participants. The approach through the 48 Hour Follow-Up Team, proved to be too soon after discharge and participants were not interested in engaging in the research; secondly, seeking assistance with recruitment from someone who was known to, and had the trust of, participants, such as the GPH Aboriginal project officer and the ISLHD Aboriginal health officers. There were also a number of challenges in achieving a broader demographic spread of Aboriginal participants as difficult to access younger age group, which were overcome through the assistance of the Aboriginal organisations. Being able to build upon the existing relationships between the Aboriginal members of the research team and regional organisations, notably the Aboriginal workforce within these organisations, was critical to the success of the project. It was through these relationships that the research team were able to gain the trust of individuals who agreed to participate in the 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 participants 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.

Participants from all participant groups recognized the importance of this research project and saw the research as an opportunity to express their strong views about the changes that needed to change at all levels – individual, organisational and systems levels. When asked about how they would like the research used participants, particularly the Aboriginal community members, emphasised the importance of dissemination of the results back to community. This will take place in the form of a community report. Other participants made a strong plea for the research to be used to achieve systems improvements which were urgently needed to address the unnecessary illness, disability and death from the very high rates of chronic illness in the Aboriginal population.

Participants believed that information from this research would help other communities.

*I think so because then we can find out really the issues in every different community 'cause we're all in different communities and we all have different ways of handling things. Some are good at it but a lot of us aren't.* **Focus group participant**

Researchers were encouraged to come back next year and share findings.

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

## 8 Conclusions and Recommendations

This study set out to explore the factors that impact on Aboriginal people's experience of chronic conditions and the management of those conditions post discharge within ISLHD. The purpose of the study was to improve planning across the care continuum. Addressing this complex area requires action at multiple levels; it also needs to take into account the diversity of the Aboriginal community within the two regions. Action taken at the individual, family and community level could help to empower Aboriginal people to take control of their chronic conditions, and thus contribute to reducing avoidable hospitalisations, patients leaving against medical advice or being readmitted for the same condition. However action at the organisational level is also needed. This includes improving organisational practices and procedures and the interpersonal and communications skills of health professionals. Ultimately, however, change at the systems level is essential to address the complex issues highlighted throughout this report. Systems level improvements include addressing workforce issues, particularly the urgent need to improve the cultural competence of ISLHD employees as well as the NGOs working in the sector. To ensure more effective, accessible, acceptable and appropriate services for Aboriginal people a systems approach needs to be informed by Aboriginal community views. The following are recommendations for how improvements might be achieved at each of these levels.

### RECOMMENDATIONS

#### That the Illawarra Shoalhaven Local Health District:

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

- Support action on the 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 the 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.

### **Recommendation 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 employs 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.

### **Recommendation 3: Improve hospital and patient 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 staff 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 GP 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 within this period to ensure ability to cope at home.

### **Recommendation 4: Enhance Aboriginal chronic disease management programs**

- Enhance the Aunty Jean’s program by:
  - Ensuring that 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 programs by providing delivery flexible options (for example on weekends and after hours).

**Recommendation 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.

**Recommendation 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 ISLHD.
  - 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 ISLHD 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.

## References

Aboriginal and Torres Strait Islander Social Justice Commissioner (2005). Social Justice Report 2005. Canberra, HREOC.

Aboriginal Health & Medical Research Council (2015). Aboriginal communities improving Aboriginal health: An evidence review on the contribution of Aboriginal Community Controlled Health Services to improving Aboriginal health. Sydney, AH&MRC.

Aboriginal Health and Medical Research Council (2013). AHMRC Guidelines for Research into Aboriginal Health: Key principles.

[www.ahmrc.org.au/index.php?option=com\\_docman&task=cat\\_view&gid=22&Itemid=45](http://www.ahmrc.org.au/index.php?option=com_docman&task=cat_view&gid=22&Itemid=45).

Aspin, C., N. Brown, T. Jowsey, L. Yen and S. Leeder (2012). "Strategic approaches to enhanced health service delivery for Aboriginal and Torres Strait Islander people with chronic illness: a qualitative study." *BMC Health Services Research* **12**(1): 143.

Australian Bureau of Statistics. (2006). "2039.0 - Information Paper: An Introduction to Socio-Economic Indexes for Areas (SEIFA) " Retrieved 1 December, 2014, from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/2039.0Main%20Features42006?opendocument&tabname>.

Australian Bureau of Statistics (2006). National Aboriginal and Torres Strait Islander Health Survey, 2004-5. cat. no. 4715.0. Canberra, ABS.

Australian Bureau of Statistics (2012b). Australian demographic statistics, March quarter 2012. Canberra, Australian Bureau of Statistics.

Australian Government (2013). National Aboriginal and Torres Strait Islander Health Plan 2013-2023. Canberra, Commonwealth of Australia.

Australian Government (2015). Closing The Gap Prime Ministers Report 2015, Commonwealth of Australia.

Australian Government Department of Health. (2016). "The Closing the Gap - PBS Co-payment Measure." Retrieved 1 August, 2016, from <http://www.pbs.gov.au/info/publication/factsheets/closing-the-gap-pbs-co-payment-measure>.

Australian Government Department of Health. (2016). "New Primary Health Networks to delivery better local care." Retrieved 1 August, 2016, from <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2015-ley036.htm>.

Australian Indigenous Health InfoNet. (2015). "Australian Indigenous Health InfoNet." Retrieved 19 June, 2016, from <http://www.healthinfonet.ecu.edu.au/>.

Australian Indigenous HealthInfoNet. (2013). "Aunty Jean's good health team program- Aboriginal chronic & complex care program." Retrieved 1 November, 2015, from <http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=28>.

Australian Institute of Health and Welfare (2005). Improving the quality of Indigenous identification in hospital separations data. AIHW cat. no. HSE 101. Canberra, AIHW (Health Services Series no. 25) Available online at: <http://www.aihw.gov.au/publication-detail/?id=6442467788>. Accessed 7 May 2011.

Australian Institute of Health and Welfare (2010). National best practice guidelines for collecting Indigenous status in health data sets, Cat. no. IHW 29. Canberra, AIHW.

Australian Institute of Health and Welfare (2011). Contribution of chronic disease to the gap in adult mortality between Aboriginal and Torres Strait Islander and other Australians. Cat. No. IHW 48. Canberra, AIHW.

Australian Institute of Health and Welfare (2014). Cardiovascular disease, diabetes and chronic kidney disease - Australian Facts Mortality. Canberra, AIHW.

Australian Institute of Health and Welfare. (2016). "Chronic disease risk factors." Retrieved 19 April, 2016, from <http://www.aihw.gov.au/chronic-diseases/risk-factors/>.

Bailie, R., J. Griffin, M. Kelaher, T. McNeair, N. Percival, A. Laycock and G. Schierhout (2013). Sentinel Sites Evaluation: Final Report. Report prepared by Menzies School of Health Research. Canberra, Australian Government Department of Health and Ageing.

Bailie, R., D. Si, G. Robinson, S. Togni and P. d'Abbs (2004). "A multifaceted health-service intervention in remote Aboriginal communities: 3-year follow-up of the impact on diabetes care." Medical Journal of Australia **181**(4): 195 - 200.

Betancourt, J., A. Green, J. Carrillo and O. Ananeh-Firempong (2003). "Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care." Public Health Reports **118**(4): 293-302.

Bradley, E. H., L. A. Curry and K. J. Devers (2007). "Qualitative data analysis for health services research: developing taxonomy, themes, and theory." Health Serv Res **42**(4): 1758-1772.

Brown, N. (2014). "Exploring Cultural Determinants of Health and Wellbeing." Lowitja Institute Roundtable Retrieved 1 November 2016, from <http://www.lowitja.org.au/cultural-determinants-roundtable>.

Burnette, L. and M. Kickett (2009). "Dislocation and Dialysis in Aboriginal Patients with Renal Failure [online]." Aboriginal and Islander Health Worker Journal **33**(4): 10-13.

Carson, B., T. Dunbar, R. Chenhall and R. Bailie, Eds. (2007). Social determinants of Indigenous health. Sydney, Allen and Unwin.

Centre for Epidemiology and Evidence (2012). The health of Aboriginal people of NSW: Report of the Chief Health Officer 2012. Sydney, NSW Ministry of Health.

Centre for Epidemiology and Evidence. (2016). "Health Statistics New South Wales." Retrieved 22 June, 2016, from [www.healthstats.nsw.gov.au](http://www.healthstats.nsw.gov.au).

Chin, N. P., A. Monroe and K. Fiscella (2000). "Social determinants of (un)healthy behaviors." Educ Health (Abingdon) **13**(3): 317-328.

Clapham, K., P. Grootemaat and F. Khavarpour (2014). The Coomaditchie Community Hub: Appendix C of the Evaluation of Two Community Sector Development Projects. University of Wollongong, Centre for Health Service Development.

Commission on Social Determinants of Health (2008). Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. Geneva, World Health Organization.

Commonwealth of Australia Department of the Prime Minister and Cabinet (2016). Closing the Gap Prime Minister's Report 2016.

Council of Australian Governments. (2008, 1 November 2012). "National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes." Retrieved 15 March, 2013, from <http://www.fahcsia.gov.au/our-responsibilities/indigenous-australians/programs-services/closing-the-gap>.

Curtis, S., D. Pegg and Illawarra Area Health Service (NSW) (2004). Aunty Jean's good health team: listening to the voices of the elders to create an Aboriginal chronic and complex care program. Unanderra, NSW, Illawarra Health.

Department of Health (2015). Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013-2023. Canberra, Australian Government.

Drury, L. (2014). Exploring the factors that impact on the management of care for Aboriginal people with Type 2 Diabetes Mellitus in the Illawarra region. Bachelor of Public Health (Honours Thesis), Faculty of Social Sciences, University of Wollongong.

Durey, A. (2010). "Reducing racism in Aboriginal health care in Australia: where does cultural education fit?" Australian and New Zealand journal of public health **34**(s1): S87-S92.

Dwyer, J., J. Kelly, E. Willis, J. Glover, T. Mackean, B. Pekarsky and M. Battersby (2011). Managing Two Worlds Together: City Hospital Care for Country Aboriginal People—Project Report. Melbourne, The Lowitja Institute.

Fredericks, B. (2004). "Urban Identity." Eureka Street **10**: 30-31.

Glaser, B. and A. Strauss (1967). The discovery of grounded theory. London, Weidenfield & Nicolson.

Gordon, R. and N. Richards (2012 ). "The Chronic Care for Aboriginal People program in NSW " NSW Public Health Bulletin **23**(3-4): 77-80.

Gracey, M. and M. King (2009). "Indigenous health part 1: determinants and disease patterns." Lancet **374**(9683): 85-75.

Harris, M. F. and N. A. Zwar (2007). "Care of patients with chronic disease: the challenge for general practice." MJA **187**: 104-107.

- Hayman, N. E., N. E. White and G. K. Spurling (2009). "Improving Indigenous patients' access to mainstream health services: the Inala experience." Medical Journal of Australia **190**(10): 604-606.
- Henry, J., T. Dunbar, A. Arnon, M. Scrimgeour, S. Manhews, L. Murakami-Gold and et al (2002). Indigenous Research Reform Agenda: Rethinking Research Methodologies. Links Monograph Series No.: 2. Casuarina, NT, Cooperative Research Centre for Aboriginal and Tropical Health.
- Houston, S. (2004). The past, the present, the future of Aboriginal health policy [doctoral thesis], Curtin University.
- Illawarra Shoalhaven Local Health District (2012). Working Together Building Healthy Futures: The Illawarra Shoalhaven Local Health District Health Care Services Plan 2012-2022.
- Jowsey, T., L. Yen, C. Aspin, N. Ward and the SCIPPS Team (2011). "People I can call on": Aboriginal and Torres Strait Islander experiences of chronic illness. Community Report. Serious and Continuing Illness Policy and Practice Study. Canberra, Menzies Centre For Health Policy.
- Kelly, J., J. Dwyer, T. Mackean, E. Willis, K. O'Donnell, M. Battersby and B. Pekarsky (2011). Managing Two Worlds Together: Study 3-The Experiences of Patients and Their Carers. Melbourne, The Lowitja Institute.
- King, M., A. Smith and M. Gracey (2009). Indigenous health part 2: the underlying causes of the health gap, Lancet. **374**: 76-85.
- KPMG (2013a). National Monitoring and Evaluation of the Indigenous Chronic Disease Package Baseline Report 2009-10. Canberra, Australian Government Department of Health.
- KPMG (2013b). National Monitoring and Evaluation of the Indigenous Chronic Disease Package First Monitoring Report 2010-11. Canberra, Australian Government Department of Health.
- KPMG (2014). National Monitoring and Evaluation of the Indigenous Chronic Disease Package Volume 2: ICDP Impact on Patient Journey and Service Availability. Canberra, Australian Government Department of Health.
- Lawrence, M., Z. Dodd, S. Mohor, S. Dunn, C. de Crespigny, C. Power and L. MacKean (2009). Improving the Patient Journey: Achieving Positive Outcomes for Remote Aboriginal Cardiac Patients. Darwin, Cooperative Research Centre for Aboriginal Health.
- Marmot, M. (2011). "Social determinants and the health of Indigenous Australians." Medical Journal of Australia **194**(10): 512-513.
- McMullen, S., P. Grootemaat, S. Winch, K. Senior, P van den Dolder, F. Facci and K. Clapham (2015). Perspectives on Chronic Disease in the Australian Indigenous Population: A Review of the Literature. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.
- National Aboriginal and Torres Strait Islander Health Council (2003). The National Strategic Framework for Aboriginal and Torres Strait Islander Health: Framework for action by Governments. NATSIHC. Canberra.

National Aboriginal Health Strategy Working Party (1989). A National Aboriginal Health Strategy. Canberra, Australian Government Publishing Service.

National Health and Medical Research Council (2003). Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research. Canberra, Commonwealth of Australia.

NSW Agency for Clinical Innovation. (2016). "48 Hour Follow Up Evaluation." Retrieved 1 August 2016, from <http://www.eih.health.nsw.gov.au/initiatives/48-hour-follow-up-evaluation>.

NSW Department of Health (2010). Chronic Care for Aboriginal People Model of Care. Sydney, NSW Department of Health.

NSW Government (2014a). NSW Stage Health Plan - Towards 2021. NSW Ministry of Health. Sydney.

NSW Government (2014b). NSW Rural Health Plan. NSW Ministry of Health. Sydney.

NSW Government. (2015). "Premier's Memorandum M2015-01-Local Decision Making." Retrieved 1 August, 2016, from <http://arp.nsw.gov.au/m2015-01-local-decision-making>.

NSW Government. (2016). "Health Illawarra Shoalhaven Local Health District." Retrieved 1 August, 2016, from [http://www.islhd.health.nsw.gov.au/about\\_us.asp](http://www.islhd.health.nsw.gov.au/about_us.asp).

NSW Health. (2015). "Chronic Disease Management Program." Retrieved 1 August, 2016, from <http://www.health.nsw.gov.au/cdm/pages/default.aspx>.

NSW Health Rehabilitation Redesign Project. (2015). "NSW Rehabilitation Model of Care: Final Report – Model of Care." from <https://www.aci.health.nsw.gov.au/resources/rehabilitation/rehabilitation-model-of-care/rehabilitation-moc>.

NSW Ministry of Health (2012). NSW Aboriginal Health Plan 2013-2023. NSW Ministry of Health. North Sydney.

Pawson, R. and J. L. Bellamy (2006). 'Realist synthesis': an explanatory focus for systematic reviews. Moving beyond effectiveness: Methodological issues in the synthesis of diverse sources of evidence. J. Popay. Londong, National Institute for Health and Clinical Excellence: 83-93.

Pawson, R., T. Greenhalgh, G. Harvey and K. Walshe (2004). Realist synthesis: an introduction. ESRC Research Methods Programme, University of Manchester. **RMP Methods Paper 2/2004**.

Preston-Thomas, A., A. Cass and P. O'Rourke (2007). "Trends in the incidence of treated end-stage kidney disease among Indigenous Australians and access to treatment." Australian and New Zealand Journal of Public Health **31**: 419-421.

QSR International Pty Ltd (2012). NVivo qualitative data analysis software; Version 10.

Rice, Z. (2013). Aboriginal Chronic Care: powerpoint presentation, Illawarra Shoalhaven Local Health District.

- Ritchie, J. and E. Spencer (1994). Qualitative data analysis for applied policy research. Analyzing qualitative data. B. R. Bryman A. London, Routledge: 173-194.
- Scrimgeour, M. and D. Scrimgeour (2008). Health care access for Aboriginal and Torres Strait Islander people living in urban areas, and related research issues: A review of the literature, Cooperative Research Centre for Aboriginal Health.
- Scrimgeour, M. and D. Scrimgeour (2008). Health care access for Aboriginal and Torres Strait Islander people living in urban areas, and related research issues: a review of the literature. Darwin, Cooperative Research Centre for Aboriginal Health. **CRCAH discussion paper no. 5**.
- Senior, K. (2003a). Health and well-being in a remote Aboriginal community, Australian National University.
- Senior, K. (2003b). A Gudbala Laif?: Health and Wellbeing in a Remote Aboriginal Community - what are the Problems and where Lies Responsibility? Canberra, Australian National University.
- Senior, K. and R. Chenhall (2013). "Health beliefs and behavior: the practicalities of "looking after yourself" in an Australian Aboriginal community." Medical Anthropology Quarterly **27**(2): 155-174.
- Sibthorpe, B., F. B. Becking and G. Humes (1998). "Positions and training of the indigenous health workforce." Australian and New Zealand journal of public health **22**(6): 648-652.
- Steering Committee for the Review of Government Service Provision (2011). Overcoming Indigenous Disadvantage: Key Indicators 2011. Canberra, Productivity Commission.
- Taylor, K. P., S. C. Thompson, M. M. Wood, M. Ali and L. Dimer (2009). "Exploring the impact of an Aboriginal Health Worker on hospitalised Aboriginal experiences: lessons from cardiology." Australian Health Review **33**(4): 549-557.
- The Lowitja Institute (2014). Cultural Determinants roundtable: Background Paper. Melbourne, The Lowitja Institute.
- van Walvaren, C., C. Bennett, A. Jennings, Austin and A. Forster (2011). "Proportion of hospital admissions deemed avoidable: a systematic review." Canadian Medical Association Journal **183**(E391-402).
- Vicki-Ann Ware (2013). Improving the accessibility of health services in urban and regional settings for Indigenous people. Closing the Gap Clearinghouse. **Resource sheet no. 27**.
- Vos, T., B. Barker, S. Begg, L. Stanley and A. Lopez (2009). "Burden of disease and injury in Aboriginal and Torres Strait Islander Peoples: The indigenous health gap." International Journal of Epidemiology **38**(2): 470-477.
- Wheeler, L. (2005). "NSW health Aboriginal health impact statement." New South Wales public health bulletin. **16**(7-8): 130.
- Williams, R., S. Curtis and O. Curtis (2004). "Aunty Jean's Good Health Team." The Chronical.

World Health Organisation. (2010, 23 February 2014). "International Statistical Classification of Diseases and Related Health Problems 10th Revision." Retrieved 19 April, 2016, from <http://apps.who.int/classifications/icd10/browse/2010/en>.

## Appendices

## Appendix 1 Chronic disease programs and services in the Illawarra and Shoalhaven

This Appendix provides a brief overview of the key services and programs available to Aboriginal people with a chronic illness in the Illawarra and Shoalhaven regions. The list is not exhaustive, and includes both targeted CDMPs and a broader range of social welfare and support services which were identified by participants in the research.

Organisation <sup>15</sup>	Scope <sup>16</sup>	State	Phase	Condition	Target	Evaluated	Description	Study Link / Additional information	Organisation Link
Pharmacies	National	All	Current	All CD	Aboriginal		The <b>Closing the Gap (CTG) Pharmaceutical Benefits Scheme (PBS) Co-payment Measure</b> improves access to PBS medicines for eligible Aboriginal and Torres Strait Islanders who are living with, or at risk of, chronic disease. Closing the Gap prescriptions attract a lower or nil patient co-payment for PBS medicines. Eligible patients can be registered at either: general practices participating in the Indigenous Health Incentive under the Practice Incentives Programme; or Indigenous Health Services in urban and rural settings		<a href="https://www.humanservices.gov.au/health-professionals/services/medicine/closing-gap-pbs-co-payment-measure">https://www.humanservices.gov.au/health-professionals/services/medicine/closing-gap-pbs-co-payment-measure</a>
ISLHD	State-wide	NSW	Current	ALL CD	Aboriginal	YES	The <b>Aunty Jean's Good Health</b>	<a href="#">(Curtis, Pegg et al.</a>	

<sup>15</sup> 'Organisation' in this table refers to the organisation responsible for the program in the Illawarra Shoalhaven

<sup>16</sup> 'Scope' in this table includes the broad scope of the program (National, State-wide, Regional) as well as where the program operates within the Illawarra Shoalhaven Local Health District boundaries

Organisation <sup>15</sup>	Scope <sup>16</sup>	State	Phase	Condition	Target	Evaluated	Description	Study Link / Additional information	Organisation Link
	Illawarra (Berkeley)  Shoalhaven (Nowra, Ulladulla)						<p><b>Program</b> (Aunty Jean's Program) was established over ten years ago in the Illawarra. The program currently operates at Berkeley (Cardiac CNC, Exercise Physiologist, Podiatrist and Diabetes Educator) Nowra and Ulladulla. A participant survey conducted by the ISLHD in 2013 showed that 83% of participants in the program were female and the average age of participants across the three locations is 59 years. Participants attend the program on an average of 2.5 years for one of the following reasons: exercise; social and friendship; health education; weight loss and maintenance; and overall health and wellbeing. The 20 survey respondents said they valued Aunty Jean's because of the impact it had had on their health, community connectedness and social interaction and the support they received from being able to share both problems and knowledge</p>	<p><a href="#">2004, Williams, Curtis et al. 2004, Australian Indigenous HealthInfoNet 2013, Rice 2013)</a></p>	
ISLHD	Regional	NSW	Current	ALL CD	Aboriginal	YES	<b>Aqua Class</b> is operated by ISLHD Aboriginal Health Education		<a href="http://www.islhd.health.nsw.gov.au">http://www.islhd.health.nsw.gov.au</a>

Organisation <sup>15</sup>	Scope <sup>16</sup>	State	Phase	Condition	Target	Evaluated	Description	Study Link / Additional information	Organisation Link
	Illawarra (Warilla)  Shoalhaven (Bomaderry)						officers. The ILSHD also partners with other organisations to run health promotion and exercise classes in various locations across the District, for example, Tai Chi and Yoga, Fighting Fit Program in Vincentia, Get Active Aerobics (Worrigee PCYC) and community gardens (Koonawarra and East Nowra) and Art for Healing (Jerrinja) (Rice 2013).		<a href="http://gov.au/">gov.au/</a>
Waminda: South Coast Women's Health and Welfare Aboriginal Corporation	Regional Shoalhaven (Nowra / Bomaderry, Wreck Bay Jerrinja)	NSW	Current	All CD	Aboriginal women	NO	<b>Dead or Deadly</b> is an ongoing 10 week program for Aboriginal women. It covers health, happiness, a fitness program, diet, self-esteem and goal setting. In conjunction with the Aboriginal Women from the Jerrinja Community, Waminda have also established a community garden which is the responsibility of the Jerrinja Communities Women's Wellbeing group.	<a href="http://www.waminda.org.au/health-and-wellbeing/">http://www.waminda.org.au/health-and-wellbeing/</a>	<a href="http://www.waminda.org.au/">http://www.waminda.org.au/</a>
ISLHD operates the state-wide program in the Illawarra and Shoalhaven	State-wide Illawarra Shoalhaven	NSW	Current	All CD	Aboriginal	YES The Enhanced 48 Follow-Up state-wide program is	The <b>48 Hour Follow-Up</b> program, was established as part of the Aboriginal Chronic Disease Care Strategy from the Integrated Chronic Care for Aboriginal People program (ICCAP) aims to improve the health outcomes of Aboriginal	<a href="http://mylink.hnehealth.nsw.gov.au/mod/page/view.php?id=16703">http://mylink.hnehealth.nsw.gov.au/mod/page/view.php?id=16703</a>	<a href="http://www.islhd.health.nsw.gov.au/">http://www.islhd.health.nsw.gov.au/</a>

Organisation <sup>15</sup>	Scope <sup>16</sup>	State	Phase	Condition	Target	Evaluated	Description	Study Link / Additional information	Organisation Link
						currently being evaluated	patients with chronic disease. Operated by the Access and Referral Centre (ARC) team, the program involves a phone follow-up from a health professional to Aboriginal participants within 48 hours of their discharge from hospital. Follow-Up covers issues such as medications (knowledge of and access to), referrals (booked and transport arranged) and general wellbeing. This is to ensure appropriate links to GPs, Aboriginal Community Controlled Health Services, Specialists, or other services to provide care post discharge.		
Grand Pacific Health	National  Illawarra (Shell Cove Family Health Centre)  Shoalhaven (Nowra)	NSW					<b>Care Coordination and Supplementary Services (CCSS)</b> is a CDMP funded under the Closing the Gap strategy. It is operated by GPH; the program runs in conjunction with SCMSAH in the Shoalhaven. The program involves provision of a dedicated care coordinator who assists in helping patients manage their condition(s). Services incorporate Closing the Gap services which supports access to primary care. GPH also		<a href="http://www.gph.org.au/">http://www.gph.org.au/</a>

Organisation <sup>15</sup>	Scope <sup>16</sup>	State	Phase	Condition	Target	Evaluated	Description	Study Link / Additional information	Organisation Link
							employs health professionals who work with individuals and local communities to provide health checks and address issues such as diabetes.		
Heart Foundation	State-wide	NSW					The <b>Koori Cook Off</b> program works in collaboration with Aboriginal and Torres Strait Islander communities to improve heart health outcomes via nutrition education. The program is based on the MasterChef model, where participants are grouped into teams and have to cook a number of meals for a panel of judges (local Elders). The program promotes the use of fresh vegetables, lean meats, healthy fats, using less salt, and drinking water. The Heart Foundation collaborates with a number of local community organisations to host the program in each of the regions.	<a href="http://www.healthinfor.net.ecu.edu.au/key-resources/programs-projects?pid=2928">http://www.healthinfor.net.ecu.edu.au/key-resources/programs-projects?pid=2928</a>	
Illawarra Aboriginal Medical Service	Regional Gerroa to Helensburgh						The <b>IAMS Chronic Disease Program</b> provides both health and community services for Aboriginal and Torres Strait Islander people in the Illawarra with the aim of improving their health and		<a href="http://www.illawarraams.com.au/">http://www.illawarraams.com.au/</a>

Organisation <sup>15</sup>	Scope <sup>16</sup>	State	Phase	Condition	Target	Evaluated	Description	Study Link / Additional information	Organisation Link
							wellbeing. The Chronic Disease Management team is managed by the Aboriginal Chronic Disease Care Worker, an outreach worker position funded by the Commonwealth under Closing the Gap). The Aboriginal health worker also refers out to other mainstream or non-government services. The program includes GP services, nursing services and an Aboriginal health worker. Participants can be referred to a range of internal and external services. The IAMS participates in the PIP program as well as providing bulk billing. GP services include a GP Management Plan and a Team care arrangement.		
Illawarra Koori Men's Support Group	Regional Albion Park	NSW	Current	All CD	Aboriginal Men	NO	The <b>IAMPAT (Illawarra Aboriginal Men's Physical Health and Training)</b> program is operated by the IKMSG.		<a href="http://shellharbourconnect.com.au/profile/illawarra-koori-mens-group-1347501522">http://shellharbourconnect.com.au/profile/illawarra-koori-mens-group-1347501522</a>

## **Organisations delivering health or social support services or programs to the Aboriginal community**

### Coomaditchie United Aboriginal Corporation (CUAC)

The Coomaditchie Hub operated by CUAC provides welfare and advocacy services to Aboriginal people in the Illawarra region as well as being active in bush regeneration, art projects and cultural heritage and community development programs (Clapham, Grootemaat et al. 2014). The Hub provides information and referral services to participants who are unable, or unwilling due to past bad experiences, to use other service providers. Services are offered flexibly to meet the needs of its participants. The Hub was described as providing a 'stepping stone' to other services. It creates a bridge between local Aboriginal residents and the services available to them that can ensure that Aboriginal people have the confidence to operate as citizens in the broader society.

<http://ahsri.uow.edu.au/chsd/projects/southernsuburbs/index.html>

### Grand Pacific Health

GPH provides primary health care services for South East NSW from Helensburgh in the north to the Victorian border in the south. GPH aims to meet local health needs and focuses on providing high-quality primary care services that include chronic disease management and care, mental health, and Aboriginal health care. GPH also provides mental health services for Aboriginal and Torres Strait Islander people through a program called Koori pathways. This program is aimed at people with mild to moderate mental health problems.

### Illawarra Aboriginal Corporation

The IAC is not-for-profit and is Aboriginal operated. The IAC has a board of Directors and employs staff across 5 sites around the Illawarra. The IAC has workplaces throughout the Illawarra and is based in the Wollongong City. The Culture Centre delivers a wide range of health and welfare programs including housing, emergency relief, aged care programs, Elders Groups, cultural services, confirmation of Aboriginality and venue hire as well as administration and management provisions. Child, youth and family services are also at the forefront of the organisation along with employment and training opportunities. The IAC is committed to local Aboriginal people's cultural, social and economic needs within the Illawarra region. The IAC also flows into Myimbarr Aboriginal Family Support, Warrigal Employment and Noogaleek Children's Centre.

### The Illawarra Aboriginal Medical Service (IAMS)

The IAMS was established in 1998 in the Illawarra, with the Dapto office opening in 2004. The IAMS provides a range of quality primary health care to the local Aboriginal community including medical, health and other multidisciplinary services. The IAMS also supports community groups within the Illawarra such as the Aunty Jean's Chronic Care Program, Illawarra Aboriginal Men's Physical Health and Training Program (IAMPHAT) and the Illawarra Koori Men's Support Group (IKMSG). The IAMS workforce is comprised of 42 staff, of which 22 (50%) identify as Aboriginal and/or Torres Strait Islander descent. Doctors, nurses and Aboriginal health workers are established within the general practice and outreach service.

### Illawarra Koori Men's Support Group

The IKMSG is a non-profit Aboriginal community organisation initiated and directed by Aboriginal men (members) living in the Illawarra area. The group is supported by the local community and has Aboriginal Elders at its helm. The group provides Aboriginal men and male youth with culturally appropriate educational programs to support men to improve their physical, social, emotional, spiritual and cultural well-being.

#### Illawarra Shoalhaven Local Health District – Aboriginal Health Services

Aboriginal Health Service is located within the Integrated Chronic Disease Management Stream with sits within the Ambulatory and Primary Health Division of ISLHD. Aboriginal health focuses on improving access to health services for Aboriginal people with chronic diseases and is responsible for the Aunty Jean's program. Aboriginal Health works to develop new models of health care that better support Aboriginal people (Illawarra Shoalhaven Local Health District 2012).

#### South Coast Medical Service Aboriginal Corporation

SCMSAC operates out of 5 sites providing holistic primary health care and other health related services including improving the equity of access to mainstream services for the Aboriginal communities in the Shoalhaven. Services provided by SCMSAC include social and emotional wellbeing services, Aboriginal children and family services and clinical services including dental services, a GP clinic and drug and alcohol services.

#### Waminda South Coast Women's Health and Welfare Aboriginal Corporation

Waminda is a culturally safe and holistic service, providing women and their Aboriginal families an opportunity to belong and receive quality health and wellbeing support. Our key focus is on providing tailored strength based care. Waminda's vision is 'that women and their ATSI families are positive, happy and healthy. They are widely admired and proud of their achievements in their own communities and the broader Shoalhaven'. Waminda addresses the social determinants of health, provides a Centre of excellence for ATSI women's health within the Shoalhaven community and is a leader in linking culture with education, health and well-being'. The centre provides a free service for women and children of all ages.

#### Weja Aboriginal Home Care

Weja provides Aboriginal home care services to eligible participants.

[https://www.adhc.nsw.gov.au/contact\\_us/home\\_care\\_branches/weja\\_Aboriginal\\_home\\_care\\_branch](https://www.adhc.nsw.gov.au/contact_us/home_care_branches/weja_Aboriginal_home_care_branch)



## Focus Group Questions

### Introduction (10mins)

- Introduce self and project
- Emphasise that this a safe place and no-one should feel uncomfortable.
- Explain what will be done – ask group a few questions and encourage everyone to answer and provide your honest opinions.
- Explain that no one will be identified
- Explain information sheet and a consent form.
- Allow time for people to fill in demographic
- Allow time for questions

### Engagement Questions (15mins)

First off, we are going to start with a few questions to gain your understanding of chronic disease and your journey in managing this.

1. Can you tell me briefly about the type of chronic illness you experience?
2. What does 'managing' chronic illness mean to you?
3. Do you have a care plan to manage your chronic disease (services such as doctor, hospital, IAMS etc.)? Ask group to give examples.
  - *Can you tell me what it has been like for you having to manage a chronic disease? What do you have to do that is different? How do you find that? What does it mean for you and your family?*
  - *Can you tell me what your initial response was when you were told you had a chronic disease?*
  - *Did someone devise a care plan for you? When did this happen? How long after first diagnosis did this occur?*

### Core Questions (15mins)

4. Can you tell me about your experiences with health professionals?
5. What do you see as working well in the health services you use?
6. What is not working well and why?
  - *What could health professionals do that would most improve your care?*
  - *What could you do that would most improve your care?*

### Exit Questions (10mins)

7. Is there anything else you would like to share about your experiences in managing a chronic disease?
8. Do you think that this research might help others with similar problems
9. How would you like us to share the results of the research with you when it is finished?

### Conclusion:

Sum up what has been said by the group. Thank each and every one of them for the contribution and participation, hand out the gift voucher to each individual.

---

## **Participant interview questions (approximately 60minutes)**

**Firstly I'd like to start by asking you a few questions about the last time you were in hospital or had to use a health service.**

1. When you were in hospital the last time can you tell me why you were there / what was the illness you had? [PROMPTS TO ENCOURAGE DISCUSSION]
  - What do you know about that condition? What does that mean for you?
  - When were you first diagnosed with this problem?
  - Have you been in hospital for the same reason/s before?
  - How many times have you been to hospital in the last 12 months? Was it for the same condition?
2. Can you tell me a little about how what it was like for you being in hospital?
3. When you were in hospital, did the hospital staff offer or suggest services that might be able to help you with your health problem at home?
  - What suggestions/information did doctors offer?
  - What suggestions/information did nurses offer?
  - What suggestions/information did the Aboriginal Hospital Liaison Officer offer?
  - What suggestions/information did the allied health workers (E.g. physio, OT, speech therapist, podiatrists, and dieticians) offer?
  - What suggestions/information did social workers offer?
  - What services did you hear about? (e.g. home care services, rehab, counselling, diabetes educator)
  - Did you receive any information/ pamphlets or brochures about these services or others services? Was that information useful?
  - Did you contact the services? Did you use them? How did you find them? Were they what you expected?

**I would like to ask you about your general management of your health problem and the supports around you**

4. Can you tell me a little about how you are managing your health problem? (E.g. Do you exercise, take medicines, try to eat well, get the flu shot?)
5. Is there anything that gets in the way of you staying well?
6. What support do you have at the moment to help you to manage your health problem? (E.g. family, friends, other?)
7. Can you tell me what support you think you need to help you to manage your health problem?

**Now I would like to ask you about the health services (e.g. specialist, doctor, GP, Aboriginal health worker etc.) you use to help you manage your health problem.**

8. Which health and support services are helping you to manage your health problem?
  - How long have they been providing you with service?
  - Do you see the same health worker each time you visit the service? Are you happy with that?
  - Overall how would you describe your experience with these services?
9. Do you have a written plan that has all the things you need to do to stay healthy?
  - What does that involve? How have you found that?
10. How easy is it for you to get to attend the services you use?
  - Are the services you need a long distance from your home?

- How do you get there? (walk, taxi, private car, bus, train)
11. Does it cost you anything to use the services?
- What do you have to pay for?
  - Can you manage the cost easily?
12. As an Aboriginal person, how appropriate have you found the mainstream health services?
13. When you think about the services you have used, would you recommend any of them to other people? Why or why not?
14. Would you change anything about the services you used?

**Now I would like to ask you about any programs you have participated in to help you manage your health problem (e.g. Aunty Jeans, Dead or Deadly, Aqua)**

15. How did you find out about the program?
16. What did you like about the program?
17. Is there anything you dislike about the program?
18. Has your health improved since you've been going to the program?
19. What are the main benefits you have gained from the program?
20. What could the program do better to meet your needs?
21. Could you tell me what you have learnt about managing your health problem/s as a result of participating in the program/s?

**Finally, to conclude, I have a few general questions about your health.**

22. Thinking about the future, what will you do to continue to manage your chronic disease?

Thank you for participating in the 'Aboriginal Chronic Disease Care Pathways' research project.

## **Semi Structured Interviews with Service Providers**

1. Can you tell me about some of your experiences in managing Aboriginal people with a chronic illness in the Illawarra or Shoalhaven regions?
2. What are some of the positive ways in which you feel you have been able to support Aboriginal people to manage their chronic illness?
3. How does referral to your service occur for Aboriginal participants? What are the processes for referral onto other services?
4. Have you faced any difficulties in your role/roles providing what you would consider to be appropriate support? What would assist you to provide more adequate support?
5. In your experience, do you feel that Aboriginal people have any distinct or different needs compared to others in managing their chronic illness/es?
6. In your opinion, what are the keys to successfully achieving appropriate health services for local Aboriginal people?
7. From your perspective, what are the key actions that are required to improve the capacity for Aboriginal people to manage their chronic illnesses?
8. Do you know of other service providers in the Illawarra and/or Shoalhaven region who are involved in (or specialise in) chronic disease management for Aboriginal people?

## **Semi structured interviews with managers of services or programs available to Aboriginal people diagnosed with a chronic disease**

### **Questions to describe Indigenous Chronic Disease Guidelines or Programs**

1. What are the programs designed to achieve against its aims and objectives?
2. What are the key activity components?
3. Who is involved in the different program components?
4. What are the roles of Indigenous community and families in the program?
5. How is Indigenous culture reflected in the program design and activities?

### **Questions about the operation of the Programs**

1. How are the programs governed / administered?
2. How are participants referred to the program? How are the referred onto other services?
3. How does the program operate for individuals?
4. Is the program operating in the way it is designed to operate?
5. How do program processes empower/marginalize Indigenous community and family?
6. How relevant to local community is the application of Indigenous culture and knowledge in the program?
7. How relevant to local community is the application of public health knowledge in the program?
8. How relevant are the current measured program outcomes to local community?

### **Questions about the cultural appropriateness of the service/program**

1. How many Aboriginal people are employed in the program?
2. Can you tell me about any strategies this service has in place to overcome issues such as cross-cultural communication? E.g. Is training provided to staff members on how to deliver culturally appropriate services to Aboriginal and Torres Strait Islander Peoples?

3. From your perspective and through your experience as a service provider in the Illawarra region, are there ways in which you think this service/program may be able to improve cultural appropriateness for local Aboriginal people? For example promotional materials, physical environment, engagement/partnerships with local Indigenous community or operational procedures and policies?
4. Can you tell me about any partnerships or involvement this service/program has with the local Aboriginal community?
  - If yes, can you describe what they are? Do you think the established partnerships have improved the way the service meets the needs of the local Aboriginal community?
  - If no, in your opinion do you think this service would benefit from developing partnerships with the local Aboriginal community? Can you tell me why you think it would/would not?
5. Are there ways in which you think this service may be able to improve the connection and trust with the local Aboriginal population?
6. In your opinion, are there barriers and facilitators for achieving this improved connection with the local Aboriginal community?
7. Can you suggest any other service providers in the Illawarra and/or Shoalhaven region who are involved in (or specialise in) chronic disease management for Aboriginal people who may be able to assist with this research?

---

## **Semi structured interviews with system stakeholders – indicative questions**

1. Can you tell me about your experience in managing or working with Aboriginal people with a chronic illness?

(ADDITIONAL PROMPT QUESTIONS)

- What models of care have you worked within in regards to managing chronic disease with Aboriginal people?
- What systems are in place for health care providers or others to help manage chronic disease for Aboriginal people within the Illawarra and Shoalhaven?
- What systems are in place for Aboriginal people to manage their own illnesses?
- What facilitates good integration of care?

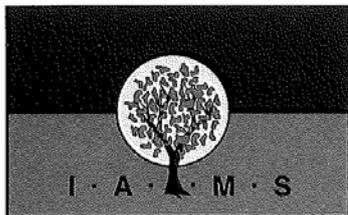
2. **In your opinion what are the barriers and facilitators for Aboriginal people accessing care for chronic conditions?**

3. **Can you suggest any other service providers or programs in the Illawarra and/or Shoalhaven region which specialise in chronic disease management for Aboriginal people?**

(ADDITIONAL PROMPT QUESTIONS)

- Are Indigenous community/families involved in the service/program?
- How is Indigenous culture reflected in the program design and activities?
- Are Aboriginal people employed in the program?
- Can you tell me about any partnerships or involvement this service/program has with the local Aboriginal community?

## Appendix 3 Ethical approvals and letters of support



### ILLAWARRA ABORIGINAL MEDICAL SERVICE Aboriginal & Torres Strait Islander Corporation

ABN 23 886 179 327 ICN: 274  
www.illawarraams.com.au

#### Wollongong

150 Church Street, Wollongong 2500  
**Phone: (02) 4229 9495 Dental: (02) 4229 9755**  
Medical Fax: (02) 4228 6153 Admin Fax: (02) 4226 3566  
PO Box 1161, Wollongong DC 2500

#### Dapto

2/130 Princes Highway, Dapto 2530  
**Phone: (02) 4262 8777 Fax: (02) 4262 8788**  
PO Box 425, Dapto 2530

Kathleen Clapham  
Australian Health Service Institute  
Innovation Campus  
University of Wollongong  
WOLLONGONG NSW 2500

9 January 2015

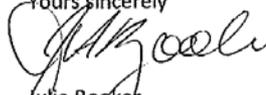
Dear Kathleen,

Re: Aboriginal Chronic Disease Pathways

The Illawarra Aboriginal Medical Service Board discussed the proposal research project being conducted by the University of Wollongong at its last meeting. The Board approves and has agreed to support the Australian Health Service Research Institute to undertake the Aboriginal Chronic disease pathways project between January 2015-January 2016.

We look forward to working with the research team which consist of Professor Kathleen Clapham, Assoc. Professor Kate Senior, Mr Scott Winch, Ms Pam Grootemaat, Ms Courtney Callister and research student employed by the University of Wollongong.

Yours sincerely



Julie Booker  
Chief Executive Officer  
Illawarra Aboriginal Medical Service

Funded by N.S.W. Health Department

Nadia Neal  
Australian Health Service Institute  
Innovation Campus  
University of Wollongong  
WOLLONGONG NSW 2500

16<sup>th</sup> July 2015

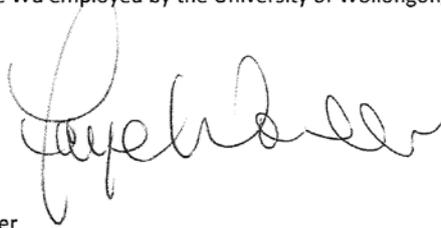
Dear Nadia,

Re: Aboriginal Chronic Disease Care Pathways

The Waminda South Coast Women's health and Welfare Aboriginal Corporation research committee discussed the proposal research project being conducted by the University of Wollongong at its last meeting. The committee approves and has agreed to support the Australian Health Service Research Institute to undertake the Aboriginal Chronic disease pathways project between January 2015- January 2016.

We look forward to working with the research team which consist of Professor Kathleen Clapham, Ms Nadia Neal, Mr Scott Winch, Associate Professor Kate Senior, Ms Pam Grootemaat, and Research Assistant Ms Darcelle Wu employed by the University of Wollongong.

Yours sincerely,



Faye Warner  
Chief Executive Officer  
Waminda South Coast Women's Health and Welfare Aboriginal Corporation



T: (02) 444800200 | F: (02) 44286602 | Email: [admin@southcoastams.org.au](mailto:admin@southcoastams.org.au)

16 April 2015

Kathleen Clapham  
Australian Health Service Institute  
Innovation Campus, University of Wollongong  
WOLLONGONG NSW 2500

Dear Kathleen,

Re: Aboriginal Chronic Disease Pathways

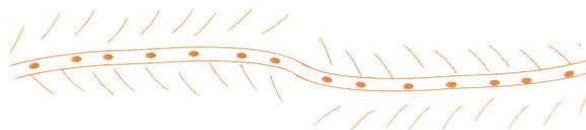
The South Coast Medical Service Aboriginal Corporation Board discussed the proposal research project being conducted by the University of Wollongong at its last meeting. The Board approves and has agreed to support the Australian Health Service Research Institute to undertake the Aboriginal Chronic disease pathways project between January 2015-January 2016.

We look forward to working with the research team which consist of Professor Kathleen Clapham, Assoc. Professor Kate Senior, Mr Scott Winch, Ms Pam Grootemaat, Ms Courtney Callister and research students employed by the University of Wollongong.

Yours sincerely

Craig Ardler  
Chief Executive Officer  
South Coast Medical Service Aboriginal Corporation

ABN: 46897866758  
PO BOX: 548, Nowra NSW 2541  
Website: [www.southcoastams.org.au](http://www.southcoastams.org.au)





*AH&MRC ETHICS COMMITTEE*

29<sup>th</sup> January 2015

**Professor Kathleen Clapham**

Professor (Indigenous Health)  
Australian Health Services Research Institute  
Innovation Campus  
University of Wollongong  
Wollongong NSW 2522

Dear Professor Clapham,

**RE: 1060/14 - Aboriginal Chronic Disease Care Pathways in the Illawarra and Shoalhaven Regions**

The Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee has considered your original application received on 24<sup>th</sup> November 2014 for ethics approval for the above project.

**The Committee agreed to approve the application, subject to the Standard Conditions and Special Conditions of Approval below:**

**Standard Conditions of Approval (where applicable to the project)**

1. The approval is for a period from 29<sup>th</sup> January 2015 until 29<sup>th</sup> January 2016 (12 months after), with extension subject to providing an Annual Progress Report on the research by 29<sup>th</sup> January 2016.
2. All research participants are to be provided with a relevant Participant Information Statement and Consent Form in the format provided with your application.
3. Copies of all signed consent forms must be retained and made available to the Ethics Committee on request. A request will only be made if there is a dispute or complaint in relation to a participant.
4. Any changes to the staffing, methodology, timeframe, or any other aspect of the research relevant to continued ethical acceptability of the project must have the prior written approval of the Ethics Committee.
5. The AH&MRC Ethics Committee must be immediately notified in writing of any serious or unexpected adverse effects on participants.
6. The research must comply with:

*Supported by the NSW Ministry of Health*

**Location**  
Level 3, 66 Wentworth Avenue  
Surry Hills NSW 2010

**Postal Address**  
PO Box 1565  
Strawberry Hills NSW 2012

**Contact**  
Phone: +61 (2) 9212 4777  
Fax: +61 (2) 9212 7211  
e-Mail: [ahmrc@ahmrc.org.au](mailto:ahmrc@ahmrc.org.au)  
web: [www.ahmrc.org.au](http://www.ahmrc.org.au)

**ABN**  
ABN 66 085 654 397

- the *AH&MRC Guidelines for Research in Aboriginal Health – Key Principles*;
  - *National Statement on Ethical Conduct in Research Involving Humans* (April 2007 – updated March 2014);
  - the *NSW Aboriginal Health Information Guidelines*.
7. The final draft report from the research, and any publication or presentation where data or findings are presented, must be provided to the AH&MRC Ethics Committee to be reviewed for compliance with ethical and cultural criteria prior to:
- any submission for publication; and/or
  - any dissemination of the report.
8. A copy of the final published version of any publication is to be provided to the AH&MRC Ethics Committee.

**Special Conditions**

9. (a) Current approval is for Stage 1 of a two-staged project.
- (b) Please provide a copy of the approval letter from the University of Wollongong/Illawarra Shoalhaven Local Health District Health Medical Research Human Research Ethics Committee prior to commencing the project.
- (c) Please provide support letters for the project from the Illawarra Aboriginal Medical Service (IAMS) and South Coast Medical Service Aboriginal Corporation (SCMSAC) prior to commencing the project.

**Please acknowledge receipt of this letter and your acceptance of the above conditions within fourteen (14 days).**

Please find attached an Annual Progress Report pro forma for use at the end of the approval period.

We appreciate your agreement that the research findings will be made available in order to assist the future development of policy and programs in Aboriginal health.

On behalf of the AH&MRC Ethics Committee,

Yours sincerely,



Val Keed  
Chairperson  
AH&MRC Ethics Committee



*AH&MRC ETHICS COMMITTEE*

1<sup>st</sup> March 2015

**Professor Kathleen Clapham**

Professor (Indigenous Health)  
Australian Health Services Research Institute  
Innovation Campus  
University of Wollongong  
Wollongong NSW 2522

Dear Professor Clapham,

**RE: 1067/15 – Stage 2: Aboriginal Chronic Disease Care Pathways in the Illawarra and Shoalhaven Regions**

The Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee has considered your original application received on 23<sup>rd</sup> January 2015 for ethics approval for the above project. Additional information received on 10<sup>th</sup> February 2015 is considered to form part of the application.

**The Committee agreed to approve the application, subject to the Standard Conditions and Special Conditions of Approval below:**

**Standard Conditions of Approval (where applicable to the project)**

1. The approval is for a period from **1<sup>st</sup> March 2015** until **1<sup>st</sup> March 2016** (12 months after), with extension subject to providing an Annual Progress Report on the research by **1<sup>st</sup> March 2016**.
2. All research participants are to be provided with a relevant Participant Information Statement and Consent Form in the format provided with your application.
3. Copies of all signed consent forms must be retained and made available to the Ethics Committee on request. A request will only be made if there is a dispute or complaint in relation to a participant.
4. Any changes to the staffing, methodology, timeframe, or any other aspect of the research relevant to continued ethical acceptability of the project must have the prior written approval of the Ethics Committee.
5. The AH&MRC Ethics Committee must be immediately notified in writing of any serious or unexpected adverse effects on participants.
6. The research must comply with:

*Supported by the NSW Ministry of Health*

**Location**  
Level 3, 66 Wentworth Avenue  
Surry Hills NSW 2010

**Postal Address**  
PO Box 1565  
Strawberry Hills NSW 2012

**Contact**  
Phone: +61 (2) 9212 4777  
Fax: +61 (2) 9212 7211  
e-Mail: [ahmrc@ahmrc.org.au](mailto:ahmrc@ahmrc.org.au)  
web: [www.ahmrc.org.au](http://www.ahmrc.org.au)

**ABN**  
ABN 66 085 654 397

- the *AH&MRC Guidelines for Research in Aboriginal Health – Key Principles*;
  - *National Statement on Ethical Conduct in Research Involving Humans* (April 2007 – updated March 2014);
  - the *NSW Aboriginal Health Information Guidelines*.
7. The final draft report from the research, and any publication or presentation where data or findings are presented, must be provided to the AH&MRC Ethics Committee to be reviewed for compliance with ethical and cultural criteria prior to:
- any submission for publication; and/or
  - any dissemination of the report.
8. A copy of the final published version of any publication is to be provided to the AH&MRC Ethics Committee.

**Special Conditions**

9. (a) Please provide a copy of the University of Wollongong/Illawarra and Shoalhaven Local Health District Health and Medical Ethics Committee approval for this project when it becomes available to you.
- (b) Please provide a support letter from South Coast Medical Service Aboriginal Corporation (Nowra) prior to commencing the project.

**Please acknowledge receipt of this letter and your acceptance of the above conditions within fourteen (14 days).**

Please find attached an Annual Progress Report pro forma for use at the end of the approval period.

We appreciate your agreement that the research findings will be made available in order to assist the future development of policy and programs in Aboriginal health.

On behalf of the AH&MRC Ethics Committee,

Yours sincerely,



Val Keed  
Chairperson  
AH&MRC Ethics Committee



Health  
Illawarra Shoalhaven  
Local Health District

Research Directorate  
Telephone: 02 4253 4800  
Facsimile: 02 4253 4803

TRIM NO: DT15/50361  
Ref: HE15/059  
APPROVAL

Professor Kathleen Clapham  
Australian Health Services Research Institute  
University of Wollongong  
Wollongong NSW 2515

Dear Professor Clapham

HREC project number: HE15/059  
Project title: **Aboriginal Chronic Disease Care Pathways in the Illawarra and Shoalhaven  
Regions Stage 2**

Thank you for submitting a Site-Specific Assessment application for authorisation of the above project. I am pleased to inform you that authorisation has been granted for this study to take place at the following site:

- Ambulatory & Primary Health Care – Illawarra Shoalhaven Local Health District

This approval is only valid with a current Human Research Ethics Committee approval.

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully



for **KRISTY PIERCE**  
Research Governance Officer

7 July 2015

c.c. Paul van den Dolder, HOD – Ambulatory & Primary Health Care Division

Research Directorate  
Level 8, Block C, Wollongong Hospital  
(LMB 8808, SCMC NSW 2521)

## Appendix 4 Steering Committee membership

<b>Name</b>	<b>Position</b>	<b>Organisation</b>
Kathleen Clapham	Professor, Indigenous Health	AHSRI, UOW
Scott Winch	Indigenous Health Leader	GMS, UOW
Kate Senior	Associate Professor	Faculty Social Sciences, UOW
Pam Grootemaat	Research Fellow	AHSRI, UOW
Virginia Marshall	Project Manager	AHSRI, UOW
Nadia Neal	Project Manager	AHSRI, UOW
Michelle Noort	Director, Integrated Care Planning and Performance	ISLHD
Paul Van Den Dolder	Director Ambulatory and Primary Health Care	ISLHD
Franca Facci	Stream Leader Integrated Chronic Disease Management	ISLHD
Zane Rice	Manager Aboriginal Health ,Chronic Care Unit	ISLHD
Pauline Brown	Director, Aboriginal Health Strategy	ISLHD