centre for health service development

Aboriginal Chronic Disease Care Pathways: Summary Report

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ahsri australian health services research institute
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NSW GOVERNMENT Health Illawarra Shoalhaven Local Health District

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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.

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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.

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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 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.

1. Introduction

Aboriginal Australians are known to 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 study 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.

The study's four key objectives were addressed in the following ways:

- 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.

2. Background and literature

2.1 Key findings from the 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.

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.

A broad range of factors are known to contribute to the higher burden of chronic disease in Indigenous people. They include 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, Marmot 2011). 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.

Overall there is a lack of research on Aboriginal peoples' experience of living with and managing chronic disease particularly people living in urban and inner regional areas, as much of the literature 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).

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).

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.

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.

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.

2.3 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.

Hospitalisation due to chronic conditions

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. For 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.

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. 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 ISLHD. 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).

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 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).

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.

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 Heath

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

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 the 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 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 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 qualitative data enabled rich in-depth contextual information to be gathered from across all participant groups. The study had a number of limitations. This qualitative study had 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.

Data collection method	**No. of sessions/ models**	**No. of Participants**
Review of guidelines for Aboriginal models of care	8	
Semi-structured interviews	61	
Aboriginal clients[1] 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
Focus group discussions with Aboriginal community members	4	27
Total		88

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

4. Experiencing the system: Aboriginal perspectives

The results of the study are presented in three chapters: Chapter four presents the findings of interviews and focus groups with the Aboriginal participants in our study; chapter five presents the views of the service providers and system stakeholder perspectives; and chapter six reports on the review of the design of Aboriginal chronic disease programs which operate in the region.

To understand the ways in which Aboriginal people with chronic disease experience the health system, in the Illawarra and Shoalhaven regions, qualitative data from interviews and focus group with Aboriginal participants were collected and analysed. This section provides detailed information about how Aboriginal people experience the health system. The information is organised 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.

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[1] Aboriginal interviewees are referred to as ‘clients’ to distinguish them from focus group participants.

- 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 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

Based on the semi-structured interviews conducted with service providers and system stakeholders, this section provides detailed information about how those in professional and service delivery positions perceive and experience health service delivery and the health system. The information obtained is organised 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 improves 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 focuses on how Aboriginal chronic disease programs are designed and operate. It is 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). Demographically, Aboriginal people in the two regions are concentrated in areas of high levels of social disadvantage, high unemployment, and lower incomes. As with Indigenous Australians in other parts of the country, Aboriginal people in these regions experience much higher rates of chronic disease. 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.

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

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.

Attitudes to health, illness and medicines

- Like Aboriginal people in more remote parts of Australia, 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.
- 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 refer to their own or others' past experiences of racism; these stories continue to influence people's perceptions and explanations of services.
- Positive comments about hospital experiences were more likely to focus on the way the person was treated by hospital staff.
- There was widespread support for increasing the Aboriginal workforce across all areas of the health system.
- The AHLO position was seen as valuable but under-resourced, under-acknowledged with unrealistic expectations from the health service and the Aboriginal community.
- 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.
- 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, particularly for people from the Shoalhaven.
- Transport problems were largely alleviated for those attending local Aboriginal CDMS where transport is provided.
- The cost of care was consistently raised as a barrier to accessing medical specialists.
- Overall, participants were satisfied with the care they received by health care practitioners in the community
- Aboriginal participants were affected by systemic health care problems, such as long waiting times in busy acute care settings.
- The recognition of Aboriginality by health care professionals and services was often problematic.

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, 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 crating 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

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
- Providing 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
- Having good networks / word of mouth
- 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.

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 off 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.

Improved 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.

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

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.

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