



Perspectives on Chronic Disease in the Australian Indigenous Population: A Review of the Literature

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Glossary

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| ABS | Australian Bureau of Statistics |
| ACCHS | Aboriginal Community Controlled Health Services |
| AMS | Aboriginal Medical Service |
| ANTAR | Australians for Native Title and Reconciliation |
| ATSI | Aboriginal and Torres Strait Islander |
| CCAP | Chronic Care for Aboriginal People |
| CDMP | Chronic Disease Management Plan |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature |
| CKD | Chronic kidney disease |
| COAG | Councils of Australian Governments |
| COPD | Chronic obstructive pulmonary disease |
| CRCAH | Cooperative Research Centre for Aboriginal Health |
| CQI | Continuous Quality Improvement |
| CVD | Cardiovascular Disease |
| eGFR | Estimated Glomerular Filtration Rate – to test kidney function |
| ESKD | End of stage kidney disease |
| IAMS | Illawarra Aboriginal Medical Service |
| ICDP | Indigenous chronic disease package |
| ICHP | Improving the Culture of Hospitals Project |
| LOS | Length of stay |
| NACCHO | National Aboriginal Community Controlled Health Organisation |
| NAIDOC | National Aboriginal and Islanders Day of Observance Committee |
| NAIHO | National Aboriginal Islander Health Organisation |
| SCRGSP | Steering Committee for the Review of Government Services |
| SSE | Sentinel Sites Evaluation |

1 Introduction

The Australian healthcare system is experiencing increasing demand due to the changing profile of the Australian population which is ageing, living longer and the shifting burden of disease from acute to chronic and complex conditions. However, the Indigenous population which makes up 3% of the total population (Australian Bureau of Statistics 2011) is considerably younger than the non-indigenous population. This is largely due to higher fertility rates, lower life expectancy as well as higher mortality rates in the middle adult age group (45–65 years), and although the Indigenous population is gradually ‘ageing,’ the majority of Indigenous Australians are between the ages of 18 to 24 years old.

Despite its younger age profile, chronic diseases are far more prevalent among Indigenous people compared to non-indigenous Australians with much higher rates of hospitalisation for these conditions in the Indigenous population (Muenchberger and Kendell 2008). Chronic diseases are the main contributors to the mortality ‘gap’ between Indigenous and non-Indigenous Australians (Australian Institute of Health and Welfare 2014); they account for about 80% of the mortality gap for people aged 35 to 74 years measured in terms of potential years of life lost (Australian Institute of Health and Welfare 2011). The chronic diseases which mostly contribute to the mortality gap between Indigenous and non-Indigenous people are: circulatory diseases, diabetes, liver diseases, chronic lower respiratory disease, cerebrovascular diseases and cancer, with cardiovascular disease being the leading cause of disease burden among Indigenous people 55 years and over (Vos, Barker et al. 2009). As the Indigenous population is also gradually ageing, Indigenous people with complex chronic conditions can be expected to access health and support services at increasing rates into the future.

These statistics suggests that addressing the causes of chronic disease has the potential for large health gains for Indigenous people. Research in the area of chronic disease in Indigenous communities has largely focused on primary health care and the risk factors associated with chronic disease but at present only 13.1% of Indigenous peoples living in NSW received a health check or assessment (Steering Committee for the Review of Government Service Provision 2011). There has been very little research to date on how Indigenous Australians with chronic conditions use or experience health services.

In 2014 the Illawarra Shoalhaven Local Health District commissioned a study to inform transfer of care planning for Aboriginal¹ people with chronic conditions, with a particular focus on the services and programs available following discharge from hospital and their experience of service provision. The study set out to assess the efficacy of the current support systems for the management of chronic disease and identify any gaps in service delivery.

The broad aim of the study was to explore the factors that impact on Aboriginal people’s experience of chronic conditions and health management in order to inform improvements

¹ Following the NSW Health Guidelines we have used the term ‘Aboriginal’ to refers to Aboriginal people of NSW (NSW Health 2004). The terms ‘Aboriginal’, ‘Australian Indigenous’ and ‘Aboriginal and Torres Strait Islander’ are used interchangeably in this document.

in care planning across the care continuum. The key objectives formulated to achieve this broad aim were to:

- describe the extent and type of chronic disease among the Aboriginal population in the Illawarra and Shoalhaven regions
- document formal chronic disease management models of care for Aboriginal patients across NSW; and
- explore and document Aboriginal people's experiences of chronic disease management; and to identify the strengths and weaknesses of current chronic disease management for Aboriginal people.

This literature review forms the first part of the study. The review does not purport to provide a systematic review or a meta-analysis of the vast field of literature on Indigenous chronic ill-health. Rather, it examines Australian and international material relevant to the study 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? 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?

2 Background

At the outset of the review it should be noted that the health status of Indigenous peoples in developed countries, as measured by life expectancy, is significantly worse than for the mainstream population of those countries; and strongly affected by experiencing the ongoing effects of colonisation. Around 1% of the world's Indigenous people live in countries with a history of British colonialism and share common law similarities in terms of colonial and post-colonial histories.

Australia is a resource wealthy nation with a numerically small, and in terms of health, significantly disadvantaged Indigenous population; most often compared to other nations such as the United States of America, Canada and New Zealand. Whilst the Indigenous populations in New Zealand, the United States and Canada experienced major health improvements up to the 1980s as well as the slowing of health improvements until the year 2000, recognises that the health of Australian Indigenous people is worse than their counterparts (Griew, Tilton, Cox and Thomas 2008).

The Australian Government's inability to narrow the gap between the life expectancy of Indigenous and non-indigenous people was much criticised. These criticisms were not only based upon statistics but on the experiences of Indigenous people and as the subject of many reports, campaigns and lobbying by Indigenous communities and their health representatives and supporters. The wide gap in Indigenous life expectancy as a national

issue was taken up by more than 40 Indigenous and non-Indigenous organisations, who called upon governments to commit to closing the life expectancy gap between Indigenous and non-Indigenous Australians within a generation (Griew et al. 2008).

The origins of the Closing the Gap Campaign was initiated in a report by Dr Tom Calma (Aboriginal and Torres Strait Islander Social Justice Commissioner 2005), the then Aboriginal and Torres Strait Islander Social Justice Commissioner. The report called on the Australian Governments to commit to achieving health equality for Indigenous people and sparked the National Indigenous Health Equality Campaign in 2006; which led to a formal launch of Close the Gap Campaign in Sydney in April 2007. On 20 December 2007, the Council of Australian Governments answered the call of NACCHO, ANTA, Oxfam Australia and other organisations pledging to close the life expectancy gap, stated at the time to be 25 years (National Aboriginal Community Controlled Health Organisation 2012)².

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 monitor progress and independently report on whether Australian governments were achieving their targets (National Aboriginal Community Controlled Health Organisation 2012).

COAGs targets as part of its objective of Closing the Gap are:

- To close the life expectancy gap by 2031, within a generation
- To halve the gap in mortality rates for Indigenous children under five by 2018, *within a decade*
- To provide access to early childhood education for all Indigenous four-year olds in remote communities by 2013, *within five years*
- To halve the gap in reading, writing and numeracy by 2018, *within a decade*
- To halve the gap in the rate of Year 12 or equivalent attainment by 2020; and
- To halve the gap in employment outcomes by 2018, *within a decade*.

Other key policies that include indicators relevant to understanding and monitoring the health of Aboriginal people are the Aboriginal and Torres Strait Islander Health Performance Framework (National Aboriginal Health Strategy Working Party 1989) and 'NSW 2021: A plan to make NSW number one'; which outlines Aboriginal health targets for the state (New South Wales Government 2011). The Indigenous Chronic Disease Package (ICDP) represented the Australian Government's contribution of \$805.5 million to the National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes.

² This much publicised figure of the gap in life expectancy was later revised due to changes in the methods to calculate life expectancy by the Australian Bureau of Statistics. A more recent the estimated life expectancy at birth for Aboriginal and Torres Strait Islander males (2010–2012), was 69.1 years, and 73.7 years for females. This was 10.6 and 9.5 years lower than the life expectancy of non-Indigenous males and females respectively. (AIHW 2014)

Initial funding from 2009-2013 was across three priority areas (Bailie, Griffin, Kelaher, McNear, Percival, Laycock and Schierhout 2013):

- tackling chronic disease risk factors
- earlier detection
- improved management and follow-up of chronic diseases in primary health care expansion of the Indigenous workforce; and
- increased capacity of the health workforce to deliver effective care

The wide gap in life expectancy between non-indigenous Australians and Indigenous peoples has continued to be recognised as a national issue for over a decade and efforts since the Aboriginal and Torres Strait Islander Commissioner's 2005 Social Justice Report. To date however, the Council of Australian Government's national policy efforts to address the problem have met with mixed results.

In the most recent Prime Minister's report on Closing the Gap, it was conceded that the target to close the gap in life expectancy within a generation, a very large part of which is attributable to chronic disease, was not on track with limited progress having been made (Australian Government 2015). Although Indigenous death rate declined significantly (by 16% thus reducing the gap by 15%, no significant change was detected between the 2016 baseline and 2013 and so the rates are not currently on track to meet the 2031 target. Chronic disease continued to account for 70% of Indigenous deaths between 2008 and 2012, and accounted for 81% of the gap in death rates between Indigenous and non-Indigenous Australians (Australian Government 2015). The Prime Minister's report recognizes the strong link between improvements in life expectancy and the underlying social determinants of health.

3 Methodology

3.1 Search strategy

A targeted literature search of peer reviewed and grey literature³ was conducted to identify studies that related to the Australian Indigenous experience of having and managing a chronic disease. Initially, a targeted search of the academic literature was conducted with a focus on Australian data through the literature databases with Medline, CINAHL and Scopus, PubMed, Australian Indigenous HealthInfoNet, AustHealth, Meditext, APAIS-Health, ATSI health and medical and sociological abstracts; international papers were identified from the Australian based research and retrieved.

³ Grey literature refers to 'that which is produced on all levels of government, academic's, business and industry in print and electronic formats, but which is not controlled by commercial publishers' New York Academy of Medicine. (2002). Retrieved 1 September, 2015, from <http://www.greylit.org/> . It includes reports (technical reports, progress and advanced reports, statistical reports etc.) conference papers, theses, bibliographies, and government reports and documents not published commercially.

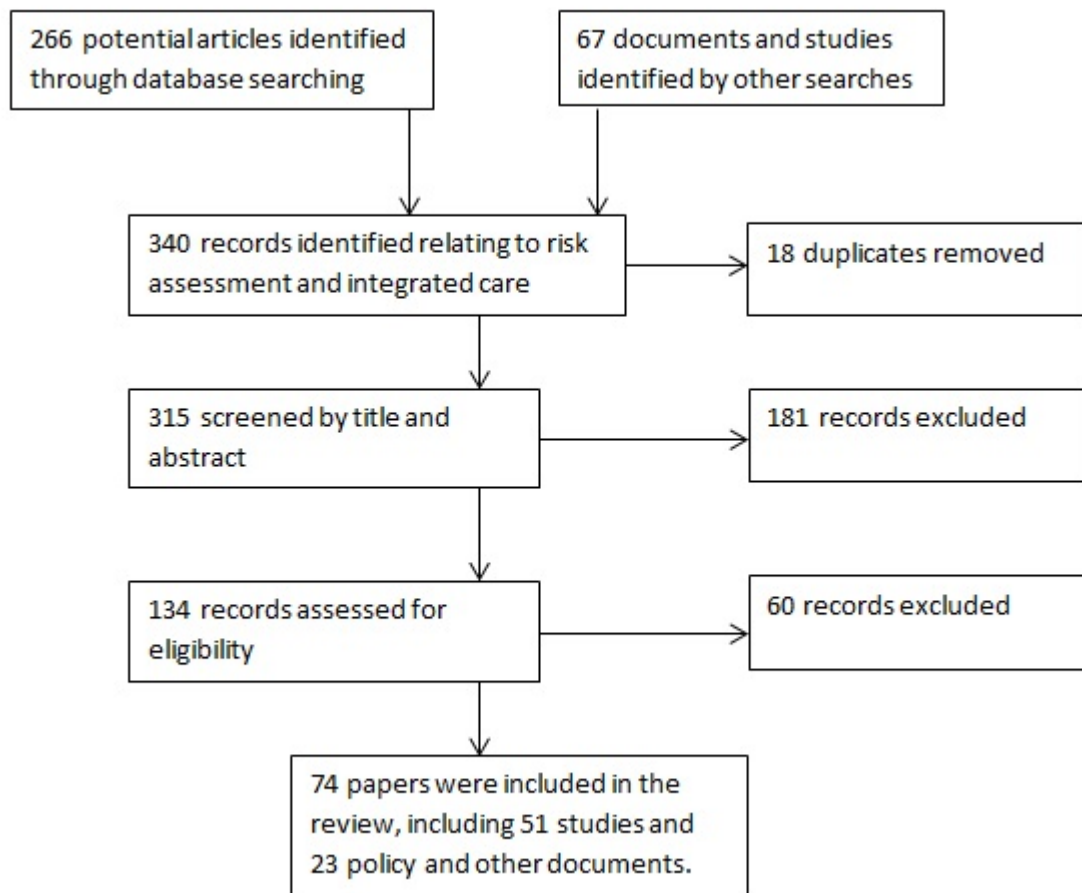
A search aimed to identify English language studies published from 2002 to 2014 was conducted using different search engines. The search strategy used combinations of terms including (“chronic disease” or “chronic illness” or “respiratory disease” or “COPD” or “asthma” or “diabetes” or “renal” or “kidney disease” or “CVD” or “cardiovascular” or “heart disease”) and (“patient journey” or “patient experience” or “experience”) and (Aboriginal or Indigenous); relating to the subject as well as risk factors, contributing factors and hospitalisation data.

The conditions of interest included chronic cardiovascular disease, diabetes, chronic kidney disease and chronic respiratory diseases. The populations of interest to the study were Indigenous people living in urban, regional and remote places. There were few resources identified after conducting this search in the peer reviewed literature, which appeared only to restrict the review. In addition a targeted website search of the grey literature was undertaken to identify relevant reports, assessments, evaluations or other materials related to the epidemiology and risk of the chronic disease. Reference lists from relevant literature also led to the sourcing of full-text articles.

From this search one hundred and thirty four journal articles were viewed and 51 studies were identified as being relevant. Policy documents from federal and state government web sites were also identified. Figure 1 below provides an outline of the search results.

The following steps were taken to establish whether an article would be included or excluded from the literature review. Titles of articles were reviewed to exclude those that were not written on Indigenous experiences or one of the four groups of chronic conditions. Abstracts of articles were then reviewed, where available, to identify if they met the inclusion criteria. All included articles were critically appraised for assessment of quality using structured critical appraisal processes.

Figure 1 *Literature search and study selection flow chart*



3.2 *Review of Indigenous chronic disease management programs*

Web searches also uncovered a large amount of information and reports on chronic disease management projects and programs, interventions, clinical audits and reports and other grey material. To capture this information, a descriptive review of Indigenous chronic disease management programs (CDMPs) and current projects in Australia was undertaken to provide an overview of the range of CDMPs which have been developed to meet the needs of Aboriginal and Torres Strait Islander people across Australia.

The review initially drew from information available through the Australian Indigenous Health InfoNet (<http://www.healthinfonet.ecu.edu.au/>) which is an innovative Internet resource that aims to inform practice and policy in Aboriginal and Torres Strait Islander health by making research and other knowledge readily accessible. Information obtained about the programs was then exported to an excel spreadsheet and classified according to: the organisation which offered or developed the program; the scope of the program in terms of being national, state-wide, regional or locally based; the State or Territory in which the program operated; the chronic conditions targeted by the program; whether or not the program had been evaluated or not. Additional web searches were conducted to obtain further description of the program, its study links and organisational links. The results of the review are found in Appendix 1.

3.3 *Theoretical perspectives*

One of the challenges of carrying out literature reviews in the area of health care and the management of chronic disease in Indigenous Australians is that the review may become merely a list of examples of where projects cite improved conditions in a small population such as in a remote community or, in a particular but narrow health condition. There is substantial literature on what improves Indigenous health including issues such as accessibility, affordability, appropriateness and accountability (Scrimgeour and Scrimgeour 2008, Ware 2013). There are also studies which show how program management changes have improved outcomes for Indigenous clients (Anderson, Cunningham, Devitt, Preece and Cass 2012, Mathur, Moon and Leigh 2006, Stamp, Miller Coleman, Milera and Taylor 2006, Burnette and Kickett 2009).

Evidence from the programs implemented at the local level, from Indigenous communities and individuals, may be seen as an important guide to practice. However very few of these programs have been evaluated or evidence any improvement that would persuade policy makers to justify changes to health policy and meet the costs involved. This is referred to as 'policy by anecdote' because much of this literature has been relied upon to justify policy changes (Griew et al. 2008).

As the aim of this project is to explore the factors that impact on Aboriginal people's experience of chronic conditions and its management, with a focus on hospitalisation, and experiences following discharge, it is also necessary to recognise that the available NSW health statistics show the numbers of 'discharge against medical advice' and 'unplanned readmission within 28 days' as important clinical indicators (Centre for Epidemiology and Evidence 2012). Whilst the figures cover all rates of disease and not just chronic disease, they are also indicative of the broader range of problems experienced by Aboriginal patients both in hospital and after discharge.

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 a planned admission. Van Walvaren et al claim that it is an indicator of the quality and continuity of care while the patient was in hospital and in the weeks following discharge (van Walvaren, Bennett et al. 2011). The NSW data in 2010-11 reveals that unplanned readmissions happened in 8.1% of admissions of Aboriginal people against 6.3% of admissions of non-Aboriginal people, with Aboriginal people 1.3 times more likely to have an unplanned readmission (Centre for Epidemiology and Evidence 2012).

Discharge against medical advice refers to patients who have been admitted to hospital then leave against the expressed advice of their treating doctor. NSW hospital data for 2010-11 shows that the proportion of hospitalisations of Aboriginal people resulting in discharge against medical advice was 2.4%, compared with 0.6% for non-Aboriginal people; with Aboriginal people 4.3 times more likely to discharge against medical advice than non-Aboriginal people (Centre for Epidemiology and Evidence 2012). Studies conducted by Choi and colleagues (Choi, Kim, Qian and Palepu 2011) and Glasgow and colleagues (Glasgow, Vaughn-Sarrazin and Kaboli 2010) claim that patients who discharge against medical advice

result in higher readmission rates, higher levels of multiple admissions, and higher rates of in-hospital mortality. The authors claim that this measure provides indirect evidence of the cultural competence and appropriateness of hospital services, and the extent of patient satisfaction with the quality of care provided

While these figures are significant and reveal the extent of the problems, the statistics have limitations in Indigenous research because they do not explain why Aboriginal people discharge against medical advice or experience an unplanned readmission within 28 days of discharge. In order to gain a deeper understanding about Aboriginal peoples experiences with the health system and how Aboriginal people manage their chronic condition, including hospitalisation and after care, the project will use a qualitative approach. This approach is most likely to yield 'thick' descriptive data and provide insight as to how Aboriginal people experience and make meaning of their journey. Qualitative data will be collected through focus group discussions and individual face to face in-depth interviews.

Although there are many schools of thought about the underlying reasons why Aboriginal people (and other marginalised groups) experience differential access and quality of care in public health systems, it is critical to value the collective memory and shared experiences of Aboriginal communities. Notably there is evidence that patients from marginalised groups show mistrust of mainstream health services; based upon previous experience, poor communication, stereotyping and even refusal of service (Alford 2005). In addition, socio-political issues can impact directly on care delivery for marginalised groups and can result in health care places being unsafe or unresponsive for some; including a lack of choice in service providers or appropriate staff can deepen people's discomfort (Stamp et al 2006). Taylor and Guerin (2006) argue that mainstream services may lack the flexibility or capacity to meet individual health needs; which creates a sense of disconnect between health and support services.

3.4 Social determinants & Indigenous health

Post-colonial theoretical frameworks that have emerged from the experience of racial oppression also provide indicators of unequal power relations that can be inherent in health system encounters. These include, where the dominant culture provides the health care. Such frameworks question the thinking behind cultural policies and how they address the historical and ongoing impacts of colonisation, disadvantage and marginalisation and contribute to racial inequality (Browne and Varcoe 2006, Sherwood and Edwards 2006). Browne and Varcoe, for example, question how some behaviour can be defined as normal and some as cultural and what creates unspoken norms that marginalise Aboriginal people.

A systems thinking approach aims to provide insight into how different measures are designed to influence various aspects of a complex health system and, the emerging patterns of interaction between the measures within the system. Attributing any observed change to specific interventions or influences within a complex intervention, in the context of a complex system is difficult; with inherent and unavoidable uncertainties (Bailie et al 2013). Complexity theory claims that while projects may result in small changes designed to improve care, these are often hard to sustain, and sustainable change requires attention at

all levels—from respectful ways of working with Aboriginal communities to systems policy and leadership (Willis, Wilson, Renhard, Chong and Clarke 2010).

The social determinants of health framework require that health interventions need to address such issues as poverty, education, racism and housing. Osborne and colleagues claim, while poor health outcomes experienced by Indigenous Australians can be linked to health behaviours such as poor nutrition, physical inactivity, smoking and alcohol consumption and that, health disadvantages are shaped by the broader social and economic conditions experienced by Aboriginal people (Osborne, Baum and Brown 2013).

Research on the social determinants of health is supported by numerous studies and substantial evidence reviewed by the WHO (2010) that states, an individual's social and economic position in society exerts a powerful influence on a person's health throughout their life (World Health Organisation 2010). Numerous studies over the last few decades have demonstrated a link between socioeconomic determinants and mortality (Booth and Carroll 2005). A question posed by Griew & Weeramanthri (2003) is that, if poor health is largely caused by issues such as poverty, education, racism, housing and employment, what role does the health system have in creating better health ?

The World Health Organisation claims that while the health system alone cannot significantly reduce health inequalities it nevertheless has a vital role in achieving that goal (World Health Organisation 2010). They argue that change can be achieved by improving how decision makers do business within the health system, which includes ensuring equity of access to health services and providing services that ameliorate and remedy the health disadvantages among sub-groups in the population; such as poverty, poor living conditions and unemployment. Further they argues that governments could improve their investment and approach to working with other sectors so that they are instrumental in developing collaborative, intersectoral solutions to create the best conditions for health among all groups (World Health Organisation 2010).

Griew and Weeramanthri (2003) claim that whilst many health service providers and policy makers acknowledge the importance of issues such as poverty, lack of education and employment, these remain in the background because they are too difficult to address; and viewed as outside of the responsibilities of the health system. The social determinants framework has also received some criticism as representing a top-down policy view of health – where there is little explanation for the way individuals and communities engage with health determinants at the micro level (Navarro 2009).

This project seeks to contribute to current understandings about the complexities involved in determining health beliefs and behaviour of Indigenous Australians through the lens of interventions based on social determinants of health. This lens examines why other western medical perspectives have limited impact until they recognise and respect social and cultural beliefs and experiences concerning health at the local level.

4 Hospitalisation: Trends in chronic disease

4.1 Chronic disease in the Australian Indigenous population

General population trends in hospitalisation for chronic diseases over the last two decades reveal that there was a slight decline in the rate of hospitalisations due to cardiovascular disease (CVD), which fell from 2,324 in 1993-94 to 2,067 per 100,000 in 2012-13, whilst hospitalisations (excluding dialysis) for chronic kidney disease (CKD) increased by 17%. Indigenous people in the lowest socioeconomic group and those living in remote and very remote areas have the highest rates of CVD, diabetes and CKD hospitalisations. For example, the diabetes hospitalisation rates of Indigenous people were four times those of non-Indigenous Australians. 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.

One of the main problems with data is that hospital records are for 'separations' (the formal process whereby an inpatient leaves a hospital or other district health service facility after completing an episode of care e.g. discharge to home, discharge to another hospital or nursing home, or death) and not individuals. Multiple admissions for the same individual occur; hospital separation rates do not usually reflect the incidence or prevalence of the disease or condition in question. People who receive treatment at hospital emergency departments of outpatients but are *not* admitted are not counted in hospital records. Hospital separation data are also affected by variations in admission practices, and the availability of and access to, hospital and non-hospital services.

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. These diseases share the end point of significant vascular pathology, leading to damage of the heart, brain, lungs and kidneys.

Cardiovascular disease is a term used to describe many different conditions affecting the heart including coronary heart disease, stroke and heart failure. The main underlying cause of CVD is a process where deposits of fat, cholesterol and other substances build up in the arteries and can lead to reduced or blocked supply of blood to the heart. A number of risk factors can contribute to the risk of developing CVD including tobacco smoking, insufficient physical activity, obesity, poor nutrition, high blood pressure, high cholesterol, diabetes.

Hospitalisation rates in 2012-2013 for CVD amongst Indigenous Australians were twice as high as for non-Indigenous Australians; 9, 2700 compared with 4,630 per 100,000 of the population. Indigenous males and females were hospitalised for CVD at similar rates. However Indigenous females were hospitalised 2.3 times the rate of non-Indigenous females. Indigenous males were hospitalised at 1.7 times the rate of non-Indigenous males. The study claims that CVD is a large contributor to the health gap between Indigenous and non-Indigenous Australians and was the greatest contributor to the mortality gap.

Figure 2 *Coronary heart disease hospitalisation rates: the principal and/or an additional diagnosis by Indigenous status and gender 2012-13*



Although length of stay (LOS) data for hospitalisation with CVD did not identify Indigenous status, the average LOS for the general population hospitalised with the principal diagnosis of CV has decreased over the last two decades; declining from 9.6 days in 1993-94 to 7.9 days in 2007-08 and to 5.4 days in 2012-13. In 2012-2013 the average LOS for a hospitalisation with CVD as an additional diagnosis was 11.2 days.

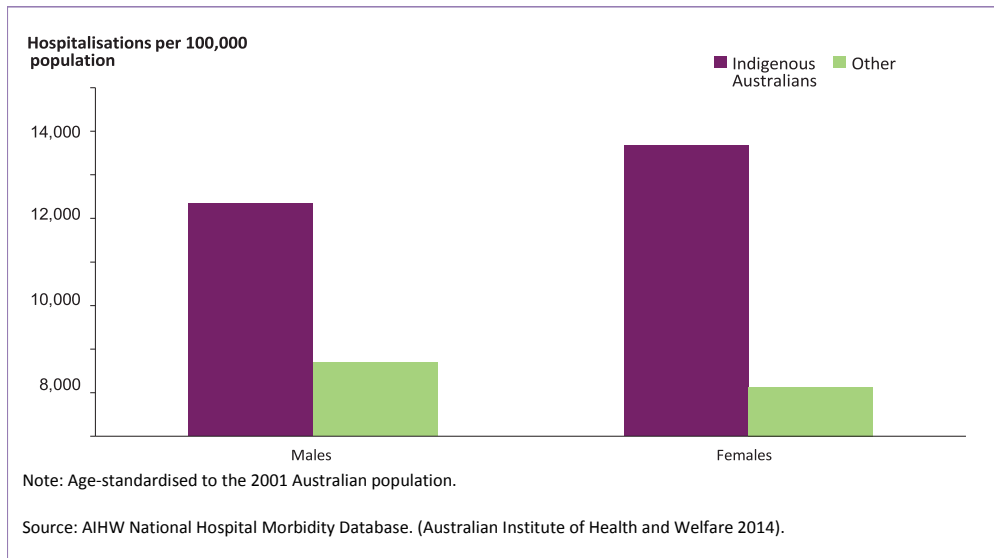
A review by Mathur et al. (2006) found that, compared with non-Indigenous Australians, Indigenous people are more likely to suffer a heart attack and to die before being admitted to hospital; and to die if admitted to hospital. In hospital, Indigenous people were less likely to receive key medical investigations or common procedures such as bypass surgery or angioplasty. The review also found that Indigenous people admitted to hospital for coronary heart diseases have more comorbidities than non-Indigenous Australians; this did not appear to account for differences in procedure rates.

Diabetes is a disease which is characterised by high levels of glucose in the blood and is caused by the inability of the pancreas to produce insulin or, by the body not being able to use insulin effectively. For the purposes of this review we will be examining figures for Type 2 Diabetes which may cause a range of complications including heart disease, CKD, loss of vision and lower limb amputation; which is the leading cause of end-stage kidney disease in Australia.

Hospitalisation rates in 2012-13 for Type 2 diabetes were four times higher among Indigenous Australians than non-Indigenous Australians. Indigenous males were three times more likely to be hospitalised for diabetes than non-Indigenous males. The rate for Indigenous females was six times higher in being hospitalised compared to non-Indigenous

females. Although LOS data for hospitalisation did not identify Indigenous status, the general population data shows an average hospital stay of 8.6 days for a principle diagnosis of diabetes and with an additional diagnosis of 7.4 day stay if diabetes was recorded.

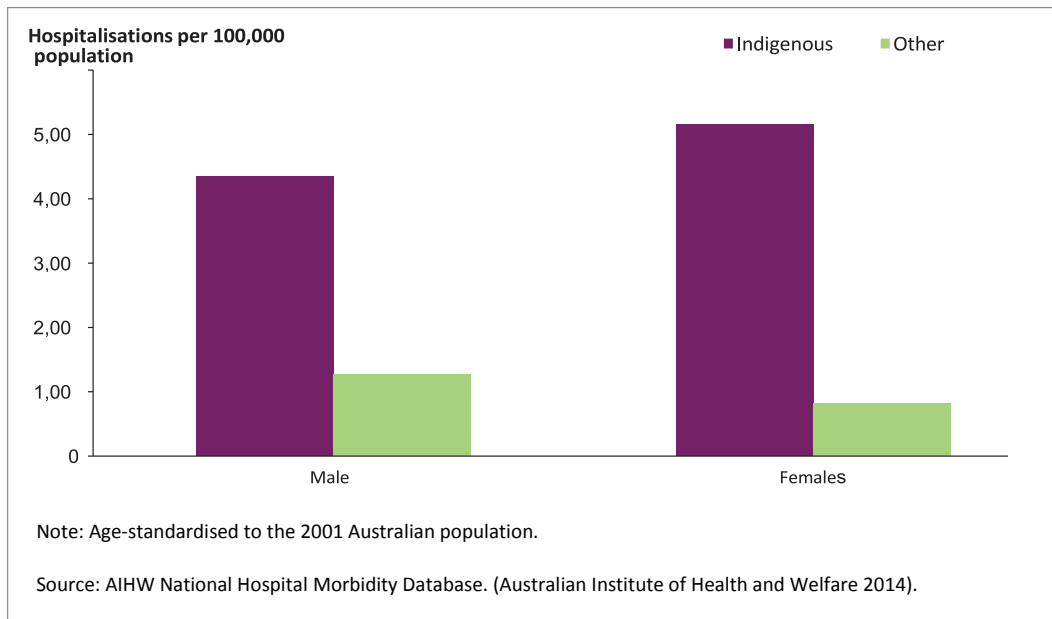
Figure 3 *Type 2 Diabetes hospitalisation rates: the principal and/or an additional diagnosis by Indigenous status and gender 2012-13*



Chronic kidney disease refers to all kidney conditions, lasting at least three months, where an individual has evidence of kidney damage or reduced kidney function. Many people are not aware they may have kidney disease due to considerable loss of kidney function before symptoms are evident. CKD has five stages indicated by such markers as eGFR. End-stage kidney disease is the most severe form of kidney disease and requires either a kidney transplant or renal dialysis. For the purposes of this review we examine all rates of CKD excluding regular dialysis.

In 2012-2013 hospitalisation rates for Indigenous Australians were nearly five times higher than for non-indigenous Australians. Indigenous males were 3.4 times more likely to be hospitalised for CKD than non-indigenous males. The rate was even higher for Indigenous females being 6.3 times the rate for non-indigenous females. Although length of stay (LOS) data for hospitalisation did not identify Indigenous status, the general population data shows the average LOS for CKD was 4.9 days and for 9.6 days where CKD was recorded as an additional diagnosis.

Figure 4 *Hospitalisation rates with CKD: the principal and/or an additional diagnosis by Indigenous status and gender 2012-13*



Unfortunately hospitalisation data for respiratory diseases, mainly asthma and chronic obstructive pulmonary disease (COPD) were only available for 2010 in all states except Tasmania; however the trends were equally disturbing. Indigenous males and females had higher hospitalisation rates for respiratory diseases than other males and females across all age groups. For both Indigenous and non-indigenous males and females, hospitalisation rates for respiratory diseases were highest among those aged 0–4 years, and 65 years and over. The greatest ratio of Indigenous to non-indigenous mortality from respiratory diseases occurred in the 45-54 year age group for males and females, where Indigenous males were hospitalised at about 5 times the rate of non-indigenous males and Indigenous females were hospitalised at over 6 times the rate of non-indigenous females. Approximately 49.4% of Indigenous Australians hospitalised for respiratory diseases were males and 50.6% were females (Australian Institute for Health and Welfare (AIHW) 2013).

Inequalities amongst populations show that Indigenous people, those in the lowest socioeconomic group and people living in remote or very remote areas have the highest rates of hospitalisation for CVD, diabetes and CKD. However when regarding remoteness as an inequality, it should be noted that patients may be transferred from a local health care facility to an urban hospital for critical care and therefore remote rates may be underestimated (Glazebrook and Harrison 2006). For example, 6.5% of diabetes hospitalisations in remote or very remote regions were transferred to a regional or city hospital. The higher hospitalisation rates for diabetes among the lower socioeconomic groups may reflect the higher incidence of diabetes among this population, which may be influenced by socioeconomic disadvantage limiting opportunities for lifestyle and risk modification (Azzopardi, Brown et al. 2012).

The Australian Institute of Health and Welfare (2014) report shows that Indigenous Australians have higher hospitalisation rates than non-indigenous Australians regardless of their comorbidity status and that the disparity rates increases with greater comorbidity— from 1.5 times that of non-indigenous Australians when only one disease is present to 7.3 times the rate of non-indigenous Australians when all three diseases are present (Australian

Institute of Health and Welfare 2014). Indigenous females had the highest disparities across all comorbidity groups—2.2 times as likely as non-indigenous females to have one disease only and 11 times more likely than non-indigenous females to have all three. Indigenous males were 1.6 times more likely than non-indigenous males to have one disease only and five times as likely as non-indigenous males to have all three.

Australian public hospital admission records in 2007–08 show that an estimated 89% of Indigenous patients were correctly identified. In other words, 11% of Indigenous patients were not identified as Indigenous, and the true number of hospital admissions for Indigenous persons was about 12% higher than reported (Australian Institute of Health and Welfare 2010).

Even though the majority of Indigenous Australians live in major urban and regional centres, current per capita expenditure on Indigenous health services is skewed towards remote health services; four in ten Indigenous-specific services are located outside metropolitan and regional centres (Australian Institute of Health and Welfare 2012). In the urban and regional context, most Indigenous people accessing services use mainstream services (non-indigenous specific), and this is expected to continue (SCRGSP 2010). Per capita expenditure on Indigenous people compared to non-indigenous people is 1.6 times higher for admitted hospital patients and 1.9 times higher for non-admitted hospital patients (AIHW 2005). After adjusting for age, Indigenous people are about twice as likely to be admitted to hospitals as non-indigenous Australians (AIHW 2005). About 94 per cent of hospitalisations involving Indigenous people are in public hospitals, compared to 60 per cent for other Australians (AIHW 2005).

4.2 Chronic disease in the Indigenous population in NSW

As this project relates to NSW the review looks at data for Aboriginal people living in this state, and who represent approximately 2.2% of the total population and 29% of the total Australian Indigenous population. Whilst many people living in NSW have experienced significant health gains in recent years, these improvements have not been equally experienced by Aboriginal people; who continue to experience greater health risks, poorer health and shorter life expectancies than non-Aboriginal people (NSW Department of Health 2010). NSW data is from the Centre for Epidemiology and Evidence unless otherwise specified (Centre for Epidemiology and Evidence 2012).

In NSW, hospitalisation rates for Aboriginal people are 1.7 times the rate of non-Aboriginal people. In the past 10 years, there has been a greater increase in hospitalisation rates for Aboriginal people than for non-Aboriginal people; an increase which may reflect a greater need for hospitalisation. This is a continuing concern; however it may also indicate improved access to hospitals and improved reporting of Aboriginal people. Hospitalisation rates for Aboriginal people for cardiovascular disease, stroke, chronic obstructive pulmonary disease and chronic kidney disease have increased significantly over the past 10 years. There has been a significant increase in the difference in hospitalisation rates between Aboriginal and non-Aboriginal people for all these causes.

The rate of cardiovascular hospitalisations from 2010-11 in NSW for Aboriginal people was 3,142/100,000 and 1993/100,000 for non-Aboriginal people. Aboriginal people are 1.6 times more likely to be hospitalised for cardiovascular disease than non-Aboriginal people. In the past 10 years there has been a significant increase in rates of hospitalisation for cardiovascular disease for Aboriginal people. This is slightly lower than the national average.

From 2010-11, hospitalisation rates for diabetes were 514/100 000 for Aboriginal people and 138/100 000 for non-Aboriginal people. In 2009-10, Aboriginal people were 2.7 times more likely to be hospitalised for diabetes than non-Aboriginal people. In the past 10 years there has been a significant increase in hospitalisation rates for diabetes for Aboriginal people, from 591/100 000 in 2001-02, to 936/100 000 in 2009-10.

The rate of chronic kidney disease hospitalisations from 2010-11 for Aboriginal people was 20,515/100,000 and 4,094/100,000 for non-Aboriginal people. In 2010-11 there was a significant difference between Aboriginal and non-Aboriginal people, with Aboriginal people five times more likely to be hospitalised for chronic kidney disease. In the past 10 years there has been a significant increase in chronic kidney disease hospitalisations for Aboriginal people.

From 2010-11, the rate of COPD hospitalisations for Aboriginal people was 17,120/100,000 and 4,413/100,000 for non-Aboriginal people. This difference is significant, with Aboriginal people 3.9 times more likely to be hospitalised for COPD than non-Aboriginal people. In the past 10 years there has been a significant increase in COPD hospitalisation rates for Aboriginal people, from 12,743/100,000 in 2001-02, with a significant widening in the difference between Aboriginal and non-Aboriginal people.

Admission rates in 2010-11 for potentially preventable hospitalisations were 5,771/100,000 population for Aboriginal people, 2.5 times higher than the rate for non-Aboriginal people of 2,291/100,000 population. Aboriginal people were 3.2 times more likely to be admitted for potentially preventable hospitalisations due to chronic conditions than non-Aboriginal people.

Unplanned readmissions within 28 days from 2010-11, 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.

In 2010-11, the proportion of hospitalisations of Aboriginal people resulting in discharge against medical advice was 2.4%, compared with 0.6% for non-Aboriginal people. This is a significant difference, with Aboriginal people 4.3 times more likely to discharge against medical advice than non-Aboriginal people. Over the past 10 years, the proportion of Aboriginal people discharging against medical advice has decreased, and has reduced the difference in rates between Aboriginal and non-Aboriginal people (Centre for Epidemiology and Evidence 2012).

In 2008, it was found that about 26% of Indigenous people aged 15 and over, living in non-remote areas had difficulty accessing health services (Australian Institute of Health and Welfare 2011); only 2.6% of the general population had difficulty (ABS 2012). The main reasons cited were long waiting times, services not being available when needed, difficulties with transport and health-care costs. Less commonly reported reasons included lack of engagement, fear of discrimination and poor treatment arising from previous experiences, and the lack of culturally appropriate services (Australian Institute of Health and Welfare 2011).

5 Risk factors for chronic disease

Health data on risk factors is also relevant to this study. Being overweight or obese is a risk factor for chronic diseases including diabetes and cardiovascular disease and is associated with higher rates of morbidity and mortality among Indigenous people. Burden of disease data attributes to 16% of the difference in health between Aboriginal and non-Aboriginal people to high body mass (Vos, Barker et al. 2009).

Regular physical activity protects against the development of health conditions such as obesity, diabetes, heart disease and hypertension. The burden of disease, especially physical inactivity, is attributed to 12% of the disparity in health between Indigenous and non-Indigenous people (Vos, Barker et al. 2009). Eating sufficient quantities of fruit and vegetables has a protective effect in nutrition-related diseases such as heart disease, as well as Type 2 diabetes and renal diseases; which are common among Indigenous people. Further, this data attributes to a 5% difference in health between Aboriginal and non-Aboriginal people in relation to the low fruit and vegetable intake of Aboriginal people (Vos, Barker et al. 2009).

Smoking is another preventable risk factor known to be associated with cardiovascular disease, chronic lung disease and some cancers (Ivers 2011). According to Senior many Indigenous people were not sure what diseases were caused by smoking, and were unsure whether 'smoking sickness' could be avoided by giving up tobacco (Senior 2003). Some people also expressed the view that it was futile to give up smoking as they would die from it anyway. The burden of disease data attributes 17% of the difference in health outcomes between Indigenous and non-Indigenous people (Vos, Barker et al. 2009).

Alcohol misuse is a major risk factor for conditions such as liver disease, pancreatitis, diabetes and some types of cancer. Alcohol misuse has also been associated with social and emotional harms such as family violence, and can lead to community dysfunction and incarceration (Willis et al. 2010). The burden of disease attributes to 4% of the difference in health outcomes for alcohol misuse between Indigenous and non-Indigenous people (Vos, Barker et al. 2009). Senior's study (2003) identified that drinking alcohol was identified as a practice introduced by Europeans. However opinions were divided in the community about the harm it had caused; with men claiming that their drinking style was one of 'responsible social drinking' and women reported their 'feelings of lack of safety when people were drinking' (Senior 2003).

The data presented represents only a cursory review of the impact from disease upon morbidity rates, which include the more severe impact for those needing to access hospital care services to manage their condition. Other important issues which are beyond the scope of this review relate to morbidity where these diseases have a major impact on primary care, outpatient care and pharmaceutical treatment.

6 Perspectives: Living with and managing a chronic disease

The National Aboriginal Health Strategy of 1989 claims that ‘health’ to Aboriginal people is when an Aboriginal person is able to determine all aspects of their life, including control over the physical environment, dignity, community self-esteem and justice. The concept of health is not merely the provision of doctors, hospitals, medicines, or the absence of disease and incapacity. Aboriginal health is defined as “not just the physical wellbeing of the individual but the social, emotional and cultural wellbeing of the whole community”. This is a whole of life view and includes the “cyclical concept of life – death – life” (National Aboriginal Health Strategy Working Party 1989). This Aboriginal holistic view of health recognises the importance of the social, emotional and cultural wellbeing of the community, as well as the physical wellbeing of the individual. Social, environmental and economic factors that contribute to poorer health experienced by Aboriginal people include inequitable community social capital, education, employment and housing (Centre for Epidemiology and Evidence 2012).

The broad aim of the project is to explore the factors that impact on Indigenous people’s experience of chronic conditions and disease management in order to inform improvements in care planning across the care continuum. The review will describe and examine Indigenous people’s views on health and in living with and managing a chronic disease. The experiences of remote and urban Indigenous peoples in Australia will be compared to that of Indigenous peoples of Canada.

6.1 Remote Experiences in chronic disease management

There is a lack of research on Indigenous peoples experience in actually living with and managing chronic disease; however literature searches revealed more studies on remote Indigenous experience. Senior’s fieldwork in the Northern Territory examined what Indigenous people considered a ‘good life’ in terms of their health. Senior claims that a sense of fatalism is widespread, with many community members, due to high levels of illness and death; believe that little can be done to prevent ill health (Senior 2003).

The following responses were provided from interviews:

As long as you can do what you want to do, then you don’t worry about health. [Male health worker aged 60+]

People with disabilities keep going as usual, they don’t complain. If the doctor tells them not to do things they don’t worry about the doctor. It’s the Aboriginal way, doing what you want to do.

(Female community member)

As long as they can do this and that, they don't worry. They don't come to the clinic until they are too late.

(Senior Aboriginal Health Worker)

Senior & Chenhall claim that local Indigenous people often do not want to know what may be wrong with them, and feel that attending a health facility or committing to a course of treatment may make things worse (Senior and Chenhall 2013).

People don't want to know about sickness inside; if they find problems they'll go and chop you up and then you'll have sickness. As soon as you touch hospital you get sickness. Medicine that they give us, it kills us. That's why we stay away from the clinic.

[Male aged 20-30]

I am a diabetic, but I don't take medicine any more. Medicine makes me more sick.

[Female aged 55]

The hospital drugs make us sick. They give us really high doses and sometimes our body can't cope with this. Probably medicine turns the other way. Maybe we are allergic to medicine.

[Male aged 30]

Aboriginal communities would reflect on a time when their people were remembered as healthy, and blame *Munanga* (Europeans) for changes in their health including the Europeans introduction in chronic diseases.

We think back and I blame Munanga. My dad used to talk about how healthy his grandparents were. They were strong; they could run without puffing. They didn't have the cigarettes or the food we eat now.

[Female aged 40-50]

They brought a lot of diseases with them. Aboriginal people before white people were happy, healthy and living a long time. Then they came and brought in tea leaf, sugar, flour and fast food ... in the past we had no diabetes, no heart failure, no flu, just bad colds and headaches and yaws.

[Female 50-60]

Senior (2003) claims that while many 'whitefella illnesses' have been viewed by Indigenous community members to have been caused by the introduction of new foods and the change from a 'nomadic to a sedentary lifestyle' Aboriginal community members were able to describe key public health messages; they were less able to make the causal link between the absence of these factors and disease. Further, Senior & Chenhall (2013) claims that the majority of people interviewed held the view that it was the clinic's responsibility to look after their health and manage their appointments, noting that Indigenous people often handed over responsibility of their condition to the health staff. D'Abbs, Schmidt, Dougherty and Senior (2008) found that Indigenous people living in remote areas believed that others were responsible for their health.

People might need some education about how to look after their bodies, but health is just common sense. People have changed; they want someone else to look after their health. People are forgetting that the responsibility for looking after your body is yours –it's in you.

[Community B]

Senior and Chenhall (2013) claims that a belief in the inevitability of ill health can create a barrier to responsibility and arise from the frequency that disease is observed to occur in the community. These patterns of illness are what community expect to occur as part of life. In this Aboriginal environment there is little incentive to modify behaviour because there is little Aboriginal evidence it will be effective.

6.2 A patient journey: remote versus the urban environment

When chronic disease reaches a stage where an Aboriginal person living in a remote community needs a greater level of care, they will often find themselves having to deal with new circumstances in health care. Although end stage kidney disease (ESKD) is not a part of this project, the experiences of people living with chronic disease illustrates the problems that remote Aboriginal people experience when they seek treatment in an urban health care environment. Research by Burnett & Kickett in Western Australia (WA) reported that loneliness results in their removal from family and land, including a sense of loss and disempowerment considered far worse than the illness (CKD) (Burnette and Kickett 2009).

Preston-Thomas, Cass and O'Rourke (2007) noted that this added to the stress of not being able to attend cultural events and obligations, added to the geographical isolation associated with treatment options which often discourages Aboriginal people from seeking treatment. Further highlighted by data reporting, with social causes identified as the second most important cause of death of Indigenous people on dialysis at 24%, after cardiac events (Australia and New Zealand Dialysis and Transplant Registry 2010).

Anderson and colleagues observe that Indigenous experience of dialysis in urban centres often involved a late, unplanned start on dialysis (Anderson et al. 2012).

I was shocked first. Yeah, shocked because nobody had ever said anything to me about kidney disease.... I was thinking to myself: "So this is what it's like to be on the machine".

[Indigenous female patient, age 60-69 years]

Most Indigenous participants had to leave home permanently to access dialysis treatment. Indigenous participants spoke of overwhelming difficulties from the constant separation from families, communities and country. All participants spoke of a range of physical and/or psychological issues associated with the dialysis treatment itself, including fear, pain, nausea, fatigue, faintness, and a range of negative feelings such as deep sadness, loneliness and homesickness. Patients commented that medical terminology or an overly complex English language, made it difficult to understand information and instructions. Some participants reported apprehension and confusion as a result of these issues and others

spoke of feeling uncomfortable and uncertain in the hospital environment; which reduced their willingness to engage with health professionals.

Relevant issues highlighted from community responses that relate to our project were claims that patients who reported being unable or unwilling to maintain the treatment regimen gave a variety of reasons, including transport problems, not understanding what was expected, the need to travel home for important events, and feelings of mistrust, anger or frustration; with some patients recalling how anger and frustration with their changed circumstances led them to neglect their treatment (Anderson et al. 2012).

Kelly and colleagues who recently mapped patient journeys from country to city hospitals, identified five factors affecting access and quality for remote Indigenous patients (Kelly, Dwyer et al. 2012). For example, the journey was tiring and stressful for many patients, noting that these problems are common for all country patients. People with chronic or complex conditions are affected more by systemic health care problems, notably in a busy city acute care setting which may be strange and difficult; however any patient may experience care problems. Communication difficulties challenged patients and staff and are common to all population groups for whom English is not their first language.

Financial resources are also a challenging issue because it is harder for those who have little or no extra money to meet the costs of transport, treatment, being admitted for health care, and to take time off from work or from home and family. Finally, the authors claim that there are ways in which Aboriginal people experience unique disadvantage in their interactions with the mainstream health system and mainstream worldviews and beliefs about health and health care are often different from others.

6.3 *The invisible minority: Urban populations*

A significant majority of Indigenous people of Australia live in urban areas. At the most recent 2011 census, around one-third of all Aboriginal and Torres Strait islander People lived in major cities of Australia, and another 22 per cent lived in an Inner Regional area (Australian Bureau of Statistics 2011). They represent a heterogeneous and mobile population, with frequent movement between urban centres and other areas. Despite this, Indigenous people living within urban areas have been described as an 'invisible minority' and are exposed to discrimination and non-Indigenous attitudes that they are not 'real Aborigines' (Scrimgeour and Scrimgeour 2008). This situation can contribute to the poor health status of Indigenous people living in urban areas, despite claims by some commentators that the overall poor health of Indigenous people is largely a result of remoteness and failed government remote community policies. The assumption is that the availability of mainstream health services in urban areas means that access to health care is not a major problem for urban-dwelling Indigenous people (Scrimgeour and Scrimgeour 2008). Houston (2004) claims there is an assumption that if Indigenous people live in close geographic proximity to a service then access is often considered the same for non-Indigenous people.

Bronwyn Fredericks, an Aboriginal woman who grew up in Brisbane, stated:

'There is no single urban Aboriginal experience or identity. The experiences are as diverse as the population and include a diversity of experience, need, prospects shaped by gender, education, religion, age and level of human security'.

and

'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).

Government initiatives to improve the access to health care for Aboriginal people living in urban areas include reforms to the Medicare Benefits Scheme; to make it accessible and in reforms to the Primary Health Care Access Program. However, expenditure on health services is not only less than for rural and remote Aboriginal communities, but also less than for urban living non-indigenous people. There is evidence that Indigenous people in urban areas are less satisfied with their access to health care than Indigenous people living in remote communities (Scrimgeour and Scrimgeour 2008).

The acceptable standard of health services for urban Indigenous people is related to the idea of cultural security, and evidence shows that almost one in ten urban Indigenous people report difficulties in understanding or being understood by service providers. Older Indigenous people report that a major barrier to accessing health services is the sense of shame around their health problems and the lack of success in following the advice of health care providers (Scrimgeour and Scrimgeour 2008).

While the experiences of Indigenous Australians living in remote communities have been reported in many studies, the lack of research on Indigenous Australians living in urban areas is not well documented. The available literature appears to concentrate on issues such as accessibility; affordability, appropriateness and accountability, rather than people's lived experience of having a chronic disease.

Kowanko et al (2102) claim, that there is a need for accessible, appropriate, accountable and affordable health services. Study participants and staff working in the health system commented that transport to a health service can be a problem for those using public transport.

I think that's the biggest thing in the Riverland, transport. A lot of people haven't got transport ... for the people who haven't got transport, and the people who aren't confident enough to go to their doctor.

[Client 10]

Limited or absent services were also identified as a problem:

It's quicker to go to the Bus (Mobile outreach bus) and get an appointment done through that way because, if it comes from mainstream you've got to wait about

*three or four weeks to see a doctor ... the only other way we can see a doctor is
Emergency.*
[Client 14]

One client got angry when the doctor didn't come last time, so he won't go this time.
[Client 12]

The issue of affordability as a problem was discussed because cost is a significant factor in accessing other services, including accident and emergency services in the Riverland with a \$40 gap fee for all, including concession card holders:

*[a]nd if they've got healthcare cards, so it's sort of an incentive, it takes that barrier
away of the cost of medication for people and then they're more likely to actually
take their medication.*
[Staff 8]

A recurring theme identified in staff and client interviews was the importance of cultural safety in the health service. A history of fear and distrust of doctors and other authority figures, experience of racism, and concerns of confidentiality deterred many Aboriginal people from seeking early advice about their health.

*I know that a lot of people in my family they won't go to the doctor unless something
is badly wrong and they can see that something's wrong.*
[Client 8]

The study by Aspin and colleagues in NSW found that urban participants encountered a combination of negative and positive experiences as a result of their chronic illness and struggled to achieve a balance in their lives as they sought to overcome challenges (Aspin, Brown, Josey, Yen and Leeder 2012). For some of the participants, the negative experiences far outweighed the positive and it was generally associated with highly critical views about the amount and quality of care and support that they received. Participants reported discriminatory treatment in many areas of their lives including health services.

*You do feel intimidated because you've copped it for so many years you've gone to
hospitals, and they make you feel that little and make you feel like shit, that's the
way that I do feel and it's left an imprint in my soul for years gone.*
[Participant B]

*In the [non-indigenous service] you're in, you're out. There's no friendliness . . . years
ago they used to treat us differently through discrimination . . . they'd make us wait
six or eight hours [for treatment] where the others would get in and out pretty quick .
. . they judge you on your looks, your dress, and then how black you are.*

[Participant P]
*Well I used to see [Specialist 1]. I don't know if I should say but I just turned off. You
know? But then [DR1] would say 'you want to go back and see him' because me
sugar reading was bad, so I have to go and see him. But personally I didn't – well see,*

I just switched off [because] he's a smartie, I'll go back to [DR1] you know? Cause I respect him. But [Specialist 1] I haven't been to him for about 4 years, I think. Been a long time, when I was diagnosed 'you should do it regularly.' I know that but I don't really want to go back.

[Participant D]

Most of the participants in this study indicated strong support for the services that they received from the AMS. Participants responses identified they had enjoyed good long-term relationships with staff; one of the major factors in their decisions to seek health care from the AMS rather than non-indigenous health services.

I used to go to the medical centre in town, before this [AMS] was built, in that big old building over there, and I used to go all the way into [suburb], to see the AMS workers, and um I'd see a lot of people, it's a great place to get together with a lot of new people, you know, a special place, and you see different ones that you know, and have a yarn to . . . I've been away for a while, and um I always come back, and the doctors are good. Everybody's very good here.

[Participant D]

The study by the SCIPPS Team (Jowsey, Yen, Aspin, Ward and the SCIPPS Team 2011) was based on the experiences of Indigenous and non-indigenous people with chronic illness in Western Sydney and the ACT. The study also documents the experiences of 19 urban Indigenous people who had a number of chronic conditions or who looked after an Indigenous person with a number of chronic conditions. The study claims that both negative and positive influences affected participants' health and well-being.

Participants identified poor access to culturally appropriate health services, dislocation from cultural support systems, exposure to racism, poor communication with health care professionals and economic hardship as being detrimental to their health. In particular, participants pointed to cultural and traditional knowledge as well as insights as being helpful from their own experiences. Many participants said that while they often felt overwhelmed and confused by the burden of chronic illness, they gained strength from being part of an Aboriginal community, having regular and ongoing access to primary health care, and being well connected to a supportive family network. Participants claimed that community Elders played an important role in increasing people's awareness of the impact of chronic illness on their communities.

Jowsey and colleagues claim that the urban study participants faced many challenges in accessing appropriate health care; which included poor access to culturally appropriate health services, limited, or no cultural support systems in mainstream health services, racism, poor communication with healthcare professionals, financial hardship, transport difficulties, managing a number of chronic health conditions at the same time, time consuming and poorly co-ordinated care between health services and staying motivated to self-manage their conditions (Jowsey, Yen, Aspin, Ward and the SCIPPS Team 2011).

Scrimgeour and Scrimgeour , based on their work in Darwin, claim that there is only a limited amount of research into health care issues for urban Indigenous people and that the

available literature shows significant barriers for Indigenous people accessing health care (Scrimgeour and Scrimgeour 2008). The authors claim that the ACCHS movement has improved access to health care for urban Indigenous people by providing culturally secure medical care for people with complex health issues. However, despite these services, barriers to health care persist and mainstream services need to develop strategies that recognise the unique needs of Indigenous communities.

6.4 A Canadian comparative: First Nation Peoples

While the literature exploring the lived experience of urban Indigenous Australians with a chronic disease is lacking, it is useful to refer to the international literature which explores the experiences of other Aboriginal peoples living with chronic disease. Canadian studies by Iwasaki and colleagues (Iwasaki, Bartlett et al. 2004, Iwasaki, Bartlett et al. 2005) argue that while broader socioeconomic, historical and political forces have shaped the lives of Aboriginal people and their individual choices it has also influenced the prevalence and the lived experience of diabetes; very little is known about specific stressful aspects of living with diabetes. Participants' in the studies were all urban First Nation peoples living in a single regional city in Canada. First Nation participants suggested that living with diabetes had a detrimental impact at a physical level such as limiting one's diet, activities, daily living; and managing symptoms and medication.

Having to watch what you eat. This being on a diet, watching your sugars—that's real stress because I was just diagnosed with diabetes about two years ago and then I had to give up a lot of stuff I like to eat. There's not being able to do the things I used to be able to do.

[First Nations female]

Many participants in the First Nations study claimed that they were easily fatigued because of their poor health conditions and for many Aboriginal groups, diabetes is a major health problem not only for themselves but for the whole family.

You worry about your family. I've got 2 children and 3 grandchildren and my family is not in the best of health. So that's been a big worry. My daughter is not well, I'm not well, my husband is not well, and my son is not well, so it's been quite stressful.

[Me'tis female]

Stress can also be related to suffering the complications of diabetes such as loss of a lower limb or loss of sight.

My husband lost his leg to diabetes, and he lost his eyes—he's going blind.

[Me'tis female]

The financial aspects of living with diabetes are noted, whereby many people cannot afford to buy food to maintain an appropriate diet and that some medications are not covered by the Canadian Medicare system.

I can't eat the foods that I should be eating because I can't really afford it. Right now I haven't taken my sugar for 4 or 5 days because I have to wait until payday so I can

get some more strips. They're very expensive. Also, groceries are quite expensive and if you try to eat the proper food and everything, it's expensive.
[First Nations female]]

Several First Nation participants talked about unemployment due to their disability and caused by their illness. The study found that unemployment was epidemic amongst the participants.

I used to be able to work and I got up every day and went to work, and came home and did whatever. Now all I do is to sit in the house. I've been on a disability, but it's not what I was used to.
[Me'tis female]

Numerous participants were living on welfare payments and their lives were constrained by financial and economic problems such as poor housing accommodation, living in crowded situations which resulted in stress brought about by the heavy drinking in the household.

You're faced with people that are getting into the wrong things. . I live in a building where there's a lot of drinking, partying ...That stresses me out.
[First Nations female]

Study participants described how stress factors in their lives are embedded in historical and cultural contexts and their responses suggest that racism and discrimination toward Aboriginal peoples still exists in the broader society. First Nations men described negative stereotypes about Native people being 'drunken Indians', the difficulty in getting jobs, people joking about Aboriginal peoples in everyday contexts, no significant improvement for the treatment of Native peoples, and the difficulty living in 'two worlds'.

Go for some job you won't be able to get because you're Native, because they figure all you want to do is [to] get a paycheque and go drink.
[First Nations Male]

In particular, there is female specific stress that is, the stress caused by being a woman in a culture where all housework and childcare are considered the responsibility of women.

[My] partner doesn't understand about diabetes, how your illness is. I do everything around the house, so sometimes I'm so tired. [My partner] does nothing, like, help me with dishes. Then yesterday I was sitting and crying, and he goes 'Oh what are you crying about, feeling sorry for yourself?' and I said, 'No, I'm just tired of everything. I gotta do the cooking, the cleaning and all the laundry. What are you gonna do when I have to get laid up for 6 to 8 weeks?'
[First Nations Female]

Another Canadian study by Sherifali, Shea and Brooks (2012), applies four sharing circles to elicit an understanding of the lived experiences of urban First Nations people in Ontario and affected by Type 2 diabetes and found that participants felt they were juggling two worlds in their diabetes care; the traditional Aboriginal world and the westernized medicine world.

Some participants explained that they felt that moving away from a traditional lifestyle and community had contributed to the problem of diabetes. Another theme identified from the data was the lack of access to timely, culturally sensitive resources, and not belonging to any one place; with some participants leaving their homeland community. Further, they explained that they struggled with feelings of marginalization with their diabetes management and support, that they were not able to access culturally sensitive diabetes education and care within an urban setting.

Whilst Australian literature describes remote and urban experiences of chronic disease as either using 'fatalistic thinking' or in experiencing difficulties accessing appropriate services, the key common themes identified in the Canadian studies were concerned with a wider range of issues. These include not only health-related issues such as the physical and psychological stress of managing diabetes and its complications, but also the financial stress of living with diabetes, the difficult economic conditions such as poverty and unemployment, trauma and violence experienced such as abuse, murder and suicide, as well as the cultural, historical and political aspects linked to being Aboriginal; such as identity problems, racism and in being female. These problems are not mutually exclusive and have important implications for policy and program planning (Iwasaki, Bartlett et al. 2004).

6.5 Indigenous patient experience & the health care system

Indigenous peoples' experiences in living with a chronic disease have been documented, but we raise the question; what happens to a patient through the hospitalisation process and beyond? While the work of Lawrence et al (2009) documents the journey of remote Indigenous patients with one particular health condition, it can easily apply to many other patients' journey. The author's claim that remote Indigenous patients found travelling long distances to unfamiliar surroundings, and isolated from family and social supports was overwhelming and confronting. Their fears were also compounded by knowing that other community members had not returned from hospital. Personal financial outlays by community were difficult to manage and the patient travel system was difficult to access; not always covering the expense of family members travelling with the patient.

Once hospitalised, many Indigenous patients experienced communication difficulties and many received inadequate explanations of medical concepts; due to inadequate communication whereby informed consent may not have been sought. In addition to this, it was said that non-indigenous staff had little understanding of Indigenous cultural practices. Further, patients with no family support suffer more anxiety than those who are accompanied by family or friends. Kelly et al claim that while many patients appreciated having an Aboriginal Liaison Officer to assist in practical, cultural and general support, other patients complained help was not available to them (Kelly, Dwyer et al. 2011).

Sometimes we see the [Aboriginal Health Liaison Officer], sometimes we don't. It is hard to contact them because they are so busy ... we need more [Aboriginal Liaison Officers]. [FG]

While some patients were less concerned, others had strong preferences for same-gender staff for personal showering, dressing and skin treatments. One woman was greatly relieved

that nursing staff supported her preference for gender-specific care, which enabled her to feel safe.

Nuh, I don't trust mens, I said no, I don't want mens, I want lady, female. I always have female, they were really good to me.

[Pt. 8]

Most patients were pragmatic about seeking specialist care, regardless of gender. However some older women wanted another woman in the room for personal and cultural safety reasons. Many patients spoke about their strong preference for same gendered wards.

We had to use the one toilet and bath between us. I didn't like the idea of going... to the toilet and there's a man in there, It would be better if it was all women, have a women's ward or whatever. I walked in once and a man was on the toilet seat.

[P9]

Several patients and carers spoke about how cold city hospitals were, and how they asked family members to bring in blankets or warmer clothes; and being reluctant to ask staff for another blanket. Others spoke of how lonely it was in hospital and how they longed to go outside. Many patients spoke about the quality of hospital food, how they longed for some 'bush tucker'; and the connection between food and healing.

Lawrence et al (2009) claimed that discharge processes from public hospitals may not consider patient needs or the location of the home community's lack of suitable primary healthcare or specialist services. Communication difficulties may mean that patients did not understand what was 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).

When I got back here, there was no one to help me ... I went to the physio, but they seemed a bit racist or something. I went to see them and they said, 'what are you doing here?' Well, I thought it was a bit obvious. She said she was too busy. I didn't like her attitude so I didn't go back.

From the paucity of available research it appears that the problems faced by Indigenous people after discharge from hospital have not attracted much attention from researchers. Lawrence et al (2009) claim that an assumption is made that once people are discharged from hospital they will be under the care of their 'usual GP'. When some people may not have a usual GP this is not seen as the problem of the hospital, however it can lead to Indigenous people being readmitted; who already have higher rates of hospitalisation than non-indigenous people and do not get adequate follow-up after hospitalisation. This is a critical issue for many Indigenous people whose usual place of residence may be outside the urban area and where the hospital is situated and do not have immediate transport to return to their home community.

The problem of inadequate follow-up after discharge can particularly relate to medication management. The usual practice within hospitals is to provide only three days of ongoing

medication and thereafter it is the responsibility of the patient to get a prescription from a GP to ensure continuity. Many Indigenous people with complex health problems are discharged with a number of medications, but due to lack of access to appropriate primary care the medications are soon finished and discontinued (Lawrence et al 2009).

NSW Health Clinical Services Redesign Program published Aunty Tilly's Story as an example of an Aboriginal woman with a chronic disease and documents her journey as an example of how all the elements of the model of care are incorporated in the patient journey and each element is identified throughout the story.

"It's been about a year since I was told I had sugar I'm not even that old. I remember it because it was NAIDOC week and I took the grand kids in for a look at the do in the park. I was there catchin up with everyone when this young one asked if they could do some health checks on me, I didn't really wanna but they had good little bags and drink bottles for the kids so I said "alright then, It won't take long will it?" She was real friendly with a big smile and I could see some other people I knew in the tent so I thought it couldn't be that bad, so in I go.

The young one weighed me, measured my belly, took me blood pressure and took a bit of blood from my finger (SCREENING). She wrote it all down for me and said I should come to the AMS for a check-up, I said "yeah I will next week aye", grabbed my bags for the kids and took off real quick, I saw my cousin and needed to get a lift home.

About a week later that young one, she rang me and asked if I'd made my doctor's appointment she said she'd do it for me and ring me to remind me in case I forgot. She rung me back like she said she would and tried getting me to the doctors. I dodged her a few times until she finally tracked me down and got me to the doctor (FOLLOW UP).

Dunno what I was worried about, the doctor was alright he gave me a good lookin over and asked me a lot questions, where I'm from, who's my mob and all that. I reckon I was there about an hour before he told me I had diabetes, I told the doctor "but I'm not sick, I'm right". I heard about diabetes cos I think it runs in my family (ASSESSMENT). While I was in there, he made sure I had more tests for other stuff, not sure what they were for, I didn't ask I just wanted to get outta there (CLINICAL INDICATORS). The doctor got that young one to talk to me about what diabetes means, what it does to ya, what you can eat and all that. She gave me this little machine for my sugars and told me how to use it (EDUCATION). She's got big plans for me about goin' for walks and other stuff but I'm right I got other stuff to do. She's ain't gunna leave me alone so I tell her "yeah one day..."

That young one's got these papers for me to help me stay out of hospital and keep me out of trouble with the doctor. If I want to know anything I can ring or go in and see her, she'll even come out and see me at home if I want, she writes stuff about what's happening to me (CARE PLANNING). She's cluey too, she told me she'd come out and take me to them appointments I reckon she'd have a feeling I wouldn't go on

my own. She said she'd stay with me too and explain anything I didn't know. She's good this one, she don't tell lies she does what she says she's gunna do (TRUST).

She rings me every now how I'm goin, she even came and seen me when I ended up in the hospital, dunno how she tracked me down, I think she was makin sure that lot from the hospital was lookin after me cause she knows my stuff. That's good cos I don't know those fellas, I feel shame telling them my business, they might wanna keep me in the hospital. She told me she was gunna come back and get me when they send me home, she reckons they've got her number, musta been when I gave it to 'em when I first come in. Old mate who works at the hospital was good to me too. He made sure I had clothes and money and that my mob was right when they come to see me (FOLLOW UP).

Last time she came to my place she asked if she could check some of the family, we said "Nah, not now, might next time". I think she put that in her book so she'll be back, you can bet on it "

Aunt Tilly's story documents all the steps taken in her journey from screening to follow up and emphasises the importance of active follow up from a health care worker at the AMS; which was vital to Aunt Tilly's journey through the health system.

6.6 Towards inclusiveness in chronic disease programs

While these stories explore Indigenous people's views on having and managing a chronic disease and experiences of the health system, they only infer what Indigenous people would want out of health programs through relating negative experiences about their conditions and their experiences in the health system. The review now examines health policy relating to chronic disease management, Indigenous health services and professional practice journals articles.

It is beyond the scope of this research to examine all historical government initiatives therefore this review will only review recent policy initiatives under the federal and NSW jurisdictions. The Indigenous Chronic Disease Package (ICDP) represents the Australian Government's contribution of \$805.5 million to the National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes. Initial funding was over four years (2009–2013) and across three priority areas and involved:

- significant new funding for preventive health
- support and funding for more coordinated and patient-focused primary health care in both Indigenous community-controlled health services and general practice
- increased access to affordable medicines and specialist and allied health care
- building the numbers and skills of the Indigenous health workforce.

The Commonwealth's Implementation Plan was endorsed by the Australian Health Ministers' Conference in September 2009 and delivery commenced in 2010. From May 2010, accredited general practices and Indigenous health services received incentives to

identify, treat and manage Indigenous people with a chronic disease. In 2010-11, the Australian Government expanded the availability of free or low cost medicines for Indigenous patients with a chronic disease or chronic disease risk factors; access to essential medical specialist care and allied health professional was increased. The National Partnership included a commitment to recruitment and/or training of more than 160 Aboriginal and Torres Strait Islander outreach workers; as well as additional health professionals, nurses, and Indigenous health project officers within Australian Divisions of General Practice (GP) and Indigenous health organisations. The Indigenous Chronic Disease Package included specific measures to tackle chronic disease risk factors, including poor nutrition and lack of exercise, the commencement of Healthy Lifestyle Workers, Healthy Lifestyle sessions and activities, and local community social marketing campaigns .

This initiative was evaluated by Bailie et al. (2013) in the Sentinel Sites Evaluation (SSE) report. In mid-2010 and early 2013, the SSE provided six-monthly reports on progress with implementation of the ICDP in 24 Sentinel Sites and found that there had been some notable achievements; however there was wide variation between local areas. The authors found that the implementation of the ICDP had shown some notable achievements and these included improved access to primary health care services and to affordable medication for many Indigenous people; improved orientation of the General Practice sector to the needs of Indigenous people; significant steps towards the early establishment of a new workforce that was focused on health promotion and in development of local health promotion initiatives; and increased attention to enhancing access to specialist, allied health and team-based approaches to chronic illness care.

Willis et al (2010) claim that while there is voluminous literature on cultural sensitivity, there are few papers that have a particular focus on culturally sensitive hospital care for Aboriginal people. From a systems perspective, cultural safety for Indigenous people in hospital can be seen as a commitment that arrangements and provision of services offered by the health system will not compromise the legitimate cultural rights, views, values and expectations of Aboriginal people (Houston 2002).

Willis et al (2010) also report, that the aim of the Improving the Culture of Hospitals Project (IHP) was to develop an evidence-based quality improvement framework (toolkit) for Australian acute health care facilities. This toolkit includes a range of resources, tools and guidelines to support the design and implementation of a Continuous Quality Improvement (CQI) strategy for improving cultural sensitivity as it relates to Indigenous Australians. Hospital case studies were undertaken to develop, then trial, the toolkit. Indigenous staff training in the use of CQI technology was also undertaken. The draft toolkit, along with the findings from the case studies, were then presented to a national Round Table meeting of senior key stakeholders in health to explore implementation and future research issues. The findings showed that hospitals that have improved cultural sensitivity share a number of characteristics including relationships with Aboriginal communities and commitment to supporting their Aboriginal workforce.

In 2008 NSW Health launched a new direction of Chronic Care for Aboriginal People (CCAP) programs and initiatives (NSW Department of Health 2010). This was driven by a number of recommendations resulting from the Walgan Tilly Redesign Program. The Walgan Tilly

project commenced in October 2007 and was the first Aboriginal Redesign project in NSW. It was developed from a number of established NSW Health initiatives to address the gaps in health care and to improve access for Aboriginal people to chronic care services. The Walgan Tilly project resulted in moving from a vascular only model to that of a chronic disease approach; focussing on four major diseases; heart disease, diabetes, chronic lung disease and kidney disease (NSW Health and Price Waterhouse Coopers 2008).

All existing and new chronic disease initiatives for Aboriginal people in NSW were placed under the CCAP whose aims were: to prevent or maintain chronic disease progression for an Aboriginal person, to improve access to affordable and available health services for Aboriginal people, to facilitate and support the social services involved in caring for an Aboriginal person, to address the cultural and environmental issues that influences an Aboriginal person's health, to reduce risk behaviours that are linked to the development and/or progression of chronic disease and to improve the clinical care of an Aboriginal person with a chronic disease.

The model provides a practical framework for both health and non-health care workers to effectively engage Aboriginal people across NSW into health or non-health services to improve access and health outcomes. It can be used by any health service providers as a framework to review and map the model to their existing programs or new strategies. This model also allows for the identification of gaps and opportunities at a local and state wide level to maximise existing resources or build business cases to provide new initiatives to address chronic diseases in Aboriginal communities. It also provides an ideal platform on which to establish committed engagement and partnerships with service providers within health and social networks. The model also describes the essential elements required for the delivery of appropriate chronic care services for Aboriginal people as being: Identification, Trust, Screening & Assessment, Clinical Indicators, Treatment, Education, Referral and Follow up. An example of how this model can be used is documented in the Aunty Tilly story in this review.

In 2012 the CCAPS program was transferred to the NSW Agency for Clinical Innovation (ACI) and falls under the Chronic Disease Management Plan (CDMP) (Agency for Clinical Innovation 2013). An aspect of the CAPPs program that is of particular interest to the current project is the 48 hour follow up program which allows for eligible Aboriginal people to be referred to the Chronic Disease Management Program (CDMP) for care coordination and self-management support in the community; and involves a phone call to the eligible Aboriginal person within two working days of discharge from hospital to check on the person's wellbeing, medication management and follow-up appointments. Aboriginal Health Workers can also support Aboriginal people identified through the 48 hour follow up to transition into CDMP. The CDMP was evaluated at agreed intervals with a final report that was due in late 2014 (Agency for Clinical Innovation 2013); the report is not yet available.

Another example in targeting the education component of this model is the Aunty Jean Good Health Model. This 'community capacity building' program was delivered in the Illawarra region of NSW (where the current project is sited) and was designed for Indigenous Australians with chronic and complex care needs. A need for this program was

identified because Indigenous Australians with chronic conditions were not engaging with, or utilising local mainstream health programs. The program aimed to develop a model of health promotion, education and self-management that could support good health behaviours. Aunty Jean's program provides regular access to health care professionals and health support, and promotes health activities such as regular physical activity and information about healthy eating. An internal evaluation of the program indicated an improved wellbeing of Aboriginal people attending the program (Williams, Curtis et al. 2004).

6.7 Indigenous organisations: Health intervention

The previous reviews of Commonwealth and NSW health interventions agree on a number of points regarding delivery of services for Indigenous populations, including the involvement of local people, knowledge and values; which is seen as the key to successful outcomes and identifies the importance of cultural competency for improving chronic disease care for Indigenous Australians. The following section examines Aboriginal Community Controlled Health Services (ACCHSs) as a way of incorporating these values.

The first Aboriginal Medical Service (AMS) was established in Redfern following the success of establishing the Aboriginal Legal Service. Predating Medibank, it was seen as a response in the need to provide accessible health services to the largely, medically uninsured Aboriginal population of Redfern. The primary health care approach adopted by Redfern and other early ACCHSs was innovative; and mirrored international aspirations for accessible, effective, appropriate, needs-based health care with a prevention and social justice focus. The impact of ACCHSs came to be more than just an effective health service provision and through employment, education, empowerment, and social action, but became key strategic sites for Aboriginal community development (National Aboriginal Community Controlled Health Organisation 2012).

ACCHSs became primary health services operated and controlled by the local Indigenous community through a locally elected management board, and provide health services to the local Indigenous communities. The values and approach of these services are underpinned by an Indigenous holistic view of health and wellbeing, and they provide culturally sensitive health services; which view the individual within their wider family, social, cultural and spiritual context. Community control is a significant element of empowering Indigenous communities to manage their own affairs (National Aboriginal Community Controlled Health Organisation 2012). In 1992, the National Aboriginal Community Controlled Health Organisation (NACCHO) was established as the new national ACCHS umbrella organisation, replacing the NAIHO. NACCHO is now the national peak body representing over 150 ACCHSs in urban, regional and remote settings.

Research conducted in South Australia and the Northern Territory found that an ACCHS was better able to address social determinants of health in its work than the other primary health care services (Baum, Legge et al. 2013). This initial finding suggests the need for further research on the Aboriginal community-controlled model; especially in terms of its ability to provide comprehensive care including curative, rehabilitative, preventive health care and health promotion (Osborne et al. 2013).

Halliday and Segal (2012) claim that a number of reviews make connections to ACCHS as a way to maximise efficiency and outcomes in the provision of Indigenous health reviews, however where reviews advocate for system wide changes and ultimately Aboriginal community control do not offer substantial evidence on system wide changes or clinical system interventions in Indigenous health, internationally or in Australia (Halliday and Segal 2012).

For instance, Carlson and Poata-Smith (2014) in their pilot study of the Illawarra Aboriginal Medical Service (IAMS) provided much anecdotal evidence on what sets Aboriginal Medical Services apart from mainstream health services and documents the cultural dimensions of the service provision offered to Aboriginal and Torres Strait Islander clients. Halliday and Segal (2012) claim that although reviews of local ACCHSs are highly valuable in documenting the gaps, possible benefits, ideal approaches and importance of inter-sectoral health interventions, there remains a lack of current literature that draws together the published evidence on what works in system level changes to inform policy.

7 Scope for improving chronic disease support

7.1 The Australian context

There are dozens of Australian studies describing interventions in chronic disease for Indigenous people. Studies have explored interventions in CVD (Mathur et al. 2006, Wilson 2010), in diabetes (Azzopardi, Brown et al. 2012), kidney disease (Stamp et al. 2006, Burnette and Kickett 2009, Anderson et al. 2012). They describe measures taken to identify and reduce systemic barriers such as poor access including transport issues, lack of affordability, appropriateness, availability, poor communication, and racism, lack of cultural awareness in non-indigenous staff, lack of health education, poor continuity of care, lack of support, fear and mistrust (Artuso, Cargo et al. 2013).

Aspin et al. (2012) argue that Indigenous people are acutely aware of the ways in which health systems can be improved. By drawing on knowledge and experience of the participants in their study, the authors identified strategic approaches to enhance health services. The authors claim that Indigenous people expressed high levels of satisfaction with Indigenous health services and Indigenous health workers. The authors claim it is imperative that significant efforts improve the recruitment and retention of Indigenous people into the health workforce and that there must be significant investment in cultural awareness education for non-indigenous staff. Aspin et al. (2012) also claim that family members can play a variety of roles which can enhance the health of people with chronic illness including carer, companion, support person and advocate. With the diverse range of information about their illnesses and complex medication regimes patients often rely heavily on the support of a family member to manage their illness and family members and carers may also need support from health services. The authors claim that health care facilities with strong levels of community involvement can make a significant contribution to improved health outcomes for Indigenous people with chronic illness.

Jowsey, Ward and Gardner (2013) suggest that a health policy area should be further explored to enhance opportunities for Indigenous people living with a chronic illness and to engage in activities where community members are able to talk about their experiences of

living with chronic illness and to exercise a sense of agency about their unique, individual experiences. The purpose of agency is to follow a holistic approach that caters to Indigenous concepts of health and illness. Griew et al. suggest family centred approaches that recognise the need for longer term relationships with individuals, families and community to address chronic illness. Ganesharajah (2009) suggests that definitions of health include ties to country and community. These types of initiatives point to inclusive ways in which health services can acknowledge and improve the experiences of Indigenous Australians living with chronic illness and contribute to 'Close the Gap' in national health disparities (Altman, Biddle et al. 2008). Hayman argues it is essential that these services have access to continuous funding in order to improve Indigenous health outcomes (Hayman 2010).

7.2 An International context

Countries with Indigenous minorities such as New Zealand, Canada and the USA have been able to achieve better Indigenous health outcomes than Australia. Kunitz (2004) provides evidence from these countries which supports the importance of establishing Indigenous-specific services. It has been recognised that separate Indigenous services have a place within the health care system and that this is consistent with governments fulfilling their fiduciary obligations under the conditions of historical and modern treaties.

A review of eleven relevant North American studies looking at the lived experiences of Indigenous people living with diabetes raises two major themes. Iwasaki et al (2004 and 2005) found that it was not only health related issues that concerned participants, but also the marginal economic conditions which participants experienced; including the cultural, historical, and political aspects linked to the identity of being Indigenous. (Iwasaki, Bartlett et al. 2004, Iwasaki, Bartlett et al. 2005) The authors claim that understanding stress experienced by Indigenous people has important implications for policy and programme planning to help eliminate or reduce at-risk stress factors, prevent stress-related illnesses, and enhance their health and life quality. Mitchell (2012) also suggests that by applying the lens of social determinants within the health paradigm on chronic illness, it may improve the understanding of the unjust conditions and social environment experienced by Indigenous peoples (Mitchell 2012).

Mendenhall and colleagues note that rather than using conventional top down service delivery to deliver care, health professionals and Indigenous communities should work together to partner contemporary biomedical knowledge with lived experience, and wisdom and customs of Indigenous people (Mendenhall, Berge et al. 2010). The authors claim that through the integration of traditional practices such as talking circles alongside the current professional knowledge and education of health professionals this will provide more culturally sensitive care. Anderson and colleagues (Anderson, Yeates, Cunningham, Devitt and Cass, 2009) and Sherifali et al. (2012) claim that by examining the stories which the study participants construct, will provide a better response to issues identified by the community and offer a culturally sensitive, appropriate and effective health care system. The authors also claim that mutually respectful relationships with health care providers and supportive family members can assist Indigenous peoples to live well with chronic disease.

Studies from New Zealand examine a constant theme and focus on Maori advancement through adopting approaches to challenge the colonising power, norms and assumptions,

and incorporating Maori knowledge as central to understanding health needs and operating health care. For example, Kerr and colleagues emphasize that action research is a powerful tool for change in health services for Indigenous people and articulate three defining principles (Kerr, Penney, Moewaka Barnes and McCreanor 2010):

- that research should be undertaken by Maori for Maori
- that Maori world views are the normative system; and
- that research is for the benefit of Maori so that Maori are not defined as the 'other'.

Maori understandings of illness and experiences of health treatment, and healthcare providers perspectives on care can be combined into Maori led actions to improve service provision and reduce entrenched health disparities experienced by Maori communities.

Jones and colleagues claim that it is imperative that an indigenous approach be taken to understanding the core issues facing Maori families and that by conducting community-partnership research underpinned by an indigenous methodology, and employing a range of appropriate methods, Maori voices may be heard in order to develop a series of culturally relevant interventions aimed at remediating health disparities (Jones, Ingham, Cram, Dean and Davies 2013).

Griew et al. (2008) claim that the reason Indigenous populations overseas have made gains in health care beyond those made by Indigenous Australians is mainly the result of under-investment in primary health care for Indigenous communities in Australia; and distinct from disadvantages experienced by Indigenous Australians from key social determinants of health. The authors' claim that gains made in recent years have been the result of modest increases in primary health care funding in contrast to the lack of improvement in addressing the social determinants. However, from the studies included in this review there may be other factors at play.

8 Conclusion

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 Closing the Gap Campaign initiated by the Aboriginal and Torres Strait Islander Commissioner in 2005, have as yet met with mixed results. The Council of Australian Government's national policy response to date has failed to meet all 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 the majority of represented between the ages of 18 to 24. 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.

This literature review forms the first part of a study to inform transfer of care planning for Aboriginal people with chronic conditions living in the Illawarra Shoalhaven Local Health District, with a particular focus on the services and programs available following discharge from hospital and the experience of service provision. The broad aim of the study was to explore the factors that impact on Aboriginal people's experience of chronic conditions and health management in order to inform improvements in care planning across the care continuum. The study set out to assess the efficacy of the current support systems for the management of chronic disease and identify any gaps in service delivery.

The literature review focused on four main conditions: chronic cardiovascular disease, diabetes, chronic kidney disease and chronic respiratory diseases, and included studies of Indigenous people across urban, regional and remote locations. It examined peer reviewed and grey literature sourced from Australia and relevant international papers in order to answer the following key 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?

Trends in chronic disease

The review of literature found that when compared to non-Indigenous Australians, Indigenous people experience a much higher prevalence for many chronic illnesses and a higher rate of hospitalisation for these conditions. From the trend data reviewed is clear that Indigenous Australians with chronic illness experience far worse health outcomes than non-indigenous Australians. The rates of chronic disease experienced by Indigenous Australians in NSW and data on the increase of hospitalisations and readmissions require urgent attention.

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. 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.

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 in 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 non-Indigenous peoples. Similarly, the available data on the hospitalisation due to respiratory diseases shows major inequities between Indigenous and non-Indigenous Australians across, 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 & Evidence (2012) show the rate of hospitalisation of Aboriginal people to be significantly higher than non-Aboriginal Australians -1.6 times higher for cardiovascular disease, 2.7 times higher for diabetes, 3.9 times higher for COPD and 5 times more likely for chronic kidney disease. The admission rates for Aboriginal people in preventable hospitalisations are 2.5 times higher and for chronic conditions are 3.2 times higher than other Australians.

Indigenous experience 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. This review has sought to examine at least some of those relative to the wider project.

Our review of current literature identifies that Aboriginal people 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. There are a number of well-known individual level risk factors for chronic disease, such as being overweight or obese, lack of regular physical activity, smoking and alcohol misuse, which occur at higher rates in the Aboriginal than non-aboriginal population.

At the global level, indigenous peoples' experience of having and managing chronic disease is influenced by their shared colonial history of racial 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 illness, morbidity and premature mortality. The 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. Indigenous Australians experience of the patient journey within the health system will be impacted by the social determinants of health because of their level of disadvantage and socioeconomic marginalisation; documented by NGOs, Australian Governments and the UN (World Health Organization 2010).

The scant literature on Indigenous Australians' experiences of living with a chronic disease highlight that significant challenges in accessing culturally appropriate health services in urban, rural and remote Australia. It is often assumed that Aboriginal people who live in urban areas have access to mainstream health care but evidence shows that Aboriginal communities 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 (Scrimgeour and Scrimgeour 2008, Houston 2004).

Making chronic disease programs more inclusive of Indigenous views

Responding to the question of whether governments and the health system has attempted or achieved to making chronic disease programs more inclusive of Indigenous views is hampered by the lack of evaluation of many Indigenous health programs. There have been some notable gains in specific areas of the NSW health system for Indigenous Australians including: the 48 hour follow up program, introduced under the CCAP; the employment of Indigenous health practitioners within hospitals; developing referral pathways with Aboriginal community controlled health services and working to improve Indigenous health outcomes through the Closing the Gap Scheme. The introduction and expansion of specific Aboriginal community health service models, such as the expansion of culturally appropriate models such as the Aunty Jean Good Health Model, in primary health service delivery, has made a significant contribution to improve health outcomes for Indigenous people.

Despite the development of Aboriginal Community Controlled Health Services over the past forty years, barriers to health care for Indigenous people and communities persist. 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.



Appendix 1 Review of Indigenous chronic disease management programs, studies and resources

| Organisation | State | Scope | Phase | Condition | Target | Evaluated | Description of Program | Study Link | Organisation Link |
|------------------------------------|----------|----------|---------|-----------|------------|-----------|--|---|---|
| Renal Health Network | National | National | Current | CKD | Mainstream | NO | Renal Health Network .This project establishes a national registry and surveillance collaboration to develop profiles of chronic kidney disease (CKD) patients in various primary care and renal practice settings, in several states. | http://www.healthnetworks.health.wa.gov.au/overview/hemantkulkarni.cfm | |
| Diabetes Australia | National | National | Current | DIAB | Mainstream | NO | The National Diabetes Services Scheme (NDSS) is an initiative of the Australian Government and administered by Diabetes Australia in collaboration with state and territory diabetes organisations. NDSS delivers diabetes-related products at subsidised prices and provides information and support services to people with diabetes. | http://www.diabetesaustralia.com.au/en/NDSS/ | http://www.diabetesaustralia.com.au/ |
| George Institute for Global Health | National | National | Current | ALL CD | Indigenous | YES | The Kanyini Vascular Collaboration is a national health services research program established to improve vascular disease outcomes for Indigenous people. An audit of case records of Indigenous Australian adults in diverse primary health settings was conducted to ascertain | https://www.mja.com.au/journal/2009/191/6/cardiovascular-disease-risk-management-Aboriginal-and-torres-strait-islander?0=ip_logi_n_no_cache%3Db9 | http://www.georgeinstitute.org.au/ |



| Organisation | State | Scope | Phase | Condition | Target | Evaluated | Description of Program | Study Link | Organisation Link |
|------------------------------------|----------|----------|---------|-----------|------------|-----------|--|---|---|
| | | | | | | | adherence to CVD risk screening and management guidelines. | 2045cc0745da3444b337367bfb4e23 | |
| George Institute for Global Health | National | National | Current | CVD | Indigenous | YES | HealthTracker is a computer-guided quality improvement intervention which aims to address barriers to improved cardiovascular disease risk management and prevention. The intervention was trailed in 60 Australian primary healthcare centers with Aboriginal and Torres Strait Islander attendees. | http://dx.doi.org/10.1161/CIRCOUTCOMES.114.001235 | http://www.georgeinstitute.org.au/ |
| Kanyini Vascular Collaboration | National | National | Current | ALL CD | Indigenous | YES | The HOME (Home based Outreach Chronic Disease Management Exploratory Study) study's objective is to determine if a home-based, patient-centred outreach model of chronic disease management (CDM) is acceptable, feasible, and appropriate for Aboriginal and Torres Strait Islander people with chronic disease (CD), their families, and their primary health care providers. | http://www.phcris.org.au/phcred/snaps/shot/2014/snaps_hot_2014.pdf | http://www.kvc.org.au/ |
| Kanyini Vascular Collaboration | National | National | Current | ALL CD | Indigenous | NO | This study is to develop the Framework for a 'Well-being Model' which aims to improve quality of care, health outcomes and importantly the quality of life for Aboriginal and Torres Strait | http://www.kvc.org.au/projects-and-studies/towards-wellbeing-model-Aboriginal-torres-strait-islander- | http://www.kvc.org.au/ |



| Organisation | State | Scope | Phase | Condition | Target | Evaluated | Description of Program | Study Link | Organisation Link |
|-----------------------------------|----------|----------|---------|-----------|------------|-----------|---|---|---|
| | | | | | | | Islander people living with a chronic disease. | peoples-living-chronic-disease/ | |
| Kidney Health Australia | National | National | Current | CKD | Mainstream | NO | The Kidney Health Australia Caring for Australasians with renal impairment (KHA-CARI) guidelines is an evidence-based project that aims to improve the health care and outcomes of paediatric and adult patients with kidney disease | http://www.cari.org.au/CKD/ckd_guidelines.html | http://www.cari.org.au/kh-a-cari_overview.html |
| Kidney Health Australia | National | National | Current | CKD | Indigenous | NO | Resources for Health Professionals is educational material that is culturally sensitive to the needs of Aboriginal and Torres Strait Islander people. It reviews resources promoting healthy lifestyle and cardiovascular disease risk reduction, with a kidney focus. | http://www.kidney.org.au/HealthProfessionals/IndigenousResources/tabid/770/Default.aspx | http://www.kidney.org.au/ |
| Malpa and Transplant Australia. | National | National | Current | CKD | Indigenous | NO | The Malpa Project enables Aboriginal people affected by kidney disease to paint their stories of hope for the future in order to raise national awareness of the severe impact which kidney disease is causing among so many Indigenous communities | http://www.malpa.org.au/?page_id=33 | http://www.malpa.org.au/ |
| National Diabetes Services Scheme | National | National | Current | DIAB | Indigenous | NO | The HITnet – The Diabetes Story is an interactive video series which is available on HITnet touchscreen kiosks in medical | https://www.ndss.com.au/resources | http://www.ndss.com.au/ |



| Organisation | State | Scope | Phase | Condition | Target | Evaluated | Description of Program | Study Link | Organisation Link |
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| | | | | | | | centres, hospitals, community and youth centres across Australia. 'The Diabetes Story' module aims to promote diabetes awareness, knowledge and NDSS registration among Aboriginal and Torres Strait Islander people. | | |
| The Australian Resource Centre for Healthcare Innovations | National | National | Current | RESP | Mainstream | | This program is an evidence-based peer-led asthma and smoking prevention program . | http://www.archi.net.au/resources/chronic/self/triple-a/ | http://www.asthma.org.au/ |
| The Lowitja Institute | National | National | Completed | ALL CD | Indigenous | NO | The Audit and Best Practice for Chronic Disease Extension Project was designed to improve the quality of services for the prevention and management of chronic disease among Indigenous people across Australia. | http://www.lowitja.org.au/sites/default/files/docs/ABCDE_Report2011.pdf | http://www.lowitja.org.au/ |
| The University of Adelaide | National | National | Current | ALL CD | Indigenous | NO | CREATE formerly The NHMRC centre of research excellence for translational research in the management of chronic disease in Indigenous populations is a project delivered by the University of Adelaide to improve the health outcomes of Aboriginal and Torres Strait Islander people with chronic disease. | http://create.joannabriggs.org/ | http://create.joannabriggs.org/ |



| Organisation | State | Scope | Phase | Condition | Target | Evaluated | Description of Program | Study Link | Organisation Link |
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| Casino Aboriginal Medical Service | NSW | Regional | Current | RESP | Indigenous | NO | The Casino AMS program provides access to health professionals for Aboriginal people suffering from chronic respiratory diseases. The aim of the program is to provide educational workshops relating to respiratory diseases and medication. | | http://www.localdirectories.com.au/Casino,NSW/Casino-Aboriginal-Medical-Service/profile/SDV5 |
| Dharah Gibinj Casino Medical Service | NSW | Regional | Current | DIAB | Indigenous | NO | Dharah Gibinj Casino clinic gives the client a 'one stop' diabetes annual cycle of care, providing assessment and treatment of their diabetes and early detection and prevention of co-morbidities. | http://www.casinoams.com/diabetes.html | http://www.casinoams.com/index.html |
| Illawarra Shoalhaven Local Health District | NSW | Regional | Completed | ALL CD | Indigenous | YES | Aunty Jean's good health team is a combined model of health promotion, education and self-management that could support and sustain the development of good health behaviours and strategies. | http://trove.nla.gov.au/work/17264661?selectedversion=NBD26893407 | http://www.islhd.health.nsw.gov.au/ |
| University of Western Sydney (UWS) | NSW | State | Current | ALL CD | Indigenous | NO | The IHOPE Project investigates how hospitals and neighbourhoods contribute to disparities in health outcomes for Indigenous people in New South Wales | http://www.uws.edu.au/centreforhealthresearch/research/ihope | http://www.uws.edu.au/centreforhealthresearch/home |
| Australian Resource Centre for | NSW | State-wide | Completed | ALL CD | Indigenous | YES | The Chronic care for Aboriginal people (Walgan Tilly) clinical services redesign project was | http://www.aci.health.nsw.gov.au/resources/Aboriginal | http://www.archi.net.au/ |



| Organisation | State | Scope | Phase | Condition | Target | Evaluated | Description of Program | Study Link | Organisation Link |
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| Healthcare Innovations | | | | | | | developed from a number of established New South Wales (NSW) health initiatives in an attempt to address the disparities in health care and improve access to and utilisation of chronic care services for Aboriginal people in NSW | health/chronic_care_for_Aboriginal_people/ccap/ccap/CAP-moc.pdf | |
| Justice Health and Forensic Mental Health Network | NSW | State-wide | Current | ALL CD | Prisoners | NO | Murr-roo-ma dhun-barn (Worimi language for 'to make strong') is run by the Aboriginal health team from Justice Health, New South Wales (NSW). The program is operational in 16 correctional facilities (including 14 adult facilities and two juvenile facilities) throughout NSW which were strategically chosen in having significant numbers of incarcerated Aboriginal people | http://www.hssevents.health.nsw.gov.au/_documents/ccap/pdf-presentations/d2_1210_murr-roo-ma.pdf | http://www.justicehealth.nsw.gov.au/ |
| NSW Health | NSW | State-wide | Completed | ALL CD | Indigenous | NO | The One deadly step program was developed in partnership with New South Wales Health and the Australian Rugby League to address chronic diseases in Aboriginal communities of New South Wales | http://www.hssevents.health.nsw.gov.au/_documents/ccap/pdf-presentations/d2_1015_one-deadly-step.pdf | http://www.health.nsw.gov.au/ |
| NSW Health | NSW | State-wide | Current | ALL CD | Indigenous | | Chronic Care for Aboriginal People (CCAP) . Launched in June 2008 by NSW Health and driven by a number of recommendations | https://www.aci.health.nsw.gov.au/resources/aboriginal/ | http://www.health.nsw.gov.au/index.asp |

| Organisation | State | Scope | Phase | Condition | Target | Evaluated | Description of Program | Study Link | Organisation Link |
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| | | | | | | | resulting from the Walgan Tilly Redesign Project. All existing and new initiatives designed for Aboriginal people with a chronic disease are now under the strategic program direction of CCAP. | health/chronic_care_for_aboriginal_people/ccap | |
| NSW Health | NSW | State-wide | Current | ALL Health | Mainstream | NO | The Get Healthy Service provides free and confidential telephone-based expert advice and plenty of motivation to help you find a healthier, happier you. The service has two streams, Information Only and a 6 month coaching program. Get Healthy includes a tailored Aboriginal program which includes three additional coaching sessions and an information book and journal containing information specific to Aboriginal and Torres Strait Islander communities. | - | http://www.gethealthynsw.com.au/?gclid=Cj0KEQjwifWnBRCB5PT57KSVw-kBEiQASV7aRl-7o-Hck0Vftdqio-QSYRKwcEEhrw-QZrA_Zm0hV8aAtRa8P8HAQ |
| Baker IDI | NT | | Completed | CVD | Indigenous | NO | The Heart of the Heart Study is a multi-project research study which aims to quantify the burden of heart disease in Aboriginal communities in Central Australia and to develop novel approaches to managing elevated risk and documented heart disease | http://dx.doi.org/10.1136/heartjnl-2012-302229 | http://www.bakeridi.edu.au/ |



| Organisation | State | Scope | Phase | Condition | Target | Evaluated | Description of Program | Study Link | Organisation Link |
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| Department of Health and Families | NT | | Completed | ALL CD | Mainstream | NO | The I'm OK project supports for people living in remote communities to access specialist health care closer to their homes. This helps them to manage their advanced CKD. | http://www.health.nt.gov.au/library/scripts/objectifyMedia.aspx?file=pdf/49/37.pdf&siteID=1&str_title=The%20Chronicle%20March%202010.pdf | http://www.ntml.org.au/contact-us |
| Healthy Living NT | NT | | Current | CVD | Mainstream | NO | The Healthy heart program is an education and rehabilitation program for anyone with heart disease | http://www.healthylivingnt.org.au/content/?id=78 | http://www.healthylivingnt.org.au/ |
| Northern Territory Department of Health, | NT | | Current | ALL CD | Indigenous | NO | MOICD aims to increase health service access for Indigenous Australians. | http://www.ntml.org.au/programs/medical-outreach-Indigenous-chronic-disease | http://www.ntml.org.au/ |
| Anyinginyi Health Aboriginal Corporation | NT | Regional | Current | DIAB | Indigenous | NO | The Diabetes educator program is for people living in the Barkly region of the Northern Territory who have diabetes. It aims to support individuals and their families to better manage their diabetes and any complications. | http://anyinginyi.org.au/programs-services/mens-health | http://anyinginyi.org.au/ |
| Baker IDI Central Australia | NT | Regional | Current | DIAB | Indigenous | NO | Supporting better diabetes care in the centre clinical outreach service aims to fill an area of unmet need in supporting diabetes care in Central Australia. | http://www.bakeridi.edu.au/research/Indigenous/ | http://www.bakeridi.edu.au/ |
| Chronic | NT | Regional | Complete | DIAB | Indigenous | NO | The Willora Diabetes Self | http://digitallibrary | http://www.h |

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| Disease Network | | national | Completed | | | | Management Project was conducted to assess the efficacy of a chronic disease self management program in the remote Indigenous community of Willora, Central Australia. | .health.nt.gov.au/podjspui/bitstream/10137/475/4/Chronicle%20Vol.%2018%20Issue%202%20September%202010.pdf | health.nt.gov.au/ |
| Menzies School of Health Research | NT SA | Regional | Current | CVD | Indigenous | NO | 'Improving the patient journey for Aboriginal and Torres Strait Islander peoples with heart disease' aims to determine the effectiveness of implementing a patient journey mapping tool to deliver better care, and to improve outcomes for Indigenous Australians presenting with acute heart failure (AHF) in the Northern Territory (NT) and South Australia (SA). | http://www.menzies.edu.au/page/News and Events/Latest News/Menzies secures critical funding to improve heart health/ | http://www.menzies.edu.au/ |
| Wurli-Wurlinjang Health Service | NT | Regional | Current | ALL CD | Indigenous | NO | Wurli-Wurlinjang Health Service provides chronic and communicable disease management service to improve the overall health of Indigenous families living in the Katherine region of the Northern Territory | http://www.wurli.org.au/program-gudbinji.htm | http://www.wurli.org.au/index.htm |
| Menzies School of Health Research | NT | State | Current | CKD | Indigenous | YES | Cultural Awareness Resources: Improving Communication (CARIC) project develops and evaluates multi-media educational resources designed | http://www.menzies.edu.au/page/Research/Projects/Kidney/Improving_communication_beta | http://www.menzies.edu.au/ |



| Organisation | State | Scope | Phase | Condition | Target | Evaluated | Description of Program | Study Link | Organisation Link |
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| | | | | | | | to assist clinicians, health and social science students, patients with kidney disease and their families to better understand the barriers and enablers for Aboriginal Australians to access kidney services | ween clinicians and Indigenous kidney patients through the development and evaluation of new educational resources/ | |
| Baker IDI | NT | Urban | Current | ALL CD | Indigenous | NO | The Town camp chronic disease project aims to assess the nature and extent of the use of health care services by Indigenous residents of the town camps surrounding Alice Springs | http://www.bakeridi.edu.au/research/Indigenous/ | http://www.bakeridi.edu.au/ |
| Menzies School of Health Research | NT | Urban | Current | DIAB | Indigenous | YES | The DRUID study: diabetes and related disorders in urban Indigenous people in the Darwin region was a partnership between researchers, health service providers and an Indigenous steering group of individuals from the Darwin Indigenous community. | http://dx.doi.org/10.1016/j.diabres.2008.01.011 | http://www.menzies.edu.au/ |
| Menzies School of Health Research | NT | Urban | Current | DIAB | Indigenous | YES | This study is a follow up to the DRUID study completed in 2009 | http://health.nt.gov.au/library/scripts/objectifyMedia.aspx?file=pdf/75/75.pdf&siteID=1&str_title=The%20Chronicle%20-%20August%202012.pdf | http://menzies.edu.au/ |

| Organisation | State | Scope | Phase | Condition | Target | Evaluated | Description of Program | Study Link | Organisation Link |
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| The Northern Territory (NT) Department of Health, | NT WA | Regional | Completed | ALL CD | Mainstream | NO | Health eTowns TelehealthNT delivered improvements in health and education outcomes for predominantly Indigenous populations in 20 towns, 41 remote communities and five hospitals across the Northern Territory, and six sites in the East Kimberley region of Western Australia. | http://nacchocomunique.com/tag/health-etowns-telehealthnt-network/ | http://www.communications.gov.au/ |
| Australian primary care collaborative program | QLD | | Current | CVD CKD | Mainstream | NO | Australian primary care collaborative program Provides general practices and Aboriginal Medical Services with an opportunity to achieve improved patient care for those living with cardiovascular disease (CVD) and chronic kidney disease (CKD). | http://www.cssaml.org.au/health-professionals/cvcdk/ | http://www.cssaml.org.au/download/newsletter-january-2014/ |
| Indigenous Diabetic Foot Program | QLD | | Current | DIAB | Indigenous | NO | The Indigenous diabetic foot program (IDFP) aims to provide quality, positive, evidence-based educational resources and workshops for Indigenous people and those who care for them. | http://dx.doi.org/10.1186/1757-1146-4-S1-P46 | http://www.jfootankleres.com/ |
| Kidney Health Australia | QLD | | Current | CKD | Mainstream | NO | The Kidney kiosk is a touch screen program that allows patients with chronic kidney disease (CKD) and their families to have access to up-to-date, nutrition-focused and educational | http://www.kidney.org.au/LinkClick.aspx?fileticket=rlg0hHh1unU%3dandta&bid=736andmid=1701 | http://www.kidney.org.au/ |



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| | | | | | | | videos, to promote self-management of their chronic illness | | |
| Queensland Children's Medical Research Institute | QLD | | Current | RESP | Indigenous | NO | In July 2011, Queensland Health launched the Indigenous respiratory outreach care (IROC) program , an initiative of the State-wide Respiratory Clinical Network. IROC aims to increase access to specialised respiratory services for Aboriginal rural and remote Queensland communities, raise awareness of respiratory illnesses, signs and symptoms, and enhance community capacity in respiratory diseases | http://www.health.qld.gov.au/caru/networks/respiratory.asp#atsi | http://www.health.qld.gov.au/ |
| Blue Care | QLD | Regional | Current | ALL CD | Indigenous | NO | Blue Care established a program in Central Queensland which aims to improve and promote better health for Aboriginal, Torres Strait Islander and South Sea Islander people living with chronic and complex care needs. The program has been adapted from Aunty Jean's good health program | | http://www.bluecare.org.au/ |
| Cooperative Research Centre for Aboriginal Health | SA | | Completed | ALL CD | Indigenous NO | | Chronic Conditions Program seeks to minimise the impact of chronic conditions in Aboriginal communities. It is conducted by the Cooperative Research Centre for Aboriginal Health (the CRAH | http://www.lowitja.org.au/chronic-conditions-program | http://www.lowitja.org.au/ |



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| | | | | | | | - now hosted by the Lowitja Institute) | | |
| Flinders University | SA | | Completed | DIAB | Indigenous | YES | Clinical management of Aboriginal people with co-existing diabetes and alcohol related health problems research project was to meet a need stated by Aboriginal Health Workers (AHWs) across South Australia (SA) for accurate, coordinated processes that produced quality outcomes for Aboriginal people with co-existing diabetes and alcohol-related health problems | http://nursing.flinders.edu.au/research/reports/AlcoholDiabetes_Final_Report.pdf | http://www.flinders.edu.au/ |
| Community Point-of-Care Services Unit of Adelaide | SA | Regional | Completed | CKD | Indigenous | NO | The Umoona kidney project of the Community Point-of-Care Services Unit of Adelaide was a program for the early detection, prevention and management of renal disease in the Umoona community at Coober Pedy | http://furcs.flinders.edu.au/cps/ukp.htm | http://furcs.flinders.edu.au/cps/ |
| Flinders University and the Aboriginal Health Council of South Australia | SA | Regional | Completed | ALL CD | Indigenous | YES | Chronic condition management (CCM) strategies in Aboriginal communities research project was to evaluate the effectiveness of tailoring mainstream chronic care management strategies to suit Aboriginal clients and settings. | http://www.lowitja.org.au/sites/default/files/docs/CCM_care_plan_poster2010.pdf | http://www.lowitja.org.au/ |
| Tasmanian Aboriginal | TAS | | Completed | ALL CD | Indigenous | YES | Cardiopulmonary rehabilitation and secondary prevention | http://dx.doi.org/10.1186/1472-6963- | http://tacinc.com.au/ |



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| Centre | | | | | | | program was available to people diagnosed with chronic obstructive pulmonary disease (COPD), ischaemic heart disease (IHD) or heart failure (CHF), or if they had at least two cardiovascular risk factors (smoking, obesity, hypertension, diabetes, dyslipidaemia). | 14-349 | |
| Aboriginal Health Promotion and Chronic Care partnership | VIC | | Current | ALL CD | Indigenous | NO | Aboriginal Health Promotion and Chronic Care partnership (AHPACC) supports Aboriginal community-controlled health organisations (ACCHOs) and community health services to work in partnership to develop and deliver local services and programs that prevent and manage the high prevalence of chronic disease within Indigenous communities. | http://docs.health.vic.gov.au/docs/doc/FBCDCD9F717F3D6DCA25787F001354F5/\$FILE/AHPACC%20Guidelines%20and%20Strategic%20Directions%202011-14.pdf | http://www.health.vic.gov.au/ |
| Diabetes Australia Vic | VIC | | Current | DIAB | Indigenous | NO | The Diabetes Australia Vic Aboriginal and Torres Strait Islander program aims to raise the profile of Diabetes Australia Vic in Aboriginal and Torres Strait Islander communities | http://www.diabetesvic.org.au/health-professionals/Aboriginal-and-torres-strait-islander | http://www.diabetesvic.org.au/ |
| Rural Workforce Agency Victoria | VIC | | Current | ALL CD | Indigenous | YES | Rural Workforce Agency Victoria aims to increase access to a range of health services, including primary health for Aboriginal and | https://www.rwav.com.au/programs/outreach-services | https://www.rwav.com.au/home |

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| | | | | | | | Torres Strait Islander people in Victoria | | |
| Australian Community Centre for Diabetes (ACCD) | VIC | Regional | Current | DIAB | Mainstream | | The Western region diabetes analysis project was undertaken by the Australian Community Centre for Diabetes (ACCD). The aim is to provide insight into the diabetes epidemic, geographic hotspots and demographic profile of the western region of Melbourne. | http://www.vu.edu.au/research/centres-and-institutes/centres/australian-community-centre-for-diabetes-accd | http://www.vu.edu.au/ |
| Heart Research Centre | VIC | Urban | Completed | ALL CD | Indigenous | NO | The Wurundjeri-project aimed to support Aboriginal people in Melbourne who have a chronic disease and are also experiencing anxiety or depression. | http://www.heartrsearchcentre.org/about-our-research/current-studies/wurundjeri-project/ | http://www.heartresearchcentre.org/ |
| Queensland Health | VIC QLD SA | | Completed | DIAB | Mainstream | NO | The Diabetes care project (DCP) was a three-year pilot that was part of the Australian Government's response to the growing incidence of chronic disease in Australia and the significant challenge that diabetes presents for the Australian community and health sector. | http://www.wbml.org.au/programs/diabetescareproject | http://www.health.gov.au/internet/main/publishing.nsf/Content/Home |
| Bentley-Armadale Medicare Local | WA | | Current | ALL CD | Indigenous | NO | The Living improvements for everyone (LIFE) program is a culturally appropriate chronic disease self-management program to help Aboriginal | http://www.baml.com.au/health-professional/Aboriginal-health-hp/life/ | http://www.baml.com.au/ |



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| | | | | | | | people better manage their health condition | | |
| Department of Corrective Services | WA | | Current | ALL CD | Prisoners | NO | The Aboriginal Health Community Re-Entry Program provide support and improve access to health services by linking Aboriginal people with appropriate health services before and after release from custody | http://www.healthinfonet.ecu.edu.au/uploads/resources/24848_24848.pdf | http://www.health.wa.gov.au/ |
| Rural Health West | WA | | Current | ALL CD | Indigenous NO | | The Medical outreach Indigenous chronic disease program (MOICDP) aims to increase access for Indigenous people to health services offered by visiting health professionals for the treatment and management of chronic diseases | http://www.ruralhealthwest.com.au/recruitment-services/outreach-in-the-outback/programs | http://www.ruralhealthwest.com.au/ |
| University of Western Australia | WA | | Current | CVD | Indigenous | NO | This University of Western Australia (UWA) research project aims to define likely reasons for inequities in cardiovascular disease (CVD) between Indigenous and non-Indigenous people in Western Australia (WA). | http://dx.doi.org/10.1177/174182671417925 | http://www.uwa.edu.au/ |
| Western Australian Centre for Rural Health (WACRH) | WA | | Current | CVD | Indigenous | NO | The BAHWA project will analyse detailed epidemiological, service utilisation and costing information on a range of heart and associated chronic diseases among Aboriginal Western | http://www.sph.uwa.edu.au/research/cardiovascular/projects/more-informed-action-to-improve- | http://www.biomedcentral.com/bmccardiovascdisord |



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| | | | | | | | Australians. | Aboriginal-heart-health-in-wa | |
| Caritas Australia | WA | Regional | Current | DIAB | Indigenous | NO | The Diabetes management and care program aims to prevent the incidence of type 2 diabetes in Indigenous communities in the Kimberley region of Western Australia. | http://www.caritas.org.au/learn/programs/australia---diabetes-management-and-care-program | http://www.caritas.org.au/ |
| Gelganyem Trust | WA | Regional | Current | CKD | Mainstream | NO | The Gelganyem Trust established a project addressing Aboriginal renal health as an urgent priority, due to the rising number of Aboriginal people developing kidney disease and the lack of essential health services in the East Kimberley | http://www.gelganyem.com.au/projects_health/02/page1.php?p=1andsection=2 | http://www.gelganyem.com.au/ |
| Kimberley Aboriginal Medical Service Council | WA | Regional | Completed | DIAB | Indigenous | YES | Diabetes Management. This study described the service characteristics of the Derby Aboriginal Health Service (DAHS) in Western Australia and documented diabetes management activities and intermediate clinical outcomes for Aboriginal and Torres Strait Islander patients with type 2 diabetes. | https://www.mja.com.au/journal/2012/197/7/quality-indicators-diabetes-care-example-remote-area-Aboriginal-primary-health | http://www.biomedcentral.com/bmchealthservres/ |
| Kimberley Aboriginal Medical Services | WA | Regional | Completed | CKD | Indigenous | NO | Chronic Kidney Disease. The program was an audit of the implementation of best-practice guidelines for patients at a | http://www.kamsc.org.au/research/Completed_Projects/CKD_Audit.html | |



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| Council | | | | | | | Kimberley Aboriginal community controlled health service who have proteinuria and chronic kidney disease (CKD). | | |
| Kimberley Aboriginal Medical Services Council | WA | Regional | Current | DIAB | Indigenous | NO | The Kimberley Diabetes Audit project is a clinical audit that will examine the impact of the implementation of the Kimberley chronic disease therapeutic protocols on the health outcomes of diabetic clients in ACCHSs in the Kimberley. | http://www.kamsc.org.au/research/Current_Projects/Kimb_Diabetes.html | http://www.kamsc.org.au/ |
| Rural Clinical School Of Western Australia | WA | Regional | Current | CKD | Indigenous | NO | The Western Desert Kidney Health Project involves a multidisciplinary team of Aboriginal health, medical and community development workers and artists, whose aim is to reduce kidney disease and diabetes by 20% over three years in 10 Aboriginal communities representing six language groups. | http://www.dca.gov.au/DCA-Initiatives/Indigenous/western-desert-kidney-health-project/ | http://westerndesertkidney.org.au/ |
| Rural Health West | WA | Regional | Current | ALL CD | Mainstream | NO | The Medical Outreach Indigenous Chronic Disease Program (MOICDP) is funded by the Australian Government Department of Health and administered by Rural Health West. It aims to improve health outcomes for people living in regional, rural, and remote areas | http://www.ruralhealthwest.com.au/recruitment-services/outreach-in-the-outback | http://www.ruralhealthwest.com.au/ |



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| | | | | | | | of Western Australia by supporting the delivery of outreach health activities | | |
| Silver Chain WA | WA | Regional | Current | ALL CD | Indigenous | NO | The Aboriginal Remote Telehealth (ART) Pilot Trial investigated the use of telehealth remote monitoring of chronic disease to improve the health Status of people living in remote corners of Western Australia | http://www.phcris.org.au/publications/infonet/2012/october/silverchain.php?promoid=523a&ndstk=ihanduid=100939&andeid=12075&andstype=infnt | http://www.phcris.org.au/index.php |
| University of Western Australia | WA | Regional | Current | DIAB | Mainstream | NO | The Fremantle Diabetes Study. Phase one aimed to identify and collect detailed data from people diagnosed with diabetes in the defined population group. Phase two was initiated due to the increase in the prevalence of type 1 and type 2 diabetes. Little improvement in the control of glycaemic levels and the need to confirm in a community based study the improvements found in the management of cardiovascular complications in patients. | http://dx.doi.org/10.1111/j.1445-5994.2006.01247.x | http://fds.meddent.uwa.edu.au/index.cfm?objectid=F24A83A1-96BA-5DAE-B4A8370E0A82751EandCFID=19535219andCFTOKEN=fd13d46f324816ae-8B0586A3-5056-A63B-8A8CBC787D7248E6andjessionid=3c30144c9102722515b5 |
| Paupiyala | WA | Remot | Complete | DIAB | Indigenous | NO | The Diabetes - let's all find | http://www.health | http://www.h |



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| Tjarutja Aboriginal Corporation | | e | d | | | | out project aimed to raise awareness on preventing and managing diabetes because one in four people, including one in two adults suffered from diabetes in the community. | way.wa.gov.au/docs/default-document-library/Case%20Study%2010.pdf | ealthway.wa.gov.au/ |
| Perth Primary Care Network | WA | Urban | Current | DIAB | Indigenous | YES | Moorditj djena is a podiatry and diabetes education program for Aboriginal and Torres Strait Islander people in the Perth metropolitan area. The primary objective of the program is to increase access to podiatry and diabetes services which are culturally secure for Aboriginal and Torres Strait Islander people | http://dx.doi.org/10.1111/1753-6405.12268 | http://www.derberbarlyerrigan.com.au/ |
| South Metropolitan Health Service in Western Australia. | WA | Urban | Current | ALL CD | Indigenous | NO | Walyup Kworpadding Koort (Healing Heart) program aims to assist Indigenous people living in the Fremantle area of Perth, Western Australia (WA) to achieve better health. | http://yarning.org.au/public/uploads/1353489052_M12-400_Walyup_Kworpadding_Koort_Brochure_NEW.pdf | http://www.smphu.health.wa.gov.au/ |
| South Metropolitan Public Health Unit | WA | Urban | N/S | DIAB | Indigenous | NO | The Journey of Living With Diabetes Is A Program for Aboriginal people at risk of and with diabetes, delivered by Aboriginal health professionals. | http://ww2.health.wa.gov.au/About-us/South-Metropolitan-Health-Service/Our-Services/Population-Health | http://www.smphu.health.wa.gov.au/ |

SOURCE: Australian Indigenous Health InfoNet <http://www.healthinonet.ecu.edu.au/> Accessed 15 February 2015.

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