Exploring Aboriginal and Torres Strait Islander knowledge, experiences and perceptions of chronic health conditions in the greater Rockhampton region

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2016
“...I am not ready to die yet.
I still have lots of things I want to do, achieve
And fight for”

Workshop Participant

Recognition Statement

The authors recognise and acknowledge the sovereignty of Aboriginal and Torres Strait Islander peoples as the original custodians of Australa. Aboriginal and Torres Strait Islander cultures are persistent and enduring, continuing unbroken from the past to the present, characterised by resilience and a strong sense of purpose and identity despite the undeniably negative impacts of colonisations and dispossession. Aboriginal and Torres Strait Islander people throughout the country represent a diverse range of people, communities and groups each with unique identity, cultural practices and spiritualities. We recognise that the current health status of Aboriginal and Torres Strait Islander people(s) has been significantly impacted by past and present practices and policies. It is not our intention to homogenise in summary health data and where possible we endeavour to disaggregate analyses to recognise geographical, social and culture diversity.

We acknowledge and pay our deepest respects to Elders past, present and future throughout Australia. In particular we pay our respects to the Darumbal people on whose country this research was carried out.

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Foreword

Within the Australian population, Aboriginal and Torres Strait Islander people have the poorest health status and are considered the most socially and economically disadvantaged. This reality is also true for Aboriginal and Torres Strait Islander peoples living in the greater Rockhampton region which is the site of this study. There are a range of factors which influence this health and wellbeing reality for the Indigenous peoples of the greater Rockhampton region, including housing, community safety and security, justice, education, culture, language, employment and income, locality, and historical processes of community development and health service development. These factors are all reflected in the responses gained from the participants in this research project.

There is a long history of research conducted on Aboriginal and Torres Strait Islander peoples, and on Indigenous peoples throughout the world. Historically, the vast majority of this research was carried out by non-Indigenous people. This research project has been led and managed by Indigenous people and in this we are proud of Central Queensland Medicare Local in working with us to undertake a project which has revealed rich, useful data that can be utilised by the community, health professionals, service providers, government and others to build on the work.

What this research has revealed is that in order for health services and the health system to make a difference to the health and wellbeing of Aboriginal and Torres Strait Islander people, there needs to be a recognition, and understanding of the need to work across the historical, cultural, social, physiological, psychosocial, economic, environmental and political contexts of individuals and groups within the broader Indigenous community. Service providers need to work together in this recognition and understanding if they are going to address the disadvantages experienced by many Indigenous peoples within the region. As the sub-population with the greatest need within the greater Rockhampton region, it is also an area where they can make the greatest difference!

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- Central Queensland Medicare Local (CQML) for funding this work and the partnership that developed in the process of the research
- the contributions made by Karen Mills of CQML who enriched the project with her input and assistance
- all of the research participants and stakeholders who contributed to the research and ultimately the learnings gained for the Rockhampton region and beyond
- support provided by our colleagues at CQUUniversity, Australia
- the intended users of the report and hope that it assists you in your work addressing the health needs of Aboriginal and Torres Strait Islander people in the Rockhampton region and beyond
Executive Summary

This research project was focused on collecting new information regarding the experiences and perceptions of chronic conditions impacting on the Aboriginal and/or Torres Strait Islander community within the Greater Rockhampton region. The aim was to provide a ‘voice’ to those people with lived experience of chronic conditions and those who care for them, as well as other peoples in the community. This may include those who are not unwell but have friends/family that are, and who may anticipate health difficulties as they grow older.

Over 60 Aboriginal and/or Torres Strait Islander people directly participated in this research, as members of data collection workshops or in one-to-one interviews. Workshops were held in Rockhampton, Gracemere and Yeppoon with adult Aboriginal and Torres Strait Islander people; in addition workshops using Audience Response Technology were held with Aboriginal and Torres Strait Islander Youth; with clients from the Alma Street Clinic and with a group of Health Care Providers. One-on-one interviews were also carried out.

Key themes from the adult workshops in Rockhampton, Gracemere and Yeppoon revealed a complex mixture of issues including the ongoing impact of social determinants on individual’s lives, the importance of identity, and fears and worries about the future, of being alone and of the unknown. The need for knowledge and education, both for individuals with chronic health conditions and community members as well as the need for increased cultural awareness training for health care providers also emerged. While isolation was a reality for some participants, an overarching strong sense of family and community emerged from the discussions, as did stories of proactive health initiatives undertaken by many participants. With appropriate management of chronic health conditions, many participants accepted their conditions and felt they were ‘still able’ and ‘still healthy enough.’

Only a small number of Indigenous youth were able to participate in the research. Nevertheless, this group showed themselves to be interested in learning more about healthy conditions and how to prevent them through adopting healthy practices, perhaps borne out of their feelings of fear and uncertainty about what to expect for their own health futures, as well as those of their family members. They readily acknowledged that Elders in the community held important information about how they have lived/are living with chronic illness; simultaneously, the youth were concerned about older family members accessing health care. Overall, the mood of the participants in the youth workshop appeared to be one of being ready and willing to talk about Indigenous health, and being thirsty for more knowledge.

At the Alma Street Clinic workshop, it was clear that the participants held a great deal of existing knowledge and awareness about chronic conditions, as all participants had direct lived experience. Similarly to the youth, this group were comfortable in sharing their stories, and believed that communication was incredibly important in helping people to feel confident about what services were available, and how best they could take care of themselves and their families. A strong message that emerged from the adult workshop was how valued the Binbi Wadja service was; by tailoring services and establishing a strong rapport with the clients, Indigenous people felt welcomed.

1 Binbi Wadja comes from the Daruumbal language and means ‘good talk’; it is a fortnightly gathering at the Alma Street Clinic, Rockhampton
and confident about their health status and how they could best manage their conditions. This kind of outcome opens the door to spreading positive messages throughout the wider Indigenous community, encouraging others to also access help and information.

The workshop with the health practitioners highlighted that these professionals felt that more could be done to support Aboriginal and/or Torres Strait Islander people to prevent and/or live with their chronic conditions. The key messages that emerged from the workshop revolved around the need for holistic care, which was centred on culturally appropriate and easily accessible services, supported by well-trained and longitudinally funded programs.

A number of themes emerged from the one-on-one interviews and many of these were clustered around a central category of communication:

- **The theme of communication to build knowledge** indicated the need for better advertising and marketing of available information and services in the greater Rockhampton region, a decrease in language barriers, and that improved education processes were vital.
- **The theme of local services** related to long waits for medical appointments, a lack of cultural understanding by hospital staff when arranging travel to Brisbane, and Allied Health Services at CQU that were ‘culturally unaware’. This lack of cultural understanding by medical staff was caused by a lack of ‘understanding of the history of Aboriginal and Torres Strait Islander people’ that impacted the ‘cultural awareness’ of medical staff.
- **The theme of preventative care** emerged when participants identified the need to lose weight, to exercise more, that isolation is an issue, that ‘rural people miss out [on services]’, that Men’s Health Workshops would be beneficial and that ‘once the chronic health condition is being managed, people live reasonably happy, contented lives’.
- **The theme of social determinants** revealed housing and travel as major issues, as was the cost of living and health care.
- **The theme of Close the Gap** identified the importance of education of entire families [and communities] about health, plus a need for consistency of funding to maintain services and programs, and the ‘need [for] a one-stop-shop for all health care needs’.
- **The theme of trust** was mentioned as a major issue for many older people who ‘just don’t trust doctors, a lot of our older people are from the stolen generation...’ and ‘[my Grandfather...didn’t trust medication’.
- **The theme of past knowledge** centred around health, diet, healing plants and concern about losing this past knowledge.
- **The theme of traditional healing** revealed many participants were interested in traditional healing and that Gumbi Gumbi was a major traditional healing plant used by many people in the greater Rockhampton region.

The central theme of communication that emerged from the interviews emphasised the importance of strong, culturally appropriate communication that at times was missing in many participants lived experiences, particularly in interactions between their doctors and other health care providers.

The outcomes of this research suggests much needs to be done in assisting Aboriginal and Torres Strait Islander people to manage and prevent chronic illness, in particular:
• focussed attention on the disjunction/s that participants identified as occurring at the general practice level, for example – a lack of knowledge about referrals to specialist care and available services
• greater communication in a culturally appropriate manner to ensure the community is aware of information and services for example, this may involve messaging in a visual format (like posters) rather than written text format
• action towards ‘Closing the Gap’ by undertaking initiatives that enables Indigenous peoples business to become everyone business
Contents

Foreword ................................................................................................................................................. 3
Acknowledgements ................................................................................................................................. 3
Executive Summary ............................................................................................................................... 4
List of figures and tables ......................................................................................................................... 9
Abbreviations used in this report ......................................................................................................... 12
Key terms and organisations ................................................................................................................. 12
About the study region .......................................................................................................................... 12
1. Introduction: Aboriginal and Torres Strait Islander people and chronic health conditions ......... 13
   1.1 Defining chronic conditions .................................................................................................. 13
   1.2 The ‘gap’ in chronic conditions for Indigenous peoples ................................................... 13
   1.3 Social determinants of health .......................................................................................... 14
   1.4 Whole of life approach ...................................................................................................... 15
   1.5 Racism, systemic racism and their impact on health and wellbeing ................................ 15
   1.6 Cultural awareness training .............................................................................................. 16
   1.7 Close the Gap Campaign .................................................................................................. 16
2. Research questions and methods ................................................................................................. 18
   2.1 Research questions ............................................................................................................. 18
   2.2 Research methods .............................................................................................................. 19
3. Desktop data collection ................................................................................................................ 20
   3.1 Incidence of chronic conditions on the greater Rockhampton region ................................. 20
4. Key findings ................................................................................................................................... 22
   4.1 Adult Workshops ................................................................................................................. 22
      4.1.1 Perceptions of the meaning of chronic illness ............................................................. 22
      4.1.2 Concerns, fears and worries about chronic conditions ............................................... 23
      4.1.3 Yarning together during the Workshop ........................................................................ 26
   4.2 Audience Response Technology Sessions .......................................................................... 37
      4.2.1 Youth Workshop ........................................................................................................... 37
      4.2.2 Youth participant’s perceptions of chronic illness ........................................................ 42
   4.3 Alma Street Clinic Workshop .............................................................................................. 43
      4.3.1 Adult Workshop at the Alma Street Clinic (Binbi Wadja) ............................................. 43
   4.4 Health Care Providers Workshop ......................................................................................... 50
   4.5 One-on-one interviews ......................................................................................................... 58
      4.5.1 Communication to build knowledge ............................................................................. 59
List of figures and tables

Figure 1 ‘Clicker’ devices in use at the Binbi Wadja workshop with adult Aboriginal and/or Torres Strait Islander people, and the service provider workshop in Rockhampton during February 2015... 20
Table 1: Key statistics relating to Aboriginal and/or Torres Strait Islander peoples within the Greater Rockhampton Region, as at 2011 (this is the latest available information) .................................................. 21
Figure 2 Wordcloud summary of adult participant’s perceptions of the term ‘chronic illness’ ............ 23
Figure 6 Summary of perceptions that emerged from yarning ...................................................... 28
Figure 7 Summary of identity themes that emerged during yarning .............................................. 29
Figure 8 Summary of knowledge/education issues that emerged during yarning ......................... 30
Figure 9 Summary of needs that emerged from yarning ............................................................. 32
Figure 10 Summary of Aboriginal and/or Torres Strait Islander peoples experiences that emerged from yarning .................................................................................................................. 34
Figure 11 Summary of proactivity and empowerment themes that emerged from yarning ............ 36
Figure 12 Youth participant responses regarding the rating of their current health (left) and health outlook by 2045 (right). Participants were asked to rank their response, on a scale of 1 to 5 .......... 37
Figure 13 Perceptions about the age at which most Aboriginal and/or Torres Strait Islander people become chronically unwell. .......................................................................................... 38
Figure 14 Perceptions regarding the condition that affects Aboriginal and/or Torres Strait Islander people the most .................................................................................................................. 38
Figure 15 Youth participant’s perceptions about the most important healthy lifestyle practices............. 39
Figure 16 Youth participant’s views about whether family and/or friends with chronic health conditions are accessing the services they need ............................................................................. 40
Figure 17 Youth participant’s preferences regarding investment to prevent chronic health conditions in Aboriginal and/or Torres Strait Islander people ................................................................. 40
Figure 18 Youth participant’s preferences regarding incentives to attend information/education sessions about chronic disease prevention ................................................................. 41
Figure 19 Youth participant’s attitudes regarding key factors to achieve and retain good health. Participants were asked to select their preferred option for the ending to the sentence: The most important thing I can do to be healthy is...? ........................................................................................................ 41
Figure 20 Indigenous youth’s perceptions about the meaning of ‘chronic illness’ ......................... 43
Figure 21 Adult participant’s responses regarding the rating of their current health (left) and health outlook by 2025 (right). Participants were asked to rank their response, on a scale of 1 to 5. 43
Figure 22 Perceptions about the age at which most Aboriginal and/or Torres Strait Islander people become chronically unwell (adult participants) ........................................................................ 44
Figure 23 Perceptions regarding the condition that affects Aboriginal and/or Torres Strait Islander people the most (adult participants) ...................................................................................... 44
Figure 24 Adult participant’s perceptions about the most important healthy lifestyle practices .................. 44
Figure 25 Adult participant’s views about whether family and/or friends with chronic health conditions are accessing health services in the greater Rockhampton region (top) and how well these services were suiting their needs (bottom) ...... 45
Following the data collection exercise with the clickers, the adult group were able to spend some time on open discussion. The first theme that emerged was ‘what it meant to be healthy’, even for individuals who may have been diagnosed with a chronic condition(s). The participants noted that their concept of ‘health’ was multifaceted, including length of life but more particularly quality of life and a person’s (positive) mental outlook.

The group again reiterated the importance of self-management and strong communication, which extended to telling their stories to family members: ‘...information for our children and grandchildren so they can be proactive’. There were concerns that modern lifestyles were contributing to poorer health outcomes in the coming generations, especially around sedentary work and activities.

The discussion then moved to the availability of fresh produce; with participants speaking about the control that the large food retailers have over supply chains, and their concerns about chemicals in the foods (‘some cities have local markets – we don’t’).
Figure 38 Health professional’s perceptions regarding the feedback their organisation receives regarding services for Aboriginal and/or Torres Strait Islander people living with chronic conditions. *Please note: many participants were prevented from answered this question due to premature shutdown of the voting system. ........................................................................................................... 56

Figure 39 Health professional’s views about the best use of resources to support chronically ill Aboriginal and/or Torres Strait Islander people. Graph indicates each participant’s preferred choice. .............................................................................................................................................................. 57

Figure 40 Health professional’s preferences regarding incentives to attend Indigenous-specific training initiatives. .............................................................................................................................................................................. 57

Figure 41 Summary of key themes that emerged from the one-on-one interviews............................................. 59

Figure 42 Summary of communication to build knowledge themes that emerged from the one-on-one interviews................................................................................................................................ 57

Figure 43 Summary of local services issues arising from one-on-one interviews ................................................. 61

Figure 44 Summary of preventative care issues arising from one-on-one interviews ................................. 63

Figure 45 Summary of social determinants emerging from one-on-one interviews......................................... 64

Figure 46 Summary of close the gap issues emerging from one-on-one interviews........................................ 65

Figure 47 Summary of trust issues emerging from one-on-one interviews...................................................... 65

Figure 48 Summary of past knowledge themes emerging from one-on-one interviews................................. 66

Figure 49 Summary of traditional healing themes emerging from one-on-one interviews........................... 67
Abbreviations used in this report

AIATSIS Australian Institute of Aboriginal and Torres Strait Islander Studies
AMS Aboriginal Medical Service
CQML Central Queensland Medicare Local
CQU Central Queensland University
GP General Practitioner
OIE Office of Indigenous Engagement

Key terms and organisations

Bidgerdii Aboriginal Medical Service (Rockhampton)
Binbi Wadja Meaning ‘good talk’; this is a fortnightly gathering at the Alma Street Clinic, Rockhampton
Gumbi Gumbi Healing plant of Dharumbal Country (Family: Pittosporaceae)

About the study region

This report provides information and data about chronic health conditions experienced by Aboriginal and/or Torres Strait Islander peoples, residing in the greater Rockhampton region. The study area is defined as the local government areas of Rockhampton Regional Council and Livingstone Shire Council\(^2\), incorporating the townships of Rockhampton, Gracemere, Mount Morgan, Yeppoon and smaller communities along the Capricorn Coast.

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\(^2\) Note: Rockhampton Regional Council incorporated Livingstone Shire during 2008-2014, until de-amalgamation. As necessary, statistics in this report reflect either RRC (in its amalgamated state) or present data totals for both RRC and LSC.
1. Introduction: Aboriginal and Torres Strait Islander people and chronic health conditions

1.1 Defining chronic conditions
Chronic conditions are distinguished from other health conditions as most chronic diseases are rarely cured and do not usually resolve spontaneously, but rather persist over time (AIHW 2014).

There are a number of key conditions that government funding recognises as the priority set of chronic conditions in Aboriginal and Torres Strait Islanders. These include: diabetes, cardiovascular disease, kidney disease, cancer and respiratory disease.

During the period 2008-2012, the main cause of deaths among Indigenous Australians were circulatory diseases (26%), cancer (20%), external causes (including transport accidents, suicide and assault) (15%), endocrine, metabolic and nutritional disorders (including diabetes) (9%), respiratory diseases (8%) and digestive diseases (6%) (AIHW 2014). 83% of deaths of Indigenous Australians are attributed to these six diseases (AIHW 2014).

The Australian Indigenous HealthInfoNet (2015) provides key statistics relating to health conditions in Indigenous Australians. It reports that:

- In 2012, cardiovascular disease was the leading cause of death for Indigenous people, accounting for 25% of Indigenous deaths.
- In 2012, the age-standardised death rate for cancer for Indigenous people was 1.5 times higher than for non-Indigenous people
- In 2012-2013, 8% of Indigenous people reported having diabetes; and in 2012, Indigenous people died from diabetes at 7 times the rate of non-Indigenous people.
- In 2012-13, care involving dialysis was the most common reason for hospitalisation among Indigenous people.
- In 2012-2013, 31% of Indigenous people reported having a respiratory condition (AIHIN 2015)

Information is also available via the Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS), released by the Australian Bureau of Statistics (ABS, 2014). In 2012–13, the proportions of Aboriginal and Torres Strait Islander people aged 2 years and over with the following long-term health conditions were:

- diabetes/high sugar levels — 8.6%
- hypertensive disease — 5.8%
- heart, stroke and vascular diseases — 3.9%
- kidney disease —1.8%.

1.2 The ‘gap’ in chronic conditions for Indigenous peoples
Aboriginal and Torres Strait Islander people generally have significantly poorer health than other Australians and typically die at much younger ages. The gap in life expectancy between Aboriginal and Torres Strait Islander people and other Australians is currently estimated to be 12 years for
males and 10 years for females (ABS). Chronic disease is a major contributor to this life expectancy gap for adults.

Four groups of chronic conditions account for approximately two-thirds of the ‘gap’ in mortality between Indigenous and non-Indigenous Australians:

- Circulatory disease (24% of the gap)
- Endocrine, metabolic and nutritional disorders (21%)
- Cancer (12%)
- Respiratory diseases (12%) (AIHW 2014)

1.3 Social determinants of health

The World Health Organisation Commission on Social Determinants of Health (2008) reported that the dramatic differences in health within a country closely relate to degrees of social disadvantage. Each individual’s circumstances are shaped by a range of social stratification factors that include the distribution of money, education, power and resources. Clearly, the distributions of wealth and other above mentioned factors all considerably change at global, national and local perspectives. Individual and population health is therefore a gestalt or ‘whole effect’ created by the social determinants of health. The Commission (CDH 2008) found abundant evidence that the true upstream drivers of health inequities reside in the social, economic and political environments. These environments are shaped by policies, which makes them amenable to change. The report further argues that the improvement of the health of populations, in authentic and lasting ways, ultimately rests on not just understanding social determinants but by governments addressing the causes of these social inequities via policy that implements equity (CSDH 2008). By showing how social factors directly shape health outcomes and explain inequities, the report challenged health programmes and policies to tackle the leading causes of ill-health at their roots, even when these causes lie beyond the direct control of the health sector.

In Australia, socio-economic status and the effects of poverty, housing, education, employment, racial discrimination, exposure to violence, trauma, stressful life events and access to community resources are social determinants impacting on Indigenous peoples lives (Gee et al. 2014; Zubrick et al. 2014). These social determinates occur simultaneously, negatively impacting Indigenous Australians health and wellbeing concurrently and cumulatively (Gee et al. 2014; Zubrick et al. 2014). AIHIN (2015) reported that the key factors contributing to Indigenous health were poor nutrition, physical inactivity, high bodyweights, immunisation status, levels of breastfeeding, and tobacco, alcohol and illicit drug use.

The medical profession influences how the health dollar is spent with populations often believing that medico-technical interventions are the primary resolution to all health issues (MacDonald 2010). Political discourse often places emphasis upon funding designated for hospital beds, more funding dedicated to medical tertiary institutions and in essence, more money pledged to support the ‘medical model’ of health rather than generating discourse and committing funding to addressing the correlation between ‘health’ and inequality in social determinants (MacDonald 2010). The social determinant approach to health is the axiom whereby the health of a population is viewed via other factors that impinge on health; those factors include social inequalities.
1.4 Whole of life approach
Utilising a whole-of-life perspective distinguishes the different stages in life, recognises key transition periods for individuals and affords strategic points of intersection between health and mental health and social and emotional wellbeing (Commonwealth Government 2013). A life course approach allows for prevention and early intervention of health risks. The top seven risk factors that contribute to the health gap between Indigenous and non-Indigenous Australians:

- Tobacco (17%)
- Obesity (16%)
- Physical activity (12%)
- High blood cholesterol (7%)
- Alcohol (7%)
- High blood pressure (6%)
- Low fruit and vegetable intake (5%) (Vos et al. 2009)

Smoking leads to a higher incidence of several diseases including chronic lung disease, cardiovascular disease and many types of cancer (Commonwealth Government 2013). Obesity, which can result from a combination of a lack of physical activity and poor nutrition, increases the risk of cardiovascular diseases and type2 diabetes (Commonwealth Government 2013). Socio-economic disadvantage and geographical, environmental and social factors influence the nutritional status of Indigenous Australians (Commonwealth Government 2013). Interventions on these issues need to encompass a multi-layered approach to risk factor modification that includes system-level and community responses along with programs targeted at individuals (Commonwealth Government 2013). Moreover, there has to be a strong focus on the impact of chronic disease, particularly for Aboriginal and Torres Strait Islander people in what is known as the mid-life bracket, if the life expectancy gap is to be closed (Commonwealth Government 2013).

1.5 Racism, systemic racism and their impact on health and wellbeing
Racism is a significant social determinate of health for Indigenous Australians, preventing people from achieving their full capabilities, undermining self-worth and confidence, which in turn leads to poorer health outcomes (Commonwealth Government 2013). Racism is embedded in Australia’s colonial history, its institutions, policies and culture, and within the psyches of non-Indigenous Australian people (Fredericks 2008). Experiences of racism are magnified by the traumatic legacy of colonisation, forced removals and other past government discriminatory policies (Commonwealth Government 2013). Racism can impact on health through numerous pathways including experiences of discrimination, psychological distress, depression, anxiety and through health risk behaviours such as smoking, alcohol and substance abuse (Commonwealth Government 2013).

While racism is frequently measured through differences in socio-economic status where there is often a link between socio-economic variables and health indicators; reducing the socio-economic gap for Indigenous peoples will lessen but not eliminate health inequalities (Larson et al. 2007). In contemporary Australia, it is institutional (or systemic) racism, embedded within institutions and systems that exclude and discriminate against Indigenous peoples through a lack of consideration of the cultural values or the marginalisation of these peoples (Dudgeon et al. 2014). The effect of this exclusion and discrimination is low self-esteem, mistrust of the dominant culture, internalised racism,
denial, poor health outcomes (Dudgeon et al. 2014) and a lack of confidence in accessing mainstream health services (AHMAC 2004).

Systemic racism consists of requirements, conditions, practices, policies or processes that maintain and reproduce avoidable and unfair inequalities across ethnic/racial groups (Paradies, Harris & Anderson 2008). Systemic racism is experienced through economic and political systems, is supported and maintained by the policies and procedures carried out by government and other institutions, and intentionally or unintentionally results in Indigenous people’s experiencing less benefit from the same policies (Larson et al. 2007).

Systemic racism is the most pervasive form of racism, covering a range of life domains such as education, housing and employment (Paradies, Harris & Anderson 2008), negatively influencing health and wellbeing (Marmot 2011). Disapproving of racism and changing the language within the system is not enough to change the situation (Fredericks 2008). Moreover, systemic racism within the health system in Australia maintains the continual marginalisation and disempowerment of Indigenous people (Fredericks 2008).

1.6 Cultural awareness training

More than thirty years ago, a submission from the South Australian Health Commission to the National Aboriginal Health Strategy Working Party detailed that problems had arisen in the health system because of the ‘failure to recognise and adequately address the very fundamental differences in the belief system on which concepts of health and illness are based in Aboriginal and Western cultures’ (Australian Government Department of Health 1989, p. 60). The Working Party acknowledged the need for culturally appropriate, relevant coursework and clinical experience for health workers to increase understanding of Aboriginal health issues (Australian Government Department of Health 1989). This led to the introduction of Cultural Awareness training programs (Downing & Kowal 2011). Course developers expected that participants would gain an increased understanding of the diversity of values, beliefs and behaviours underlying Indigenous Australian’s and their own cultures (Thomson 2005). However, research suggests that Indigenous cultural training programs in Australia are relatively ineffective (Downing, Kowal & Paradies 2011; Thomson 2005). This can partly be attributed to the tendency of Cultural Awareness programs to focus on the people working in the health system while little or no attention is given to the system itself (Thomson 2005). Cultural respect is included within the Cultural Awareness framework and involves a whole of system approach that works in a rigorous way across the health sector at different levels in order to lift the performance of the system overall (AHMAC 2004). The effectiveness, (or ineffectiveness), of Cultural Awareness programs can impact on the health of Indigenous peoples.

1.7 Close the Gap Campaign

In 2005, the Aboriginal and Torres Strait Islander Social Justice Commissioner, Tom Calma, released the Social Justice Report 2005 that called on Australian governments to initiate strategies to achieve equality in health care for Indigenous Australians within a 25 year timeframe (Aboriginal and Torres Strait Islander Social Justice Commissioner 2005). This report instigated the ‘Close the Gap’ public awareness campaign that was backed by peak Indigenous and non-Indigenous bodies, non-government organisations and human rights organisations who worked together with the aim of achieving equality of life and health expectations for Indigenous peoples (Closing the gap 2013). In 2008 the ‘Closing the Gap’ strategy was endorsed by the Australian government (COAG n.d). The
A national approach to closing the gap between Indigenous and non-Indigenous Australians began with a framework for dealing with Indigenous disadvantage (DFHCSIA 2013). It included six ambitious targets:

1. closing the life expectancy gap within a generation (by 2031)
2. halving the Indigenous child mortality rate for children under 5 within a decade (by 2013)
3. ensuring all remote community Indigenous children aged 4 have access to early childhood education (by 2013)
4. halving the gap in reading, numeracy and literacy for Indigenous student’s within a decade (by 2018)
5. halving the gap in year 12 equivalent attainment for Indigenous students by 2020
6. halving the gap in employment levels for Indigenous people within a decade (by 2018) (DFHCSIA 2013).

As part of the Close the Gap efforts since 2011, the Australian Government has worked with Aboriginal and Torres Strait Islander people to develop the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 (ref). The vision of the Health Plan includes strategies to address social inequalities and determinants of health. The principles of the Health Plan see health equality as a human rights issue that is associated with accountability and is grounded in partnership with Aboriginal and Torres Strait Islander people through community engagement, input and control. The central priority of the Health plan is that of valuing culture by emphasising that Aboriginal and Torres Strait Islander people have the right to live a healthy, safe and empowered life with a healthy strong connection to their culture and country. An important feature of the Health Plan is the Recognition Statement that declares that Aboriginal and Torres Strait Islander people are the first people of Australia and that their culture is dynamic and continues to change, develop and grow in response to both contemporary and historical circumstances. The Australian Government recognises that while Aboriginal and Torres Strait Islander people share a continuing legacy of strength, determination and resilience, the interruption of culture, experiences of dispossession and intergenerational trauma have had significant impacts for Aboriginal and Torres Strait Islander people (Commonwealth Government 2013).

Amongst other initiatives, the Health Plan also builds upon the United Nations Declaration on the Rights of Indigenous Peoples which also adopts a strengths-based approach that supports policies and programmes designed to promote the improvement of health, social and emotional wellbeing, resilience and positive health behaviours for Indigenous peoples (Commonwealth Government 2013).
2. Research questions and methods

The project aimed to explore Aboriginal and Torres Strait Islander peoples knowledge, experience and perceptions of chronic health conditions in the greater Rockhampton region. In exploring these issues, the research aimed to identify changes that may be made to improve chronic disease prevention and care and management of Indigenous people with chronic health conditions. The research also intended to inform teaching and learning practices used in relevant higher education and/or vocational education settings. Recommendation 331 of the Royal Commission in Aboriginal Deaths in Custody expressed that research should assist in bringing about solutions. To this end, the research also aimed to make a contribution towards improving health outcomes and thus the lives of Indigenous peoples.

It is intended that the broader community benefit from the research outcomes through:

- improved regional knowledge and awareness of the impact of chronic disease
- the generation of information that informs regionally-relevant approaches to chronic disease prevention and care and management of Indigenous people with chronic disease/s
- the generation of information that informs teaching and learning practices used in relevant higher education and/or vocational education settings within Central Queensland region. This may include innovation in the areas of Cert IV for Aged Care, Disability support, Indigenous health workers, Allied Health, Community Health and other areas.

A National Ethics Application form was considered by the CQUniversity Human Research Ethics Committee on 11 November 2014, and full clearance was granted as follows:

H14/10-213 – Exploring Aboriginal and Torres Strait Islander knowledge, experiences and perceptions of chronic disease conditions in the greater Rockhampton region.

The period of ethics approval is from 12 December 2014 to 30 December 2015.

The research utilised The Ethical Guidelines for Research with Aboriginal and Torres Strait Islander Peoples and the AIATSIS Guidelines, specifically for people whose languages may be an Aboriginal and/or Torres Strait Islander language.

2.1 Research questions

The research primarily addressed three topics, as below:

Research Question 1: What is the lived experience of Indigenous people residing in the greater Rockhampton Region living with chronic health conditions?

Research Question 2: What regionally-relevant approaches to chronic disease prevention and care and management of Indigenous people with chronic disease/s need to be implemented in the greater Rockhampton region?

Research Question 3: What knowledge/education will improve teaching and learning practices used in higher education and/or vocational education settings within the Central Queensland region? What innovation in the areas of Cert IV for Aged Care, Disability Support, Indigenous health workers, Allied Health, Community Health and other areas will improve chronic disease outcomes for Indigenous people?
These questions encompass primary and critical care issues.

The subsidiary research questions included:

1. What is the role of respecting, developing and/or extending cultural awareness in the improvement of chronic disease management and prevention for Indigenous people?
2. What statistics, data and information are currently available regarding the major chronic diseases, priority chronic health conditions and/or the increasing occurrence of chronic disease in the greater Rockhampton Region?
3. What primary care models for prevention of chronic disease for Indigenous people in the greater Rockhampton Region can be developed?
4. What are the policy and resource implications for regional health services servicing Indigenous people in the Rockhampton Region? For example, how can regional health primary and critical care health services be better equipped to support Indigenous people with chronic disease conditions? How does this intersect with the Close the Gap goals?

2.2 Research methods

The project was heavily based in community consultation, with the aim of collecting new primary data on the knowledge, experiences and perceptions of chronic diseases impacting on the local Aboriginal and Torres Strait Islander population, from a range of stakeholders (inclusive of gender, age and health status variations). The project used an exploratory, mixed methods approach to collect and analyse different data sets.

Firstly, a desktop analysis was conducted to determine what information was already available with respect to Indigenous health and heath services in the greater Rockhampton region.

Secondly, qualitative and quantitative data were gathered through four adult workshops that were held in Rockhampton, Gracemere, Yeppoon and the Alma Street Clinic (Binbi Wajda)\(^3\); through a youth workshop and through a workshop with local health care providers.

The qualitative aspects of this workshops comprised a number of activities including opportunities for participants to verbally share their experiences, through facilitated focus groups, ‘personal reflections’ and ‘yarning together’, with information being captured by the research team on butcher’s paper. Participants were also able to record additional thoughts and feelings privately, in an activity where they could write or draw on a piece of paper, which was then submitted anonymously.

With regards to quantitative data, four of the six workshops incorporated the use of Audience Response Technology (more commonly known as ‘clickers’). These are hand-held voting devices that are deployed together with an electronic presentation format (e.g. PowerPoint presentation). This technique is particularly valuable for two reasons – one, it allows participants to enter their responses anonymously; and two, the collated results can then be reported in real-time via a projector screen, which provides a platform for further discussion and analysis amongst the group. The devices are particularly well-suited to multiple choice question formats; here, participants are

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\(^3\) Note: A workshop was also offered in Mount Morgan, however no participants were attracted.
able to select one option only from a prepared list. This is helpful in determining from participants their ‘most preferred’ or prioritised option, rather than capturing all of the possibilities in a list.

Thirdly, to further explore the themes that emerged from the workshops and desktop phase, one-on-one interviews were conducted with participants from the greater Rockhampton region. A total of ten interviews were conducted during April-May 2015, using opportunistic and ‘snowball’ sampling. The interviews were conducted using a semi-structured technique, to explore Aboriginal and Torres Strait Islander peoples and experiences and perceptions of living with chronic health conditions, any concerns they may have about availability of support within the region and any suggestions they may have for improvement.

For both workshops and individual interviews, local people who are known to the community were asked to assist in recruitment, in addition to broadcasting the information on general and social media, and making use of both organised and informal community networks. Data analysis was undertaken through an open-ended process of thematic coding and cross-referencing across the various sources.

3. Desktop data collection

3.1 Incidence of chronic conditions on the greater Rockhampton region

Central Queensland has a resident population of Aboriginal or Torres Strait Islander people that is approximately twice the national average (Commonwealth Government, 2013).

The age structure of the Aboriginal and/or Torres Strait Islander people within the Greater Rockhampton region differs slightly to the state average, and this is important in considering the incidence and impact of chronic health conditions on the population. For example, Queensland reports a slightly lower proportion of youth (37.5% in the state, compared with 40.1% for greater Rockhampton) as well as slightly lower proportion of aged persons (3.4% in the state, compared with 3.7% for greater Rockhampton) (see Table 1).

Aboriginal and/or Torres Strait Islander people living in the Greater Rockhampton region also appear to have slightly higher mobility rates than elsewhere in Queensland, with almost a quarter of people

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4 This process involves asking current participants to recommend others who may be interested in taking part.
5 A copy of the survey instrument is available on request to the research team.
having changed address in the previous year, and over half having changed address in the previous five years (Table 1). This is important in considering Aboriginal and/or Torres Strait Islander people’s access to, and continuity of, health care.

Table 1: Statistics relating to Aboriginal and/or Torres Strait Islander peoples within the Greater Rockhampton Region, as at 2011 (this is the latest available information).

<table>
<thead>
<tr>
<th>Total resident populations (usual residents)</th>
<th>109,336</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal and Torres Strait Islander population</td>
<td>5,998</td>
</tr>
<tr>
<td>- Total</td>
<td>5.5%</td>
</tr>
<tr>
<td>Population breakdown</td>
<td></td>
</tr>
<tr>
<td>- Aboriginal</td>
<td>5,162 (4.7%)</td>
</tr>
<tr>
<td>- Torres Strait Islander</td>
<td>449 (0.4%)</td>
</tr>
<tr>
<td>- Both Aboriginal and Torres Strait Islander</td>
<td>387 (0.4%)</td>
</tr>
<tr>
<td>Aboriginal and Torres Strait Islander population by gender</td>
<td></td>
</tr>
<tr>
<td>- Male</td>
<td>2,938 (49%)</td>
</tr>
<tr>
<td>- Female</td>
<td>3,060 (51%)</td>
</tr>
<tr>
<td>Aboriginal and Torres Strait Islander population</td>
<td>19</td>
</tr>
<tr>
<td>Median age (years)</td>
<td></td>
</tr>
<tr>
<td>Proportion aged 0 to 14 years</td>
<td>40.1%</td>
</tr>
<tr>
<td>Proportion aged 65 years and over</td>
<td>3.7%</td>
</tr>
<tr>
<td>Aboriginal and Torres Strait Islander population – proportion who had a different address:</td>
<td></td>
</tr>
<tr>
<td>- one year ago</td>
<td>24.1%</td>
</tr>
<tr>
<td>- five years ago</td>
<td>50.1%</td>
</tr>
<tr>
<td>Aboriginal and Torres Strait Islander population</td>
<td>5.3%</td>
</tr>
<tr>
<td>Proportion with profound or severe disability</td>
<td></td>
</tr>
</tbody>
</table>

4. Key findings

This section presents a summary of the key findings from the workshops as well as the one-on-one interviews. Within the confines of this research report, the voices of participants and their direct quotations have been used wherever possible.

The Rockhampton, Gracemere and Yeppoon Adult workshops used extensive discussion sessions and these are detailed under section 4.1.

The Youth Workshop, Health Care Provider’s Workshop and Alma Street Clinic Workshop all included the use of interactive audience technology, and thus are presented in section 4.2 through the use of graphs and accompanying text. Notes were taken during discussion times at all these workshops and vignettes of these notes are also included in the findings.

The key themes arising from the one-on-one interviews are presented in Section 4.5.

4.1 Adult Workshops

Three workshops were held for Aboriginal and/or Torres Strait Islander adults who were either living with chronic illnesses, or were carers of Aboriginal and/or Torres Strait Islander people with chronic health conditions. The workshops were held in the communities of Rockhampton, Gracemere and Yeppoon (Capricorn Coast) during February and March 2015.

A total of fourteen participants attended the workshops at Rockhampton, Gracemere and Yeppoon (Capricorn Coast), with almost all of these being Aboriginal and/or Torres Strait Islander people living with chronic health conditions. A minority of other participants were either health care workers, or carers and/or partners of Aboriginal and/or Torres Strait Islander people with chronic health conditions.

The following sections provide a snapshot of the key themes and discussion points that arose during the workshops. To maintain anonymity of participants, data from the three workshops has been merged.

4.1.1 Perceptions of the meaning of chronic illness

After all participants were welcomed into each workshop, the first activity involved recording their perceptions about the definition of chronic illness. It was important that this activity was undertaken at the commencement of the session, such that participant’s pre-existing understanding of chronic illness could be recorded, before they had the opportunity to learn more about this issue via the informed discussion and particularly, through the guest speaker’s presentations.

Participants were asked to response in their own words to the question: What do you think about chronic health conditions?, and encouraged to talk about how they understood the term ‘chronic illness’ as well as what their lived experience of chronic conditions had been to date. Participants talked through this activity with a group facilitator and concepts and/or phrases that were shared by the participants were documented on butcher’s paper. The wordcloud below presents a summary of this information, using participant’s own words wherever possible (Figure 2).

Much of these conversations appeared to revolve around ‘what counts’ in terms of a chronic condition; how participants had experienced and/or managed their health concerns to date (or
those of their families); and how Indigenous people could be empowered to learn more and influence their experience of chronic illness:

- In terms of ‘what counts’, some participants recognised that there were key health conditions that were routinely acknowledged as being ‘chronic’, especially diabetes. There was some interest in discussing the word ‘chronic’ itself, and how it compared with other medical terms (such as ‘terminal’).

- Regarding their lived experience of chronic conditions, participants volunteered information on the logistics – such as where to access care, travelling, juggling appointments, understanding medication – as well as the spiritual and emotional side, touching on areas such as ‘earth-mother’, vulnerability, shame and grief.

- Regarding empowerment and learning about dealing with chronic conditions in the community, participants noted the need for communication and information, particularly around leading a healthy lifestyle, with factors such as weight, alcohol and smoking being mentioned. Equally, however, there was discussion about making positive changes, sharing information with the younger generations, and drawing on aspects of their Indigeneity to cope with ill health (such as Dreamtime stories and traditional healing).

Figure 2 summarises participants perceptions of the meaning of chronic illness in a Wordcloud.

4.1.2 Concerns, fears and worries about chronic conditions

Personal reflections about chronic health conditions and their impact on participant’s lives were introduced by the workshop facilitator. Participants were invited to think about any concerns, fears or worries that they may harbour for themselves, their families and their community, regarding chronic conditions. Given the potentially sensitive nature of this information, this activity was carried out as a private reflection. A sheet of blue paper was handed to each participant, who were then asked to write or draw the first thing that came to mind about the fears or worries they had about chronic conditions. A short activity followed this exercise to ensure that participants were not left to dwell on their concerns, fears or worries. Figure 3 presents a summary of the key themes about participants concerns, fears and worries about chronic health conditions.
The key themes that emerged from this activity are described below, in the participant’s own words:

**Fears about the future**
- [For] Myself – leaving my wife alone – who will look after my family? – I don’t want to die – I am not going to die – not having children – not being able to help/support hers.
- [For] Others – losing someone I love – being alone without my wife
- Loss of job

**Worry about the future**
- Be able to be independent later in life. Who will look after me if I become mentally dependent (e.g. Alzheimer’s disease?)
- Don’t want to see chronic disease normalised, something that is inevitable
- Passing on to family members
- Affordability of medication
- Not being able to help other family members

**Fear of death**
- Death, Cures, Types of Medication, Support, Information, Family
- Life and Death (lifespan)
- I’ll die before my time is due

**Fear of being alone**
- I fear being alone despite being someone who loves quiet and having time on my own

**Fear of the unknown**
- Fear of the unknown
- Interruption to lifestyle
Fear of being a burden

- That I won’t be a good wife. That I will dependent for everything like showering, toileting, eating, moving
  
  “I don’t want to die yet
  I am not ready to die yet
  I still have lots of things
  I want to do, achieve
  And fight for”

- Slowly losing all things it takes to be an asset to my family. * Addictions cannot be overcome in most cases *

Fear of loss of independence

- Being incapable of looking after myself

Fear about own health

- That I’ll get more [chronic illnesses]

Fear about family’s health

- I’ll inherit chronic disease from family or pass it down to children
- My fear is that my children will grow up knowing the same cycle of health (or lack of) that is with us today. I want to educate them into knowing change is OK.
- That my sons and grannies will suffer the same [chronic health conditions]
- A long ongoing family dispute has caused tension between me and my father. He now lives with other family members who do not look after him. Our pigheadedness is stepping in the way of talking to one another. So when I see him up the street (or constantly drinking in the pub) he is looking more and more unhealthy. He is not getting any younger, vision impaired, diabetic and fading away to nothing.

Worry about family’s health

- I worry about Mum. She is getting more angry and bitter as she is getting older and sicker. I don’t know if it is the sickness making her this way or because she doesn’t want to get older.

Worry about clash of cultures/beliefs

- Following wishes of the affected person
- Clash of cultures/beliefs

Worry about lack of knowledge

- Lack of knowledge
- Ignorance regarding alternative forms of medication

Worry about government policies

- Chronic disease is always going to be amongst our mob, my worries are that the way the government is going that we’re repeating history of breeding out.
**Social Determinants**

- Assistance, care aids
- Accommodation – suitable accommodation for living – when people come from out of town, accommodation we only have is Red Cross!! We need a Murri McDonald House. (Lol)
- Access to Mental Health Services for assistance–

This mixture of themes is represented in the wordcloud below, which was developed using the words and phrases that participants recorded on their blue paper (Figure 4).

![Figure 4 Wordcloud summary of key phrases reported during personal reflections on fear and worries related to chronic health conditions.](image)

**4.1.3 Yarning together during the Workshop**

During the workshops the facilitator raised questions to the participants that asked what it meant to them to be healthy; what worried them about chronic health conditions; whether they ever yarred to family or friends about it; what they thought was the most important thing to do to be healthy; what would they do about chronic health if they had the money and finally, whether services in Rockhampton met their needs. The discussions were loosely modelled on the same questions that were followed in the semi-structured instrument used to guide the one-on-one interviews.

Six major themes emerged from the discussions – these being (1) personal perceptions, (2) identity, (3) knowledge, (4) needs, (5) education/experience and (6) proactivity and empowerment (refer to Figure 5).

This indicated that the lived experience of chronic health conditions in Aboriginal and Torres Strait Islander people is a complex space, with many overlapping and sometimes opposing or contrary thoughts, feelings and perceptions. This might be visualised as per below, illustrating that an
‘overlapping’ effect that exists within individuals, as well as in families and in communities. This may be an important concept when designing or implementing policy and practice-based responses to health care and management.

![Diagram of themes: Perception, Knowledge/Education, Experience, Identity, Needs, Proactive/Empower]

**Perceptions**
While some participants’ personal perceptions about their chronic health conditions included accepting their illness/es, many identified that they were ‘still able’ and ‘still healthy enough’. Some said they wanted to ‘live longer’ and encouraged ‘re-education’ because ‘you don’t have to accept death’. Many said they are ‘not afraid to die’, and one participant shared ‘my sons were the reason I kept living, I needed a reason to live’.

The wellbeing of family were a major concern for those living with chronic health conditions, highlighted by one participant who said, ‘I look after myself so I can look after my wife.’ Good health was identified by one participant as ‘a healthy spirit mostly’.

At one workshop, an animated discussion took place about happiness and health, with participants saying, ‘not having to rely on the health system’ and ‘not having to rely on tablets’ would mean happiness for them. Travel and medication was highlighted as an issue particularly for those whose medication required refrigeration and who travel to remote communities that have no power.

The desire for intimacy and a yearning for past [good] health was touched upon, as was the sadness over fighting between families in some communities where ‘legal processes [for land rights cases] were interrupting cultural processes’. Social media was mentioned as a positive as well as a sometimes negative form of communication for those who used it to talk about their health issues or to connect with family.

Figure 6 presents a summary of the subsidiary themes that emerged around participants personal perceptions of the impact of chronic health conditions on their lives.
Identity
The importance of identity was illustrated through one participant’s journey: ‘I didn’t know I was Aboriginal until I was 29, finding out healed me’.

Some participants felt they needed to ‘re-claim and empower ourselves’ while one participant felt that ‘responsibility for your own self empowers [you]’.

The confusing use of language was an issue identified across each of the different data collection approaches as well as during the yarning sessions and was explained as ‘brochures are not part of our world’. Further, the education and information presented by health professionals was ‘confusing’.

The theme of self-talk was introduced by one participant who explained, ‘My aunty has cancer, but doesn’t embed the word in her body, she doesn’t talk about it’, with others sharing it was important to ‘listen to myself’ and to ‘hear your own good voice, not your bad voice’.

Traditional knowledge was important, and was perceived as ‘dying out’ as explained by one participant who movingly told this story as being a member of the Stolen Generation; ‘I was separated from my family at three months old and put in the mission hospital at Cherburg. An old lady had me and she handed me back. The superintendent there put me in a place where they put babies, in the dormitories. Dormitories were separated, for single men and single women. The women without husbands were allowed to take the babies. I was taught out there, traditional stuff, how to track and fish. I was lucky, I learnt language. [You need to] go and get the knowledge and hang on to it, it’s dying out...To a white man it means nothing, I can’t even use my language, no one knows it...’
Figure 7 summarises the subsidiary themes relating to ‘identity’ that emerged from yarning.

**Knowledge/Education**

Awareness of a ‘good’ doctor was a primary concern for participants (a theme identified across all the data collection points), and evidenced in the yarning sessions by comments such as you ‘need to doctor shop’ and ‘it’s scary finding a new doctor’. One participant felt ‘your doctors need to know [everything], they’re almost God, they do everything’. While another participant said ‘if doctors won’t tell me about my own body, or treat me like an equal, I leave’.

The need for ‘GPs to know what’s out there to give to people’ included knowledge of ‘medical aides for incontinence’ and that ‘Centrelink has a supplement’ for these aides. One participant shared, ‘I got a disability parking sticker’ from the GP.

Government systems were identified as a ‘barrier’ particularly when navigating Centrelink where some participants said ‘the cut-off to help is low’ and ‘everything isn’t covered by CTG’. Doctors need to identify CTG on prescriptions, otherwise patients have to return to the doctor to tick the box. Participants said ‘everything isn’t covered [by CTG] and GPs need to know this’. Another shared that, ‘Murri’s don’t like to assert themselves or go back to get CTG [from the doctor], they don’t like going back’. One participant said that ‘in the last six months doctors and even diabetics have started to realise about CTG’ with another participant sharing “Always remind me to put CTG on your scripts” my doctor tells me. Otherwise you have to go back to the doctor’. Many workshop participants felt ‘CTG isn’t closing the gap’.

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6 Closing the Gap (CTG) – PBS Co-payment measure allows eligible Aboriginal and/or Torres Strait Islander people access to cheaper Pharmaceutical Benefits Scheme (PBS) medicines. GP’s assess eligibility which is related to an existing chronic disease or the risk of getting a chronic disease. [http://www.humanservices.gov.au/customer/services/medicare/indigenous-access-program](http://www.humanservices.gov.au/customer/services/medicare/indigenous-access-program)
An issue with information flow when visiting specialists at the hospital was illuminated by participants with many saying, ‘When you go to see about something, you wait 4 hours, you come out of that appointment, then you see the pharmacist etc, and you tell the same story to three different people. You tell people over and over again your story, the information flow needs fixing’. Some participants thought that ‘the system [is] good, but it’s knowing how to weave through the paperwork’.

Some participants felt ‘there needs to be better planning for services, and [especially] for northern Rocky’ and ‘a hospital half way between Rocky and Emu Park and Yeppoon would be good’.

Issues around medication brought about vigorous conversation at the workshops. Worries about ‘forgetting tablets when travelling’ and the ‘restriction on how many tablets you can get’ impacted on participants lives.

Concern over past information and research where the information or results are not used or have disappeared was a concern for participants who felt information and projects were being repeated. One participant said, ‘Elders have heard the same thing over and over again. How do we access the prior answers about others who have lived in poverty etc. where is it? For example the suicide stuff, it’s great stuff, but where is it? It’s been ignored’.

Figure 8 presents a summary of the knowledge/education issues that came out of the yarning sessions.

Figure 8 Summary of knowledge/education issues that emerged during yarning

**Needs**
Participants expressed the desire for a ‘one-stop-health-hub. A big multicultural medical centre, within which there is more Indigenous faces, from the people that mows the grass to the people that provide the services. Where kids can play, where there is a cafeteria’.

Another participant explained, ‘Melbourne has a community controlled Indigenous medical centre, it has a fire pit, notice board, budgeting advice, continued support, pharmacy, doctors, funeral service,
child care, methadone program, Hepp C program, gym, and emergency housing. It’s called the Victorian Aboriginal Health Service or VAHS. It has worked in with Jamie Oliver, bush food, modern food, and fusion. It’s a health hub, a one stop shop in health, with access to all services in one. It works in collaboration with educational institutions to provide access to other facilities and with allied health, with dental health. In America there is university hospitals. It reduces costs and educates students’.

Participants spoke about Aboriginal Medical Services, ‘I think Bidgerdii is an excellent one-stop-shop but they have to refer when other health requirements are needed and that’s when it gets difficult. There are barriers when people are referred away from Bidgerdii, and people don’t want to go to hospital’.

A lack of local specialists was also identified by participants. ‘Government sponsored dental is not available now and because of taking meds my teeth fell apart’ and ‘Mt Morgan has a dental clinic once a week’. Also identified was the lack of ‘Ophthalmologists, [they] need to be subsided, things need to change much more’ and ‘we need Nutritionists’. ‘Constant travel due to lack of specialist services’ was a major issue, with one participant saying ‘we need visiting clinics’. ‘Brain surgery and prostate cancer surgery in Rockhampton’ were identified as the type of surgery’s that require travel and time away from communities. While a lack of local specialists were identified as an issue, so too was the availability of local doctors in some communities, ‘we’re sick of locums, we want a permanent doctor, some doctors want to stay but the hierarchy won’t let them’.

Cultural safety was an issue with one participant saying, ‘There are a lot of blackfellas in the Emu Park clinic. We feel comfortable, and culturally safe. There’s even stuff in there for us like pictures on the wall...It’s good, even if they don’t know, the GPs want to know. It’s [Emu Park] is different to Rocky’.

Privacy was an issue also touched upon with one participant saying, ‘You need to be careful who you talk to, what you disclose. Sometimes I don’t want to burden people, or I don’t want anyone knowing my business’.

The need for more Indigenous health workers was highlighted at the workshops; ‘There needs to be training for Indigenous people to look after Indigenous people’.

The social determinants of housing and transport were major barriers for many participants. Participants suggested to ‘bring services to the people’, ‘improve housing’, and ‘get medications delivered’. One participant shared that ‘an old man of 80 from Emu Park has to get from the Coast to Rocky to Brisbane and all the services for him are in Rocky’.

Money was also an issue raised in the workshops from having ‘enough money to survive’ to the need to ‘audit our services more...so money is not being sucked up’ and the sharing of knowledge about Ozcare who ‘gives a $570 allowance to use but most people are not aware, education needed’.

House visits were identified as a way of reaching out to people in the community. ‘If they don’t come to you, take it to them. Do it the right way, ask “can I visit?” Then chat about things, then you get them to open up and you can ask, “do you know what diabetes is etc?” You need to go to the people, to their homes...it’s the best place, otherwise there are excuses like “I’ve got no car etc.” They don’t
want to face up to issues, but we all need help’. Another participant said, ‘I agree with going to people if they won’t come to you’.

One participant felt ‘Life is a teacher itself, I listened to people with the right answers, good answers’.

Figure 9 summarises the needs that were identified during yarning.

Figure 9 Summary of needs that emerged from yarning

**Experience**

Workshop participants iterated that education about chronic health conditions is needed, and often this need for education ‘doesn’t come up until you are in that point of care’.

Participants said that educating young people should be a priority, with one participant saying, ‘I have a problem with young kids not being educated about chronic disease, especially your own kids’.

Many said this education should also be part of children’s school education:

- ‘Reintroduce practical things to schools, start at Prep’
- ‘At school we learnt Mothercraft, it’s not in schools anymore’
- ‘Incentives to go to school like the ARTIE Program with dental care, milk at school, and exercise scholarships’
- ‘Jonathon Thurston was bought in to a school to grow veggies at the school, they had chooks for their eggs, and it was all used in the canteen, kids could see the process’
- ‘In primary school Healthy Harold came around to the school. He was a giraffe and you learnt about body systems, healthy diets, the food pyramid and songs about being healthy’
- ‘In High School too I learnt about foods but not so much about exercise’
Participants also spoke of the need to educate the Western domain, ‘I don’t think anything changes until the Western domain knows who we are... in the education system, knowing our history, good and bad history, they need to know it’.

Some participants discussed the need to live ‘both ways’ by ‘learn[ing] to walk in both worlds. Through understanding, and talking about bringing both worlds together. We need to love both worlds, we can’t change it now, so bring it together, with no colour issues, with all Australians together’.

The need for culturally appropriate information was acknowledged during yarning. ‘We need knowledge about the system, [and it needs] culturally appropriate information about “us”. [For] understanding, and to feel comfortable’.

The facilitator asked participants ‘what would assist with improving community health?’ and received the following responses:

- Having things accessible
- Near to a bus stop
- Easy to get to
- In the community
- Knowing what’s out there
- Knowing how to access it
- Confidence to access it

To follow up the last statement about ‘confidence’ made by a participant, the facilitator asked ‘what is this confidence, how would you describe it?’ The participant thought deeply and responded with, ‘The relationship mainly. When you get to know someone, [it’s] seeing the same doctor again and not having to go through your life story over and over again. Sometimes you keep telling the story and they don’t listen’.

‘Not being listened to’ was a major issue, with one participant saying ‘education needs to take into account doctors won’t listen to us. We need to be not just heard, but for them to act on what we say’, and ‘to stop ignoring us. We have a voice, but no one’s listening, have they got headphones on?’, ‘nothing changes’.

Poor customer service in Rockhampton was identified as a negative experience around food service and food choice. ‘Customers ask, but businesses won’t do it’, ‘it is a culture’ and ‘Rocky drags the chain...’ One family has been banned from an eating establishment, and are ‘not welcome because we asked for no butter or margarine. We asked for wholemeal bread and no chips.’ The café would not vary the menu to offer healthy options as asked for by the customers making it difficult for people to have any agency with regards to their health. Racism was also evident in some establishments; ‘I didn’t get served because I’m black’.

Past experiences were also exchanged in the workshops with regard to the change in Aboriginal and Torres Strait Islander peoples diet and the link with chronic disease. One participant recollected the change in foods; ‘One in four Aboriginal people with diabetes, it’s shocking. In the mission we had
rations, sago, tea, rice, split peas, syrup and flour, you had to fill up the ration bag. They were fortnightly rations. The line-up for meat was crazy, and there wasn’t enough. That’s why we still hunted for food, but we would cross into white people’s property hunting kangaroos and the police would come out’.

Figure 10 summarises Aboriginal and/or Torres Strait Islander peoples lived experiences around chronic health conditions in the greater Rockhampton region.

![Figure 10](image)

**Figure 10 Summary of Aboriginal and/or Torres Strait Islander peoples experiences that emerged from yarning**

**Proactive Health/empowerment**

Participants were asked if they yarn to their family or friends about health matters, almost everyone said yes:

- ‘We always have these discussions at home, we live for today, we plan, we organise. Life is what you make it, you are what you eat. Life isn’t easy and health, it’s not easy. We deal with mental problems and health problems’.
- ‘My sister had told me I need to lose weight. She’s the family “mother”. She said, “you’re older now, and diabetes is in our family”. She’s pregnant now and I’m bigger than her. We’re trying to look after the elder people in our family. It’s about us younger ones being more influential in the health as well. Its issues focused’.
- ‘I’m younger and it’s easier to be healthy. I’m doing a program at the moment for 12 weeks and it’s HARD. I used to be a big fan of take-out like KFC. Changing that way of eating was hard, but easy. In their program they give you the shopping list so it’s easy. I’ve been on the program for four weeks and everything looks a lot brighter’.
- ‘They say take away is addictive. Even the smells make us want to eat it’.

Exercise was a theme that emerged in response to a question about preventing chronic health conditions. ‘I like walking on the beach and that keeps me healthy’ and ‘sometimes I’m too tired
after work to put my boots on to go [for a walk]. The need for exercise consistency was mentioned as was going to the gym. The need for more sports scholarships was also discussed.

Addictions were mentioned with many people identifying ‘giving up smoking’ as important to good health. One participant encouraged others by saying, ‘you’ve got to check your health, sometimes we get lazy and we don’t go. When I came from the mission, you had to go’.

Goals were associated with being healthy; ‘...even with all these things going on [with my health] I aim to be the best I can even though it’s difficult sometimes’. ‘Life balance’ was an issue that was also mentioned in the workshops, as was the ‘need to empower our people with their own decisions’.

The ‘worries people have trying to aim for healthy’ were impacted by such things as the ‘time, energy, motivation and access to needs’. Some participants were concerned about their jobs and trying to fit in healthy activities; ‘you have to work to earn a living, and sometimes illness stops you going to work. You ask yourself, “can I get there? Am I going to make it today?”’ Eat more ‘veggies’ and make ‘correct food choices’ were other suggestions for good health. ‘We need branding like “McFresh” that serves good food. The reason you eat take-away is because you’re time poor, and that equals fast food’ was a recommendation for fast food alternatives. ‘Stay away from processed foods if you want to live longer, it’s your choice...I eat the right food, [it’s] salt and fat, that’s what they put it [chronic disease] down to’ one participant suggested.

A discussion about the ‘willpower’ needed to maintain healthy activities caused some to groan; ‘I still like a drink, and choccy cake etc. I still need to push myself, everyday can be difficult’. ‘5/2 fasting for two days’ was mentioned by one participant as a way to maintain weight and health.

Fresh food was another theme that emerged from the workshop discussions. ‘Fresh food is expensive’, the need to ‘subsidise fresh food’ and ‘it needs to be delivered fresh’ were comments surrounding the theme.

Community gardens were a theme that emerged from the workshop discussions with a description of ‘gorilla gardens’ given where ‘the use of vacant blocks is negotiated, and plants can be grown there’. ‘Instead of trees with flowers around town, they could grow fruit trees’ was a suggestion for an increase in local fresh produce, as was ‘you could grow veges in the medium strips and along the footpaths’.

Figure 11 presents a summary of the themes that arose around proactive health and empowerment issues during the yarning sessions.
Figure 11 Summary of proactivity and empowerment themes that emerged from yarning

The workshops gave participants from the greater Rockhampton region the opportunity to share their knowledge, experiences and perceptions of chronic health conditions in the area. The diagrams used to illustrate the major themes and the sub themes show both overlapping relationships and the relationship to the central (or major) theme depicted in the centre of the large circle.
4.2 Audience Response Technology Sessions

4.2.1 Youth Workshop

A Youth Workshop was held at CQU University North Rockhampton, Queensland on the 13th February 2015. It must be acknowledged that the sample size was small, with initially four participants rising to five, partway through the session. Nevertheless, a rich dataset was captured through a combination of both quantitative clicker data together with the qualitative discussion points.

The youth participants had a mixed outlook in regards to their current health; with one reporting it was ‘awesome’ but others indicating that they felt their health was poor (Figure 12). On discussion, one participant indicated that they had recently been unwell. Half of the participants felt uncomfortable, or unclear, about reporting their health outlook for 30 years’ time. On discussion, it emerged that participants found it difficult to ‘forecast’ their health over such a long timescale; participants also indicated that early death was of concern, particularly for those who’d already had family members diagnosed with chronic conditions. However, it was also noted that health outcomes were gradually improving (e.g. due to medical advances and more knowledge about prevention, care and management).

Figure 12 Youth participant responses regarding the rating of their current health (left) and health outlook by 2045 (right). Participants were asked to rank their response, on a scale of 1 to 5.

The youth participants held consistent views about the age at which they expected most Indigenous people to become vulnerable to chronic health conditions, with everyone selecting the 30-50 year age bracket (Figure 13). During the discussion, one participant commented ‘everyone I know gets sick around 30-40 [years old]’. Participants discussed the view that Indigenous individuals have shorted life expectancies that the Australian average; with one person remarking that those in their 20s ‘spend their time partying, then settle down, then pay for it’. It was noted amongst the group that the expected onset of chronic conditions at this time of adulthood could be particularly problematic when coincided with raising a young family and/or caring for aging relatives, meaning that the unwell individual has a number of pressures to deal with.
The youth group had mixed perceptions about the condition(s) that were the leading cause of ill health amongst Aboriginal and/or Torres Strait Islander people in the region, with diabetes showing strongly, followed by cancer and mental health issues (Figure 14). During the discussion, one participant sharing that both herself and her husband have been affected by mental illness, and that in her opinion, attitudes and information regarding this condition had improved: ‘I talk about it now, it’s out of the closet now – I think it helps people to know’. Others in the group noted that other issues, such as alcoholism and family violence, had not appeared on the list as ‘chronic conditions’. An additional comment to this was the role of alcohol and unhealthy eating in exacerbating/accelerating the onset of chronic disease amongst the local community. This provided a useful segue to the following question, regarding healthy lifestyle practices.
The youth participants felt that access to Indigenous health services, and making Indigenous people’s business everyone’s business were both very important practices that could contribute to better health outcomes for the Greater Rockhampton region (Figure 15). When asked to describe how this might occur, one participant suggested the value of early-awareness, including school-based education to ‘let them know before they are in the cycle’. Many of the group indicated that they had received school-based education themselves, with one relating a particularly powerful activity where the NSW Aboriginal Health Service had attended the school for a demonstration on the impact of cigarettes on the human lung: ‘I was 10 and never forgot what cigarettes did to lungs’. Nevertheless, participants also indicated that the school system was lacking in passing on ‘history’, and they highlighted the role that community Elders play in this respect.

![Figure 15](image.png)

**Figure 15** Youth participant’s perceptions about the most important healthy lifestyle practices.

The next series of questions in the activity were focussed on availability and access to health services in the Greater Rockhampton region. There was a very mixed result when the youth were asked to relate their experiences of friends and family’s access to health services, and how well these services met their needs (Figure 16). On the issue of accessibility, a number of themes emerged. Firstly, transport and/or the need to travel long distances (particularly in the case of accessing specialist care), was raised as a key issue amongst the group. Participants indicated how difficult it was for family members to travel, as well as to stay in other centres for extended periods, in order to be able to access help, for example: ‘[He] had chest pain for 3 weeks ...[but] it’s hard to remain in Rocky if there is no support’. Secondly, it was acknowledged that accessibility also meant that the individual themselves had to first admit that they needed help: this is not always easy, and one participant relayed an instance whereby a family member was regularly visiting the doctor but not being honest and open about their symptoms (‘I’m all right’); this was only resolved when a family member finally accompanied them to an appointment. Another replied that in fact her experience had been that symptoms had to be almost exaggerated before the general practitioner would escalate the case to receive priority care; particularly as she had presented at a younger age than perhaps other patients (due to her Aboriginality).

There was also a very mixed result amongst the youth regarding priority areas for investment, to assist people in the Greater Rockhampton region who were living with chronic conditions (Figure 17).
The group commented that ‘we need all of those options on the list!’ The widespread use of Gumbi Gumbi\(^7\) to address a number of ailments was discussed. The need for clear communication with doctors was regarded as incredibly important: the participants felt strongly that local doctors must have good communication skills, and that practitioners from other cultures were often difficult to engage with (“Have you got any English speaking doctors?”). There was also frustration at the poor information sharing between doctors and patients (‘my doctor wouldn’t tell me about my x-rays’); and having to repeat information across numerous staff, particularly when presenting for hospital-based services. Finally, there were concerns that some medical staff had misplaced preconceptions about Aboriginal peoples, which affected their dealings with them: “you’re Aboriginal, you drink, so that’s the cause of your problems”.

\[\text{Figure 16} \text{ Youth participant’s views about whether family and/or friends with chronic health conditions are accessing the services they need.}\]

\[\text{Figure 17} \text{ Youth participant’s preferences regarding investment to prevent chronic health conditions in Aboriginal and/or Torres Strait Islander people.}\]

\(^7\) Healing plant of Dharumbal Country (Pittosporum angustifolium FAMILY: PITTOSPORACEAE)
The final two questions explored Indigenous youth’s attitudes to working towards healthy(ier) lifestyles. Participants welcomed the idea of having a celebrity guest present information about healthy lifestyle choices, particularly if the person could be an Indigenous individual who themselves had experienced chronic illness (e.g. ‘Steve Renouf has diabetes’) (Figure 18). One male participant was particularly interested in accessing gym membership. The group also indicated the importance of providing healthy catering at any events (‘proper food – no sugar business’).

When reflecting on their own journey to healthier lifestyles, the youth participants strongly believed in the value of exercise in maintaining good health and wellbeing (Figure 19). It was acknowledged that physical fitness can also provide mental health benefits; although finding the time to fit exercise in was a challenge (particularly for those with jobs and/or young families). There was also discussion on the role of healthy eating, and the roles and responsibilities for ensuring this happens: ‘women shop – women control the sugar purchases’; and ‘our menu is the same every night – what the kids will eat, and thinking about the cost of the food’.

![Figure 18](image1.png) Youth participant’s preferences regarding incentives to attend information/education sessions about chronic disease prevention.

![Figure 19](image2.png) Youth participant’s attitudes regarding key factors to achieve and retain good health. Participants were asked to select their preferred option for the ending to the sentence: The most important thing I can do to be healthy is...?
4.2.2 Youth participant’s perceptions of chronic illness

Participants at the youth workshop were asked to comment on their understanding of the term ‘chronic illness’, in the same way that the activity was handled at the adult workshops. The wordcloud below depicts the key ‘themes’ or concepts that emerged from this activity (refer Figure 20).

It is useful here to compare contrast the perceptions of the Indigenous youth with those of their adult counterparts. Certainly, there was a similarity in that both groups related acknowledged that particular health conditions could be labelled as chronic (e.g. diabetes, heart health, kidney disease). At the youth workshop, there was also some interest in discussing the word ‘chronic’ itself, and how it compared with other medical terms (such as ‘terminal’).

A particularly strong theme in the youth cohort was that of chronic conditions being a confronting topic (‘it’s major, like serious’; ‘scary’; ‘early death’) and one that seemed to be poorly communicated (‘don’t want to talk about it’; ‘don’t know until too late’ and even ‘taboo’). This sense of uncertainty and fear did not appear to be as strong in the adult cohort, perhaps because almost all of these participants had direct, lived experience of chronic conditions.

Participants also reflected on their experiences of how older family members were living with chronic conditions. Here, participants noted their concerns for older family members who they felt were not taking heed of the help available; either through avoiding doctor’s visits, not being transparent in reporting their symptoms, or by choosing to continue with unhealthy habits (for example, a reluctance to ‘change their ways’).

One positive aspect of the conversation with the youth was that the participants commented how important and valuable it was that regional sporting events included a strong focus on keeping fit, as well as understanding your own health. For example, the Reconciliation Football Carnival offers health checks for players; this was seen as a great way to reinforce healthy living messages and being ‘forewarned’ about susceptibility to health conditions in the future.
4.3 Alma Street Clinic Workshop

4.3.1 Adult Workshop at the Alma Street Clinic (Binbi Wadja)

Audience Response Technology was used as a component of the workshop with the adult participants, following much the same sequencing as the questions used during the youth session. There were around 19 adults present at the workshop, which translated to approximately 17 participants in the data collection activity, as some people left and/or arrived during the course of the session to attend medical appointments.

Firstly, adult participants were asked to rank their current health status, with over 60% reporting themselves to be in the middle of the scale (Figure 21). Of note, the participants contrasted between being ‘sick’ or ‘having a medical condition’ with the more broader perspective of personal wellbeing, for example: ‘your health status might not be good but you can still feel okay’. Next, participants were asked indicated their expectations for their health in ten years’ time: one-third of the participants expected that their health would in fact be better by 2025; whilst a further third expected no change (Figure 21). This prompted some strong discussion, with some participants stating that they intended to ‘improve and be awesome’, whilst others noted that health problems were something that ‘comes with age’.

The adult participants had very consistent views about the age at which Indigenous peoples become chronically unwell, with 80% of the group voting for the 31-50 years age bracket (Figure 22). On discussion, it appeared that this reflected the participant’s own experiences and that of their families, in terms of when people began to report health problems. However, it was raised that diabetics may be reported at even younger ages. The discussion also included comments that the over-30s demographic typically had lower levels of daily exercise (e.g. as lives become increasingly busy with work and family care duties), and that this may contribute to health difficulties. The group also noted the strong desire to want to shift the graph ‘to the other end of the scale’ – that is, to adopt healthy practices such that Indigenous peoples could enjoy good health for longer.
The adult participants felt that diabetes and cardiovascular disease were the two conditions that most commonly impacted on Indigenous peoples in the greater Rockhampton region (Figure 23). There was some discussion about the difference between Type I and II diabetes, and participants noted that they were aware that diabetes was particularly serious given that it could in turn impact on cardiovascular and renal health.

The adult group reported widely different perspectives regarding the importance of different healthy lifestyle practices (Figure 24). Approximately one-quarter of the group indicated that access to Aboriginal and Torres Strait Islander health services was the most important factor. In fact, when the items relating to ‘access to services’ were combined, these represented some 60% of the group. On discussion, the participants noted that self-management could have been included as an option, and that many of them would have picked ‘all of the above’, had it been listed.
Next, the participants were asked to report on access to regional health services and how well these suited their needs (and those of the Indigenous community more broadly). The group felt strongly that services were being well utilised, with almost 50% accessing the full range of services on offer in the region, and around 40% of the group agreeing that these services met their needs (Figure 25). As this contrasted markedly with the information that had already been recorded from the youth and health professional’s workshops, the group was invited to discuss this further. The group talked about how valuable access to services was for maintaining or improving their health: ‘this group is deadly’, ‘if everyone accessed, Aboriginal and Torres Strait Islander people would have better health’. They also noted that a strong community had formed around the Clinic itself (‘it’s passed on by word-of-mouth’), and people enjoyed visiting for not only the health services, but also the social interaction.

Notwithstanding this, the group was also able to talk about things they felt were missing from Indigenous health services in the region. The key themes that emerged from this discussion were:

- **Information:** allowing the Indigenous community to know what is on offer (for example, through Medical Local). There was support for more organised ways to spread this information (‘it needs to be broader than word of mouth’),
- **Accessibility:** this included themes such as
  - a culturally safe environment
  - the availability of transport (for example, from northside to southside)
  - access to specialists within the region (avoiding the need to travel away)
  - opening hours: where people with chronic illness are in employment, it is difficult to access services during business hours.
The group of participants where next asked about the ways in which they would prioritise investment for prevention of chronic health conditions in Aboriginal and/or Torres Strait Islander people. Over half of the group indicated that access to Indigenous healing treatments/services would be their foremost priority (Figure 26). There were no votes for transport services, despite this having been raised as an issue in the earlier discussions. However, participants noted that they felt that all of the listed option were important (however only one item could be chosen when using the clickers). The group discussion also touched on the importance of education, which had not been listed in the question: the participants felt that educating people about the symptoms and impact of chronic conditions was important, as well as ‘what’s out there to help’. The group also acknowledge the need to start education young (for example, healthy eating programs at schools). One participant raised the issue that it was important to think about the timeframes over which (government) investment was likely to be available, and then to prioritise spend accordingly.
Figure 26 Adult participant’s preferences regarding investment to prevent chronic health conditions in Aboriginal and/or Torres Strait Islander people.

The final two questions explored the adult participant’s attitudes and opinions on healthy lifestyle practices. There were mixed feelings about the types of incentives that might be useful in encouraging Indigenous adults to attend information sessions on chronic disease prevention (Figure 27). Some in the group noted that incentives were secondary ‘it’s self-motivation that gets me here’. Overwhelmingly, the participants noted that the Alma Street Clinic had provided them with a sense of trust and confidence, which they found extremely valuable. For example:

- ‘a lot of Indigenous people feel shy to go to a gym, but I would come here to go to a gym’;
- ‘I don’t like everyone looking at me, [but] here they look after you; people care, always a smile’;
- ‘...my first time here, I’m amazed, it’s like a social gathering’;
- ‘It’s good to talk to one another about what we’ve got [in terms of health conditions]’; and
- ‘You go away feeling good after being here’.

Figure 27 Adult participant’s preferences regarding incentives to attend information/education sessions about chronic disease prevention.
The last clicker question related to personal habits that were important for achieving and maintaining good health. The adult participants showed strong preferences for healthy eating and daily exercise, although they noted that this may be particular to those who attended the clinic (‘we are constantly told about what to eat ... you are what you eat!’).

![Clicker Results]

**Figure 28 Adult participant’s attitudes regarding key factors to achieve and retain good health. Participants were asked to select their preferred option for the ending to the sentence: The most important thing I can do to be healthy is...?**

Following the data collection exercise with the clickers, the adult group were able to spend some time on open discussion. The first theme that emerged was ‘what it meant to be healthy’, even for individuals who may have been diagnosed with a chronic condition(s). The participants noted that their concept of ‘health’ was multifaceted, including length of life but more particularly quality of life and a person’s (positive) mental outlook:

- ‘I might be old but I’m not over the hill, I’ve decided this is my year’
- ‘I’m in my 60s but it’s about me, grannies and great grannies’

The group again reiterated the importance of self-management and strong communication, which extended to telling their stories to family members: ‘...information for our children and grandchildren so they can be proactive’. There were concerns that modern lifestyles were contributing to poorer health outcomes in the coming generations, especially around sedentary work and activities:

- ‘kids playing those games all the time on X Box...I’ve put it away in our house’
- ‘energy drinks and smoking and sitting and sitting – it’s a serious issue this sitting all the time’.

The group were asked to consider what unique features the greater Rockhampton region may have in terms of health and health services. One participant noted that the region offers a good opportunity for future studies ‘we are a local people, we’re not transient. We’re not a huge population, and you can study it up’. Another queried the impact of local mining activity, around dust in the air and waterways, and more disposable incomes because of the mines leading to more
reliance on takeaway food. One participant pointed out that Rockhampton has an aging housing stock:

‘We have a lot of old homes here – a long time ago asbestos was used in these houses. I have four children with asthma. It concerns me watching my kids grow – and all have respiratory problems – we live in these old homes and [its] all I can think of’.

The discussion then moved to the availability of fresh produce; with participants speaking about the control that the large food retailers have over supply chains, and their concerns about chemicals in the foods (‘some cities have local markets – we don’t’).

The discussion concluded with a reiteration that the group felt strongly about the value of Medicare Local. In part, this was precipitated by news received earlier by the group, about the possible defunding of the clinic. The participants were worried about losing access to a service that they felt had provided them with excellent levels of service and the support they needed to live healthier lives.
4.4 Health Care Providers Workshop

The health care provider’s workshop explored a number of themes, with many items being similar to those posed at the Indigenous youth and Indigenous adult workshops. Approximately 19 people participated in the data collection exercise, however it should be noted that responses to each question were not mandatory, and some participants chose not to answer some items.

The cohort comprised representation from allied health, hospital, Aboriginal medical services and ancillary organisations, and with a diversity of professional roles amongst the group (Figure 29). Almost all organisations present were directly involved in service provision to Indigenous clients (Figure 30). The absence of general practitioners was noted, with some participants in the audience clarifying that they were hospital doctors rather than GPs. The facilitator queried the absence of GPs, and some discussion ensued as to how to raise more awareness of initiatives such as this research; including strategic use of existing communications such as the ‘Drift’ newsletter and existing local networks (e.g. the medical community, the university community).

Figure 29 Summary of health care provider participants by organisational type (top), professional role (bottom).
The participants were asked to indicate the chronic health condition that was responsible for the highest number of presentations to their service(s), by Aboriginal and/or Torres Strait Islander people. Whilst it is clear that the profile of clients varies with the type and nature of the service provider, participants indicated that diabetes was a key condition across the region (Figure 31). On discussion, it was acknowledged that many clients had mental health conditions, and that many more individuals are likely to remain undiagnosed. The participants felt that this overall profile was generally similar to other regional areas of Australia.

Participants were then asked to indicate levels of complex chronic conditions in their clients: here, the proportion varied by organisation, with approximately one-quarter of participants being unsure of the likely presentation rates of complex cases (Figure 32). However, on discussion, it was determined that this related to the client-provider relationship, with hospital doctors in particular having only short and/or on-off interactions with clients, which made it difficult to understand their full health profile.
Figure 32  Proportion of Aboriginal and/or Torres Strait Islander people presenting to health services with complex chronic conditions. Note: these data are workshop participant’s perceptions only, and have not been validated against client or organisational records.

Workshop participants were asked to share their thoughts on the most important aspect for supporting local Aboriginal and/or Torres Strait Islander people living with chronic health conditions. Approximately half of the participants indicated a preference for primary health care services that can deliver (Figure 33). On discussion, the health professionals indicated that primary health care starts in the community; empowering youth and adults with a preventative, holistic approach, including a focus on self-management. It was noted that primary health wasn’t something that could be adequately ‘fixed in hospitals’; and participants felt that there was a need to ‘include more Indigenous content in the curriculum...[creating] a place for both’.

Figure 33  Key aspects for support Aboriginal and/or Torres Strait Islander people living with chronic health conditions in the greater Rockhampton region. (Participants were asked to select their preferred choice from a list of options).

The participants were then asked questions relating to the accessibility and suitability of health services for Aboriginal and/or Torres Strait Islander people in the region. Almost all participants indicated that the level of access was ‘limited’ or ‘some’; and that the services had limited or only partial suitability for the local Indigenous community (Figure 34). One participant in the group queried how many Aboriginal and Torres Strait Islander peoples were resident in the region;
however the discussion largely revolved around the aspects of ‘suitability’ of the existing services. The key areas of focus included:

- cultural appropriateness: ‘Central Queensland doesn’t do Indigenous services well [although] Bidgerdii does an amazing job and needs to be expanded’;
- the need for multi-disciplinary, holistic and longitudinal care: ‘can’t do it in 15 minutes with a GP’ and ‘there’s not enough chronic health prevention’.
- System-wide difficulties, particularly around referrals and locally accessible services. Here, there was acknowledgement that specialist care generally meant referral to Brisbane; although Townsville and other centres may have capacity to offer treatment. There was also mention that referrals for services were difficult to obtain from GPs, which meant that unwell individuals were missing out, and that organisations were not seeing enough patronisation of their programs.

![Graph showing health professional's perspectives on Indigenous people's level of access to health services in the greater Rockhampton region (top) and how well the existing services meet their needs (bottom).]
The health professionals were then invited to discuss possible gaps in service provision across the region, in the context of chronic conditions in the Indigenous population. All but one participant agreed that gaps exist (Figure 35). On discussion, the key gaps appeared to relate to the themes of cultural appropriateness (or lack thereof), access to specialists and choice of treatment location, which had already been identified from the earlier questions. However, it was also noted that a significant gap existed in the area of adolescent and primary health, including service to schools as well as how to access those youth who were not participating in the school system. One participant also commented that there was the need to ‘work on a prevention model…promoting a multidisciplinary approach’.

![Figure 35](image)

Figure 35  Health professional’s perceptions about whether gaps in services exist for Aboriginal and/or Torres Strait Islander people living with chronic conditions.

On the question of how best to improve primary health care services, the participants voted strongly for educational/informational resources (Figure 36). However, more than half of the audience indicated that they would have selected ‘all of the above’, had that been one of the listed options. It was noted that timing and context was an important factor in delivering education and/or information; one participant noting that ‘the problem is getting people motivated to come in…when we did fishing and camping trips, we got lots of participants … sitting around the campfire [was the] best time to give information’. Participants also noted the importance of long-term funding consistency, noting that short-term investment windows by government were unhelpful as these resulted in the closure of well-run programs as funding dries up; and/or diversion of resources away as the organisation attempts to seek alternative funding options.
There was a diversity of opinions in the room regarding the best way to develop better models of care for Aboriginal and/or Torres Strait Islander people with chronic health conditions. As with the previous question, just over half of participants indicated that they would have selected ‘all of the above’ had this been available. Much of the discussion following this item was related to strong regional leadership, particularly where this withstood election cycles to create real and lasting change:

- ‘leaders in this region need to get some guts … make directives and make it happen’
- ‘I’m tired of who’s been elected … so much research is never used because of change’
- ‘it is vital to upskill the workforce – we need an effective workforce leader’.

There was also strong interest in mentoring and upskilling, including recognition and training for graduates, so that they were better equipped to deal with local conditions: ‘never learnt anything about Indigenous health – and was not exposed to it – but as a graduate I was given Woorabinda … I found that very challenging’.

Participants were invited to share their thoughts regarding any feedback that their service/organisation has received in relation to the care of Indigenous clients with chronic conditions.
A mix of both positive and negative feedback was apparent (Figure 38), although it was identified that formal mechanisms for feedback were not used by all organisations ‘no surveys, there’s no time or effort put into feedback’; whereas others reporting using annual surveys.

Figure 38 Health professional’s perceptions regarding the feedback their organisation receives regarding services for Aboriginal and/or Torres Strait Islander people living with chronic conditions. *Please note: many participants were prevented from answered this question due to premature shutdown of the voting system.

Next, the health professionals were asked for their thoughts regarding prioritisation of spend in order to best to support chronically ill Aboriginal and/or Torres Strait Islander people in the region. There was a diversity of views held (Figure 39), but there was a general consensus in the need to direct funds to ‘provide services on-the-ground’ and to tailor this to local need: ‘asking consumers what they would like and how they would like it’. Whilst cultural training was supported by some participant, another pointed out that ‘I don’t believe you can train people unless you immerse … there should be cultural humility – go on camping trips with Elders; immersion equals cultural competence’.
Data were collected from a sample of 18 health professionals. The respondents were asked to rank their top five priorities for addressing chronic disease among Aboriginal and Torres Strait Islander people. The results are shown in Figure 39. The most common priority was providing a culturally appropriate environment, followed by affordable medication, education resources, counselling, and cultural training of staff. A small number of respondents indicated other priorities.

The final question explored the health professional’s preferences in terms of attending training events that were specific to addressing issues of chronic disease within the regional Indigenous population. Guest speakers and interprofessional learning were popular (Figure 40), with some participants commenting: ‘multi-disciplinary teams all coming together and learning – it’s powerful … but it’s not here in CQ’. Others noted the availability of cultural awareness training through Queensland Health and via the Allied Health Clinic located on the CQUniversity campus, as well as online. A community of practice approach is used for mental health, where members work on case scenarios.

The open discussion that occurred after the final clicker question identified a number of useful areas for further exploration. These included the need for programs and services to be of a continuing nature (‘people are sick of pilots’); and training of Aboriginal and Torres Strait Islander people to provide the frontline services (‘having an Aboriginal face... it helps to bring people into the clinic easier’).
4.5 One-on-one interviews

The one-on-one interviews aimed to collect an in-depth ‘narrative’ of Aboriginal and Torres Strait Islander peoples’ perceptions of living with chronic health conditions, any concerns they may have about availability of support within the region, and their experiences of diagnoses, treatment and caring duties. Participants therefore included people who have lived experience of (their own) chronic health condition, carers, and those who have observed the journeys of local friends or family as they live with a chronic health condition. Interviewing these participants helped to understand the needs, experiences and perceptions of individuals living with chronic health condition/s and any concerns they may have about support within the region.

At the start of each interview, the participant was asked to give their definition of chronic health conditions. While some felt ‘it’s a condition you have for the rest of your life’, others said ‘it impacts your life for six months or more’, ‘it’s preventable’, ‘it requires ongoing treatment’ and ‘a lot of Indigenous families don’t understand chronic disease, they think it’s hereditary, “I’ve been born with this disease” they say’. Movingly, one participant quietly said, ‘It’s [pause], lately [pause] our people, and it’s a long term health condition’.

Participants were then asked what they knew about chronic health conditions in their family. ‘I know everything about my family conditions’ one participant said, while others shared that ‘we have a high presence of chronic conditions in our family...I’m a big believer that a lot of chronic conditions are hereditary’, ‘many people have multiple conditions and they all [can] live to a long age’ and ‘some know about it [the illness] and brush it away, some live with it and know they can get treatment’. Other participants said, ‘Dad’s whole family died from chronic illness, diabetes and high blood pressure’, ‘in my family and community there’s a lot of diabetes, heart disease and lung problems, it runs in generations, a cyclic effect’ and ‘My Uncle was diagnosed with diabetes, his toes went, then his legs, they used insulin, but he didn’t understand the management’.

The subsequent questions explored participants experience and perceptions of chronic health conditions particularly through the lens of help, education and information received about chronic health conditions, the services available, suggested improvements and a brief exploration of the use of, and/or the desire to seek, traditional healing treatments.

Eight major themes clustered around the central theme of ‘communication’ arose from analysis of the interviews – these being (1) communication to build knowledge, (2) local services, (3) preventative care (4) social determinants, (5) close the gap, (6) trust, (7) past knowledge and (8) traditional healing treatments (refer to Figure 41). Viewing these themes as a whole, it appears that many of the issues raised are linked to communication (see Figure 41). This contributed to an overlapping effect around the central theme of communication that emphasised the importance of strong, culturally appropriate communication.

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8 Seven of the ten participants had chronic health conditions including asthma, diabetes, heart disease and rheumatoid arthritis
4.5.1 Communication to build knowledge

Knowing what services were available, knowing how to interpret information, and knowing where to access information was a major issue for many participants, with comments such as:

- ‘I didn’t know there was an Aboriginal and Torres Strait Islander clinic in town’,
- ‘[People] get a list of goals and medications from the GP, they look at it and don’t know what its about’
- ‘[The information is] not broken down to people with chronic disease. A lot of my family has failed, all you hear is “I don’t know if I’m doing this right”’
- ‘I couldn’t find any information anywhere, I couldn’t find pamphlets at the doctors, nowhere’
- ‘There is a lack of information at the doctors and when they leave the doctors’

Language was a barrier for many. Some of the language around diabetes for example, ‘[people] don’t understand’. Explanations given are broad, ‘they do not understand that medication is important or how to manage Type 1 and Type 2 diabetes’. Other issues with language included:

- ‘When [people] go to the doctor they get told “you’ve got diabetes” and some of the language around diabetes they don’t understand, no step-by-step explanation is given’
- ‘Layman’s terms need to be used to relay information, not medical jargon’
- ‘It’s better off coming from one-on-one talks instead of a brochure’
- ‘[Information] is well explained at the one-on-one home visits’
- ‘Bulk billing doesn’t mean there’s going to be a bill’; the use of the word ‘bill’ is confusing and ambiguous
- ‘Aboriginal people are visual learners...’
- ‘[Indigenous people] like looking at pictures rather than reading words’
• ‘I put Indigenous posters around my workplace. They are like hens teeth now’
• ‘There’s a really good old poster of a pregnant woman. The baby inside her has got a smoke in one hand and a can in the other. No words are needed to say what goes inside affects the baby’
• ‘The stereotyping of Indigenous people smoking and drinking, you are constantly bombarded with the question “Do you smoke? Do you drink?”...it’s how the system is setup, it’s on the forms’.

Consistent with the data collected during the workshops, the interviews revealed that much of the information about the services are available in the greater Rockhampton region is communicated via word-of-mouth. ‘People don’t know, it’s about educating’ one participant felt. ‘It’s about access, awareness and education’ another remarked. One participant felt education should ‘start with kids in school, like [the] Deadly Ears program’. One participant explained that the extended family needs to be included in the education process. Currently, while the participant and their family understands preventative measures for chronic health conditions, their extended family does not, and the participant’s family is impacted by the unhealthy lifestyle of their extended family.

One participant said ‘I went a few years without being diagnosed’ another said, ‘In the beginning they probably didn’t seek help because they didn’t have the education’.

Many participants iterated that better communication is a primary concern. Their suggestions included:

• Marketing of what is available needs to reach those who need it
• Extensive marketing of what is available in the Rockhampton region that includes comprehensible language
• Better advertising of the organisations and groups already operating in the Rockhampton region, for example advertising on radio 4US
• Improved education processes about chronic health conditions

Following is a summary of the communication themes that emerged from the one-on-one interviews (refer Figure 42).
4.5.2 Local services

Issues around local services and medical staff surfaced particularly when the final question *Is there anything else you would like to add?* was asked. ‘Doctors and nurses ...don’t understand Aboriginal and Torres Strait Islander differences...A lot is around understanding the two different cultures and what’s appropriate when interacting with people...they aren’t ‘aware’ of their ‘mistakes’ and the effect they have on people’. ‘It fails when they don’t understand the history of Aboriginal and Torres Strait Islander people’.

Long waits for doctors appointments were highlighted with one participant saying that it was ‘sometimes hard to get an appointment with my medical centre’. Another said ‘I’d rather go to Victoria and get it [the surgery] right. We’ve had some negative outcomes with hip transplants in this area’, and ‘if you know where to go, the services are there [in Rockhampton]’.

One participant shared ‘they sent me to [Allied Health] at CQU first. I went out there, looked around and thought, what’s this? I was the only Indigenous person there. It was no good for me, and it was a long way to get there...You feel right when an Indigenous person is there, you feel like they’re looking after you’. Another participant felt the same way, ‘Allied Health at CQU, it doesn’t feel comfortable being in the university grounds and the people were culturally unaware’.

Travel was a major concern raised by all participants with particular attention paid to cultural awareness; ‘With travel, if done culturally appropriately... [will] make the client happy or else they won’t go to their appointment. Happy equals comfort and feeling safe and well looked after’.

Many participants spoke about the local AMS:

- ‘AMSSs need to improve; some people won’t go because they fear that people working there can access their medical records and personal information’
- ‘About 40% of the Indigenous community use AMSs [in the Rockhampton region] others follow the GP they like from practice to practice’
• ‘They go on about cultural appropriateness and environment. You can have a painting on the wall, but it’s about being comfortable when [you] walk in, not a lot of AMSs have this’
• ‘If someone doesn’t want to access the practice [AMS] they shouldn’t have to. Sixty percent of the community doesn’t access [it]. It’s a lot to do with trust and who’s there, if they’re fighting with someone who works there, those people can access their personal records and that’s the problem with AMSs’
• ‘…they have an eye specialist at Bidgerdii that seems to be going well. We’ve got everything we need through to aged care and Bidgedii and Binbi Wadja directs us in the right place’
• ‘It would be good if specialists went to Bidgerdii on the northside’
• ‘The doctors at Bidgerdii are fine, it’s their practice I wasn’t happy with’
• ‘Bidgerdii is excellent’

A participant who worked in the chronic health field in a multi-disciplinary clinic [Binbi Wadja] with Aboriginal and Torres Strait Islander people said ‘having all these clinicians in one place at the one time...the clinicians can break [the information] down and let them know “you ate those tarts and your sugar was up”, it keeps them [clients] honest’.

Many participants considered that almost everything they require for chronic health care is available in Rockhampton, except for cancer treatments and radiation, an asthma clinic, eye specialists and a rehabilitation unit, particularly post-surgery. Several mentioned dental services ‘need to come back, and not [be linked to] a health care card’.

In summary, approximately seven key themes emerged around local service issues during the one-on-one interviews (refer Figure 43).

Figure 43 Summary of local services issues arising from one-on-one interviews
4.5.3 Preventative care

Issues around preventative care emerged from the one-on-one interviews with one participant saying, ‘the majority of my family is overweight’ and another, ‘we don’t get enough exercise...there’s not enough education about that sort of thing’. Several participants felt ‘we need to lose weight, [and] exercise more’. Isolation was also an issue with several participants saying they knew ‘many people in the community that do not have support or seek help and they are the ones who are suffering’. Several participants also felt that Aboriginal and Torres Strait Islander people in ‘our rural areas miss out’.

One participant felt ‘men’s health workshops [and] a yarning group’ would be useful in the Rockhampton region, particularly if they had ‘high profile health person’ who presented on men’s health issues, and who attendees could then ‘bounce questions off and they’ve got the answers, not “I’ll get back to you on that”’.

Several participants also noted that ‘once the chronic health condition is being managed, people live reasonably happy, contented lives’.

Following is a summary of key themes that emerged around preventative care issues during the one-on-one interviews (refer Figure 44).

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**Figure 44 Summary of preventative care issues arising from one-on-one interviews**

4.5.4 Social determinants

Social determinants, also mentioned in the workshops, were likewise an issue that emerged from the one-on-one interviews with ‘housing’ a major concern for some. One older participant felt ‘a two bedroom, lowset unit’ would be particularly helpful as opposed to the current abode that is an older highset home.

Travel is possibly the most mentioned problem, with better ‘access to transport’ and improved ‘transport [for] Mt Morgan, Gracemere and Yeppoon’ identified as pressing issues, particularly with late medical appointments in Rockhampton and most bus runs finishing at around 7.30pm.
The cost of living was also mentioned particularly in relation to food prices; ‘it’s easy to say go on a diet to pre-diabetics, but can they afford the food?’

Inability to afford medical services was touched upon by several participants who explained ‘if there is a cost involved, people will not go’.

One participant, who received free podiatrist visits, shared ‘I’ve got shoes now [that] I couldn’t afford and my feet are much better now’.

An older participant living with chronic health conditions expressed the desire for in-home help, particularly around the yard; ‘I’ve still got rubbish under my house from the floods’. The participant did not know where to go to ask for such help.

Figure 45 illustrates key themes surrounding social determinants that emerged during the one-on-one interviews (refer Figure 45).

![Figure 45 Summary of social determinants emerging from one-on-one interviews](image)

### 4.5.5 Close the gap

Issues around the ‘Close the Gap’ policy emerged during the one-on-one interviews. One participant felt ‘they don’t take social determinants into account, that’s where they need front line workers...but there’s no prevention, they wait for intervention. Everyone learns from everybody, it’s transgenerational. They go back home and everyone else is doing it. You need to educate the whole family. **They’ll never close the gap** because of this stuff and that’s how I see it from being in my community’. When asked ‘what will close the gap?’ the participant explained, ‘more funding to organisations that can have front line workers and have right role descriptions, train the right people. And consistency of funding and programs’.

One requirement mentioned multiple times was the ‘... need [for] a one-stop-shop for all health care needs, it’s vital’ as was the necessity for funding to maintain health care services and programs. Another participant said ‘hopefully we can close the gap through education’.
Figure 46 presents the issues around the ‘Close the Gap’ policy that emerged during the one-on-one interviews.

4.5.6 Trust

Trust was mentioned as a major issue, particularly for older people ‘to trust doctors’ and organisations. One participant explained ‘they [older people with chronic health conditions] seek other medications first, like Gumbi Gumbi before going to a doctor. A lot just don’t trust doctors, a lot of our older people are from the stolen generation, with all the different policies [that] affect[ed] them, they have no trust of doctors either’.

One participant said, ‘my Grandfather lived off Gumbi Gumbi until he died, he didn’t trust medication’ and another participant shared that ‘a lot in my family will not go for Western medicine, white man’s drug’s. My in-laws use Gumbi Gumbi. My family are into Noni juice’.

These issues around trust emerged during the one-on-one interviews and are illustrated in Figure 47.
4.5.7 Past knowledge
Several participants said that ‘going back in the day’, ‘they [our predecessors] were healthy people, their medicine worked, they survived’. Another participant felt ‘DNA has memeory…we need to eat what [our] ancesetors ate…if you go through past photos, the men looked fit, well, cut and athletic’, and ‘traditional food has a bearing…if you eat what your ancestors ate, your health would be a lot better’.

In relation to past food and plants, one participant said, ‘old people talk about the plants they used to use, but knowing the processes is difficult to know now. Our old people are passing away and information is hard to get.’ Another participant felt, ‘we’re losing touch with these things. In my Dad’s day they knew people who knew how to do this [traditional healing]. Bring it back’. One participant said ‘the old ladies used to boil onions for ear aches and used cold tea for eyes’.

Past knowledge and the desire to maintain this knowledge particularly about diet, health, plants and foods emerged as a key theme during the one-on-one interviews (refer Figure 47).

4.5.8 Traditional healing
Almost all participants said they would try traditional healing methods, particularly the younger participants, with comments such as, ‘most likely [pause]. Absolutely ‘ and ‘I’d have a go, have a listen’. Some felt the knowledge is lost now, and one participant was cautious and avoided the issue saying it (knowledge of traditional healing) wasn’t available in Queensland. Other comments by participants included:

- ‘Those with chronic disease seek other medication first, like Gumbi Gumbi before going to a doctor’
- ‘Gumbi Gumbi, my family swears by it. And a good feed of kangaroo and porcupine now and then’
- ‘I know people who swear by Gumbi Gumbi, for headaches, wounds, to bathe in, for any ailment’
- ‘Gumbi Gumbi, I was brought up with it. So I wouldn’t use it, I’m well assimilated [laughter]’
• ‘I’d try anything if it was going to heal me’
• ‘Growing up we used Gumbi Gumbi. The majority are on Gumbi Gumbi. A lot resist medication because back in the day their parents used bush medicine and didn’t seek treatment’
• ‘Gumbi Gumbi is big in this area, many people use it, many were brought up with it — a teaspoon once a week, it was added to their baths [as well]’

Some participants thought Gumbi Gumbi could be developed into other products like skin cream. Most participants did not want to leave the discussion about traditional healing. It seemed a disjoint to enter back into the regular research questions as listed. Many participants said ‘it was good to talk about these issues’.

Following is a summary of themes surrounding traditional healing that emerged during the one-on-one interviews (refer Figure 49).

![Figure 49 Summary of traditional healing themes emerging from one-on-one interviews](image-url)
5. Discussion

5.1 Lived experiences in the Greater Rockhampton Region

Participants in the research project have had the opportunity to have their voices heard, and to provide a legacy for others who suffer from chronic disease/s. In this way, their contributions count to something that is lasting and to something that has the capacity to improve the lives of other Indigenous Australians.

A key aspect of the lived experience is the disjunction that is being experienced at the point of GP referral. GPs are the frontline primary care workers that attend to presenting patients, and according to the participants interviewed, this is where communication and understanding can and does break down.

5.2 Communication

A major outcome of this project was the need for greater communication in a culturally appropriate manner to ensure the community is aware of information and services available. The research has brought forward issues that may be important when designing and implementing information based brochures, posters, and services for Aboriginal and Torres Strait Islander people, when planning health services and disseminating information to GPs, when disseminating information about chronic health conditions, prevention and services to Aboriginal and Torres Strait Islander people as well as the importance of alternative medicine in Aboriginal and Torres Strait Islander culture.

5.3 Closing the Gap

This research was undertaken to assist in developing solutions for improved life expectancy of Aboriginal and/or Torres Strait Islander people in the Greater Rockhampton Region. In particular, this includes a focus on ‘Closing the Gap’ on Indigenous health and working towards equity policy, research and practice.

It is intended that the broader community benefit from the research outcomes through:

- improved regional knowledge and awareness of the impact of chronic disease
- the generation of information that informs regionally-relevant approaches to chronic disease prevention and care and management of Indigenous people with chronic disease/s
- the generation of information that informs teaching and learning practices used in relevant higher education and/or vocational education settings within Central Queensland region. This may include innovation in the areas of Cert IV for Aged Care, Disability support, Indigenous health workers, Allied Health, Community Health and other areas.
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