Improving diabetes care and management in Torres Strait remote primary health care settings

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Statement on Access

I, the undersigned, the author of this thesis, which is a partial requirement for the degree of Doctor of Public Health, understand that James Cook University will make it available for use within the university library and, via the Australian Digital Theses network, for use elsewhere.

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30 March 2017

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Name

Statement on Sources

The Material presented in this thesis titled "Improving Diabetes Care and Management in Torres Strait Remote Primary Health Care Settings" is my work and has not been submitted for the award of any other degree or diploma in any other university or institution or tertiary education. To the best of my knowledge, this Thesis contains no material previously published or written by another person, except where due reference is made in the text.

30 March 2017

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Statement of the Contribution of Others

Nature of Assistance	Contribution	Names, Affiliations of Co-Contributors
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Abstract

Background: Torres Strait Islanders (TSI) have the highest prevalence of Type 2 diabetes in Australia with about a third of the adult population affected; the incidence of Type 2 diabetes and other co-morbid conditions are also extremely high at around 3%. A review in 2005 noted that newer diabetes cases were younger, more obese and had poorer glycaemic control compared to 6 years previously. Clinicians report anecdotally that many patients are prescribed insulin therapy; however, it is unknown if patients are collecting their medication from local primary health care centres. Diabetes is associated with significant depression, which can result in poorer clinical outcomes, including increased mortality. Little is known about the prevalence of depression among TSI adults with diabetes. Models of chronic disease management in the Torres Strait region remains an ongoing discussion that supports better self-management of diabetes amongst patients.

Study Aims: The overall aim of this thesis is to provide epidemiological evidence to support the development of community level interventions to address the most important risk factors associated with the health of Torres Strait Islanders with Type 2 diabetes. 1. Review patient level factors on behavioural aspects of diabetes management and care including psychological insulin resistance and depression. 2. Review health service factors that impact on diabetes management and care.

Methods / Design: Study 1: 29/197 adults with poorly controlled diabetes who have refused insulin treatment, were interviewed using validated instruments Insulin Treatment Appraisal Scale (ITAS) and Barriers to Insulin Treatment Questionnaire (BITQ). Study 2: A descriptive cross-sectional survey in 2013 and 2014, Interviews with 188/197 adults with diabetes in five remote Torres Strait Islands using the Patient Health Questionnaire (PHQ)-9. Study 3: A Retrospective clustered cohort study of the impact of the intervention on care processes, intermediate clinical outcomes in 285 adults with known diabetes. At baseline 197 participants from five remote Torres Strait Island communities (mostly the Eastern group of Islands) consented to be enrolled in the survey. A

further 88 records from the western group of islands were audited from 2012 - 2015 and serves as a comparator group

Target population: Adults diagnosed with Type 2 diabetes located in the remote Island communities of the Torres Strait region with primary health care services provided by Queensland Health.

Results: Study 1: Thirty- four percent (n=197) had poor glycaemic control. Compared to those with HbA1c ≥8.5% and taking insulin (n=37), the 29 insulin-naïve participants were more obese, more likely to smoke and drink alcohol, have lower mean HbA1c and fewer years with diabetes. Among the insulin-naïve group, those reporting higher 'barriers' (BITQ scores) were older and with lower formal education than those reporting fewer barriers. TSI participants consistently scored low on 'knowledge' items in the ITAS, especially those which would guide insulin initiation (insulin improves glucose control and prevents complications).

Study 2: Ninety – five percent (n=197) completed PHQ-9 interviews. The median PHQ-9 score was 5.5 (IQR 0-7); 42% of respondents scored 0-4 (none-minimal), 46% scored 5-9 (mild) and 12% scored10+ (moderate –severe). Mean Hba1c was 8.3% (67.4 mmol). HbA1c was not related to PHQ-9 scores (β=0.20, P = 0.323), however exercise in hours (β =0.34, P < 0.001) and screen time in hours (β = 0.11, P < 0.001) were significant predictors of depression after adjusting for other study variables.

Study 3: At baseline, overall (n=285), 61% were women, 75% were aged over 50, 67% were obese (Body Mass Index (BMI), higher in the comparator group), 65% were poorly controlled (Hba1c>8.5%) and 18% were smokers (lower in comparator group). At baseline (2012) GP management plans (GPMP) and team care arrangements (TCA) were more likely to be completed in the eastern group 93% vs. 39% with 90% referred to a dietician, diabetes educator or podiatrist. However, in 2015 a decrease in the GPMP from 93% vs. 20% in the eastern group. It appeared that participants in the eastern group had better glycaemic control than those in the western group (34% had hba1c> 8.5%

compared to 39% in the eastern group) and this difference persisted through to 2015.

Conclusion: Improving patient level factors on behavioural characteristics of diabetes care requires better communication between service providers and clients, taking consideration of local cultural contexts and beliefs. Simple health promotion activities could improve mental health and general well-being in this population. Understanding patient behaviour can assist service providers to deliver appropriate service delivery that involves clients' input. Overall, patients with Type 2 diabetes are hesitant to commence insulin therapy, mild depression scores were evident that do not appear to have an effect on glycaemic control. However, care planning, referrals, and other clinical measures important to diabetes care, and actual numbers of consultations appeared to decline dramatically between 2012 and 2015 in all sites. This suggests that a more systematic approach to population-level diabetes care is required.

List of Abbreviations

Acronym	Name
BITQ	Barriers to Insulin Treatment Questionnaire
BMI	Body Mass Index
GPMP	GP Management Plan
Hba1c	Glycosylated Haemoglobin Concentration
HHS	Hospital and Health Service
ITAS	Insulin Treatment Appraisal Scale
NGSP	National Glycohaemoglobin Standardization Program
NHMRC	National Health & Medical Research Council
PIR	Psychological Insulin Resistance
SI	Systeme International
TCA	Team Care Arrangement
TCHHS	Torres and Cape Hospital and Health Service
TSI	Torres Strait Islanders

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1.1 Thesis Overview

The Doctor of Public Health Degree is a professional doctorate which differs from a "traditional" doctoral thesis. This thesis comprises of three studies that come together to demonstrate the overall competence in the public health discipline. The structure of this thesis is also non-traditional as this document demonstrates a professional doctorate for graduates with professional experience in a range of public health areas rather than a deep dissertation with a narrow focus. The research component comprises two-thirds of the degree; three studies undertaken, publications, and the elements outlined in the course structure of the Doctor of Public Health degree at James Cook University in 2012 (see table 1).

Table 1.1
Doctor of Public Health Course Structure

Component (code)	Study Units
Doctor of Public Health Thesis (PD7219: 48)	48
Doctoral Conference Presentations (TM6015)	6
Extended Doctoral Attachment (TM6014)	9
Credit Points – Previous studies	9
Total	**72 units**

This thesis is submitted containing published materials in agreement with James Cook University Higher Degree Research Thesis Format Guidelines clause 10. The contribution of each author to the publication is provided in a table outlined in Appendix A. Chapter 1 provides a background to the chapters, a contextual description of the Torres Strait Region, The Torres and Cape Hospital and Health Service (TCHHS) and the eight study sites (five Intervention sites and three control sites). A brief description of the life

expectancy gap of Aboriginal and Torres Strait Islanders compared to non-Indigenous Australians is also included along with an overview of depression and diabetes, psychological insulin resistance (PIR) and workflow.

The body of the thesis is presented in six chapters. Chapter 2 a scoping review focused on Australian studies relating to diabetes management in remote Torres Strait Islander communities. Chapters 3, 4, 5 and 6 describe five published papers deriving from the field research. Chapter 7 is an unpublished paper also deriving from the overall research.

Chapter 3 outlines the challenges faced by Remote Area Nurses in effectively managing the care of Torres Strait Islanders living in the Torres Strait region and summarises some of the past and present interventions implemented to improve the management of diabetes in the Torres Strait Islands. Chapter 4 is a short report of all the diabetes cases in the five intervention sites that were recruited into the cohort study. Chapter 5 explores self-reported knowledge and attitudes to insulin treatment among those participants recruited in Study one. Chapter 6 examines the association between self-reported depression, socioeconomic, behavioural, and clinical indicators amongst all participants recruited in the study. Chapter 7 describes demographics, care processes, intermediate clinical outcomes and other clinical measures important to diabetes care in the overall cohort during 2012 -2015.

Chapter 8 is an overview of Conference Presentations presented at National and International conferences as a requirement outlined in the Doctor of Public Health Degree (TM6015). These presentations complement the published papers discussed above. This chapter also the outlines the international knowledge exchange and potential international collaboration as part of the Extended Doctoral Attachment (TM6014).

Chapter 9 consolidates Chapters 4, 5, 6 and 7 and outlines the results of study one, two and three in the context of the scoping review. This section also includes a reflection of the overall research, strengths and limitations of this thesis and concludes by suggesting directions for further research.

1.2 Introduction / Background

The overall aim of this thesis is to provide epidemiological evidence to support the development of community level interventions to address some of the most important risk factors associated with the health of Torres Strait Islanders with Type 2 diabetes. The first aim is to review patient level factors, specifically the behavioural aspects of diabetes management including depression and psychological insulin resistance amongst Torres Strait Islanders with Type 2 diabetes. The second aim is to review health service factors that impact on diabetes care and management in remote Torres Strait Primary Health Centres (see figure 1 –research studies).

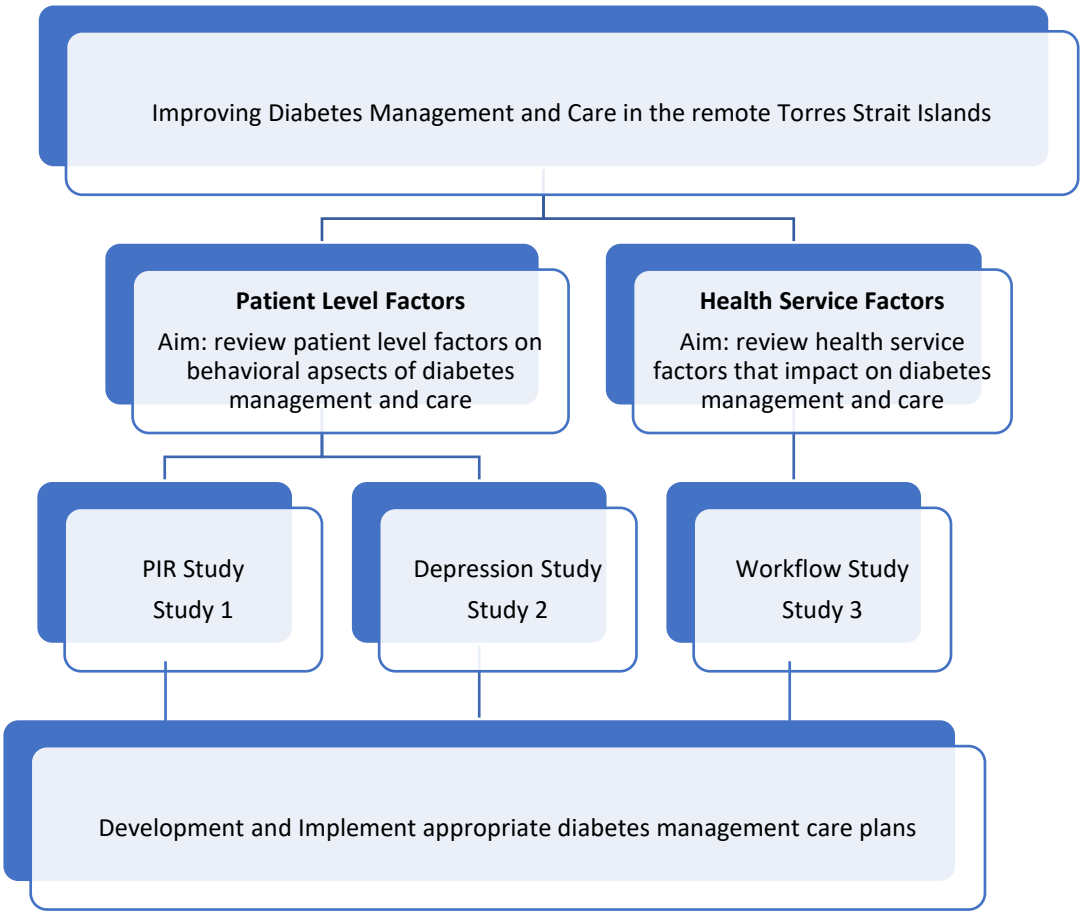

Figure 1.1 Research Studies

The Torres Strait is a unique region of Queensland, Australia; named after a Spanish navigator Luis Vas de Torres, who sailed through the Strait in 1606 [1]. The Torres Strait lies between the northernmost point of Cape York Peninsula, Queensland and South of the Western Province of Papua New Guinea with an

estimated population of 15,000 in 2011 [2]. Local Australians who identify as Torres Strait Islander mostly inhabit this region.

Torres Strait Islanders are historically, culturally and ethnically distinct from Aboriginal Australians [3] However, researchers and government agencies combine the two distinct Indigenous populations, mostly referenced as Aboriginal and/ or Torres Strait Islander. The early 1960's saw over 50% of Torres Strait Islanders migrate to the mainland of Queensland seeking better living conditions, health, education and employment opportunities. Mainland Torres Strait Islanders continued to live in mainland Australia, the men seeking employment within the Queensland, New South Wales and Western Australia Railway in the early 70's [4]. In 2011, over 42,000 Torres Strait Islanders resided on the mainland particularly Townsville and Cairns; however, over 40% still commute between mainland Australia and the Torres Strait region [5].

1.2.1 The Torres Strait Islands

The scattered Islands of the Torres Strait have been inhabited for over 2,800 years, however, archaeologists may find earlier evidence in the near future [2]. The islands and their surroundings waters and reefs provide a highly diverse set of land and marine ecosystems with many rare or unique species. The Islands are grouped into five clusters (see figure 2): (1) Eastern Island - Mer (Murray Island), Erub (Darnley Island), Ugar (Stephen Island) (2) Central Islands– Masig (York Island), Poruma (Coconut Island), Iama (Yam Island), Warraber Island (3) Top Western – Saibai Island, Boigu Island, Dauan Island (4) Near Western – Mabuiag Island, Moa Island (Kubin Village & St Pauls Community), Badu Island (5) Inner Islands - Thursday Island, Horn Island and Prince of Wales Island.

1.2.2 Study Sites

Eight study sites are described throughout this thesis, five intervention sites, and three control sites. The five intervention sites include: Mer, Erub, Ugar, Saibai and Masig Islands (Figure 1.2). The three control sites include: Boigu Island, Mabuiag Island and St Pauls Community (Moa Island) (Figure 1.2).

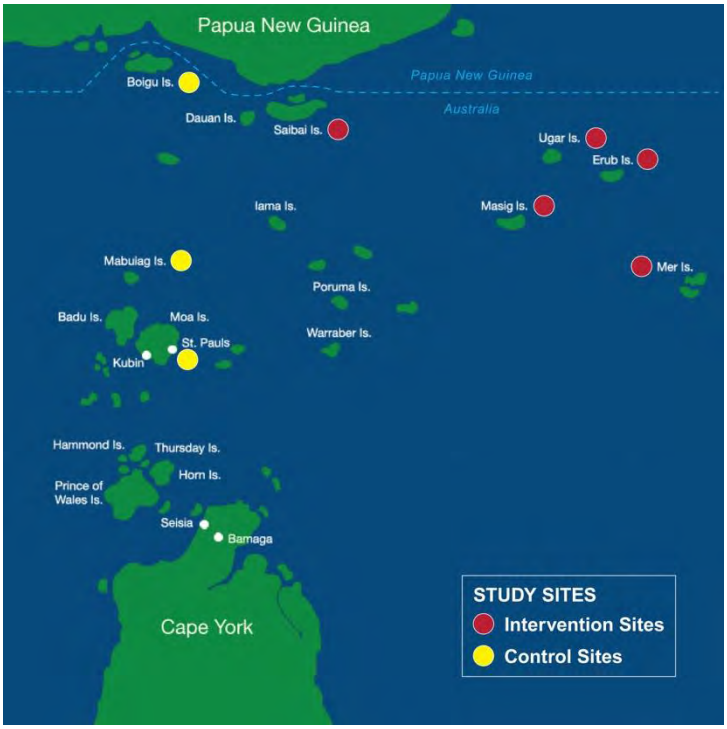

Figure 1.2 Torres Strait region and study sites

The Torres Strait Island Regional Council governs these islands; the council consists of 15 divisions, each of which is represented by one councilor, with a mayor being elected by the entire region. The inner islands (Thursday Island, Horn Island, Prince of Wales and Hammond Island) have a separate council, The Torres Shire Council, with a separate mayor being elected. The Torres and Cape Hospital Health Service provide health care to these communities via the local Primary Health Care Centres and two hospitals at Thursday Island and Bamaga.

1.2.3 Torres and Cape Hospital and Health Service

The Torres and Cape Hospital and Health Service (TCHHS) is the most northerly Queensland Hospital and Health Service (HHS) and covers over 158,000km^2 (see Figure 1.3) The TCHHS is one of Australia's largest health service providers to Aboriginal and Torres Strait Islander peoples with over 60% of the service area population identifying as Aboriginal and/or Torres Strait Islander [6]

Figure 1.3 Torres and Cape Hospital and Health Service Footprint

The TCHHS comprises of 31 primary health care centres, two hospitals located at Thursday Island and Bamaga, a multi-purpose health service at Cooktown and an integrated health service at Weipa.

In December 2013, it was publicly announced that two of these Hospital and Health Services – Cape York and Torres Strait-Northern Peninsula – were to be amalgamated. Due to their small size, neither Cape York nor Torres Strait–Northern Peninsula HHS had the critical mass for efficient stand-alone administration. On July 01st 2014 the two HHS became the Torres and Cape

Hospital and Health Service. Therefore, the two studies mentioned in this thesis commenced under the Torres Strait – Northern Peninsula Hospital and Health Service in 2012, later in 2014 under the entity "The Torres and Cape Hospital and Health Service [7].

1.2.3.1 Northern Sector – Torres and Cape Hospital and Health Service

Northern Sector – Torres and Cape Hospital and Health Service formally known as the Torres Strait and Northern Peninsula Area Hospital and Health Service extends from the tip of Cape York Peninsula north of the active international border between Australia and Papua New Guinea. This region is an extremely remote area – Accessibility / Remoteness Index of Australia scores 15+. Many challenges are faced by the health service due to geographical isolation, which includes the attraction and retention of staff, and climate. Service delivery in this region is underpinned by the Torres Model of Enhanced Primary Health Care, which focuses on primary prevention, early detection and intervention, health promotion and protection, community development and self-determination [8]

1.2.4 Life Expectancy Gap

Aboriginal and Torres Strait Islander people made up 3% of the total Australian population in 2011, 6% (n=38,100) identified as Torres Strait Islanders and 4% (25,600) identified as both Aboriginal and Torres Strait Islander [9] Chronic Disease accounts for more than 60% of the life expectancy gap for Aboriginal and Torres Strait Islanders, much of which is preventable [10].

Despite the small representation in the Australian population, Aboriginal and Torres Strait Islanders are much more likely to die before the age of 80 years compared to non – Indigenous people [11] The Australian Bureau of Statistics reported a 10.6-year life expectancy gap between Aboriginal and Torres Strait Islanders and non-Indigenous boys and 9.4-year life expectancy gap between Aboriginal and Torres Strait Islander girls born between 2010 and 2012 [9].

A recent report by the Primary Health Network – Northern Queensland in 2016 confirmed life expectancy gap between Torres Strait Islanders in the remote

outer islands of the Torres Strait and the average Queenslander. The life expectancy in the Torres and Cape region is on average 12 years less than the state of Queensland. Female Torres Strait Islanders averaged 70 years' life expectancy versus 84 years for Queenslanders and male's 65 years vs. 79.1 years [12]. Community members and health professional's need to work collaboratively to improve health outcomes of Torres Strait Islanders in order to minimise this life expectancy gap.

1.2.5 Health Care in Remote Communities of Australia

Over recent years the health of Aboriginal and Torres Strait Islanders has improved [13] however, it remains an ongoing challenge for many health professionals. Patients, their families and also health service providers face many challenges especially those living in remote areas of Australia. Environmental or geographical factors including travel distance to access health services or any government agencies can be a costly and time-consuming experience to those communities in remote areas [14]. Social and emotional wellbeing have escalated in remote communities. contributing to the existing health concerns.

Patients living in remote communities have higher rates of ill health and mortality compared to those living in larger cities [15]. One – fifth of the Aboriginal and Torres Strait Islander population live in remote and very remote areas [13]. Poorly controlled circulatory disease, endocrine, metabolic and nutritional disorders (particularly diabetes) were the biggest contributors to the gap in death rates between Aboriginal and Torres Strait Islander and non –Indigenous Australians. Aboriginal and Torres Strait Islanders were five times as likely as non – Indigenous Australians to die from endocrine, nutritional and metabolic conditions, such as diabetes [10]. The limited health care services, employment opportunities, and increased mental health issues, may explain some of the issues and poor health that Aboriginal and Torres Strait Islanders are confronting in remote areas.

1.2.6 Diabetes - Aboriginal and Torres Strait Islander Australians

Aboriginal and Torres Strait Islanders are reported to have the fourth highest rate of diabetes in the world. It is estimated that between 10-30% of Aboriginal and Torres Strait islanders have Type 2 diabetes. Diabetes rate in Torres & Cape region is four times higher than that of Queensland. Almost two in three people in the Torres and Cape region are overweight or obese. Poorly managed diabetes represents a serious public health problem for Aboriginal and Torres Strait Islanders [16]. The complications associated with poorly controlled diabetes remains an ongoing and challenging problem for patients and health services. These challenges can impact on better self-management for patients with Type 2 diabetes. The estimated prevalence of diabetes based on self-reported data among Aboriginal and Torres Strait Islanders ranges from 8.6% to 11.1% based on biomedical data [17]. The factors that contribute to the high prevalence of diabetes among this population include a combination of broad historical, social, cultural as well as proximal health risk factors [18]. Aboriginal and Torres Strait Islanders have an increased risk of developing diabetes, particularly Type 2 diabetes, from some behavioural and biomedical risk factors including physical inactivity, poor diet, tobacco smoking, being overweight or obese, high blood pressure and high blood cholesterol [16]. Overall the leading cause of death in the Torres and Cape region are heart disease and Cancer. Diabetes research in Torres Strait region is described in detailed in chapter three and throughout the thesis to avoid repetition.

There are three common types of diabetes, Type 1, Type 2 and gestational diabetes. Type 1 is an autoimmune condition that is characterised by hyperglycemia resulting from the body's inability to produce insulin. Type 1 diabetes is mostly diagnosed in childhood and adolescence and is relatively uncommon in the Aboriginal and Torres Strait Islander population [19]. Type 2 diabetes is characterised by hyperglycemia due to insulin resistance and/or deficiency in insulin production. This kind of diabetes is usually diagnosed in adulthood; however, there is an increase in children and adolescents in the Torres Strait region and more predominant in Aboriginal and Torres Strait Islander communities being diagnosed with Type 2 diabetes [20]. The third form of diabetes is known as Gestational diabetes, caused by placental hormones

that block the action of insulin, leading to insulin resistance and high blood sugar levels in pregnant women not previously diagnosed with other forms of diabetes. Gestational diabetes is common in Aboriginal and Torres Strait women. It usually disappears after the baby is born, although it puts the mother at increased risk later in life of developing Type 2 diabetes and increases the risk of obesity and diabetes in the offspring [21].

1.2.7 Depression and Diabetes

Research shows that living with a chronic disease like diabetes doubles the risk of developing depression [22]. Making decisions every day about how to best manage this complex condition can also contribute to increased risk of depression. Those patients who are diagnosed with diabetes are always reminded of the risk of developing complications from poorly managed diabetes. This can be confronting and contribute to the risk of developing depression. [23]

Patients who suffer depression, over time, may find everyday tasks such as managing diabetes difficult. Maintaining a healthy diet, physical activity regime, ongoing medications and blood testing can be daunting to many patients with diabetes [24]. The link between depression and diabetes amongst Torres Strait Islanders has not been established. This link is important to understand those patients who reside in the Torres Strait region attitudes towards their overall diabetes management and whether depression contributes to poor glycaemic control.

1.2.8 Psychological Insulin Resistance

Psychological insulin resistance or PIR is a syndrome that has been termed by researchers when patients or clinicians resist initiating insulin therapy [25]. Psychological insulin resistance occurs on several levels which also includes emotional (e.g., anxiety about the expected impact on daily life, depression or guilt associated with needing insulin); cognitive (e.g., distorted beliefs about insulin treatment); behavioural (e.g. unpleasant negative consequences such as pain, bruising, hypoglycemia, weight gain); social (e.g., feeling stigmatised); and relational (influencing factors from the medical health team) [26]. These

barriers lead to reduced uptake and irregular use of insulin by many clients with Type 2 diabetes, resulting in poor glycaemic control, and an increase in avoidable complications. McDermott study [27] identified only 16% (n=921) of Torres Strait Islanders were prescribed insulin therapy, even though they had a mean HbA1c of 9%. This may suggest PIR is evident and impacts on decision making. The development of a deeper understanding of the barriers to insulin uptake will assist researchers and clinicians to develop more effective strategies to help clients overcome the obstacles and as a consequence potentially result in improved patient outcomes. For example, by developing an understanding of the barriers linked to insulin use, health professionals will be able to devise specific strategies that can be implemented in clinical practice with clients when they begin insulin therapy.

1.2.9 Work Flow – Diabetes Care

An annual audit of clinical records of Torres Strait Islanders on diabetes registers in 21 Primary Health Care Settings, showed clinical care of adults with diabetes has improved, and more people with diabetes are now being diagnosed [28]. However, a similar audit conducted five years later with the same population in one of the 21 primary healthcare settings, used clinical records of those registered as having diabetes from Ferret (a chronic disease information system used extensively in the Torres Strait). The results indicated that the number of diabetic care processes undertaken had declined over a five-year period [29]. This could suggest a lack of understanding and knowledge amongst clinicians around effective diabetes workflow / chronic disease models if any, due to high turnover in clinicians in these remote islands of the Torres Strait. It could also indicate that the clinicians tend to focus on acute care rather than chronic care and lack of chronic care systems in the health services model. This requires further investigation.

1.2.9.1 Glycaemic Control

Glycaemic control is measured by glycosylated haemoglobin concentration (HbA1c) and is an important indicator of overall diabetes management [30]. Hba1c measurements are an indicator of time-averaged blood glucose levels

(previous 2-3 months) and are used as the best marker of long-term diabetes control [31] Hba1c is now reported in Australia using the new Systeme International (SI) units (mmol/mol, no decimal point) and National Glycohaemoglobin Standardization Program (NGSP) units (percentage, one decimal point) [32]. Table 1.2 shows average blood glucose levels with the corresponding HbA1c % mmol.

Table 1.2
Hba1c (NGSP and SI units)

HbA1c (%) NGSP units	HbA1c (mmol/mol) SI units	Average Blood Glucose mmol/l
13	119	18
12	108	17
11	97	15
10	86	13
9	75	12
8	64	10
7	53	8
6	42	7
5	31	5

The global target for glycaemic control is an Hba1c <7% [33]. Adequate glycaemic control is imperative in preventing microvascular and macrovascular complications associated with Type 2 diabetes.

Poor glycaemic control is linked to many complications, including coronary artery and peripheral vascular disease, stroke, diabetic neuropathy, amputations, renal failure, and blindness. Many of the complications associated with diabetes can be reduced with appropriate community-based primary health care interventions.

1.3 Summary

Aboriginal and Torres Strait Islanders are experiencing high rates of Type 2 diabetes in Australia which requires ongoing support and programs to reduce the life gap expectancy between Aboriginal and Torres Strait Islanders and non-Indigenous Australians. Those living in remote areas face many challenges, lack of government services and underlying social determinants of

health. Understanding patient's behaviours, attitudes and their journey with diabetes towards a sustainable workflow in the primary health care setting remains unexplored amongst Torres Strait Islanders living in the Torres Strait region. The three studies reported in this thesis provide epidemiological evidence for the improvement of Type 2 Diabetes management and care in the remote primary health care centres of the Torres Strait region.

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Chapter. 2: Diabetes Care and Management in Remote Torres Strait Islander Communities in Queensland, Australia: A Scoping Review

Introduction

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2.1 Introduction

Type 2 Diabetes Mellitus (T2DM) is an ongoing public health challenge for remote Aboriginal and Torres Strait Islander communities of Australia, for both clients and health services. Limited infrastructure, high health staff turnover coupled with inexperience in diabetes management and care contribute to high rates of diabetes complications in this population [1]. Much of this can be improved with better clinical systems for chronic care in the community.

Health behaviors and attitudes can influence patients' self-management of diabetes [2]. Barriers to treatment and motivation to enhance optimal adherence to care plans, such as depression or distress may exacerbate poorly control diabetes among patients in remote locations.

Studies locally and internationally have shown the serious effects of complications associated with poorly controlled T2DM [3]. High rates of preventable hospitalisations related to diabetes complications remain a feature of the health system in the Torres Strait. Patient and health service factors impacting on diabetes care and management remain an experiment. Underpinning a sustainable chronic disease model also remains a constant debate to establish better outcomes to patients with T2DM and the service provider.

Chronic disease management aims to provide an opportunity to identify, and through the initiation of management strategies, reduce subsequent exacerbation of the chronic disease, with the ultimate goal of improving the patient's health [4]. Chronic disease management in primary health care involves appropriate prevention; early detection, early identification, and adoption of best practice management strategies in the primary health care setting [5]

Models of chronic disease management or models of care describe the delivery of health care within the health system. Models of care have been defined as "designs for the provision of a particular type of health care service that consists of identified core elements and principles and have a framework that can be implemented and evaluated" [5]. According to Davidson and colleagues (2006), models of care should be evidence – based, founded upon an

assessment of patient and health provider needs, incorporate evaluation of health–related and interventional outcomes and involve a multidisciplinary approach if applicable [6].

A sophisticated chronic illness model developed by Wagner, Austin et al. (2001) has been endorsed by World Health Organization as a framework for innovation in the management of chronic diseases. This comprises six elements: community; the health system; self-management support; delivery system design; decision support and clinical information systems [7].

According to the literature most successful interventions in chronic disease management delegate a primary care doctor or nursing case manager who ensure that patients receive proved clinical and self-management support services. Most practices in Australia do not have standardised or organised approaches to collecting, summarizing, and reviewing individual or collective patient data to facilitate care. Active chronic illness management calls for a delivery system design that encourages and enables productive interactions, a computerized disease registry that includes critical information about each patient and the performance and results of important aspects that enables care teams to call in patients with specific needs, deliver planned care, receive feedback, and implement reminder systems [7].

In a systematic review of diabetes care programs featuring elements of a chronic care model, Bodenheimer and colleagues [8], found that 32 of the 39 studies reported that interventions improved at least one care process (e.g., periodic measurement of HbA1c, urine albumin and serum lipids levels) or patients' clinical outcome measure (e.g., levels of HbA1c, complications). A Danish study included in the above systematic review demonstrated the evidence around chronic care model effectiveness. This randomised trial included 970 patients treated by 474 general practitioners with a program involving decision support. Ongoing regular follow –up, reminder systems, and self-management support based on individual support, significantly lowered HbA1c, blood pressure and cholesterol levels than those in control groups. Other studies suggest that well-defined chronic disease care interventions can improve process and outcomes measures for diabetes [9].

2.2 Study Objective

The objective of this scoping review is to examine and map all available published literature, which investigates diabetes care and management in remote Torres Strait Communities in Queensland, Australia.

2.3 Review Methodology

The systematically rigorous scoping study, as proposed by The Joanna Briggs Institute Reviewers' Manual (2015) [10] was chosen for this review to conduct a comprehensive and systematic search of the literature to identify the literature in diabetes care and management in remote Torres Strait communities in Queensland, Australia. This review follows the six-stage scoping review framework outlined by Arksey and O'Mally (2005) [11]. The sixth stage (identify this) was not included in this scoping review as it was considered optional.

2.3.1 Stage One: Identify the Research Question

The research question developed for this scoping review was:

What are the gaps in the current literature that may assist in improving diabetes care and management in the remote Torres Strait Islander communities in Queensland, Australia?

2.3.2 Stage Two: Identify Relevant Studies

A comprehensive search of the literature using appropriate peer –reviewed journal articles published between 1990 – 2017 were sought from the following five electronic databases; PubMed, EBSCO HOST, OVID, Informit and Google Scholar. Key search terms included "diabetes" and "Aboriginal or Torres Strait Islander" and "remote Australia." Also, a search from "Google" was undertaken to assess any other primary sources and full-text articles. All items were printed and categorized into identified databases for the selection criteria. There was no repetition of the search.

2.3.3 Stage Three: Study Selection

The inclusion criteria were: (1) Articles focusing on Aboriginal and Torres Strait Islander populations (2) Published peer-reviewed journals (3) A focus on remote primary health care services (4) Approved ethics statement (5) Written in English. Articles considered descriptive only (without a clinical or management focus), no data analysis of findings, duplicated data, not conducted in a Torres Strait Island remote location or organisational reports were excluded. The second author (RM) reviewed each paper with the lead author (ST) to determine whether to include the paper or exclude. Using the above key search descriptors, 348 articles were identified across the five databases. Of those, ten were included in the final review (see Figure 2.1).

2.3.4 Stage Four: Charting the Data

A framework for mapping the results was developed summarising the identified articles in a standardised format as described by The Joanna Briggs Institute Reviewers' Manual (2015) [10]. A descriptive summary of each reviewed article with the primary information was presented in a table with the identified headings; author(s), year of publication, study aim/purpose, population/sample size, methodology, intervention type, outcomes and key findings. A second reviewer (RM) validated the data by reviewing each selected article based on the inclusion/exclusion criteria. The information presented in Table 2.1.

2.3.5 Stage Five: Collating, Summarizing and Reporting Results

The final stage of the review, as proposed by Levac, Colquhoun and O'Brien (2010) [12] identified the implications of the study findings for policy, practice or research. Reporting consisted of the outcomes and key findings related to diabetes care.

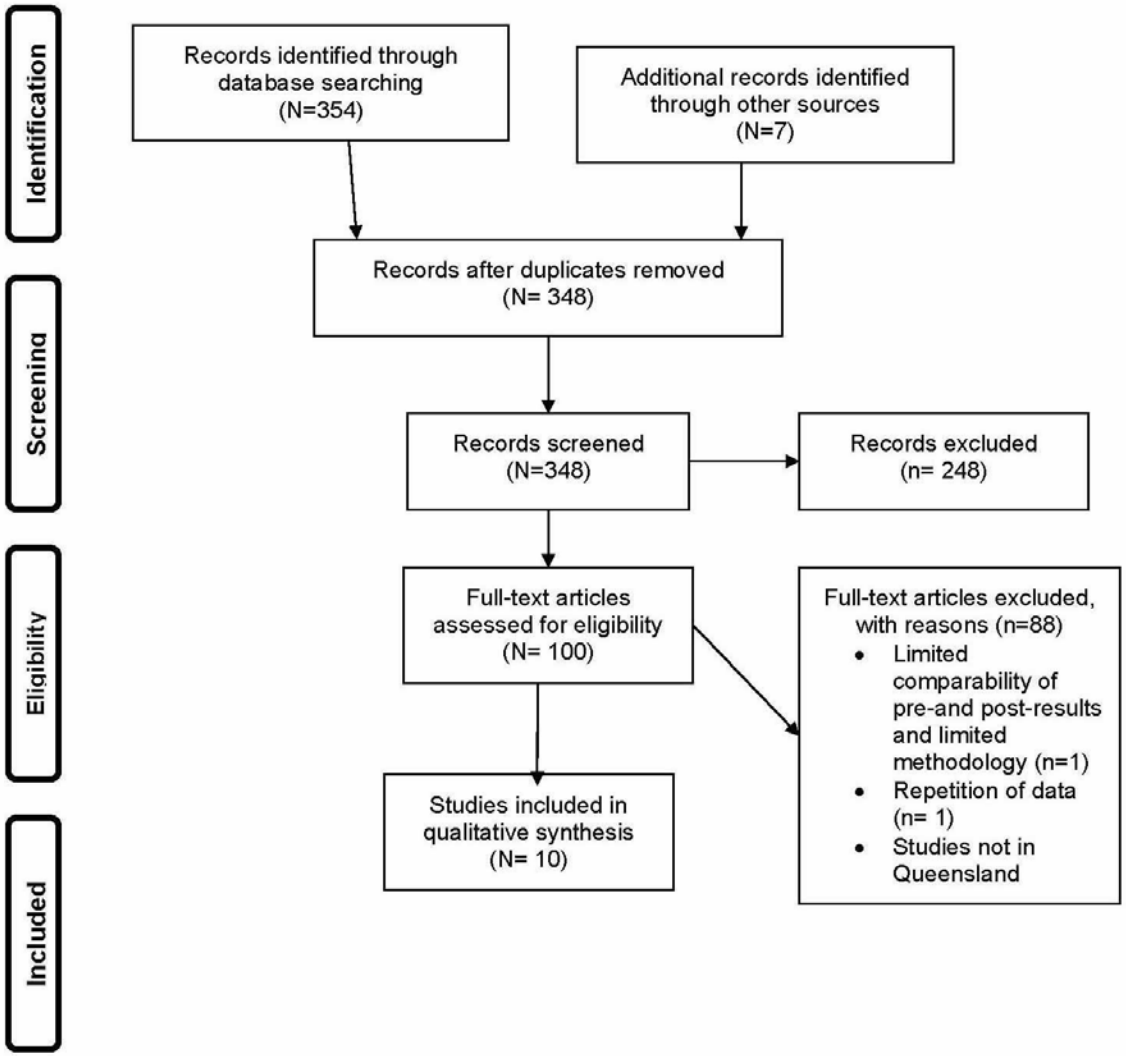

Figure 2.1 PRISMA flow diagram: flowchart of the selection process for inclusion of articles in the scoping review.

2.4 Results and Discussion

One hundred full - text articles assessed for eligibility, 88 full-text articles were excluded as the research setting was not in Queensland, Australia as per the research question. A total of 10 studies met the inclusion criteria (Table 2.1). The study designs included five studies clinical audits, one cohort study, one randomized controlled trial, one randomized unblinded cluster trial, one cross-sectional study and one cost analysis (see Table 2.1– Details of primary studies identified and reviewed). Six studies were conducted in both remote Aboriginal and Torres Strait Islander communities in Australia. Four studies were carried out in the Torres Strait Region alone. The sections that follow discuss the different issues arising in the literature in diabetes care and management in the Torres Strait region.

Table 2.1
Details of primary studies identified and reviewed

Author / Year	**Larkins et al (2016)**
Study Aim / Purpose	Examine trends in quality of care and examine health service characteristics
Population/ Sample Size	N = 73 PHC Services. 40/73 services located in Queensland. 62 / 73 was remote locations.
Methodology	Longitudinal clinical audit between 2005 - 2013
Intervention Type	Nil Intervention
Outcomes	Quality of care varied across sites.
Key findings	First time trends in performances associated with activity have been empirically developed from large Primary Health Care data. No correlation between CQI and health service characteristics
Author / Year	**Matthews et al (2014)**
Study Aim / Purpose	Examine trends in the quality of Type 2 diabetes audits by year (2006 -2012) and individual patient factors on delivery of services re: current guidelines
Population/ Sample Size	132 Aboriginal and Torres Strait Islander community health centres in five states / territories. 79% were located in remote areas
Methodology	Clinical audit

Intervention Type	Nil Intervention
Outcomes	Type 2 diabetes could be improved through quality improvement programs re: regular attendance (reminder systems) and improved recording.
Key findings	Better coordination and documentation of care improved care delivery in remote areas. Health Centres in remote areas increases odds of greater improvement in care processes.

Author / Year	**McDermott et al (2004)**
Study Aim / Purpose	Assess primary care processes and clinical characteristics of adults with diabetes
Population/ Sample Size	Aboriginal and Torres Strait Islander adults with diabetes in 27 centres. 21 remote primary healthcare centres in the Torres Strait Region (n=921), 3 in Cape York (n=252) and 3 in the Northern Territory (n=194) between
Methodology	Clinical audit between September 2002 and February 2003.
Intervention Type	Nil intervention
Outcomes	High proportion requiring treatment for blood pressure and proteinuria are receiving it. A dissonance on high routine checks and Lack of therapeutic action on glycaemia. Intensive management of glycaemia including insulin, and nutrition and exercise is needed.
Key findings	Diabetes checks are routinely conducted in remote Aboriginal and Torres Strait Islander communities. Hypertension and albuminuria are treated appropriately but glycaemia is not well controlled. Aboriginals are more likely to have albuminuria than Torres Strait Islanders. “Therapeutic nihilism” and “clinical inertia” may be an explanation.

Author / Year	**McDermott et al (2011)**
Study Aim / Purpose	Evaluate the contribution of non-traditional risk factors to coronary heart disease (CHD) incidence
Population/ Sample Size	N = 1706 Aboriginal and Torres Islanders adults from 26 communities in Far North Queensland
Methodology	Cohort study
Intervention Type	Nil Intervention
Outcomes	High prevalence of glycaemia and albuminuria especially when combined for much of the excess CHD risk beyond the traditional Framingham risk factors
Key findings	Very high background prevalence of diabetes and albuminuria and excess incidence of CHD. Age-specific CHD incidence rate were similar in gender. Baseline prevalence of diabetes was 12.4% in Aboriginals and 22.3% in Torres Strait Islanders. Glycaemia threshold lower than that for a diagnosis of diabetes also increase CHD risk.

Author / Year	**McDermott et al (2015)**
Study Aim / Purpose	Evaluate the effectiveness of a community-based health worker led case management approach to the care with adults with poorly controlled type two diabetes.
Population/ Sample Size	N = 213 Indigenous Australian adults with poorly controlled diabetes in 12 remote northern Australia

Methodology	Randomised Controlled Trial – randomisation was the community health service, which was allocated to either the health worker led case management intervention or to a waitlist control group.
Intervention Type	Intervention communities were allocated an Indigenous Health Worker. A caseload of between 9 – 26 clients. The role of these health workers included, help clients manage appointments; understand medications and nutrition and effects of smoking. Working with families to support the client in self-management.
Outcomes	A culturally safe, community level health worker led model of diabetes care for high risk patients was not effective in improving diabetes control in remote communities.
Key findings	Some diabetes care process demonstrated a significant impact. A longer-term evaluation is required to capture further benefits.

Author / Year	**McDermott and Segal (2006)**
Study Aim / Purpose	Estimate the direct cost and downstream savings of improved quality of diabetes services, compared to usual care in the primary health care settings.
Population/ Sample Size	Cost impact analysis over 6 years (2000 – 2005) comparing cost of quality improvements with actual and projected savings in avoidable diabetes – related hospitalizations. 21 primary health care centres, two hospitals, and a population of 9,600 mostly Torres Strait Islanders including 1,000 adults with known diabetes in the Torres Strait region.

Methodology	Incremental cost analysis of health care cost (hospitalisation and patient travel cost funded by the health service) under comparator and intervention conditions.
Intervention Type	This study, the intervention consists of an improved diabetes service, which includes a visiting specialist service, preparation of registers, care plans and recall systems for patients with diabetes. The comparator is the service model prior to the intervention (no improved diabetes services).
Outcomes	Investments in quality improvement in primary diabetes care using a chronic disease model will achieve cost savings through prevention of expensive diabetes –related hospitalisations.
Key findings	Hospitalisation for infections declined by 2%. Estimated Diagnosis –Related Group cost in 2002 for infections and amputations, averaged $4,242 per episode (n=99). In 2003 56 cases avoided, potentially “saved” $237,552. Current costing indicates Renal dialysis and ambulatory peritoneal dialysis similar cost $65,000 per year. Present value program cost $490,000 x 6 years = $2,600,000.

Author / Year	**McDermott et al (2003)**
Study Aim / Purpose	To investigate whether improvements were sustained two years after a randomised cluster trial in 1999 showing improvement in diabetes care processes and reduced hospital admission.
Population/ Sample Size	21 primary health care centres in the Torres Strait Region. Population of 9600 including 921 diabetics.
Methodology	Three year follow up clinical audit of 21 Primary Health Care Centres, and review of admissions to hospital in the previous 12 months.

Intervention Type	Nil Intervention
Outcomes	Appropriate management structures and clinical support for diabetic patients can lead to improvements in care processes, control blood pressure and preventable complications that result in admission to hospital.
Key findings	Diabetes registers increased from 555 in 1999 to 921 in 2002. Care processes and clinical interventions improved. Good glycaemic control (HbA1c $\leq$7%) increased from 18% to 25% with increase in insulin (7% vs. 16%). Well-controlled hypertension (<140 / 90) increased 40% vs. 64%. Admitted to hospital with a diabetes related condition decreased 25% vs. 20%. Weight increased 87kg vs. 91kg.

Author / Year	**McDermott et al (2001)**
Study Aim / Purpose	Evaluate a system for improving diabetes care managed locally by Health Care Workers.
Population/ Sample Size	21 primary Health Care Centres in the Torres Strait and Northern Peninsula Area and 678 people with diabetes.
Methodology	Randomised, unblinded cluster trial over one year (1 March to 29 February 2000)
Intervention Type	Diabetes recall system established at eight of the 21 sites, staff training in basic diabetes care, regular phone calls, a two-monthly newsletter and mid-project workshop.
Outcomes	A simple recall system, managed by local healthcare workers and supported by a diabetes outreach service, achieved significant improvements in diabetes care and reduced hospitalisations.

Key findings	Improvements seen may be due to the “Hawthorne effect” not sustainable after the intervention stops. A new diabetes outreach team, combined with guidelines, audit and feedback, had small impact on improving care or reducing hospitalisation. Mid project workshop suggested improved staff understanding of the need to follow up clients. 30 % of the hospital admissions for diabetes-related conditions can be prevented by simple measures, managed by local health workers.
Author / Year	**Si et al (2011)**
Study Aim / Purpose	Examine documented levels of depression among people with diabetes
Population/ Sample Size	62 (17 from North Queensland) Indigenous community health centres from four Australian states and territories. (N=1592)
Methodology	Between 2005 and 2009, clinical audits of diabetes care
Intervention Type	Nil Interventions
Outcomes	The study inconsistent with the evidence showing high prevalence of mental distress among Indigenous Australian people with diabetes
Key findings	8.8% (n=1592) had documented depression. 62 patients had a record of diagnosis of depression but no prescription of an SSRI. Prevalence of documented depression among patients with diabetes was 11.2%.
Author / Year	**Taylor et al (2016)**

Study Aim / Purpose	Explore self-reported knowledge and attitudes to insulin treatment among a group of adults with poorly controlled diabetes.
Population/ Sample Size	N=29 poorly controlled insulin –naïve type 2 diabetics in 5 remote Torres Strait Islander communities.
Methodology	Cross sectional survey in 2014 with 29 adults with HbA1c
Intervention Type	Nil Intervention
Outcomes	Better education around glycaemic control with medication and discussion of perceptions and exchange of experience with peers.
Key findings	Mostly negative perceptions of insulin, which could be significant barrier to better glycaemic management. Perceived barriers to insulin treatment are high in this population. Better communication between service providers and clients may improve uptake of insulin.

2.4.1 Diabetes Care Workflow and Cost-Impact of Care Models

Studies have suggested better coordination and documentation of care can improve delivery of diabetes care in remote communities [13-19]. Two studies described the use of local health workers [16,19]; however, there is limited description of the skill mix of these health professionals or their experience in working with diabetic patients in remote communities. Training and workshops were provided to these health care workers, but there was no mention if the training was provided through a Registered Training Organization or a formal qualification was gained.

Although five studies were clinical audits [13-15,18,20] which showed positive outcomes towards clinical care processes, a description of the individual health professional performing the clinical care assessments and point of patient engagement would be beneficial to gain a fair understanding of diabetes workflow. One study investigated the cost impact analysis over six years (2000-2005) comparing cost of quality improvement with actual and projected savings in avoidable diabetes –related hospitalisations [17]. This is a significant finding and most relevant to improve health service factors related to diabetes management and care. The study found over six years in the year 2000, a net present value cost of AUS$570,000.00 is estimated for the new service. A breakdown of the annual cost of a diabetes quality improvement program in the year 2000 valued at AUS$490,000.00 was clearly described. The figures are old, however, relevant to this region of Australia. To our knowledge, this is the only cost impact analysis of diabetes care conducted in the Torres Strait region.

2.4.2 Medication Adherence

Limited description of medication adherence or compliance was evident in the majority of studies, or mention of patients collecting medications from local Primary Health Care Centers or pharmacies if available. A handful of studies identified lack of therapeutic action on glycaemia [15,18,21]; however, a later study [18] mentioned increases in prescribed insulin in patients with T2DM in the Torres Strait region (7% vs. 16%), appropriate treatment for hypertension and albuminuria (40% vs. 64%). One study made mention of the high glycaemia and albuminuria and accounted for much of the excess coronary heart disease

risk beyond the traditional Framingham risk factors [22]. One study examined knowledge and attitudes to insulin treatment and concluded that among patients who may have benefitted from insulin treatment but who did not take it up there were mostly negative perceptions towards insulin therapy [21].

2.4.3 Behavioral Aspects Towards Diabetes Care

Most of the studies lack information or recommendations towards behavioral change towards diabetes care and management from patients and health professionals. One study mentioned “therapeutic nihilism” and “clinical inertia” [15] however limited suggestions were included on possible solutions to clarify these concepts and improve care processes. Improving health service delivery is an important and essential area to improve diabetes outcomes in remote locations; however, patients themselves also need to change and enhance their attitudes towards diabetes care and self-management. One study in the review documented levels of depression among people with diabetes attending Indigenous primary health care centers, a key ingredient to understanding patient behavior [20]. The study found a prevalence of 8.8% of documented depression among people with diabetes, however, concluded that further investigation into screening tools, capacity and barriers involved diagnosing and managing depression was required.

2.5 Limitations of This Review

This scoping review was limited to the Torres Strait region and no other remote locations in Australia. The review did not search the gray (or unpublished) literature and included only indexed and peer –reviewed studies or those most likely to be used by researchers, clinicians and policy makers to inform research, policy and practice.

2.6 Conclusion

Ten studies met the inclusion criteria and were examined to identify the gaps to improving diabetes care and management in the remote Torres Strait Islander communities. Three gaps in the literature were evident

1. A detailed diabetes care workflow that can be sustainable and affordable to the health service provider;
2. Greater focus on actual medication adherence or understanding the barriers to quality use of medicines in this population, as opposed to identifying what patients were prescribed by their local Medical Officer to treat T2DM; and
3. Specific patient and health service factors than enhance behavioral change to improve self-management of T2DM in this context.

The study aims and methodology are articulated well in all of the identified studies with good intentions to improve diabetes care and management in the Torres Strait region. Intervention studies are imperative to improve care, however, documentation of the implementation of these interventions needs improvement. Further research is warranted to investigate the current gaps in the literature identifying improvement in diabetes care and management in the remote Torres Strait Island communities.

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Chapter. 3: Diabetes in Torres Strait Islanders: Challenges and Opportunities for Remote Area Nurses

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3.1 Introduction

Chapter 3 comprises a manuscript published in the Contemporary Nurse Journal titled "Diabetes in Torres Strait Islanders: Challenges and opportunities for remote area nurses'. This paper sets the scene for this research in the Torres Strait region and outlines previous and present diabetes interventions implemented. The Torres Strait region was chosen for this Doctor of Public Health research based on the high prevalence of Type 2 diabetes and the avoidable complication associated with Type 2 diabetes as previously mentioned in the other chapters. It also continues from previous research outlined in Chapter 2.

The manuscript is aimed for Remote Area Nurses, who have clinical governance in the remote primary health care settings in the Torres Strait. Remote Area Nurses, play a fundamental role in the prevention treatment and management of diabetes. This role in diabetes care may be as a specialist or part of general care –primary or secondary. These nurses provide the first point of contact for a range of primary care services and often act as sole primary health care providers alongside the Indigenous Health Workers. Ideally, they practice in a holistic, comprehensive, collaborative manner and provide care for people who are acutely and chronically ill.

Remote Area Nurse require skills and knowledge to provide population –based public health and illness prevention programs in a range of areas such as mental health, chronic disease management, emergency care retrieval and transfer, men's and women's health, adolescent health, palliative care, aged care, maternal, infant and child health. This role also extends to providing clinical leadership to the Indigenous Health Workers, clinical administration, environmental health, education and research. Nurses are not experts in all the mentioned areas, however, they collaborate with experts remotely to provide a competent standard of care. They use best practice treatment and management protocols to provide and co-ordinate the different care required in the region.

Remote Area Nurses seeking employment in the Torres Strait region need relevant background information to understand the provision of diabetes programs to inform current service, including orientation to chronic care models and local cultural awareness. Chapter 7 outlines more in depth the workflow of a Registered Nurse working with people with Type 2 diabetes in the remote islands of the Torres Strait.

3.2 Article: Diabetes in Torres Strait Islanders: Challenges and opportunities for remote area nurses

 Contemporary Nurse (2013) **46**(1): 46–53.

Diabetes in Torres Strait Islanders: Challenges and opportunities for remote area nurses

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Abstract: *Torres Strait Islanders living in the Torres Strait region have the highest prevalence of Type 2 diabetes in Australia; more than three times the rate of other Australians. Abdominal obesity and insulin resistance are the main causes for these high rates of the disorder. Further, Aboriginal and Torres Strait Islanders diagnosed with diabetes have poorer glycaemic control and much lower rates of insulin use than non-Indigenous Australians diagnosed with Type 2 diabetes alongside extremely high rates of renal failure and other comorbidities. Interventions have been instigated in order to overcome these issues. Previously a simple recall system managed by local health workers achieved significant improvements in diabetes care, reduced diabetes-related hospitalisations by 40% and led to the implementation of a chronic disease register and recall system throughout the Torres Strait region. Nurses, Indigenous health workers and other health professionals play important roles in ensuring these interventions continue.*

Keywords: diabetes, Indigenous, Torres Strait Islanders, nurses

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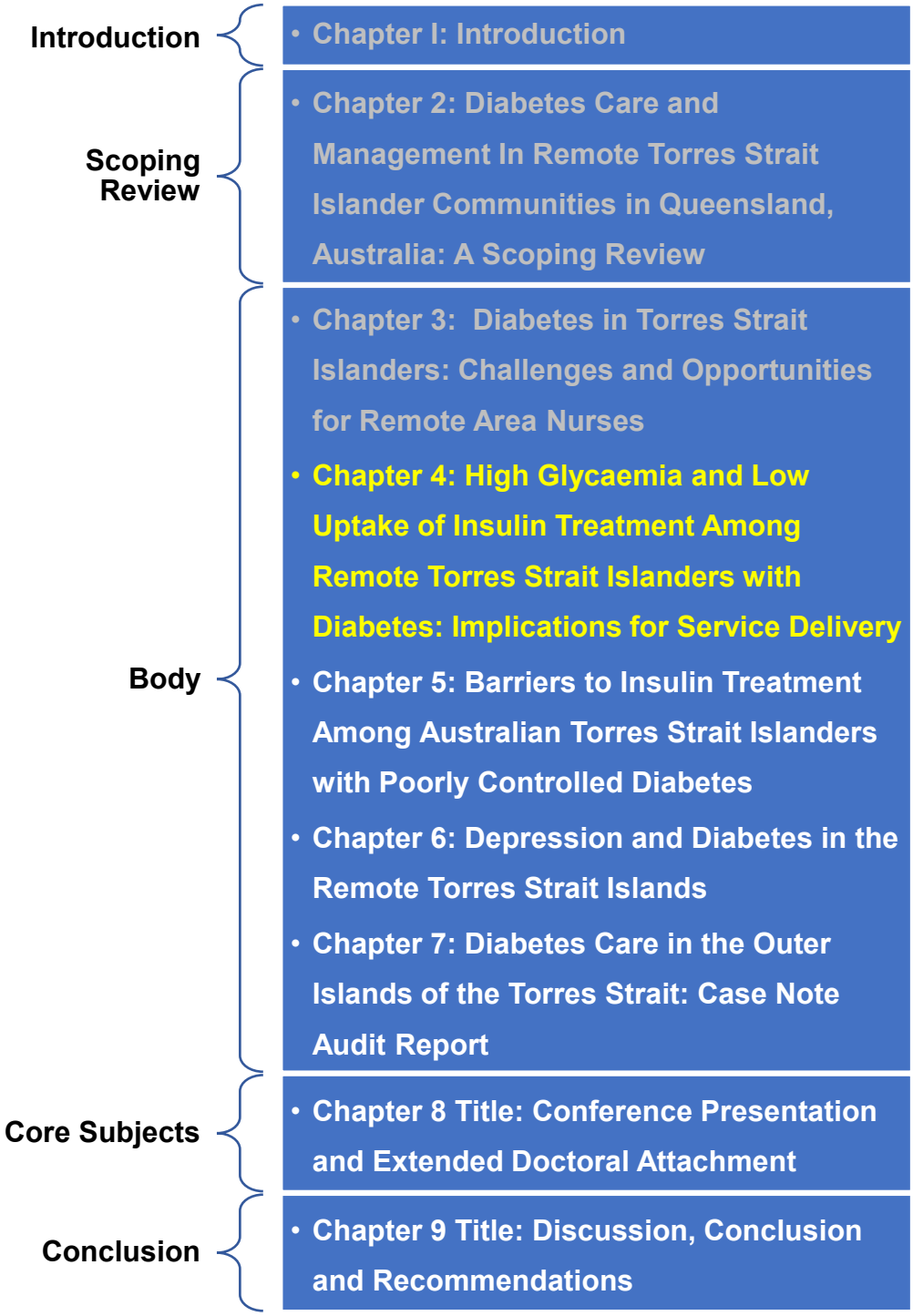
Chapter. 4: High Glycaemia and Low Uptake of Insulin Treatment Among Remote Torres Strait Islanders with Diabetes: Implications for Service Delivery



4.1 Introduction

Chapter 4 comprises a short report published in The Australian Journal of Rural Health entitled “High glycaemia and low uptake of insulin treatment among remote Torres Strait Islanders with diabetes: Implications for service delivery”.

This report briefly outlines all diabetes cases in five of the remote outer Islands of the Torres Strait (Mer Island, Darnley Island, Stephen Island and Saibai Island).

This report is an introduction to Chapter 5, discusses issues around insulin therapy. Table 4.1 outlines the known diabetics in the five mentioned communities. The total population in the five identified communities was 1119, of whom 18% (n=197) were known diabetics on the diabetes register in 2012. 100% (n=197) were recruited into the overall study from five remote Torres Strait Island communities.

Table 4.1
Known diabetes cases in five remote sites in the Torres Strait.

Community	Total Population (2011 Census)	Known Diabetics on Register (2012)	Patients Recruited to Overall Study
Mer Island	310	61	61
Darnley Island	402	43	43
Stephen Island	39	12	12
Saibai Island	198	48	48
Yorke Island	170	33	33
Total	1119	197 (18%)	197 (100%)

4.2 Article: High glycaemia and low uptake of insulin treatment among remote Torres Strait Islanders with diabetes: Implications for service delivery

AJRH The Australian Journal of Rural Health

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Aust. J. Rural Health (2016) ••, ••–••

Short Report

High glycaemia and low uptake of insulin treatment among remote Torres Strait Islanders with diabetes: Implications for service delivery

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Torres Strait Islanders have the highest prevalence of Type 2 Diabetes in Australia.[1] Between 2005/06 and 2009/10, there were on average 123 diabetes separations per year in the Torres Strait and Northern Peninsula Hospital and Health Service. A review in 2005 noted that newer diabetes cases were younger, more obese and had poorer glycaemic control compared to 6 years previously.[2]

Here we briefly report all diabetes cases in five of the most remote outer islands of the Torres Strait conducted in 2013 who were recruited into a cohort study. These very remote islands are serviced by local primary care workers, nurses and only intermittently visited by specialist outreach teams and general practitioners.

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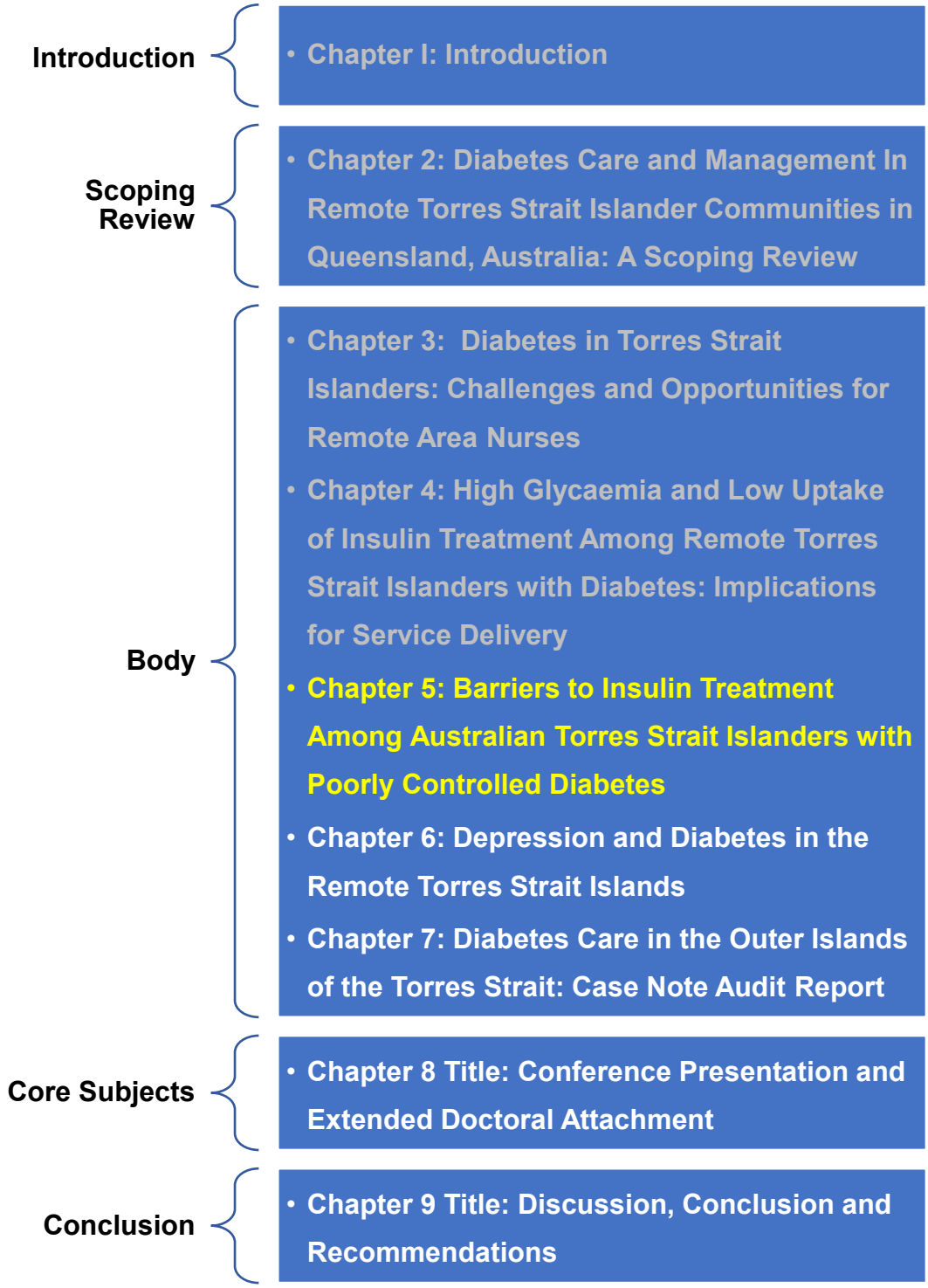
Chapter. 5: Barriers to Insulin Treatment Among Australian Torres Strait Islanders with Poorly Controlled Diabetes



5.1 Introduction

Chapter 5 comprises a manuscript published in The Australian Journal of Rural Health titled "Barriers to insulin treatment among Australian Torres Strait Islanders with poorly controlled diabetes". This research paper is described here as Study 1. It reviewed patient level factors on behavioural aspects of diabetes management regarding Psychological Insulin Resistance. The paper outlines the methods, measures, statistical analysis and results of the research.

Table 5.1 describes the known diabetics in five identified communities and those participants who met the inclusion criteria for Study 1. 15% (n=197) met the inclusion criteria (Hba1c => than 8.5% and not prescribed insulin therapy. 97% (n=30) of the participants who were eligible and consented for Study 1 received an interview, one participant died beforehand.

Table 5.1
Participants Study 1

Community	Total Population (2011 Census)	Known Diabetics on Register (2012)	Patient Recruited to Overall Study	Patients Eligible for Study 1	Patients Interviewed
Mer Island	310	61	61	9	9
Darnley Island	402	43	43	8	8
Stephen Island	39	12	12	3	3
Saibai Island	198	48	48	5	4 (1 died)
Yorke Island	170	33	33	5	5
Total	1119	197 (18%)	197 (100%)	30 (15%)	29 (97%)

5.2 Article: Barriers to Insulin Treatment Among Australian Torres Strait Islanders with Poorly Controlled Diabetes

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Original Research

Barriers to insulin treatment among Australian Torres Strait Islanders with poorly controlled diabetes

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Abstract

Objective: *To explore self reported knowledge and attitudes to insulin treatment among a group of adults with poorly controlled diabetes in the Torres Strait islands.*
Design: *Cross-sectional survey in 2014, interviews with 29 adults with HbA1c ≥ 8.5% (69 mmol mol^{-1}) and not taking insulin, using Insulin Treatment Appraisal Scale (ITAS) and Barriers to Insulin Treatment Questionnaire (BITQ) scores.*
Setting: *Five remote Torres Strait Island communities in the Torres Strait region.*
Participants: *Poorly controlled insulin-naïve type 2 diabetics.*
Main outcome measures: *BITQ and ITAS scores on items related to knowledge and attitudes to insulin treatment, clinical and demographic measures.*
Results: *Overall, 34% of the cohort had poor glycaemic control. Compared to those with HbA1c ≥ 8.5% and taking insulin (*n = *37), the 29 insulin-naïve participants were more obese, more likely to smoke and drink alcohol, have lower mean HbA1c and fewer years with diabetes. Among the insulin-naïve group, those reporting higher 'barriers' (BITQ scores) were older and with lower formal education than those reporting fewer barriers. Torres participants consistently scored low on 'knowledge' items in the ITAS, especially those which would guide insulin initiation (insulin improves glucose control and prevents complications).*
Conclusion: *Compared to other published studies, the Torres participants had higher scores for BITQ 'barrier' items and lower 'knowledge' scores. This suggests better education around glycaemic control with medication and discussion of perceptions and exchange of experiences with peers who are taking insulin might improve the uptake of insulin in this high-risk group.*

KEY WORDS: *psychological insulin resistance, Torres Strait Islander, type 2 diabetes.*

Introduction

Type 2 diabetes is a chronic progressive condition[1] where many patients will eventually require insulin in addition to oral hypoglycaemic agents to control glycaemia and prevent complications.[2] Current guidelines recommend commencement of insulin when dietary and maximum oral hypoglycaemic treatment fails to maintain adequate blood glucose control to maintain HbA1c levels below 8.5% (69 mmol mol^{-1}).[3] However, many patients are reluctant to commence insulin treatment for a variety of reasons,[4] some of which reflect poor knowledge of modern delivery methods and many of which relate to beliefs about stigma, danger and inconvenience.[5] These negative and complex perceptions have been collectively called 'psychological insulin resistance' (PIR)[6] and recently developed insulin appraisal scales have been validated in adults with diabetes in Australia.[7]

Torres Strait Islanders have the highest prevalence of diabetes in Australia, and high rates of avoidable complications, especially renal failure, skin ulceration and lower limb amputation.[8] Clinical reports suggest that glycaemic control is especially poor[9] compared to other groups with diabetes; however, rates of insulin treatment remain low,[10] suggesting opportunities to improve guideline-concordant care and reduce complications in the primary care setting. Anecdotal evidence suggests that PIR is high in this population, as reported by clinicians.

The Insulin Treatment Appraisal Scale (ITAS) is a brief, psychometrically validated instrument that can

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What is already known on this subject?

- *Torres Strait Islanders have the highest prevalence of type 2 diabetes in Australia and high rates of avoidable complications.*
- *Many patients are reluctant to commence insulin treatment for a variety of reasons which include stigma, danger and inconvenience.*

What does this study add?

- *Poorly controlled insulin-naïve type 2 diabetics in the remote Torres Strait region mostly had negative perceptions of insulin, which could be significant barriers to better glycaemic management.*
- *Perceived barriers to insulin treatment are high in this population, especially among those who are older with fewer years of formal education.*
- *Improving the uptake of insulin for those who could benefit from it will require better communication between service providers and clients.*

be used in insulin-naïve patients to assess both positive and negative perceptions of insulin treatment and what changes might be expected from these perceptions.[11] The Barriers to Insulin treatment Questionnaire (BTIQ) measures has been validated in two populations of adults with diabetes in Germany.[12]

The present study aimed to investigate the perceptions and beliefs of Torres Strait Islander adults with poorly controlled diabetes with respect to using insulin to control blood sugar using the ITAS and BTIQ scales. We anticipated this information might be useful in both understanding perceptions and knowledge of insulin with a view to better communication by clinicians and the more effective use of medicines in this high-risk group.

Methods

The study population was selected from the register of 197 adults with T2DM in five outer islands in the Torres Strait region (see Fig 1) who all provided consent for interview and data collection. Sixty-seven (34%) of these had HbA1c levels ≥8.5% and of these 29 were not taking insulin. The 29 insulin-naïve

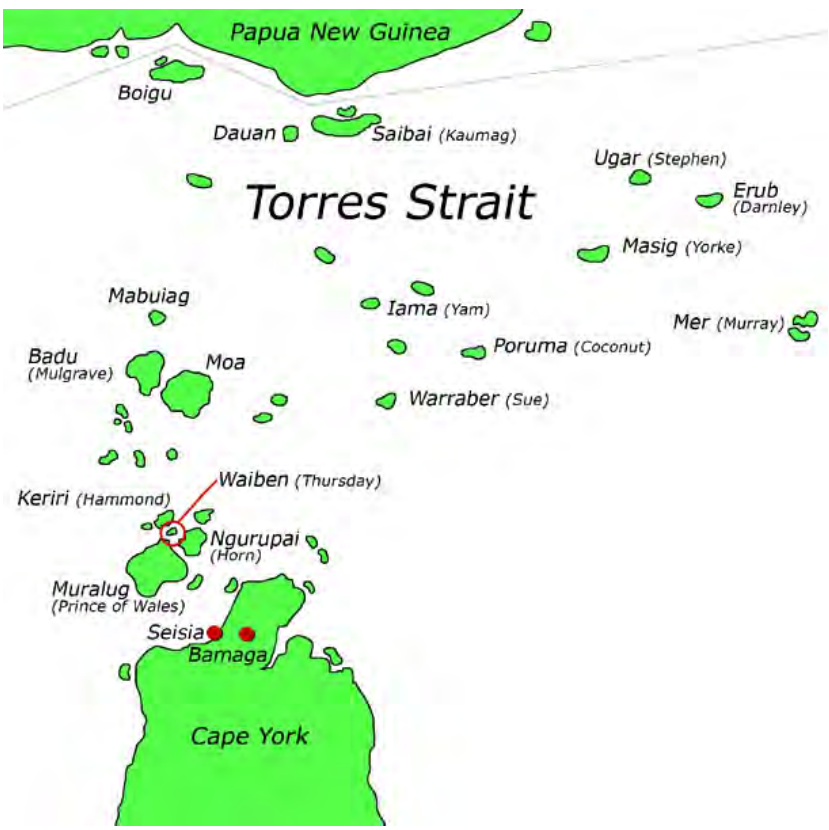

FIGURE 1: *Map of the Torres Strait Region.*

participants were interviewed by one of us fluent in local Creole, using the ITAS and BITQ instruments in the participant's home or local health service. Clinical data were abstracted from clinic files (patient hard copy files, patient information system – Best Practice, Ferret and Auslab). Interview data included years of formal education, current employment, current household income, smoking and alcohol intake, average time

TABLE 1: *Categorical demographic and behavioural variables by HbA1c (%) and insulin prescription status of Torres Strait Islanders with diabetes*

	HbA1c < 8.5	HbA1c ≥ 8.5		
Demographic, behavioural and diabetes care variables	No. (%)	On insulin No. (%)	Not on insulin No. (%)	Total No. (%)
Total	130	37	30	197
Gender				
Male	51 (39.2)	9 (24.3)	15 (50.0)	75 (38.1)
Female	79 (60.8)	28 (75.7)	15 (50.0)	122 (61.9)
Age				
<35 years	2 (1.5)	3 (8.1)	4 (13.3)	9 (4.6)
35–49 years	21 (16.2)	9 (24.3)	7 (23.3)	37 (18.8)
50+ years	107 (82.3)	25 (67.6)	19 (63.3)	151 (76.6)
Body Mass Index (BMI)				
Healthy BMI (18.5–24.9)	15 (11.5)	4 (10.8)	2 (6.7)	21 (10.7)
Overweight BMI (25.0–29.9)	37 (28.5)	10 (27.0)	5 (16.7)	52 (26.4)
Obese BMI (30+)	78 (60.0)	23 (62.2)	23 (76.7)	124 (62.9)
Employment				
Employed fulltime	42 (34.1)	13 (37.1)	9 (30.0)	64 (32.5)
Employed part-time/casual	5 (4.1)	3 (8.6)	5 (16.7)	13 (6.6)
Not currently employed	76 (61.8)	19 (54.3)	16 (53.3)	111 (56.3)
No response/missing	7	2	0	9
Education				
Year 12 not completed	86 (69.9)	20 (57.1)	17 (56.7)	123 (62.4)
Year 12 completed	10 (8.1)	6 (17.1)	6 (20.0)	22 (11.2)
TAFE course	21 (17.1)	9 (25.7)	7 (23.3)	37 (18.8)
Undergraduate	6 (4.9)	0 (0.0)	0 (0.0)	6 (3.0)
No response/missing	7	2	0	9
Household income				
<$20 000	2 (1.6)	1 (2.9)	0 (0.0)	3 (1.5)
$20 000–$59 999	69 (56.1)	17 (48.6)	18 (60.0)	104 (52.8)
$>60 000	52 (42.3)	17 (48.6)	12 (40.0)	81 (41.1)
No response/missing	7	2	0	9
Smoking				
Non smoking	104 (84.6)	30 (85.7)	19 (63.3)	153 (77.7)
Yes smoking	19 (15.4)	5 (14.3)	11 (36.7)	35 (17.8)
No response/missing	7	2	0	9
Alcohol				
No alcohol	91 (74.0)	24 (68.6)	17 (56.7)	132 (67.0)
Alcohol	32 (26.0)	11 (31.4)	13 (43.3)	56 (28.4)
No response/missing	7	2	0	9
Coordination of diabetes care				
Extremely well (1)	14 (11.4)	1 (2.9)	2 (6.7)	17 (8.6)
Very well (2)	98 (79.7)	28 (80.0)	26 (86.7)	152 (77.2)
Fairly well/Badly (3)	11 (8.9)	6 (17.1)	2 (6.7)	19 (9.6)
No response	7	2	0	9

(hours) watching television per week, regular physical exercise, years since diagnosis, self-reported medication adherence and perceptions of quality of diabetes care. Clinical data included most recent HbA1c, blood pressure, lipids, renal function and prescribed medicines.

Ethics approval was obtained from the Human Research Ethics Committee Cairns and Hinterland, Cape York, Torres Strait – Northern Peninsula Hospital and Health Service (now known as Far North Queensland Ethics Committee) – HREC Reference number: HREC/13/QCH/126-875. Ethics approval was also provided by the Human Research Ethics Committee – James Cook University, approval number HREC/H5666. A student non-commercial research agreement was established between The Torres and Cape Hospital and Health Service and the first author (ST).

Measures

Responses to the 14 BITQ items were scored from 1 (Strongly Disagree) to 10 (Strongly Agree) with a score of 7–10 indicating Agree/Strongly Agree. A total BITQ score for each person was derived by summing responses to the 14 items. The scores for three positively worded BITQ items, 4, 5 and 6, were first reversed so a high score indicated low positive appraisal of insulin. Dividing each person's total score by 14, the number of BITQ items, derived an average of the total score. Five sub-scales measuring different components of insulin resistance were created following the method of Petrak *et al.*[12]

Responses to the 20 ITAS items (1 = Strongly Disagree, 5 = Strongly Agree) were summed to create a total score for each person. Four items, 3, 8, 17 and 19, were reversed prior to creation of this total score. Summing scores from the 16 negatively worded items created a total negative sub-scale. The positive sub-scale was the sum of the unreversed four positive items. Exercise was measured as a 7-day recall of daily moderate to very hard physical activity in minutes. Total daily minutes were summed to create an aggregated exercise time in minutes and then hours for the preceding 7 days. Screen time was recorded as total hours watching TV, videos, games and internet per night during the preceding 7 days. Total hours per night were summed to create an aggregated screen time in hours.

Statistical analysis

Descriptive statistics were used to explore the distribution of categorical demographic and behavioural variables by three groups of glycaemic control and insulin prescription status groups. These groups were HbA1c

TABLE 2: *Continuous demographic, clinical and behavioural variables by HbA1c (%) and insulin prescription status among Torres Strait Islanders with diabetes, one-way analysis of variance (ANOVA)*

Demographic, clinical and behavioural variables	HbA1c < 8.5 (n = 130)		HbA1c ≥ 8.5–Insulin prescription status				Total (n = 197)		P
			Prescribed (n = 37)		Not prescribed (n = 30)				
	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI	
Age	60.66	(58.50–62.82)	55.51	(51.33–59.69)	52.05	(47.19–56.91)	58.38	(56.57–60.20)	0.001
HbA1c (%)[a]	6.73	(6.63–7.00)	11.12	(10.66–12.48)	9.97	(9.57–11.24)	7.37	(7.18–7.98)	<0.001
Body Mass Index (BMI)	32.52	(31.34–33.71)	32.26	(30.21–34.31)	35.33	(32.28–38.38)	32.90	(31.92–33.88)	0.115
Exercise	4.43	(3.90–4.96)	4.14	(3.21–5.08)	5.08	(3.88–6.27)	268.55	(242.91–294.20)	0.442
Screen time[a]	28.00	(24.62–28.00)	28.00	(21.00–35.00)	28.00	(14.00–34.10)	28.00	(28.00–28.00)	0.540
Years with diabetes	8.87	(7.66–10.08)	13.30	(10.57–16.03)	7.96	(5.70–10.23)	9.53	(8.51–10.55)	0.002
Diabetes care (1 = Very good, 9 = Very poor)									
Knowledge of treatment	3.89	(3.61–4.18)	3.49	(3.00–3.97)	4.10	(3.55–4.65)	3.85	(3.63–4.07)	0.243
Appointment attendance[a]	2.00	(2.00–2.00)	2.00	(2.00–2.81)	3.00	(2.00–3.00)	2.00	(2.00–2.00)	0.096
Medication adherence	2.00	(1.81–2.19)	2.20	(1.87–2.53)	2.57	(2.10–3.03)	2.13	(1.97–2.29)	0.037
Coordination of diabetes care	1.98	(1.89–2.06)	2.14	(2.00–2.29)	2.00	(1.86–2.14)	2.01	(1.95–2.07)	0.137

[a]Variable not normally distributed, medians reported and Kruskal–Wallis one-way analysis of variance by ranks.

(%) <8.5, HbA1c (%) ≥8.5 and prescribed insulin and HbA1c (%) ≥8.5 and not prescribed insulin (Table 1). Continuous demographic variables were compared between these groups using means, confidence intervals and one-way analysis of variance (ANOVA). Medians and Kruskal–Wallis one-way ANOVA ranks were used for non-parametric variables (Table 2). The distribution of mean ITAS and BITQ scores for 29 insulin-naïve participants with poorly controlled glycaemia (HbA1c%≥8.5) was assessed across categorical demographic and behavioural variables. Categories of age and education were aggregated to accommodate the small number of participants. Differences in mean scores between categories in these variables were tested using ANOVAs and independent sample t-tests (Table 3).

Tables 4 and 5 display the mean scores and standard deviations for individual BITQ and ITAS items, respectively. The scores displayed for positive items on both scales are based on unreversed values, although these values were then reversed during the derivation of total summed scores. Results from other published comparison studies are included in these tables. Confidence intervals for means and proportions for this study and comparison studies were calculated and are reported in the text when comparing items and total scores across studies.

Results and discussion

Sixty-seven (34%) of the 197 adults with diabetes had poor glycaemic control (HbA1c ≥ 8.5%). They were younger, more likely to be obese, more likely to be smokers and alcohol drinkers than those with better glycaemic control (Table 1). They reported more years living with diabetes and lower medication adherence. In the poorly controlled group, those taking insulin had higher median HbA1c (11.1%, 98 mmol mol^{-1}) and longer duration of diabetes (13.3 years) compared to those not taking insulin (9.8%, 84 mmol mol^{-1}

TABLE 3: *Distribution of Insulin Treatment Appraisal Scale (ITAS) and Barriers to Insulin Treatment Questionnaire (BITQ) scores of Torres Strait Islanders with diabetes, by baseline characteristics*

	ITAS scores				BITQ scores		
Baseline characteristics	No.	Mean	(95% CI)	*P* value	Mean	(95% CI)	*P* value
Total	29	66.3	(62.5–70.1)		84.9	(79.7–90.1)	
Gender							
Male	15	66.2	(60.1–72.3)	0.967	87.4	(81.9–92.9)	0.320
Female	14	66.4	(61.1–71.6)		82.2	(72.4–92.0)	
Age group							
≤49 years	11	61.2	(53.6–68.7)	0.028	81.6	(70.1–93.1)	0.329
>50 years	18	69.4	(65.5–73.3)		86.9	(81.2–92.5)	
BMI category							
Healthy BMI (18.5–24.9)	1	–	–		–	–	
Overweight BMI (25.0–29.9)	5	65.4	(51.4–79.4)	0.680	77.4	(60.1–94.7)	0.424
Obese BMI (30+)	23	66.1	(61.8–70.4)		86.5	(80.5–92.5)	
Employment							
Employed fulltime	9	67.1	(59.6–74.6)	0.127	85.3	(74.1–96.5)	0.345
Employed part-time/casual	5	58.2	(41.4–75.0)		76.8	(51.9–101.7)	
Not currently employed	15	68.5	(64.1–72.8)		87.3	(81.4–93.3)	
Education							
Year 12 not completed	16	71.5	(68.6–74.4)	0.001	89.3	(84.1–94.4)	0.058
Year 12 completed and higher	13	59.8	(53.5–66.2)		79.5	(69.6–89.5)	
Income							
$20 000–$59 999	17	66.4	(60.9–71.8)	0.961	85.9	(79.8–91.9)	0.655
$>60 000	12	66.2	(60.3–72.0)		83.5	(72.9–94.1)	
Smoking							
Nonsmoking	18	68.2	(64.1–72.3)	0.195	86.7	(80.3–93.0)	0.386
Yes smoking	11	63.2	(55.1–71.2)		82.0	(71.5–92.5)	
Alcohol							
No alcohol	16	69.1	(64.9–73.3)	0.086	87.3	(81.7–92.8)	0.317
Alcohol	13	62.8	(55.9–69.6)		82.0	(71.6–92.4)	

TABLE 4: *Barriers to Insulin Treatment Questionnaire (BITQ), item content, mean score and distribution of responses to individual items, mean subscales and total BITQ scores*

Barriers to Insulin Treatment Questionnaire (BITQ) (1–10)	Torres Strait *n* = 29			Petrak *et al.* (2007) *n* = 448	
	Mean	(sd)	A/SA%	Mean	(sd)
Scale 1: 'Fear of injections and self-testing'	5.25	(2.56)		3.19	(2.78)
1. I am afraid of the pain when injecting insulin	5.69	(2.70)	51.7	3.62	(3.33)
2. Besides the pain, I am just afraid of injections	5.69	(3.00)	62.1	3.58	(3.50)
3. I am afraid of the pain during regular blood-sugar checks	4.38	(2.38)	27.6	2.37	(2.64)
Scale 2: 'Expectations regarding positive insulin-related outcomes'	4.57	(1.93)		7.36	(1.87)
^4. Insulin works better than pills	3.97	(2.51)	20.7	8.19	(2.41)
^5. People who get insulin feel better	4.90	(2.35)	27.6	7.42	(2.46)
^6. Insulin can reliably prevent long-term complications due to diabetes	4.86	(1.87)	20.7	6.46	(2.38)
Scale 3: 'Expected hardship from insulin therapy'	5.30	(1.36)		4.20	(2.74)
7. I just do not have enough time for regular doses of insulin	5.48	(2.18)	27.6	3.30	(3.04)
8. I cannot pay as close attention to my diet as insulin treatment requires	5.17	(2.12)	17.2	4.73	(3.25)
9. I cannot organise my day as carefully as insulin treatment requires	5.24	(1.75)	13.8	4.58	(3.38)
Scale 4: 'Stigmatisation by insulin injections'	6.47	(1.70)		4.30	(2.52)
10. Injections in public are embarrassing to me. Pills are more discreet	7.17	(2.48)	72.4	5.45	(3.78)
11. Regular insulin treatment causes feelings of dependence	5.62	(1.86)	20.7	5.06	(3.46)
12. When people inject insulin, it makes them feel like drug addicts	6.62	(2.44)	65.5	2.38	(2.70)
Scale 5: 'Fear of hypoglycaemia'	6.79	(2.09)		6.21	(2.73)
13. Regarding insulin overdose, I am afraid of the unpleasant accompanying symptoms	6.90	(2.14)	58.6	6.61	(2.92)
14. Regarding insulin overdose, I have concerns about possible permanent damage to my health	6.69	(2.09)	55.2	5.81	(3.11)
Total (sum score 14 items, 3 negatively recoded)	84.90	(13.79)			
Average of total scores	6.06	(0.99)		4.17	(1.55)

Scoring: 1 = Strongly Disagree, 10 = Strongly Agree. (sd), standard deviation; A/SA, Agree/Strongly Agree (7–10); ^, positive BITQ items. Scales are the sum of all responses divided by number of questions. Average of total score is the sum of all scores divided by the total number of items in the scale.

and 7.9 years, respectively). Self-reported knowledge of treatment and satisfaction with care coordination was similar between groups (Table 2).

Of the 29 insulin-naïve participants with poor control who completed the ITAS and BITQ, ITAS scores were significantly higher among participants aged 50 years and over (ITAS = 69.4, 95% CI: 65.5–73.3) compared to all younger participants (ITAS = 61.2, 95% CI: 53.6–68.7, $P = 0.028$). Similarly, participants who had not completed year 12 had significantly higher ITAS scores (ITAS = 71.5, 95% CI: 68.6–74.4) compared to those with higher levels of education (ITAS = 59.8, 95% CI 53.5–66.2, $P = 0.001$). There was a similar relationship between education and BITQ scores; however, the differences only just approached significance, t(1.98), $P = 0.058$ (Table 3).

On the BTIQ scale, mean responses were higher for scale 1 ('fear of injections', $M = 5.25$, 95% CI: 4.28–6.23); lower for scale 2 ('positive expectations regarding insulin treatment', $M = 4.57$ 95% CI: 3.84–5.31) and higher for scale 4 ('stigmatisation from injections', $M = 6.47$, 95% CI: 5.83–7.12), in comparison with the

TABLE 5: *Insulin Treatment Appraisal Scale (ITAS), item content, mean score and distribution of responses to individual items, mean subscales and total ITAS scores*

	Torres Strait *n* = 29			Snoek *et al.* (2007) *n* = 146			Truscott *et al.* (2014) *n* = 499		
Insulin Treatment Appraisal Scale (ITAS) (1–5)	Mean	(sd)	A/SA%	Mean	(sd)	A/SA%	Mean	(sd)	A/SA%
1. Taking insulin means I have failed to manage my diabetes with diet and tablets.	3.8	(0.8)	75.9	3.4	(1.40)	54.0	3.5	(1.30)	58.3
2. Taking insulin means my diabetes has become much worse.	3.8	(0.8)	75.9	3.9	(1.60)	73.0	4.0	(1.00)	80.2
^3. Taking insulin helps to prevent complications of diabetes.	3.2	(0.8)	37.9	3.8	(1.10)	62.0	3.9	(1.00)	76.4
4. Taking insulin means other people see me as a sicker person.	4.1	(0.9)	86.2	3.2	(1.30)	41.0	3.3	(1.10)	46.3
5. Taking insulin makes life less flexible.	3.2	(0.6)	34.5	3.8	(1.10)	70.0	3.6	(1.10)	58.7
6. I'm afraid of injecting myself with a needle.	3.3	(1.2)	58.6	3.1	(1.50)	47.0	3.3	(1.40)	47.9
7. Taking insulin increases the risk of low blood glucose levels (hypoglycaemia).	3.3	(0.8)	41.4	3.1	(1.10)	52.0	3.4	(1.00)	46.5
^8. Taking insulin helps to improve my health.	3.1	(1.0)	37.9	3.6	(1.00)	53.0	3.8	(0.08)	67.7
9. Insulin causes weight gain.	3.0	(0.9)	34.5	3.1	(0.90)	23.0	3.1	(0.08)	18.2
10. Managing insulin injections takes a lot of time and energy.	3.1	(0.9)	27.6	3.6	(1.10)	61.0	3.3	(1.00)	40.9
11. Taking insulin means I have to give up activities I enjoy.	3.1	(0.8)	34.5	2.6	(1.10)	19.0	2.7	(1.00)	16.8
12. Taking insulin means my health will deteriorate.	3.3	(1.2)	62.1	2.7	(1.10)	23.0	2.8	(1.00)	18.6
13. Injecting insulin is embarrassing.	3.7	(1.2)	79.3	2.6	(1.30)	23.0	2.7	(1.10)	21.6
14. Injecting insulin is painful.	3.3	(1.3)	65.5	3.3	(1.20)	43.0	3.1	(1.00)	32.1
15. It is difficult to inject the right amount of insulin correctly at the right time every day.	3.2	(1.0)	44.8	3.2	(1.20)	40.0	3.0	(0.90)	23.2
16. Taking insulin makes it more difficult to fulfil my responsibilities (at work, at home).	3.1	(0.9)	34.5	2.9	(1.20)	27.0	2.8	(0.90)	17.8
^17. Taking insulin helps to maintain good control of blood glucose.	3.2	(0.7)	27.6	3.7	(1.00)	59.0	3.9	(0.80)	74.7
18. Being on insulin causes family and friends to be more concerned about me.	4.3	(0.8)	86.2	3.5	(1.10)	55.0	3.6	(0.90)	57.7
^19. Taking insulin helps to improve my energy level.	3.1	(0.9)	31.0	3.2	(0.70)	25.0	3.3	(0.70)	30.9
20. Taking insulin makes me more dependent on my doctor	3.1	(0.8)	27.6	3.4	(1.10)	40.0	3.4	(0.90)	47.3
Total ITAS (sum score 20 items, 4 negatively recoded)	66.3	(9.9)		61.0	(2.80)		60.7	(10.10)	
Total positive items ITAS	12.5	(2.9)		14.0	(2.90)		14.9	(2.40)	
Total negative items ITAS	54.8	(7.5)		55.0	(2.70)		51.6	(10.20)	

Scoring: 1 = Strongly Disagree, 5 = Strongly Agree. (sd), standard deviation; A/SA, Agree/Strongly Agree (4–5); ^, positive ITAS items.

same scales from a recent German study. The derived confidence intervals from the German study for the three scales were: $M = 3.19$, 95% CI: 2.93–3.45; $M = 7.36$, 95% CI: 7.19–7.53; and $M = 4.30$, 95% CI: 4.07–4.53, respectively, and none of these intervals overlapped with the current study (Table 4).

Responses to the 'positive' ITAS scales ('taking insulin prevents complications; improves glucose control and improves health') were generally low with less than 40% agreeing or strongly agreeing. Responses to the negative scales were generally high (more than 60% agree or strongly agree) especially for 'others see

me as a sicker person', 'injecting insulin is embarrassing' and 'painful', in comparison with a recent report from an Australian group (Table 5).

Conclusion

This study of a group of high-risk Torres Strait Islanders with poorly controlled diabetes and who were not taking insulin found mostly negative perceptions of insulin which could be significant barriers to better glycaemic management. The few published studies in other groups using these instruments showed much lower negative perceptions and much higher positive perceptions than the Torres Strait Islanders.

Limitations to this study include a very small study sample, although 100% of those approached agreed to participate (29 out of 30 completed the questionnaires, one participant died prior to the interview) suggesting that the responses are representative of this population. Another limitation is the lack of validation of these instruments in this population, where English is not the first language for many. However, the survey was administered by one of the investigators who is from these islands and who speaks fluent Creole.

These results, when compared to reports from other populations including in Australia, suggest that perceived barriers to insulin treatment are high in this population, especially among those who are older with fewer years of formal education. Improving the uptake of insulin for those who could benefit from it will require better communication between service providers and clients, including more time taken to explore these issues in depth and taking account of local cultural contexts and beliefs.

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Author contributions

ST – prepared the manuscript, developed the research design and assisted the supervisory team. Undertook initial community engagement, patient recruitment and data collection. RM – principal supervisor of (ST) and contributed to the development of the research design, project proposal and manuscript development. FT – conducted the statistical analysis and manuscript development.

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Chapter. 6: Depression and Diabetes in the Remote Torres Strait Islands

6.1 Introduction

Chapter 6 comprises an article published in the Health Promotion Journal of Australia, entitled “Depression and Diabetes in the remote Torres Strait Islands”. This paper forms Study 2; it investigated patient level factors on depression and diabetes. The paper outlines the methods, results and discussion of the research. Depression and Diabetes form part of the patient-level factors on behavioural features of diabetes management, previously mentioned in Chapter 1.

Table 6.1 summarises the number of participants interviewed in Study 2 using the Patient Health Questionnaire (PHQ)-9. 95% (n=197) of participants were surveyed in 2014.

Table 6.1
Participants Study 2

Community	Total Population (2011 Census)	Known Diabetics on Register (2012)	Participants Recruited to Overall Study	Participants Interviewed
Mer Island	310	61	61	61
Darnley Island	402	43	43	43
Stephen Island	39	12	12	6
Saibai Island	198	48	48	45
Yorke Island	170	33	33	32
Total	1119	197 (18%)	197 (100%)	188 (95%)

6.2 Article: Depression and Diabetes in the Remote Torres Strait Islands

Health Promotion Journal of Australia
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Depression and diabetes in the remote Torres Strait Islands

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Abstract

Issue addressed: Diabetes is associated with significant depression, which can result in poorer clinical outcomes, including increased mortality. Little is known about the prevalence of depression among Torres Strait Islander adults with diabetes.

Methods: Self-reported depression was measured using the Patient Health Questionnaire (PHQ)-9 translated into Torres Strait Creole, and associations with socioeconomic, behavioural and clinical indicators in Torres Strait Islander adults with diabetes in five remote Torres Strait Islands were examined.

Results: Seventy-three men and 115 women completed interviews. The median PHQ-9 score was 5.5 (IQR 0–7); 42% of respondents scored 0–4 (none–minimal), 46% scored 5–9 (mild) and 12% scored 10+ (moderate–severe). Mean HbA1c was 8.3% (67.4 mmol). HbA1c was not related to PHQ-9 scores ($\beta = 0.20$, $P = 0.323$), however exercise in hours ($\beta = -0.34$, $P < 0.001$) and screen time in hours ($\beta = 0.11$, $P < 0.001$) were significant predictors of depression after adjusting for other study variables.

Conclusions: This sample of remote living Torres Strait Islanders reported relatively low rates of depression compared with national samples, and depression was not related to glycaemic control. Exercise and screen time were the strongest predictors of depression based on PHQ-9 scores. This represents an opportunity for health promotion.

So what? These findings provide an indication of the health impact of physical activity in rural and remote communities. Local health and education services, councils and sporting bodies should work collaboratively to promote sustainable physical activity programs.

Key words: Aboriginal and Torres Strait Islanders, health behaviours, type 2 diabetes.

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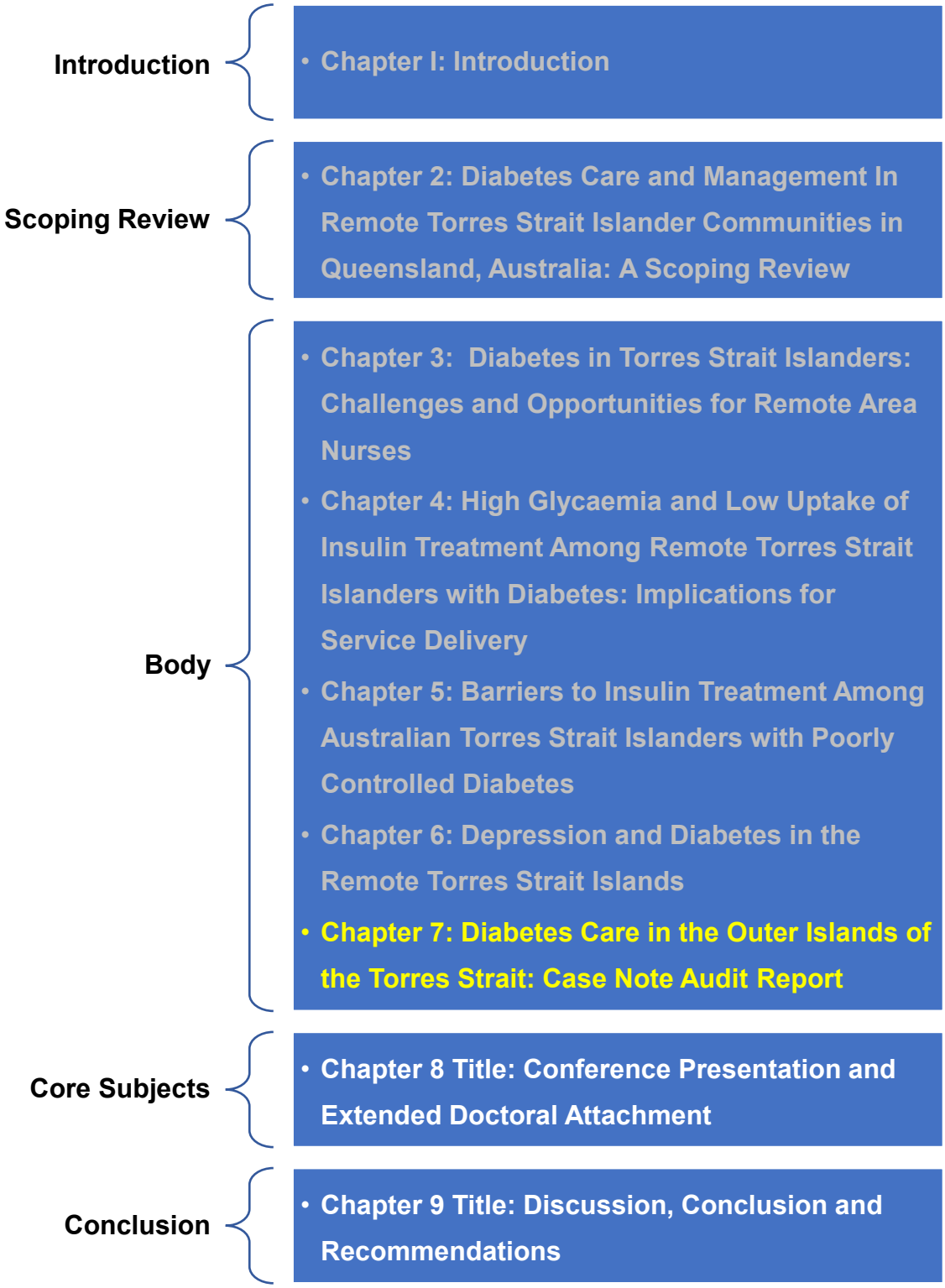
Chapter. 7: Diabetes Care in the Outer Islands of the Torres Strait: Case Note Audit Report



7.1 Introduction

Chapter 7 is an unpublished paper submitted to the Australian Journal of Primary Health Care titled "Diabetes Care in the outer islands of the Torres Strait: Case note audit report". This manuscript forms Study 3; it describes the provision of diabetes services and the impact of diabetes management in eight remote Torres Strait Islands. The methods, statistical analysis and results are discussed in this chapter.

The eight participating communities were clustered into Eastern Group and Western Group. The Eastern Group included Mer Island, Darnley Island, Stephen Island, Saibai Island, and Yorke Island. The Western Group included Mabuiag Island, Boigu Island and St Pauls Community – Moa Island. The Executive Members of the Torres and Northern Peninsula Area Hospital and Health Service (now known as Northern Sector –Torres and Cape Hospital and Health Service) chose the eight study sites in 2012.

Participants in the Western Group did not consent in the overall study; however, ethics was approved to conduct audits in this group with no patient interaction. Table 7.1shows 15.1% (n=1887) had known Type 2 diabetes, 100% of the known diabetics had their clinical files audited.

Table 7.1
Patient Files audited – Study 3

Community	Total Population (2011 Census)	Known Diabetics on Register (2012)	Patient Recruited to Overall Study	Patient Files Audited
Mer Island	310	61	61	61
Darnley Island	402	43	43	43
Stephen Island	39	12	12	12
Saibai Island	198	48	48	48
Yorke Island	170	33	33	33
Mabuiag Island	260	30	0	30
Boigu Island	208	31	0	31
St Pauls Community – Moa Island	300	27	0	27
Total	1887	285 (15.1%)	197	285 (100%)

7.2 Article: Diabetes care in the outer islands of the Torres Strait: Case note audit report, 2012-15

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Abstract

Background: Management of diabetes in the primary care setting is a key part of prevention of complications. In the Torres Strait, prevalence of diabetes and complication rates are high. We aimed to assess the level of service provision for diabetes care in the outer islands of the Torres Strait from 2012 to 2015.

Objective: To review the provision of diabetes services and the impact of diabetes management in 8 remote Torres Strait Islands.

Methods / Design: A Retrospective case note audit of care processes and intermediate clinical outcomes in 285 adults with known diabetes. At baseline 197 participants from five remote Torres Strait Island communities (mostly the Eastern group of Islands) consented to be enrolled in the survey. A further 88 records from the Western group of islands were audited from 2012 -2015 and serves as a comparator group.

Results: At baseline, overall (n=285), 61% were women, 75% were aged over 50, 67% were obese (Body Mass Index (BMI)>30, higher in the comparator group), 65% had poorly controlled glycaemia (Hba1c>8.5%) and 18% were smokers (lower in comparator group). GP management plans (GPMP) and team care arrangements (TCA) were more likely to be completed in the Eastern group 93% vs. 39% with 90% referred to a dietician, diabetes educator or podiatrist. Among participants with data available in 2015, there was a decrease in completed GPMPs from 93% to 20% in the Eastern group. At baseline, it appeared that participants in the Eastern group had better glycaemic control than those in the Western group (35.2% had Hba1c>8.5%

compared to 39% in the Western group). By 2015, poor glycaemic control was 35% and 47% respectively among those with data available.

Conclusion: The provision of diabetes care planning, referrals and clinical measures important to diabetes care and actual numbers of consultations appeared to decline dramatically between 2012 and 2015 in all sites.

Keywords

Type 2 Diabetes, Torres Strait Islanders, Health Services

Background

Diabetes has escalated as a 'silent pandemic'[1], and is now the world's fastest growing chronic disease [2], representing a severe public health challenge. Aboriginal and Torres Strait Islanders in Australia are three times more likely to have diabetes than non-Indigenous Australians [3]. Evidence suggest, Aboriginal and Torres Strait Islander children are 8 times more likely to develop Type 2 diabetes than non-indigenous children in Australia [4]. The diabetes epidemic in the remote Torres Strait Islands of Australia is ongoing and alarming. About a third of the adult population are affected, however, the incidence of Type 2 diabetes and other co-morbid conditions are also extremely high at around 3%[5].

The Torres and Cape Hospital and Health Service (TCHHS) is the only service provider to the people of the Torres Strait region. Two Remote Area Nurses (RAN), usually experienced in emergency care, and three Generalist Indigenous Health workers, provide 13 core services to the individual outer islands, although the frequency may vary depending on the island. A visiting GP and outreach teams from Thursday Island provide a service on a scheduled basis. The majority of RAN's employed in the outer Island Primary Health Care Centers focus on acute care and after hours' emergency call outs, which potentially leaves patients' chronic care plans incomplete.

In 2012, an Indigenous registered nurse (RN) with extensive knowledge and experience in diabetes management and care in the Torres Strait region was employed by the TCHHS manage Type 2 diabetes patients only and work collaboratively with existing teams in five remote Torres Strait Island

communities from 2012-13. The RN spent eight weeks in the Eastern Island communities to complete tasks in three phases (see below phases). After 2013, the RN position was ceased and usual care was provided by existing staff.

Three phases:

Phase 1: Patent Engagement

1. Visit patients in their homes.
2. Overall diabetes education and explanation of their diabetes management according to the chronic disease guidelines.
3. Clinical appointments were made, according to the patient's preference.
4. Patient attended appointments at their clinics. Preparation for GP Management Plan (GPMP) and Team Care Arrangement (TCA), clinical and biomedical markers were taken.
5. Data entered into the existing patient information system 'Best Practice'.
6. Appointment was made to see visiting GP.

Phase 2: Health Service Uptake

1. GP reviewed patient, GPMP, TCA, results and referred if needed.

Phase 3: Referrals

1. GP referred all patients to the diabetes team (Diabetes Educator, Dietician, Podiatrist)
2. GP referred identified patients to a medical specialist (Endocrinologist, Nephrologist, Cardiologist, Optometrist).
3. GP referred lifestyle factors if required (smoking, nutrition and weight loss).
4. GP, RN, local health team to review patients (GPMP, TCA, clinical and biomedical markers) after 6 months.

The purpose of this research was to investigate the impact of these intervention over four years. Two years with the RN and another two years without the RN in the Eastern group of islands, compared with three other Torres Strait communities in the Western group that did not participate in the formal care planning process, but received "usual care" from 2012-15.

Methods

A total of 285 clinical records of resident adults with known diabetes who lived in eight outer island group were audited for each of the years 2012, 13, 14 and 15. Audits performed in 2012 – 13 were taken manually from clinical files, the existing patient information systems (Best Practice and FERRET) and AUSLAB (Clinical and Scientific Information System). Data for 2014 – 15 were extracted from the existing patient information system (Best Practice only) by staff at TCHHS in Cairns, QLD. At baseline, 188 participants from five outer islands of the Torres Strait (majority of the Eastern group of islands) consented to be enrolled in the survey, which included interviews. A further 88 records from the Western group of islands were audited from 2012-15, which serves as a comparator group.

Data items extracted from participants' files included demographic details, diagnostic investigations, vaccinations, lifestyle measures, clinical measures, management plans, referrals, mental health status and pathology. These correspond to data items in the Chronic Disease Guidelines. If there were missing data in the extraction, it was assumed that the relevant activity had not been performed.

The study was approved by the Human Research Ethics Committee Cairns & Hinterland, Cape York, Torres Strait – Northern Peninsula Hospital & Health Services (currently known as Far North Queensland Human Research Ethics Committee) (HREC/13/QCH/125-874) in 2012 and 2016 with support from TCHHS. Ethics approval was also approved by the Human Research Ethics Committee –James Cook University (H5665). A student non-commercial research agreement was established between the TCCHS and the first author (ST). All data collected are stored in a secure web environment, a Public Health Research Data Management System based at the University of South Australia. The data are governed by the first author (ST) at James Cook University.

Statistical Analysis

Descriptive statistics were used to examine demographic and behavioral variables, clinical measures and care processes, in the intervention and

comparison groups across each of the four years of the study period (2012-2015). Means and standard errors are reported for normally distributed continuous clinical measures and medians and interquartile ranges for skewed measures.

Results

During the entire study period, the proportion of measures with missing data increased as a result of care processes either not undertaken or not recorded. At baseline (2012), most pathology measures had less than 10% missing data, however by 2015, many measures had between 20-30% missing data. Missing data for clinical care processes followed a similar trend, with many measures having more than 60% missing data in 2015. In text, numbers and percentages are reported with missing data excluded from denominators. However, to display the extent of incomplete information, missing data are shown as percentages of total denominators in Tables 1-4.

The large proportion of missing data in the later years of the study compromises any interpretation of changes over time in health outcomes and care processes. It is possible the demographic, behavioural and health profile of participants who continued engaging with the health services during the entire study period are different compared to those who discontinued and had incomplete data. To examine this possibility, the baseline pathology and body measures of participants in these two groups were compared (data not tabled). Demographics: At baseline, 61% of participants were women, 75% were aged over 50, 67% were obese (BMI>30, higher in the comparator group), 65% had poorly controlled glycaemia (Hba1c >8.5%) and 18% were smokers (lower in comparator group) (Table 1)

Table 1 - Demographic characteristics of Torres Strait Islanders with diabetes, by Eastern and Western groups, 2012Care processes

Variable	Baseline (Study 1 - 2012)					
	Eastern Group		Western Group		Total	
	No.	(%)	No.	(%)	No.	(%)
Demographic characteristics	**197**		**88**		**285**	
Gender						
Female	122	(61.9)	52	(59.1)	174	(61.1)
Male	75	(38.1)	36	(40.9)	111	(38.9)
Age group						
<35 years	9	(4.6)	6	(6.8)	15	(5.3)
35 - 49 years	37	(18.8)	19	(21.6)	56	(19.6)
50+ years	151	(76.6)	63	(71.6)	214	(75.1)
BMI Category						
Healthy BMI (18.5 - 24.9)	21	(10.7)	3	(3.4)	24	(8.4)
Overweight BMI (25.0 - 29.9)	52	(26.4)	5	(5.7)	57	(20.0)
Obese BMI (30+)	124	(62.9)	43	(48.9)	167	(58.6)
Missing	0	(0.0)	37	(42.0)	37	(13.0)
Diabetes and Insulin status						
hba1c<8.5	130	(66.0)	48	(54.5)	178	(62.5)
hba1c>=8.5 - On Insulin	37	(18.8)	18	(20.5)	55	(19.3)
hba1c>=8.5 - Not On Insulin	30	(15.2)	13	(14.8)	43	(15.1)
Missing	0	(0.0)	9	(10.2)	9	(3.2)
Alcohol	43	(21.8)	8	(9.1)	51	(17.9)
Smoking	41	(20.8)	10	(11.4)	51	(17.9)
Employment						
Employed fulltime	64	(32.5)	-		64	-
Employed part-time/casual	13	(6.6)	-		13	-
Not currently employed	111	(56.3)	-		111	-

Education					
Year 12 not completed	123	(62.4)	-	123	-
Year 12 completed	22	(11.2)	-	22	-
TAFE course	37	(18.8)	-	37	-
Undergraduate	6	(3.0)	-	6	-
Income					
<$20,000	3	(1.5)	-	3	-
$20,000-$59,999	104	(52.8)	-	104	-
$>60,000	81	(41.1)	-	81	-

At baseline (2012) GP management plans and team care arrangements (TCA) were completed by an outreach team (including RN) for 93% of the 197 Eastern group participants (Table 2). More than 90% were referred to a dietician, diabetes educator or podiatrist. However only around 30% of those referred were actually seen by the relevant health provider in that or the following year.

Table 2 - Clinical care processes of Torres Strait Islanders with diabetes, by Eastern and Western groups, 2012-2015

Clinical care processes	Baseline (2012)				Follow up (2013)				Follow up (2014)				Follow up (2015)			
	Eastern Group		Western Group		Eastern Group		Western group		Eastern Group		Western Group		Eastern Group		Western Group	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Status																
Alive	**197**		**88**		**196**		**88**		**193**		**88**		**191**		**86**	
Deceased	**0**		**0**		**1**		**0**		**4**		**0**		**6**		**2**	
GP Management Plan - Indicator																
No	12	(6.1)	53	(60.2)	11	(5.6)	42	(47.7)	1	(0.5)	0	(0.0)	0	(0.0)	0	(0.0)
Yes	184	(93.4)	34	(38.6)	168	(85.7)	45	(51.1)	48	(24.9)	31	(35.2)	39	(20.4)	22	(25.6)
Missing	1	(0.5)	1	(1.1)	17	(8.7)	1	(1.1)	144	(74.6)	57	(64.8)	152	(79.6)	64	(74.4)
Team Care Arrangement																
No	13	(6.6)	61	(69.3)	13	(6.6)	57	(64.8)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Yes	183	(92.9)	25	(28.4)	166	(84.7)	30	(34.1)	47	(24.4)	27	(30.7)	40	(20.9)	22	(25.6)
Missing	1	(0.5)	2	(2.3)	17	(8.7)	1	(1.1)	146	(75.6)	61	(69.3)	151	(79.1)	64	(74.4)
Care Plan																
No	5	(2.5)	5	(5.7)	2	(1.0)	6	(6.8)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Yes	189	(95.9)	82	(93.2)	176	(89.8)	81	(92.0)	48	(24.9)	31	(35.2)	41	(21.5)	22	(25.6)
Missing	3	(1.5)	1	(1.1)	18	(9.2)	1	(1.1)	145	(75.1)	57	(64.8)	150	(78.5)	64	(74.4)

Diabetes educator referred															
No	17	(8.6)	44	(50.0)	35	(17.9)	32	(36.4)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Yes	178	(90.4)	33	(37.5)	139	(70.9)	45	(51.1)	51	(26.4)	30	(34.1)	61	(31.9)	27	(31.4)
Missing	2	(1.0)	11	(12.5)	22	(11.2)	11	(12.5)	142	(73.6)	58	(65.9)	130	(68.1)	59	(68.6)
Diabetes educator seen															
No	94	(47.7)	5	(5.7)	60	(30.6)	7	(8.0)	1	(0.5)	0	(0.0)	0	(0.0)	0	(0.0)
Yes	59	(29.9)	30	(34.1)	63	(32.1)	37	(42.0)	15	(7.8)	1	(1.1)	41	(21.5)	7	(8.1)
Missing	44	(22.3)	53	(60.2)	73	(37.2)	44	(50.0)	177	(91.7)	87	(98.9)	150	(78.5)	79	(91.9)
Dietician referred															
No	12	(6.1)	45	(51.1)	39	(19.9)	36	(40.9)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Yes	182	(92.4)	33	(37.5)	138	(70.4)	46	(52.3)	49	(25.4)	31	(35.2)	56	(29.3)	32	(37.2)
Missing	3	(1.5)	10	(11.4)	19	(9.7)	6	(6.8)	144	(74.6)	57	(64.8)	135	(70.7)	54	(62.8)
Dietician seen															
No	108	(54.8)	6	(6.8)	98	(50.0)	7	(8.0)	1	(0.5)	0	(0.0)	0	(0.0)	0	(0.0)
Yes	55	(27.9)	29	(33.0)	20	(10.2)	21	(23.9)	12	(6.2)	2	(2.3)	33	(17.3)	12	(14.0)
Missing	34	(17.3)	53	(60.2)	78	(39.8)	60	(68.2)	180	(93.3)	86	(97.7)	158	(82.7)	74	(86.0)
Podiatrist referred															
No	15	(7.6)	47	(53.4)	36	(18.4)	37	(42.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Yes	179	(90.9)	32	(36.4)	141	(71.9)	47	(53.4)	50	(25.9)	30	(34.1)	58	(30.4)	26	(30.2)

Missing	3	(1.5)	9	(10.2)	19	(9.7)	4	(4.5)	143	(74.1)	58	(65.9)	133	(69.6)	60	(69.8)
Podiatrist seen																
No	100	(50.8)	6	(6.8)	70	(35.7)	9	(10.2)	1	(0.5)	1	(1.1)	0	(0.0)	0	(0.0)
Yes	54	(27.4)	23	(26.1)	57	(29.1)	17	(19.3)	13	(6.7)	1	(1.1)	34	(17.8)	5	(5.8)
Missing	43	(21.8)	59	(67.0)	69	(35.2)	62	(70.5)	179	(92.7)	86	(97.7)	157	(82.2)	81	(94.2)
Endocrinologist referred																
No	190	(96.4)	82	(93.2)	171	(87.2)	81	(92.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Yes	5	(2.5)	6	(6.8)	5	(2.6)	7	(8.0)	1	(0.5)	0	(0.0)	1	(0.5)	1	(1.2)
Missing	2	(1.0)	0	(0.0)	20	(10.2)	0	(0.0)	192	(99.5)	88	(100.0)	190	(99.5)	85	(98.8)
Endocrinologist seen																
No	0	(0.0)	0	(0.0)	3	(1.5)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Yes	3	(1.5)	2	(2.3)	1	(0.5)	2	(2.3)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Missing	194	(98.5)	86	(97.7)	192	(98.0)	86	(97.7)	193	(100.0)	88	(100.0)	191	(100.0)	86	(100.0)

In the *comparator group at baseline* (2012), 39% of the 88 participants had a GPMP, 29% a TCA, and 94% had a “Care Plan” (Table 2). Of these, 33 (40%) were referred to a diabetes educator and of those, 30 (91%) were actually seen. Similarly, for dietician referral and being seen, 32 (39%) of those with a Care Plan were referred to a podiatrist and of those, 23 (72%) were seen that year.

Follow-up care processes: Between 2012 and 2015, six participants in the Eastern group had died and two in the Western group (Table 2). For the remaining participants, there was a large proportion of missing data in the later years for every item collected. In 2015, pathology and body data for certain indicators were missing for 14%-100% of participants, and 60-100% of clinical care process data were missing for both groups.

In 2015, in the Eastern group, 20% had a GPMP and TCA, compared to 26% in the Western Group (Table 2). In the Eastern group, 61 (32%) were referred to a diabetes educator and of those, 41 (67%) were seen. In the same group, 56 (29%) were referred to a dietician and of those, 33 (59%) were seen, 58 (30%) were referred to a podiatrist and of those, 34 (59%) were seen. In the Western group (comparator), 27 (31%) were referred to a diabetes educator and of those, 7 (26%) were seen, 32 (37%) were referred to a dietician and of those, 12 (38%) were seen, 26 (30%) were referred to a podiatrist and of those, 5 (19%) were seen.

Overall, care planning, referrals and actual numbers of consultations appeared to decline dramatically between 2012 and 2015 in all sites (Table 2).

Clinical measures:

As summarized in Table 3, at baseline it appeared that participants in the Eastern group had better glycaemic control than those in the Western group (34% had Hba1c >8.5% compared to 39% in the Eastern group) and this difference persisted through to 2015, however by 2015 there was a large amount of “missing” (not done) values in the Eastern group (30%) so comparison is difficult. Glycaemic control appeared to get worse in the Western group and stay steady in the Eastern group.

Table 3 - Clinical characteristics of Torres Strait Islanders with diabetes according to Chronic Disease Guidelines, by Eastern and Western groups, 2012-2015

Target measures	Baseline (2012)				Follow up (2013)				Follow up (2014)				Follow up (2015)			
	Eastern Group		Western Group		Eastern Group		Western Group		Eastern Group		Western Group		Eastern Group		Western Group	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
TOTAL PARTICIPANTS																
Status																
Alive	**197**		**88**		**196**		**88**		**193**		**88**		**191**		**86**	
Deceased	**0**		**0**		**1**		**0**		**4**		**0**		**6**		**2**	
HbA1c categories (%)																
<=7.0	78	(39.6)	26	(29.5)	69	(35.2)	21	(23.9)	67	(34.7)	27	(30.7)	49	(25.7)	14	(16.3)
7.0-8.5	52	(26.4)	22	(25.0)	46	(23.5)	25	(28.4)	38	(19.7)	19	(21.6)	41	(21.5)	25	(29.1)
>8.5	67	(34.0)	31	(35.2)	65	(33.2)	40	(45.5)	56	(29.0)	34	(38.6)	49	(25.7)	34	(39.5)
Missing	0	(0.0)	9	(10.2)	16	(8.2)	2	(2.3)	32	(16.6)	8	(9.1)	52	(27.2)	13	(15.1)
Blood glucose level (BGL)																
BGL Fasting (mmol/L)																
<6	17	(8.6)	0	(0.0)	10	(5.1)	2	(2.3)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
6-8	9	(4.6)	4	(4.5)	10	(5.1)	1	(1.1)	0	(0.0)	1	(1.1)	0	(0.0)	1	(1.2)

>8	18	(9.1)	6	(6.8)	13	(6.6)	9	(10.2)	0	(0.0)	0	(0.0)	1	(0.5)	0	(0.0)
Missing	153	(77.7)	78	(88.6)	163	(83.2)	76	(86.4)	193	(100.0)	87	(98.9)	190	(99.5)	85	(98.8)
BGL Non - fasting (mmol/L)																
<6	25	(12.7)	2	(2.3)	14	(7.1)	7	(8.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
6-7	16	(8.1)	11	(12.5)	35	(17.9)	13	(14.8)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
8-10	28	(14.2)	14	(15.9)	24	(12.2)	11	(12.5)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
>10	62	(31.5)	28	(31.8)	59	(30.1)	38	(43.2)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Missing	66	(33.5)	33	(37.5)	64	(32.7)	19	(21.6)	193	(100.0)	88	(100.0)	191	(100.0)	86	(100.0)
Total Cholesterol (mmol/L)																
>=4.0	118	(59.9)	50	(56.8)	99	(50.5)	54	(61.4)	76	(39.4)	46	(52.3)	69	(36.1)	37	(43.0)
<4.0	74	(37.6)	29	(33.0)	72	(36.7)	26	(29.5)	53	(27.5)	24	(27.3)	55	(28.8)	28	(32.6)
Missing	5	(2.5)	9	(10.2)	25	(12.8)	8	(9.1)	64	(33.2)	18	(20.5)	67	(35.1)	21	(24.4)
LDL-C (mmol/L)																
>=2.0	137	(69.5)	60	(68.2)	118	(60.2)	55	(62.5)	88	(45.6)	48	(54.5)	81	(42.4)	42	(48.8)
<2.0	49	(24.9)	15	(17.0)	44	(22.4)	23	(26.1)	39	(20.2)	21	(23.9)	38	(19.9)	20	(23.3)
Missing	11	(5.6)	13	(14.8)	34	(17.3)	10	(11.4)	66	(34.2)	19	(21.6)	72	(37.7)	24	(27.9)
HDL-C (mmol/L)																
<=1.0	128	(65.0)	59	(67.0)	105	(53.6)	54	(61.4)	77	(39.9)	54	(61.4)	66	(34.6)	42	(48.8)

>1.0	64	(32.5)	19	(21.6)	66	(33.7)	26	(29.5)	52	(26.9)	16	(18.2)	58	(30.4)	23	(26.7)
Missing	5	(2.5)	10	(11.4)	25	(12.8)	8	(9.1)	64	(33.2)	18	(20.5)	67	(35.1)	21	(24.4)
Triglycerides (mmol/L)																
>=2.0	55	(27.9)	25	(28.4)	52	(26.5)	37	(42.0)	45	(23.3)	35	(39.8)	0	(0.0)	0	(0.0)
<2.0	137	(69.5)	53	(60.2)	119	(60.7)	43	(48.9)	83	(43.0)	32	(36.4)	0	(0.0)	0	(0.0)
Missing	5	(2.5)	10	(11.4)	25	(12.8)	8	(9.1)	65	(33.7)	21	(23.9)	191	(100.0)	86	(100.0)
eGFR (mL/min/1.73m2)																
Stage4/5 (<=29 or on dialysis)	8	(4.1)	3	(3.4)	8	(4.1)	6	(6.8)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Stage3B (30-44)	12	(6.1)	9	(10.2)	4	(2.0)	4	(4.5)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Stage3A (45-59)	20	(10.2)	11	(12.5)	21	(10.7)	14	(15.9)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Stage2 (60-89)	83	(42.1)	26	(29.5)	61	(31.1)	22	(25.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Stage1 (>=90)	73	(37.1)	33	(37.5)	84	(42.9)	42	(47.7)	0	(0.0)	0	(0.0)	0	(0.0)	1	(1.2)
Missing	1	(0.5)	6	(6.8)	18	(9.2)	0	(0.0)	193	(100.0)	88	(100.0)	191	(100.0)	85	(98.8)
HbA1c - Insulin prescription																
Prescribed Insulin																
Hba1c <8.5%	20	(10.2)	8	(9.1)	17	(8.7)	6	(6.8)	0	(0.0)	0	(0.0)	2	(1.0)	0	(0.0)
Hba1c >=8.5%	37	(18.8)	18	(20.5)	35	(17.9)	26	(29.5)	1	(0.5)	0	(0.0)	0	(0.0)	0	(0.0)

Missing	0	(0.0)	0	(0.0)	2	(1.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Not prescribed insulin																
Hba1c <8.5%	110	(55.8)	40	(45.5)	98	(50.0)	40	(45.5)	105	(54.4)	46	(52.3)	88	(46.1)	39	(45.3)
Hba1c >=8.5%	30	(15.2)	13	(14.8)	30	(15.3)	14	(15.9)	55	(28.5)	34	(38.6)	49	(25.7)	34	(39.5)
Missing	0	(0.0)	9	(10.2)	14	(7.1)	2	(2.3)	32	(16.6)	8	(9.1)	52	(27.2)	13	(15.1)
Haemoglobin (g/L)																
<100	2	(1.0)	3	(3.4)	4	(2.0)	3	(3.4)	4	(2.1)	3	(3.4)	2	(1.0)	2	(2.3)
100-115	15	(7.6)	6	(6.8)	18	(9.2)	10	(11.4)	21	(10.9)	11	(12.5)	14	(7.3)	7	(8.1)
>115	172	(87.3)	69	(78.4)	154	(78.6)	71	(80.7)	135	(69.9)	68	(77.3)	118	(61.8)	66	(76.7)
Missing	8	(4.1)	10	(11.4)	20	(10.2)	4	(4.5)	33	(17.1)	6	(6.8)	57	(29.8)	11	(12.8)
Urinary albumin excretion (mg/L)																
>=20.0	46	(23.4)	24	(27.3)	48	(24.5)	27	(30.7)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
<20.0	134	(68.0)	43	(48.9)	119	(60.7)	47	(53.4)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
Missing	17	(8.6)	21	(23.9)	29	(14.8)	14	(15.9)	193	(100.0)	88	(100.0)	191	(100.0)	86	(100.0)

LDL and HDL cholesterol levels were worse at baseline in the Western group than the Eastern group and appeared to improve in the Eastern group over the audit period to 2015. However, by 2015 there is a large number of missing tests in all sites. Triglycerides, which are a key risk factor for cardiovascular deaths, were apparently not done at all in 2015 in any sites.

Renal failure (progression measured by eGFR derived from serum creatinine, which should be done at least annually for all diabetics) is a major complication in the Torres Strait. Renal function was not recorded for any of the diabetics in 2014 or 2015. Similarly, for Urinary ACR, another key measure of renal function.

Other clinical measures important to diabetes care

BMI, Waist circumference, blood pressure, tobacco and alcohol were recorded for nearly 100% of participants at baseline (2012) in the Eastern group but the Western group had large numbers of missing values for these. These are measures usually done by health workers and/or nurses on site and do not depend on blood tests.

At follow-up (2015) there were very large proportions of clients who did not get these checks done, especially BP, smoking and WC measures. Overall, it appears that over the 4 years there was a decline in these services recorded for the clients with diabetes in all sites. For those who did have these checks done, there appeared to be better BP control in the Eastern group (Table 4).

Table 4 - Body measures and behavioural characteristics of Torres Strait Islanders with diabetes according to Chronic Disease Guidelines, by Eastern and Western groups, 2012-2015

Target measures	Baseline (2012)				Follow up (2013)				Follow up (2014)				Follow up (2015)			
	Eastern Group		Western Group		Eastern Group		Western Group		Eastern Group		Western Group		Eastern Group		Western Group	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Status																
Alive	**197**		**88**		**196**		**88**		**193**		**88**		**191**		**86**	
Deceased	**0**		**0**		**1**		**0**		**4**		**0**		**6**		**2**	
Body Mass Index (kg/m^2)																
Low-average (<25)	21	(10.7)	3	(3.4)	20	(10.2)	1	(1.1)	15	(7.8)	2	(2.3)	15	(7.9)	4	(4.7)
Overweight (25-29.9)	52	(26.4)	5	(5.7)	46	(23.5)	7	(8.0)	46	(23.8)	12	(13.6)	37	(19.4)	8	(9.3)
Obese-Moderate (30-34.9)	59	(29.9)	19	(21.6)	54	(27.6)	23	(26.1)	46	(23.8)	25	(28.4)	45	(23.6)	27	(31.4)
Obese-Severe (35-39.9)	33	(16.8)	11	(12.5)	32	(16.3)	12	(13.6)	25	(13.0)	17	(19.3)	22	(11.5)	15	(17.4)
Obese- Very severe (>=40)	32	(16.2)	13	(14.8)	27	(13.8)	15	(17.0)	25	(13.0)	10	(11.4)	26	(13.6)	11	(12.8)
Missing	0	(0.0)	37	(42.0)	17	(8.7)	30	(34.1)	36	(18.7)	22	(25.0)	46	(24.1)	21	(24.4)

Blood Pressure (mmHg)

>=130/80	130	(66.0)	41	(46.6)	105	(53.6)	50	(56.8)	99	(51.3)	50	(56.8)	100	(52.4)	55	(64.0)
<130/80	67	(34.0)	26	(29.5)	74	(37.8)	37	(42.0)	68	(35.2)	32	(36.4)	53	(27.7)	21	(24.4)
Missing	0	(0.0)	21	(23.9)	17	(8.7)	1	(1.1)	26	(13.5)	6	(6.8)	38	(19.9)	10	(11.6)

Smoking

No	154	(78.2)	36	(40.9)	139	(70.9)	43	(48.9)	124	(64.2)	23	(26.1)	121	(63.4)	28	(32.6)
Yes	41	(20.8)	10	(11.4)	37	(18.9)	13	(14.8)	30	(15.5)	6	(6.8)	31	(16.2)	8	(9.3)
Missing	2	(1.0)	42	(47.7)	20	(10.2)	32	(36.4)	39	(20.2)	59	(67.0)	39	(20.4)	50	(58.1)

Alcohol (standard drinks)

None	149	(75.6)	27	(30.7)	120	(61.2)	28	(31.8)	81	(41.1)	7	(8.0)	30	(15.7)	12	(14.0)
<=2	27	(13.7)	4	(4.5)	25	(12.8)	9	(10.2)	1	(0.5)	0	(0.0)	0	(0.0)	0	(0.0)
>2	16	(8.1)	4	(4.5)	16	(8.2)	4	(4.5)	3	(1.6)	1	(1.1)	0	(0.0)	0	(0.0)
Missing	5	(2.5)	53	(60.2)	35	(17.9)	47	(53.4)	181	(93.8)	80	(90.9)	161	(84.3)	74	(86.0)

Waist circumference (cm)																
Healthy (<80 females, <94 males)	12	(6.1)	0	(0.0)	14	(7.1)	1	(1.1)	3	(1.6)	0	(0.0)	3	(1.6)	1	(1.2)
High risk (80-88 females, 94-102 males)	26	(13.2)	1	(1.1)	20	(10.2)	2	(2.3)	12	(6.2)	6	(6.8)	8	(4.2)	5	(5.8)
Very high risk (>88 females, >102 males)	151	(76.6)	25	(28.4)	139	(70.9)	28	(31.8)	83	(43.0)	17	(19.3)	51	(26.7)	8	(9.3)
Missing	8	(4.1)	62	(70.5)	23	(11.7)	57	(64.8)	95	(49.2)	65	(73.9)	129	(67.5)	72	(83.7)

Discussion and Conclusion

The Department of Health Strategic Plan 2016-2020 document outlines a strategy to improve equitable health outcomes, by providing services to address chronic disease and improve “Closing the Health Gap” targets for Aboriginal and Torres Strait Islander Queenslanders [6]. Diabetic patients who reside in the remote Islands of the Torres Strait region of Queensland are more disadvantaged with respect to availability of chronic care services to address the increasing prevalence of diabetes. This study found that a dedicated and experienced RN in diabetes care and management at baseline (2012 -13) was effective in completing diabetes care process according to the Chronic Disease Guidelines, however this was not sustained after this dedicated role was discontinued. This highlights the need for a systematic approach to chronic care which includes ongoing clinical audit and review following a continuous clinical quality improvement framework, rather than relying on a single individual. A high percentage of GPMP and TCA were completed with an increase of referrals compared to the comparator group. Although in the two years without the RN (2014-15) glycaemic control was constant in the Eastern Group, however, a significant decrease in care planning, referrals and number of consultations between 2012-2015 occurred in all sites. Renal function test (eGFR, Urinary ACR) records were limited (2/285) for any patient 2014-15. Other possible explanations for the large amounts of missing data for 2014-15 in all communities could include patients moving to another location, died, poor data extract from the patient information system or care process were not complete according to the Chronic Disease Guidelines. This requires further investigation.

A similar study in remote communities in far North Queensland, investigating a health worker led case management approach to Type 2 diabetes patients demonstrated effectiveness in some diabetes care process and glycaemic over 18 months [7]. Utilising Indigenous Health Workers to improve care coordination is insufficient to improve diabetes outcomes [8], and a poor investment by standard economic metrics [9]. Nurse led models in other populations have shown to be acceptable and feasible to health service providers and patients [10].

Limitations of this study included clinical measures extracted from the existing patient information system (Best Practice) alone, not from AUSLAB (Clinical and Scientific Information System).

Studies from other settings suggest better engagement with primary care services, together with improved diet, physical activity and appropriate medication (self-management) can improve clinical outcomes and quality of life for patients and their families. Local clinical staff could benefit from a greater degree of Indigenous clinical leadership, together with a closer working relationship with clinical services, especially medical, allied health and mental health. This will ensure the annual cycle of care is completed for all chronic care patients; undertake regular review of Key Performance Indicators attached to chronic disease management including reporting on clinical indicators.

List of Abbreviations

BMI – Body Mass Index

GPMP – GP management plans

Hba1c - Glycosylated Haemoglobin Concentration

RN – Registered Nurse

TCA – Team Care Arrangements

TCHHS – Torres and Cape Hospital and Health Service

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respects to the research, authorship and/or publication of this report

Authors' Contribution

ST: Prepared the manuscript, developed the research design with assistance of RM. Undertook initial community engagement, patient recruitment and data collection 2012-2013.

FT: Conducted the statistical analysis and manuscript development

RM: Contributed to the development of the research design, project proposal and manuscript development and editing.

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Chapter. 8: Doctoral Conference Presentation / Extended Doctoral Attachment

8.1 Introduction

This chapter briefly outlines the various placements and conference presentations undertaken during the Doctor of Public Health Degree. Firstly, the Doctoral Conference Presentation is a core component of this doctorate. Students demonstrate a high-level capability of communicating effectively in public professional forums of their public health peers. Successful completion of this subject is a necessary prerequisite for the award of Doctor of Public Health (see Appendix B, Doctoral Conference Presentation report). The conference presentation outlined below derived from the research.

Table 8.1
Conferences attended and presented

Conference	Date and Location of Conference	Conference presentation: Title	Type of presentation
The Annual Scientific Meeting of the Australian Diabetes Society and the Australian Diabetes Educators Association	28th August 2014, Melbourne, Victoria, Australia.	“Psychological Insulin Resistance amongst Torres Strait Islanders with Type 2 diabetes: Study protocol	Poster - National
National Institute of Diabetes and Digestive and Kidney Diseases - Branch Conference.	April 24th, 2015 Phoenix, Arizona, United States of America.	"Improving Diabetes Care and Management in Torres Strait Remote Primary Health Care Settings."	Oral – International
The Annual Scientific Meeting of the Australian Diabetes Society and the Australian Diabetes Educators Association.	27th August 2015 Adelaide, South Australia, Australia.	“Depression and Diabetes in the Torres Strait”	Oral – National
National Primary Health Care Conference.	03rd November 2015 Canberra, Australian Capital Territory, Australia.	"Barriers to insulin treatment among Torres Strait Islanders with poorly controlled diabetes."	Oral – National

Secondly, The Extended Doctoral Attachment forms part of this degree, with the opportunity to expand and explore future research opportunities.

The Extended Doctoral Attachment - students are expected to spend time working in an area of Public Health relevant to their Doctor of Public Health thesis. The Doctor of Public Health Placement may be in any area of Public

Health Research. The placement will take place in a recognised, national, regional or International center of excellence related to the research topics.

The Doctor of Public Health degree has initiated international collaboration and knowledge exchange. This has been the highlight of the doctoral candidature.

8.2 The Extended Doctoral Attachment

This placement took place the University of California, San Diego, California, USA, from 12th January until 24th April 2015 (see Appendix C, Extended Doctoral Attachment report). This Placement was correlated to Study 1 and 2.

8.3 Collaboration and Exchange

The Collaboration and Exchange awards help Australian Heart Foundation funded scholars visit other research facilities to Collaborate and share knowledge. This award offers funding to visit research facilities across Australia and overseas, to develop new national and international collaborations (see Appendix D, Letter of Offer and Conditions of Award).

This award was held at the Banting & Best Diabetes Centre at the University of Toronto, Canada, between 03/06/2016 – 23/06/2016 and later at Management of Department of Professional Communication in Electronic Media and Social Media –University of Duisburg –Essen, Germany from 27/06/2016 – 08/07/2016. This placement was associated with Study 3.

This award also gave the opportunity to attend The Expert Mechanism on the Rights of Indigenous Peoples at the United Nations, Geneva, Switzerland during 11/07/2016 – 15/07/2016.

The Ninth session of the Expert Mechanism on the Rights of Indigenous Peoples provides the Human Rights Council with thematic advice, in the form of studies and research on the rights of Indigenous peoples as directed by the council (see Plate 8.1).

Plate 8.1 Mayor Vonda Malone and Sean Taylor at The Expert Mechanism on the Rights of Indigenous Peoples at the United Nations, Geneva, Switzerland, 2016.

8.4 International Knowledge Exchange and Future Collaboration

- Centre for Chronic Disease Prevention – James Cook University, Cairns, Australia
- The Behavioural Diabetes Institute, San Diego, United States of America
- Taking Control of Your Diabetes Institute, San Diego, United States of America
- National Institute of Health, Phoenix, United States of America
- Global Health – Diabetes Research Group, Toronto, Canada
- Clinical Research Institute of Montreal, Montreal, Canada

Chapter. 9: Discussion, Conclusion and Recommendations

9.1 Introduction

The fundamental aim of this thesis was to provide epidemiological evidence to support the development of community level interventions to address major risk factors associated with Type 2 Diabetes in the Torres Strait region. Firstly, review patient level factors on behavioural aspects of diabetes management including psychological insulin resistance and depression amongst Torres Strait Islanders with Type 2 diabetes. Secondly, evaluate health service factors that impact on diabetes care and management in remote Torres Strait Primary Health Centres. The intent of this final chapter is not to repeat what has already been discussed in previous chapters but rather to consider what the findings of the research mean regarding the current literature. The implications of the research findings and how this may influence the Torres and Cape Hospital and Health Service improve clinical service delivery around Diabetes Care and Management.

The overall research highlighted some key findings that were absent in the current literature that may assist in improving diabetes care and management in the remote Torres Strait communities in Queensland, Australia. Chapter 2 outlined three gaps that were identified from ten studies (1). Understanding barriers to quality use of medicines as opposed to identifying what patients are prescribed (2). Behavioural change to improve self-management of T2DM (3). A more detailed diabetes workflow that is sustainable and affordable to health service providers. Study 1, 2 and 3 examine the identified gaps in the literature, the results as previously mentioned in this thesis are published in Chapter 5, six and seven.

The Torres Strait Islanders as previously referred to in Chapter 1 are historically, culturally and ethnically distinct from Aboriginal Australians. The population of the Torres Strait region has an estimated population of 15, 000 in 2011. There are at least 274 islands scattered over the Torres Strait region but only seventeen islands are inhabited. Eight of the seventeen inhabited

islands participated in the overall research. The eight participating communities, previously discussed in Chapter 7 where chosen by the former Executive Team - Torres Strait & Northern Peninsula Hospital and Health Service in 2012. The population of the eight communities in 2011 was 1887 residents - fifteen percent had known diabetes. Study 1 and Study 2 describe participants who consented into the overall research from Mer Island, Darnley Island, Stephen Island, Saibai Island and Yorke Island. Study 3 participants were clustered into two groups- Eastern Group and Western Group. The Eastern Group were the participants who consented from Mer Island, Darnley Island, Stephen Island, Saibai Island and Yorke Island. The Western Group participants did not consent to the overall research; however, ethics approval was achieved for clinical audits on those participants with no participant interaction.

9.2 Study 1 Discussion

Limited studies in the Torres Strait region have described behavioural aspects of diabetes management and care or barriers to the use of medications. Study 1, is the first known survey in the Torres Strait region, also, in any Indigenous Australian communities to explore psychological insulin resistance (PIR) amongst patients with poorly controlled diabetes and who were not taking insulin. The BITQ survey is a reliable and valid measure of psychological insulin resistance in patients with Type 2 diabetes. This instrument can be used by both clinicians and researchers to assess barriers to insulin treatment. This survey and the ITAS tool was not validated in this papulation as we used a local researcher who could speak the local language. The ITAS tool can be used in insulin –treated patients to assess positive and negative perceptions regarding insulin treatment. Both surveys were used and recommended by experts in the field. Although the sample size was small in this study, 100% (n=30) consented to participate. This study demonstrated mostly negative perceptions towards insulin therapy, potentially a barrier to self-management of diabetes. The mean HbA1c was higher for those who were prescribed insulin than those who were not. This suggests that physicians have a higher threshold for initiating insulin in this population than others. Given the relative

infrequent availability of primary care or specialist physicians in these communities, perhaps it is appropriate to have a higher threshold. This need to be investigated further.

Other studies in different populations, showed much lower negative attitudes and much higher positive attitude than the Torres Strait Islanders. However, the results suggest that perceived barriers to insulin treatment are high in Torres Strait Islanders, in particular among those who are older with fewer years of formal education.

This represents a challenge for diabetes educators and other clinicians to provide appropriate training sessions to patients on the importance of insulin therapy. Health promotion materials advocating the benefits and positives of insulin therapy need to be expressed clearly and suitable for the target audience. Language barriers may influence misunderstanding or misinterpretation; however, a study by Taylor, McDermott and Li (2012), identified Torres Strait Islanders demonstrated adequate functional health literacy [1]. The finding suggests patients are capable of reading, understanding, and interpret the primary medical text. Evidence from existing literature discusses personal behaviours cause more than 50% of chronic diseases [2]. Day–to-day management of diabetes is primary the responsibility of the person and his/her family with ongoing support from local health professionals.

Changing behaviour to increase medication adherence especially insulin therapy requires ongoing professional support. This shift will require further investigation to adapt a model of care that supports changing patient's behaviour. Designing and implementing such a program may be difficult and challenging, however, not impossible. The use of psychologists or appropriately experienced and trained health professionals to address the complex mix of medical, behavioural and social change may be an appropriate strategy in the Torres Strait region. Evidence has demonstrated that psychology plays an integral role in diabetes self-management and care, including an understanding of the individual differences and ability to initiate and maintain behaviour change [3]. Current chronic guidelines do not utilise this health professional who

has shown to be of great benefit to patients who struggle or resist medications to manage their diabetes in other populations.

The Diabetes Team (Diabetes Educator, Dietician and Podiatrist), Remote Area Nurses and Indigenous Health Workers could benefit from the recommendations of a psychologist when engaging people who struggle with self-management and poorly controlled diabetes. Diabetes Educators and Remote Area Nurses must focus on the person, their barriers towards health care and adopt a more patient-centred approach. A patient-centred approach has been described as respecting the patient's preferences and diversity in the decision –making process when planning the patient's care and treatment [4]. Patient -centred care also includes the opportunity for patients to comment, ask questions and make complaints about their current health care. Through this approach, health professionals are required as per standard practice to explain to patients their current diabetes care, explore their feelings and beliefs and expectations. This method has shown in other populations to increase patient satisfaction, improve the quality of life, engagement and task orientation and reduce anxiety [5]. The geographical location of the Torre Strait region and the burden of travel cost to the health service and patients for ongoing specialist appointments can theoretically be reduced if this model is adopted. Evidence supporting patient –centred care involving a multidisciplinary team (Medical Officers, Psychologist, Diabetes Team, Remote Area Nurses and Indigenous Health workers) is more efficient, potentially reducing diagnostic tests and unnecessary referrals. Further investigation is needed in the Torres Strait region to explore the benefits of a psychologist and a patient-centered care model by Remote Area Nurses for the many local people who are diagnosed with Type 2 diabetes.

9.3 Study 2 Discussion

The link between depression and diabetes amongst Torres Strait Islanders was described for the first time in this region. Depression has been investigated in Aboriginal and Torres Strait Islander populations in other parts of Australia, but not exclusively in the Torres Strait region or amongst diabetic patients in the Torres Strait region. Study 2 identified relatively low mean PHQ-9 score

compared with general surveys and previous studies of depression among people with diabetes in the Australian population 5.1 vs. 7.9. Moderate-severe depression scores were lower in this sample compared to other studies among people with diabetes 12.2% vs. 22.6%. However, the association between lower education, unemployment and depression seen in this study is similar to other settings in Australia. This study found no association between glycaemic control, BMI, and depression. A multivariate analysis of depression scores was performed to predict the association between PHQ-9 scores and numerous variables. The only two factors found to be associated with depression (screen time and exercise) could be effects of depression, rather than causes, however, our study concluded simple health promotion activities could improve mental health and general well-being in this population.

Understanding patient behaviour can assist service providers to deliver appropriate service delivery that involves clients input. Evidence from a meta-analysis by Mezuk and Colleagues suggested a weaker correlation between existing diabetes and the risk of depression [6]. Si et al. study concluded a greater need for diagnosing and managing depression [7]; this supports the importance of a psychologist or a credential health professional as previously mentioned above. Although mild self-reported depression was identified in Torres Strait Islander with diabetes using the PHQ-9 instrument, this was not a clinical diagnosis. Fisher et al., 2007, describe people with diabetes who have concerns about perceived support, emotional burden, access to quality health and self-management as diabetes –related distress [8]. People living with diabetes may be angry, scared, and feel that diabetes controls their lives. Some people with diabetes often express concerns about the serious long term-complications of poorly controlled diabetes. A study in the United States of America investigating factors associated with diabetes- related distress from 267adults with Type 2 diabetes found younger people might have additional stressors of family responsibilities, work, and financial challenges. BMI was significantly related to diabetes – related distress in these populations [9]. However, in the Torres Strait Study 2 found no association between BMI and depression. Although the PhQ-9 tool did not collect people's attitudes towards their diabetes, diabetes-related distress could be present amongst this

population. Further investigation is warranted amongst Torres Strait Islander to investigate the association between distress and diabetes and the impact on diabetes care and management.

Health professionals providing diabetes education may need to include strategies that increase self-efficacy to improve healthy weight through diet and exercise. A greater need for education groups discussing self-efficacy and attitudes towards self-management should be considered in this population. However, family and carer support is limited in this setting and requires a greater focus to those who care for family members diagnosed with Type 2 diabetes. A tokenistic approach by employing Indigenous Health Workers with limited knowledge and experience in self-efficacy towards better self-management of diabetes is not recommended. On the other hand, current health workers with a Certificate IV in Primary Health Care or higher need to focus on a family-centred care. This method is beneficial for Indigenous Health Workers to liaise with patient's families and gain family support towards better self-management of diabetes. The family-centred care model involves family members actively engaging and collaborating in the process of care delivery. The Centred family care should complement the goals recommended in the patient –centred care involving the multidisciplinary team at a family level [10]. Indigenous Health Workers are community members of the local communities who play a more influential role amongst patient's family and friends, gain their trust and provide recommendations if needed to other health professionals on behalf of individual households. The Indigenous Health Workers can provide ongoing support to families are carers and mediate between other health professionals and the patient. Family members of people diagnosed with diabetes at most times struggle to assist in their care; this can be a potential barrier to self-management. A growing body of evidence in the literature describes a family –centred care model which can improve health, mental health and wellbeing of the patient, also self-management of diabetes [11]. The opportunity to enhance skills knowledge and qualifications of Health Workers to support family-centred care may be suitable in the longevity of support to the patient, families and the carer. The family centred care needs to be considered

in any project aiming to improve diabetes care and management in remote communities.

9.4 Study 3 Discussion

Study 3 reviewed the provision of diabetes services and the impact of diabetes management on eight remote Torres Strait Islander communities. A particular workflow outlining an experience Indigenous Registered Nurse with formal tertiary training in diabetes care and management and vast experience in remote Indigenous communities provided diabetes care and management to five communities in Eastern group of islands in the Torres Strait region between 2012 – 2013 was noted. This role provided educational advice on patient's clinical care process and the importance of attending clinical appointments according to the chronic disease guidelines. Quality time with individual participants to understand barriers to attending health appointments was taking into consideration when arranging clinical appointments at the local primary health care centre. Although a high attendance rate was seen in 2012 and 2013 in the Eastern group, this was not sustained after the role was discontinued. There was a significant decrease in the provision of diabetes care planning, referrals and clinical measures important to diabetes care and actual numbers of consultations in all eight sites. The reduction in the delivery of diabetes care signifies an alarming problem for managers in these remote islands towards chronic disease management.

Remote Area Nurses are more likely to obtain clinical governance within these remote primary health care sites and provide acute clinical care. However, the high turnover in nursing staff is phenomenal and an ongoing challenge in all rural and isolated locations of Australia. Sustainable and affordable chronic disease programs that provide satisfactory and quality outcomes would not be achievable through a fly-in-fly-out (FIFO) style, however a more local focus. A FIFO model may demonstrate positive results, increase attendance rate if outreach staff can remain in the remote locations for a fixed time, one or two weeks not one or two days. A revisit to the local communities needs to be ongoing on a quarterly basis. Revisiting the communities allows for community members to take full advantage of the services while allowing the program to

filter through the community. A framework with the main performance indicators by all clinical staff in these sites would support better clinical management of chronic disease that supports patient-centred care.

A local approach by McDermott et al. (2003) demonstrated a randomised cluster trial supporting local Indigenous health workers to manage registers, recall and reminder systems, and care plans can improve care processes, control of blood pressure, and preventable complications that result in admission to hospital [12]. The Torres and Cape Hospital and Health Service should consider the study design, combined with the methodology of the Registered Nurses outlined in study 3. Both studies represent the importance of a systematic approach to managing diabetes care in the remote islands of the Torres Strait. However, another appropriate study design by McDermott et al. (2015) investigated if community –based health workers supported by a clinical outreach team [13] would be beneficial to remote primary health care settings focusing on coordination of care and family-centred care. Although the community health workers demonstrated a modest intervention effect, poorly controlled diabetes was still present [14]. The papers deriving from this project to date, while describing implementation failure, do not sufficiently describe the experience, formal education and knowledge of community health workers or the clinical outreach team in working with patients in remote communities. This lack of information implies that the staff in this trial may have had inadequate experiences in remote care. A fuller description of the precise components of the intervention should be included in publications to enable duplication of studies where applicable and to avoid misinterpretation of the outcomes. Further investigation is warranted to explore the full potential of this study design focusing primarily on family centred care, combined with improved care coordination and better communication between the multidisciplinary team.

Comparing Indigenous Health Workers vs. Remote Area Nurses, both professions seem to lack clinical guidance around chronic disease management in the existing clinical organisation structure. A more sophisticated patient information system that produces daily reports for existing ground staff may support an effective weekly task agenda. The Torres and Cape Hospital and Health Service currently operating two patient information

systems (1. “Best Practice” 2. FERRET). "Best Practice" is a patient information system designed by Dr Frank Pyefinch, a pioneer of clinical software in Australia. Best Practice Clinical is a Structured Query Language application that is “rich in functionality while being fast, stable and robust. The software benefits general practice, allied health, the medical and surgical specialist with a range of integration, connectivity and deployment tools to enhance health outcomes for General Practice”. This software allows health professionals maintain quality electronic patient records, transfer information securely between agents (e.g. results from pathology services) and manage preventative health care protocols for patients. “Best Practice” was the preferred patient information system used in Study 3 to enter all clinical data as directed by the former Executive Team of the Torres Strait & Northern Peninsula Area Hospital and Health Service.

FERRET, on the other hand, is an electronic patient information, reminder and recall system. The system supports the delivery of health care, including, early detection, management of chronic disease and primary prevention. Medical Practitioners, Nurses, Health Workers, Allied Health, and administration staff can enter information. These workers enter data after or during individual client consults. The primary focus of this system is achieving health outcomes for clients rather than just monitoring inputs and activities related to customer care. This system supports a population health model and quality improvement purposes.

Although FERRET supports a population health model and management of chronic disease management including diabetes, it is not readily compatible with the other core services in the Remote Primary Health Care settings. This makes the provision of daily service in these sites challenging with a low uptake from Remote Area Nurses and other clinicians. Indigenous Health Workers are more likely to use FERRET to support recalls. “Best Practice” is not compatible with a population health model or quality improvement in comparison to FERRET, however, only recalls patients if staff manually enters the recall into the appropriate space. The weak data extracted from “Best Practice” may have been the reason why missing variables were evident in this study and requires further investigation to improve reporting of data. GPMCP, TCA and diabetes

cycle of care templates are available in "Best Practice” for clinicians to use within their practice, yet are more suitable to a standard GP setting rather than a shared care model for chronic conditions.

“Best Practice” and FERRET are relevant and practical patient information systems, yet both do not support the primary health care services in the outer island primary health care settings. A more sophisticated patient information system that captures the principal features of “Best Practice” and FERRET with an approach to provide daily and weekly tasks would be more appropriate for this setting. This will allow the high turnover of staff to follow a formal procedure to capture all relevant work that needs to be completed according to existing clinical guidelines. Demand for a systemic approach to chronic care, including clinical audits and review following continues clinical quality framework, rather than relying on a single individual is mandatory.

A single staff member alone may not improve clinical attendance rates. Due to the high staff turnover in all professions, poor communication skills and language barriers, the Torres and Cape Hospital and Health Service could benefit from an application tool through social media that supports chronic disease patients and the chronic disease guidelines via the existing patient information system. Patient confidentiality needs to be considered and explored intensively. The application tool may improve attendance of clinical appointments and better communication between patients and health services through a sophisticated technology method.

9.5 International Placements

9.5.1 San Diego – United States of America

Patient Level Factors - The Extended Doctoral Attachment placement, based at the Behavioural Diabetes Institute (BDI) – San Diego, provided applied skills and experience in an extended work placement environment related to Study 1 and two. I had the opportunity to exchange knowledge on many occasions with patients with Type one and Two diabetes to discuss nine key personal barriers with Clinical Associate Professor William Polonsky (Director – BDI) in San Diego.

1. Chronic depression.
2. Poor coping styles.
3. Eating disorders.
4. Lack of knowledge about diabetes.
5. Inaccurate health beliefs.
6. Negative feelings about diabetes.
7. Fear of injections and hypoglycaemia.
8. Fear and frustration about weight gain.
9. Unrealistic or unclear expectations about self-care.

Six strategies for patients with diabetes towards building a better relationship with health care providers derived from these discussions:

1. Prepare for your visit.
2. Ask about your results of your medical test.
3. Use the ABC's of effective communication: Assertiveness, brevity, and clarity.
4. Be an active participant in deciding about changes in your diabetes care (especially your self-care).
5. Take the risk of being open and honest
6. Be aware of the pressure under which your health care team must operate.

The opportunity to attend the "Taking Control of Your Diabetes" (TCOYD) conference gave an insight towards behavioural issues within a diverse population in California with patients diagnosed with diabetes. The results from Study 1 and two reflect the same problems discussed at this conference. Three major themes have never lost their importance or magnitude during any of the TCOYD conferences:

1. You have the primary responsibility for taking control of your diabetes
2. You are your own best advocate
3. Be smart and be persistent.

These themes sound straightforward and ideal for patients in the Torres Strait region, however, in reality, the challenge is ongoing and needs to be explored.

9.5.2 Toronto - Canada

Health Service Factors - The international clinical placement at the Banting and Best Diabetes Centre at the University of Toronto complemented Study 3. This internship gave an insight into diabetes model of care, data linkage and understanding Aboriginal communities in Ontario, Canada. This knowledge exchange with various research centres gave a different perspective in service delivery compared to the Torres Strait region. The Torres Strait as previously mentioned on numerous occasion throughout this thesis has a high prevalence of Type 2 diabetes. The current Diabetes Team on Thursday Island does not supplement the figures. The diabetes team is limited to one diabetes educator, one podiatrist and one dietician. Outreach Teams in Ontario seem to support people living with prediabetes or diabetes. They offer one – on -one or group consultations on lifestyle behaviours and support towards better glycaemic control. The diabetes team in Torres Strait offers more an outreach service providing one – two days' clinical visits. Similar to the TCHHS, a majority of their services adapt to culturally specific needs across the diverse languages, backgrounds, and barriers to health. However, unlike the NS-TCHHS a nurse-led model of chronic disease, oppose to an Indigenous health worker led model. Primary Health Care and the approach to diabetes care in remote communities are more advance in the Torres Strait region compared to Ontario, Canada from observation during the clinical placement. This statement may be incorrect, however, professionally, the two populations and existing research centres could benefit from a collaboration approach to improving health service delivery and data linkage in both regions.

9.6 Reflection on the fieldwork

The fieldwork for the Doctor of Public research was a challenge and a memorable journey. It is highly recommended that any researchers wanting to pursue field research in remote Aboriginal and Torres Strait Islander are not committed to other priorities. The extensive time away from the base can have an impact on the researcher's personal relationship with their partners or other commitments. During 2012 – 2014 the Torres Strait and Northern Peninsula Area Hospital and Health Service created a Project Officer – Chronic Care

Systems Management position. This post gave me the opportunity to recruit participants in Study 1, 2 and 3 and provide the clinical workflow as outlined in Chapter 7. The credentials of being an employee of the current Hospital and Health Service allowed access to both patient information systems, clinical and scientific information system, patient files, staff accommodation, office space and access to a vehicle if needed. Accessing these services externally can be a lengthy and tedious process. Later in 2012, a 0.5 fellowship from the Centre for Research Excellence in Chronic Disease Prevention in Rural and Remote Communities contributed to the research project. This joint role caused some confusion within staff at the Torres Strait & Northern Peninsula Area Hospital and Health Service who were not involved in the original discussion and provided barriers to accommodation on one of the participating sites. This issue was later resolved, however, could have been avoided if better communication strategies were situated between visiting and new staff and existing staff members. Conducting research in the Torres Strait Outer Island Primary Health Care Settings requires the researcher to be independent and able to work independently and collaboratively. Local staff in the individual communities are willing to support researchers, however, only when time permits. The researcher needs to be able to communicate and work effectively under community protocols. An essential ingredient to achieving your goals would be to find a key player in the community and exchange knowledge. This key player would be able to assist when needed if the local staffs are attending to other commitments.

Time management plays an important role when being in the field - coordinating appointments, clinical work, interviews, audits, providing assistance to the other clinicians while you're in their clinics. I spent six – eight weeks in the five participating communities to ensure all clinical work was completed to achieve the required goals. A high response and attendance rate from participants to all the appointments was achieved in the overall research. A full explanation of the purpose of the required appointment and how this will benefit the individual and community demonstrated to be effective. Participants actively engaged in the research projects as they witness the researcher was engaging, open-minded, outgoing and willing to listen and learn from their

experiences with diabetes. They did not see a researcher only wanting data and taking their information that will only benefit the researcher and not everyone involved. Over time during the life of the field work, community members expressed how proud and respect my passion towards improving diabetes care in the remote Torres Strait and the overall health issues of Aboriginal and Torres Strait Islander people. The outcomes achieved was demonstrated by the nomination and winning the Ken O'Brien Achiever Award at the 2014 Torres Strait Employment and Training Recognition Awards. The staff at the Saibai Island Primary Health Care Centre gave me a wood carving of a crocodile that was handmade by a local artist for my contribution to their clinic. The crocodile now lives in my office at the Centre for Chronic Disease Prevention as a token of my field work along with the award from the Torres Strait Employment and Training Recognition Awards.

I had the opportunity to take a sixth-year dental student from James Cook University on one of my outer island field trips. The student had a chance to examine the dental care of all the diabetic patients on Yorke Island. The dental student also assessed 44 primary school aged children aged 4 to 12. This was the first dental professional to visit the island in eight years, meaning that many of the children had no experience with a dentist or what a dental visit involved. Furthermore, vast amounts of untreated dental caries (decay) and periodontal disease were present throughout the community. The common presentation for type 2 diabetes patients was generalised periodontal disease, with many of the patients having poorly controlled blood glucose levels. None were aware of the effects of diabetes on oral health but were interested to learn that poor diabetes controlled led to increased gum disease and subsequent earlier loss of teeth. The general attitude of patients was that their teeth would simply slowly get looser until they needed to be extracted. However, after oral hygiene education sessions with each patient and increased knowledge that this was preventable, a much more positive attitude towards trying to retain teeth through tooth and periodontal care was noticed. After all, knowledge is power and that is something these patients dearly need. Further investigation is warranted around diabetes and oral health.

This trip also gave the student the opportunity to provide public health education sessions at the local Primary School. The dental student was successful and found this approach rewarding.

During the life of my Doctor of Public Health Studies, the Torres Strait Islanders Media Association or more commonly known “Radio 4 Meriba Wakai" (4MW) on Thursday Island took an interest in my research. On some occasions, I was interviewed about my research journey and the progress. The media helped informed those participants who consented to the overall research project and members of the Torres Strait Region my ongoing research mission in the Torres Strait, the published papers, conference presentations and the International placements deriving from the research.

The Torres Strait region, mostly the outer islands have areas where there is a weak mobile network. Telstra is the only provider to the Torres Strait Region. These black spots can interrupt your project if the use of the internet is required. The Primary Health Care clinics are situated in apparent locations with optimal coverage. The majority of the time, in the evening, the researcher will be alone, the internet can be your best friend. Unless you are required to assist in an emergency situation, however, it unlikely depending on staff. After work walks or social events with local staff can be a great way to debrief your day or having critical friends or colleagues back in your community to release the frustrations of the research or just a general chat. Having these networks is mandatory to keep sane and maintain a healthy well-being in these remote locations. A walk along the beach will become a regular event.

I had the opportunity to be involved and witness some celebrations in the participating communities, which include Mabo Day, Coming of the Light Festival, a wedding, birthday parties and fundraising events. Most of the community members enjoy the company of visitors attending these functions. Attending social events in the communities is worthwhile to maintain the connection with your participants and community. It builds on the trust of the community, adds weight to your research project and your status in the community. The people living on these remote islands are happy, full of life, love to laugh and smile. They are willing to help improve the health of their

communities through the support from government agencies. The overall experience in working with community members in the outer Islands will linger forever. The community greatly appreciate the fieldwork, and the ongoing commitment towards improving health outcomes. Their ongoing support will continue through the years ahead.

9.7 Study Strengths

The overall support obtained from various organisations to support this doctoral research was phenomenal. Maintaining ongoing professional relationship with the primary stakeholders within the area of field research is essential. Providing mutual agreements and commitment to improving health service delivery is a key ingredient to gaining respect from health service providers. Avoiding internal and external politics can influence field research and achieving outcomes.

A key strength of this study, the researcher, was local, spoke local Creole, had strong networks within the community and health service and other organisations. Vast experience working with Aboriginal and Torres Strait Islander people in primary health care, public health and diabetes management and care. Bonevski et al. 2014, identified in a systematic review earlier research in Aboriginal and Torres Strait Islander remote communities or with socially disadvantaged groups have had low response rates to research. The reason for the low response rates includes mistrust in research or researchers, from being mistreated in medical research, a negative impact on communities and health service providers, mostly around misuse of data and burden on health service providers. Perceptions that participation presents no personal benefit to the individual, families or communities and may cause exploitation, stigma, mistreatment or potential harm [15].

Gaining trust from Aboriginal and Torres Strait Islander community members to participate in research is an essential and core component of the project especially the sample size. Using strategies to explain the importance of the research project and the study design to improve the health and well-being of community members living in remote communities can influence your

recruitment rate. 100% (n=198) recruitment rate was demonstrated in the overall study, 29 out of 30 (one participant died before the interview) completed the BITQ and ITAS questionnaire. 95% (n=188) of participants completed the PHQ-9 (5% relocated or passed away during the interview phase) which was embedded in the Diabetes Care Project Survey. The high recruitment rate and survey completion may suggest community members are interested in studies that will make a difference to their health outcomes and improve knowledge that is locally operated.

Another valuable strength to this study was the Extended Doctoral Attachment which forms part of the Doctor of Public Health degree. The international knowledge exchange and

International placements in San Diego – United States of America, Phoenix – United States of America, Toronto - Canada, and Duisburg - Germany has opened opportunities for future collaboration into the Torres Strait region. This opportunity will help improve diabetes care and management in the Torres Strait region through an international collaborative and innovative approach.

9.8 Study Limitations

This study was limited to a small sample completing the BITQ and ITAS questionnaires. The PHQ-9 may overestimate levels of depression among people with diabetes. Certain questions are also somatic symptoms and behaviours associated with diabetes. There was a lack of clinical confirmation of depression from the PHQ-9 score. BITQ, ITAS, and PHQ-9 were not validated in this population, where English is not the first language for many; however, the investigator speaks fluent Creole.

The study was limited to Torres Strait Islanders living in the remote islands of the Torres Strait region, with no comparison to those Torres Strait Islanders living in mainland Australia. Therefore, generalisability is limited. Staff at the Torres and Cape Hospital extracted data from “Best Practice” for 2014 / 2015 - missing variables was evident, this may suggest inadequate data extract from the current patient information system (“Best Practice”).

9.9 Conclusion

In summary, the geographical locations of the Islands in the Torres Strait are isolated, travel is expensive, and the cost of emergency care is phenomenal. Diabetes in the Torres Strait region will continue to accelerate; complications associated with poor glycaemic control will remain a burden to the TCHHS. This requires urgent attention as previous research has mentioned and provided substantial evidence as outlined in chapter 2. We know, from a sample of diabetics in the Torres Strait region, health literacy is not a concern; barriers to insulin therapy is evident and no longer anecdotal evidence. Depression is present amongst patient with T2DM, however, mild, without no clinical diagnoses; planning, referrals and clinical measures important to diabetes care and actual numbers of consultations decreased over a four-year period. The decline in the provision of consultations will continue if the Remote Area Nurses remains to focus primarily on acute care and after hours 'emergency' presentations in the outer islands. A simple recall card and reminder system have achieved positive outcomes in the Torres Strait. Both Indigenous health workers and Remote Area Nurse could benefit from a sophisticated and reliable patient information systems the explores all core services and provides weekly and daily tasks. Better communication between all health staff and community members towards better health is imperative and achievable via a collaborative approach with existing government services, University and Research Centres and other agencies. This has been demonstrated through this research experience.

Study Recommendations

Three recommendations for ongoing research to better improve diabetes care and management in the remote islands of the Torres Strait include:

1. A conference between clients with diabetes and clinicians using established models in similar populations, e.g., Behavioural Diabetes Institute – San Diego and Taking Control of Your Diabetes Institute –San Diego.
2. Improve diabetes management through social media applications.

3. International collaboration monitoring a cohort of Indigenous people with T2DM in Australia (Torres Strait Islanders), United States of America (Pima Indians) and Canada (Canadian Aboriginals).

9.10 Discussion on Recommendations

The first recommendation is a conference between client's diabetes and clinicians using established models in similar populations, e.g., Behavioural Diabetes Institute – San Diego and Taking Control of Your Diabetes Institute – San Diego. This conference will assist people living with diabetes and their carer to become personally empowered to put their diabetes high on their priority list to self-manage their condition or family members condition. This model will involve an international collaboration with the Taking Control of Your Diabetes Institute in San Diego and existing services to collaborate and better understand the many complicated facets of diabetes care. The aim of this project would be to improve communication between health professionals and clients with diabetes, to support the uptake of self-management. Further discussion is required with the Behavioural Diabetes Institute and Taking Control of Your Diabetes Institute for funding and implementation. The second recommendation is to improve diabetes management through social media applications that support diabetes patients via the existing patient information systems. The aim of this research is to improve attendance rates amongst patients with diabetes. This research would be in collaboration with the Management of Department of Professional Communications in Electronic Media / Social Media – University of Duisburg-Essen, Germany. The third recommendation is an International Collaboration approach, monitoring a cohort of Indigenous people with T2DM in Australia (Torres Strait Islanders), United States of America (Pima Indians) and Canada (Canadian Aboriginals). The aim would compare service delivery models and review key performance indicators attached to diabetes management among different Indigenous populations. This would be a collaboration between Centre for Chronic Disease Prevention – James Cook University, The Behavioural Diabetes Institute – San Diego, National Institute of Health, Phoenix – United States of America, Global Health – Diabetes Research Group, Toronto – Canada and the Clinical

Research Institute of Montreal – Canada. This would require a meeting to discuss further steps and research funds.

The evidence provided throughout the three studies, and the three recommendations have provided epidemiological evidence to engage better and support community level interventions to address risk factors associated with Type 2 Diabetes in the Torres Strait. Ongoing and future collaborations with the Torres and Cape Hospital and Health Service is imperative to assist with funding, staff and support to improve clinical outcomes amongst people with diabetes. The Torres and Cape Hospital and Health service should consider research as part of their core business. This would provide evidence base practice to the Torres Strait region.

This doctoral research experience has been a professional journey that will linger forever. The amazing travel time away from the base to collect data has been a challenge to my personal life, however, matured my professional career. The time away to attend the international knowledge exchange was the highlight of this research experience. The local, state, national and international networks will continue to expand, and future collaboration will continue to enhance patient outcomes.

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Appendices

Appendix A: Published Materials in the Thesis – Co-authors' Agreement

Thesis Title:	Improving Diabetes Care and Management in Torres Strait Remote Primary Health Care Settings.		
Name of Candidate:	Sean Matthew Taylor		
Chapter No.	Details of Publication (s) on which chapter is based	Nature and Extent of the intellectual input of each author, including the candidate	I confirm the candidate's contribution to this paper and consent to the inclusion of the paper in this thesis
3	Taylor, S., Usher, K., McDermott, R. Diabetes in Torres Strait Islanders: Challenges and opportunities for remote area nurses. Contemporary Nurse (2013) 46 (1): 46-53.	Taylor wrote the first draft of the paper which was revised with editorial input from Usher and McDermott.	Name: Kim Usher Signature: Name: Robyn McDermott Signature:
4	Taylor,S., McDermott, R. High glycaemia and low uptake of insulin treatment among remote Torres Strait Islanders with diabetes: Implications for service delivery. The Australian Journal of Rural Health (2016).	Taylor conceived the study, collected data from clinical files and prepared the first manuscript. McDermott contributed to the study design and manuscript development.	Name: Robyn McDermott Signature:
5	Taylor, S., Thompson, F. McDermott, Barriers to insulin treatment among Australian Torres Strait Islanders with poorly controlled diabetes. The Australian Journal of Rural Health (2016).	Taylor prepared the manuscript, develop the research design and assisted the supervisory team. Undertook initial community engagement, patient recruitment and data collection. Thompson conducted the statistical analysis and manuscript development. McDermott contributed to the	Name: Fintan Thompson Signature Name: Robyn McDermott Signature:

		development of the research design, project proposal and manuscript development.	
6	Taylor,S,. McDermott, R., Thompson, F., Usher, K. Depression and diabetes in the remote Torres Strait Islands. Health Promotion Journal of Australia (2016).	Taylor prepared the manuscript, develop the research design and assisted the supervisory team. Undertook initial community engagement, patient recruitment and data collection. McDermott contributed to the development of the research design, project proposal and manuscript development. Thompson conducted the statistical analysis and manuscript development. Usher contributed to the manuscript development.	Name: Robyn McDermott Signature: Name: Fintan Thompson Signature: Name: Kim Usher Signature:
7.	Taylor,S., Thompson, F., McDermott, R. Diabetes care in the outer islands of the Torres Strait: Case note audit report, 2012-15	Taylor prepared the manuscript, develop the research design and assisted the supervisory team. Undertook initial community engagement, patient recruitment and data collection. Thompson conducted the statistical analysis and manuscript development. McDermott contributed to the development of the research design, project proposal and manuscript development.	Name: Fintan Thompson Signature: Name: Robyn McDermott Signature:

Appendix B: Doctoral Conference Presentation Report

Sean Taylor

Doctoral Conference Presentation Report – TM6015

Doctor of Public Health – James Cook University

2016

Purpose of Doctoral Conference Presentation

"Students will demonstrate a high level capability of communicating effectively in public professional forums of their public health peers. Evidence of attainment of this skill will be effective preparation and presentation of aspects of their work at a minimum of three relevant national / or international conferences. Successful completion of this subject is a necessary prerequisite for the award of Doctor of Public Health and the Doctor of Public Health Studies"[1]

Learning Outcomes

- Develop technical and other skills required for effective communication;
- Effectively communicate original research to public health professionals in public forums at national and international levels.

Conferences Attended - Overview:

- **The Annual Scientific Meeting (ASM) of the Australian Diabetes Society and the Australian Diabetes Educators Association:** The ASM is attended by nearly 2,000 health care professionals from Australia and overseas with a special interest in diabetes education and management. The three day conference aims to promote best practice, informative and practical educational sessions. Discussions range from technology to scientific discovery in diabetes [2].

- **National Institute of Diabetes and Digestive and Kidney Diseases - Branch Conference:** The NIDDK supports a wide range of medical research. The Institute conducts basic, translational and clinical research across a broad spectrum of research topics and serious, chronic disease and conditions. The NIDDK supports research training for students and scientist and a range of education and outreach programs [3].

- **National Primary Health Care Conference:** The National Primary Health Care Conference brings leading international and national speakers providing a platform to engage, challenge and exchange ideas where pivotal issues for the future of primary health care in Australia can be discussed and where delegates will learn from the experience, opinions and perspective of sector leaders and their peers [4].

Table 1: Conference's attended and presented

Conference	Date and location of Conference	Conference presentation: Title	Type of presentation
The Annual Scientific Meeting of the Australian Diabetes Society and the Australian Diabetes Educators Association	28th August 2014, Melbourne, Victoria, Australia.	"Psychological Insulin Resistance amongst Torres Strait Islanders with Type 2 diabetes: Study protocol	Poster - National
National Institute of Diabetes and Digestive and Kidney Diseases - Branch Conference.	April 24th 2015 Phoenix, Arizona, United States of America.	"Improving Diabetes Care and Management in Torres Strait Remote Primary Health Care Settings".	Oral – International
The Annual Scientific Meeting of the Australian Diabetes Society and the Australian Diabetes Educators Association.	27th August 2015 Adelaide, South Australia, Australia.	"Depression and Diabetes in the Torres Strait"	Oral – National
National Primary Health Care Conference.	03rd November 2015 Canberra, Australian Capital Territory, Australia.	"Barriers to insulin treatment among Torres Strait Islanders with poorly controlled diabetes"	Oral – National

Conference Presentations

Conference Title

The Annual Scientific Meeting of the Australian Diabetes Society and the Australian Diabetes Educators Association (ADS-ADEA) – Melbourne, Victoria, Australia. 28th August 2014

Abstract Title

"Study Protocol: Psychological Insulin Resistance amongst Torres Strait Islanders with Type 2 diabetes".

Sean Taylor, Robyn McDermott, Adrian Esterman, Kim Usher
Centre for Chronic Disease Prevention, Faculty of Medicine, Health & Molecular Sciences – James Cook University, Cairns, Queensland, Australia.

Abstract - Poster

Background: Despite the well-recognised benefits of insulin therapy in Type 2 diabetes, research has shown that patients are hesitant to commence insulin therapy, a syndrome that is termed by researchers as *psychological insulin resistance or PIR.* PIR occurs on several levels, emotional: cognitive; behavioural; social and relational. Anecdotally, there is a high proportion of Torres Strait Islanders with poorly controlled diabetes who appear to refuse insulin treatment.

Study Aims: This study will identify any potential psychological resistance factors, which are salient for Torres Strait Islanders living in the Torres Strait region who have poorly controlled diabetes, using validated instruments.
Methods / Design: A descriptive cross sectional study using the "barriers to insulin treatment questionnaire" and the insulin treatment appraisal scale" to measure barriers to insulin therapy"

Sample size: Of the 198 adults with diabetes in 5 remote Torres Strait communities, 67 (34%) have an HbA1c equal or greater than 8.5%. Of these 30 are eligible for this study (not currently receiving insulin). 30 respondents will give this study 80% power to detect a correlation coefficient of 27% or more, as a measure of agreement between the two scales.

Discussion: Low rates in insulin therapy and self-monitoring in this high risk population needs to be investigated and addressed appropriately. PIR is potentially an important barrier to treatment escalation.

Documents

- Poster
- Acceptance Notification

PSYCHOLOGICAL INSULIN RESISTANCE AMONGST TORRES STRAIT ISLANDERS WITH TYPE 2 DIABETES

(STUDY PROTOCOL)

• Sean Taylor • Robyn McDermott • Adrian Esterman • Kim Usher
Centre for Chronic Disease Prevention, Faculty of Medicine, Health & Molecular Sciences - James Cook University, Cairns, QLD, Australia

BACKGROUND

Despite the well-recognised benefits of insulin therapy in Type 2 diabetes, research has shown that patients are hesitant to commence insulin therapy, a syndrome that is termed by researchers as "psychological insulin resistance or PIR. PIR occurs on several levels, emotional; behavioural; social and relational. Anecdotally, there is a high proportion of Torres Strait Islanders with poorly controlled diabetes who appear to refuse insulin treatment.

STUDY AIMS

This study will identify any potential psychological resistance factors, which are salient for Torres Strait Islanders living in the Torres Strait region who have poorly controlled diabetes, using validated instruments.

METHODS / DESIGN

A descriptive cross sectional study using the 'barriers to insulin treatment questionnaire' and the "insulin treatment appraisal scale" to measure barriers to insulin therapy.

Figure 1: Mer Island

Figure 2: Study setting – Torres Strait

Table 1: Participants in 5 Torres Strait Communities

COMMUNITY	TOTAL POPULATION (2011 Census)	KNOWN DIABETICS ON REGISTER (2012)	PATIENTS RECRUITED TO OVERALL STUDY	PATIENTS ELIGIBLE FOR PIR STUDY	PATIENTS INTERVIEWED
Mer Island	310	61	61	9	9
Darnley Island (Erub)	402	44	44	8	8
Stephen Island (Ugar)	39	12	12	3	3
Saibai Island	198	48	48	5	4
Yorke Island (Masig)	170	33	33	5	5
TOTAL	1119	198	198	30	29

SAMPLE SIZE

Of the 198 adults with diabetes in 5 remote Torres Strait communities, 67 (34%) have an HbA1c equal or greater than 8.5%. Of these 30 are eligible for this study (not receiving insulin). 30 respondents will give this study 80% power to detect a correlation coefficient of 27% or more, as a measure of agreement between the two scales.

DISCUSSION

Low rates in insulin therapy and self-monitoring in this high risk population needs to be investigated and addressed appropriately. PIR is potentially an important barrier to treatment escalation.

PROGRESS TO DATE

- Doctor of Public Health Studies - Confirmation seminar completed 2013.
- Ethics approved: Cairns & Hinterland Health Service District Ethics Committee - HREC and James Cook University - HREC.
- Patient recruitment completed.
- Interviews completed.
- Data entry completed.

CONTACT DETAILS

Sean Taylor - Doctor of Public Health Candidate - James Cook University
Email: sean.taylor1@jcu.edu.au | Mobile: 0428 711 404

*The research reported in this paper [or presentation] is a project of the Australian Primary Health Care Research Institute, which is supported by a grant from the Commonwealth of Australia as representing by the Department of Health. The information and opinions contained in it do not necessarily reflect the views or policy of the Australian Primary Health Care Research Institute or the Australian Government Department of Health."

Queensland Government | JAMES COOK UNIVERSITY AUSTRALIA | AITHM AUSTRALIAN INSTITUTE OF TROPICAL HEALTH & MEDICINE | CENTRE FOR CHRONIC DISEASE PREVENTION

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has been removed

Conference Title

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) – Phoenix, Arizona, United States of America. April 25th 2015.

Abstract Title

"Improving Diabetes Care and Management in Torres Strait Remote Primary Health Care Settings".

Sean Taylor, Robyn McDermott, Adrian Esterman, Kim Usher
Centre for Chronic Disease Prevention, Faculty of Medicine, Health & Molecular Sciences – James Cook University, Cairns, Queensland, Australia.

Abstract - Oral Presentation

Background: The life expectancy gap for Indigenous Australians is 13-17 years and mostly due to preventable chronic disease (diabetes, heart, lung and renal problems) in adults. Once people have these conditions, many complications can be prevented with good primary-level chronic care. I propose two studies to help improve diabetes care process and outcomes in remote Torres Strait primary care settings.

Study Aims: (Study 1) To understand the extent of and underlying beliefs behind "psychological insulin resistance" among TSI with poorly controlled diabetes who refuse insulin. (Study 2) To evaluate the impact of active patient engagement, systematic diabetes care planning and referrals (the intervention) on diabetes care processes, intermediate clinical outcomes and avoidable hospitalisations and disease progression over 2 years, in 5 PHC centers in the Torres Strait, compared to a similar group of "usual care" centers.

Methods / Design: Study 1: Study Design: Interviews with 30 adults with poorly controlled diabetes who have refused insulin treatment, using validated instruments Insulin Treatment Appraisal Scale and Barriers to Insulin Treatment Questionnaire (BITQ). Correlations with demographic, clinical (vascular stage, co morbidities, metabolic control) and Quality of Life measures (AQol, SF-12).
Study 2: Study Design: Retrospective clustered cohort study of the impact of the intervention on care processes, intermediate clinical outcomes and avoidable hospitalisations in adults with diabetes in 5 intervention sites (n=200) and 3 control sites (n=140). The primary outcome measure will be HbA1c reduction in a 12-month period; secondary outcome measures will be % receiving care processes according to guidelines (checks), BP control, renal disease progression, avoidable hospitalisations and CVD endpoints (events, deaths).

Target population: Adults diagnosed with Type 2 diabetes located in 8 Torres Strait Island communities with primary health care services provided by Queensland Health.

Sample Size: (Study 1) Of the 198 diabetics who have to date consented to participate in the cohort study, 67 (34%) have HbA1c equal or greater than 8.5%. Of these 30 are eligible for Study 1 (refused insulin treatment). With 30 respondents, the minimum level of accuracy for any questionnaire item would be ±17%. With this sample size, a multiple linear regression test of $r=0$ (alpha = 0.05) for 2 normally distributed covariates will have 80% power to detect r^2 of 0.27. (Study 2) With mean HbA1c change as the primary outcome measure, a sample size of 64 in each group will have 80% power to detect an effect size of 0.5 using a two-group t-test with a 0.05 two-sided significance level. However, allowing for a smaller effect size, potential patient withdrawals, and any impact of clustering, we will aim to recruit 150-200 patients in each arm.

Outcomes and Significance: We expect study 1 to improve our understanding of patient-level factors behind the currently high levels of insulin refusal among TSI adults with diabetes who could benefit from it. This in turn will enable a better-targeted and hopefully more effective clinical approach to true patient engagement in self-management of diabetes in this very high-risk population. Study 2 will answer the question "Will active patient engagement in care planning and referral for diabetes improve clinical and other outcomes among high risk adults with diabetes in remote TSI communities?".

IMPROVING DIABETES CARE AND MANAGEMENT IN TORRES STRAIT REMOTE PRIMARY HEALTH CARE SETTINGS

JAMES COOK UNIVERSITY AUSTRALIA

CENTRE FOR CHRONIC DISEASE PREVENTION

Heart Foundation

Queensland Government

Sean Taylor

(BNS, GradCertDiabEdm, BHSc(Hons)
Research Fellow / Doctor of Public Health Candidate
Centre for Chronic Disease Prevention
James Cook University

Phoenix 24th April 2015

MER ISLAND EASTERN TORRES STRAIT

TORRES STRAIT

EDDIE KOIKI MABO

TORRES STRAIT FLAG

THURSDAY ISLAND
HUB - TORRES STRAIT REGION

MABUIAG ISLAND

TORRES STRAIT CULTURE

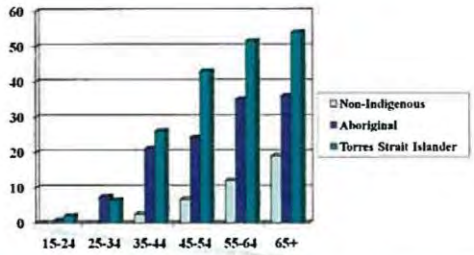
SUPERVISORS

PROFESSOR ROBYN MCDERMOTT
PROFESSOR OF PUBLIC HEALTH MEDICINE
JCU

PROFESSOR KIM USHER
PROFESSOR OF NURSING
JCU

PROFESSOR ADRIAN ESTERMAN
PROFESSOR OF BIOSTATISTICS
JCU

PREVALENCE OF DIABETES, INDIGENOUS NQ (WPHC)AND AUSTRALIA (AUSDIAB), 1999 - 2000



DIFFERENCES IN POPULATION (SOURCE: MCDERMOTT, R., TULIP, F. & SCHMIDT,B. MJA 2004)

Measure	Aboriginals (Northern Territory and Cape York) n = 446	Torres Strait Islanders n=921	Non – Indigenous Australians N=2077
Mean age (years)	51.5	52.4	62.5
Mean HbA1c level	8.7%	9%	7.8%
Insulin treatment-alone or combined with other medication	10.5%	16%	34.4%

STUDY AIM

AIM: (Study 1) To understand the extent of and underlying beliefs behind "psychological insulin resistance" among TSI with poorly controlled diabetes who refuse insulin. (Study 2) To evaluate the impact of active patient engagement, systematic diabetes care planning and referrals (the intervention) on diabetes care processes, intermediate clinical outcomes and avoidable hospitalisations and disease progression over 2 years, in 5 PHC centers in the Torres Strait, compared to a similar group of "usual care" centers

METHODS / DESIGN

Diabetes currently a major problem, previous studies have shown that primary health care level management needs improvement.

Patient level factors

Study 1 Psychological Insulin Resistance Amongst Torres Strait Islanders with Type 2 diabetes

Study design: A descriptive cross-sectional study, the proposed study will include surveys, questionnaires and clinical data.

Health service factors

Study 2 A Sustainable Work Flow –Diabetes Care and Management in Remote Torres Strait Islands

Study design: Retrospective clustered cohort study of the impact of the intervention on care processes and intermediate clinical outcomes in a cohort of adults with diabetes in 5 intervention sites and 3 control sites.

Torres Strait Islanders with Type 2 Diabetes (5 Communities)

These patients who meet the inclusion criteria will participate in Study 1

All patients recruited with a medical diagnosis of Type 2 diabetes will participate in Study 2

Both studies will help inform the development and implementation of appropriate diabetes management care plans

DR PH COHORT
TOTAL KNOWN DIABETICS APRIL – DECEMBER 2012
SNAP SHOT

COMMUNITY	TOTAL POPULATION	KNOWN DIABETICS ON REGISTER	PATIENTS RECRUITED
Murray (Mer)Island	310	61	61
Darnley (Erub) Island	402	44	44
Stephen (Ugar) Island	39	12	12
Saibai Island	198	48	48
Yorke (Masig) Island	170	33	33
TOTAL	1119	198 (18%)	198 (100%)

Mean Age	Mean HbA1c	Mean eGFR	Mean BP
56.9	8.2%	69.7	135/78

DR PH COHORT TORRES STRAIT ISLANDS
N=198
DIABETICS AND INSULIN

Diabetics prescribed insulin 28%(n=55)

Mean Age	Mean HbA1c	Mean eGFR	Mean BP
56.2	10.%	62.7	136/74

Diabetics prescribed insulin with HbA1c greater than 8.5% 19 %(n=37)

Mean Age	Mean HbA1c	Mean eGFR	Mean BP
54.5	11.3%	69.8	13

Diabetics not prescribed insulin. HbA1c greater than 8.5% - PIR Cohort 15% (n=30)

Mean Age	Mean HbA1c	Mean eGFR	Mean BP
50.8	10.5%	72.6	142/84

PSYCHOLOGICAL INSULIN RESISTANCE AMONGST TORRES STRAIT ISLANDERS WITH TYPE 2 DIABETES
STUDY 1

WHAT IS PSYCHOLOGICAL INSULIN RESISTANCE (PIR)?

- PIR is a syndrome were there is considerable resistance on the part of patients and clinicians to initiate insulin therapy (Polonsky and Jackson 2004)
- Patients refuse insulin therapy primarily because of unwarranted fears and misperceptions (Philips 2005).
- Clinicians are reluctant to begin what they perceive as a complex therapy, due to a great deal of monitoring (Philips 2005)

PSYCHOLOGICAL INSULIN RESISTANCE (PIR) SEVERAL LEVELS

(GHERMAN,VERESIU ET AL, 2011)

- Emotional – anxiety, depression or guilt
- Cognitive – distorted beliefs
- Behavioral – pain, bruising, hypoglycemia, weight gain
- Social – feeling stigmatized
- Relational – influencing factors from the medical health team

METHODOLOGY

PSYCHOLOGICAL INSULIN RESISTANCE (PIR) AMONGST TORRES STRAIT ISLANDERS WITH TYPE 2 DIABETES

RESEARCH AIM:

Aim of study 1 – Identify any PIR factors which are salient for Torres Strait Islanders who have poorly controlled diabetes using standard instruments

RESEARCH HYPOTHESIS

There is a high proportion of Torres Strait Islanders who have PIR, and this is related to poor glycemic control

Identify self-reported attitudes to insulin management by Torres Strait Islander patients with poorly controlled diabetes.

PSYCHOLOGICAL INSULIN RESISTANCE (PIR) AMONGST TORRES STRAIT ISLANDERS WITH TYPE 2 DIABETES

RESEARCH QUESTIONS:

Does PIR exist in Torres Strait Islanders with poorly controlled diabetes?

What are the features of self-reported PIR amongst Torres Strait Islanders with Type 2 diabetes using BITQ and ITAS tools?

Do these self-reported PIR measures have an apparent impact on individual glycemic control and general diabetes care?

A SUSTAINABLE WORKFLOW – DIABETES CARE AND MANAGEMENT IN REMOTE TORRES STRAIT ISLANDS STUDY 2

A SUSTAINABLE WORKFLOW-DIABETES CARE AND MANAGEMENT IN REMOTE TORRES STRAIT ISLANDS

STUDY AIM

Overall, to improve diabetes care and management in Torres Strait remote primary health care settings through the improvement of information flow and access to primary health care services by:

- Implementing a model of baseline assessment and pathology (adult health check) with patients with type 2 diabetes in the Torres Strait incorporating formal care planning
- A sustainable workflow that enhances patients ability to achieve optimal glycemic control

A SUSTAINABLE WORKFLOW-DIABETES CARE AND MANAGEMENT IN REMOTE TORRES STRAIT ISLANDS

RESEARCH HYPOTHESIS

The intervention (complex workflow in 3 stages: patient engagement, GP Management care plan, Referrals) will result in better health care processes and outcomes for people with diabetes in the Torres Strait compared to "usual care"

RESEARCH DESIGN

Retrospective clustered cohort study of the impact of the intervention on care processes and intermediate clinical outcomes in a cohort of adults with diabetes in 5 intervention sites and 3 control sites.

INTERVENTION – STUDY 2

Part 1 PATIENT ENGAGEMENT

- Home visit
- Education and explanation
- Clinic appointment
- Preparation for GP Management Plan(GPMP) and Team Care Arrangements (TCA),Anthropometry, clinical and biomedical markers
- Data entered into Best Practice

Part 2 HEALTH SERVICE UPTAKE

- GPMP and TCA -date completed and signed

Part 3 REFERRALS

- Allied health professionals (Diabetes Educator, Dietician, Podiatrist)
- Medical Specialist (Endocrinologist, Nephrologist, Cardiologist, Optometrist)
- Lifestyle factors (smoking, nutrition, weight loss)
- Review GPMP and TCA after 6 months

EXPECTED OUTCOMES

- Improve our understanding of patient-level factors – Insulin refusal
- Better targeted and effective clinical approach in self management of diabetes
- Understand if patient engagement in care planning and referral for diabetes improve clinical outcomes

THANK YOU

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Documents

- Presentation slides
- Acceptance Notification

Conference Title

Australian Diabetes Society & Australian Diabetes Educators Association
26th – 28th August 2015 - Adelaide Convention Centre, Adelaide - South Australia. Thursday 27th August

Abstract Title

"Depression and diabetes in the Torres Strait".

Sean M Taylor, Fintan Thompson, Robyn McDermott
Centre for Chronic Disease Prevention, Faculty of Medicine, Health & Molecular Sciences – James Cook University, Cairns, Queensland, Australia.

Abstract – Oral Presentation

Background: Diabetes is known to be associated with significant depression, which can result in poorer clinical outcomes, including increased mortality. Little is known about the prevalence of depression among Torres Strait Islander adults with diabetes.
Objectives: To examine self-reported depression and clinical markers in Torres Strait Islander adults with diabetes using the PhQ-9.

Method: Face-to-face interviews, including – PhQ, income, employment, education, lifestyle behaviour measures and clinical data (Hba1c, eGFR, Cholesterol, BP, weight, and waist) in a sample of 188 adults with T2DM in 5 remote outer islands of the Torres Strait.

Data Analysis: Levels of depression were compared across demographic and behavioural variables and clinical measures were analysed by categories of depression. Non- parametric test were used to detect differences between groups and multiple liner regression was used to predict PhQ-9 scores

Results: Seventy-three men (mean age =58.4), and 115 women (mean age 57.8) completed interviews. The mean PhQ-9 score was 5.1 (mild): 42% of respondents scored between 0-4 (non – minimal), 46% scored between 5-9 (mild) and 12% scored 10+ (moderate – severe). Mean HbA1c was 8.3% (67.4 mmol). The correlation coefficient was 0.006 between HbA1c and PhQ-9 scores (P=0.626) however, exercise in minutes (β =-0.01, $p<0.001$) and screen time in hours (β= 0.12, $p<0.001$) were significant predictors of depression after adjusting for all other study variables.

Conclusion: This sample of remote living Torres Strait Islanders reported relatively low rates of depression compared to national samples and depression was not related to glycemic control. Exercise and screen time were the strongest predictors of depression based on PHQ-9 scores. This represents an opportunity for health promotion.

Documents

- Presentation slides
- Acceptance Notification

DEPRESSION AND DIABETES IN THE TORRES STRAIT

1. Sean Taylor (Research Fellow / Doctor of Public Health Candidate)
2. Robyn McDermott (Professor of Public Health)
3. Fintan Thompson (Data Manager)

ADS & ADEA Annual Scientific Meeting
Adelaide, August 2015

JAMES COOK UNIVERSITY AUSTRALIA

CENTRE FOR CHRONIC DISEASE PREVENTION

Queensland Government

Heart Foundation

BACKGROUND LITERATURE DEPRESSION AND DIABETES

- Rates of depression and multiple barriers to care are higher in those living in rural and remote settings (Brown, 2005)
- Depression may lead to poorer outcomes, exercise, diet and medication regimes and is psychologically and behaviorally demanding (Gressard et al, 2011)
- There is a high correlation between depression and Type 2 diabetes, however a weaker relationship concerning diabetes and risk of depression (Bi- directional relation between depression and diabetes) (Marsh, 2008)

STUDY AIM: TO ASSESS THE EXTENT OF SELF-REPORTED DEPRESSION USING PHQ-9 AND CLINICAL FEATURES OF ADULTS WITH T2DM IN 5 OUTER ISLANDS IN THE TORRES STRAIT (2013)

- Main depression measure included PHQ-9 scores at interview
- Interviews conducted in person by ST, using Creole expressions in addition to standard English where appropriate
- Demographic characteristics: Age, Sex, ethnicity, income, years of education, current employment
- Main clinical measures: Years since diagnosis, HbA1c, BP, BMI, lipids, UACR
- Behavioural measures: TV screen time, alcohol consumption, self-reported exercise, tobacco smoking.

DEPRESSION

- *" mental disorder, characterized by sadness, loss of interest or pleasure, feelings, or guilt or self-worth, disturbed sleep or appetite, feelings or tiredness and poor concentration"* (World Health Organization)

TORRES STRAIT REGION

SAMPLE: AIM TO INTERVIEW ALL KNOWN PEOPLE WITH DIABETES IN 5 COMMUNITIES

COMMUNITY	TOTAL POPULATION (2011 CENSUS)	KNOWN DIABETICS ON REGISTER (2012)	PARTICIPANTS RECRUITED	PARTICIPANTS INTERVIEWED
MER ISLAND	310	61	61	61
DARNLEY (ERUB) ISLAND	402	44	44	44
STEPHEN (UGAR) ISLAND	39	12	12	6
SAIBAI ISLAND	198	48	48	45
YORKE (MASIG) ISLAND	170	33	33	32
TOTAL	1119	198 (18%)	198 (100%)	188 (95%)

SNAP SHOT: DEPRESSION SCORES USING PHQ-9 (N=188)

Variable	Non –Minimal (0-9)	Mild (5-9)	Moderate – Severe (10+)	Total	95% CI	P value
Total	79 (42%)	86 (46%)	23 (12%)	188	(4.5 -5.7)	
Gender						
Male	33 (45%)	33 (45%)	7 (10%)	73	(4.0-5.9)	0.827
Female	46 (40%)	53 (46%)	16 (14%)	115	(4.4 -5.9)	
Age Group						
<35 Years	4 (44%)	3 (33%)	2 (22%)	9	(1.4-11.0)	0.010
35 -49 years	22 (63%)	11 (31%)	2 (6%)	35	(1.8 – 4.4)	
50+ years	53 (37%)	72 (50%)	19 (13%)	144	(4.8 -6.1)	

MEAN PHQ-9 DEPRESSION SCORE & BASELINE CHARACTERISTICS

Variable	No.	Mean	95% CI	Median	P value
Total	188	5.1	(4.5 – 5.7)	5.5	
Gender					
Male	73 (39%)	4.9	(4.0 – 5.9)	5.0	0.827
Female	115 (61%)	5.2	(4.4 – 5.9)	6.0	
Age Group					
<35 Years	9 (5%)	6.2	(1.4 – 11.0)	6.0	0.010
35 -49 Years	35 (19 %)	3.1	(1.8 – 4.4)	0.0	
50 + Years	144 (76%)	5.5	(4.8 – 6.1)	6.0	
Employment					
Full-time	64 (34%)	3.7	(2.8 – 4.6)	3.5	0.004
Part-time / Casual	13 (7%)	3.8	(2.2 – 5.4)	5.0	
Unemployed	111(59%)	6.0	(5.2 – 6.8)	6.0	

MEAN DEPRESSION SCORE & BASELINE CHARACTERISTICS

Variable	No.	Mean	95% CI	Median	P value
Education					
<Year 12	123 (65%)	5.7	(5.0 – 6.5)	6.0	0.008
Year 12 completed	23 (12%)	4.7	(2.7 – 6.7)	5.0	
TAFE Course	37 (20%)	3.6	(2.4 – 4.9)	3.0	
University	6 (3%)	1.5	(-0.3 – 3.3)	1.0	
Household income					
<$20,000	3 (1%)	0.7	(-2.3 – 3.5)	0.00	0.122
$20,000 - $59,999	104 (55%)	5.4	(4.6 – 6.2)	6.0	
>$60,000	81 (43%)	4.8	(3.9 – 5.7)	5.0	
BMI					
Normal	19 (10%)	5.9	(3.7 – 8.0)	6.0	0.208
Overweight	50 (26%)	4.1	(3.0 – 5.1)	3.5	
Obese	119 (63%)	5.4	(4.6 – 6.1)	6.0	

MEAN DEPRESSION SCORE & BASELINE CHARACTERISTICS

Variable	No.	Mean	95% CI	Median	P value
Smoking					
Non smoking	153 (81%)	5.0	(4.3 – 5.7)	5.0	0.784
Smoking	35 (19%)	5.4	(3.9 – 6.8)	6.0	
Alcohol					
No Alcohol	132 (70%)	5.1	(4.3 – 5.8)	5.0	0.879
Alcohol	56 (30%)	5.1	(4.0 – 6.2)	6.0	
High Risk Alcohol					
No	2 (1%)	4.0	(-46.8 – 54.8)	4.0	0.842
Yes	54 (29%)	5.1	(4.0 – 6.2)	6.0	
Diabetes and Insulin status					
Hba1c <=8.5	125 (66%)	5.0	(4.2 – 5.7)	5.0	0.407
Hba1c >8.5 –on insulin	37 (20%)	5.7	(4.4 – 7.0)	6.0	
Hba1c<8.5 not on insulin	26 (14%)	4.7	(2.8 – 6.5)5.0	5.0	

CLINICAL CHARACTERISTICS AND DEPRESSION SCORE

Variable	Non – minimal (95% CI)	Mild (95% CI)	Moderate – Severe (95%CI)	Total (95%CI)	P Value
HbA1c (%)	7.9 (7.4 – 8.4)	8.6 (8.1 -9.2)	8.3 (7.1 – 9.5)	8.3 (8.0 – 8.7)	0.102
Waist (cm)	107 (104.6 – 110.3)	109 (105.6 – 112.0)	110 (99.4 – 120.5)	108 (106.1 – 110.6)	0.890
BP	135 / 81 (131 – 139) (78 – 83)	134 / 78 (129 -9 – 138.2) (75.8 – 80.5)	134 / 72 (123.8 – 144.1) (67.3 – 76.7)	134 / 78 (131.7 – 137.2) (76.8 – 80.1)	0.684 0.008
Cholesterol (mmol/l)	4.5 (4.2 – 4.7)	4.2 (4.0 – 4.5)	4.4 (3.6 – 5.1)	4.4 (4.2 – 4.5)	0.083
Exercise (min)	256 (215.8 – 297.2)	250 (220 – 280.7)	140 (74.8 – 205.2)	281 (256.0 – 306.9)	0.000
Screen Time (hrs)	16.5 (12.5 – 19.6)	33 (30.1 – 35.1)	30 (24.6 – 35.7)	27 (23.4 – 27.7)	0.000
Years with diabetes	8.3 (6.8 – 9.7)	10 (8.7 – 11.9)	11 (7.3 – 14.8)	9 (8.5 – 10.6)	0.140

PREDICTORS OF DEPRESSION (PHQ-9)

Variable	Coefficient	95 % CI	P-value
HbA1c	0.006	(-0.19 – 0.31)	0.626
Age (years)	0.06	(0.01 – 0.11)	0.010
Exercise (min)	-0.01	(-0.01 – 0.01)	0.000
Screen time (hrs)	0.12	(0.08 – 0.16)	0.000
BMI (kg / m2)	0.04	(-0.04 – 0.13)	0.313
Years with diabetes	0.11	(0.02 – 0.20)	0.016

A higher depression score in this population appears to be correlated with age, years with diabetes and time watching TV, and inversely correlated with exercise. There is no relationship with glycemic control or BMI

LIMITATIONS

- Limited to Torres Strait Islanders living in the remote islands of the Torres Strait
- No comparison to those Torres Strait Islanders living on the mainland
- This study does not give an accurate representation of all those who identify as Torres Strait Islanders, but a reflection of those Torres Strait Islanders living in the remote Torres Strait Islands.

CONCLUSION

- The mean PHQ – 9 depression score in this sample - 5.1 (mild)
- The mean HbA1c 8.3%
- Depression was not related to glycemic control
- Exercise and screen time were the strongest predictors of depression based on PHQ – 9 scores

ACKNOWLEDGMENTS

- National Heart Foundation – Australia
- Centre for Chronic Disease Prevention - JCU
- Queensland Health – Torres and Cape Hospital and Health Service
- Mer Island Community, Darnley Island Community, Stephen Island Community, Saibai Island Community and Yorke Island Community
- Participants
- Diabetes Team – Thursday Island Primary Health Care Centre
- University of South Australia – Population Health

TRUE OR FALSE

- Question:
- Diabetes is the leading cause of adult blindness, amputation and kidney failure?

FALSE

Answer:

FALSE: To a large extent, **if poorly managed,** diabetes is the leading cause of adult blindness, amputation and kidney failure

Well managed diabetes is leading cause of NOTHING!

Behavioural Diabetes Institute
San Diego – California USA

THANK YOU

This administrative form
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Conference Title

National Primary Health Care Conference – Canberra, Australian Capital Territory. 03rd November 2015

Abstract Title

"Barriers to insulin treatment among Torres Strait Islanders with poorly controlled diabetes"

Sean M Taylor, Fintan Thompson, Robyn McDermott
Centre for Chronic Disease Prevention, Faculty of Medicine, Health & Molecular Sciences – James Cook University, Cairns, Queensland, Australia.

Abstract – Oral Presentation

Background: Adults with diabetes in the Torres Strait show poor glycemic control and diabetes-related complications compared to other populations with diabetes in Australia. Despite this, few are receiving treatment with insulin as recommended by guidelines.

Objective: To explore self reported knowledge and attitudes to insulin treatment among a group of adults with poorly controlled diabetes in the Torres Strait islands.

Methods: Cross-sectional survey in 2014, interviews with 29 adults with HbA1c >=8.5% (69 mmol/mol) and not taking insulin, using Insulin Treatment Appraisal Scale (ITAS) and Barriers to Insulin Treatment Questionnaire (BITQ) scores.

Main outcome measures: BITQ and ITAS scores on items related to knowledge and attitudes to insulin treatment, clinical and demographic measures.

Results: Overall, 34% of the cohort had poor glycemic control. Compared to those with HbA1c >=8.5% and taking insulin (n=37), the 29 insulin naïve participants were more obese, more likely to smoke and drink alcohol, have lower mean HbA1c and fewer years with diabetes. Among the insulin-naïve group, those reporting higher "barriers" (BITQ scores) were older and with lower formal education than those reporting fewer barriers. Torres participants consistently scored low on "knowledge" items in the ITAS, especially those which would guide insulin initiation (insulin improves glucose control, and prevents complications).

Conclusion: Compared to other published studies, the Torres participants had higher scores for BITQ "barrier" items and lower "knowledge" scores. This suggests better education around glycemic control with medication and discussion of perceptions and exchange of experiences with peers who are taking insulin might improve the uptake of insulin in this high-risk group.

Documents

- Presentation slides
- Acceptance Notification

BARRIERS TO INSULIN TREATMENT AMONG TORRES STRAIT ISLANDERS WITH POORLY CONTROLLED DIABETES

JAMES COOK UNIVERSITY AUSTRALIA

CENTRE FOR CHRONIC DISEASE PREVENTION

- Sean Taylor (Research Fellow / Doctor of Public Health Candidate)
- Professor Robyn McDermott (Professor of Public Health Medicine)
- Fintan Thompson (Data Manager)

National Primary Health Care Conference
Canberra 03rd November 2015

Queensland Government

Heart Foundation

Australian National University

BACKGROUND LITERATURE

- Patients with Type 2 diabetes will eventually require insulin therapy in addition to oral hypoglycemic agents (Lavie & Fonseca, 2013)
- However, many patients are reluctant to commence insulin therapy for a variety reasons (Polonsky, 2007)
- Negative and complex perceptions have been collectively called "psychological insulin resistance" PIR (Polonsky, 2007)
- Torres Strait Islanders have the highest prevalence of diabetes in Australia (McDermott, Tulip, & Spargo, 2007)
- Anecdotal evidence suggest that PIR is high in this population, as reported by clinicians

STUDY AIM

- To investigate the perceptions and beliefs of Torres Strait Islander adults with poorly controlled diabetes with respect to using insulin to control blood glucose using The Treatment Appraisal Scale (ITAS) and The Barriers to Insulin Treatment Questionnaire (BITQ)

MAIN OUTCOME MEASURES

- BITQ and ITAS scores on items related to knowledge and attitudes to insulin treatment
- Demographic characteristics Age, sex, ethnicity, income, years of education, current employment (2012-2014)
- Main clinical measures: Years since diagnosis, HbA1c, BP, BMI, lipids, UACR (2012)
- Behavioural measures: TV screen time, alcohol consumption, self-reported exercise, tobacco smoking (2013-2014)

SURVEY INSTRUMENTS

BARRIERS TO INSULIN TREATMENT QUESTIONNAIRE (BITQ)

1 -10 point Likert Scale (totally disagree – totally agree)

14 Questions

I am afraid of the pain when injecting insulin.

Besides the pain, I am just afraid of injections.

I am afraid of the pain during regular blood-sugar checks.

Insulin works better than pills.

People who get insulin feel better.

Insulin can reliably prevent long-term complications due to diabetes.

I just don't have enough time for regular doses of insulin.

INSULIN TREATMENT APPRAISAL SCALE (ITAS)

strongly disagree – strongly agree

20 Questions

Taking insulin means I have failed to manage my diabetes with diet and tablets

Taking insulin means my diabetes has become much worse.

Taking insulin helps to prevent complications of diabetes.

Taking insulin means other people see me as a sicker person.

Taking insulin makes life less flexible.

Taking insulin increases the risk of low blood glucose levels (hypoglycaemia).

Taking insulin helps to improve my health

SURVEY INSTRUMENTS

The Insulin Treatment Appraisal Scale (ITAS)

- ITAS is a brief, psychometrically validated instrument that can be used in insulin – naive patients to assess both positive and negative perceptions of insulin

The Barriers to Insulin Treatment Questionnaire (BITQ)

- BITQ is a reliable psychometric instrument that measures fear of injections and self testing, expectations regarding positive insulin – related outcomes, hardship, stigmatisation and fear of hypoglycaemia

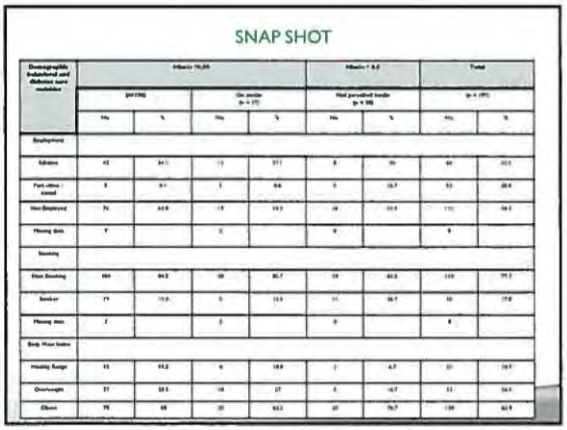
- Interviews conducted in person by ST, using Creole expressions in addition to standard English where appropriate (2013 -2014)

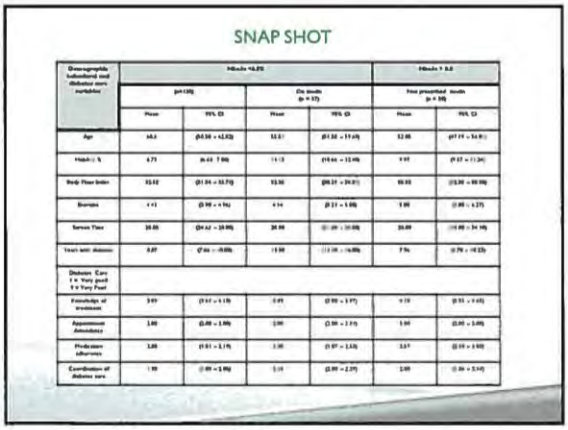
TORRES STRAIT REGION

SAMPLE

Community	Total Population (2011 Census)	Known Diabetics on Register (2012)	Patient Recruited to Overall Study	Patients Eligible for PIR Study	Patients Interviewed
Mer Island	310	61	61	9	9
Darnley Island	402	44	44	8	8
Stephen Island	39	12	12	3	3
Saibai Island	198	48	48	5	4 (1 died)
Yorke Island	170	33	33	5	5
Total	1119	198 (18%)	198 (100%)	30 (15%)	29 (97%)


SNAP SHOT


SNAP SHOT


SNAP SHOT


INSTRUMENTS BY BASELINE CHARACTERISTICS

BITQ MEAN SCORE

BITQ (1-10)	Torres Strait n = [illegible]		[illegible] et al (2007) n = [illegible]	
	Mean	(sd)	Mean	(sd)
Scale 1 "Fear of [illegible] and self-testing"	[illegible]	[illegible]	[illegible]	[illegible]
Scale 2 "Expectations regarding positive insulin-related outcomes"	[illegible]	[illegible]	[illegible]	[illegible]
Scale 3 "Expected hardship from insulin therapy"	[illegible]	[illegible]	[illegible]	[illegible]
Scale 4 "Stigmatisation by insulin injection"	[illegible]	[illegible]	[illegible]	[illegible]
Scale 5 Fear of hypoglycemia	[illegible]	[illegible]	[illegible]	[illegible]

Scoring 1 = Strongly Disagree 10 = Strongly Agree
Scales are the sum of all responses divided by number of questions. Average of total scores divided by total number items in the scale

MEAN SUBSCALES AND TOTAL ITAS SCORES

ITAS Scale (1-5)	Torres Strait n = [illegible]		[illegible] et al (2007) n = [illegible]		[illegible] et al ([illegible]) n = [illegible]	
	Mean	(sd)	Mean	(sd)	Mean	(sd)
Total ITAS (sum score 20 items, 4 negatively recoded)	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Total Positive scale ITAS	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Total Negative scale ITAS	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]

Scoring
1 = Strongly Disagree
5 = Strongly Agree

CONCLUSION

- Mostly negative perceptions of insulin perceptions of insulin which could be significant barrier to better glycemic control
- Few published studies in other groups showed lower negative perceptions and much higher positive perceptions than Torres Strait Islanders
- Limitations: Study included a small sample – although 100% approached and agreed to participate
- Lack of validation of these instruments in this population, however the survey was administered by myself who speaks fluent creole
- Compared to other reports , this study suggest that perceived barriers to insulin treatment are high in this population, especially older with fewer years in formal education.
- Better communication between service providers and clients including cultural contexts and beliefs may improve uptake of insulin therapy

ACKNOWLEDGMENTS

- National Heart Foundation – Australia
- Centre for Chronic Disease Prevention – JCU
- Queensland Health – Torres and Cape Hospital and Health Service
- Mer Island Community, Darnley Island Community, Stephen Island Community, Saibai Island Community and Yorke Island Community
- Participants
- Diabetes Team – Thursday Island Primary Health Care Centre
- University of South Australia – Population Health

THANK YOU

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National Primary Health Care Conference 2015

Innovation, Challenges & Opportunities

Acceptance/Withdrawal Form

Acceptance/withdrawal of presentation to be received at PHAA by 22 September 2015

All presenters must register by 22 September 2015 - http://www.phaa.net.au/events/event/NPHCC

Please return one completed form per presentation.

I wish to inform you that **I WILL / I WILL NOT** be presenting my oral presentation/workshop

Presenter's Name: SEAN TAYLOR

(Please list names of presenters only)

Phone _____

Email: sean.taylor1@jcu.edu.au

Paper Title & Paper Number: Barriers to Insulin ~~treatment~~ treatment among Torres Strait Islanders with poorly controlled diabetes

(This is listed on the accompanying offer letter)

I understand that this notification forms a copyright release for my abstract submitted for the conference.

All rooms will be provided with equipment for electronic presentations. Please indicate your A-V requirements:

- ☐ PowerPoint – Windows PC running Microsoft PowerPoint 2010 (Windows 7)
- ☐ I will have audio/video on my PowerPoint presentation
- ☐ My presentation will be from a MAC computer
- ☑ I require assistance during my presentation with operating the audio-visual equipment indicated above

Please contact the secretariat or Frank Meany at frank@onevision.com.au if you have any questions re audio-visual requirements.

- ☑ I am willing to be contacted for media enquiries about my presentation.
  mobile contact: _____

Please check **all** details carefully and note any changes or special requirements in the space provided below.

Changes/Special Requirements

_____

Reminder: Please email to events@phaa.net.au by 5.00 pm, 22 September 2015. Failure to confirm your acceptance by the due date will lead to withdrawal of your paper from the program book

References

1. https://secure.jcu.edu.au/app/studyfinder/?subject=TM6015.
2. http://www.adea.com.au/events/annual-scientific-meeting/2014-2/.
3. http://www.niddk.nih.gov/Pages/default.aspx.
4. https://phaa.eventsair.com/QuickEventWebsitePortal/nphcc/nphcc2015.

Appendix C: Extended Doctoral Attachment Report

Sean Taylor

Extended Doctoral Attachment Report

University of California, San Diego

&

The Behavioral Diabetes Institute

San Diego, California

2015

Sean Taylor

Extended Doctoral Attachment - University of California, San Diego (UCSD)

TM6014 – Extended Doctoral Attachment – Doctor of Public Health,

James Cook University

Credit Points: 09

CONTENTS

1. Brief Summary

Professor Steven V. Edelman and Associate Professor William Polonsky (Bill) contributed to my learning outcomes whilst being in San Diego, from January 12th – April 27th, 2015. During my internship, quality time was spent with Bill and Dr Susan Guzman discussing the behavioural aspects of diabetes, especially "Psychological Insulin Resistance"(PIR) and Depression and Diabetes. I participated in focus groups with patients with Type 1 and Type 2 diabetes plus parents of children diagnosed with Type 1 diabetes.

Bill and I brainstormed the existing knowledge about "PIR" and other behavioural aspects around diabetes and possible research in the Torres Strait region. I developed a questionnaire, however, this tool was not validated and I proposed further research investigating the "Psychological Medication Resistance".

I completed the final draft of my study protocol paper titled "Psychological Insulin Resistance Amongst Torres Strait Islanders with Type 2 Diabetes: a study protocol.

Bill requested I attend the "Taking Control Of Your Diabetes" (TCOYD) conference in Santa Clara, California. During this conference I established networks with health professionals (Larry Fisher, Ian Blumer and Jeremy Pettus to name a few) and patients with Type 2 diabetes. Valuable information gained, plus, assisting researchers with an online research database. Discussions were made regarding trialling the TCOYD conference in Cairns on a smaller scale.

I volunteered my Monday nights at the UCSD Student –Run Free Clinic Project, a project worth considering in the Torres Strait Region. A well-run clinic by health professionals and students who volunteer their time to under served community members in Downtown San Diego. I assisted in registration, phlebotomy, assisting students and other health staff with patients with Type 2 diabetes.

I made contact with Dr Robert Nelson at the Diabetes Epidemiology and Clinical Research Section, Phoenix Epidemiology and Clinical Research Branch, The National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) – Phoenix, Arizona, to discuss Diabetes Research amongst the Pima Indians. Pima Indians have similar rates of Diabetes compared to Torres Strait Islanders living in the Torres Strait region. The Diabetes Epidemiology and Clinical Research Section invited me to present my research

proposal at their local conference. Roughly 40 people attended my presentation, and I was introduced to a number of researchers in the diabetes area. Future collaboration work was discussed. I was reimbursed USD$200 for my travels from San Diego – Phoenix.

Overall my experience in San Diego and other parts of the USA will linger forever. The networks, the distance travelled, future collaboration, the learning experience and most of all, the quality time spent with the team at The Behavioral Diabetes Institute made this internship a successful and fruitful event. Professionally, the Extended Doctoral Attachment taught me to be more confident in discussing my research, and the Torres Strait region to other researchers. I am now able to critique and provide constructive feedback to other research more openly. My knowledge and experience in the behavioural aspect of diabetes have enhanced and my view towards chronic disease has shifted towards patient self-management with the appropriate support from Health Professionals.

2. Purpose of Extended Doctoral Attachment

To fulfil the requirements for TM6014 – Extended Doctoral Attachment that forms part of the Doctor of Public Health degree at James Cook University. A 16 weeks Extended Doctoral Attachment at the University of California, San Diego, California, USA, from 12th January until 24th April 2015.
During the 16 weeks in San Diego, my learning outcomes where achieved at The Behavioral Diabetes Institute, San Diego, California, USA.

The Extended Doctoral Attachment - students are expected to spend time working in area of Public Health relevant to their Doctor of Public Health thesis. The Doctor of Public Health Placement may be in any area of Public Health Research. The placement will normally take place in a recognised, national, regional or International centre of excellence of the area under study [1]

2.1 Learning Outcomes

- Acquire advance methodologies and knowledge useful for the development of the students Doctor of Public Heath thesis.

- Gain skills and experience in an extended work placement environment related to the student area of research.

Thesis title: "Improving Diabetes Care and Management in Torres Strait Remote Primary Health Care Settings".

Study 1: Psychological Insulin Resistance amongst Torres Strait Islanders with Type 2 diabetes
Study 2: A Sustainable Workflow – Diabetes Care and Management in Remote Torres Strait Islands.

3. Content of the Extended Doctoral Attachment

The Extended Doctoral Attachment consisted of varies activities:

- Staff discussion
- Group discussions with patients with diabetes
- Attending the TCOYD conference in Santa Clara
- Brainstorming future research in the Torres Strait Region
- Study Protocol manuscript
- Discussion re: Diabetes and Depression manuscript
- Critiquing research papers around the behavioural aspects of diabetes E.g PIR and depression
- Discussion with Bill and Suzan around the research in the Torres Strait region and how community members adhere to their diabetes care and management
- Networking with other health professionals who work in Chronic disease especially diabetes.
- Participating in a student =run free diabetes clinic
- Develop a Questionnaire re: "Psychological Medication Resistance"
- Lunch with staff at the Behavioural Diabetes Institute

3.1Type 1 Diabetes Workshop

Assisted Bill in a workshop on a Wednesday evening targeting patients diagnosed with Type 1 diabetes in Corona Del Mar, Orange County, California. 12 ladies from the age of 19 years old – 65years participated in a group discussion raising issues relating to their diabetes care and management. Bill presented a power point presentation titled "

Diabetes Burnout, What to do when you can't take it anymore". A group discussion, I shared success stories of patients in the Torres Strait region, plus gave a brief overview of the people in the Torres Strait region. Bill discussed 9 personal barriers:

1. Chronic depression
2. Poor coping styles
3. Eating Disorders
4. Lack of knowledge about diabetes
5. Inaccurate health beliefs
6. Negative feelings about diabetes
7. Fear of hypoglycemia
8. Fear and frustration about weight gain
9. Unrealistic or unclear expectations about self-care

6 Strategies for building a better relationship with Health Care Providers

1. Prepare for your visit
2. Ask about your results of your medical test
3. Use the ABC's of effective communication: assertiveness, brevity, and clarity
4. Be an active participant in deciding about changes in your diabetes care (especially your self-care)
5. Take the risk of being open and honest
6. Be aware of the pressure under which your health care team must operate

My professional experience and knowledge towards Type 1 diabetes is limited. The ladies share their personal experience and how they cope with their overall diabetes care.

Joanne Laufer Milo, a Type 1 diabetic who hosted the event, signed a copy of her book titled "The Savvy Diabetic, a survival guide". Joanne made the comment to me, " Thank you for all that you do in the community"

3.2 Type 2 Diabetes Worksop

Participated in a workshop held on a Saturday targeting patients with Type 2 diabetes.. I assisted Dr Susan Guzman at The Diabetes Behavioural Institute in San Diego. 6 participants over the age of 50 years old attending a full day workshop titled " Getting on Track". Four main points were discussed:

1. Taking Stock
2. Emotional Obstacles
3. Social Obstacles
4. Planning for action

One of the highlights from this workshop, An African American lady was referred to the workshop by her GP. At first this lady was very shy and nervous, well educated however, just felt uncomfortable sharing her concerns. I shared stories about patients in the Torres Strait and family members who are diagnosed with Type 2 diabetes. This lady looked at me with amazement, she realized that she not the only person struggling with her diabetes. By the end of the workshop, she engaged with confidence and admitted she was in denial of accepting her diabetes after 20 years.

Take away Lessons that was shared to all who participated:

1. You are not alone with diabetes
2. There are good reasons why people have been struggling with diabetes
3. You can take small steps to get on track
4. You know where to start.

3.3 Type 1 diabetes parent's Workshop

The Type 1 diabetes parent's workshop was held on a Tuesday evening by a qualified psychologist seeking the experience to hold workshops to parents regarding their child diabetes. This workshop was more of a discussion, were two sets of parents openly discussed their concerns and strategies. The highlight for me in this workshop was the question " How does a parent let go of their child's diabetes care, and let the child become independent once they attend Collage". Not many responses from the group, nor could Bill answer the question. This open my mind, many patients who are elderly and diagnosed with Type 2 diabetes in the Torres Strait Region have at least one career. How do we reinforce the career to let the person who has the disease be more independent? During my time at BDI, Bill mentions the diabetes police, they come in all

shapes and sizes: husbands, wives, parents, children, brothers, sisters, friends, co-workers, and health professionals. These people may make secret plans, plotting how to keep their love ones under constant observation and make sure they stay on the straight and narrow. This may make it hard for the individual to self manage. A interesting but fruitful workshop.

3.3 UCSD Student – Run Free Clinic

Located: 1420 Third Ave – Downtown San Diego

During my data collection in the Torres Strait, I enjoyed working with students who are interested in learning about field research in remote communities. I made mention to Professor Steven Edelman during a meeting, Steven guided me to a UCSD Student – Run Free Clinic. We discussed the opportunity for knowledge exchange between UCSD students and James Cook University students.
I enjoyed my Monday evenings at the clinic, working with Michelle Johnson and students.

In partnership with the community, the UCSD student – run free clinic provides respectful, empowering, high quality health care with the underserved while inspiring the next generation of health professionals.

The UCSD Student-Run Free Clinic Project, in partnership with the community, provides accessible, quality healthcare for the underserved in a respectful environment in which students, health professionals, patients, and community members learn from one another [2].

The project seeks to sustain health through...

- Free medical and preventive care
- Health education
- Access to social services

Services Offered

- Medical Services
- Dental Services
- Affiliated Acupuncture Clinic
- Social and Community Services Referrals

- Legal Clinic
- Health Counselling and Education
- Educational and training for Medical students
- Education and training for Pharmacy Students

4. Networks

The friendship, and knowledge exchanged with the below mentioned health professionals was the highlight of my internship. Their assistance to help me gain the knowledge and experience, plus their interest in the Torres Strait region will never be forgotten. Future collaboration work is amongst the horizon. They made me feel welcome and open their doors for learning. Some of the below mention colleagues are now considered as friends.

- Professor Steven V. Edelman – Endocrinologist, TCOYD, San Diego, California
- Associate Clinical Professor William Polonsky – The Behavioral Diabetes Institute, San Diego
- Susan Guzman – Clinical Psychologist – The Behavioral Diabetes Institute, San Diego
- Larry Fisher – Diplomate in Clinical Psychology and Professor - Department of Family & Community Medicine and Psychiatry, University of California, San Francisco
- Michelle DeFazio – Office Manager – Behavioral Diabetes Institute. San Diego
- Mark Heyman – Diabetes Psychologist and Director – Centre for Diabetes and Mental Health
- Steven A. Alper – Social Worker – Behavioral Diabetes Institute. San Diego
- Athena Philis-Tsimikas – Endocrinologist – Scripps Diabetes Care, Scripps Whittier Diabetes Institute
- Michelle Johnson – Medical Officer – Free Diabetes Clinic, University of California, San Diego
- Sunny Smith – Medical Officer – Free Diabetes Clinic, University of California, San Diego
- Robert Nelson - Senior Investigator, Diabetes Epidemiology and Clinical Research Section, Phoenix Epidemiology and Clinical Research Branch
- Madhumita Sinha – Paediatrician, Diabetes, Epidemiology and Clinical Research Section, Phoenix Epidemiology and Clinical Research Branch

- Jonathan Krakoff – Endocrinologist, Metabolic Studies, Diabetes, Epidemiology and Clinical Research Section, Phoenix Epidemiology and Clinical Research Branch
- Bill Knowler – Epidemiology Section, Diabetes, Epidemiology and Clinical Research Section, Phoenix Epidemiology and Clinical Research Branch
- Clifton Bogardus – Branch Chief, Metabolism, Obesity, Diabetes and Genetics, The National Institute of Diabetes and Digestive and Kidney Disease, Phoenix, Arizona
- Ian Blumer – Diabetologist, Charles H Best Diabetes Centre, University of Toronto
- Jeremy Pettus – Endocrinologist, Assistant Professor of Medicine, UCSD
- Evan Guzman – Interaction Designer, Student of Art Centre Collage of Design

5. Visa

Please find attached documents: Appendix

1. The Graduate Division at the Department of Medicine at the University of California, San Diego.
2. DS-2019, Certificate of Eligibility for Exchange Visitor (J Visa) Status.
3. Copy of J1 Visa
4. Copy of B1/B2 Visa

Visiting graduate Student – University of California, San Diego – VG0010324 Expiration date: April 27, 2015.

J1 visa – Control number 20143466350001 Expiration date: 16 March 2015
Short Term Scholar – DS-2019 – NOO12352167 P-1 – 02849
B1 via – Control Number 2014246635001 expiration Date: 17 December 2019

The J1 visa expired on the 16th March 2015, however the Graduate Division extended the Extended Doctoral Attachment until 27th April 2015 using the B1 visa.

6. University of California, San Diego
Located: Gilman Drive, La Jolla 92122

The Department of Medicine at the University of California, San Diego offered me a Visiting Graduate Student position. The Visiting Graduate Student title is a courtesy designation for pre-doctoral graduate student pursuing research at UCSD related to their degree program at their home institution.
The University of California, San Diego is a student-centred, research-focused, service-oriented public institution that provides opportunity for all. Recognized as one of the top 15 research universities worldwide, a culture of collaboration sparks discoveries that advance society and drive economic impact [3].

6.1 Mission

UC San Diego will transform California and a diverse global society by educating, by generating and disseminating knowledge and creative works, and by engaging in public service.

6.2 Vision

We will align our efforts to be a student-centred, research-focused, service-oriented public university.

6.3 UCSD values are supported by five overarching university goals.

1. Delivering an educational and overall experience that develops students who are capable of solving problems, leading, and innovating in a diverse and interconnected world
2. Cultivating a diverse and inclusive university community that encourages respectful open dialogue, and challenge itself to take bold actions that will ensure learning is accessible and affordable for all
3. Nurturing and supporting a collaborative and interdisciplinary research culture that advances the frontiers of knowledge, shapes new fields, and disseminates discoveries that transform lives.
4. Supporting and promoting just and sustainable forms of economic development, shared prosperity, and social and cultural enrichment regionally and globally
5. Creating an agile, sustainable and supportive infrastructure by ensuring a dedication to services, people, and financial stewardships.

7.Professor Steven V. Edelman: University of California San Diego

In Collaboration with Associate Professor William Polonsky, Professor Steven Edelman offered to host my extended Doctoral Attachment on behalf of the University of California, San Diego.

Dr. Edelman is a professor of medicine in the Division of Endocrinology, Diabetes & Metabolism at the University of California at San Diego (UCSD) and the Veterans Affairs (VA) Healthcare System of San Diego and the director of the Diabetes Care Clinic, VA Medical Centre. He achieved high honors during his undergraduate studies at the University of California at Los Angeles and was the valedictorian of his medical school class at the University of California Davis Medical School. Dr. Edelman received his internal medicine training at the University of California Los Angeles, and completed his clinical endocrinology fellowship training at the Joslin and Lahey Clinics in Boston, Mass. Plus, as a research fellowship at UCSD.

Dr. Edelman has strong interests in education and patient advocacy. He is the founder and director of Taking Control of Your Diabetes (TCOYD), a not-for-profit organization with the goal of teaching and motivating patients in diabetes self-care. Since 1995, TCOYD has reached hundreds of thousands of people living with diabetes through a variety of education portals including national conferences, publications, television, and community programs.

Dr. Edelman's has written more than 200 articles and five books. He has won numerous awards for teaching and humanitarianism and was recognized by San Diego Magazine as a Top Doctor eight of the last nine years, an honor only achieved by a handful of physicians. He was chosen as the teacher of the year amongst the over 400 faculty members at UCSD numerous times. He was awarded the Diabetes Educator of the year by the American Diabetes Association in 2009, the Distinction in Endocrinology award by the American Association of Clinical Endocrinologists in 2011 and recently named in US News and World Report amongst the top 1% of endocrinologists in the US. Of all his accomplishments, Dr. Edelman is most proud of his compassionate, smart and successful daughters, Talia and Carina [4].

8. Associate Clinical Professor William Polonsky: The Behavioral Diabetes Institute

Dr William Polonsky received his PhD in clinical psychology from Yale University and has served as Chairman of the National Certification Board for Diabetes Educators, Senior Psychologist at the Joslin Diabetes Centre in Boston and Instructor in Psychiatry at Harvard Medical School. He is an active researcher in the filed of behavioural diabetes, a licensed clinical psychologist and certified diabetes educator. Dr. Polonsky has served on the editorial boards of numerous lay and professional journals in diabetes, including Diabetes Care, Clinical Diabetes, Diabetes Forecast, Diabetes Self-Management and Diabetes Health. Dr Polonsky is Co- Founder and President of the Behavioral Diabetes Institute, and Associate Clinical Professor in Psychiatry, University of California San Diego [5].

9. The Behavioral Diabetes Institute – San Diego, California
Located: 5405 Oberlin Drive, Sorrento Valley, San Diego, CA 92121

The Behavioral Diabetes Institute (BDI) was the location of my internship (see appendix 5). BDI is a non-profit organisation located in San Diego, California, focuses on addressing the social, emotional, and psychological barriers to living a long and healthy life with diabetes. To better understand and overcome these obstacles, BDI is actively engaged in research examining the psychological aspects of diabetes and evaluating innovative behavioural interventions. In addition, BDI directly offers an array of unique, behaviourally –oriented products and services for: people with type 1 diabetes; people with type 2 diabetes; parents of children and teens with diabetes; spouses and partners of people with diabetes; and interested health care professionals. Online courses face-to face workshops and seminars, professional training programs [6].

10. Taking Control Of Your Diabetes (TCOYD)
Located: 1110 Camino Del Mar, Suite B, Del Mar, California 22014

TCOYD conference is one of the highlights of my program. I hope to bring the TCOYD conference to Cairns. Discussions have been sought with Professor Robyn McDermott (Director – Centre for Chronic Disease Prevention (CCDP), James Cook University).

The TCOYD Mission:
Guided by the belief that every person with diabetes has the right to live a healthy, happy, and productive life, Taking Control OF Your Diabetes educates and motivates people with diabetes to take a more active role in their condition and provides innovative and integrative continuing diabetes education to medical professionals caring for people with diabetes.

TCOYD is a full day conference that people with diabetes become personally empowered to put diabetes high on their priority list in order to successfully manages their condition. Separate type 1 and Type 2 tracks allow TCOYD to individualise the topics of importance for each group so they are able to receive precise and type- specific information in a focused hands – on format. Unique to TCOYD events, people are brought together multiple times throughout the day in order to work together and better understand the many complicated facets of diabetes care [7].

11. The National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) – Phoenix, Arizona
Located: 1550E Indian School Road, Phoenix, Arizona, 85014
The NIDDK, sent a formal invitation to me requesting I present my research proposal to staff at the NIDDK – Phoenix, Arizona. Travel cost reimbursed, and future collaboration work discussed between the NIDDIK and CCDP re: Pima Indians and Torres Strait Islanders.

The NIDDK supports a wide range of medical research through grants to universities and other medical research institutions across the country. The Institute also supports government scientists who conduct basic, translational and clinical research across a broad spectrum of research topics and serious, chronic diseases and conditions related to the institute's mission. In addition, the NIDDK supports research training for students and scientists at various stages of their careers and a range of education and outreach programs to bring science-based information to patients and their families, health care professionals and the public [8].

12. Funding Source

1. The Roberta Sykes Indigenous Education Foundation provided $8000.00 towards flights and accommodation to attend my Extended Doctoral Attachment in San Diego (see appendix 6.

The Roberta Sykes Indigenous Education Foundation provides partial funding for Indigenous postgraduate students to undertake research, at a recognised overseas academic institution, as part of their Australian postgraduate study program. The period of study at the overseas institution can vary from a few months to a year [9].

2. The National Heart Foundation provided a Scholarship wage of $40000.00 annually with a top up from The Centre for Research Excellence: Research Fellow: 0.2 Research Fellow @ 40000.00 per annum.
3. Student Funds – James Cook University covered cost associated with the Visa and conference and accommodation cost at Santa Clara.
4. My personal funds covered the remaining cost for accommodation at San Diego and CHI insurance.

12.1 Total Cost of the Extended Doctoral Attachment: AUS$15,171.83 excluding food, car hire, fuel, mobile phone use and incidentals.

Provider	Expense	Amount	Currency	AUD Convert	Resource
UC San Diego International Faculty & Scholar Office	Processing Fee – Prospective Exchange Visitor	$350.00	USD	$402.99	Student Funds
UC San Diego International Faculty & Scholar Office	Fast-track processing fee – ISO	$200.00	USD	$235.93	Student Funds

US Dept Homeland Security	VISA Fee – SEVIS 1-901	$180.00	USD	$218.05	Student Funds
US Embassy	VISA Fee – J-1 Visa	$176.00	AUD	$176.00	Student Funds
QANTAS	Return flight Cairns – Sydney (Visa interview)	$446.00	AUD	$446.00	Student Funds
Wotif – Sofitel	Accommodation – Sydney = 1 night	$184.50	AUD	$185.00	Student Funds
QANTAS	Cairns – Los Angeles (return)	$3000.00	AUD	$3000.00	Roberta Sykes
CHI Insurance	Travel Insurance	$899.00	AUD	$899.00	Personal
Inner City Apartments	Accommodation – San Diego January 09th - April 28th 2015	$6,400	USD	$8012.37	Roberta Sykes / Personal
Taking Control of Your Diabetes Conference	Registration Fee	$45.00	USD		Student Funds
Wotif -	Accommodation – Santa Clara		USD		Student Funds
Total		**$11,880.00**	USD	**$15,171.83**	

13: Extended Doctoral Attachment Preparation

- The preparation and guidance towards the process of the Extended Doctoral Attachment from staff at James Cook University was limited. I took the initiative and researched the step-by-step process.
- Professor Adrian Esterman made the initial contact with Associate Clinical Professor William Polonsky (The Behavioral Diabetes Institute)
- Applied for a Roberta Sykes Fellowship – Granted $8000.00 (Assistance from Dr Jenni Judd, Professor Robyn McDermott, Professor Kim Usher, Sainty Kaigey and David Abendego)
- Requirements for the Roberta Sykes Fellowship: Be accepted into a recognised overseas academic Institution. Bill gained support from his colleague Professor Steven Edelman at UCSD to meet the criteria.
- Travel, visa and accommodation was investigated personally
- Professor Robyn McDermott supported financial assistance associated with the visa from my student funds.

14: My Experience

My adventure in the USA was memorable and an experience that taught me many things about myself as a Doctoral Student. This was not my first personal overseas trip, however, my first professional overseas experience. I travelled to the east coast of the USA before arriving in San Diego.

Before the commencing my Extended Doctoral Attachment, I spent two weeks in Manhattan – New York City. Travelled to Niagara Falls in Canada and Washington DC. I explored Manhattan by foot and by bus, gaining many friends who were seeking an adventure.

The staff at BDI made me feel welcome and at home. The experience gained whilst working at the BDI include, Psychological Insulin Resistance, Patients perspective around diabetes care and management, plus, the role of mental health professionals in diabetes care. Depression and stress with patients with diabetes. Food habits, and dealing with patients who struggle with their overall diabetes care and management. This has strengthened my knowledge and understanding into my own research in the Torres Strait islands, plus, interpreting my own data.

I reflected back to the Torres Strait and compared information gained, My learning highlight was attending the TCYOD conference in Santa Clara. Witnessing patients and health professionals in the same complex and attending same workshops. The take

home message for me from that conference, not matter what your home address, the issues are still the same globally. The issues around diabetes are not all related to cultural differences however behavioral issues.
The people of the USA were interested in the Torres Strait Islands. Many did not know where the Torres Strait was located. A significant period of my time was sharing my knowledge and experience of the Torres Strait Islands. This gave me the confidence to talk more freely about my research and be the expert in my area of fieldwork.
My father travelled to San Diego, spent two weeks. A road trip with dad was probably the highlight of my adventure. We adventured to Las Vegas, the Grand Canyon and Los Angeles.

Accommodation was booked at Inner City Apartments in La Jolla. This accommodation targets international students. No lease, fully furnished apartments, Utilities covered in your monthly rent. During the last month of my stay, I requested to stay in Little Italy – Downtown San Diego.
Places I visited whilst being in USA:

- New York City
- New Jersey
- New York
- Niagra Falls – Canada
- Washington D.C
- San Diego
- Los Angeles
- San Francisco
- Las Vegas
- West Grand Canyon
- Tijuana – Mexico
- Phoenix

I drove 6,899km in total during my stay in California.

In conclusion, the learning experience at BDI was priceless, the new friends and colleagues made will linger forever. The road trip adventure with friends and my father was the highlight. In essence, everyone who I met during my journey made my Extended Doctoral Attachment a success and shared their story and adventure. The next adventure in my Doctor of Public Health studies waits.

15: Reference list

1. https://secure.jcu.edu.au/app/studyfinder/?subject=TM6014.
2. http://meded.ucsd.edu/freeclinic/.
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4. http://tcoyd.org/tcoyd-team/steven-v-edelman-md.html.
5. http://www.behavioraldiabetesinstitute.org/about-us/board.
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8. http://www.niddk.nih.gov/Pages/default.aspx.
9. http://www.robertasykesfoundation.com/roberta-sykes-fellowship.html.

16: APPENDIX.

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Appendix D: Letter of Offer – Collaboration and Exchange Award

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Appendix E: Heart Foundation Scholarship Notification

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Appendix F: PIR Ethics Approval Letter

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Appendix G: Workflow Ethics Approval Letter –QLD 2014

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Appendix H: Workflow Ethics Approval Letter –QLD 2016

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Appendix I: PIR Ethics Approval Letter – JCU 2014

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Appendix J: Workflow Ethics Approval Letter –JCU 2014

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Appendix K: Authorisation Letter – TCHHS

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Appendix L: Research Collaboration Agreement

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Appendix M: Participants information Sheet PIR

University of South Australia

JAMES COOK UNIVERSITY AUSTRALIA

Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations: ***Psychological Insulin Resistance*** *amongst Torres Strait Islanders with Type 2 Diabetes.*

You are invited to participate in the above research project being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with Mer Island Health Service. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

The aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at Mer Island Health Service and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Mer Island Health Service or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Mer Island Health, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

- From any hospital admissions in Queensland (from 2003 to end of project)
- Any Emergency Department visits in Queensland (from 2013 to end of project)
- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Mer Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

You will also be asked if you would like to be interviewed about your health which will include three surveys about your lifestyle, chronic disease and about how you feel about the insulin therapy you are receiving.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at Mer Island Health Service. A report about your health will go to staff at Mer Island Health Service. You will be able to discuss this report and what it means with staff at Mer Island Health Service.

Your name and details will be kept confidential. It is possible that the results will be published and presented at conferences. Your health information will be kept securely in the University of South Australia for at least 5 years from the date of publication.

Your participation in this study is completely voluntary. If you do not want to be in the study that will have no effect on your ability to keep going to Mer Island Health Service for your health care. If you decide to participate then

decide later you want to stop being in the study at any stage, or to withdraw any information you have supplied, you are free to do so without prejudice.

If you would like to participate, please indicate that you have read and understood this information by signing the two accompanying consent forms and returning it to your health worker.

If you need any further information, or have any concerns, please do not hesitate to contact researcher Robyn McDermott on mob: [redacted] or email: robyn.mcdermott@jcu.edu.au
If you have any concerns about the conduct of the project, you are welcome to contact administrator Martin Paterson of the Queensland Health - Human Research Ethics Committee on ph: 07 3234 0034 or email: regu@health.qld.gov.au

Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations: ***Psychological Insulin Resistance*** *amongst Torres Strait Islanders with Type 2 Diabetes*.

You are invited to participate in the above research project, which is being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with Darnley Island Health Centre. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

The aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at Darnley Island Health Centre and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Darnley Island Health Centre or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Darnley Island Health Centre, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

- From any hospital admissions in Queensland (from 2003 to end of project)
- Any Emergency Department visits in Queensland (from 2013 to end of project)
- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Darnley Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

You will also be asked if you would like to be interviewed about your health which will include three surveys about your lifestyle, chronic disease and about how you feel about the insulin therapy you are receiving.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at Darnley Island Health Centre. A report about your health will go to staff at Darnley Island Health Centre. You will be able to discuss this report and what it means with staff at Darnley Island Health Centre.

Your name and details will be kept confidential. It is possible that the results will be published and presented at conferences. Your health information will be kept securely in the University of South Australia for at least 5 years from the date of publication.

Your participation in this study is completely voluntary. If you do not want to be in the study that will have no effect on your ability to keep going to Darnley Island Health Centre for your health care. If you decide to participate then

decide later you want to stop being in the study at any stage, or to withdraw any information you have supplied, you are free to do so without prejudice.

If you would like to participate, please indicate that you have read and understood this information by signing the two accompanying consent forms and returning it to your health worker.

If you need any further information, or have any concerns, please do not hesitate to contact researcher Robyn McDermott on mob: or email: robyn.mcdermott@jcu.edu.au
If you have any concerns about the conduct of the project, you are welcome to contact administrator Martin Paterson of the Queensland Health - Human Research Ethics Committee on ph: 07 3234 0034 or email: regu@health.qld.gov.au

Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations: ***Psychological Insulin Resistance*** *amongst Torres Strait Islanders with Type 2 Diabetes*.

You are invited to participate in the above research project, which is being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with Saibai Island Primary Health Care Centre. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

The aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at Saibai Island Primary Health Care Centre and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Saibai Island Primary Health Care Centre or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Saibai Island Primary Health Care Centre, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

- From any hospital admissions in Queensland (from 2003 to end of project)
- Any Emergency Department visits in Queensland (from 2013 to end of project)
- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Saibai Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

You will also be asked if you would like to be interviewed about your health which will include three surveys about your lifestyle, chronic disease and about how you feel about the insulin therapy you are receiving.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at Saibai Island Primary Health Care Centre. A report about your health will go to staff at Saibai Island Primary Health Care Centre. You will be able to discuss this report and what it means with staff at Saibai Island Primary Health Care Centre.

Your name and details will be kept confidential. It is possible that the results will be published and presented at conferences. Your health information will be kept securely in the University of South Australia for at least 5 years from the date of publication.

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If you would like to participate, please indicate that you have read and understood this information by signing the two accompanying consent forms and returning it to your health worker.

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University of South Australia

JAMES COOK UNIVERSITY AUSTRALIA

Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations: ***Psychological Insulin Resistance*** *amongst Torres Strait Islanders with Type 2 Diabetes*.

You are invited to participate in the above research project, which is being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with Stephen Island Health Centre. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

The aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at Stephen Island Health Centre and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Stephen Island Health Centre or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Stephen Island Health Centre, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

- From any hospital admissions in Queensland (from 2003 to end of project)
- Any Emergency Department visits in Queensland (from 2013 to end of project)
- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Stephen Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

You will also be asked if you would like to be interviewed about your health which will include three surveys about your lifestyle, chronic disease and about how you feel about the insulin therapy you are receiving.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at Stephen Island Health Centre. A report about your health will go to staff at Stephen Island Health Centre. You will be able to discuss this report and what it means with staff at Stephen Island Health Centre.

Your name and details will be kept confidential. It is possible that the results will be published and presented at conferences. Your health information will be kept securely in the University of South Australia for at least 5 years from the date of publication.

Your participation in this study is completely voluntary. If you do not want to be in the study that will have no effect on your ability to keep going to Stephen Island Health Centre for your health care. If you decide to participate then

decide later you want to stop being in the study at any stage, or to withdraw any information you have supplied, you are free to do so without prejudice.

If you would like to participate, please indicate that you have read and understood this information by signing the two accompanying consent forms and returning it to your health worker.

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University of South Australia

JAMES COOK UNIVERSITY AUSTRALIA

Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations: ***Psychological Insulin Resistance*** *amongst Torres Strait Islanders with Type 2 Diabetes*.

You are invited to participate in the above research project, which is being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with Yorke Island Primary Health Care Centre. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

The aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at Yorke Island Primary Health Care Centre and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Yorke Island Primary Health Care Centre or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Yorke Island Primary Health Care Centre, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

- From any hospital admissions in Queensland (from 2003 to end of project)
- Any Emergency Department visits in Queensland (from 2013 to end of project)
- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Yorke Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

You will also be asked if you would like to be interviewed about your health which will include three surveys about your lifestyle, chronic disease and about how you feel about the insulin therapy you are receiving.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at Yorke Island Primary Health Care Centre. A report about your health will go to staff at Yorke Island Primary Health Care Centre. You will be able to discuss this report and what it means with staff at Yorke Island Primary Health Care Centre.

Your name and details will be kept confidential. It is possible that the results will be published and presented at conferences. Your health information will be kept securely in the University of South Australia for at least 5 years from the date of publication.

Your participation in this study is completely voluntary. If you do not want to be in the study, that will have no effect on your ability to keep going to Yorke Island Primary Health Care Centre for your health care. If you decide to

participate then decide later you want to stop being in the study at any stage, or to withdraw any information you have supplied, you are free to do so without prejudice.

If you would like to participate, please indicate that you have read and understood this information by signing the two accompanying consent forms and returning it to your health worker.

If you need any further information, or have any concerns, please do not hesitate to contact researcher Robyn McDermott on mob: or email: robyn.mcdermott@jcu.edu.au
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Appendix N: Participants Information Sheet Workflow

University of South Australia

JAMES COOK UNIVERSITY AUSTRALIA

Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations:
***A Sustainable Workflow** - Diabetes Care and Management in Remote Torres Strait Islands.*

You are invited to participate in the above research project being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with Mer Island Health Service. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

The aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at Mer Island Health Service and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Mer Island Health Service or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Mer Island Health, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

- From any hospital admissions in Queensland (from 2003 to end of project)
- Any Emergency Department visits in Queensland (from 2013 to end of project)
- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Mer Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at Mer Island Health Service. A report about your health will go to staff at Mer Island Health Service. You will be able to discuss this report and what it means with staff at Mer Island Health Service.

Your name and details will be kept confidential. It is possible that the results will be published and presented at conferences. Your health information will be kept securely in the University of South Australia for at least 5 years from the date of publication.

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University of South Australia

JAMES COOK UNIVERSITY AUSTRALIA

Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations:
A Sustainable Workflow *- Diabetes Care and Management in Remote Torres Strait Islands.*

You are invited to participate in the above research project, which is being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with Darnley Island Health Centre. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

The aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at Darnley Island Health Centre and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Darnley Island Health Centre or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Darnley Island Health Centre, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

- From any hospital admissions in Queensland (from 2003 to end of project)
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- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Darnley Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at Darnley Island Health Centre. A report about your health will go to staff at Darnley Island Health Centre. You will be able to discuss this report and what it means with staff at Darnley Island Health Centre.

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University of South Australia

JAMES COOK UNIVERSITY AUSTRALIA

Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations:
A Sustainable Workflow *- Diabetes Care and Management in Remote Torres Strait Islands.*

You are invited to participate in the above research project, which is being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with Saibai Island Primary Health Care Centre. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

The aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at Saibai Island Primary Health Care Centre and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Saibai Island Primary Health Care Centre or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Saibai Island Primary Health Care Centre, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

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- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Saibai Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at Saibai Island Primary Health Care Centre. A report about your health will go to staff at Saibai Island Primary Health Care Centre. You will be able to discuss this report and what it means with staff at Saibai Island Primary Health Care Centre.

Your name and details will be kept confidential. It is possible that the results will be published and presented at conferences. Your health information will be kept securely in the University of South Australia for at least 5 years from the date of publication.

Your participation in this study is completely voluntary. If you do not want to be in the study, that will have no effect on your ability to keep going to Saibai Island Primary Health Care Centre for your health care. If you decide to participate then decide later you want to stop being in the study at any stage, or to withdraw any information you have supplied, you are free to do so without prejudice.

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University of South Australia

JAMES COOK UNIVERSITY AUSTRALIA

Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations:
A Sustainable Workflow *- Diabetes Care and Management in Remote Torres Strait Islands.*

You are invited to participate in the above research project, which is being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with Stephen Island Health Centre. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

The aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at Stephen Island Health Centre and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Stephen Island Health Centre or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Stephen Island Health Centre, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

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- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Stephen Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

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University of South Australia

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The aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at Yorke Island Primary Health Care Centre and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Yorke Island Primary Health Care Centre or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Yorke Island Primary Health Care Centre, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

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- Any Emergency Department visits in Queensland (from 2013 to end of project)
- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Yorke Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at Yorke Island Primary Health Care Centre. A report about your health will go to staff at Yorke Island Primary Health Care Centre. You will be able to discuss this report and what it means with staff at Yorke Island Primary Health Care Centre.

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Your participation in this study is completely voluntary. If you do not want to be in the study, that will have no effect on your ability to keep going to Yorke Island Primary Health Care Centre for your health care. If you decide to participate then decide later you want to stop being in the study at any stage, or to withdraw any information you have supplied, you are free to do so without prejudice.

If you would like to participate, please indicate that you have read and understood this information by signing the two accompanying consent forms and returning it to your health worker.

If you need any further information, or have any concerns, please do not hesitate to contact researcher Robyn McDermott on mob: or email: robyn.mcdermott@jcu.edu.au
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University of South Australia

JAMES COOK UNIVERSITY AUSTRALIA

Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations:
A Sustainable Workflow *- Diabetes Care and Management in Remote Torres Strait Islands.*

You are invited to participate in the above research project being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with Boigu Island Health Service. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

The aim of this study is to better prevent heart disease, kidney disease and diabetes, and for people who already have these diseases or a mental health illness, provide better health care so that people stay well and out of hospital. To do this, we will look at the health care you are receiving at Boigu Island Health Service and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Boigu Island Health Service or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Boigu Island Health, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

- From any hospital admissions in Queensland (from 2003 to end of project)
- Any Emergency Department visits in Queensland (from 2013 to end of project)
- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Boigu Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at Boigu Island Health Service. A report about your health will go to staff at Boigu Island Health Service. You will be able to discuss this report and what it means with staff at Boigu Island Health Service.

Your name and details will be kept confidential. It is possible that the results will be published and presented at conferences. Your health information will be kept securely in the University of South Australia for at least 5 years from the date of publication.

Your participation in this study is completely voluntary. If you do not want to be in the study that will have no effect on your ability to keep going to Boigu Island Health Service for your health care. If you decide to participate then

decide later you want to stop being in the study at any stage, or to withdraw any information you have supplied, you are free to do so without prejudice.

If you would like to participate, please indicate that you have read and understood this information by signing the two accompanying consent forms and returning it to your health worker.

If you need any further information, or have any concerns, please do not hesitate to contact researcher Robyn McDermott on mob: or email: robyn.mcdermott@jcu.edu.au
If you have any concerns about the conduct of the project, you are welcome to contact administrator Martin Paterson of the Queensland Health - Human Research Ethics Committee on ph: 07 3234 0034 or email: regu@health.qld.gov.au

University of South Australia

JAMES COOK UNIVERSITY AUSTRALIA

Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations:
A Sustainable Workflow *- Diabetes Care and Management in Remote Torres Strait Islands.*

You are invited to participate in the above research project being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with Mabuiag Island Health Service. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

The aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at Mabuiag Island Health Service and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at Mabuiag Island Health Service or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in Mabuiag Island Health, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

- From any hospital admissions in Queensland (from 2003 to end of project)
- Any Emergency Department visits in Queensland (from 2013 to end of project)
- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of Mabuiag Island (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at Mabuiag Island Health Service. A report about your health will go to staff at Mabuiag Island Health Service. You will be able to discuss this report and what it means with staff at Mabuiag Island Health Service.

Your name and details will be kept confidential. It is possible that the results will be published and presented at conferences. Your health information will be kept securely in the University of South Australia for at least 5 years from the date of publication.

Your participation in this study is completely voluntary. If you do not want to be in the study that will have no effect on your ability to keep going to Mabuiag Island Health Service for your health care. If you decide to participate then decide later you want to stop being in the study at any stage, or to withdraw any information you have supplied, you are free to do so without prejudice.

If you would like to participate, please indicate that you have read and understood this information by signing the two accompanying consent forms and returning it to your health worker.

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Plain language statement – Chronic disease risk/chronic disease diagnosis

Project Title: Prevention and management of chronic conditions in rural and remote high risk populations:
A Sustainable Workflow *- Diabetes Care and Management in Remote Torres Strait Islands.*

You are invited to participate in the above research project being conducted by **Sean Taylor** of James Cook University and **Professor Robyn McDermott** who works at both the University of South Australia and James Cook University QLD and will be working closely with St Paul's Community Health Service. You have been invited because you have a risk of developing heart disease/kidney disease/diabetes/ you have heart disease/kidney disease/diabetes/a mental health illness.

TThe aim of this study is to better manage diabetes. To do this, we will look at the treatment you are given, the health care you receive at St Paul's Community Health Service and follow up any other health care you receive (for example if you go to hospital) to see if your health improves or not. This will show us if the health care you receive at St Paul's Community Health Service or in the rest of the health system needs to be improved, and if so, in what ways.

If you agree to participate, you would be asked to allow the research team to use information about your health care for heart disease, kidney disease, diabetes and mental health illness in St Paul's Community Health, from 2003 to end of project (including what medications you take, how your diabetes is managed and also the different services you use at the health service) and join this up with information about health care you get in other places. The other health care information is:

- From any hospital admissions in Queensland (from 2003 to end of project)
- Any Emergency Department visits in Queensland (from 2013 to end of project)
- Records of any medication for heart disease, kidney disease, diabetes or mental health illness that you take (from 2008 to end of project)
- Medicare records for when you see a doctor (GP or specialist from 2008 to end of project)
- Blood and urine test records (for cholesterol, blood sugar tests, kidney tests of blood and urine, from 2003 to end of project)
- Royal Flying Doctor Service records if you get transport for health care out of St Paul's Community (from 2013 to end of project)

Please be aware this data collection may potentially include all contact you have had with the health services listed.

All the information that is collected on your health care will be kept confidential. That is, your name and details will not be shared with anyone except your health care team at St Paul's Community Health Service. A report about your health will go to staff at St Paul's Community Health Service. You will be able to discuss this report and what it means with staff at St Paul's Community Health Service.

Your name and details will be kept confidential. It is possible that the results will be published and presented at conferences. Your health information will be kept securely in the University of South Australia for at least 5 years from the date of publication.

Your participation in this study is completely voluntary. If you do not want to be in the study that will have no effect on your ability to keep going to St Paul's Community Health Service for your health care. If you decide to participate then decide later you want to stop being in the study at any stage, or to withdraw any information you have supplied, you are free to do so without prejudice.

If you would like to participate, please indicate that you have read and understood this information by signing the two accompanying consent forms and returning it to your health worker.

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Appendix O: Participants Consent Forms

This administrative form has been removed

Appendix P: BITQ Survey

University of South Australia

JAMES COOK UNIVERSITY AUSTRALIA

Sub Study 1:

Barriers to Insulin Treatment Questionnaire (BIT)

On the following pages are expectations and concerns that people with diabetes might have about their condition and treatment. By marking your response on a scale from 1 to 10, please let us know how much you agree or disagree with each of the following statements.

1 I am afraid of the pain when injecting insulin.

totally disagree **totally agree**

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

2 Besides the pain, I am just afraid of injections.

totally disagree **totally agree**

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

3 I am afraid of the pain during regular blood-sugar checks.

totally disagree **totally agree**

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

4 Insulin works better than pills.

totally disagree **totally agree**

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

5 People who get insulin feel better.

totally disagree **totally agree**

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

6 Insulin can reliably prevent long-term complications due to diabetes.

totally disagree **totally agree**

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

7 I just don't have enough time for regular doses of insulin.

totally disagree **totally agree**

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Barriers to Insulin Treatment Questionnaire (BIT)										
8	I can't pay as close attention to my diet as insulin treatment requires.									
	totally disagree									**totally agree**
	1	2	3	4	5	6	7	8	9	10
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
9	I can't organize my day as carefully as insulin treatment requires.									
	totally disagree									**totally agree**
	1	2	3	4	5	6	7	8	9	10
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
10	Injections in public are embarrassing to me. Pills are more discreet.									
	totally disagree									**totally agree**
	1	2	3	4	5	6	7	8	9	10
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
11	Regular insulin treatment causes feelings of dependence.									
	totally disagree									**totally agree**
	1	2	3	4	5	6	7	8	9	10
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
12	When people inject insulin, it makes them feel like drug addicts.									
	totally disagree									**totally agree**
	1	2	3	4	5	6	7	8	9	10
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
13	An insulin overdose can lead to extremely low blood-sugar levels ("hypoglycemia"). I am afraid of the unpleasant accompanying symptoms.									
	totally disagree									**totally agree**
	1	2	3	4	5	6	7	8	9	10
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
14	An insulin overdose can lead to extremely low blood-sugar levels ("hypoglycemia"). I have concerns about possible permanent damage to my health.									
	totally disagree									**totally agree**
	1	2	3	4	5	6	7	8	9	10
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Appendix Q: ITAS Survey

University of South Australia

JAMES COOK UNIVERSITY AUSTRALIA

Sub Study 1:
INSULIN TREATMENT APPRAISAL SCALE (ITAS)

From your own knowledge about insulin treatment, please indicate to what extent you agree or disagree with the following statements. Please tick the box that best describes your own opinion.

	strongly disagree	disagree	agree nor disagree	agree	strongly agree
1. Taking insulin means I have failed to manage my diabetes with diet and tablets.	☐	☐	☐	☐	☐
2. Taking insulin means my diabetes has become much worse.	☐	☐	☐	☐	☐
3. Taking insulin helps to prevent complications of diabetes.	☐	☐	☐	☐	☐
4. Taking insulin means other people see me as a sicker person.	☐	☐	☐	☐	☐
5. Taking insulin makes life less flexible.	☐	☐	☐	☐	☐
6. I'm afraid of injecting myself with a needle.	☐	☐	☐	☐	☐
7. Taking insulin increases the risk of low blood glucose levels (hypoglycaemia).	☐	☐	☐	☐	☐
8. Taking insulin helps to improve my health.	☐	☐	☐	☐	☐
9. Insulin causes weight gain.	☐	☐	☐	☐	☐
10. Managing insulin injections takes a lot of time and energy.	☐	☐	☐	☐	☐
11. Taking insulin means I have to give up activities I enjoy.	☐	☐	☐	☐	☐
12. Taking insulin means my health will deteriorate.	☐	☐	☐	☐	☐
13. Injecting insulin is embarrassing.	☐	☐	☐	☐	☐
14. Injecting insulin is painful.	☐	☐	☐	☐	☐
15. It is difficult to inject the right amount of insulin correctly at the right time every day.	☐	☐	☐	☐	☐
16. Taking insulin makes it more difficult to fulfil my responsibilities (at work, at home).	☐	☐	☐	☐	☐
17. Taking insulin helps to maintain good control of blood glucose.	☐	☐	☐	☐	☐
18. Being on insulin causes family and friends to be more concerned about me.	☐	☐	☐	☐	☐
19. Taking insulin helps to improve my energy level.	☐	☐	☐	☐	☐
20. Taking insulin makes me more dependent on my doctor.	☐	☐	☐	☐	☐

version 1 - 15/02/2002

21. Have you had any discussion with your doctor about Insulin therapy

22. Would you take your insulin if prescribed by your doctor

23. Do you think you would be able to manage insulin therapy

version 1 - 15/02/2002

Appendix R: DCP Survey

Sub Study 1: **DCP PATIENT SURVEY- 2012**

PLEASE READ, COMPLETE AND RETURN IN THE ENVELOPE PROVIDED

An Australian Government Initiative

Diabetes Care Project

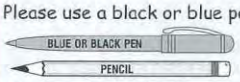
Empowering patients. Supporting practices.

INSTRUCTIONS

Please mark your responses like this ○●○○.

Please keep numbers or letters within the boxes provided. For example: 4 5

Please use a black or blue pen or lead pencil.



If you make a mistake, completely cross out the bubble and shade the appropriate one. For example: ✱●

If you do not know an answer, please choose the best answer for you.

Please mark only one response for each question.

- ○ If you would prefer to complete this survey online, a version is available to complete at the following location: www.dcp.org.au/english. You will need your DCP ID (7 Digit code below) to complete the survey online.
- ○ 如果您想以阿拉伯文完成本問卷，請到以下網址在網路上填: www.dcp.org.au/chinese 。您必須輸入您的DCP號碼 (下列的七位數號碼) 才能完成網路問卷。
- ○ Nếu Quý vị muốn hoàn thành khảo sát này bằng Tiếng Việt, phiên bản khảo sát Tiếng Việt trực tuyến hiện có tại địa chỉ sau: www.dcp.org.au/vietnamese Quý vị sẽ cần nhập mã DCP ID (7 chữ số dưới đây) để hoàn thành khảo sát trực tuyến
- ○ Se preferisce compilare il presente questionario in italiano, è disponibile una versione online al seguente sito internet: www.dcp.org.au/italian. È necessario essere in possesso del proprio DCP ID (codice a 7 cifre riportato qui di seguito) per poter completare il questionario online.
- ○ Εάν επιθυμείτε να συμπληρώσετε την έρευνα στα ελληνικά, μια έκδοση της είναι διαθέσιμη στην ακόλουθη ιστοσελίδα www.dcp.org.au/greek Θα χρειαστείτε το DCP ID (ο παρακάτω 7-ψήφιος κωδικός) για να συμπληρώσετε την έρευνα
- ○ Bu anketin Türkçe versiyonuna, www.dcp.org.au/turkish adresinden ulaşabilirsiniz. Anketi internet üzerinden tamamlayabilmek için DCP ID numaranıza (aşağıdaki 7 haneli sayı) ihtiyacınız olacaktır
- ○ إذا كنتم تفضلون إكمال هذا الاستبيان بلالغة العربية، فهناك نسخة إلكترونية متوفرة على الإنترنت من خلال الموقع التالي: www.dcp.org.au/arabic وسوف تحتاجون إلى استخدام رقم DCP ID (والمكون من 7 رموز كما موضح أدناه) لإكمال هذا الاستبيان على الإنترنت.

The first set of questions asks for some general information about you

Please answer the following questions:

1. **What is your name?**
   FIRST GIVEN NAME _____ FAMILY NAME _____
2. **What is your date of birth?** DAY ___ MONTH ___ YEAR ___
3. **What is your sex?** ○ Male ○ Female
4. **What is your postal address?**
   STREET ADDRESS _____
   SUBURB _____ STATE ___ POSTCODE ___
5. **What is your Medicare number?** ____ - _____ - _
6. **When were you diagnosed with diabetes?** MONTH ___ YEAR ___

DCP ID

1

7. **What treatment are you currently receiving for diabetes?** *Select all relevant*
   - ○ Diet and exercise ○ Tablets ○ Insulin

8. **Do you have Type 1 or Type 2 diabetes?**
   - ○ Type 1 ○ Type 2 ○ Don't know

9. **When did you begin taking medication for your diabetes?** ☐☐ ☐☐ MONTH YEAR

10. **How well do you speak English?**
    - ○ Very well ○ Well ○ Not well ○ Not at all

11. **Do you require an interpreter for your doctors appointments?**
    - ○ No ○ Yes

12. **What is your ethnicity?**
    - ○ Anglo-Celtic
    - ○ Other European
    - ○ Asian
    - ○ Pacific Islander
    - ○ African
    - ○ Other

13. **Do you identify yourself as Aboriginal/Torres Strait Islander?**
    - ○ No ○ Yes – Aboriginal ○ Yes – Torres Strait Islander

14. **What is your highest education qualification?**
    - ○ Never went to school
    - ○ Year 8 or below
    - ○ Year 9, 10, 11 or equivalent
    - ○ Year 12 or equivalent
    - ○ Certificate
    - ○ Diploma
    - ○ Bachelor Degree or above

15. **What is your employment status?**
    - ○ Employed
    - ○ Unemployed
    - ○ Retired
    - ○ Other

16. **What is your annual, pre-tax, household income?**
    - ○ Less than $20,000
    - ○ $20,000–$39,999
    - ○ $40,000–$59,999
    - ○ $60,000–$79,999
    - ○ $80,000–$99,999
    - ○ Over $100,000

17. **Do you currently smoke cigarettes?**
    - ○ No ○ Yes

18. **If answered yes to Question 17, how many cigarettes on average a day do you smoke?** ☐☐

19. **How many alcoholic drinks do you consume on average, per week?** ☐☐

20. **What conditions, other than diabetes, do you regularly seek treatment for?** *Select all relevant*
    - ○ Chronic Heart Disease
    - ○ Arthritis
    - ○ Asthma
    - ○ Other lung condition
    - ○ Stroke
    - ○ Cancer
    - ○ Mental health condition
    - ○ Other

21. **Do you hold a Health Care Card?**
- ○ No
- ○ Yes

22. **Do you have private health insurance?**
- ○ No
- ○ Yes

23. **If you answered yes to Question 22, who is your private health insurance provider?**
- ○ Medibank
- ○ BUPA
- ○ HCF (The Hospitals Contribution Fund)
- ○ HBA
- ○ HBF
- ○ NIB
- ○ AHM
- ○ Australian Unity
- ○ MBF Alliance
- ○ Teachers Health Fund
- ○ GMHBA
- ○ Other

24. **Are you accessing any special services for your diabetes offered by a private health insurer?** *E.g. telephone coaching*
- ○ No
- ○ Yes

25. **How many individual Allied Health sessions did you attend in the last 12 months that you or your heath insurer had to pay the full fee for (not a co-payment)?**
- ○ Zero
- ○ 1-2
- ○ 3-4
- ○ 5 or more

26. **Are you part of any other State or Federal Health programs?**
- ○ Closing the Gap
- ○ Coordinated Veterans Care program
- ○ Other

27. **Have you been in hospital (elective or emergency) since January 2010?** *Please mark all relevant*
- ○ No
- ***In Queensland***
  - ○ Public
  - ○ Private
- ***In South Australia***
  - ○ Public
  - ○ Private
- ***In Victoria***
  - ○ Public
  - ○ Private
- ○ Other

28. **Would you like to participate in focus groups throughout the pilot process?**
- ○ No
- ○ Yes

The next set of questions asks you about managing your own care

Please mark the number that most closely fits your answer.

		Very Good					Satisfactory			Very Poor
1.	My knowledge of my condition is:	⓪	①	②	③	④	⑤	⑥	⑦	⑧
2.	My knowledge of the treatment of my condition is:	⓪	①	②	③	④	⑤	⑥	⑦	⑧
3.	My ability to share in decisions made about the management of my condition is:	⓪	①	②	③	④	⑤	⑥	⑦	⑧
4.	My ability to arrange appointments as recommended by my Doctor or Health Service Provider is:	⓪	①	②	③	④	⑤	⑥	⑦	⑧
5.	My attendance at appointments is:	⓪	①	②	③	④	⑤	⑥	⑦	⑧
6.	My ability to take my medication as directed by my doctor is:	⓪	①	②	③	④	⑤	⑥	⑦	⑧
7.	My understanding of why I need to observe, measure, and record symptoms is:	⓪	①	②	③	④	⑤	⑥	⑦	⑧
8.	My ability to observe, measure, and record my symptoms is:	⓪	①	②	③	④	⑤	⑥	⑦	⑧
9.	My understanding of what to do when my symptoms get worse is:	⓪	①	②	③	④	⑤	⑥	⑦	⑧
10.	My ability to take the right action when my symptoms get worse is:	⓪	①	②	③	④	⑤	⑥	⑦	⑧
11.	My progress towards adopting habits that improve my health is:	⓪	①	②	③	④	⑤	⑥	⑦	⑧

The next set of questions asks you about the care you have received from your GP

Please judge the diabetes care you have received during the *past 12 months* from your regular GP and select the number which most closely fits your answer

		Poor	Fair	Good	Very Good	Excellent
1.	The waiting time before consulting the doctor	○	○	○	○	○
2.	The duration of the consultation with the doctor	○	○	○	○	○
3.	The time I have to wait until my next appointment with the doctor	○	○	○	○	○
4.	The clarity of information I receive from the doctor	○	○	○	○	○
5.	The amount of information I receive from the doctor	○	○	○	○	○
6.	The usefulness of the information I receive from the doctor	○	○	○	○	○
7.	The opportunity to ask questions to the doctor during the consultation	○	○	○	○	○
8.	The emotional support given by the doctor	○	○	○	○	○
9.	The medico-technical competence of the doctor (e.g., knowledge about diabetes, ability to maintain/achieve favourable effects on your diabetes)	○	○	○	○	○
10	The extent to which the doctor is informed about the (past) treatment of my diabetes	○	○	○	○	○
11.	The extent to which the diabetes care provided by doctor is integrated with the care of other health providers that I have visited (e.g., the diabetes nurse specialist or other medical specialists)	○	○	○	○	○
12.	The opportunity to share decisions with the doctor about the treatment of my diabetes	○	○	○	○	○
13.	The ease of making new appointments with the doctor	○	○	○	○	○
14.	The overall quality of my diabetes care by the doctor is	○	○	○	○	○

The next set of questions asks you about everyone involved in your care

1. **In general, how well is your diabetes care coordinated?**
   - ○ Extremely well
   - ○ Very well
   - ○ Fairly well
   - ○ Badly

Think about all the *different staff* involved in your diabetes care. How much would you agree with the following statements?

		Agree very strongly	Agree strongly	Agree	Disagree	Disagree strongly	Disagree very strongly
2.	They all give me the same information and advice	○	○	○	○	○	○
3.	They all know my medical history	○	○	○	○	○	○
4.	They all know about my diabetes treatment	○	○	○	○	○	○
5.	They share an agreed plan of treatment for my diabetes	○	○	○	○	○	○

The next set of questions asks about how you feel you are coping in general

Over the *last 2 weeks*, how often have you been bothered by any of the following problems?

		Not at all	Several days	More than half the days	Nearly every day
1.	Little interest or pleasure in doing things	○	○	○	○
2.	Feeling down, depressed, or hopeless	○	○	○	○
3.	Trouble falling or staying asleep, or sleeping too much	○	○	○	○
4.	Feeling tired or having little energy	○	○	○	○
5.	Poor appetite or overeating	○	○	○	○
6.	Feeling bad about yourself—or that you are a failure or have let yourself or your family down	○	○	○	○
7.	Trouble concentrating on things, such as reading the newspaper or watching television	○	○	○	○
8.	Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	○	○	○	○
9.	Thoughts that you would be better off dead or of hurting yourself in some way	○	○	○	○

If you checked off *any* problems, how *difficult* have these problems made it for you to do your work, take care of things at home, or get along with other people?

- ○ Not difficult at all
- ○ Somewhat difficult
- ○ Very difficult
- ○ Extremely difficult

The next set of questions asks you specifically how you are coping with your diabetes

Mark the response that gives the best answer for you. Please provide an answer for each question.

Which of the following diabetes issues are currently a problem for you?

		Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem
1.	Not having clear and concrete goals for your diabetes care?	○	○	○	○	○
2.	Feeling discouraged with your diabetes treatment plan?	○	○	○	○	○
3.	Feeling scared when you think about living with diabetes?	○	○	○	○	○
4.	Uncomfortable social situations related to your diabetes care (e.g., people telling you what to eat)?	○	○	○	○	○
5.	Feelings of deprivation regarding food and meals?	○	○	○	○	○
6.	Feeling depressed when you think about living with diabetes?	○	○	○	○	○
7.	Not knowing if your mood or feelings are related to your diabetes?	○	○	○	○	○
8.	Feeling overwhelmed by your diabetes?	○	○	○	○	○
9.	Worrying about low blood sugar reactions?	○	○	○	○	○
10.	Feeling angry when you think about living with diabetes?	○	○	○	○	○

		Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem
11.	Feeling constantly concerned about food and eating?	○	○	○	○	○
12.	Worrying about the future and the possibility of serious complications?	○	○	○	○	○
13.	Feelings of guilt or anxiety when you get off track with your diabetes management?	○	○	○	○	○
14.	Not "accepting" your diabetes?	○	○	○	○	○
15.	Feeling unsatisfied with your diabetes physician?	○	○	○	○	○
16.	Feeling that diabetes is taking up too much of your mental and physical energy every day?	○	○	○	○	○
17.	Feeling alone with your diabetes?	○	○	○	○	○
18.	Feeling that your friends and family are not supportive of your diabetes management efforts?	○	○	○	○	○
19.	Coping with complications of diabetes?	○	○	○	○	○
20.	Feeling "burned out" by the constant effort needed to manage diabetes?	○	○	○	○	○

The next set of questions asks about your general quality of life

Mark the response that best fits your situation

1. **Do you need any help looking after yourself?**
   - ○ I need no help at all
   - ○ Occasionally I need some help with personal care tasks
   - ○ I need help with the more difficult personal care tasks
   - ○ I need daily help with most or all personal care tasks

2. **When doing household tasks:**
   For example: preparing food, gardening, using the video recorder, radio, telephone or washing the car.
   - ○ I need no help at all
   - ○ Occasionally I need some help with household tasks
   - ○ I need help with the more difficult household tasks
   - ○ I need daily help with most or all household tasks

3. **Thinking about how easily you can get around your home and community:**
   - ○ I get around my home and community by myself without any difficulty
   - ○ I find it difficult to get around my home and community by myself
   - ○ I cannot get around the community by myself, but I can get around my home with some difficulty
   - ○ I cannot get around either the community or my home by myself

4. **Because of your health, your relationships (for example: with your friends, partner or parents) generally:**
   - ○ Are very close and warm
   - ○ Are sometimes close and warm
   - ○ Are seldom close and warm
   - ○ I have no close and warm relationships

5. **Thinking about your relationship with other people:**
   - ○ I have plenty of friends, and am never lonely
   - ○ Although I have friends, I am occasionally lonely
   - ○ I have some friends, but am often lonely for company
   - ○ I am socially isolated and feel lonely

6. **Thinking about your health and your relationship with your family:**
   - ○ My role in the family is unaffected by my health
   - ○ There are some parts of my family role I cannot carry out
   - ○ There are many parts of my family role I cannot carry out
   - ○ I cannot carry out any part of my family role

7. **Thinking about your vision, including when using your glasses or contact lenses if needed:**
   - ○ I see normally
   - ○ I have some difficulty focusing on things, or I do not see them sharply
     For example: small print, a newspaper or seeing objects in the distance.
   - ○ I have a lot of difficulty seeing things. My vision is blurred.
     For example: I can see just enough to get by with.
   - ○ I only see general shapes, or am blind
     For example: I need a guide to move around.

8. **Thinking about your hearing, including using your hearing aid if needed:**
   - ○ I hear normally
   - ○ I have some difficulty hearing or I do not hear clearly
     For example: I ask people to speak up, or turn up the TV or radio volume.
   - ○ I have difficulty hearing things clearly
     For example: Often I do not understand what is said. I usually do not take part in conversations because I cannot hear what is said.
   - ○ I hear very little indeed
     For example: I cannot fully understand loud voices speaking directly to me.

9. **When you communicate with others: (For example: by talking, listening, writing or signing.)**
   - ○ I have no trouble speaking to them or understanding what they are saying
   - ○ I have some difficulty being understood by people who do not know me. I have no trouble understanding what others are saying to me.
   - ○ I am only understood by people who know me well. I have great trouble understanding what others are saying to me.
   - ○ I cannot adequately communicate with others

10. **Thinking about how you sleep:**
    - ○ I am able to sleep without difficulty most of the time
    - ○ My sleep is interrupted some of the time, but I am usually able to go back to sleep without difficulty
    - ○ My sleep is interrupted most nights, but I am usually able to go back to sleep without difficulty
    - ○ I sleep in short bursts only. I am awake most of the night

11. **Thinking about how you generally feel:**
    - ○ I do not feel anxious, worried or depressed
    - ○ I am slightly anxious, worried or depressed
    - ○ I feel moderately anxious, worried or depressed
    - ○ I am extremely anxious, worried or depressed

12. **How much pain or discomfort do you experience:**
    - ○ None at all
    - ○ I have moderate pain
    - ○ I suffer from severe pain
    - ○ I suffer unbearable pain

Thank you for completing this survey.

Please return the survey and consent forms in the reply paid envelope.