

# **Developing a model of care to improve the health and well-being for Indigenous people receiving renal dialysis treatment**

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## **Abstract**

The high levels of end-stage renal disease among Indigenous Australians, particularly in remote areas of the country, are a serious public health concern. The magnitude of the problem is reflected in figures from the Australian and New Zealand Transplant and Dialysis Registry that show that Indigenous Australians experience end-stage renal disease at a rate almost 9–10 times higher than other non-Indigenous Australians. A majority of Indigenous Australians have to relocate to receive appropriate renal dialysis treatment. In some Australian states, renal treatment is based on self-care dialysis which allows those Indigenous Australians to be treated back in their community. Evidence clearly shows that reuniting renal patients with community and family improves overall health and well-being for those Indigenous Australians. With the appropriate resources, training, and support, self-care management of renal dialysis treatment is an effective way for Indigenous people with end-stage renal failure to be treated at home.

In this context, the study was used to gain insight and further understanding of the impact that end-stage renal disease and renal dialysis treatment has had on the lives of Indigenous community members. The study findings are from 14 individually interviewed people from South East Queensland. Data from the interviews were analysed using a combination of thematic and content analysis. The study methodology was based on qualitative data principles where the Indigenous community members were able to share their experiences and journeys living with end-stage renal disease.

Many of the experiences and understanding closely relate to the renal disease pattern and the treatment with other outside influences, such as social, cultural, and environmental influences, all having an equal impact. Each community member's experience with end-stage renal disease is unique; some manage with family and medical support, while others try to manage independently. From the study,

community members who managed their renal dialysis treatment independently were much more aware of their renal health status.

The study provides recommendations towards a model of care to improve the health and well-being is based on self-care and self-determination principles.

### **Keywords**

End-stage renal disease, kidney failure, public health, Indigenous health, self-care management, self-determination, and chronic disease.

## List of acronyms and abbreviations

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Service
ACR	Albumin Creatinine Ratio
AHMAC	Australian Health Ministers Advisory Council
AICHS	Aboriginal and Islander Community Health Service
AIHW	Australian Institute of Health Welfare
APD	Automated peritoneal dialysis
ANZDATA	Australian and New Zealand Dialysis and Transplant Registry
ATSIC	Aboriginal and Torres Strait Islander Commission
CAPD	Continuous ambulatory peritoneal dialysis
CRD	Chronic Renal Disease
ESRD	End-stage Renal Disease
ESRF	End-stage Renal Failure
HD	Haemodialysis
HHD	Home haemodialysis
IMPAKT	Improving Access to Kidney Transplantation project
KHA	Kidney Health Australia
PD	Peritoneal dialysis
RN	Registered Nurse
NHMRC	National Health and Medical Research Council
QUT	Queensland University of Technology
UHREC	University Human Research Ethics Committee
WHO	World Health Organisation

**Note:** The term 'Indigenous' has been used throughout the thesis for all Aboriginal and Torres Strait Islander Australians, unless distinctly referenced otherwise in texts, journals, or papers.

**Statement of Authorship**

The work contained in this thesis has not been previously submitted for a degree or diploma at any other higher education institute. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signed: \_\_\_\_\_

*Crece*

Date: \_\_\_\_\_

*18/5/2010*

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# Chapter 1 : Background

## 1. Introduction

In Australia, the health of Indigenous people continues to deteriorate compared to that of the majority population. End-stage renal disease (ESRD), along with a number of other chronic diseases, burdens the lives of Indigenous Australians to a much higher extent and affects all aspects of Indigenous society. End-stage renal disease affects not only the individual but also impacts greatly on the well-being of Indigenous families and communities. Renal health statistics and the experience of living with ESRD have been well documented by individual Renal units, relevant Commonwealth and State health departments, and organisations including Kidney Health Australia. However, there have been only a few studies documented for Indigenous Australians living with ESRD from a social, cultural, emotional, and physical viewpoint. This introductory chapter will provide a brief overview of the following key areas:

- renal health status for Indigenous people
- renal dialysis and treatment options overview
- peritoneal dialysis
  - continuous ambulatory peritoneal dialysis
  - automated peritoneal dialysis
- haemodialysis kidney transplant
- associated factors for Indigenous people with
  - prior experience
  - research aims, objectives, and questions
- significance of the thesis
- contents of the thesis
- summary

## **1.1 Renal health status for Indigenous people**

In Australia, over the past 20 years, there has been increasing evidence towards the appalling state of end-stage renal disease for Indigenous people. Indigenous Australians face a significantly higher burden of ESRD, which Hoy (1996) describes as an increasing epidemic. In some areas of Australia, end-stage renal disease is almost nine times higher among Indigenous than among non-Indigenous Australians. ‘A striking gradient exists from urban to remote regions, where standardised end-stage renal disease incidence is 20–30 times the national incidence’ (Cass et al. 2004, p. 767). This current state of poor renal health has had a major impact on public health policy and is considered a very expensive form of treatment affecting State and Commonwealth health budgets.

End-stage renal disease is more prevalent among Indigenous people than among other Australians. The dramatic difference between the numbers of Indigenous people with ESRD who require dialysis compared with other Australians is quite remarkable. Deaths from kidney failure are eight times greater for Indigenous males and five times greater for Indigenous females than for the general population. The most common principal diagnosis in Australian hospitals in the period 1998–99, for both Indigenous males and females, was for care involving dialysis with haemodialysis being the most common procedure. (Australian Bureau of Statistics and Australian Institute of Health Welfare, 2001).

Treatment options for end-stage renal disease consist of hospital-based or home-based haemodialysis, continuous ambulatory peritoneal dialysis, or renal transplantation. A number of Indigenous communities do not have appropriate renal health facilities available; therefore, Indigenous people with ESRD have to leave their families and traditional country to live in the nearest town or city for treatment. Having to leave family and traditional country creates a range of problems and ultimately affects the health and well-being for the Indigenous person and their family.

Even for those Indigenous people who live where there are renal health facilities available, issues such as transport, family responsibility, and time away from home present problems for them and their families. Satellite dialysis units, CAPD, and home haemodialysis give Indigenous people with end-stage renal dialysis the opportunity to be treated in their own communities. This represents a disruption to social capital within the family and community. A number of studies and programs have shown that allowing Indigenous people to be treated in their own communities and to remain with their family and on traditional country, helps the social, cultural, and spiritual well-being for that person and their family (Willis 1995; Bennett et al. 1995; Preece 1997; Devitt & McMasters 1998a).

A number of renal units around Australia have programs to try to help Indigenous people return home and continue their dialysis treatment. In 1999, through the Royal Darwin Hospital and Top End Renal Services, Australia's first Indigenous satellite dialysis unit opened on the Tiwi Islands. In another remote situation, residents from the two Western Desert Aboriginal communities, Kintore and Kiwirrkura, raised over \$1 million as part of the Western Desert "Nganampa Walytja Palyanjaku Tjutaku—Making our families well" project. These two communities are situated hundreds of kilometres from Alice Springs on the Northern Territory (NT), Western Australian (WA), and South Australian (SA) borders and have community members on haemodialysis treatment in Alice Springs, Broome, or Kalgoorlie. Dr Paul Riverland, coordinator of the Western Desert project, stated that 35 pieces of Aboriginal art were auctioned in Sydney in 2000 and the money raised was used to purchase haemodialysis units that would allow Aboriginal people to return permanently to their homelands and be treated in their community (personal communication, 10 Nov 2004).

'At the beginning of 2001, only five of the 16 Aboriginal and Torres Strait Islander Commission (ATSIC) regions with the highest Indigenous ESRD incidence rates had satellite dialysis units' (Thomson 2003, p. 348). ATSIC did not have a budget for renal services; however, were responsible for funding a number of infrastructure projects such as sewerage and housing. In late September 2003, the Kimberley

Satellite Dialysis Centre opened, and it is the first dialysis unit run from an Aboriginal Medical Service. The dialysis unit is funded by the Western Australian Health Department and is proving to be an effective model of treating end-stage renal dialysis for Indigenous people in remote communities. For the last 15 years, Western Australia's renal unit at the Royal Perth Hospital has been training and supporting Aboriginal people to learn self-care dialysis treatment so that they can return home to family and country and continue their treatment (Australian and New Zealand Society of Nephrology, 2003).

The Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) is an organisation set up by KHA and the Australia and New Zealand Society of Nephrology to monitor dialysis and transplant treatments. All patients with end-stage renal disease are on the ANZDATA registry. ANZDATA is funded by the Australian and New Zealand governments and KHA. 'Of the 1883 patients starting ESRD treatment in 2001, 170 (9.0%) were Indigenous Australians. Ten years earlier, 42 of the 979 new cases of ESRD (4.3%) were Indigenous' (ANZDATA 2002). According to Graeme Russ, the number of Indigenous Australians with end-stage renal disease is increasing over time (ABS & AIHW 2003, p. 137).

While dialysis and kidney transplantation are both life saving treatments, kidney transplantation is considered the best form of treatment for most people with end-stage renal disease. The proportion of Indigenous people receiving kidney transplants is much lower than the proportion of non-Indigenous people with ESRD receiving kidney transplants. There are a number of reasons that Indigenous people are less likely to receive a transplant, including multiple illnesses, being less likely to find a suitable donor, or being too ill to undergo the surgery required to receive a transplant (ABS & AIHW, 2003). In comparison, there are a number of factors that contribute to the low rates of transplants among Indigenous Australians: poor compliance, lack of compatible donors, and infections (ANZDATA 1999). A national research project titled, Improving Access to Kidney Transplantation (IMPAKT), funded by a National Health and Medical Research Council (NHMRC) grant, commenced in 2004 and

identified barriers for Indigenous Australians' access to kidney transplantation for treatment of ESRD.

'There is evidence that suggests that renal disease is often unrecognised and that a lack of preparation (including delayed referral) for the management of chronic renal failure and end-stage renal failure (ESRF) may be responsible for the poor outcomes of tertiary-level care' (Couzos & Murray 2003, p. 424). To receive the best care in terms of renal health, Indigenous people often experience first hand many problems associated with renal failure. Indigenous people face many challenges to survive on renal dialysis such as poor health status and their own suffering (Reid and Trompf, 1991).

## **1.2 Renal dialysis and treatment options overview**

Renal dialysis is a form of treatment used when one or both of a person's kidneys no longer work and are unable to filter waste products and fluid from the body. Dialysis is the process of cleansing and filtering the blood. There are three main treatment options:

- Peritoneal dialysis
  - Continuous ambulatory peritoneal dialysis
  - Automated peritoneal dialysis
- Haemodialysis
- Kidney transplant

### **1.2.1 Peritoneal dialysis**

Peritoneal dialysis uses the body's own natural peritoneal membrane as the semi-permeable membrane through which the blood can be filtered. Dialysis fluid flows into the peritoneal cavity through a small soft plastic tube that has been permanently inserted into the patient's abdomen during a minor operation. About 15 cm of this tube (PD catheter) remains outside your abdomen, providing a means for attaching the bags of dialysis fluid. Dialysis takes place while the fluid is inside the peritoneal cavity—excess water and waste products from the blood are drawn across the

membrane into the dialysis fluid. This process is called an exchange and the fluid is changed every few hours. As there is risk of infection, it is important to perform the exchange without contamination and in as sterile an environment as possible.

### **1.2.2 *Continuous ambulatory peritoneal dialysis***

Continuous ambulatory peritoneal dialysis is the term used when the fluid exchange in your peritoneal cavity is changed manually. The process takes between 20–30 minutes. The advantages of CAPD are that it can be performed anywhere that is convenient and requires no needles. By connecting a bag of fresh dialysis fluid (above the patient on a stand) and a drainage bag (on the floor) to the catheter, the exchange uses gravity to drain the used fluid out of the peritoneal cavity into the drainage bag and the fresh dialysis fluid is then replaced. With continuous ambulatory peritoneal dialysis, diet and fluid intake is less restricted than on haemodialysis. The disadvantages of CAPD include having a permanent catheter exiting from the abdomen and a risk of infection in the peritoneal cavity or at the site where the catheter exits the body. It is also necessary to find available space for the boxes of supplies that will be needed.

### **1.2.3 *Automated peritoneal dialysis***

For automated peritoneal dialysis, the fluid exchanges are performed at night using a machine. The APD machine controls the timing of exchanges, drains the solution, and fills the peritoneal cavity with the new solution via a catheter. The machine measures the amount of fluid going in and out and is easy and safe to use. The machines can be used anywhere where electricity is supplied. The process takes between 8–10 hours. APD suits some people because it frees up the day: ideal for those in employment, school children, and for those who need a carer to help them perform their dialysis.

### **1.2.4 *Haemodialysis***

With haemodialysis, the blood is circulated and cleansed outside the body. A minor operation is required to join an artery and vein to create a fistula or access. The fistula is usually in the arm. During haemodialysis, two needles are inserted into the fistula. Blood is withdrawn by one needle, cleaned through a filter, and returned via the

second needle. Only a small amount of blood is out of the body at any one time. The sessions take three days per week with each session taking three to five hours. In some cases, a temporary fistula is placed in the lower neck until the permanent fistula is ready for use. Haemodialysis can be performed either at a hospital renal unit, or in a self-care centre or at home. Waste and fluid build up in the body between sessions so diet and fluid intake is restricted. The main risk associated with haemodialysis is blockage or infection with the fistula.

### **1.2.5 Kidney transplant**

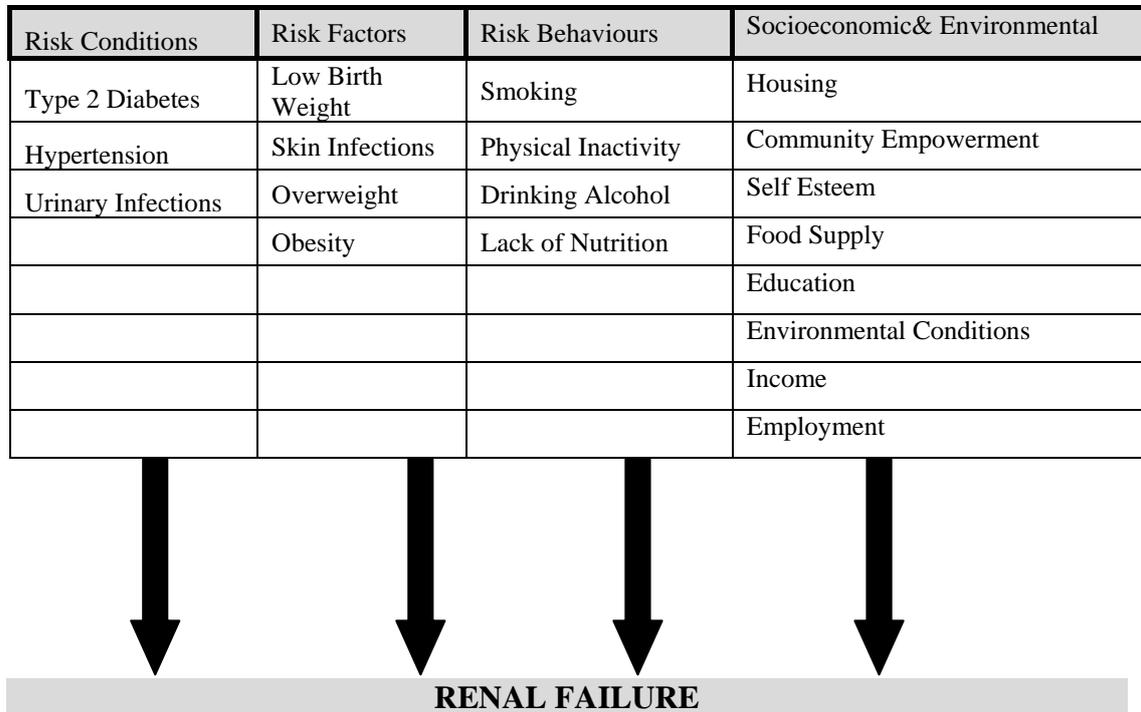
Kidney transplantation is the best treatment for most people with end-stage renal disease. While transplantation is not a cure, it allows patients to live a more normal life. A lack of donor organs means longer waiting times for a kidney transplant. A kidney transplant involves surgically removing a kidney from one person and implanting it into another person. Kidneys are obtained from a living related donor (close relative) or a cadaveric donor (a person who has died).

## **1.3 Associated factors for Indigenous people with end-stage renal disease**

The incidence of kidney failure in Indigenous people has been attributed to a number of associated factors, including high levels of glomerulonephritis following streptococcal infections and increasing prevalence of the metabolic syndrome (e.g. high blood pressure, type 2 diabetes, obesity, and heart disease (ABS & AIHW 2003).

Data from ANZDATA suggests that glomerulonephritis, type 2 diabetes, and hypertension have been attributed as the primary causes of high end-stage renal disease rates among Indigenous Australians. For non-Indigenous Australians, the primary causes are glomerulonephritis and diabetes (ANZDATA 2003).

Catford et al. (1997) reveals there are a number of associated factors that contribute to poor health for Indigenous people on renal dialysis. Table 1.1 displays how associated factors are broken down into the following four areas:



**Table 1.1 Health strategies from Deakin, 1997**

Adequate training is available for individuals and families on all of the available treatment options. From my experience, training is dependent on individuals' seriousness of ESRD; some patients start with haemodialysis in centre until their health has improved then they might want to learn to perform CAPD. It could be months until they can return home.

A number of communities have set up designated rooms or demountables where dialysis machines and facilities are set up for patients returning home. These are set up close to health clinics.

After two years of dialysis and a kidney transplant, a well-known Indigenous Australian, Jimmy Little, realised the importance of all Australians being able to access quality health care no matter where they lived. He wanted to make a contribution to improving Indigenous health, particularly kidney health, across

regional and remote Australia. In mid 2006, he joined forces with a group of concerned business people to create the Jimmy Little Foundation (JLF), which aims to work for a healthier future for Indigenous Australians. One initiative is a program called Return to Country, which focuses on renal dialysis patients returning home for treatment and connecting with family, community, country, and culture.

It is important to understand all of the associated risk factors and how they contribute to poor health outcomes for Indigenous people with end-stage renal disease; however, equally important are the social, environmental, and cultural factors that affect the health and well-being for this population. The health of Aboriginal and Torres Strait Islander people is defined as, 'Not just the physical well-being of the individual but the social, emotional and cultural well-being of the whole community. This is a whole of life view and it also includes the cyclical concept of life-death-life' (National Aboriginal Health Strategy Working Party 1989). Aboriginal and Torres Strait Islander people throughout Australia commonly accept this holistic view of health.

To achieve healthier outcomes, some Indigenous people have taken effective steps towards self-determination by the development of Aboriginal Community Controlled Health Services (ACCHSs). There are approximately 150 ACCHSs across Australia, each autonomous and independent of each other and of the government. 'ACCHSs are primary health care services initiated and managed by local Aboriginal communities to deliver holistic and culturally appropriate care to people within their community. Each Board of Directors is elected from local Aboriginal communities. Aboriginal communities around Australia have been establishing such services since the early 1970s in response to a range of barriers inhibiting Aboriginal access to mainstream primary health care services, and in recognition of the principles of self-determination' (National Aboriginal Community Controlled Health Organisation 2002, p. 2).

The role of Indigenous health workers, community participation in health programs, and community consultations are all essential elements of improving health for

Indigenous people. The concept of 'self-determination' is not a new one, but rather a realistic way forward to improve health for Indigenous people in this country.

To quote Commissioner Mick Dodson:

*The practical exercise of self-determination is the necessary foundation for any genuine, sustainable improvement in the health of our peoples. If Aboriginal and Torres Strait Islanders peoples are not involved as the primary agents of change then the root causes of so much of our ill health will not be touched. In the field of health, as in so many other areas of our lives, self-determination is essential, not merely as a matter of right but as a matter of practicality. Good health cannot be delivered to our communities: it must be grown-up and sustained within; nothing else will work. Community planning which genuinely reflects the considered views of the community members is required to carry forward an inclusive approach to health specific to the actual circumstances, needs and aspirations of individual communities.*

(Aboriginal and Torres Strait Islander Social Justice Commissioner 1994).

This statement clearly describes the core relevance of self-determination for Indigenous people. Indigenous people need to be the primary agents of change. Indigenous people need to take control of their own health through self-determination if any major changes are to happen.

#### **1.4 Prior experience**

The concept that Indigenous people can manage their chronic diseases effectively through self-determination evolved from my experience working as a diabetes and renal health worker at an ACCHS in Far North Queensland approximately six years ago. The main emphasis of the program was to help improve health for Indigenous people in this particular community by placing back on the individual the responsibility for their own health and well-being. Taking into consideration that all people are unique and have different health requirements, an overall health assessment was completed. In this process, establishing a full history of each client was needed so that specific health management action plans could be integrated to each individual diabetic client.

Close links were established to other related organisations associated with diabetes and renal health care management. Involvement of family members was a vital key and highly encouraged. All Indigenous diabetic clients that attended the clinic were referred to specialist care with ongoing support, monitoring, and follow-up care by the diabetic health worker. Consistency and continuity of follow-up care and ongoing support in all areas was of paramount importance to this program's successful operation.

The program consisted of a number of very practical approaches that suited each client to help them overcome any difficult situation that they may have encountered with their health conditions. For example, clients may have run out of medication three days before they received their pension. Usually, the client would present to the clinic feeling unwell due to not taking their medication. Financial budgeting skills through Lifeline helped improve this situation, and assistance through their regular pharmacist, who provided advice and extra medications (paid by the client when they collected their scripts on pension day) ensured that they would not run short again.

This practical solution helped a number of clients who seemed to be in similar situations. Although this solution helped to sort out the medication issue, there were a number of other major issues such as transport, housing and accommodation, and financial pressures confronting Indigenous clients that attended the clinic. These were slowly worked out over a period of time with the client, family members, and the health worker. During this time, there were no free medications handed out or supplied by drug companies. Supplying free medication or having them supplied by a drug company does not help Indigenous people be self sufficient in their overall management of diabetes or renal health care.

Weekly diabetic sessions were being conducted by the diabetic health worker and Senior Medical Officer, and monthly diabetic sessions with the visiting Endocrinologist and the diabetic health worker. Other qualified health professionals,

such as podiatrists, ophthalmologists, nephrologists, dentists, dieticians, and diabetic educators, were consulted (when referred) as part of an ongoing care strategy.

Provision of cross-cultural and culturally appropriate resources were made available for ongoing health education and health promotion in diabetes management. Health awareness, knowledge, and education were increased by practical clinic sessions covering diet, exercise, medication, and treatment, which were formatted in a style appropriate to the needs of each individual with specific messages.

<b>Example</b>	<i>Why can't I see and walk properly and what should I do?</i>
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The message: Diabetes is a multi-system disease; it can affect my kidneys, eyes, skin, heart, and blood circulation. This is not common knowledge or understood by Indigenous diabetic clients attending the clinic. Clients often interpreted diabetes as 'sugar in the blood' and nothing more.

<b>Example</b>	<i>Why do I have to take my tablets daily and why I must see the doctors when I have none left?</i>
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The message: When I take my tablets, my health problems are under control and I feel well. When I don't take my tablets, I become sick. When I know I am going to need some more tablets, I will go to the clinic and see the doctor for another script.

<b>Example</b>	<i>Why do I have to watch what I eat?</i>
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The message: Some foods are good for my diabetes and some are not. If I eat the foods that keep my diabetes under control, I feel well. If I eat the foods that are not good for my diabetes, I become sick.

<b>Example</b>	<i>Why do I have try and exercise more?</i>
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The message: Any form of exercise is good for your health; exercise to a level that you feel comfortable with and slowly increase the level and amount when you are able. Walking was a very popular exercise amongst the diabetes clients.

Although improvements in health status were gradual among the Indigenous diabetic and renal clients in this community, the ability to self-manage through self-determination principles was developed by improving health knowledge, which, in turn, led to a process of changed behaviours to create an environment that would sustain these changes (Preece 1997).

It was evident that an Indigenous renal health worker was needed full time to liaise with Indigenous people suffering from end-stage renal disease who came from remote areas of Far North Queensland and Torres Strait Islands for dialysis treatment. The role of the renal health worker was a voluntary position primarily to support Indigenous people with end-stage renal disease. A large majority of Indigenous people with ESRD in this particular region did not have any support and stressed a number of times that they missed their home community and family members, which greatly impacted on their health. Other issues associated with relocating permanently for dialysis treatment were cultural isolation, geographic isolation, accommodation, economic, transport, kidney health knowledge, quality of life, and breakdown in the family support network (Preece 1997; Devitt & McMasters 1998a). In the larger hospital settings, qualified counsellors or Indigenous social workers are available on request to help deal with any issues Indigenous people with ESRD encounter.

## **1.5 Research aim, objectives, and questions**

The main aim of the research was to:

**Develop a model of care for Indigenous people receiving renal dialysis treatment.**

In order to achieve this aim, the research followed three main objective areas:

- Gain a comprehensive understanding of the literature to provide a sound basis for the research.

- Contribute to the existing knowledge about health and well-being for Indigenous people with end-stage renal disease.
- Identify social and cultural factors that arise for Indigenous people with end-stage renal disease.

The research will determine three broad questions:

1. Why do Indigenous people have shorter life expectancy rates following initiation of renal dialysis treatment?
2. Will this research elucidate factors that contribute to mortality and morbidity among Indigenous people with end-stage renal disease?
3. How do Indigenous people with end-stage renal disease in an identified community cope?

These findings of this research, and other research conducted, will contribute to our knowledge about end-stage renal disease in Australian Indigenous populations. The research questions were proposed by analysing data from a number of ANZDATA sources (1999; 2002; 2003), an unpublished dissertation by Preece (1997), and two books written by Devitt and McMasters (1998a; 1998b).

The main hypothesis addressed is that Indigenous people with ESRD face a significantly higher number of challenges, including the associated risk factors, and are struggling to survive on dialysis treatment. Furthermore, differences in social and cultural beliefs also contribute to this increasing problem.

A study completed in Far North Queensland (Preece, 1997) found that Indigenous people who had to relocate for dialysis treatment faced many social and cultural issues, all of which had a significant impact on their health and well-being. At times, the social and cultural issues were far more important than the medical circumstances for that renal patient. This was a daily and common occurrence within the Indigenous renal population in Far North Queensland, yet not understood by renal staff within health services.

## **1.6 Significance of the thesis**

The research and outcomes from this thesis will provide valuable information towards a best-practice model of care that will help improve the health and well-being of Indigenous people on renal dialysis.

The model of care will address issues of relevance for people not only with end-stage renal disease but also for their families, and for health professionals and health carers who provide care and support for Indigenous people with ESRD. The research will also clarify factors that contribute to the rates of mortality and morbidity among Indigenous people with ESRD. This thesis aligns with the National Indigenous Health Research Priority areas that address cardiovascular disease, type 2 diabetes, and high blood pressure. This is important because of the increasing number of Indigenous Australians with end-stage renal disease. The significance of this health problem is summarised in the following five points:

### ***Increased understanding of the associated risk factors***

The research contained in this thesis will look at associated risk factors that contribute significantly to the rates of mortality and morbidity among Indigenous patients with end-stage renal disease. By using a population-based sample in the Brisbane area, the data collected will help increase the understanding and knowledge of how Indigenous people cope with their ESRD. In a number of ways, this research extends from earlier research conducted in Indigenous communities and most significantly will contribute to the body of knowledge that already exists to improve Indigenous renal health status.

### ***The impact of social and cultural issues***

The research in this thesis will identify and explore the relationship between social and cultural values, and how they affect Indigenous ESRD sufferers and their families. It is also important that health care professionals understand the significance of social and cultural values to Indigenous people, and also how Indigenous people

place a greater value on their social and cultural well-being than they do on their health status.

### ***Analysis of the disparity of survival rates for Indigenous people with ESRD***

Figures from ANZDATA 1999–2001 and 2002–2003 reveal that, compared to other Australians, Indigenous people with end-stage renal disease do not survive on renal dialysis treatment and this is a major public health concern. In this thesis, the analysis of the data collected will attempt to establish the underlying causes for this.

### ***Cost analysis of ESRD***

Different funding models exist for renal health between the Commonwealth Government and the State Governments. A cost analysis of end-stage renal disease treatment will explore these current funding arrangements.

### ***Developing a model of care appropriate for Indigenous people with ESRD***

Various models of self-care exist in the Australian health system and throughout the world to help people manage their health. However, the model of care developed in this thesis will focus on giving responsibility back to the individual to manage their state of health. Part of giving ownership back to individuals for their health problems is encouraging them to change behaviours. One important aspect of behaviour change involves understanding how an individual moves through a process of behavioural change until the point where the behaviour becomes habit (Lorig & Associates 2001). The information available from this research may help to deliver a more effective model of care for Indigenous people with end-stage renal disease.

## **1.7 Contents of the thesis**

This thesis is presented in a report format. As such, it contains an introduction to the primary focus of renal failure and renal disease for Indigenous people in Australia. Chapter 2 provides the literature review of Australian and international literature on

Indigenous health with emphasis on Indigenous renal health. Chapter 2 also contains associated risk factors, costs of renal treatment, renal prevention programs, various State and Commonwealth policies on renal health, chronic disease programs, primary health care, and self-care in chronic diseases. Chapter 3 contains the methodology and explains the research approach and design. Chapter 4 gives a detailed overview of the findings from the interviews conducted with Indigenous community members with end-stage renal disease. The discussion in chapter 5 will analyse the findings thoroughly and chapter 6 will include the conclusion and recommendations towards the development of a model of care for Indigenous people with end-stage renal disease. A list of relevant appendices, tables, and figures are provided at the end of the thesis along with a complete reference list.

## **1.8 Summary**

The introductory chapter provides a brief overview of the status of renal health for Indigenous people in Australia, the types of treatment modality and the associated risk factors. Also included is the aim of the research, together with objectives and the research questions. The relevance of the research to Indigenous renal health is contained within this introductory chapter. Finally, by identifying the underlying issues that make dialysis treatment difficult for Indigenous people, this research will help contribute to a better understanding of Indigenous Australians' experiences living with end-stage renal disease. A model focusing on self-determination principles could be the key to improved outcomes for Indigenous Australians with end-stage renal disease. The following chapter outlines relevant literature on Indigenous health, Indigenous renal health, and government policies and programs.

## **Chapter 2 : Literature Review**

### **2. Introduction**

The first part of this chapter will provide literature on Indigenous health and contributing factors. The second part of this chapter gains extensive insight into Australian and international literature on renal disease with particular emphasis on Indigenous renal health. Associated risk factors for renal disease, costs of renal treatment, and a description of renal prevention programs are also incorporated into this chapter. The third and final part of this chapter will provide literature on Australian State and Commonwealth policies in relation to renal health. The impact that chronic disease programs and primary health care have in relation to renal health, and the important role that self-care has within renal health management will be included. The chapter is presented in three parts and includes the following:

#### **Part 1: Indigenous health**

- definition of health
- an Australian overview on Indigenous health
- employment
- unemployment
- low income
- education
- housing
- access to health services
- Indigenous population.

#### **Part 2: Renal health in focus**

- an Australian overview of renal health
- an Indigenous perspective of ESRD
- associated risk factors for ESRD
- costs of ESRD treatment
- renal prevention and screening programs in Indigenous communities
- international Indigenous health

- international Indigenous people and ESRD.

### **Part 3: Government Policy and Programs in Renal Health**

- State and Commonwealth Policy
- chronic disease programs and primary health care
- self-care.

## **2.1 Indigenous health**

The following areas of discussion in Part 1 include a definition of health for Indigenous Australians and an overview on Indigenous health. A number of factors contributing to poor Indigenous health will also be presented.

### **2.1.1 Definition of health**

As discussed briefly in Chapter 1, the definition of health for Aboriginal and Torres Strait Islander people is:

*Health is not just the physical well being of the individual, but the social, emotional and cultural well being of the whole community. This is a whole of life view and it also includes the cyclical concept of life-death-life.*

(National Aboriginal Health Strategy Working Party, 1989, p. ix).

In 1989, the National Aboriginal Health Strategy was developed through extensive national consultations with Aboriginal and Torres Strait Islander community representatives and government agencies and, for the first time, set national directions in Aboriginal and Torres Strait Islander health policy. This policy provided a framework that reflected social and cultural determinants of Aboriginal and Torres Strait Islander health, and highlighted the need for improvements in environmental health in Aboriginal and Torres Strait Islander communities. Specific strategies were identified to address health and well-being issues of the whole community including social, economic, cultural, and environmental determinants (National Aboriginal and Torres Strait Islander Health Council 2001).

In 1994, an evaluation was conducted on the 1989 National Aboriginal Health Strategy which found that the National Aboriginal Health Strategy was never effectively implemented and other portfolios such as housing, essential services, and local governments were not party to the strategy (National Aboriginal and Torres Strait Islander Health Council 2001). The evaluation also found that the State Tripartite Forums set up to implement the strategy had little or no input into government policy directions concerning access to housing and basic services and did not have much influence on health service provision (National Aboriginal and Torres Strait Islander Health Council 2001).

A number of national reports and recommendations have been released with significant implications for Aboriginal and Torres Strait Islander health. A number of recommendations from the reports are incorporated into the National Aboriginal and Torres Strait Islander Health Council 2001.

### **2.1.2 An Australian overview on Indigenous health**

It has been well documented that the state of Indigenous health in Australia is a result of the tragic historical events of colonisation and the enormous impact that this has had on the Indigenous population. To quote Mick Dobson:

*Our situation today is vitally linked to our situation in the past.*

(Aboriginal and Torres Strait Islander Social Justice Commissioner, 1994).

As a result of colonisation, Indigenous Australians continue to experience not only poor health, but also high rates of unemployment, low socioeconomic status, and low educational attainment (National Aboriginal and Torres Strait Islander Health Council 2001).

Aboriginal and Torres Strait Islander people suffer a greater burden of ill health than other Australians. Indigenous people are more likely to experience disability and reduced quality of life due to ill health, and die at younger ages (ABS & AIHW, 2001;

ABS & AIHW, 2003). The Australian Bureau of Statistics and Australian Institute of Health and Welfare report that for Aboriginal Australians and Torres Strait Islanders:

- life expectancy is from 19–21 years less than the general population
- rate of death is five to six times that of the general Australian population
- infant mortality rates are 2.5 times that of the general population
- age-specific death rate is up to five times higher than all of the Australian rates in every age group.

(ABS & AIHW, 2001; ABS & AIHW, 2003)

Indigenous Australians suffer too much ill health, and the overall health status is poor in every aspect compared to the rest of the Australian population. Aboriginal and Torres Strait Islander people continue to have lower life expectancy rates, higher mortality and morbidity rates, multiple chronic diseases, higher injury and disability rates, higher hospital admissions, and higher incarceration rates (National Aboriginal and Torres Strait Islander Health Council 2004).

Aboriginal and Torres Strait Islanders continue to die silently under these statistics, yet there is comprehensive support within Australia to improve the health of Aboriginal and Torres Strait Islanders. The 2001 Census data indicated that Indigenous Australians experienced lower incomes, higher rates of unemployment, poor education outcomes, and lower rates of home ownership compared to non-Indigenous Australians; all of which impacted on a person's health and sense of well-being (ABS & AIHW, 2003). To try to understand why Indigenous health is poor compared to the rest of the Australian population, one must understand the many contributing factors to this moral and intractable problem. In conjunction with Australia's society and health system, a range of factors including historical, socioeconomic, environmental, social, and political factors contribute to the poor health status of Indigenous Australians.

### **2.1.3 Employment**

While a large majority of Indigenous Australians live in rural and remote areas, there are few employment opportunities for them. Indigenous Australians are encouraged to undertake community work, otherwise known as Community Development Employment Projects (CDEP)—a ‘Work for the Dole’ scheme. ‘At the 2001 Census, 42% of Indigenous Australians aged 15 years and over were employed compared with a non-Indigenous employment rate of 58%. Compared to 1996 figures, 41% of all Indigenous Australians were employed. A higher proportion of Indigenous males (47%) than females (36%) were in employment, with a similar pattern observed for non-Indigenous persons in this group (66% of males and 52% of females). About one in six Indigenous persons classified as employed was participating in CDEP. In 2001, 17 800 Indigenous CDEP participants were identified, which accounted for 20% of Indigenous male employment and 15% of Indigenous female employment’ (ABS & AIHW, 2003, p. 24).

Unemployment for Indigenous Australians has an enormous impact on health for Indigenous Australians and has a detrimental effect on overall health and well-being. ‘The Indigenous unemployment rate recorded in the 1996 Census was nearly 23%, which is about 2.5 times higher than the non-Indigenous rate of 9%’ (Altman, cited in Thomson 2003, p. 30).

### **2.1.4 Low income**

The relationship between socioeconomic status and ill health has been well documented. People at the lowest socioeconomic level, such as Indigenous people, experience the highest rates of illness and death (Lynch & Kaplin, 2000). As Indigenous people have low employment status they also have low income status. ‘In 1996, the median weekly income (the income most commonly received) by Indigenous individuals aged 15 or over was \$190, and for families it was \$502. For all Australians, these figures were \$292 and \$730 respectively. Census data showed that Indigenous incomes were towards the lower end of the income scale; about 49% of Indigenous people received an income of less than \$200 per week compared with 37% of other Australians. Only 2% of Indigenous adults had weekly incomes greater than \$800 in contrast with 10% of other Australians’ (Altman, 2003, p. 30).

### **2.1.5 Education**

Education is important for all Australians; it is linked to better employment opportunities. Low education and health status are both causes and effects of low economic status. The 1996 Census information on education status indicates that a far higher proportion of Indigenous people than non-Indigenous Australians had never attended school (3%) or left school before the age of 16 (44%). Furthermore, fewer Indigenous people had post-school qualifications (24%) or were attending a tertiary institution in 1996 (14%) than their non-Indigenous counterparts (25% and 40%) (Altman cited in Thomson 2003, pp. 32-3; ABS, 2001).

### **2.1.6 Housing**

Indigenous Australians experience some of the worst housing and associated living conditions of any group within the Australian community. Indigenous Australians experience above normal levels of overcrowding, and have lower rates of home ownership. This overcrowding among Indigenous Australians is directly linked to such diseases as scabies and rheumatic fever, and contributes to family and community disharmony (Thomson cited in Couzos & Murray 2003, p. 53). For those Indigenous people who live in discrete communities in Australia, there are other factors contributing to poor health outcomes. These factors relate to infrastructure problems such as poor housing environment, lack of water supply, poor sewerage, continuous flooding, and pending and lack of power supply (Aboriginal and Torres Strait Islander Commission 1999). The Australian Government has channelled substantial extra resources into Indigenous housing and associated infrastructure.

Over the last 20 years, Indigenous housing has accounted for 20% of the Federal Government's total spending on public and community housing. A majority of the spending is channelled through approximately 750 local Indigenous community-controlled housing organisations throughout Australia, and, in recent years, the Australian Army has also been assisting in the construction of housing and infrastructure in remote and isolated areas (Office of Aboriginal and Torres Strait Islander Health 2003).

### **2.1.7 Access to health services**

Indigenous people experienced lower levels of access to health services than the general population, even though they were twice as likely to be hospitalised. Also, compared with the general population, Indigenous people are nearly twice as likely to live outside urban centres, and are therefore more likely to live further from a range of health services and facilities (AIHW 2002). Other barriers that Indigenous people face in accessing health services include isolation, distance, transport difficulties, economic disadvantage, communication problems—including difficulties with English—cultural differences, and distrust of mainstream services (ABS & AIHW, 2002).

### **2.1.8 Indigenous population**

According to the Australian Census 1996, the Indigenous population accounts for only 2.1% of the Australian population (approximately 386,049), yet experiences excessive burdens of mortality and morbidity within the health system (ABS & AIHW, 2001; 2003). The Indigenous population is 'relatively young, with 39% younger than 15 years old compared with 20% of the non-Indigenous population (Thomson 2003). Almost 13% of the non-Indigenous population is aged 65 or older, but only 2.6% of the Indigenous population is within that age range' (Thomson 2003, p. 493).

Currently, the Commonwealth government has implemented Shared Responsibility Agreements between the Commonwealth, State and local community councils. It is premature to determine the outcomes on Indigenous health at this stage of these new arrangements.

## **2.2 Renal health in focus**

The major areas of discussion in Part 2 present an overview of renal health in Australia, with particular reference to Indigenous Australians and International Indigenous populations with end-stage renal disease. Associated risk factors and costs for ESRD will be presented, as well as renal prevention programs in Indigenous communities.

### **2.2.1 An Australian overview of renal health**

In Australia, renal health problems are common. Approximately half a million Australians may be affected by early renal disease, yet it often goes undiagnosed and untreated. Over three million Australians are 'at risk' of chronic renal disease (CRD), one million have blood in the urine, one million suffer from kidney stones, approximately 250,000 suffer from urine infections, and 275 children younger than 20 are either on dialysis or have had a transplant. A high proportion of Australians have impaired renal function, which results in 3,700 Australian adults being diagnosed with renal failure for the first time. More than 50% of those patients are under 65 years of age. The most expensive renal health problem is the treatment of end-stage renal failure. For the Australian population, a number of factors contribute to the high incidence of ESRD, including the growing burden of diabetes and acceptance of elderly patients onto dialysis programs. Currently in Australia, 13,448 people are receiving treatment as maintenance dialysis or transplantation and the number is increasing by approximately 6% per annum (Kidney Health Australia, 2004).

### **2.2.2 An Indigenous perspective of end-stage renal disease**

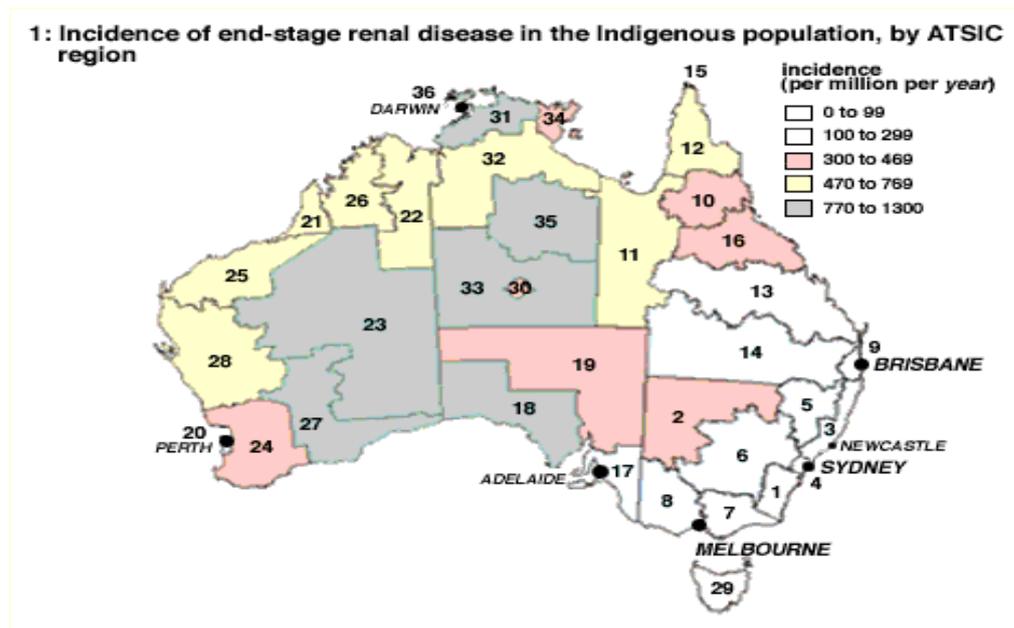
The *Weekend Australian* (31 March 2003, p. 10) reported that Aboriginal people in remote Australia were succumbing to a new plague: end-stage renal disease—a wave of kidney collapse and linked sickness that threatens to decapitate and destroy traditional Aboriginal society. With almost one in five Indigenous Australians living in remote communities, the encumbrance of ESRD among Indigenous Australians is very concerning, particularly for those Indigenous Australians living in remote and rural areas (Cass et al. 2004). Among the number of health issues faced by Indigenous Australians is chronic renal disease, which is preventable. People with CRD are at high risk of premature heart attack, stroke or death due to cardiovascular disease. If undetected and/or undertreated, CRD is likely to progress to irreversible renal damage. End-stage renal disease is reached once approximately 90% of kidney function is lost (Cass et al. 2004).

The rates of end-stage renal disease are highest in northern Australian communities, where the incidence of renal failure among Indigenous people has been described as 'epidemic' in proportion (Hoy 1996). For Indigenous people living in remote areas of Australia, the rate of ESRD is significantly higher than anywhere else in Australia. Kidney disease can also lead to the need for dialysis or transplant. This situation is reflected in the fact that 44% of all principal procedures in hospitals recorded for Indigenous people in 1998–99 were for haemodialysis (ABS & AIHW, 2001). Each person with end-stage renal disease has dialysis three times per week. Research conducted in urban areas show that the incidence of ESRD among Indigenous people is much lower, but still higher than the national incidence rate (Cass et al. 2001).

A study conducted by Cass et al. in 2001 evaluated regional variation in the incidence of end-stage renal disease in Indigenous Australians and examined the proximity to ESRD treatment facilities of Indigenous renal patients. Data was obtained from ANZDATA regarding 719 Indigenous patients who commenced ESRD treatment from 1<sup>st</sup> January 1993 to 31<sup>st</sup> December 1998. The average annual incidence of end-stage renal disease was calculated 'on the 36 ATSI regions using population estimates based on the 1996 Census figures and calculated standardised incidence ratios with 95% confidence intervals for each region.' (Cass et al. 2004, p. 24)

A comparison was completed between the number of new cases with treatment facilities in each region. The results from the study found that the incidence of end-stage renal disease among Indigenous Australians is highest in remote regions, where it found, in some cases, up to 20–30 times the national incidence for all Australians. Forty-eight per cent of Indigenous ESRD patients come from regions without dialysis or transplant facilities, and 16.3% come from regions with only satellite dialysis

facilities available.



**Figure 2.1 Incidence of ESRD in the Indigenous population, by ATSI regions.**

(Source: Cass et al. 2001 p. 24–7)

There are four primary explanations for the burden of end-stage renal disease among Indigenous Australians (Cass et al. 2004, p. 768). These are:

1. **‘Primary renal disease explanations**—population differences result from a higher incidence and greater severity of primary diseases that cause ESRD, especially diabetes.
2. **Genetic explanations**—genetic differences determine various patterns of ESRD.
3. **Early development**—some forms of adverse intra-uterine environment affect kidney development, leading to a vulnerability to ESRD.
4. **Socioeconomic disadvantage**—greater socioeconomic disadvantage in Indigenous populations results in higher burden of ESRD.’

Evidence obtained from ANZDATA shows that from as early as 1993–2001 there has been a significant increase in the number of new cases of Indigenous people with end-stage renal disease (Cass et al. 2001). Table 2.1 shows the number of new Indigenous cases by state and territory.

State	1993–95	1996–98	1999–2001
Northern Territory	97	115	140
Queensland	89	93	131
Western Australia	77	100	95
New South Wales & ACT	37	54	60
South Australia	23	19	33
Victoria	5	9	16
Tasmania	0	0	1

**Table 2.1 Number of new Indigenous cases treated with ESRD, 1993–2001**

The following tables, 2.2 and 2.3, describe the number of Indigenous and non-Indigenous people with ESRD on different modality, and the number that have been transplanted in the Northern Territory. The Northern Territory has a population of approximately 200,000 in which there is a higher proportion of Aboriginal people in the population (28–30%) than in any state or territory, and the population is relatively young with only 3% being older than 65 compared with 12% nationally (ABS 2001).

Area	Indigenous	Non-Indigenous	Total
Darwin	78	12	<b>90</b>
Katherine	15	0	<b>15</b>
Nguiu (Tiwi Is.)	10	0	<b>10</b>
Tennant Creek	9	0	<b>9</b>
Alice Springs	88	3	<b>91</b>
<b>Total:</b>	200	7	<b>215</b>

**Table 2.2 Number of Northern Territory people on haemodialysis in a renal unit centre.**

	Top End		Central		NT total		TOTAL
	Indigenous	non-Indigenous	Indigenous	non-Indigenous	Indigenous	non-Indigenous	
PD	15	7	11	5	26	12	<b>38</b>
Tx	19	29	20	0	39	29	<b>68</b>

**Table 2.3 Number of Northern Territory people on peritoneal dialysis (PD) or transplant (Tx).**

Northern Territory, Queensland, and Western Australia have excessively high numbers of new Indigenous cases with end-stage renal disease. The Northern

Territory has the highest number of Indigenous ESRD patients in Australia. Darwin and Alice Springs have the highest number of Indigenous renal patients on haemodialysis. Haemodialysis is conducted in urban and regional centres or in hospitals and is the most common form of treatment for Indigenous people with ESRD (Hoy 1996).

The high percentage of Indigenous people on haemodialysis in Darwin (86%) and Alice Springs (97%) reflects the worsening situation of end-stage renal disease in the Northern Territory. One hundred per cent of patients on renal dialysis in Katherine, Tiwi Islands, and Tennant Creek are Indigenous.

These figures show that Indigenous people are disproportionately represented in the renal health area. Stephanie Bell, Director of Central Australia Aboriginal Congress, advised that in Alice Springs the number of renal patients may have increased dramatically due to the influx of people from the Pitjantjatjara homelands (personal communication, 9 Nov 2004). Table 2.4, below, reflects the total number of Australians who, in 2003, were receiving dialysis, or with transplants, by state or territory and Indigenous status.

State	Aboriginal	Torres Strait Islander	Non-Indigenous	TOTAL
NT	245	1	66	312
QLD	188	47	2270	2505
WA	181	1	1102	1284
NSW	104	1	4102	4207
SA	53	0	1068	1121
VIC	27	0	3375	3402
ACT	7	0	330	337
TAS	3	0	277	280
<b>TOTAL</b>	<b>808</b>	<b>50</b>	<b>12 590</b>	<b>13 448</b>

**Table 2.4 Numbers from ANZDATA of Australians receiving dialysis or with transplants by State or Territory and Indigenous status, 2003.**

The Northern Territory, Queensland, Western Australia, and New South Wales show high numbers of Indigenous renal patients. In comparison to non-Indigenous renal

patients, Indigenous patients are younger, more likely to be female, more likely to present late to medical care, and more likely to have concurrent illnesses including diabetes and heart and respiratory disease (Cass et al. 2002). While Indigenous Australians represent just over 2.1% of the total Australian population, they account for 10% of new patients commencing treatment for end-stage renal disease (ANZDATA, 2003; ABS & AIHW, 2003).

In Queensland, there are high numbers of Indigenous people on dialysis treatment. The centres where the Indigenous numbers are considerably high are Cairns, Townsville, Mt Isa, and Rockhampton. For Indigenous people with end-stage renal disease in remote Cape York and Torres Strait Islander communities, the closest renal facilities are in either Cairns or Townsville. The Mt Isa renal unit is a satellite unit of Townsville. A number of patients who administer their dialysis treatment themselves are returning back home to their community, which is proving to be quite successful for the patient, their family, the community, and the service provider. The total number of renal patients in Queensland is 2505, with 235 Indigenous renal patients (ANZDATA 2003).

A literature search found numerous studies conducted from a scientific, medically focused point of view, which are crucial and important to renal health research. However, only a small number of studies relevant to Indigenous renal health from a cultural, social, emotional, and historical perspective were found (Bennett et al., 1995; Willis, 1995; Lowe et al., 1995; Anderson, 1996; Hoy, 1996; Preece, 1997; Devitt & McMasters, 1998a, 1998b; Cass et al., 2001; Cass et al., 2002; Gorham 2001).

In a qualitative study conducted on a group of Aboriginal and Torres Strait Islander dialysis and transplant patients in Far North Queensland, a number of factors such as cultural, social, religion, sorcery, medication, and the overall dialysis experience influenced treatment outcomes. Compared to the view of medical staff, factors such as compliance with dialysis and medication influenced by a lack of understanding were regarded as problem areas for Indigenous patients (Bennett et al. 1995). Health

professionals reported that education was provided, considerable time was spent with patients explaining procedures, and patients were given a manual to read. In the research, a need for improved, comprehensible information and the development of culturally appropriate support systems were recommended (Bennett et al. 1995).

In a paper by Jon Willis (1995), high technology treatments such as dialysis and transplantation pose a number of problems for central Australian Aboriginal renal patients. The first problem is that the renal patients would have to relocate from traditional country and family, which compromises quality of life and has social and cultural consequences for the traditionally oriented Aboriginal people in Central Australia. Willis also described the growing recognition of increased health funding that is tied up in developing and applying high technology treatments—such as dialysis and transplantation—at the expense of more basic health services—such as prevention strategies for patients progressing to end-stage renal disease, particularly through management of diabetes mellitus, and detection and treatment of streptococcal skin and urinary tract infections leading to glomerulonephritis.

Lowe, Kerridge, and Mitchell (1995), in a paper titled *These sorts of people don't do very well: Race and allocation of health care resources*, outline subtle influences of racial determinants in decisions about resource allocation with particular reference to an Australian Aboriginal woman with end-stage renal disease. Noncompliance 'with medical treatment including hospitalisation, medication, diet, and lifestyle' has been noted throughout renal health literature as key barriers to accessing resources such as kidney transplants. A health professional may determine 'noncompliance (the extent to which a patient's behaviour does not coincide with medical or health advice) for a number of reasons, including the inability to understand instructions due to illiteracy or language differences, and the inadequate information transfer between the health professional and patient' (Lowe, Kerridge, & Mitchell 1995, p. 357).

Within a rather complex health system, 'language difficulties, poor communication, a lack of cultural sensitivity, and an inadequate understanding of the health needs and

social conditions of Aboriginal people are also major barriers to appropriate health care' (Lowe, Kerridge, & Mitchell 1995, p. 359).

With a high burden of end-stage renal disease within the Australian Indigenous population, Anderson (1996) in *Race Matters* argues quite strongly on the ethics of allocation of health resources for Aboriginal Australians with end-stage renal disease. Issues such as geographic isolation, medical criteria, and general medical conditions (such as the existence of other diseases like diabetes) have been used to exclude patients from transplant programs (Anderson 1996). Complex barriers are embedded within the doctor-patient relationship. Health professionals need to be educated about Aboriginal culture to take into account Aboriginal values in the clinical and decision-making process appropriately.

A national study called "Improving Indigenous Patient Access to Kidney Transplantation" (IMPAKT), led by Dr Alan Cass, aims to look at how health systems in different states and territories provide transplantation to kidney patients. IMPAKT will also be working with local Aboriginal Community Controlled Health Services, renal units, and hospitals to develop strategies to improve access to kidney transplantation. The study is made up of a number of separate studies. These are:

1. a survey of kidney specialists' views and decision-making practices
2. a study of patient education and decision making
3. a cohort study to track patient outcomes
4. a review of 'work up' requirements
5. a modelling study of different allocation algorithms

The remoteness of many Aboriginal people faced with the prospect of dialysis not only affects the optimal choice of therapy but leads to significant stressors. There is a failure in Social Services to assess the social and domestic needs of renal patients away from the bush communities, leading to underestimates of the impact of these social dislocations (Thomas 1998). About 90% of the Aboriginal people who received haemodialysis in Alice Springs were from the bush communities, often more than 200 kilometres away. The family disruption involved in a move to regional dialysis units

is therefore significant. Often there is a failure to match these health needs with accommodation services. Only a minority of patients were able to get a housing commission accommodation in Alice Springs in 1996 (Thomas 1998).

Another qualitative study undertaken in Darwin, “Sharing the true stories: improving communication between Aboriginal patients with ESRD and health care workers”, found that miscommunication regarding fundamental issues in diagnosis treatment and prevention occurred—often unrecognised by patients. Other factors also relating to miscommunication were found to be lack of control by the patient, differing modes of discourse, dominance of the biomedical model, lack of shared knowledge and understanding, cultural and linguistic distance, lack of staff training in intercultural communication, and failure to call on trained interpreters (Cass et al. 2002).

The most comprehensive literature found, *Living on Medicine: A cultural study of end-stage renal disease among Aboriginal people*, completed by Devitt and McMasters (1998a), specifically documented the rather difficult experiences that Aboriginal people faced leaving their communities in remote Australia to take up renal dialysis treatment in Alice Springs. Alice Springs renal dialysis unit has many Aboriginal people from remote areas from the Northern Territory, Western Australia, South Australia, and Queensland. The shock of end-stage renal disease, combined with cultural isolation from land, community, and family, impacted greatly on the Aboriginal renal patients. The social, cultural, physical, and geographical implications were enormous and ultimately life threatening to Aboriginal patients with end-stage renal failure who undertook dialysis treatment in Alice Springs (Devitt & McMasters 1998a). The interviews of 57 patients, their families, communities, and medical carers captured the extraordinary complications that Aboriginal people with renal failure struggle with: everyday life situations, a complex medical treatment keeping them alive, and living in an environment that is alien to them.

### **2.2.3 Associated risk factors for end-stage renal disease**

There are many associated risk factors for end-stage renal disease. In Australia’s general population, the most common cause of ESRD is glomerulonephritis, a

condition which causes inflammation of the filtering units of the kidneys—the nephrons. The second most common cause of ESRD within the general population is diabetes. Diabetes not only causes damage directly to the filtering membranes in the kidney but also damages blood vessels throughout the body, increasing the risk of high blood pressure, which in itself can cause renal failure (Kidney Health Australia 2003a). End-stage renal disease is more likely to be caused by diabetes, to occur in women, and to start at a younger age (ANZDATA 1999). There are many associated risk factors for kidney disease including diabetes, high blood pressure, infections, low birth weight, and obesity. All of these are more common among Indigenous people than among non-Indigenous people (ABS & AIHW, 2001).

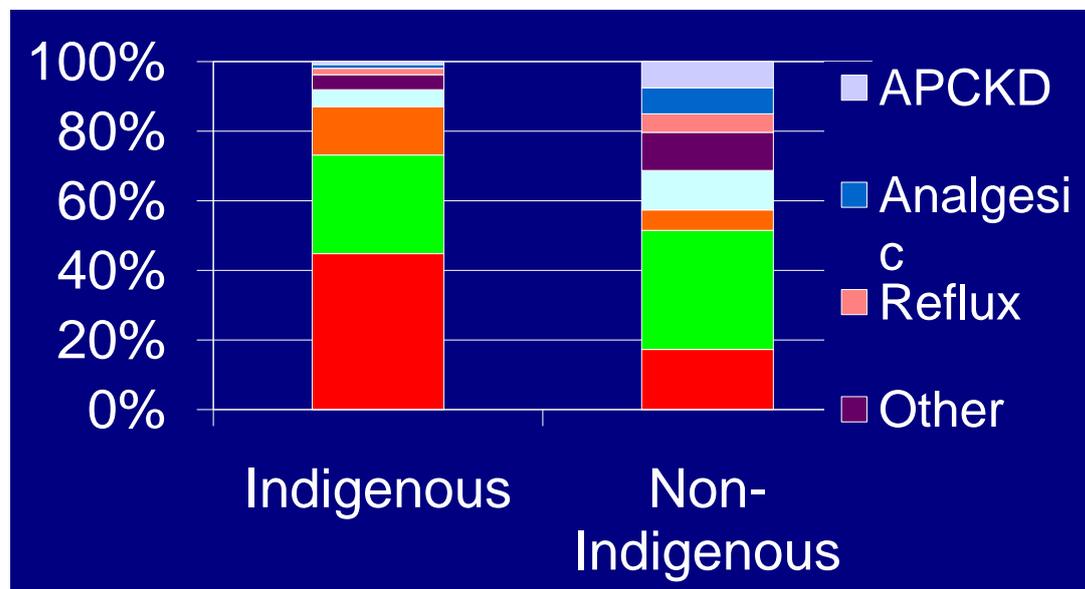
Younger Indigenous women are more at risk of ESRD because of the prevalence of diabetes, higher birth rates and overall poor health status.

The mortality rate of end-stage renal disease for Indigenous people is excessively high in comparison to the non-Indigenous population. This is due to poor management, treatment, and awareness of renal disease at all stages, as well as a higher incidence of contributory factors (Hoy 1996). The main causes of ESRD include chronic glomerulonephritis, diabetes exacerbated by recurring urinary tract infections and other infections (such as scabies), obesity, hypertension, poor nutrition, and lack of exercise (Bennett et al. 1995). These factors may occur simultaneously and progressively compounding the decline in renal function accompanied with age (Hoy 1996).

There are two types of diabetes: type 1 and type 2. Type 1, otherwise known as juvenile onset diabetes or insulin dependent diabetes, tends to occur in young adults and children. With this particular form of diabetes, the body produces little or no insulin, and people with insulin dependent diabetes must receive daily insulin injections (Commonwealth Department of Health and Aged Care 1999). This type of diabetes is relatively rare in Indigenous people; however, type 2 diabetes is a

significant health problem for Indigenous people and is the leading cause of end-stage renal disease (Kidney Health Australia 2003a).

Diabetes type 2, adult onset diabetes, also known as non insulin-dependent diabetes, occurs when the pancreas produces close to normal amounts of insulin but the body is unable to use it properly (Commonwealth Department of Health and Aged Care 1999). Diabetes is attributed as the primary cause of more than 50% of ESRD cases among Indigenous Australians (Cass et al. 2004). Indigenous people who have type 2 diabetes often develop the disease earlier than other Australians, and often die at younger ages (AIHW 2002). Table 2.5 below shows primary renal disease explanation (ANZDATA 1999).



**Table 2.5 Proportions of primary disease in new ESRD patients, by Indigenous status, Australia, 1993-1998.**

Source: ANZDATA, 2003

In diseases with multifactorial causation, including ESRD gene-environmental, interactions are complex and disease patterns will be strongly influenced by environmental factors. The striking regional variation in end-stage renal disease incidence (Figure 2.1) largely reflects differences in socioeconomic status. An index of SES disadvantage that includes measures of house overcrowding, low birth weight, educational attainment, employment, and income is strongly correlated with ESRD incidence in Aboriginal people (Cass et al. 2004).

Strong evidence links house overcrowding to the scabies and streptococcal skin infection with progression to end-stage renal disease. This is one example of a number of possible explanatory pathways that link socioeconomic disadvantage with the biological processes that lead to kidney damage and ESRD (Cass et al. 2002).

At a population level, the Smoking, Nutrition, Alcohol, and Physical Activity (SNAP) Guide (The Royal Australian College of General Practitioners National Standing Committee—Quality Care 2004) to behavioural risk factors in general practice was developed by the National Vascular Disease Prevention Partnerships. The guide was designed to assist general practitioners and practice staff to work with patients on lifestyle risk factors such as smoking, nutrition, alcohol, and physical activity. Risk factors for heart, stroke, and vascular diseases are far more prevalent in people from low socioeconomic status backgrounds and Indigenous Australians (The Royal Australian College of General Practitioners National Standing Committee—Quality Care 2004). There are a number of health risk activities associated with diabetes, including poor nutrition, obesity, and lack of physical activity. Nutrition-related diseases such as heart disease, type 2 diabetes, obesity, and renal disease are principal causes of ill health among Aboriginal and Torres Strait Islander people (AIHW 2002). A large number of Indigenous Australians smoke tobacco, which increases the risk of coronary heart disease, stroke, peripheral vascular disease, numerous cancers, and a variety of other diseases and conditions (ABS & AIHW, 2003). Aboriginal and Torres Strait Islander people are at greater risk than non-Indigenous Australians of hospitalisation and/or death from these conditions (ABS & AIHW, 2003). Smoking during pregnancy is also a risk factor for low birth weight that further complicates the health of the mother and unborn child. Smoking cigarettes is a single risk factor that causes a high burden of disease for the total Australian population (The Royal Australian College of General Practitioners National Standing Committee—Quality Care 2004).

Excessive alcohol consumption is a major risk factor for conditions such as liver disease, pancreatitis, diabetes, some cancers, and epilepsy (ABS & AIHW 2003).

Evidence from numerous surveys shows that Aboriginal and Torres Strait Islander people are less likely than non-Indigenous Australians to drink alcohol; however, those who do so are more likely to consume it at hazardous levels (ABS & AIHW 2003).

It has been widely acknowledged that the diets of many Aboriginal and Torres Strait Islander people have undergone rapid changes from a fibre-rich, high protein, low saturated fat ‘traditional’ diet to one in which refined carbohydrates and saturated fats predominate (NHMRC 2000). External factors such as physical environment, dispossession of land, socioeconomic status, historical and cultural issues, and access to fresh food in remote areas impact on the choices Indigenous Australians have in terms of nutrition and diet (ABS & AIHW 2003).

For many Indigenous people obesity has become a significant health problem. Often it results from a high intake of highly refined carbohydrates and alcohol and a low level of physical activity (NHMRC cited in Thomson 2003 p. 84). Obesity is associated with several of the main causes of Indigenous morbidity and mortality, including cardiovascular disease, diabetes, renal disease, respiratory disorders, gastrointestinal diseases and pregnancy complications (Thomson 2003, p.84).

#### **2.2.4 *Costs of renal failure***

All states and territories offer to a greater or lesser extent haemodialysis, peritoneal dialysis, and transplantation. The costs of renal services vary across the nation and are commonly described in terms of the level of service required to provide or support a particular modality (Gorham 2001). Location of a modality also adds to the ongoing costs. This description distinguishes:

- hospital-based services—‘in centre’
- services provided outside a hospital but in a health facility—‘satellite’
- care managed by an individual in their own home—‘self management’

(Gorham 2001)

The cost to keep people on dialysis exceeds \$360 million per year and is likely to double in 10 years. As the number of Australians on dialysis is growing at 6% annually, this means that the costs over the next 10 years will be \$5 billion for dialysis alone from the nation's public purse (Kidney Health Australia, 2003b). Approximate costs for renal treatment were gathered from the Princess Alexandra Hospital renal unit in Brisbane, and again these vary from renal unit to renal unit, and from state to state or territory.

**In-centre haemodialysis (ICHD)\$51 356/year**  
**Satellite haemodialysis (SHD)\$47 517/year**  
**Home haemodialysis (HHD) \$44 580/year**  
**Peritoneal dialysis \$44 175/year**

Delivering dialysis in remote areas poses unique challenges, which have encouraged the development of various models of service delivery (Cass et al. 2004). In Western Australia, community haemodialysis has been supported in remote areas since the late 1980s with patients and their buddies managing their own dialysis but using facilities attached to Primary Care clinics. The Northern Territory opened a satellite haemodialysis unit with nursing support in 2002 in a Top End remote community. In Broome, a satellite dialysis unit opened and is linked to an Aboriginal Primary Health Care facility. This is the first of its kind to be run from an Aboriginal Primary Health Care facility.

Renal dialysis attendance in Broome has improved since patients have returned to Broome compared to when patients were in Perth, isolated and many thousands of kilometres from their family and community. In Alice Springs, the "Western Desert Nganampa Waltyja Palyaku Tjurtaku" is currently piloting a moving satellite dialysis service between Alice Springs and Kintore, a very remote community on the Northern Territory–Western Australia borders. Patients spend time in Alice Springs then rotate back out to Kintore (Cass et al. 2004). So far, this model is proving to be successful.

Queensland, far more any state or territory in Australia, has shown an effort to help treat renal disease by announcing that it will spend \$16 million in 2004–05 as part of

larger budget in which \$33.8 million has been allocated over three years. For the 2004–05 period, money will be spent on surgery costs to prepare renal patients for dialysis (\$500,000), specialised clinical training for renal services (\$250,000), and teleconference services that link patients in remote areas to health professionals (\$500,000) (Queensland Renal Association Incorporated 2004).

Over the next three years, Queensland's Beattie government will spend the following on renal health:

- \$3.4 million to establish and operate at Cooktown a four-bed satellite renal service linked to Cairns, servicing Hopevale and Wujul Wujul
- \$3.4 million for a four-chair satellite dialysis service for the Torres Strait Island region based on Thursday Island
- \$6.3 million for eight new renal chairs on the Gold Coast
- \$7.4 million for a new nine-chair renal dialysis unit and five new nurses at the Redland Hospital
- \$2.8 million for an additional four renal chairs at Rockhampton hospital and to employ two new renal nurses and an Indigenous health worker
- \$5.3 million to establish and operate an eight chair dialysis unit the Sunshine Coast Community Health centre

### ***2.2.5 Renal prevention programs in Indigenous communities***

In Australia, there has been a number of early detection, renal prevention, and screening programs conducted. The Tiwi Islands Renal Disease Program (Northern Territory) and Umoona Kidney Prevention Project (South Australia) (Umoona Tjutagku Health Service, 1998) are two such programs that conducted community screening to detect early stages of renal disease in Aboriginal people by measuring the urine–albumin–creatinine ratio (ACR) (Gorham 2001).

In the Tiwi Island program, urine samples were sent to a laboratory in Darwin and tested; while in the Umoona project, urine samples were tested in the community with a DCA 2000 analyser from Bayer Australia. The small portable DCA 2000 provided an accurate quantitative measurement of ACR in seven minutes, with the result immediately available to the patient, health worker, and health care team (Gorham 2001). An advantage of the DCA 2000 is that accurate results helps the health care

staff implement treatment and education on the day rather than waiting a few days for results to come back from a laboratory (Gorham 2001).

Patients appreciate having a result on the day followed by effective follow-up treatment, health education, and health promotion, which help improve ongoing management of their health. Another important advantage of the DCA 2000 is that local Aboriginal health workers are trained to perform the urine ACR test (as well as Quality Assurance checks). This ensures that the program is sustainable and that the community take some ownership of the program (Gorham 2001).

Those adult Aboriginal people who identified overt albuminuria were offered an antihypertensive medication (Perindopril) or Coversyl (Gorham 2001). This medication has been effective in slowing down the progression of renal disease in adult Aboriginal people (Hoy et al. 2000). The Umoona Kidney project was handed over to the Umoona community in December 2000 as a self-sustaining program supported by Commonwealth and State funding from 1998–2000; however, no further government funding had been secured to continue the program.

On the other hand, the Tiwi Island project received funding from the Office of Aboriginal and Torres Strait Islander Health and Rio Tinto through Kidney Health Australia and a drug company that supplied the antihypertensive. In total, over \$1 million was received to continue the massive screening and handing out of blood pressure medication in Aboriginal communities. However, this particular program, by handing out medication, does not empower Aboriginal people to take control of their health, nor can it be sustained in the community. The results from the Tiwi Island project showed quick and easy results, which were published in many peer-reviewed journals. Once the project finishes, community life returns to normal. Some serious questions should have been raised earlier in the program about sustainability and accountability. Unfortunately, as the money was promised from Dr Michael Woolridge, who was the Federal Health Minister at the time, it would have been a

hard case to argue. No independent evaluations were conducted in either of the programs.

Prevention models must be delivered within a culturally appropriate framework and with the full collaboration of the community. There are a number of models for prevention and intervention, and each community must decide which model, or combination of models, meets their needs. The models are:

***Do nothing:*** The incidence of renal disease will continue to rise to a certain level where it will stabilise because there is a finite population.

***Opportunistic screening:*** This type of screening is clearly incomplete, and it is less likely to provide adequate follow up. The primary focus for people who are screened in this way is what brought them to the clinic in the first place, and they are less likely to return for results or follow up (Gorham 2001).

***External Education and Prevention Team:*** Similar to the Umoona Kidney and Kidney Disease Research Program, which involve outside organisations visiting communities to provide Aboriginal Health Workers with training, education, and assistance with screening and prevention programs. Renal Outreach programs also fit this model (Gorham 2001).

***Increase resources:*** Give communities enough resources so they can deliver prevention education without compromising the need to deliver acute services disease (Gorham 2001).

***Mass screening:*** Mass screening involves screening the entire community, and it is logistically problematic. It is resource intensive and often results return too late to be relevant to either the client or the service provider. As results cannot be given to the client immediately, this type of screening involves following up on results later and

bringing clients back to the clinic for information and education. Unless clients feel unwell they are unlikely to be interested in the results despite the identification of early stages of renal disease (Gorham 2001).

***Invitational screening:*** This is a variation on opportunistic screening, in which community members are encouraged to attend for screening through education, family referral, and word of mouth. This model involves short one-on-one education sessions and is believed to promote the best outcomes for behaviour change (Gorham 2001).

### **2.2.6 International Indigenous health**

The poor health status of other Indigenous populations around the world, such as New Zealand Maoris, Pacific Islanders, American Indians and Alaska Natives, and African Americans, has been described as similar to that of the Australian Aboriginal and Torres Strait Islander population. A report from New Zealand, *Progress towards closing social and economic gaps between Maori and non-Maori*, found that Maori health status levels were considerably lower than those of non-Maori across a range of health indicators (Maori Health, 2000). Several health conditions can be either the cause or the consequence of ill health and/or socioeconomic status. The incidence of health conditions such as diabetes and obesity are predicted to reach epidemic proportions. In New Zealand, a number of socioeconomic factors such as adequate income, labour force participation status, and educational achievement influence the way that people actively engage in certain health behaviours; tobacco smoking, alcohol consumption, and lack of physical activity influence a person's health outcomes (Maori Health, 2003).

Over four million residents of the United States can claim American Indian or Alaska Native ancestry completely or partially. With over 500 tribes living on nearly 300 reservations, most American Indians are drawn together by core values such as an

emphasis on spirituality, recognition of the sacredness of all living things, and respect for the land and the natural world (American Indian Health, 2003).

For American Indians and Alaska Natives, the leading causes of death were diseases of the heart (stroke) followed by cancer, accidents, diabetes, and chronic liver disease/cirrhosis. In America, the overall death rate for stroke was 56.2 per 1000 persons; however, the 1999 stroke death rate for American Indians and Alaska Natives was 39.7 per 1000 persons. Native Americans are 2.6 times more likely to have type 2 diabetes mellitus than non-Hispanic whites of similar age. Other causes of greater than average mortality include tuberculosis, suicide, pneumonia, influenza, and homicide. Deaths attributing to alcoholism are also high among American Indians (American Indian Health, 2003). Among American Indians and Alaska Natives aged 18 and older, the following have one or more cardiovascular disease risk factors: hypertension, current cigarette smoking, high blood pressure, cholesterol, obesity, or diabetes (American Heart Association, 2003).

For African Americans, cardiovascular disease ranks as the number one killer. Of nearly 288,000 blacks who die each year, 37% of deaths is caused by cardiovascular disease. Cancer ranks next at almost 22%. All other causes of death account for about 41%. Approximately four in every 10 non-Hispanic black adults have cardiovascular disease. This includes diseases of the heart, stroke, high blood pressure, congestive heart failure, congenital cardiovascular disease defects, hardening of the arteries, and other diseases of the circulatory system (American Heart Association, 2003).

In 2001, for every 100,000 persons in the United States, about 330 people died from cardiovascular disease. This is the age-adjusted cardiovascular disease death rate for the total population. Among the African American population, the cardiovascular disease death rate was even higher, particularly for males: 511 males and 377 females died per 100,000 persons. The rate of high blood pressure in African Americans is among the highest in the world, and African Americans are less likely to engage in physical activity, more likely to be overweight or obese, and more likely to have

diabetes—all of which raise their cardiovascular disease risk (American Heart Association, 2003).

### ***2.2.7 International Indigenous people and end-stage renal disease***

Globally, end-stage renal disease is a growing concern for many Indigenous populations such as Maoris, Pacific Islanders, American Indians and Alaska Natives, African Americans, Hispanics, Canadian Indigenous peoples, and Asians.

The burden of end-stage renal disease for New Zealand's Maori population and Pacific Islanders is similar to that of the Aboriginal and Torres Strait Islander population of Australia. The high excess of end-stage renal disease in Maori and Pacific Islanders is due mainly to type 2 diabetic nephropathy, increased rates of glomerulonephritis, and hypertensive renal disease. Indigenous women in Australia were more at risk to have end-stage renal disease compared to Indigenous men; however, for Maori and Pacific Islanders, both male and female numbers were equal (Stewart, McCredie & McDonald 2004).

American Indians have the highest rates of diabetes in the world and about half of the adult Pima Indians have diabetes. Pima Indians have over 20 times the rate of new cases of kidney failure as the general population. For the Pima Indians, the greatest change in lifestyle was consumption of fat in their diets. In the 1890s, the traditional Pima Indian diet consisted of only about 15% fat and was high in starch and fibre. Traditionally, physical activity played a role in their lifestyle. A number of studies on Pima Indians link genetic factors such as the “thrifty gene” to explain why so many Pima Indians are overweight (National Institute of Diabetes and Digestive and Kidney Diseases, 2003).

The incidence of end-stage renal disease among American Indians and Hispanics in the United States is at least double the incidence in the rest of the population as a result of the increasing rate of diabetes (Sequist et al. 2004). Although African Americans make up 12% of the United States population, 29% of African Americans

are treated for kidney failure. African Americans aged 25–44 are 20 times more likely than their white counterparts to develop hypertension-related kidney failure (National Institute of Diabetes and Digestive and Kidney Diseases, 2003).

Due to high rates of diabetes, high blood pressure, and glomerulonephritis, African Americans have an increased risk of developing kidney failure. The leading cause for end-stage renal disease is type 2 diabetes. Risk factors for type 2 diabetes include family history, impaired glucose tolerance, diabetes during pregnancy, hyperinsulinemia and insulin resistance, obesity, and lack of physical activity. While hypertension is the leading cause of deaths for African Americans, it is the second leading cause of kidney failure for African Americans (National Kidney Foundation, 2003).

Canadian Aboriginal people consist of three diverse groups including Indians or First Nation people, Inuit, and Metis. Metis are ancestors of children from mixed marriages between Indians and whites. The rate of end-stage renal disease is between two and a half and four times higher than those found in the general population. Up to 60% of cases are due to diabetic end-stage renal disease, while the remainder of ESRD cases were caused by a variety of types of glomerulonephritis. For Canadian Aboriginals, an epidemic of diabetic end-stage renal disease threatens to exhaust health care resources in many parts of the country unless effective early recognition and prevention programs are established and implemented (Dyck 2001).

### **2.3 Government policy and programs in renal health**

Major areas of discussion in Part 3 include State and Commonwealth policies on renal health, Chronic Disease Programs and Primary Health Care. Self care will also be included.

### **2.3.1 State and Commonwealth policy on renal health**

In an open letter to the Prime Minister, John Howard, and the Leader of the Opposition, Mark Latham, a group of Australian Directors of renal units and Australian nephrologists stated: ‘in Australia, there is no national strategy addressing chronic kidney disease issues and management. There are no systematic programs (government or non-government) in place addressing ways to bridge the gaps between the evidence and advances in clinical care that have occurred over the last decade’ (Kidney Health Australia 2003–04).

This statement reflects the current State and Commonwealth policy gaps in renal health. While this statement was made by a group of interested and concerned nephrologists, they were part of a larger group, including nurses, patients, advocacy groups, social workers, general practitioners, and Aboriginal health workers who gathered at the First National Indigenous Dialysis and Transplant Symposium in May 2004 to give their perspectives on the challenges of delivering and receiving high quality renal care to a population that commonly suffers poor social and economic circumstances, and high rates of renal and urological disorders. The only setback for this historic meeting is that only two consumers were on the agenda to give their perspectives on how they managed their end-stage renal disease in the renal health system.

Instigated as part of the 2003–2008 Australian Health Care Agreement, the Health Reform Agenda focused on providing the best care and health outcomes, regardless of jurisdictional boundaries. Reference groups of clinicians, bureaucrats, and consumers provided advice on key themes and areas for reform. Reform themes were:

- Improving health outcomes for Australians rather than just a focus on funding, program arrangements, and jurisdictional responsibilities
- Improving coordination and integration of services
- Developing the national infrastructure to support reform.

As part of the Health Reform Agenda, the Australian Health Ministers Advisory Council (AHMAC) in March 2004 funded the Remote Area Renal Services for

Indigenous Australians project. A consultant was appointed, and a Health Reform Agenda Working Group subcommittee managed the project with Commonwealth and jurisdictional representatives. The project had two objectives:

- to comprehensively review and document the current status of remote area renal services for Indigenous Australians with ESRD (i.e. services pertaining to dialysis and transplantation, and barriers to accessing needed services)
- to develop strategies that improve the access, timelines, and quality of remote area renal services for Indigenous Australians with ESRD and hence optimise their health outcomes.

Both objectives have been completed in relevant documents. The first objective (Phase 1), reviewing the status of remote area renal services for Indigenous Australians and to identify barriers to their accessing needed services, was completed in October 2004. A draft (Phase 2) has developed eleven strategies to improve access, timeliness, and quality of remote area renal services for Indigenous Australians was completed in December 2004. These are: principles, prevention of chronic renal disease, remote infrastructure, renal service standards, transplantation, workforce in primary health care, renal services, patient education and training of carers, sharing information and resources, Aboriginal and Torres Strait Islander participation, and a remote area renal services development working group.

If AHMAC supports the proposed strategies, all Australian states will have to help finance and support these initiatives (Cass et al. 2004). The adoption of these strategies would also assuage the nephrologists' claims in their open letter that 'there is no systematic programs within the health system supporting kidney disease early detection and management aimed at preventing progression and chronic kidney disease is not an agreed national priority in health and no national strategy or action plan has been developed that addresses the problem' (Kidney Health Australia 2003–04).

### **2.3.2 Chronic disease programs**

Around the world, the disposition of ill health is evolving rapidly as the population is ageing. As medical treatment and health services continue to improve, so does the

number of people living with a chronic disease or a number of chronic diseases. Australia is one of many countries at risk to succumb to the burden of chronic disease. The expected increase in the population age in the future (2016) suggests that chronic diseases will be more common and will impact on the health system's ability to provide better service delivery, better individual health care, and better use of all the available health resources.

High levels of chronic diseases affecting Indigenous Australians are a serious problem, not only for the individual with their multiple health issues but also for the family and their community. This in turn affects the health care system and the ongoing multi-team professional care needed to assist them towards better health. Practical and doable changes in the way people manage their health are needed if any real improvements are to be made. For Indigenous Australians, renal disease and failure are serious health issues among other high levels of chronic diseases such as heart disease and diabetes.

For ACCHSs throughout Australia, chronic diseases such as diabetes, heart disease, and renal disease are priority health issues. Through the Department of Health and Ageing office, 12 projects throughout Australia have been funded as part of the Sharing Health Care Initiative—chronic disease prevention and management demonstration projects. Four Indigenous-specific projects have also been funded (Commonwealth Department of Health and Ageing, 2003).

### **2.3.3 Primary health care**

Primary health care is an essential comprehensive approach that can contribute to significant improvements in health in developing countries and among Indigenous populations in developed countries comparable to Australia. The definition of primary health care delivery based on the WHO/UNICEF Declaration of Alma-Ata (1978) is:

*...essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self reliance and self-determination. It forms an*

*integral part both of the country's overall health system, of which it is the central function and main focus, the overall social and economic development of the community with the national health system bringing care as close as possible to where people live and work, and constitutes the first elements of a continuing health care process.*

In 1999, the Commonwealth Department of Health and Aged Care introduced Enhanced Primary Health Care: a range of Medicare items intended to provide more preventative care for older Australians and improve care coordination between general practitioners, health professionals, and other professionals providing care for people of any age with chronic conditions and complex care needs. The enhanced Primary Health Care provided a framework for a multidisciplinary approach to health care through a more flexible, efficient, and responsive match between care recipients' needs and services (Commonwealth Department of Health and Ageing, 2003).

#### **2.3.4 Self care in chronic disease**

The concept of self-care management in the area of health is not a new idea but rather a practical solution towards helping the patient manage their day-to-day health needs. In some cases, patients manage multiple chronic diseases and their complex treatments, medications, specialists' appointments, and the ongoing battle to keep well. Family interaction and support and social support also determine how patients manage their health.

Patient education is complex and has a critical role in self-care management. Patient education has evolved over the past few years and it is no longer considered enough for patients to learn and practise specific skills; rather, patients must manage their own diseases. Approaches to patient self-care management must assist patients in gaining both skills and, more importantly, the confidence to apply these skills on a day-to-day basis. It also must assist the patient to cope with changing roles and changing emotions (Lorig & Associates 2001).

There are three distinctive features of the self-care management model for patient education. These are (a) dealing with the consequences of disease illness not just the

physiological disease, (b) being concerned with problem solving, decision making, and patient confidence rather than with prescriptions and adherence, and (c) placing patients and health professionals in partnership relationships (Lorig & Associates 2001). The conceptual basis for self-care management is self-efficacy theory. Self-efficacy theory is:

1. The strength of belief in one's capability to do a specific task or achieve a certain result is a good predictor of motivation and behaviour.
2. One's self-efficacy belief can be enhanced through performance mastery modelling reinterpretation of symptoms and social persuasion (Lorig & Associates 2001).

Assisting people to be as independent as possible in managing their health is an important role of health care providers. Accomplishing independence often requires changing behaviour, which is very challenging for individuals, their families, and professionals working with them. Many factors influence behaviour change including knowledge, skills, health beliefs, attitudes, and social support (Shortridge-Baggett 2001).

In respect to health behaviour, a number of models have been developed from evidence-based research on how individuals make decisions concerning their health. The two most commonly and accepted models are the Health Belief Model and the Transtheoretical Model. The Health Belief Model is one of the most widely accepted models of health behaviour and evolves from research about why people engage in preventative health behaviours (Glanz, Lewis & Rimer 1997). On the other hand, the Transtheoretical Model is derived from several psychological theories of behaviour change, and depends on what stage people are at in relation to behaviour (Glanz, Lewis & Rimer 1997). There are five stages: precontemplation, contemplation, preparation, action, and maintenance (Glanz, Lewis & Rimer 1997).

Empowering individuals to self-care is an important concept when managing multiple chronic conditions. As described in Chapter 1, empowering diabetic patients to self-

care was essential to the patient's overall health and well-being. Empowerment has been associated with an increased sense of competence and self-worth acquired through applying skills that enable effective problem solving and coping, and reduce stress. In order for change to occur, empowerment needs to happen at a number of levels. These include:

- individual (psychological) empowerment: improved perception of self-worth and mutuality with social environment
- organisational empowerment: stronger social networks and community or organisation competence to collaborate and solve problems
- community empowerment: actual improvements in environmental or health conditions

(Harvey 2001)

## **2.4 Summary**

In all facets of life including health, education, employment, and life expectancy, Indigenous people face an uphill battle. This continual merry-go-round of problems for Indigenous Australians has to stop eventually. This chapter has provided an overview of current Australian literature on the health status of Indigenous people with a specific focus on Indigenous renal health. Renal disease for Indigenous people, especially in remote Australia, is of great concern with higher numbers succumbing to the disease. Renal disease takes an enormous toll on the patient and their families, who in some cases have to relocate to receive treatment. State and Commonwealth health budgets are also affected. While a great deal of funding has been allocated to help treat kidney disease, now there has to be more money spent on adequate screening programs and more culturally appropriate health promotion and prevention strategies for end-stage renal disease, especially within the Indigenous population. Prevention models need to occur more aggressively within communities with enough resources to help manage renal disease and the number of other chronic illnesses.

A whole of government approach is required, from workforce planning to information sharing, with the focus centred on the patient and their family. Lack of their own renal

health knowledge is a major factor for Indigenous people with end-stage renal disease. If Indigenous people do not really understand what has happened to their renal health, what are the chances of understanding the many complex problems that will arise going through the end-stage renal disease journey and process?

The area of renal disease and its treatment is multifaceted filled with funding and work force issues, service delivery complexities, and non-existent policies. A number of Indigenous renal health programs demonstrate some credible results; however, sustainability, accountability, and empowering the individual seem to be lost somewhere in the maze. Where is the patient in this maze? The focus of this research is the need to understand more fully that the patient's experiences and views with end-stage renal disease. The next chapter presents the research methodology used to conduct the research into the patient's experience with end-stage renal disease.

# Chapter 3 : Research Process

## 3 Introduction

This chapter will report on research methods and design used in the study. The chapter is presented in three parts and includes the following:

- **Part 1: Research objectives and questions**
- **Part 2: Methods**
- **Part 3: Reliability and validity and ethical process**

### 3.1 Research objectives and questions

This study examines how Indigenous community people and their families manage and cope with end-stage renal disease. The overall aim of the study was to *‘Develop a model of care for Aboriginal and Torres Strait Islander people on renal dialysis treatment’*. The aim of the study was formulated by the following research objectives:

- to gain a comprehensive understanding of the literature to provide a sound basis for the research
- to contribute to the existing knowledge about health and well-being for Indigenous people with end-stage renal disease
- to identify social and cultural factors that arise for Indigenous people with end-stage renal disease.

To achieve these objectives the following three broad questions were formulated:

1. How do Indigenous people in an identified community cope with ESRD?
2. Why do Indigenous people have shorter life expectancy rates following initiation of renal dialysis treatment?
3. Will this research elucidate factors that contribute to mortality and morbidity among Indigenous people with ESRD?

### 3.2 Methods

The key areas of discussion in Part 2 include:

- methodology research design
- developing interview instrument

- piloting interview instrument
- interview instrument
- interview process
- recruitment process—organisation
- recruitment process—participants
- collecting data
- analysing data.

### **3.2.1 Methodology research design**

The methodology for the study comprised of a qualitative three-stage analysis that was conducted over two years. The original period for the study was one year; however, modifications were made to the original time frame at the end of Stage 1 and early into Stage 2, which affected the remaining study. It was during these stages of the study that the organisation responsible for recruiting participants and counselling support changed. Justifications for the changes are explained in section 3.2.6. Outlined below is the original timeframe for study:

<b>Stage 1</b> <i>April–June 2002</i>	<b>Stage 2</b> <i>July–October 2002</i>	<b>Stage 3</b> <i>November 2002–March 2003</i>
Conduct literature review	Recruit organisation	Analyse data
Develop instrument	Recruit participants	Write thesis
Pilot instrument	Transcribe interviews	Share results

Living with renal failure and being on renal dialysis treatment affects people in many different ways. An important aspect of this study was to interview Indigenous community members who undergo renal dialysis treatment to gain an insight and a better understanding of how Indigenous people manage and cope with their end-stage renal disease. Another aspect was to explore how family members and friends perceive end-stage renal disease and how they deal with any problems that may arise.

Qualitative research has been used in many cross-cultural settings as it allows the research to develop ‘rich’ descriptions collected through the participants’ personal experiences. Qualitative enquiry usually answers questions pertaining to what the

experience is like, that is, what it is like to have a particular illness, have surgery, or be in an accident. Qualitative research is used to describe how groups of people live or how they cope with their daily lives (Morse & Field, 1995).

Qualitative or interpretive field research involves the investigation of specific individuals in their social setting. The researcher seeks to understand the thoughts, feelings, and experiences of individuals, focusing on direct face-to-face knowledge of patients or clients as humans coping with their conditions and treatments in a given social setting (Polgar & Thomas, 1995).

Qualitative research is a method of naturalistic enquiry that is usually less obstructive than quantitative investigations and does not manipulate a research setting. It aims to study people in their natural social setting and to collect naturally occurring data (Bowling 2002).

Qualitative research was selected as the most appropriate method for this particular type of research as it provides the opportunity for the researcher to sit down with community members in an environment comfortable to them to discuss their feelings and experiences with renal disease and failure. Qualitative research allowed community members to share their stories about end-stage renal disease and the daily struggles they have to endure.

### ***3.2.2 Developing the interview instrument***

The task of developing and piloting the interview instrument was conducted over a timeframe of nine weeks. Developing the interview instrument began on 3 June 2002 and was completed in five weeks. During the five weeks of developing the instrument, a number of steps were followed to ensure that the best and most appropriate instrument was developed. The first step involved defining what information was to be obtained from the participants. This required linking research objectives and questions, discussions with others, and reading or reviewing relevant studies and research instrument designs.

A number of studies, reports, and research designs were examined during development of the interview instrument. These included:

- *A review of health-related quality of life measures used in end-stage renal disease* (Edgell et al., 1996)
- *The World Health Organisation Quality of Life Assessment Instrument (the WHOQOL)*
- *Outcomes measures and health education and other health care interventions* (Lorig et al., 1996)
- *Indigenous perceptions of renal transplants in Far North Queensland* (Preece, 1997)
- *A diabetes study* (McWilliams et al., 1997)
- *Living on medicine: A cultural study of end-stage renal disease among Aboriginal people* (Devitt & McMasters, 1998b)
- *On the machine: Aboriginal stories about kidney troubles* (Devitt & McMasters, 1998b)
- *Understanding Aboriginal domains of health and the development of an instrument to measure quality of life* (Senior, 1998)
- *Patient education: A practical approach* (Lorig & Associates, 2001)
- *Aboriginal and Torres Strait Islander health at the end of the 20<sup>th</sup> Century* (Australian Indigenous Health InfoNet, 2001)
- *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples* (ABS, 2001).

At this stage of instrument development, a *draft* comprehensive list of topics was prepared but was not yet translated into a specific interview instrument.

The next step in developing the interview instrument was the formulation of a draft instrument. This involved gathering the list of comprehensive topics and research design to create a format for the interview instrument. Phrasing and design of the questions and the overall design of a survey instrument are important components for the validity of the obtained information. If the survey instrument is badly designed, then the responses may not accurately reflect the real situation for the respondents (Polgar & Thomas 1995). Additionally, the interview instrument had to be comparable to allow the raw data analyses to note themes, similarities, and differences between each Indigenous community member with end-stage renal disease.

In the final stages of instrument development, it was clear what information the interview wished to gain. A thorough list of topics specifically linked to the research questions and objectives were incorporated into the instrument. Ensuring a comprehensive list is developed that addresses the research questions and objectives also helps prevent any unnecessary information from being collected (Miles & Huberman 1994).

Some participants receive different modality of dialysis treatment. For example, some participants on haemodialysis may receive treatment in a hospital setting or they may have home dialysis, spending an average 4–5 hours on treatment. Some of the haemodialysis participants who receive treatment in a hospital setting may have to wait up to another two hours for transport, while participants on continuous ambulatory peritoneal dialysis attend to their daily dialysis treatment either at home, work, or in an environment in which they are comfortable. Continuous ambulatory peritoneal dialysis treatment occurs four times a day taking 30–60 minutes for each exchange to be completed. The fact that the interviews for haemodialysis participants were to occur on one of their free days away from the renal unit, and for CAPD participants during free time at home, the instrument needed to be relatively efficient and effective to cover the number of concepts adequately. The instrument used to collect participants' information is the only crucial link to capture their experiences of end-stage renal disease.

A good survey instrument yields critical information and provides important windows into the heart of the topic of interest (Litwin 1995). A draft interview instrument was completed on 15 July 2002 ready for pilot testing which began immediately.

### ***3.2.3 Piloting the interview instrument***

The task of piloting the interview instrument was conducted over a timeframe of four weeks. Pilot testing is a necessary and important part of instrument development and helps towards developing the best and most appropriate instrument. It provides useful

information about how your instrument functions in the field. Although it requires extra time and energy, the pilot test is a critical step in assessing the practical application of your instrument (Litwin, 1995). The draft was pilot tested with a combination of experts and community members who were able to contribute valuable information towards improving the instrument.

The community members consisted of a small group of Indigenous people from an Indigenous organisation located in Brisbane. Experts included a renal specialist from the Princess Alexander Hospital, two academic staff members from the School of Public Health at the Queensland University of Technology (QUT), and Oodgeroo Indigenous staff members at QUT Kelvin Grove campus. During pilot testing on the instrument, content validity was used to measure how appropriate the items seem to a set of reviewers who have some knowledge of the subject matter. The assessment of content validity typically involves an organised review of the interview instrument contents to ensure that it includes everything it should and does not include anything it should not (Litwin, 1995). Feedback received from the pilot test required that minor modifications be made on the draft. Some of the modifications included rearranging the format to allow the instrument to flow better, shifting demographics to the end of the instrument, specifying educational grades and what they mean, rewording six of the questions, and including extra options that were overlooked on some of the questions. Redrafting another version of the interview instrument with the necessary modifications was completed on 30 July 2002. Once a second and final draft was completed to an acceptable standard, the instrument was ready to be administered to the full sample of respondents. Results from the pilot test are in Appendix 1: *Results of Pilot*.

#### **3.2.4 Interview instrument**

The instrument used for the interview consisted of eight parts that covered a range of areas, including social support, lifestyle, transport, health and kidney well-being, other medical conditions, health service use, and demographics. The instrument used to conduct the interviews is in Appendix 2: *Survey Instrument*. The following is an outline of the interview instrument used for the study.

**Part A—questions related to:**

- what community people came from
- whether their family left the community to help them
- what support while **on** dialysis and what support while **not on** dialysis
- what support structures to manage daily routine
- what extra support would be needed to help manage their kidney health
- whether dialysis affected family relationships and relationships with friends
- whether they are satisfied with support received from family and friends
- what they rated the support received from family and friends
- what level of satisfaction and rating they gave to medical support.

**Part B—questions related to:**

- accommodation
  - who lives in the accommodation
- government concessions
- income and expenses
  - does being on dialysis affect finances
- smoking and alcohol
- physical activity.

**Part C—questions related to:**

- transport
  - distance to and from hospital
  - transportation costs
  - mode of transport
  - ideas towards improving transport.

**Part D—questions related to:**

- general health and well-being
- family history of renal problems
- past treatment dialysis; current treatment
- general knowledge of own renal health
- where knowledge on renal health was received

- compliance with attending dialysis treatment.

**Part E—questions related to:**

- background of other medical conditions
- types of medication
- medication compliance.

**Part F—questions related to:**

- health service use
- frequency of attending health professional appointments
- frequency of attending renal health appointments.

**Part G—questions related to:**

- demographic data.

**3.2.5 Interview process**

Before each interview was conducted, the researcher explained fully the nature of the study to each participant. An Information Sheet (Appendix 3) was given to each participant; they had a choice to read by themselves or have the researcher read it to them. Participants kept the information sheet during and after completion of the interview for reference. A Consent Form (Appendix 4) was also fully explained to each participant and completed. Time was allocated for participants to ask any questions about the study. Participants indicated that they understood what the study was about and signed the Consent Forms. During the initial phase of explaining the study and the Information Sheet to each participant, the researcher also asked permission to tape record the interviews.

Two participants indicated that they felt comfortable with having their interview recorded. This process was approved through the University Human Research Ethics Committee (UHREC) at QUT on 17 April 2002. During the process of ethical approval, the interviews were not peer-reviewed. Also, relating back to the process of gaining ethical approval, the tapes used to record the interviews were destroyed so that no one could be voice recognised. This was a concern raised by a majority of the

participants. The tapes were destroyed once the interviews were transcribed fully, checked, and rechecked.

The interview process consisted of semi-structured, individual face-to-face interviews that took between approximately 40–60 minutes to complete. This particular method is ideal when the researcher knows most of the questions to ask but cannot predict the answers (Morse & Field, 1995). The interview format was a combination of open and closed questions, which allowed participants to answer each question thoroughly. It is useful because this technique ensures that the researcher will obtain all of the information required and gives the participant freedom to respond and illustrate concepts (Morse & Field, 1995).

The face-to-face method of data collection had many advantages compared to mailing the instrument, telephone interviews, and participating in focus groups. It was not feasible to mail the interview or conduct telephone interviews as the nature of the topics were sensitive and required an in-depth interview technique (Bourque & Fielder 1995). Face-to-face interviews permit the non-verbal reactions of the participant to be observed and perhaps the development of a closer rapport arising from the more natural setting (Polgar & Thomas 1995).

Given that the sample size was relatively small, the geographic location to travel to the participants was an advantage. All of the participants lived within close proximity of Brisbane city and were easily accessible by vehicle transport. As each participant is unique, so are their responses; focus groups were not suitable for this particular type of research as individual life stories needed to be captured.

To minimise any restraints on the interview, participants were interviewed in an environment of their choice. Participants in the study were interviewed in the comfort of their own homes and in separate rooms away from any distractions (where possible) to minimise inhibition in their responses (Bowling 2002). This method also enabled the researcher to get a richer insight into each participant's way of life at their

home environment, and how they coped with end-stage renal disease. The decision not to interview participants while they were 'in-patients' receiving renal dialysis treatment in hospitals was made for the following reasons. First, the process of gaining ethical approval and clearance from five major hospitals would have been too great an obstacle given the short timeframe, and second, privacy issues were taken into consideration not only for the participants on dialysis but also for nearby patients on dialysis treatment and attending medical staff.

One researcher conducted all of the interviews for the study, ensuring consistency and similar interviewing style and technique for each interview. After each interview was completed, the interviews were transcribed into a readable format and taken back to each participant as an ongoing quality control management strategy. Participants checked the information recorded for accurateness and to validate and correct any errors in the information obtained from the researcher. This validation process was written and explained in the information sheet, which was introduced to each participant at the beginning of data collection. The transcribed data was also checked against the recording for accuracy. Four (30%) interview transcripts were selected at random and checked for accuracy. These were found to be of an acceptable level.

### ***3.2.6 Recruitment process: Organisation***

Approval to recruit participants through the Queensland Branch of the Australian Kidney Foundation was given 'in principle' during a Queensland branch (AKF State Executive Committee) meeting in August 2001. The study commenced in March 2002. A letter of support and confirmation of counselling support were received from the Australian Kidney Foundation's State President and Executive Manager.

In addition, the study received two other letters of support; the first one was from the Chief Executive Officer of the Queensland Aboriginal and Islander Health Forum (QAIHF) (Appendix 5). The QAIHF is the collective of ACCHSs and other Aboriginal community controlled initiatives in Queensland (Queensland Aboriginal and Islander Health Forum, 2000).

The second letter of support was received from the Chief Executive Officer of Aboriginal & Islander Community Health Service (AICHS) (Appendix 6). These letters of support were helpful in gaining support for the National Health and Medical Research Council training scholarships for Indigenous Health Research.

However, due to unforeseen circumstances for the national body of the Australian Kidney Foundation, the Queensland branch was not in a position to support the study. The Australian Kidney Foundation went through a national restructuring program and the Queensland branch was not going to operate to full capacity. It was therefore not feasible to recruit participants through this branch. The Australian Kidney Foundation is now called Kidney Health Australia.

The next step was to approach another organisation to recruit participants. The procedure of finding an organisation to recruit participants is probably the most important aspect of this study. If participants were not recruited, there would be no justification or reason for this study. It was at this stage that Aboriginal and Islander Community Health Service was approached to be the recruiting organisation for the study. A meeting was held on 21 August 2002 where an overview of the study proposal called '*Developing a model of care to improve the health and well-being for Aboriginal and Torres Strait Islander people on renal dialysis treatment*' was presented to the Chief Executive Officer of AICHS.

Advice by the Chief Executive Officer was to seek written approval from the AICHS Council of Management. It is important when working with Indigenous organisations that appropriate protocols be followed, and the first protocol was to gain this permission and approval. AICHS is located in Woolloongabba, Brisbane, and delivers a vast range of health-related services to the Indigenous population of South East Queensland. The method of recruiting participants through AICHS was vital for the study. Involving ACCHSs in the process of recruiting was strongly supported by the NHMRC's Draft Values and Ethics in Aboriginal and Torres Strait Islander Health

Research (RAWG 2002). Community controlled health services operate differently from mainstream health services. The organisational structure of AICHS is attached in Appendix 7.

A letter addressed to the Chairperson of the Aboriginal and Islander Community Health Service, seeking permission to recruit participants, was completed at the end of August 2002 in time for the next scheduled Council of Management meeting on 9 September 2002 (Appendix 8). Permission to recruit was approved by the Council of Management via verbal and written correspondence from the Chief Executive Officer of AICHS on 19 September 2002 (Appendix 9). Also provided from AICHS was a letter confirming counselling support (Appendix 10).

To gain ethical approval for the amendments from the original plan, notifications were made immediately to QUT's Secretary of the UHREC for the purpose of an extension.

### **3.2.7 Recruitment process: Participants**

Once approval was finalised from AICHS Council of Management, the task of completing a letter to recruit participants was completed. A first draft of the recruitment letter was completed by the researcher and emailed to the Chief Executive Officer of AICHS on 30 October 2002 for any comments. Comments from the Chief Executive Officer, which recommended a couple of minor adjustments, were received the following week. A re-drafted recruitment letter was completed and given back to the Chief Executive Officer for approval. In total, two draft recruitment letters were completed over two weeks before the final recruitment letter was ready for recruiting participants through AICHS (Appendix 11).

The central and regional medical database from AICHS located the potential participants for the study and each of the participants received an A5 envelope from the Chief Executive Officer of AICHS in early November 2002.

The recruitment envelope contained the following:

- a letter outlining the purpose of the study; an invitation to participate in the study; and some information about the researcher, what is involved in the interview process, and their rights—outlining that all information collected is confidential.
- one A4 sheet indicating ‘yes’ or ‘no’ to be involved in the study; if ‘yes’ was marked, participants were required to supply their name, a contact number, and the best time to call; if ‘no’ was marked, the participants were required to supply only their name.
- one A5 reply paid envelope addressed to the Chief Executive Officer.

Participants were asked to read the recruitment letter. If participants were interested in participating further, then they were required to complete the attached A4 sheet and return it separately to the Chief Executive Officer in the reply paid envelope. Participants were given a period of two weeks to complete this process.

Once the names of the participants were finalised by the recruiting organisation, AICHS, the researcher was contacted and the process of data collection began. However, as documented in 3.2.8, data collection continued well over the allocated time frame, which affected the study.

### **3.2.8 Data collection**

Sixteen people were required for the data collection phase of the study. Sixteen people were approached to participate in the study. From the total, 15 people were interested in participating in the study with 14 people completing the interviews. One person declined and one person, sadly, passed away. In the original time frame, two months was allocated for data collection. On reflection, this was ambitious. Data collection for the study was conducted over six months from December 2002–May 2003 in three separate intervals. The process of changing from Kidney Health Australia to the Aboriginal and Islander Community Health Service was unexpected and ultimately led to data collection commencing in December 2002. The Christmas and New Year period was not ideal for data collection due to AICHS reduced operating hours over the break. This major factor contributed to further delays of data collection.

The first round of interviews occurred from the end of November 2002 until the end of December 2002. From the first round of interviews, six participants were interested in the study with five interviews conducted. One of the participants indicated interest during the recruitment phase but passed away during that time.

The second round of interviews took place from mid January 2003 to early February 2003 in which another five participants were interested and five interviews were completed. At this stage of data collection, 11 out of 12 interviews had been completed.

The remaining and final round of interviews was conducted until May 2003 in which another four participants were recruited with three interviews completed. From this final round of interviews one person indicated they were not interested in participating in the study. On completion of the final interview, full saturation was achieved. The process to recruit participants was slow, and, sadly, one of the potential participants had passed away.

While the data collection phase continued well beyond the planned time frame, early identification of this meant that written requests for extensions to the funding body, NHMRC and QUT's University Human Research Ethics Committee (UHREC) had to be completed and approved within specified time frames.

### **3.2.9 Data analysis**

The information from the interviews was analysed using a combination of thematic and content analyses. Thematic analysis involves the search for and identification of common threads that extend throughout the entire set of interviews. Themes are usually quite abstract and therefore difficult to identify. A theme may be beneath the surface of the interviews but once identified appears obvious (Morse & Field 1995). Thematic analysis was the standard process as it focused on exploring themes in participants' responses.

The process of data analysis began with the interviews being read and reread four times in their entirety and then transcribed. The information was then checked against each of the participant's interviews. Once completed the hard copy of each interview was taken back to the participant to validate and correct any written information. A theme codebook was developed to identify common threads or themes from the interviews. The information from the interviews was labelled and defined for coding purposes only; the raw data that met the criteria set out in the codebook was coded under the corresponding themes. Examples of how the themes appeared from the information are provided in the theme codebook in Appendix 12.

Content analysis is analysis by topic and each interview is segmented by these topics into categories. When each category is reasonably full and saturation reached, that is, no new data is emerging, the researcher may write descriptive paragraphs about the categories and look for relationships between the categories (Field & Morse 1995). The instrument was segmented into categories, which made the task of completing content analysis a little easier. The focus of this study was not only to address the research questions but also to explore how Indigenous community members cope with end-stage renal disease.

### **3.3 Reliability and validity and ethical process**

The major areas of discussion in Part 3 include:

- reliability and validity
- ethical considerations

#### **3.3.1 Reliability and validity**

Reliability is the measure of the extent to which random variation may have influenced the stability and consistency of the results (Morse & Field, 1995). When conducting reliability in thematic analysis, consistency of coding is crucial and largely dependent on the nature of the research and whether data is collected over a long period of time (reliability of coding over time) or by a number of observers (reliability of coding among viewers) (Boyatzis, 1998). Reliability in this study was measured as the consistency of judgment in assigning codes to the raw data and providing detailed

steps in the research process. Thematic codes using the codebook were found to be of an acceptable reliability.

Validity in qualitative research means the extent to which the research findings represent reality (Morse & Field 1985). Criterion validity covers correlations of the measure with another criterion measure, which is accepted as valid (referred to as the 'gold standard'). However, this is not possible where there are no 'gold standards' to measure against them (Miles & Huberman 1994, Bowling 2002). Another method used to measure validity in qualitative research is the use of triangulation. This would involve comparing results with independent measures among the same group of participants (Miles & Huberman 1994).

### **3.3.2 Ethical considerations**

All research conducted at QUT requires ethical clearance from the University Human Research Ethics Committee (UHREC). Ethical clearance was sought towards the end of February 2002, in time for the study to commence in April 2002. The first ethics application to UHREC received conditional ethical approval 'only' subject to nine minor changes. These changes were completed promptly and returned to the Secretary of UHREC. The committee then required an indicative draft of the types of questions that might be asked for the data collection phase to occur later in the year. An indicative draft was completed and emailed to the Secretary of UHREC on 2 April 2002. On 17 April 2002, full ethical clearance was granted by UHREC and the study was permitted to commence officially (Appendix 13). During stages of the study, three progress reports were submitted to the QUT's Centre of Health Research outlining specific challenges faced by the researcher.

## **3.4 Summary**

This chapter has provided a description of the methodological processes that were undertaken during the research phase of this study. Perhaps the most significant feature of this chapter was the flexibility to change from one recruiting organisation to another and how this affected the remaining study. For circumstances beyond the

control of the researcher, it is essential to have other strategies ready in case the original plan for organisation recruitment does not work. Another feature of this study was the process of following correct Indigenous protocols when dealing with Indigenous organisations. The ability to contact appropriate Chairpersons and Chief Executive Officers requesting support and help with recruiting participants, however time consuming, really made the difference towards achieving the necessary goals of recruiting the maximum number required for the study. This is reflected in the number of support letters that were written to gain funding support and ethical approval within the University.

Building strong links and networks with Indigenous organisations can make a dramatic difference, and can determine if the research will be effective or unsuccessful. The process of actively involving Indigenous organisations during all stages of the research allows Indigenous people from these organisations to participate, develop, and own the research to some degree. Networking and forming working relationships enables the research to achieve its outcomes. The role that Aboriginal Community Controlled Health Services play in ongoing care and support for clients receiving dialysis—managing co-morbidities and clients’ broader health needs—is important. The outcomes for the organisation would also be reflected in the research findings filtering back to improve the health and well-being for Indigenous people with renal problems that attend their organisation. In summary, a number of methodical steps were followed to ensure that, at each stage, processes were completed correctly. Without completing each stage correctly, it would have been difficult to continue on to other components within the methodology. The next chapter presents the results from the participants’ interviews.

# Chapter 4 : Results

## 4 Introduction

This chapter of the study presents results from interviews that were conducted with community members who receive renal dialysis treatment in the Brisbane region. The participants involved in the study were interviewed as members of the community and not while they were in-patients receiving hospital-based renal dialysis treatment. The purpose of the interview was to gain insight into and further understanding of the impact that end-stage renal disease and renal dialysis treatment has had on participants' and their families' lives. The study also offered the opportunity for participants to discuss their reflections and personal feelings about end-stage renal disease. The results include supportive narrative from each of the participants. The structure of this chapter will focus on the following areas:

### **Participant profile**

includes age, gender, ethnicity, educational level, and origin.

### **Lifestyle factors**

includes employment, accommodation, and socioeconomic status.

### **Lifestyle behaviours**

includes physical activity, cigarette smoking, and alcohol consumption.

### **Social support**

includes duration in Brisbane; family, friends, medical support; and relationships with family and friends.

### **Transport factors**

includes distance covered, type of transport, and cost of transport.

### **Health and renal health well-being**

includes description of health and family and a history of renal health problems and duration on dialysis treatment.

### **Other health conditions**

includes a description of other health conditions and medication and treatment compliance.

### **Health service utilisation**

includes a description of other health care services used.

### **Towards self care**

includes suggestions from participants towards self-care management.

## 4.1 Participant profile

This section presents demographic information on participants' age, gender, ethnicity, highest education level completed, and origin. Sixteen interviews were required for the study, with 14 interviews completed. Eight females and six males were interviewed. Eight participants identified as Aboriginal, four participants identified as Torres Strait Islander, and two participants identified as being of both Aboriginal and Torres Strait Islander descent. The ages of the participants varied from late 20s through to late 60s. The average age of the participants was 48 years.

Thirteen participants were from Queensland and one participant was from interstate. Specifically, two participants from Queensland were from Brisbane. The highest education level completed was a university degree, completed by one participant. Four participants completed Grade 12 while five participants completed Grade 10. Four participants completed Grade 7 primary school level of education. These findings indicate that the majority of the participants have completed some formal education. Table 4.1, below describes the participants' age and gender distribution.

Age	Female	Male
20–29	2	
30–39		
40–49	2	6
50–59	2	
60 and over	2	
<b>TOTAL</b>	<b>8</b>	<b>6</b>

**Table 4.1 Respondents' age and gender distribution.**

## 4.2 Lifestyle factors

The interviews collected in this section present information on participants' lifestyle factors with particular emphasis on employment, accommodation, and socioeconomic status. This section also presents information on participants' lifestyle behaviours, which include cigarette smoking, alcohol consumption, and physical activity.

#### **4.2.1 Employment status**

In this next component of the study, participants described their current employment status. Eleven participants (79%) were physically unable to work due to their medical condition. Two participants (14%) were in the process of looking for work and one participant (7%) was working full-time. Therefore, participants' major source of income varied from different pensions to paid employment. Government funded pensions, distributed by Centrelink, are issued based on individual circumstances and assessment by Centrelink staff. From the 14 participants, eight receive a disability pension, two receive Newstart—an unemployment allowance pension, two receive age pension and one receives sole parent pension. All of the participants are on some form of government concession card, which offers a range of different discounts and allowances depending on the type of card issued.

#### **4.2.2 Accommodation status**

In this part of the study, participants were asked to describe their accommodation and who resided with them. Six participants described their accommodation as living in a self-contained house, five as living in a flat or unit, one as living in a duplex, and two as living in a hostel and nursing care facility arrangement. The following responses were recorded when participants were asked who resided with them in their accommodation. Ten participants indicated that they lived with their partner (husband or wife) and other family members. Other family members consisted of one to four adults (mostly adult females) and children aged from under five years of age through to early adolescence. Of 14 participants, seven females were in charge of their household.

From the 10 participants who lived with their partner and other family members, the most number of people recorded in one household was four adults and three children. Some participants also indicated that these figures fluctuated greatly from time to time due to the arrival or departure of relatives. Relatives or extended family members could easily increase the number of household members anywhere from five to 10 adults and up to 10 children. Two participants lived by themselves with the occasional visit from family members who would only visit for short periods during the day or

evening. One participant stated that they lived with up to 25 people in a hostel living arrangement and another participant lived with 55 people in a nursing care facility.

#### **4.2.3 Socioeconomic status**

The next part of the study and Table 4.2 present findings on how being on renal dialysis treatment affects each participant’s financial situation.

<b>Affect on finances</b>	<b>Number of responses</b>
Not at all	0
Slightly	0
Moderately	2
Quite a bit	5
Very much	7

**Table 4.2 Participants' response to how much being on renal dialysis affect their finances.**

All participants responded clearly that renal dialysis treatment does affect their finances to some degree. Five participants indicated that being on renal dialysis affects their finances quite a bit and seven participants indicated that being on renal dialysis affects their finances very much. Two participants indicated that their finances were moderately affected. From the participants’ major source of income described in (4.2.1), which includes a majority of Centrelink pensions and a wage, all of the participants indicated that they pay each of the following main expenses on top of other expenses incurred. The six main expenses include:

##### **Rent or mortgage**

all of the participants contribute financially to the rent or mortgage of their accommodation. Each participant pays different amounts according to their accommodation location and the duration of time spent in their accommodation.

##### **Transport**

transport costs are reported in more detail in 4.5 of this section.

##### **Utilities**

all of the participants contribute financially towards electricity or gas expenses. Some participants have organised a direct debit from their accounts, which makes the burden of receiving these bills a little easier.

##### **Groceries**

all of the participants pay different amounts towards grocery expenses.

## Telephone

all of the participants pay different amounts towards their telephone expenses. Some participants indicated that visiting relatives sometimes make a lot of phone calls and that their telephone has been disconnected until they were able to repay the bill. This would be repaid over a number of payments until the debt is cleared, then a reconnection fee is charged to reconnect the telephone.

## Medication

all of the participants pay towards medication costs. Medication costs are reported in more detail in section 4.7.

Participants' narratives describe how being on renal dialysis treatment affects their finances, how they cope, and how they do not cope.

**P1** *I did have a couple of debts that I paid over time; well, every fortnight it was automatically taken out from my pension. I have cleared that up now. If I keep things under control, I am okay. I struggle from time to time. I have a tombstone celebration coming up but after that I will be alright.*

**P2** *From my disability pension that I get, all of my expenses get taken out automatically and I usually end up with \$10-\$20 spare. I would like to go shopping but I can't do that; I'm always broke.*

During these interviews, participants indicated ongoing stress and feeling depressed about how financially broke they were. This impacted on their emotional and physical well-being. Always being broke from pension to pension makes life hard especially when buying food.

**P3** *It's a struggle but we have to survive and get on with life. We pay all our bills on time with a little extra left over.*

**P4** *I have insurance, cleaning, and internet bills to pay on top of the other bills. My renal failure reduces my work hours which reduces my pay. I'm struggling a bit.*

**P5** *All my bills come out of my pension automatically. I am always broke. Being on dialysis and on a pension is hard.*

If participants had outstanding debts from government agencies, an agreement would be entered into to repay the loan back through fortnightly installments which were automatically taken out of participants' pensions. Initially, this process would seem

beneficial to the participant especially if the loan was for an emergency situation (e.g. bond to rent a house). The long term effect is that, over time, participants learn to live with what they have even though it is not very much.

- P6** *We plan our bills; we learn to live with what we have. It's never ending.*
- P7** *My fridge is on hire and I pay that every month. It's only when I need to get a taxi my budget blows out.*
- P8** *I live close to the hospital so that helps a bit. All the bills seem to come at once. I find it hard to pay the toll if I need to travel to the Western suburbs.*

Living in close proximity to a nominated renal unit is advantageous. If a health emergency were to occur, patients would only be a short distance from the hospital. Living close also saves the participant considerable transport costs and time.

- P9** *I am not sure if I am on the right pension. I try and look for work but it's hard to employ someone who might not be able to manage with things. I am always tired after treatment. It's hard to cope with my current income.*
- P10** *We struggle and try to keep to a budget: day care, housing commission bond, Foxtel, and transport costs.*
- P11** *I am in a difficult situation with my mobile phone carrier. I would like to pay my debt off but I am not allowed. I am getting very high interest on my current mobile phone bill and I cannot afford this. I use to work part-time and managed my finances well before I became sick. Now I cannot work and have to rely on the disability pension and I try to cope by paying my bills on time—just my mobile phone bill to clear now.*
- P12** *We pay an insurance payment for funeral services. Our phone is incoming calls only which help keep our phone bill down. Our daughter has a mobile if we need it for any emergency. It all comes down to being organised.*
- P13** *When I was working full-time and getting an income, I really did not care, but now that I'm on a pension, I watch every cent. It's hard at times but we manage. We have Foxtel for the children.*

Participant 13 indicated the transition from feeling a little unwell one week to being on renal dialysis treatment the following week was quite drastic and complex to understand at first. Sudden life changes, including receiving major surgery one week and commencing renal dialysis the next, certainly make life a lot harder to cope with. This participant also stated that they are still trying to cope with the difference from receiving a good fortnightly wage to a reduced fortnightly pension from Centrelink.

The participant indicated that with a wage they were able to buy things and pay expenses without worrying about finances compared to now being on a pension: finances are really restricted and they have to watch every cent.

**P14** *With the little income I receive, I pay most of that on bills. On top of that I have to try and find employment, which is difficult for me as I am tired constantly from dialysis treatment. As I was staying with my sister and her family, I only paid a small contribution towards rent and electricity bills.*

In summary, it is evident from the participants' narrative and responses that being on renal dialysis treatment does affect their financial situation. With very little income, participants have to cover a wide range of expenses and all of the participants indicated that they are struggling and finding it difficult to cope financially. Even for those participants who indicated that they budget their income, they are still struggling through hardships. Seven participants indicated further expenses on top of the main expenses already supplied. These include personal loans, hire of household white goods, insurance, cleaning, child care, clothing for children, mobile phone, internet, and Foxtel connection. Although some of these items could easily be eliminated to help ease the financial burden, it was unanimous that these provided a diversion to an otherwise poor quality of life.

### **4.3 Lifestyle behaviours**

The following data presents participants' responses in relation to lifestyle behaviours such as physical activity, cigarette smoking, and alcohol consumption.

#### **4.3.1 Physical activity**

The next component presents findings in relation to physical activity undertaken by each participant. The definition of physical activity is any activity that requires a physical effort above that of a normal lifestyle activity. The activity must be sustained for a period of time and be performed on a regular basis (Australian Council for Health, Physical Education, and Recreation, 2003). Taking part in physical activity and normal lifestyle activity for each participant depended on each individual's health condition, mobility, and living circumstances. Participants indicated a number of

lifestyle activities were undertaken such as housework, gardening, cleaning, shopping, and washing clothes. Although some of the lifestyle activities were not considered physical activity by the above definition, participants found that carrying out some of the lifestyle activities were strenuous and challenging.

Table 4.3 shows a series of tables that describe individual participants' physical and lifestyle activity, and the frequency in which the physical and lifestyle activity occurred.

<b>Participant 1:</b>		<b>Participant 2:</b>	
<b>Activity</b>	<b>Frequency</b>	<b>Activity</b>	<b>Frequency</b>
Housework	3–4 times per week	Move wheel chair	>4 times per week
Gardening	1–2 times per week	Physio appointment	1–2 times per week
Wash clothes	>4 times per week		
Cooking	>4 times per week		
Move wheel chair	>4 times per week		
Drum practice	1–2 times per week		

<b>Participant 3</b>		<b>Participant 4</b>	
<b>Activity</b>	<b>Frequency</b>	<b>Activity</b>	<b>Frequency</b>
Walking	3–4 times per week	Walking	1–2 times per week
Cleaning	1–2 times per week	Tidy up	1–2 times per week

<b>Participant 5</b>		<b>Participant 6</b>	
<b>Activity</b>	<b>Frequency</b>	<b>Activity</b>	<b>Frequency</b>
Walking	1–2 times per week	Never	Never

Participant 7		Participant 8	
Activity	Frequency	Activity	Frequency
Walking	>4 times per week	Washing	1–2 times per week
Cleaning	>4 times per week	Walking	>4 times per week
Gardening	>4 times per week	Housework	1–2 times per week
Shopping	>4 times per week		

Participant 9		Participant 10	
Activity	Frequency	Activity	Frequency
Walking	3–4 times per week	Walking	3–4 times per week
Washing	3–4 times per week	Housework	3–4 times per week
		Laundry	1–2 times per week
		Shopping	1–2 times per week

Participant 11		Participant 12	
Activity	Frequency	Activity	Frequency
Walking	1–2 times per week	Walking	>4 times per week
Gardening	>once a week	Physio appointment	>4 times per week

Participant 13		Participant 14	
Activity	Frequency	Activity	Frequency
Walking	3–4 times per week	Walking	>4 times per week
Yard work	3–4 times per week	Housework	>4 times per week
House work	3–4 times per week		

**Table 4.3 Respondents' physical activity and frequency**

Participants concluded that they considered lifestyle activities such as housework, gardening, cleaning, shopping, washing clothes, attending appointments, and moving around in their wheel chairs to be physical activity for them. Eleven of the 14 participants undertook walking as a separate physical activity to one of their daily normal lifestyle activities.

Of those 11 participants who undertook walking as an exercise, four indicated that they walked more than four times per week, another four walked three to four times per week, and three participants walked once or twice per week. Time spent walking varied from each participant. The most time spent walking was fifteen 15–20 minutes, while the least time spent walking was 10 minutes.

In summary, 13 out of 14 participants identified that they engaged in some form of physical activity or lifestyle activity while one participant indicated no participation in any in any physical activity or lifestyle activity.

#### **4.3.2 Cigarette smoking**

In relation to cigarette smoking, nine participants indicated that they have been cigarette smokers during their adult lifetime and five participants have never been cigarettes smokers. Of those nine participants who indicated they have smoked cigarettes in their adult lifetime, five currently smoke cigarettes and four do not. Of the four participants who ceased smoking, the major reason to cease smoking was health related. One of four participants also mentioned cost as an additional reason to giving up smoking. The five participants who currently smoke cigarettes know about the health consequences and smoke for enjoyment.

#### **4.3.3 Alcohol consumption**

In relation to alcohol consumption, 11 participants indicated that they have drunk alcohol in their adult lifetime and three participants indicated they have **not** drunk alcohol at all. Of all participants, one currently consumes alcohol while thirteen do not consume alcohol at all. This means that from those eleven participants who consumed alcohol in the past, 10 participants have given up consumption of alcohol. For the 10 participants who gave up alcohol, two reasons were given. One was health related and the other was the restriction of fluid intake. Some people with kidney failure need to limit their fluid intake depending on how the kidney failure is affecting their kidneys and how much urine is being passed (Kidney Health Australia 2002).

## 4.4 Social support

This set of findings establishes how long participants have lived in Brisbane and if participants and their families had to leave their community to come to Brisbane specifically because of their end-stage renal disease and to commence renal dialysis treatment. It also establishes what support structures are in place for participants when receiving and not receiving renal dialysis treatment.

Also, these findings will present participants' satisfaction with their support and how they rated their support. In the final part of these findings, participants were asked to contribute ideas towards making it easier for them to manage their renal health. Self support, family support, friends support, and medical support have been frequently used throughout this set of findings. The term self support means being able to manage any task independently and the other three support areas include support received from family members, support from friends, and support from the medical team.

### 4.4.1 Duration in Brisbane

All of the participants indicated that they had lived in Brisbane for many years with the longest time being forty years and the shortest time being one year. Table 4.4 describes the duration participants have lived in Brisbane.

Duration in Brisbane (years)	Number of participants
1–10	3
11–20	5
21–30	4
31–40	2
<b>TOTAL</b>	<b>14</b>

Table 4.4 Duration participants have lived in Brisbane.

### 4.4.2 Participants and family members relocating from community

The following section describes why participants left their community and if any of their family members also left to support them. Some of the participants have

described family involvement in the following narrative. From 14 participants, two specifically left their community in North Queensland and Western Queensland to commence renal dialysis treatment. As described below, participants left their respective communities because there were no adequate renal facilities available for them; therefore, they had to relocate or die. Two participants' narratives describe leaving their community to receive better renal health facilities and care.

**P5** *When I left my community I was really sick. My kidneys were bad. I was all puffed up and I could not walk properly. None of my family moved to Brisbane; they all out at the community. I am coping for now. Some days are good and some days are really bad.*

**P8** *Where I was living had no modern kidney dialysis treatment. I really had no choice; I had to move or I would not be here. My wife and son moved to Brisbane. My wife also had kidney problems as well so we supported each other I suppose.*

Six participants left their community for a combination of employment and family reasons. These participants indicated that they left their community well before being diagnosed with end-stage renal failure, and well before commencing renal dialysis treatment. Participants' narratives on employment and family reasons included:

- P1** *My husband and me came down here to Brisbane to look for work. We moved to Brisbane well before I got sick. Apart from my hubby and me, the only family we had down here in Brisbane was my brother, his wife, and their three children. It was good to have some family around to help with moving to another place.*
- P2** *Because I wanted to leave my community anyway and get a job, and plus I did not have any kidney failure at that stage. That came later on. I left my community only with my daughter who was one and a half.*
- P3** *My uncle bought a place here in Brisbane and sent for us to look after the place. My husband and daughter came to Brisbane with me. We moved down here from the North. I did not have kidney problems then.*
- P4** *Although I could get excellent treatment in Sydney where I was first diagnosed with end-stage renal failure. I wanted to come back home to Brisbane for family support as I have no family in Sydney. My family were already in Brisbane ready to help me with my ESRF.*
- P6** *I travelled to Brisbane from south of the border and came up here to look for employment opportunities. I came here by myself and did not get sick until later on.*
- P14** *As I relocated from up North by myself, my first option was to go to a major town in North Queensland but I had family down here in Brisbane so I decided on moving to Brisbane to be closer to my family.*

Six participants indicated that they were already established and living in Brisbane either by themselves or with family members prior to commencing renal dialysis treatment. Participants' narratives on already being established in Brisbane are as follows:

- P7 I was already living in Brisbane but had to move closer to my family and closer to my local doctor. I moved closer to my family because they help with a lot of things. They only live two streets away and they help me cope.*
- P9 I was not suffering with kidney failure when we moved to Brisbane. I moved with my boyfriend and his family.*
- P10 I was already here living in Brisbane.*
- P11 I was a Brisbane resident and my family were here with me.*
- P12 My family and I were already living in Brisbane; this was well before I started my dialysis treatment.*
- P13 I was with my first family and we were already living here in Brisbane. That's seems like a long time ago now. My first family were here already. My second wife is very supportive and has helped me cope with the shock of it all.*

In summary, participants relocated for various reasons with family support. Two relocated when their end-stage renal disease had come to a stage where without appropriate and essential treatment they would not be here today. Other participants relocated mainly to seek employment opportunities and because family members were also relocating. A large number of participants relocated well before their kidney health had deteriorated to a stage requiring dialysis treatment. When participants left their community, they were asked if family members also left their community to help support them. Four participants moved to Brisbane with family members, while six participants already had family members living in Brisbane. Four participants had moved to Brisbane independently.

#### **4.4.3 Support when not receiving renal dialysis**

Participants were asked what support they received when **not** receiving renal dialysis treatment. Responses were not mutually exclusive; participants could tick more than one support option. Table 4.5 summarises the information collected from participants in relation to support when **not receiving** renal dialysis treatment.

No	S	P	Fa	Fr	C	M	O	No	S	P	Fa	Fr	C	M	O
1	3		3					8	3		3				
2	3				3	3		9	3	3		3		3	
3	3							10	3	3	3	3			
4	3		3				3	11	3		3				
5	3				3			12					3		
6	3	3						13	3	3					
7	3		3					14	3	3	3				3

**Table 4.5 Respondents' support options**

**Key for Table 4.5**

Participants represented 1–14

S= self support

P= partner(wife/husband) support,

Fa = family support

Fr = friends support

C= Carer support

M= medical team support

O= organisation support

In summary, the most identified option for 13 participants was self support; 12 of those indicated one to three other supportive options. The next most identified option for seven participants was family support. Five participants identified partner support and three participants identified support from carers. Two participants identified support from friends, organisations, and medical teams. One participant identified carer support when not on renal dialysis treatment. Only one participant in the study was solely self supportive with no other support options mentioned.

Participants advised that when they were not receiving renal dialysis treatment other support options are in place to help manage their daily routine. This could be family helping with shopping or neighbours driving them to appointments. Participants reported a number of different options in relation to receiving support when not on renal dialysis treatment. Three participants' narratives describe how they manage their daily routine at home including activities such as shopping, buying groceries and obtaining their medication through a local pharmacy.

- P1** *When I go shopping, my daughter usually helps me. Sometimes I feel slack, you know tired from the dialysis and my daughter goes by herself. Sometimes I like to get out of the house. I get support from the hospital when I need it.*
- P3** *We get fruit and groceries delivered, and a pharmacy at Morningside delivers our medication weekly. My husband cooks and cleans the unit.*
- P7** *I go shopping and do things by myself. My little granddaughter helps me sometimes with my shopping. When I need them, they are only a phone call away.*

Being restricted by their renal dialysis treatment, medical conditions, and surrounding environment, four participants indicated that they require assistance with their daily routine.

- P2** *I can eat by myself but I need assistance with showering and going to the toilet. All care is provided through the carers and nursing home.*
- P5** *I barely manage my daily routine. I have a part-time carer who looks after my shopping and cleaning and gets some of my tablets ready. When my carer is not here I do not cope that well.*
- P6** *My wife does all the shopping, cleaning, and cooking. I've had three strokes, so I find it hard to help her. Respite come in and help sometimes.*
- P12** *My carer attends to all of my daily routine needs: scripts, shopping, paying bills, etc. We are pretty well organised with everything—you have to be. It's about getting into a routine that suits you and your medical condition and making the most of it.*

Four participants indicated that they can manage their daily routine with some assistance through support from family. Other options for support include church and work colleagues.

- P4** *Family support in various ways with meals, washing, transport, regular household cleaners. I find it hard to clean the house. At work, my colleagues assist in the office. My work is understanding and lets me manage my hours.*
- P10** *My partner and friend help with housework and cooking. Sometimes my friend will assist with lifts to the hospital. My church also is very supportive.*
- P11** *My family assists with my daily routine only when I need them; otherwise, I manage my own PD and I go to medical appointments by myself.*
- P13** *My wife does all the shopping, getting my tablets. I still do a lot of things, painting the house, and yard work. I was working full-time up until two months ago. I am in shock still, I think, trying to keep busy not to worry about it.*

From the 14 participants, three can manage their daily routine quite sufficiently with support from family members available if requested.

- P8** *I do everything myself like shopping, cleaning and cooking. I try to manage the best I can.*
- P9** *I manage most things like shopping. I take myself to appointments at the hospital.*
- P14** *I managed mostly on my own. My family are here to support me if I need them.*

In summary, 13 out of the 14 participants had strong family support compared with one participant who had indicated **no** family support whatsoever. Participants who have suffered major medical illnesses as well as coping with their renal failure are restricted by their medical conditions and need carers, family members, and professional staff to help manage their daily routine. Family support is crucial and quite strong for some participants. Assistance through either church or work colleagues was indicated. Three participants try to manage their daily routine independently with family support as an option.

The participants who indicated strong family support were less stressed and were able to cope better knowing that the family were available if requested. The participant with no family support indicated that distance and transport were the main issues for no family support. This participant is restricted by their renal dialysis treatment, other

ongoing medical conditions, being wheelchair bound and being quite young living in an aged-care nursing facility.

#### **4.4.4 Relationships with family**

The following findings establish how being on renal dialysis treatment affects relationships with family members. From participants’ responses about how being on renal dialysis treatment affects relationships with family members, three indicated that relationships were affected very much because of time spent away from their families while on dialysis treatment. Also, for participants who are sole responsible carers for their families, this means that they have to place responsibility on another family member while on dialysis treatment.

Time away from family members varies for each participant and depends on treatment modality. One participant stated that their relationship with family was affected quite a bit, mainly due to the time spent attending renal dialysis treatment. Three participants’ relationships were moderately affected and one participant’s relationship with family was slightly affected. Overall, six participants indicated that being on renal dialysis treatment does not affect relationships with family members. Table 4.6 describes participants’ responses on how being on renal dialysis treatment affects relationships with family members.

<b>Family:</b>	<b>No of Responses</b>
Not at all	6
Slightly	1
Moderately	3
Quite a bit	1
Very much	3
<b>TOTAL</b>	<b>14</b>

**Table 4.6 Participants describe how renal dialysis treatment affects relationships with family members.**

Narratives from participants describe how being on renal dialysis treatment affects relationships with family members. The following two participants describe trying to

be as organised as possible and having a good system in place regarding their renal dialysis treatment.

- P1 My family are good but usually I try to be organised. They are always there for me when I need them.*
- P3 We have a good system in place. We understand what the routine is with my dialysis treatment. My husband does a lot of support for me and when my children are in town they all help and support me.*

Another two participants indicated that relationships are affected because they do not get to see their family, which impacts on their social, emotional, and physical well-being. One of the participants indicated that their family does not fully understand the consequences and reality of renal dialysis treatment. Distance was another issue raised.

- P2 Because I tried to be there for my grandchildren and see them grow up. My children did not have any grandparents on my side of the family and I think it really means a lot to them if I'm there to watch the grandchildren grow up. I don't really rely on them as they don't live close to me. They visit me every now and then. I am really happy when they visit.*
- P5 Well because I don't see them very much, it's hard. I don't think they understand what has happened to me. I would like more contact with them but it's a long way to travel.*

This participant describes becoming more dependent on parents, which worries them as they are ageing.

- P4 I have become more dependent on my parents, which is difficult as they are ageing. My parents would go out of their way to help me.*

A further two participants indicated that when they receive renal dialysis treatment it gives their family the opportunity to relax and take a break.

**P6** *I go to dialysis and my wife finds this time to do things like relax. I do not have any children and my wife is my only family. My wife does everything for me; she is very organised and my only main support.*

**P12** *Being on dialysis gives me some space, but it also gives my family a break from me. Some days I might have a bad day after coming off dialysis with a lot of pain and I am not a happy person to be around. My wife, children, brothers, and sisters are great support for me. We all talk and support each other. Gives me the guts to go on.*

This participant indicated that time spent away from family members while receiving renal dialysis was a concern. Going from once being able to manage household chores and many physical activities around the house to a position of not being fully able to contribute or help around the house was demoralising.

**P7** *I would like to spend more time with my family. Being on dialysis takes the most of three days out of the week for me. My family come over and ask me what I need doing around the house and outside in the yard.*

This participant cares for a young son and describes not being able to take the son fishing as much as they would like.

**P8** *I spend a lot of my spare time with my son. I can't take my son fishing as much as I would like. My son understands what I have to go through and is supportive when I need things done.*

Five participants indicated that relationships with family are not affected while on renal treatment for a number of reasons. Participants mention that their boyfriend or partner is a great support and family members also are supportive. One participant mentions when on dialysis treatment they are restricted for that amount of time, which is difficult.

- P9** *Because I am independent, my relationship with my family is not affected. My boyfriend is really a great support.*
- P10** *Only with recreational things. A lot of love from my family. Sometimes they will ring me at the hospital and check if I'm okay. They are very supportive. My partner is always there for me.*
- P11** *In a sense of being with my family it has not affected our relationship. It's only been an adjustment for them. My family support is great. I get enough love from my family and that keeps me going strong.*
- P13** *I spend more time with my son and children, which helps me keep strong. I can get cranky at times after my dialysis. I feel a bit guilty because I ask my family to help sometimes when I know I can do something myself. When I start my dialysis I am restricted for that certain amount of time.*
- P14** *I have a partner here to help. When I need help my family and partner are here for me.*

In summary, most of the participants indicated that their families understand what they have to go through when they are having renal dialysis treatment, and are as supportive as they possible can be. Being on renal dialysis takes time away from their families three days per week for four to five hours, as well as travelling time to and from the renal unit which can take anywhere between 15 minutes to two hours depending on what transport is used.

#### **4.4.5 Relationships with friends**

These findings establish how being on renal dialysis treatment affects relationships with friends. From participants' responses about how being on renal dialysis treatment affects relationships with friends, one participant indicated relationships were affected very much, another participant stated that relationships with friends were affected quite a bit, while two participants indicated that relationships with friends were moderately affected. Overall, 10 participants indicated that being on renal dialysis does not at all affect their relationship with friends. Table 4.7 describes participants' responses to how being on renal dialysis treatment affects relationships with friends.

Affects relationships with friends	Number of responses
Not at All	10
Slightly	0
Moderately	2
Quite a bit	1
Very much	1
<b>TOTAL</b>	<b>14</b>

**Table 4.7 Participants' descriptions of how renal dialysis treatment affects relationships with friends.**

Participants' narratives describe how being on renal dialysis treatment affects relationships with their friends. The following narratives describe two participants expressing not being able to socialise and not being to socialise as freely.

*P1 I don't really socialise very much anymore, so being on dialysis does not affect my relationships with my friends.*

*P4 Can't socialise as freely as I could in the past.*

These two participants indicated they had no friends at the renal dialysis unit, but had a lot of friends when they were younger whom they have since lost touch with. One participant expressed having no friends at all.

*P2 I don't have any friends here. When I was younger, I had heaps of friends but I have not seen them for years.*

*P8 I don't have any friends.*

Two participants expressed that their friends more or less are not interested in them since commencing renal dialysis treatment.

*P5 I really thought my friends who I use to drink with would help me a bit, but they are not interested. They all disappeared when I got sick.*

*P10 They don't want to know me because I am sick.*

Two participants describe making friends while on dialysis and using this as support outlet for them.

**P6** *I've made new friends while on the dialysis machine. We support each other and that's good.*

**P14** *I have a lot of friends here at dialysis.*

One participant mentioned that they would not ask friends for help because they were independent and did not want to bother their friends. Another participant found support from their friends at church every Sunday.

**P3** *I have a lot of friends but they do not help me. I don't ask them for help.*

**P7** *My friends at church are not affected as my church day is Sunday and I do not attend dialysis on Sunday.*

Four participants indicated that support from friends is not affected while being on renal dialysis treatment.

**P9** *My life on dialysis does not affect my life with my friends.*

**P11** *My friends are very supportive with my PD and they understand.*

**P12** *My friends are good; they ring here and organise when they are coming to visit. Usually, when I am not on dialysis they visit.*

**P13** *I use to drink a lot with my friends now they just come around to see me. They know I have to watch my fluid intake.*

In summary, it is obvious for a couple of participants that life on dialysis does not affect relationships with their friends while another two participants indicated that they have friends situated within the renal dialysis units. Other participants expressed that they do not socialise as freely or like they use to due to dialysis treatment and being a little older in age. Some of the participants indicated that while their friends might not understand what's involved in their dialysis treatment their friends would support them if family members were not available.

#### 4.4.6 Satisfaction with family and friends' support

When asked if participants were satisfied with the support received from their family, 13 participants indicated that they were satisfied while one participant was not satisfied with family support. When asked if participants were satisfied with support received from their friends, six participants indicated they were satisfied while one participant was not satisfied. Seven participants did not respond to this question as they did not rely on friends to help or support them.

Table 4.8 describes how participants rated their support received from their family members and friends.

Family		Friends	
Support Level	No of Responses	Support Level	No of Responses
Excellent	6	Excellent	2
Very good	4	Very good	3
Good	2	Good	0
Fair	2	Fair	2
Poor	0	Poor	0
<b>TOTAL</b>	<b>14</b>	<b>TOTAL</b>	<b>7</b>

**Table 4.8 Participants rating family members' and friends' support.**

Narrative from the five participants who responded to the question if they were satisfied with support from their friends while on renal dialysis treatment follows. Participants have a range of support from their friends: being there for each other, support with cooking if the participant feels unwell after renal dialysis treatment, sharing of information, and helping a participant to get to their appointments.

- P6** *We try and be there for each other.*
- P9** *I have one friend who is really supportive.*
- P10** *Help with cooking meals for me sometimes. I don't feel like doing anything when I get home from dialysis.*
- P11** *I get support in a lot of ways one of my friends has the same health problem as me and we share a lot of information to help us both through things.*
- P12** *If my carer is not available my friends will take me to my appointments.*

#### **4.4.7 Support on dialysis treatment**

Participants were asked what support they got when **receiving** renal dialysis treatment. Again, responses were not mutually exclusive; participants could tick more than one support option. In summary, the most identified option was medical support chosen by seven participants, while four participants indicated self support with assistance from family members, organisation support, and partner support. Only three participants preferred to handle their renal dialysis treatment independently. This means that a majority of the participants do not self manage their renal dialysis treatment independently and rely mainly on medical staff, family members, and partners for support while receiving renal dialysis treatment. Table 4.9 below summarises the information collected from participants in relation to support when **receiving** renal dialysis treatment.

No	S	P	Fa	Fr	C	M	O	No	S	P	Fa	Fr	C	M	O
1						3		8						3	
2						3		9	3						
3						3		10	3					3	
4	3		3				3	11	3		3				
5						3		12	3						
6						3		13	3	3					
7						3		14	3						

**Table 4.9 Respondents' support options.**

#### Key for Table 4.9

Participants represented 1–14  
S= self support  
P= partner/wife/husband support  
Fa= family support  
Fr = friends support  
C= Carer support  
M= medical team support  
O= organisation support

#### **4.4.8 Satisfaction with medical support**

When asked if participants were satisfied with support received from medical support, 13 participants indicated that they were satisfied with medical support while one participant was not satisfied. Table 4.10 describes how participants rated their medical support.

<b>Support rating</b>	<b>Number of responses</b>
Excellent	2
Very good	7
Good	4
Fair	1
Poor	0
<b>Total</b>	<b>14</b>

**Table 4.10 Participants rating of medical support**

Participants' narratives further describe their medical support. Overall, a majority 12 participants were very positive towards medical support received from their renal units. One of the 12 participants expressed that the Indigenous liaison officer based at their hospital did not have any contact with any of the Indigenous renal patients.

- P1** *The medical team are very good. I have moved out to another hospital so I will be seeing another kidney doctor and starting out all over again.*
- P2** *The team are good.*
- P3** *Because they look after me good.*
- P4** *PD unit staff always available.*
- P5** *The doctors and nurses are good. They tell me things but I don't understand what the hell they are saying.*
- P6** *The doctors and nurses are good but the liaison officers at the hospitals do not have the time of day for us.*
- P7** *Both at the hospital and down at my local community health service the medical support is very efficient.*
- P8** *The medical team is good. The system could improve by taking more than two patients at any one time when we go on to dialysis.*
- P11** *My medical support is very good down here. I have been to a couple of hospitals up North and they do not compare with the standard down here.*
- P12** *The medical team are very good to me. They assist me when I need things done. Otherwise, I stick to myself and do my own dialysis at the hospital.*
- P13** *The nurses mainly have helped me get over some very rough patches by telling me exactly what is going on with my dialysis and medical condition. The little things are important to me. The more knowledge or information I have on my condition I am more relaxed and that really helps with my surrounding environment.*
- P14** *The team is very good to me. I get on better with the nurses than the doctors.*

Two participants indicated that renal dialysis is uncomfortable due to two nurses being inconsistent with greeting, attitudes, and lack cultural understanding. Both of these participants attend the same renal unit.

- P9** *Only two nurses at the unit who are set in their ways make dialysis treatment uncomfortable.*
- P10** *Sometimes the RNs greet you, sometimes they don't. Attitudes are not good. RNs lack cultural understanding. It's a shame that there are no Indigenous RNs at the unit.*

In summary, a large majority of participants mentioned medical support, which included renal health care, staff was good, very efficient, and readily available. One

participant mentioned that the standard of care down here in Brisbane is high compared to two previous hospitals visited in North Queensland. One participant mentioned that the local Indigenous liaison officers do not have any time for the Indigenous renal patients. A system of increasing the number of renal patients going on to renal dialysis at nominated times was mentioned, but this would depend on the number of renal staff on shift and any unforeseen environmental factors (e.g. transport being late or any complications).

## 4.5 Transport

This component solely focuses on transport needs and the distance participants have to travel to and from their renal dialysis treatment. Two participants live less than five kilometres away from their renal unit while 10 participants live between 6–15 kilometres away from their renal unit. One participant lived between 16–30 kilometres away from their renal unit and one participant lived between 31–45 kilometres away from their renal unit. No participants indicated that they lived more than 45 kilometres away from their renal unit. Table 4.11 displays the distance participants live from their renal dialysis unit.

Distance (km)	No of people
<5 km	2
Between 6–15 km	10
From 16–30 km	1
From 31–45 km	1
>45 km	0

**Table 4.11 Distance participants live from their renal dialysis unit.**

### 4.5.1 Transport costs to and from renal dialysis treatment

Participants travel to their renal dialysis treatment in a number of ways including a community transport service and public and private transport. Seven of the 14 participants use the Lands Community Service for transport, which costs approximately between \$4–10 per trip. The overall fare is determined by the distance

travelled; therefore, if you live between 31–45 kilometres away, you would be paying \$10 per trip, which adds up \$60 per week (\$120 per fortnight). These costs add more financial strain on participants. Five participants attend renal dialysis treatment by public transport, which includes bus, train, and taxi services. Two participants attend renal dialysis treatment in their own vehicle.

Transport costs are in addition to participants’ ongoing weekly expenses. As discussed in 4.2.3, the amount of money used by the participants on all types of transport is quite substantial. Table 4.12 displays the amount of money participants spend on weekly transport costs.

Amount	No of people
Less than \$20	6
Between \$20–\$40	6
Between \$40–\$60	2

**Table 4.12 Participants' transport costs.**

Narratives from six participants on transportation follow.

These two participants use the Lands Community Service and are happy overall with the service although waiting times after dialysis are a concern.

**P3** *I use the community lands service. They provide a good service. Sometimes I have to wait around but overall it’s good.*

**P4** *As I rely on public transport, sometimes I have to wait around at the hospital. It’s not good when I might be feeling a bit under the weather.*

This participant uses public transport a majority of the time and at other times are transported by friends.

**P10** *Transport with friends sometimes; catch a train most of the time.*

This participant walks to and from the train station, which takes about 20–30 minutes, catches a train to and from the renal unit, and on days when it's raining or cold the participant will not attend their dialysis treatment.

**P14** *I walk to and from the station, catch a train to and from the hospital and return home again. It's all very tiring. In winter it is hard to get motivated because it is freezing.*

This participant completes their renal dialysis at home and requires transport via a taxi service when attending appointments.

**P11** *I complete PD at home and when I need to go to my appointments I catch a taxi as my knees are not good.*

This participant attends their dialysis treatment via a community transport service. However, when attending appointments, the distance to travel is much greater and the participant has to find their own means of transport.

**P12** *A local service takes me to my dialysis treatment and to my local appointments. When I have to go to the renal unit to see my kidney specialist I have to find my own way. One time I was really stuck and for whatever reason my name was not on the transport list to return home and I had to ring my brother to come and pick me up. Blackfella was sitting around all day and evening waiting. I got home at 8pm and felt like crap.*

#### **4.5.2 Improving transport**

Participants were asked if they had any suggestions that could help improve any of their transport issues. Seven participants did not have any suggestions that could help improve any of their transport issues. Suggestions relate to parking problems at the renal units, transport services being more efficient, parking permits, a courtesy bus provided by AICHS, or taxi vouchers. If renal dialysis patients have vehicles of their own, parking permits are issued to them to help with the ongoing parking situation at renal units. Narratives from the other seven participants follow:

- P1 The service is very good. Always on time and makes a difference when you want to start early and finish early you don't have to wait around the hospital. You could be at home relaxing or doing whatever.*
- P4 More parking at the renal hospital I attend. I think it's an internal problem.*
- P6 Only with the timing as I get up really early. Maybe they could try and come a bit earlier.*
- P7 Dialysis patients should be given first priority. We are always late because the transport is always late which impacts on us and the time we get off the machines. We get a scenic tour with six to eight patients in the transport and it takes time to pick us all up and drop us at home.*
- P10 Taxi vouchers or a courtesy bus would be great.*
- P12 If I pay a donation towards transport costs to include other areas like where I attend my specialist appointments. I am left to get there on my own and sometimes it's hard to find transport that will take you. I would catch public transport with my wife to assist me but I have serious back problems.*
- P13 Before the renal unit organised a parking permit I was paying \$11.50 per visit to the renal unit. This added up for me as I was not going financially well.*

#### **4.6 Health and renal health well-being**

The finding in this section presents how participants view their general health. It will also establish each participant's history and family history of renal health problems. This section will also determine the duration participants have had renal health problems, how long each participant has been on renal dialysis treatment, and which treatment they currently receive. If participants have received both continuous ambulatory peritoneal dialysis and haemodialysis treatment, they were asked why they transferred from one to the other and if they are happy being on that type of treatment.

Participants were given the opportunity to explain in their own words what they understood about their renal health situation, and where and who they had received information from regarding their renal health. This section will establish if

participants have ever missed dialysis treatment, and how participants feel about kidney transplantation.

#### **4.6.1 Description of health**

In this first component, participants were asked to describe their health. One described their health as excellent, two described their health as very good, six described their health as good, two described their health as fair, and three participants described their health as poor. From the information obtained, it is clear that a majority, 11 participants, described their health from good to fair to poor. The single group with the highest number of responses was good with six responses. Table 4.13 describes how participants describe their health.

<b>Health Description</b>	<b>No of Responses</b>
Excellent	1
Very good	2
Good	6
Fair	2
Poor	3
<b>TOTAL</b>	<b>14</b>

**Table 4.13 Participants' view of own health.**

#### **4.6.2 Family history of renal health problems**

Participants were asked to describe whether any of their family had a history of renal health problems. Six participants indicated a family history of renal health problems while eight indicated no family history of renal health problems. Of those six participants who indicated a family history of renal health problems, five identified a history within the female side of the family through either a sister or mother.

#### **4.6.3 Individual renal health problems**

When participants were asked how long they have experienced kidney problems, the responses varied. The shortest time was less than six months; the longest time was over 25 years. One participant indicated renal health problems for less than six

months while another two participants indicated between 7–12 months. Seven participants indicated renal health problems between one to five years while three indicated renal health problems between 6–10 years. One participant indicated renal health problems greater than 10 years. The group between one to five years registered the most participants with a total of seven. Table 4.14 displays the duration each participant has had renal health problems.

<b>Duration of renal problems (months/years)</b>	<b>No.</b>
0–6 months	1
7–12 months	2
1–5 years	7
6–10 years	3
>10 years	1
<b>TOTAL</b>	<b>14</b>

**Table 4.14 Duration that participants have had renal health problems.**

#### **4.6.4 Duration of renal dialysis treatment**

For this component, participants were asked how long they have been receiving renal dialysis treatment. Again, responses varied with the shortest time being less than six months; the longest time being 6–10 years. One participant indicated that they had recently commenced renal dialysis treatment within the last six months while two participants had been on renal dialysis treatment between 7–12 months. Seven participants indicated they had been on renal dialysis treatment between one to five years while four indicated renal dialysis treatment between 6–10 years. The group between one to five years registered the most participants with a total of seven. Table 4.15 displays the duration of time each participant has been receiving renal dialysis treatment.

<b>Duration on renal treatment (months/years)</b>	<b>No.</b>
0–6 months	1
7–12 months	2
1–5 years	7
6–10 years	4
>10 years	0
<b>TOTAL</b>	<b>14</b>

**Table 4.15 Duration that participants have been on renal dialysis treatment.**

In summary, six of the 14 participants, once diagnosed with renal health problems, commenced renal dialysis treatment immediately. Three participants indicated suffering renal health problems for more than 11 years. Of those three, one of the participants indicated having had renal health problems for 28 years and only commencing dialysis treatment in the last year. Another participant indicated having had renal health problems for 14 years and having been on dialysis treatment for eight years. Another participant indicated having renal problems for 15 years and commencing dialysis treatment within the last year.

Five participants indicated a range of different time frames of having renal health problems compared to commencing renal dialysis treatment. Of those five, two participants indicated a similar period of 10 years with renal health problems; one of those participants indicated that they have been on dialysis treatment for six years and the other on dialysis treatment for six months. From the remaining three participants, one indicated renal health problems for eight years with seven years on dialysis treatment while another one has had renal health problems for four years with three years on dialysis treatment. The last participant in this group has had renal health problems for over a year and has commenced dialysis treatment in the last four months. Three participants indicated that they had been on renal dialysis treatment less than one year compared to seven participants who have been on renal dialysis treatment between two to five years and four participants who have been on renal dialysis treatment from 6–10 years.

#### **4.6.5 Selection of renal dialysis treatment**

Participants indicated they had received different renal dialysis treatment during their experience with end-stage renal disease. From 14 participants, seven indicated both continuous ambulatory peritoneal dialysis and haemodialysis treatments were received in the past; another seven indicated only haemodialysis treatment received in the past. When participants were asked what treatment they currently receive now, three indicated being on CAPD only, and the remaining 11 were currently receiving haemodialysis. Four participants who had tried continuous ambulatory peritoneal dialysis initially before switching over to haemodialysis described that being on CAPD did not suit them for a number of reasons. One described their constantly being sick, another two described having a number of bad infections, and one described that CAPD did not suit their responsibilities at home (e.g. looking after grandchildren). Narratives from the four participants who indicated they tried CAPD but changed over to haemodialysis treatment follow:

- P1 I was on CAPD with the machine at night and that did not suit me. I got sick all the time. After I switched to HD and I feel that treatment is better for me.*
- P3 On CAPD I had a few bad infections. One infection I swallowed a fish bone and had a lower bowel infection because of the fish bone.*
- P7 I was on CAPD but the doctors took me off that. It really didn't suit me. At the time, I was looking after four grandchildren and still trying to complete CAPD on top of that.*
- P8 CAPD did not work for me, caused constipation and endless peritoneal infections. When I was back home, if I got really sick I had to travel to the main renal unit which was 900 kilometres away by bus. I felt every bump in the road.*

Three participants indicated they commenced haemodialysis treatment initially, one participant experienced a problem with their CAPD catheter, while two participants commenced haemodialysis until taught how to complete continuous ambulatory peritoneal dialysis. Narratives from the three participants follow:

- P4** *Went on HD when PD catheter became dislodged from preferred placement. Now back on CAPD.*
- P11** *When I first became sick I was on HD to treat me immediately but when I was taught how complete the CAPD procedure that suited me.*
- P13** *When I was in hospital I had the dialysis in my neck and have had so many operations. I have had all the tests done you can imagine. I am on CAPD now but have the other HD ready in case. I am thinking about a transplant. My wife and me are going to another hospital in the next couple of weeks to talk to someone and get information and watch a video on transplants.*

Three participants indicated that pre-existing medical conditions, strokes, and heart failure influence their choice of renal dialysis treatment. These options are discussed in detail with appropriate health staff, each participant, and their family members. Narratives from three participants on haemodialysis who have existing medical conditions follow:

- P2** *I have only had HD treatment. CAPD would not have suited me with my current health situation. I've had a stroke.*
- P6** *I've only been on HD because of my heart condition.*
- P9** *I have only been on HD since my kidney failure.*

Four participants indicate a number of reasons as to why they receive HD treatment. Their narratives follow:

- P10** *Only been on HD since I first got sick.*
- P5** *Because I've only been on HD. I am too sick to be trying the other one. My body is really struggling.*
- P12** *I only have been on the HD since my dialysis started seven years ago. I had two options and decided on this dialysis treatment as it suited me better.*
- P14** *I have only been on HD. The other dialysis would not suit me.*

In summary, seven participants indicated they had received haemodialysis treatment only because of their other associated health problems. The other seven participants received both forms of treatment haemodialysis and continuous ambulatory peritoneal dialysis. Of those seven, a number of reasons were given as to why they changed from

one to the other. Four participants who were on CAPD gave a number of reasons as to why they changed over to HD. These include constantly being ill, infections with peritoneal dialysis catheter, problems with peritoneal dialysis catheter that lead to infections, home environment and child responsibility, constipation, endless peritoneal infections, and that peritoneal dialysis treatment did not suit them. Three participants indicated that they started on haemodialysis until they were well enough and were able to be trained to manage their CAPD at home. Currently, three participants receive CAPD treatment and 11 participants receive HD treatment.

#### ***4.6.6 Happy with current renal dialysis treatment***

Participants were asked if they were happy with their type of kidney dialysis treatment. A majority (13) of the participants indicated that they were happy with their treatment while one participant was not happy with their treatment. Participants were asked to describe why they were happy or unhappy with their type of treatment. Participants describe a number of reasons as to why they are happy with their dialysis treatment either on CAPD or HD. On haemodialysis, 10 participants described feeling good, feeling a lot better, feeling 100%, having more time to themselves, and enjoying their freedom. Narratives from those 10 participants who were happy with their HD type of treatment follow:

- P1** *I just feel a lot better.*
- P3** *CAPD did not suit me. I am happy on HD. After dialysis treatment, I get up from the chair and I feel really good.*
- P5** *At the beginning I was very shocked about all this stuff (dialysis treatment) and the needles and the pain. But I need to be on this treatment for the rest of my life. It's keeping me alive.*
- P6** *This treatment keeps me going so I have to be happy.*
- P7** *HD is much easier for me and as well I feel that HD is a better treatment option for me. I do get more time to myself.*
- P8** *I find it better treatment for me but everyone is different, hey. That will do me.*
- P9** *HD makes me feel 100% better. You also get a two-day break.*
- P10** *I have never tried PD. I know you have to be careful with all the infections on PD.*
- P12** *On HD, because I put myself on, I can see if anything goes wrong. I can also blame myself. I can also check my own needles. I have control over my dialysis which is very good for me.*
- P14** *I feel good on this one, until I get a transplant.*

Participants on continuous ambulatory peritoneal dialysis describe freedom aspects, not going near or to hospitals three days per week, not sitting on a machine, and not liking the sight of blood pumping through the machines. Narratives from three participants who are happy with their CAPD type of treatment follow:

- P4** *My freedom fits better with an independent lifestyle.*
- P11** *CAPD really suits me because as I do not have to be near the hospital and I do not like the sight of my blood pumping through the HD machines.*
- P13** *Going into the hospital three days per week and sitting on a machine would drive me crazy. I prefer CAPD as it gives me some freedom.*

One participant indicated that they were not happy on their haemodialysis treatment. The participant was not happy about sitting in a recliner to receive their treatment—cramps occur often with kidney dialysis treatment. This participant would rather receive their treatment lying down on a bed than on a recliner.

**P2** *I like to sit on my good side. Because all I do is sit on my arse. I would like to move positions a bit while I'm on HD. I get cramps in the reclining chairs and I would rather lie on the bed than sit in the chair. There is only one bed and a rather big man gets first preference. I've been asking the staff all the time over and over if I can get on the bed. But nothing is done. This bloke who is a 'migloo' (very big fat fella) he's on the bed all the time. My head aches while I'm on the recliner chair.*

#### **4.6.7 Understanding of own renal health**

Participants were asked what they understood of their kidney health situation and how they became unwell with their kidney condition. One participant fully understood exactly what had happened to their kidney health. The following narrative describes what the participant understood about their kidney health:

**P4** *IgA nephropathy following a post streptococcal glomerulonephritis contact at the EKKA [the Royal Brisbane Show] when I was 15. This lead to progressive scarring of my kidneys resulting eventually to ESRF.*

Ten participants described other medical conditions as a possible cause to their kidney failure. These conditions include diabetes or sugar, high blood pressure or hypertension, kidney stones, leaky kidneys, and kidney infections. Two of nine participants described not drinking enough water as another possible cause to their kidney failure. One of the participants described that pregnancy caused their kidney failure to occur.

- P2** *It's like I have kidney failure which has lead to this. I wasn't probably drinking enough water. Diabetes is a killer disease and it's all connected to each other.*
- P6** *Over the years, I've had leaky kidneys which is not good. My sugar made things worse and now I have no kidney function at all.*
- P7** *When I had my first child I had bad kidneys and after that I did not receive any advice about my kidney health situation. My local doctor picked up that I my kidneys were not functioning properly and I had kidney failure not so long after that. My blood pressure also is a problem.*
- P8** *When I was living in the bush working in the railways, I did not have any water plus I suffer from high blood pressure and diabetes. All this has to do with my kidney health now.*
- P9** *My kidney problem started from a kidney infection and they do not work.*
- P11** *I think my kidneys were not working for a long time before they decided to pack it in. I did not have the knowledge to maintain my diabetes and I did not even know I had diabetes. If I would have been educated better about my sugar, I would have been right. My sugar levels are very well controlled.*
- P12** *I am on dialysis because I had hypertension for a very long time and that in the end affected my kidneys. My kidneys have shrunk the doctors told me.*
- P13** *A long time ago the doctor told me I had an infection in one of my kidneys and it spread to the other one. Now my kidneys are stuffed. Why couldn't they treat it before it spread?*
- P14** *How I understand my kidney problem is that I had two large kidney stones that damaged my kidneys. When I finally got medical help I was in kidney failure and I more or less started treatment after a couple of operations.*

Four participants indicated that they do not understand what happened to their kidney health. From participants' responses, it is clear that while information was explained to one of participants, this participant was in shock still while another was feeling sick and had evidence of blood in the urine. One participant indicated that they did not know the in-depth information relevant to their condition and they are still in the learning process while another participant indicated that an infection in one kidney had spread to the other kidney. Narratives from the four participants follow:

- P1** *I can't describe properly what has happened to my kidneys. The doctors told me but I am not sure about what they said. I go to the toilet at night time a lot. I think I have some of my kidney working.*
- P3** *I know and understand a little about my kidney health. It's all been explained to me but at the time it was all a major shock.*
- P5** *I was feeling sick, my urine had blood in it, and my kidneys do not work.*
- P10** *I only know the surface. I do not know the in-depth stuff about dialysis and my kidney health. I go by a lot what the RNs tell me. I am still learning I suppose.*

In summary, a majority of the participants indicated that they knew the basic information about why their kidneys stopped functioning. Nine participants indicated that other medical conditions as an underlying cause to their kidney failure.

Participants rated their knowledge on their kidney health, as outlined below in Table 4.16. Two participants rated their knowledge as excellent, four participants as very good, two participants as good, three participants as fair, and three participants as poor.

Response	No of responses
Excellent	2
Very good	7
Good	2
Fair	3
Poor	3

**Table 4.16** Participants rate their kidney health knowledge.

#### **4.6.8 Where renal health knowledge is obtained**

Participants indicated that they had received knowledge about their kidney health from a range of health professionals including registered nurses, renal physicians, general practitioners, diabetes educators, and a dietician. A majority, 12 participants, indicated that registered nurses had been proactively involved in helping them gain knowledge on their kidney health. Other participants in the study indicated that

reading booklets on kidney health, and other resources such as the Internet, helped them gain knowledge. From the study, nine participants indicated that they would like to learn more about their renal health while the remaining five participants indicated that they would not like to learn any more about their kidney health.

Following are nine participants' narratives describing different ideas about receiving more kidney health knowledge, receiving information about nutritional advice and how different foods affect their kidneys, receiving consistent individual health information updates, and receiving information that is easy to read and understand for individuals and family members:

- P1** *The doctors and nurses have told me about my kidney health. I sometimes forget and maybe a little sheet with some basic information on my kidney health might help me.*
- P3** *I think something to describe my kidney health situation would be useful.*
- P4** *I have reached a stage in my renal health where I realise I have a life shortening illness. I want to find out prognostic options and make lifestyle adjustments to maximise my outcomes.*
- P6** *Maybe about the different foods and how they affect my kidney.*
- P7** *I know with all the information available and the easy to read material each patient should be given their own his/her kidney health information sheet. For privacy reasons no names have to be on the sheet and update when appropriate.*
- P9** *An easy to read and easy to understand booklet.*
- P10** *I would like to learn more about my diet and generally about my own kidney health. My blood tests and results and what they mean.*
- P12** *A bit more knowledge would not go astray.*
- P13** *I am not real comfortable with what I know so more information would be good for me and my family to understand.*

Five participants described different situations where they know enough information or are happy with their level of information about their kidney health. If they want to know anything, they ask a registered nurse. One of the five participants indicated that they are not interested in knowing any more information in relation to their kidney health.

- P2** *I think I know all that I need to—to get me through anyway. If I want to know anything, I just ask the nurse and she gives me the answer.*
- P5** *All I know is that my kidneys do not work and I do not want to learn about my kidneys.*
- P8** *No. I am not interested; besides, it's too late now.*
- P11** *I am happy with my level of information that I know on my kidney health. If you look in the dialysis community, the people who have a very good/good understanding of their kidney health are coping far better and have control of their kidney health than those who do not know much about their kidney health.*
- P14** *I know all about my kidney health.*

Participants were asked if they had ever missed renal dialysis treatment. Two participants had mentioned they had missed renal dialysis treatment. One was in the early stages of beginning continuous ambulatory peritoneal dialysis; they had overslept and forgot to complete their CAPD exchange. This situation has not occurred again. The other participant sometimes forgets to complete their CAPD exchange. Narrative from the two participants:

- P13** *I have never missed my CAPD; only in the first week when I fell asleep after dinner and slept through until the next morning. I did not change the bag before I went to sleep.*
- P4** *Yes, I am quite forgetful.*

Nine participants' narratives on why they have never missed their kidney dialysis treatment follow:

- P1** *I am too scared, I suppose. I don't want to get sick and die. The nurses told me if I miss it the treatment I would get really sick.*
- P3** *I do not want to get sick. It's important to go to dialysis treatment and I have never missed treatment.*
- P6** *Never will miss treatment.*
- P7** *I don't miss dialysis treatment but we are always late. Luckily the nurses know we are late and save our spots for us.*
- P8** *Every day I know what I have to do in my life and where I have to be.*
- P9** *It's important to do your dialysis otherwise you get very sick.*
- P11** *Never miss my CAPD treatment; only sometimes I am late because of other people running late in which case I get excess fluid and that affects me.*
- P12** *I am not game.*
- P14** *It's important for me to go to dialysis.*

In one participant's case, if they miss their treatment, the local renal unit will send the local police around to check if participants are okay. This particular participant indicated that they did not want to police around at their house.

- P10** *It's important to go to dialysis. I do not want to die. Even if you don't go to dialysis the unit will send the police around to check. I do not want the police around here.*

For two participants, the ambulance collects them for their dialysis treatment; therefore, missing dialysis is not an option. One of the participants indicated that they are too sick to miss their treatment.

- P2** *I always go and I have not missed my dialysis treatment. The ambulance picks me up.*
- P5** *Well, it's hard because the ambulance arrives so I cannot skip it. I am too sick to miss any treatment.*

In summary, from all of the participants' responses, it is clear that they have indicated the importance of attending their renal dialysis treatment and they have never missed their treatment. Sometimes participants might be late for continuous ambulatory peritoneal dialysis or haemodialysis treatment, but usually they would catch up when convenient for them. For the participants who indicated they were sometimes late, the

reason that they gave for their lateness was attending appointments at their hospitals and endless waiting times. The other reason was the ambulance being late in pick-ups, which affects the time that participant has to go on the machine subsequently affecting the time they get off the machine.

#### **4.6.9 Kidney transplants**

In this section, participants were asked to describe how they felt about kidney transplants. Three participants indicated that other medical conditions influenced their not receiving a kidney transplant. The following narratives describe participants' responses about kidney transplants:

- P1** *I would not mind having one, but I don't know. The doctors have discussed it with me but I have had two heart attacks since the discussion so my chances are zero, I'd say.*
- P6** *I've already been told I cannot have one because of my heart condition.*
- P11** *I tried for a kidney transplant but my health is not good. I had some tests done but failed. I gave up that idea.*

Four participants were either too scared or nervous to have a kidney transplant. One particular participant's fear of having a kidney transplant increased because family members had received transplants and did not survive. The opportunity arose for one of the participants but they felt that they were not ready to have a transplant.

- P3** *Not good. My two sisters both had transplants and both have died. I am scared of having a transplant.*
- P8** *I don't want one. A lot of my friends have had transplants and did not survive.*
- P9** *Nervous. I am on the transplant list and did have the opportunity to have a transplant but knocked it back. I felt I was not ready to have a transplant, but now I am more mature and ready.*
- P10** *I am scared. Scared about rejection, and going back on dialysis if the transplant does not work. Will my body accept the new kidney?*

Four participants were positive towards receiving a kidney transplant. One of the participants already had received bilateral corneal transplants; therefore, looked forward to receiving a kidney transplant.

- P4** *I have already had bilateral corneal transplants. I am fairly amenable to the kidney transplant. I expect it to be challenging at first but having seen some friends after transplant, I look forward to a good result.*
- P2** *I feel that I have a good reason to have one and I would be happy. My daughter will donate one of her kidneys to me.*
- P12** *I am all for kidney transplants. I am on the waiting list and my brother will donate one of his kidneys.*
- P14** *I am on the list to have a transplant. I also feel very positive about a kidney transplant.*

One participant indicated that transplant information had been explained but that they did not fully understand the information. Another participant indicated that their kidney specialist had never had a conversation about the transplant process while another participant indicated that they were in the process of obtaining further information in relation to transplants. The following narratives describe their responses:

- P5** *The doctors and nurses explained about kidney transplants but I don't understand them or what they are trying to say.*
- P7** *I have never given any thought to transplants. My kidney doctor has never had a proper conversation with me. I am too old anyway.*
- P13** *At this stage we are finding out more information on transplants.*

In summary, participants had mixed feelings about renal transplants. Three participants indicated other associated risk factors and poor health (e.g. heart problems and strokes) as the main barrier to their receiving a kidney transplant, while three participants indicated that they were scared or nervous about the whole concept of renal transplants. This was evident in two of the participants' responses who indicated that they had family or friends receive a renal transplant but did not survive. Other responses were to do with not fully understanding the process towards getting a kidney transplant and with being too old. Four participants felt positive towards

receiving a kidney transplant or the possibility of a family member donating a kidney was discussed. One of those participants indicated they were already on the transplant list. Discussions with their doctors, nurses, and family members were mentioned.

#### **4.7 Other medical conditions**

This section presents information on whether participants have other medical conditions. All of the participants in this study have renal failure requiring dialysis treatment. Twelve participants indicated that they have other medical conditions, while two participants indicated that they do not have any other medical conditions. Of those 12 participants who indicated other medical conditions, a combination of the following medical conditions were present.

- type 2 diabetes
- high blood pressure
- cardiovascular disease
- respiratory disease
- mental health

Eight participants indicated that they have type 2 diabetes, while six indicated that they have high blood pressure. Five participants indicated they have cardiovascular disease, while another five indicated they have respiratory disease. One participant indicated a mental health condition. From 12, 11 participants in the study have at least two to four other medical conditions associated with their renal failure.

##### **4.7.1 Medication compliance**

Participants in the study have other medical conditions together with renal failure and need to consume a range of different medications daily in order to control their medical conditions. Seven participants indicated that they have gone without medication for a number of reasons. Their narratives describe their view on medication compliance:

- P1** *When I was younger, I thought I could go without them. I was strong but it all caught up with me. It's hard because sometimes I cannot get my scripts filled if I run out and I have to wait for the doctor at the hospital to write the prescription. Some of my tablets I am on, my doctor at AICHS cannot write; they are only issued through the hospital pharmacy.*
- P2** *At the nursing home, all my tablets are organised for me. Sometimes I might miss one or two tablets because I think they are not doing what they are suppose to do.*
- P4** *Sometimes I just get fed up with the whole routine.*
- P5** *Sometimes I forget to fill my scripts at the hospital and at times I have no money to buy them so I go without.*
- P6** *I have forgot at times to fill the scripts. And the cost. I've felt sick so I missed taking them.*
- P10** *Cost of the medication. When I get scripts some are available through the hospital system and some are available through my GP. Inconvenient at times as I have to make appointments around my dialysis, attend appointments sit and wait. Get the script filled. Takes between one to two hours. The hospital system could be improved by getting your scripts filled while on the machine or leave and collect the following time you attend dialysis.*
- P11** *Only on a couple of occasions, I have gone without my medication mainly because I did not have the money. I am ahead on my scripts and I do not miss them now as they help me feel better. I get my scripts either through the hospital or AICHS.*

Seven participants indicated that they have never gone without their medication. Of those seven, two participants indicated that medications are provided by a local pharmacy or nursing centre in weekly medication packs; therefore, medication is organised for them. This service is paid for by each participant individually. Narratives from the seven participants who have never gone without their medication follow:

- P3 I never go without tablets because the pharmacy provides them.*
- P7 I really try my best not to. If I can see that my medication is running low, I go and get a script at my local doctor and get my medication.*
- P8 Although my tablets are in this container and it's all over the place, I know when they are running out.*
- P9 I know how important it is to take my medication.*
- P12 Very seldom. All of my tables are organised for me, usually with the help of my wife who is my carer. I know through experience that it is important to your health to take your tablets.*
- P13 My tablets are organised through the local chemist so I do not miss them.*
- P14 I have never gone without my tablets. My tablets help keep everything under control, which makes me happy.*

In summary, participants consume a number of medications to control their medical conditions. Seven participants indicated a number of reasons that they have gone without their medications. The most common reasons were the cost of the medications, sometimes forgetting to take their medication, being too sick to go out and get them, being fed up with the whole routine of end-stage renal disease, and the availability of the scripts and a doctor who can prescribe them. Seven participants who indicated that they have never gone without their medications try to organise their medication by themselves, or their partner helps organise their medication. Also, medications are organised through the local pharmacy and nursing home, which helps participants take medications daily and routinely.

#### **4.8 Health service utilisation**

This section establishes if participants used health services and the frequency in which they attended their related health appointments. Participants in the study accessed a range of government health services, community controlled health services, and privately funded health services. Participants were asked how often they saw their local GP in the past 12 months. All of the participants accessed their local GP a

number of times, depending on their health needs. If participants were unwell, they accessed their GP more frequently or until they were better. Three participants saw their GP weekly, two saw their GP fortnightly, and three saw their GP monthly. The remaining participants indicated that they had seen their GP bimonthly and trimonthly.

Participants were asked how often in the past 12 months they saw their renal specialist. All of the participants indicated either monthly, bimonthly, or trimonthly visits to their kidney specialist. If participants were unwell, the frequency of visits to the kidney specialist would increase.

Participants were asked if other health professionals were consulted in the past 12 months. Participants indicated that they have consulted the following: an endocrinologist, a diabetes educator, social workers, welfare workers, a nutritionist, an optometrist, a physiotherapist, and health workers. The participants consulted the above professionals at outpatients' clinics within government health services and community controlled health services. One of the participants also consulted a naturopath. The naturopath was consulted at a private clinic.

Family members accompanied participants when they attended their appointments, or they attended appointments by themselves. Six participants indicated that they had problems attending their medical appointments, while eight did not have any problems attending their appointments. Problems experienced vary from transport issues, limited parking, waiting time at appointments, and not feeling well enough to attend appointments. If participants missed their appointment, they would have to wait until the next available appointment, which in some cases could be weeks away.

#### **4.9 Towards better management of end-stage renal disease**

Finally, participants were asked if they could think of any extra help or support to make it easier for them to manage their kidney health. Two participants considered

home assistance, better organised medications, and carer ‘burnout’ as factors towards better management of end-stage renal disease. The nominated carer receives a carer’s pension from Centrelink. If they want to go on a holiday or a break, other family members are asked to help. If no help is forthcoming, the participant has to fend for themselves. A family member mentioned that the nominated carer gets paid to do a job; therefore, it is their responsibility to see that the participant is cared for at all times. Narratives from two participants follow:

**P1** *I know my daughter gets burnt out, so maybe another family member to help me while she has a break. Also maybe a better system to sort my tablets out. Getting around the house and having better access to things. Home assistance to help when my daughter needs a break. I think she gets burnt out.*

This participant suggested better care and better organised medications.

**P5** *I need better care from my carer. I know one day I might need to go into a nursing home. Tablets are all over the place. It’s a mess.*

Increasing strength and mobility by attending a physiotherapist was suggested by this participant.

**P2** *My life is pretty boring; I need some help with getting my muscles strong again. I use to get this with the physio they have here, but have not had any physio for a long time. I wish they could make a tablet to get rid of the phosphate, and being tied to the machine is one of the most boring things around.*

Assistance with exercising and removal of empty PD boxes was suggested for this participant.

**P4** *Assistance with exercising and removal of PD boxes.*

This participant suggested some activities within the renal unit when people are receiving their dialysis treatment.

*P3 Some activities would be good and it might liven the place up.*

This participant suggested two ambitions. One is to become a pastor and the other to work in the area of youth with drug problems.

*P6 My ambition is to become a pastor and work with youth who have drug problems. Maybe to help people achieve goals they set.*

This elderly participant suggested moving into a low-set house; currently, walking up and down the stairs is an issue. This participant has made all of the necessary applications with support letters from their local GP and renal specialist.

*P7 In the future, I'd like to move to a low-set house. The stairs are getting harder for me.*

This participant indicated that because of all the different medications, sometimes the medication doses vary depending on fluid levels, chemistry, and blood pressure levels. Taking different doses is confusing at times. A couple of options were mentioned by the participant to improve the situation. Options include a dosette box or Webster packs. A Webster pack contains weekly doses of medication specific to each participant. These can be organised through a hospital pharmacy or a local pharmacy. This participant also suggested more contact with the Aboriginal and Torres Strait Island liaison officers employed at Queensland Health hospitals.

*P8 My medication could be sorted a lot better. I would like to see more support for elderly patients at the hospital and more contact with the Aboriginal and Torres Strait Islanders liaison officers. They avoid us.*

This participant suggested that their type of pension from Centrelink requires the participant to look for employment continually while also trying to attend dialysis treatment. Personal safety walking to the train station and catching a train to and from dialysis in the evening was an issue for this participant.

**P9** *The type of pension that I am on does not suit dialysis treatment and sometimes catching the train late at night is a problem for my safety.*

This participant suggested more support from the hospital volunteers and better transport system to make life easier. A courtesy bus was suggested. This would need a great deal of work to have a courtesy bus picking up and dropping off patients to and from renal dialysis.

**P10** *More support for the people on the afternoon shift. The volunteers visit only in the AM. We miss out on games. Better transport system to make life easier. Maybe a courtesy bus to help with transport through one of the local organisations.*

This participant suggested that medical appointments could be better scheduled to correspond with their renal dialysis treatment. The only problem with this is that the renal specialist does not work on the days that the participant attends dialysis. Also, transport was a problem as it is difficult to catch public transport into appointments. The journey on public transport takes about one and a half hours. Their partner usually has to attend with the participant to ensure that they do not fall over.

**P9** *Medical appointments to suit my dialysis days. It's hard because my kidney doctor can only work out here on this day, which is not my dialysis day. Also with transport, I cannot catch the public bus as my knees are really bad. My family help when I need them but I am a pretty independent person. My life goes on 100% and my dialysis is around my life and not the other way around.*

This participant was content with dialysis treatment and the surrounding environment making friends with other renal patients and getting on well with the renal staff.

**P12** *No suggestions. I like it how it is. I have friends at the dialysis unit, the nurses are great—we laugh and joke around. We all get on really well; it's like another family for me.*

This participant would like to purchase a PD machine. A benefit of a PD machine is that the participant would be able to complete their dialysis every night and not the current regime of four times per day. This would allow the participant more freedom.

**P12** *I would like to purchase a PD machine that operates at night so I would have the day free. The way it is now with my dialysis, changing the bag over every four to five hours, four times a day, seven days a week is taking its toll. Washing my hands all the time is definitely taking its toll.*

This participant and family members would consider buying a car to make it easier for transportation but indicated that no employment would make the task of applying for a personal loan to buy a car rather difficult.

**P14** *Maybe our family needs to consider to buy a car, but it's hard to get a loan if you do not have a job. So no other suggestions for me or my family.*

From participants' responses, it is clear that a number of suggestions were made to improve their life while on renal dialysis treatment. Suggestions were made at a number of different levels. Individual- and family-level suggestions were made towards better management of medication, improving home environment for better access, personal safety, home assistance when carers need time to relax, purchasing better transport facilities, seeking assistance through a physiotherapist to improve mobility, removing empty PD boxes, and reviewing types of pensions. Regarding receiving care within the hospital, suggestions were made towards more support for elderly, more contact with local Indigenous liaison officers at hospitals, more activities within renal units, and more contact with hospital volunteers.

#### **4.10 Summary**

This chapter has provided an overview of specific results from 14 participants interviewed who receive dialysis treatment for end-stage renal disease. Renal dialysis treatment affects people in many different ways. A majority of the participants stressed that this was the first opportunity to discuss their life living with end-stage

renal disease in a research format. Each participant is from a diverse social and cultural Indigenous background; each brings their unique life experiences from living with renal disease. Results from participants reflect a range of demographic, employment, social, family and medical support, and information on each participant's dialysis treatment. A majority of the participants were living in rented accommodation. A vital aspect of this chapter was that either family, partner, or carer support was an important factor to how participants managed their end-stage renal disease.

All of the participants struggle financially, which impacts on their health and well-being. Transport is an essential part of participants' struggles with end-stage renal disease. Most participants use and rely on public transport and a community transport service. Other information gathered relates to frequency of health services used and suggestions from participants towards improving any concerns that they had. Participants suggested a range of ideas to contribute towards managing their renal health more effectively, but if the resources are not available to assist them, no changes or improvements will occur.

# Chapter 5 : Discussion

## 5 Introduction

This chapter of the study draws together participants' results and outlines main points of discussion. The structure of this chapter focuses on the following five discussion areas:

### Part 1: Demographic information

- comparison of end-stage renal disease rates
- educational level
- where participants originate from

### Part 2: Lifestyle factors and behaviours

- employment issues—main source of income
- accommodation and housing issues
- socioeconomic issues
- physical activity
- cigarette smoking and alcohol consumption

### Part 3: Social support factors

- self support
- support from family and friends
- family issues
- medical support on dialysis treatment
- transport issues

### Part 4: Health and kidney health well-being

- description of individual health
- kidney health problems
- duration and modality of dialysis treatment
- kidney health knowledge
- kidney transplants
- medication compliance

## **Part 5: Health Service Utilisation**

- description of other health care services used

### **5.1 Demographic information**

The major areas of discussion in Part 1 include:

- comparison of end-stage renal disease rates
- educational level
- where participants originate from

#### **5.1.1 Comparison of end-stage renal disease rates**

While this study was a small cohort, the results clearly reveal that there were more Indigenous females with end-stage renal disease than males. There were eight females and six males. Two of the eight females were aged between 20–29 years of age. The 40–49 age group registered the most participants with a total number of eight, six of whom were male. Table 4.1 describes the participants' age and gender.

ANZDATA reports that from 1998 to the end of September 2003, there were 509 Indigenous females and 399 Indigenous males with end-stage renal disease. From each year (1998 –Sep 2003) there were higher numbers in each Indigenous female category, the highest margin being in 1999.

These results reflect similar patterns occurring on a national level with higher rates of end-stage renal disease among Indigenous females compared to Indigenous males. In total, the number of Indigenous people with end-stage renal disease from 1998 to the end of September 2003 was 908. Indigenous people with ESRD are younger and more likely to be female (Cass et al. 2004). When comparing non-Indigenous males and females with end-stage renal disease, a reverse situation is evident. From 1998 to the end of September 2003 there were 5598 males compared to 3762 females with ESRD. In total, the number of non-Indigenous people with ESRD over that period was 9360

(ANZDATA, 2003). Table 5.1 describes Australian patients with end-stage renal disease by race gender and year who have commenced dialysis treatment.

<b>Race</b>	<b>Year of ESRD</b>	<b>Female</b>	<b>Male</b>	<b>Total</b>
<b>Indigenous</b>	1998	70	67	<b>137</b>
	1999	98	59	<b>157</b>
	2000	84	66	<b>150</b>
	2001	104	71	<b>175</b>
	2002	90	80	<b>170</b>
	1 Jan 2003–30 Sept 2003	63	56	<b>119</b>
	<b>TOTAL</b>	<b>509</b>	<b>399</b>	<b>908</b>
<b>Non-Indigenous</b>	1998	586	884	<b>1470</b>
	1999	641	950	<b>1591</b>
	2000	673	930	<b>1603</b>
	2001	693	1042	<b>1735</b>
	2002	661	1051	<b>1712</b>
	1 Jan 2003–30 Sept 2003	508	741	<b>1249</b>
	<b>TOTAL</b>	<b>3762</b>	<b>5598</b>	<b>9360</b>

**Table 5.1 Australian patients with ESRD by race, gender, and year.**

Source: ANZDATA, 2003

In Queensland, figures show similar patterns of higher numbers of Indigenous females with end-stage renal disease compared to Indigenous males. Table 5.2 shows Queensland patients with ESRD by race, gender, and year.

<b>Race</b>	<b>Year of ESRD</b>	<b>Female</b>	<b>Male</b>	<b>Total</b>
<b>Indigenous</b>	1998	19	17	<b>36</b>
	1999	27	17	<b>44</b>
	2000	22	20	<b>42</b>
	2001	30	20	<b>50</b>
	2002	31	28	<b>59</b>
	1 Jan 2003–30 Sept 2003	15	22	<b>37</b>
	<b>TOTAL</b>	<b>144</b>	<b>124</b>	<b>268</b>
<b>Non-Indigenous</b>	1998	108	150	<b>258</b>
	1999	122	140	<b>262</b>
	2000	130	170	<b>300</b>
	2001	124	162	<b>286</b>
	2002	128	185	<b>313</b>
	1 Jan 2003–30 Sept 2003	109	142	<b>251</b>
	<b>TOTAL</b>	<b>721</b>	<b>949</b>	<b>1670</b>

**Table 5.2 Queensland patients with ESRD by race, gender, and year.**

(Source: ANZDATA, 2003)

When compared to statistical data from ANZDATA, the 45–54 age group registers the highest number of Indigenous patients. There were 173 Indigenous females and 138 Indigenous males in that age group. When compared to the non-Indigenous patients in that same age group, again the numbers are higher with 518 non-Indigenous females and 860 non-Indigenous males. It is interesting to note that the patient numbers for Indigenous patients older than 55 with end-stage renal disease declines dramatically for both females and males. Patient numbers for non-Indigenous patients with ESRD seem to increase.

There are 10 female and six male Indigenous patients who are over 75 years of age with ESRD compared to 624 female and 1008 male non-Indigenous patients. The figures represented for Indigenous people reflect the current national life expectancy rates for Indigenous people. Table 5.3 describes breakdown of new Australian patients with end-stage renal disease by race, gender, age, and year.

Race	Gender	Age at start	1998	1999	2000	2001	2002	2003	Total
Non-Indigenous	Female	<15	9	5	6	10	8	9	47
		15-24	19	21	25	25	17	16	123
		25-34	40	45	48	40	44	33	250
		35-44	57	62	70	68	64	48	369
		45-54	84	93	88	101	94	58	518
		55-64	141	129	127	138	118	92	745
		65-74	172	204	205	182	185	138	1086
		>=75	64	82	104	129	131	114	624
		<b>Total</b>	<b>586</b>	<b>641</b>	<b>673</b>	<b>693</b>	<b>661</b>	<b>508</b>	<b>3762</b>
	Male	<15	16	15	16	16	17	7	87
		15-24	26	31	29	21	27	23	157
		25-34	70	58	76	71	54	44	373
		35-44	110	94	70	104	80	82	540
		45-54	141	154	154	147	158	106	860
		55-64	172	169	183	204	213	134	1075
		65-74	230	285	235	292	283	173	1498
		>=75	119	144	167	187	219	172	1008
		<b>Total</b>	<b>884</b>	<b>950</b>	<b>930</b>	<b>1042</b>	<b>1051</b>	<b>741</b>	<b>5598</b>
Indigenous	Female	<15	0	2	0	1	0	0	3
		15-24	3	1	3	1	2	2	12
		25-34	5	5	8	4	6	5	33
		35-44	12	21	19	16	15	9	92
		45-54	23	34	24	32	33	27	173
		55-64	17	22	23	34	21	14	131
		65-74	9	10	6	13	11	6	55
		>=75	1	3	1	3	2	0	10
		<b>Total</b>	<b>70</b>	<b>98</b>	<b>84</b>	<b>104</b>	<b>90</b>	<b>63</b>	<b>509</b>
	Male	<15	0	1	0	0	0	0	1
		15-24	2	2	1	1	1	0	7
		25-34	4	6	8	6	3	4	31
		35-44	17	16	13	17	18	10	91
		45-54	28	18	19	26	28	19	138
		55-64	9	9	17	16	23	14	88
		65-74	4	7	7	5	6	8	37
		>=75	3	0	1	0	1	1	6
		<b>Total</b>	<b>67</b>	<b>59</b>	<b>66</b>	<b>71</b>	<b>80</b>	<b>56</b>	<b>399</b>

**Table 5.3 Breakdown of new Australian patients with ESRD by race, gender, and year.**

(Source: ANZDATA, 2003)

Data from the 1996 Census report that Australia's Aboriginal and Torres Strait Islander population was approximately 386 049, which represented 2.1% of the total Australian population (ABS & AIHW 2001). However, 'Indigenous Australians

represent 10% of new patients commencing treatment for end-stage renal disease' (Cass et al. 2004, p. 768).

### **5.1.2 Education**

All of the participants in this study have completed some formal education. The highest level completed was a university degree while a majority have completed their senior and junior high school certificates (Grade 12 and 10). Four participants mentioned that they had completed Grade 7 primary level of education. Level of education plays a large role in how participants understand and perceive their kidney health situation.

Participants felt comfortable with their level of education. Individual levels of education are not the issue; it is how their renal health and general health information is explained and understood by each participant. There is no universal best approach as people are different and their individual requirements need to be addressed. Each renal unit has their own methods of explaining kidney health to each patient. If participants have some language differences, these need to be considered and thought through carefully when explaining the necessary information to renal participants. This system seems to work for some hospitals but there are gaps in other hospitals where the necessary information is not being explained properly. Improvements could be made by better explaining the complexities of kidney failure and kidney dialysis with simple, appropriate resources and individual kidney health updates. Education material that is not appropriate to Indigenous people with end-stage renal disease and their families is a barrier. All of the participants spoke English as their first language except for three who spoke English as a second language. These participants were able to speak English for the interview and did not require the services of an interpreter. The situation in the other parts of Australia is very different. English may be the third or fourth language spoken, requiring the services of an interpreter. While this process is time consuming, it is necessary to overcome the communication barriers.

### **5.1.3 *Where participants originate***

Participants in the study came from all over Queensland and interstate. For many Indigenous people with end-stage renal disease, relocating from their community to receive vital treatment is common practice. Two participants specifically left their community to commence kidney dialysis treatment. However, a majority of the participants in this cohort had relocated from their community well before their kidney health was affected and for a variety of reasons. These were mainly employment and family reasons. Participants mentioned that when they moved to Brisbane they were much younger in age. The majority of participants in this study had been established in Brisbane for some time; the shortest time was one year and the longest time was 40 years. Family members also relocated with their loved ones to help and support them. Four participants moved with family members while six participants already had family members living in Brisbane. Another four mentioned that they moved independently to Brisbane with no family to help or support them.

## **5.2 Lifestyle factors and behaviours**

The major areas of discussion in Part 2 include:

- employment issues—main source of income
- accommodation and housing issues
- socioeconomic issues
- physical activity
- cigarette smoking and alcohol consumption

### **5.2.1 *Employment issues—main source of income***

All of the participants in this study come from diverse backgrounds with varied training experience and life skills. Participants who were physically unable to work due to their medical conditions indicated that they had gainful employment throughout their working lives but were unable to work to the same capacity due to end-stage renal disease. This group contained participants who were older (over 50 years of age), except for three participants (under 50 years of age) who had suffered stroke. Participants who had suffered strokes found that getting by day-by-day was

difficult enough. This group of participants received a disability pension and were unable to look for work. Two participants over 65 years of age are entitled to receive the age pension. One participant receives a sole parent pension and has lost their partner to end-stage renal disease. Therefore, looking after a child, managing the daily routine, and managing their own renal health is difficult.

Two participants indicated that they were on a Newstart allowance pension, which requires following set procedures and lodging application payment forms every fortnight in order to receive payments. Set procedures include providing the contact details of potential employers to whom the person has submitted a job application, being available for training courses, and being able to participate in voluntary work. Participants had no problems fulfilling these requirements but did mention they were drained of energy and were not motivated to look for work after completing their haemodialysis treatment. Given that haemodialysis treatment takes three days out of the week, with up to five hours on the machine, the two participants indicated that part-time employment was the most suitable option for their dialysis treatment. Gaining suitable employment and completing any form of dialysis treatment is a challenge and depends on each individual's physical, mental, and emotional well-being at the time. Serious consideration needs to be given to one's physical, mental and emotional well-being if any improvements are to occur.

The only participant in the study working full-time is on continuous ambulatory peritoneal dialysis and manages their renal dialysis treatment while at work. In the wider community, most people with end-stage renal disease return to some form of work successfully. Realistically, Indigenous people with ESRD are not in the same situation as in the wider community. Indigenous people with ESRD would need secure work in the first place in order to return successfully to some form of work. Indigenous employment rates are at an all-time low across Australia. This makes it even more challenging for an Indigenous person with end-stage renal disease to gain any form of employment.

The necessity for potential employers to be flexible and to understand the complexities of dialysis treatment is crucial towards improving the employment situation for Indigenous people with end-stage renal disease. The main goal for Indigenous people with ESRD is trying to keep well and healthy in order to gain some kind of quality of life and, if well enough, to be considered for a kidney transplant (if they choose that option).

### **5.2.2 Accommodation and housing issues**

All of the participants indicated that they had adequate accommodation and housing except for three, who indicated that they were waiting for QBuild to install safety equipment (e.g. installing safety rails in shower, toilet, and bedroom; and modifying toilet and shower facilities) so that participants do not fall down. The process with QBuild starts at the local GP who refers patients to another department for an assessment. An assessor visits and approves the installation of safety equipment. This has been known to take anywhere between 6–12 months, depending on how many applications are lodged. Priority cases take shorter amounts of time.

Access for wheelchairs was also an issue raised by two participants. All of the participants indicated that the distance they lived from a health facility (e.g. hospital) influenced their accommodation and housing needs. While a large majority of the participants are in properties nearer to such facilities, the rental of some of these properties tends to be more expensive which impacts on the patient's financial situation and stress levels.

Overcrowding was an issue raised by participants. This had an ill effect on participants' overall health. While the overcrowding was due mostly to relatives visiting, this caused pressure and strain for those Indigenous people with end-stage renal disease. Trying to cope with dialysis and aspects of the accommodation (e.g. no hot water, excessive phone bills, and higher food bills) takes its toll on two of the participants. From an urban and national perspective, it must be acknowledged that accommodation and housing for Indigenous people with end-stage renal disease is an area that needs addressing.

### **5.2.3 Socioeconomic issues**

Being on renal dialysis treatment clearly has an impact on the majority of participants' finances. The main expenses encountered by participants were rental, transport, utilities, groceries, medication, and telephone. If these main expenses were not covered by participants, it would cause a great deal of stress. Seven participants had other expenses such as day care, Internet and Foxtel connection, personal loans, hire of white goods, insurance, cleaning, and mobile phone bills.

All of these expenses are organised by each participant and are budgeted to certain extents. Even for those who plan their incoming finances, all participants are struggling financially. Of concern was the issue raised that if finances were not available, participants would miss taking their medication. This situation has to be monitored better at home and in the hospital while on dialysis so that this does not occur.

An idea to help Indigenous people with end-stage renal disease cope with financial situations would be to seek the assistance of a continual support system, either through a renal social worker or qualified Indigenous staff from Centrelink providing support from outside the hospital setting. The system has to change and we as health carers need to be more proactive than reactive. We need to put in place a better system of communication with and getting to know people with end-stage renal disease and their backgrounds. This would be more proactive than waiting for a referral from a doctor (and the time it takes for this process to occur) to act on a problem.

### **5.2.4 Physical activity**

All of the participants indicated that they had engaged in some form of physical activity adequate to their physical capabilities and home environment. A large majority of participants felt tired after renal dialysis treatment, which impacted on their physical activity. A program targeted to support Indigenous people with end-stage renal disease to increase their physical activity may be required. Being a

reasonable weight, along with a number of other criteria requirements, may help increase the chances of going on to a transplant list if the participant wishes.

### **5.2.5 Cigarette smoking and alcohol consumption**

Of concern were four participants who indicated that they currently smoke cigarettes. Smoking is a risk factor for other major health problems. Although participants knew that they should not be smoking because of the numerous lectures given by health professionals, they smoked because they enjoyed it and it gave them a sense of relaxation after the renal dialysis treatment. Only one person in the cohort gave up smoking mainly due to the cost but also for health-related reasons.

People with end-stage renal disease have to watch their fluid intake. Alcohol being consumed by a participant affects their medications and renal dialysis treatment. One participant knew that they should not drink so much alcohol because their fluid levels were always too high. Health professionals can only advise and educate to a certain point. Responsibility has to be taken by participants to try to decrease or eliminate their alcohol consumption otherwise their fluid levels will continue to be too high which impacts on their health.

## **5.3 Social support factors**

A majority of the participants identified a number of social support factors while living with end-stage renal disease. The major areas of discussion in Part 3 include:

- self support
- support from family and friends
- family issues
- medical support on dialysis treatment
- transport issues

### **5.3.1 Self support**

The terms self support or self care mean being actively involved in managing your dialysis treatment independently. Once trained, haemodialysis participants can prepare the dialysis machine, insert the needles, adjust the pump speeds and machine settings, and chart progress under supervision (Baxter 1999). From the study group only one participant was able to fully self support their own haemodialysis treatment without assistance. Continuous ambulatory peritoneal dialysis participants are able to perform their dialysis at home or work and this usually takes about 30–40 minutes in total. About four to five bag exchanges per day are required. Three participants were trained in continuous ambulatory peritoneal dialysis and were able to self support their dialysis. These participants expressed that they did not have enough money to purchase the APD machine which performs dialysis overnight while patients sleep. APD might be a better option than CAPD because it frees up the days and works in well with people who are employed, have child responsibility, or need a carer to help them perform their dialysis.

### **5.3.2 Support from family and friends**

Participants in the study identified a range of support factors to help them manage their daily routine. This included family helping with shopping or friends driving them to appointments. Eight participants described support from family members to help with shopping, cleaning, cooking, buying groceries, buying medication, and paying bills. One elderly participant had their fruit and vegetables delivered when they required it and had their medications delivered on a monthly basis through their local pharmacy. This was paid for in advance out of their pension and helped reduce some of the burden to try and manage these tasks constantly. One participant required daily assistance from nursing staff to help them with showering and getting dressed, while two participants received support via their carer to do the cleaning, shopping, and buying medication. Two participants could manage their daily routine independently and, if requested, support from family was available. Only one participant identified that they were self supportive, requiring no assistance from anyone.

Being on kidney dialysis does affect relationships with family members. Participants identified time spent away from home and family and being solely responsible to care for other family members as key issues how kidney dialysis affects their relationships with family. One participant identified that because their family does not understand the process of kidney dialysis treatment, it is harder for them to cope. Another factor raised by a participant was the distance the family lived away. It was too far to travel and too costly to arrange appropriate transport. A participant identified becoming more dependent on ageing parents, which was a concern. A participant who is raising a child independently identified that the time spent away from his child was worrying. Five participants identified that relationships with family members are not affected. These family members have adjusted to their loved one's life with end-stage renal disease. Overall most participants' families understand to a degree what their loved one has to go through, and they try to be as supportive as possible.

Being on kidney dialysis treatment affects some participants' relationships with their friends. Two participants described that since commencing kidney dialysis, they cannot socialise as freely as they could in the past. Two participants described that their friends are not interested in them and did not want to know them since they commenced dialysis treatment. On the other hand, friendships were made within the kidney dialysis unit and that was a good support outlet for those participants. Another participant was independent and did not want to bother their friends for help, while friends from a local church group helped support a participant through some very rough days.

Overall, participants' life on kidney dialysis was not affected when it came to support from friends. Friends helped by being understanding, coming to visit them, and helping where necessary if family members are not available.

### **5.3.3 Family issues**

Caring for people with end-stage renal disease is demanding work. Suggestions were made to relieve family members who constantly care for participants by providing some training in basic renal health care for other family members to assist when necessary. This would help to decrease the rate of carer burnout. When participants experience family burnout issues, they are usually the ones to suffer with no assistance and left to manage on their own. This causes stress; sometimes, they do not eat because they cannot manage. When this situation happens, family disruption and friction is very high because the family member who is responsible for caring has gone for a break while still claiming payment for being a carer.

There needs to be a better system to address this situation. Usually, nothing is done until the carer returns from their break and the whole process starts again. Caring for a person on renal dialysis treatment full-time is very difficult; therefore, a strategy to coordinate another family member to assist would reduce the burnout of family members. This would involve approaching the family as a whole and discussing the situation. When the participant is on dialysis and being transported, the carer has a lot of free time. The main caring areas would be to prepare meals, cleaning, shopping, paying bills, and help to coordinate medication and appointments times with the doctors.

Information from participants indicates that if the main carer is not willing to accept responsibility, they should not benefit from Centrelink payments. Overall, a majority of participants did emphasise that family support was strong and this helped towards being more positive about being on renal dialysis treatment and getting through life on a daily basis. Participants were satisfied with the support received from their family and friends.

### **5.3.4 Medical support on dialysis treatment**

A majority of participants in this study receive support when on dialysis treatment. The main support was through medical assistance: either helping participants get on

and off the machine, and self support, where the participant is able to self manage their dialysis. A large number of participants were very positive towards the medical care they received with only two participants feeling uncomfortable at their dialysis unit. Lack of cultural understanding was mentioned by a participant. Another participant identified that at the hospital they attend for their dialysis, the Indigenous Liaison Officer has no contact with them and there are no Indigenous nurses in the dialysis unit.

### **5.3.5 Transport Issues**

It is evident that the costs associated with transportation have an effect on all of the renal dialysis participants. Transport options include a community transport service, public transport, and private vehicles. A majority of the participants use a community transport service which has various costs attached. Estimated total costs for those participants are between \$4–\$10 per trip which equates to \$40–\$60 per week and \$80–\$120 per fortnight. These costs put more strain and stress on each renal dialysis participant's financial situation. Other concerns with this form of transport are the waiting times and waiting around after dialysis is completed. Some of the participants just want to go home (as they are tired), rest in the comfort of their own home, and not wait around in renal dialysis unit.

Some participants use public transport options including train, bus, and taxi services. A concern raised by a participant is that if the weather is bad (cold or raining) the participant will not attend their renal treatment. In bad weather, the participant has to walk from home to the train station, catch a train, walk to the renal unit, and reverse this when dialysis is completed. Transport is a very important issue for renal dialysis participants and some suggestions were made to help improve the situation. In one facility, the provision of parking permits for dialysis patients helped improve the situation of very costly parking fees. At another facility, parking spaces have been made available outside the renal unit but if they are full, patients have to park elsewhere, sometimes a long way away.

Another suggestion was that a courtesy bus be provided by AICHS. This option is not viable as there are four renal units operating over a vast area. In Cairns, the Indigenous renal patients were collected by a bus provided by the local Aboriginal and Torres Strait Islander Health Service 'Wuchopperen'. Unlike Brisbane, it is easier in Cairns as there are two renal units within 150 metres of each other. This service has recently ceased due to lack of funding. Currently, the Cairns region is undertaking a major fundraising effort through the Cairns Renal Association Inc. and Rotary Australia, which aims to raise enough money to purchase a bus. The Gold Coast Renal Association Inc. has one of the best transport models in Australia. Through grants and donations, the Gold Coast Renal Association Inc. is able to provide transport to and from dialysis for their patients, and this is coordinated by volunteers who drive the buses.

## **5.4 Health and kidney health well-being**

The major areas of discussion in Part 4 include:

- description of individual health
- kidney health problems
- duration and modality of dialysis treatment
- kidney health knowledge
- kidney transplants
- medication compliance

### **5.4.1 Description of Individual Health**

Participants' responses about their individual general health status were mixed. Considering the nature of end-stage renal dialysis compounded with the process of dialysis treatment and other chronic illnesses, only one participant described their health as excellent, two participants viewed their health as very good, six participants viewed their health as good, two participants viewed their health as fair, and three participants viewed their health as poor.

A majority of the participants expressed that how they feel from one day to the next may change suddenly. It depends on whether they have had a good sleep, if they are not sick with the flu, if they have eaten, if they have bills to pay with no income, if there are no family problems to worry about, if they are in any pain, and generally how they feel within themselves. All of these factors influence how individual participants feel about their general health.

#### **5.4.2 Kidney health problems**

Individual participants had experienced a range of different periods with kidney health problems before their kidneys no longer worked and then required dialysis treatment. The shortest time was less than six months and the longest time was more than 20 years. Six participants commenced dialysis treatment immediately once diagnosed with renal failure. These participants identified a range of different emotions and physical responses including feeling very sick most of all, shocked, uncertain of the future, sad, 'why me', and thinking about what treatment to undertake. It was evident that the participants who had experienced kidney health problems over a longer time frame seemed to cope better and were well prepared for the commencement of dialysis treatment.

A strong family history of end-stage renal disease is evident from the female cohort. From the six that reported a family history of ESRD, five female participants reported a family history through either a sister or mother. Participants proposed a number of different causes of their end-stage renal disease. One participant thought the cause of their ESRD was due to physically working in the hot sun and not drinking enough water combined with their hypertension. Two participants were unaware they had diabetes and stressed that if they had been better educated about diabetes they would have learnt to control their sugar levels a long time ago. Four participants did not know the cause to their end-stage renal disease. The causes of participants' end-stage renal disease include diabetes, high blood pressure, leaky kidneys, kidney infections, kidney stones, and pregnancy.

Cause	No.
Diabetes	3
High blood pressure	1
Both diabetes and high blood pressure	1
Kidney stones	1
Leaky kidneys or kidney infections	3
Pregnancy and high blood pressure	1
Do not know	4

**Table 5.4 Participants' view of the cause of their ESRD.**

Participants identified up to four other health problems associated with their kidney failure. Overall, a majority of the participants knew the basic information about why their kidneys stopped functioning with a majority of those referring to medical conditions as the underlying cause of their kidney failure.

#### **5.4.3 Duration and modality of dialysis treatment**

Seven participants received more than one mode of dialysis treatment. These modes include continuous ambulatory peritoneal dialysis or haemodialysis. Four of the seven participants who had experienced more than one mode of treatment changed over from CAPD to HD. The reasons for this change included the number of infections, constantly being ill, the treatment not suiting them, and family responsibilities at home. Three of the seven participants identified that they were on haemodialysis initially because they were too ill but preferred continuous ambulatory peritoneal dialysis. These participants underwent the necessary operations and training about how to manage their own CAPD treatment at home. CAPD was preferred because it gave the people the freedom of performing dialysis in their home or work environment; they had family support at home, and did not have to travel and from the renal unit three days per week. A majority of the participants (50%) identified they were on haemodialysis.

From this group, three participants had no choice because of pre-existing health conditions such as stroke and heart failure. The remaining four participants in this group identified they had only been on haemodialysis since being diagnosed, they

preferred HD to CAPD, and, most importantly, they were too sick to try continuous ambulatory peritoneal dialysis. A majority of the participants indicated that they were happy with their current mode of treatment.

The environment in a renal unit was the only complaint. The participants happy with their haemodialysis treatment advised that it keeps them alive, makes them feel better, is a better treatment option, and has less chance of infections. The common reasons given for being happy with continuous ambulatory peritoneal dialysis treatment included not going to the hospital three days per week, not sitting on a machine, and not liking the sight of blood pumping through the machines.

#### **5.4.4 Kidney health knowledge**

A majority of the participants in this study sought information on their kidney health from a range of health professionals. These included kidney nurses, kidney doctors, general practitioners, nurses, diabetes educators, and a dietician. While information may help some participants' knowledge on their kidney dialysis treatment, one participant indicated that they did not understand the information received from their medical team. A majority of the participants identified that kidney nurses were proactively involved in helping them gain knowledge on their kidney health. Other participants identified other sources of information such as the Internet and booklets.

Nine participants identified that they would like to learn more about their kidney health through nutritional advice and how different foods affect their kidneys; consistent, personalised health information updates; and information that is easy to read and understand for them and their families. Five participants identified that they were happy with the level of information received. One of those five participants was not interested in knowing any more information on their kidney health.

#### **5.4.5 Kidney transplants**

Kidney transplants were a sensitive issue to the participants but were discussed very openly and with interest. It was evident that participants had mixed feelings about

kidney transplants. None of the participants had received a kidney transplant in the time they have been on dialysis treatment. Two participants advised that they were on the transplant list. Three participants were unable to receive a transplant because of other health conditions. Participants were able to discuss the kidney transplant process with their doctors and expressed that they were happy with the information received. The situation for another four participants was a little different. While they had been informed about the kidney transplant process, they had had a family member or friend receive a kidney but not survive. These participants felt scared, nervous, and had a fear of rejection.

Four participants mentioned that they were feeling positive towards receiving a kidney transplant. One of these participants had already received a bilateral corneal transplant and believed the kidney transplant process would be challenging. This participant had seen some friends after their kidney transplant and was very optimistic. Two of the participants who were positive about transplants mentioned that a family member would donate one of their kidneys. Participants seemed a little unclear about what exactly their family member would have to go through to donate a kidney. There are risks associated with transplants and these need to be highly stressed and fully understood by not only the participant but also the family member.

One participant mentioned that information from doctors and nurses about kidney transplants had been explained to them but they did not understand the information. Another participant mentioned that the kidney doctor had never had a proper conversation explaining the process for transplantation. Another participant was in the process of obtaining additional information on kidney transplants.

#### **5.4.6 Medication compliance**

Participants in this study have other health conditions in addition to renal failure, and they consume a large number of medications daily to control these conditions. Half the participants mentioned that they had gone without their medication due to the cost, sometimes forgetting to fill scripts, being too sick to go out and get them, being fed up with the whole routine of end-stage renal disease, and the availability of scripts and a

doctor who can prescribe them. Some scripts and medication can be issued only by the hospital pharmacy while other scripts and medication can be obtained from a local doctor.

The other half of the group had never gone without their medication due to local pharmacies providing medication packs for participants, or participants, carers, or their partners organising medication. Through experience, participants knew how important taking their medication was and tried not to miss their medication. When they did miss their medication, they felt unwell.

## **5.5 Health service utilisation**

The major areas of discussion in Part 5 include:

- description of other health care services used

### ***5.5.1 Description of other health care services used***

The participants in this study predominantly used a range of health services including government health services, community controlled health services, and private health services that bulk billed. Over a 12-month period, all of the participants accessed their local GP a number of times depending on their health needs. The frequency of visits depended on if participants were feeling unwell. If they were unwell, they would access their GP more frequently. Participants also accessed their GP for ongoing health care needs and prescriptions.

Over a 12-month period, participants in this study consulted their kidney specialist monthly, bimonthly, and trimonthly. The frequency of visits to their kidney specialist depended on how their kidney health and dialysis treatment was going. For a few of the participants who attended a renal unit for treatment, the visits with their kidney specialist were coordinated with their treatment days. However, some participants had to make special trips back to the renal unit on another day for appointments with their kidney specialist. The plan to have appointments either before or after your kidney

dialysis treatment is a practical, easy solution but unfortunately not all kidney dialysis units offer this service. Ultimately, there may not be enough kidney specialists to provide this service to all kidney dialysis units.

Over a 12-month period, participants accessed a range of other health professionals that included Aboriginal health workers, a diabetes educator, a diabetes specialist or endocrinologist, a social worker, a welfare worker, a nutritionist, an optometrist, a physiotherapist and a naturopath. These health professionals were consulted at outpatients' clinics within government health services and community controlled health services. The naturopath was consulted in a private clinic.

Participants attended these appointments with family members or by themselves. Six participants advised that they had problems attending these appointments. These problems included transport to and from appointments, limited parking, waiting times, and generally not feeling well enough to attend the appointments. If they missed their appointment because they were not well, they would have to wait until the next available appointment. In some cases, this time frame would be too long and an urgent appointment would have to be made.

## **5.6 Summary**

This chapter has provided key discussion areas from the study that found that Indigenous females are more likely than Indigenous males to have end-stage renal disease. There were more non-Indigenous males than females with end-stage renal disease. These research findings support national statistics from the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). Other research studies show strong evidence that Indigenous community members who leave their community to receive renal dialysis treatment in another town or city do not cope very well. Indigenous people who leave their community face many issues to survive including missing family, missing community, cultural isolation, financial, accommodation, transport, and trying to cope with their illnesses.

Most participants and their family members in this study left their community well before being diagnosed with end-stage renal disease. They have faced many issues including social, cultural, financial, accommodation, and transport. A number of participants receive income from Centrelink pensions and struggle financially. The final chapter of this thesis presents a conclusion, limitations, and strengths of the study and directions towards a model of care.

## Chapter 6 : Conclusion and Recommendations

### 6 Introduction

This final chapter will provide a conclusion, limitations, and strengths of the study and recommendations towards a model of care. This study had three broad research questions. They were:

1. How do Indigenous people in an identified community cope with end-stage renal disease?
2. Why do Indigenous people have shorter life expectancy rates following initiation of renal dialysis treatment?
3. Will this research elucidate factors that contribute to mortality and morbidity among Indigenous people with end-stage renal disease?

Chapter 4 reported specific individual data on a small urban Indigenous sample with end-stage renal disease. The small group receive a complex medical treatment (dialysis) to stay alive. By using qualitative research principles, the researcher gained useful insight into the participants' lives and how participants cope and do not cope with everyday life issues. The findings reported in Chapter 5 highlight a number of issues for Indigenous community members with end-stage renal disease. A number of contributing factors were obtained which include social support structures, housing, family, environmental and financial issues, current health status, other medical conditions, individual renal health status, and knowledge, all of which contribute to overall health and well-being. Australian literature indicates that a number of Aboriginal and Torres Strait Islander people have to relocate to receive dialysis treatment. However, most of the participants in this study left their respective communities to seek employment or for family reasons. Only two participants left their community specifically for ESRD treatment.

The data illustrated that urban Indigenous community members with end-stage renal disease cope to a certain extent and the factors discussed above combine with stress contribute to their ill health. It could be stated that Indigenous people have shorter life

expectancy rates following initiation of renal dialysis treatment because they have other major chronic illnesses to contend with and, generally, have poorer health than the general population. Indigenous people also have to contend with a range of socioeconomic factors, environmental factors, and family factors. These factors contribute to the mortality and morbidity of Indigenous people with end-stage renal disease. A very distressing and low point of the study is that a number of participants have passed away. In the 12 months from 6 February 2004, four people had passed away. Two of the four participants had only commenced renal dialysis treatment in a short period before they passed away.

## **6.1 Limitations and strengths of the study**

A limitation of the study may have been that health professional staff were not involved in the research process of data collection. Health professional staff that care for the Indigenous ESRD patients may have contributed valuable information and insight into how the renal health system supports or does not support Indigenous people with end-stage renal disease. However, this was a qualitative study focusing on Indigenous people with ESRD to hear their unique stories and their journeys.

Another limitation could have been in researcher bias as the same researcher conducted the interviews and transcribed and analysed the data. To prevent researcher bias from occurring, measures to address this are described in the Research Methodology section of Chapter 3.

More Indigenous people with end-stage renal disease could have been recruited; however, given the overall total number of Indigenous people around Brisbane with ESRD receiving dialysis, the set target of 16 interviews was relatively adequate and sufficient. A strength of the study was its qualitative nature. By using qualitative research methods this study provided a comprehensive insight into a cross section of issues encountered by Indigenous people with end-stage renal disease in the South East Queensland.

A final strength of the study was the flexibility in organising a replacement organisation to recruit participants. The ability to work with the organisation where participants were recruited from was instrumental to gathering participants for the study.

## **6.2 Conclusion**

In conclusion, this qualitative study has shown how Indigenous people with end-stage renal disease continually struggle with their complex health issues and dialysis treatment. There is a real need for much broader community discussion on the social, cultural, and environmental issues that surround Indigenous people with ESRD. Participants expressed both negative and positive issues that they faced every day while living and managing ESRD. Participants were asked if they had ideas or suggestions on how their issues could be resolved. It is important to involve participants in this decision-making process to gather their thoughts on how an issue may be resolved.

While the study was about developing a model of care, a number of factors determine this outcome. The concept that Indigenous people can manage their chronic diseases effectively through 'self-determination' has worked at a community health setting with no major funding grants attached. The price of healthy Indigenous patients is invaluable. The model involves working with individuals thoroughly on each aspect of their health, social, and economic factors. Two significant factors made a difference for this model. One was the continual support offered to all the patients and the second involved the support of family members. Each patient was given the opportunity to come up with practical solutions.

Each person with end-stage renal disease is unique. Therefore, a model of care that reflects individual needs would be appropriate.

## **6.3 Recommendations**

### **Support Indigenous patients with ESRD**

1. Provide a more coordinated approach to support Indigenous ESRD patients at both micro (individual and family) and macro (health organisations and renal units) levels. Working with end-stage renal disease patients in coordination with related services (home care, meals on wheels) would ensure the best possible outcomes for the patient. Encourage family and community support for Indigenous patients with end-stage renal disease.
2. Provide clear roles and responsibilities for all family members who care for Indigenous people with end-stage renal disease. Provide support and training through government agencies for family members who decide to become carers.
3. Encourage Indigenous patients with end-stage renal disease to join renal advocacy agencies.
4. Promote Indigenous health professional staff to work in renal health.

### **Education resources for Indigenous patients with ESRD**

5. Promote better educational resources to inform Indigenous patients and family members about end-stage renal disease. Educational resources that are easy to understand and culturally appropriate have to be developed. There is no uniformed national or state approach to how renal education is being delivered to Indigenous patients with ESRD.
6. Assist in developing a better system to identify what stage of renal education the patient would require. Promote development of individual renal health and health updates for patients covering all aspects of current health status. Keep patients consistently up to date.

### **Prevention of ESRD**

7. Promote prevention of end-stage renal disease more aggressively and widely in Indigenous organisations and encourage family members to attend.

### **Accommodation for patients with ESRD**

8. Lobby various government and Indigenous organisations to address the accommodation crisis for Indigenous patients with end-stage renal disease.

# Appendices

## Appendix 1 Results of Pilot

### Introduction

- Relatively comfortable with the process of data collecting and interviewing, started with a brief introduction of where I am from where my family are from and some of my working background. This helps develop rapport and break down any barriers. Next an overview of the purpose of the interview and what their role was, keeping in mind to keep things simple. An overview from the information sheet was discussed in full. Allowed for question time. Two questions were asked one about confidentiality and the other about ethical approval through the Aboriginal and Islander Community Health Service.
- Both questions were answered to a satisfactory level. Discussed the consent form. Important to explain what the consent form means to people in the pilot study and the ethics process without dwelling on it.
- Rapport generally went well. The format of filling out one question at a time and discussing their responses was positive.

### Structure of Interview

- Questions were in logical order. Initially, the questions did not seem to flow, the structure of the interview needs improvement.

### Interview Questions

- Minor changes were required. Demographics to go in the beginning but advised to change this section to last as they were least threatening. Explain what educational grades Junior High (8-10) and Senior high school grades (11-12). Be specific on usual work situation. Delete some extra words in the heading of social support,, be specific when rating what “type of medical/personal social” support, include an option to tick more than one option in accommodation section, this would allow the researcher to gain how many people live in a particular household, include a introductory sentence “blurb” on the physical activity section, delete a question on patient travel assistance(irrelevant question), specify improving transport related questions, include 5 yearly options for duration on kidney dialysis treatment,

include why they changed from HD to CAPD or other way around, specify time period in seeing any kidney health specialist.

### **Interview Quality**

- Given the interview takes between forty minutes to just over one hour the questions in the interview are quite specific to obtain the necessary information in this time. I have to be patient in the interviews, let the people tell me their stories.

## Appendix 2 SurveyInstrument

Date of interview:

### INSTRUCTIONS

Being on kidney dialysis treatment affects people in many different ways. This instrument will ask you about your experiences while you have been on kidney dialysis treatment. You will be asked to talk about your surrounding environment, family support, your social and cultural well-being and your background. All information from the surveys will be combined so that no individuals can be identified. There will be no names on the instrument and all information will be confidential.

### PART A: SOCIAL SUPPORT

The first set of questions asks about the people who give you help or support.

Q1 Did you have to leave your community to come to Brisbane to receive kidney dialysis treatment?

Yes

No

Please describe why you chose this option: \_\_\_\_\_

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Q2 Did your family leave the community to come to Brisbane to support you while on kidney dialysis treatment?

Yes

No

Please describe how this has helped you cope/not cope with treatment: \_\_\_\_\_

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Q3 When you are not on kidney dialysis treatment what support do you have?

(Tick as many that apply)

- Self
- Husband/Wife/Partner
- Carer/s
- Friend/s
- Family members
- Organisation (eg AICHS)
- Medical team
- Other (please list) \_\_\_\_\_

Q4 What support do you have, if any, to help you manage your daily routine?  
(Please list anything you think may be relevant for example-family help you with your shopping or neighbours might drive you to appointments)

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Q5 When you are on kidney dialysis treatment what support do you have?  
(Tick as many that apply)

- Self
- Husband/Wife/Partner
- Carer/s
- Friend/s
- Family members
- Organisation (eg AICHS)
- Medical team
- Other (please list) \_\_\_\_\_

Q6 Can you think of any extra help or support would you need to make it easier for you to manage your kidney health? (Please list anything at all that you can think of)

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Q7 How much does being on kidney dialysis treatment affect your relationship with your family? (eg husband, wife, partner, children, etc)

- Not at all
- Slightly
- Moderately
- Quite a bit
- Very much

Please describe why you choose this option: \_\_\_\_\_

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Q8 How much does being on kidney dialysis treatment affect your relationships with your friends?

- Not at all
- Slightly
- Moderately
- Quite a bit
- Very much

Please describe why you choose this option: \_\_\_\_\_

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Q9 Are you satisfied with the support you receive from your family? (eg husband, wife, partner, children, etc)

- |                          |                          |
|--------------------------|--------------------------|
| Yes                      | No                       |
| <input type="checkbox"/> | <input type="checkbox"/> |

Please describe further: \_\_\_\_\_

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Q10 How would you rate your support you receive from your family? (eg husband, wife, partner, children, etc)

- Excellent
- Very good
- Good
- Fair
- Poor

Q11 Are you satisfied with the support you receive from your friends?

- |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|
| Yes                      | No                       | Not Applicable           |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please describe further: \_\_\_\_\_

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Q12 How would you rate your support you receive from your friends?

- Excellent
- Very good
- Good
- Fair
- Poor
- Not Applicable

Q13 Are you satisfied with the medical support you receive? (eg doctors, nurses, healthworkers etc)

- |                          |                          |
|--------------------------|--------------------------|
| Yes                      | No                       |
| <input type="checkbox"/> | <input type="checkbox"/> |

Please describe further: \_\_\_\_\_

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Q14 How would you rate your medical support you receive?

- Excellent
- Very good
- Good
- Fair
- Poor

**PART B: LIFESTYLE**

This section asks about your lifestyle.

Q15 How would you describe your accommodation in Brisbane? (Please tick)

- Self contained house
- Flat/Unit
- Hostel
- Nursing home
- Other \_\_\_\_\_

Q16 Who lives with you in your accommodation? (Tick as many that apply)

- Live alone
- Husband/Wife/Partner
- Hostel members                      How many.....
- Nursing home members              How many.....
- Family members                      How many.....
- Children under 5 years:              How many.....
- Children aged 5 to 9 years:              How many.....
- Children aged 10 to 14 years:              How many.....
- Children aged 15 to 19 years:              How many.....

Q17 Are you covered by any of these government health concession cards?  
(Tick as many that apply)

- Pensioner Concession Card
- Commonwealth Seniors Card
- Health Benefits Card
- Health Care Card
- Safety Net Concession Card
- Safety Net Entitlement Card
- None of these
- Other (please list) \_\_\_\_\_

Q18 What is your major source of income? (Tick as many that apply)

- Employment Wages
- Age Pension
- Pension Bonus Scheme
- Disability Support Pension
- Sickness Allowance
- Special Benefit
- Carer Allowance
- Mobility Allowance
- Other (please specify) \_\_\_\_\_

Q19 From this income, what expenses do you have to pay?  
(Tick as many that apply)

- Rent/Mortgage
- Electricity/Gas
- Telephone
- Transport Costs
- Groceries
- Medication
- Other (please list) \_\_\_\_\_

Q20 How much does being on kidney dialysis treatment affect your finances?

- Not at all
- Slightly
- Moderately
- Quite a bit
- Very much

Please describe further: \_\_\_\_\_

Q21 Have you ever been a smoker?

Yes      No  
     

Q22 Do you smoke now?

Yes      No  
     

Q23 Have you ever drank alcohol?

Yes      No  
     

Q24 Do you drink alcohol now?

Yes      No  
     

Q25 In a normal week, what physical activities do you engage in?  
(Examples: gentle activities such as gardening/yard work, walking, shopping)  
**Please list activity down left hand side of table**

Please tick a box that best represents frequency of activity.

ACTIVITY (List below)	Never	Less than Once a week	Once or twice a week	Three to 4 times per week	More than four times a week
1.					
2.					
3.					
4.					
5.					
6.					

**PART C: TRANSPORT**

These questions ask about distance and transportation to kidney dialysis treatment.

Q26 How many kilometres do you live from the hospital that you attend for dialysis treatment?

- Less than 5kms
- Between 6-15kms
- From 16-30kms
- From 31-45kms
- More than 45kms
- Other (approximate distance) \_\_\_\_\_

Q27 On average how much money would you spend on transport costs on a weekly basis?

- Less than \$20
- Between \$20-\$40
- Between \$40-\$60
- More than \$60
- Other (please specify) \_\_\_\_\_

Q28 How do you travel to the hospital to attend kidney dialysis treatment? (Tick as many that apply)

- Private transport
- Public transport
- Ambulance
- Other (please specify) \_\_\_\_\_

Any comments: \_\_\_\_\_

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Q29 Do you have any suggestions that could help improve any of the transport issues we have discussed?

Please list \_\_\_\_\_

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**PART D: HEALTH AND KIDNEY WELL-BEING**  
The next set of questions asks about your health and kidney well-being.

Q30 How do you feel today?

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Q31 In general how would you best describe your health.

- Excellent
- Very good
- Good
- Fair
- Poor

Q32 How long have you had kidney problems for?

Years..... Months.....

Q33 Does anyone in your family have kidney problems?

- |                          |                          |
|--------------------------|--------------------------|
| Yes                      | No                       |
| <input type="checkbox"/> | <input type="checkbox"/> |

If yes, please state your relationship to them \_\_\_\_\_

Q34 How long have you been on kidney dialysis treatment?

- 0-6months
- 7-12 months
- 1 year-5 years
- 6 years -10 years
- More than 10 years

Q35 In the past which of these kidney dialysis treatments have you received?

- Peritoneal Dialysis (CAPD)

- Haemodialysis (HD)
- Both (CAPD and HD)

If both, why did you change from one to the other: \_\_\_\_\_

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Q36 Which of these kidney dialysis treatments do you currently receive now?

- Peritoneal Dialysis (CAPD)
- Haemodialysis (HD)

Q37 Are you happy being on this type of kidney dialysis treatment?

- |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|
| Yes                      | No                       | Unsure                   |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please tell us why you have chosen this option: \_\_\_\_\_

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Q38 Do you understand what has happened to your kidney/s?

- |                          |                          |
|--------------------------|--------------------------|
| Yes                      | No                       |
| <input type="checkbox"/> | <input type="checkbox"/> |

In your own words could you tell us about your kidney health: \_\_\_\_\_

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Q39 Overall, how would you rate your knowledge of your kidney health?

- Excellent
- Very good
- Good
- Fair
- Poor

Q40 Where did you receive your knowledge of kidney health?  
(Tick as many that apply)

- General Practitioner(GP)
- Dietitian/nutritionist
- Diabetes educator
- Podiatrist
- Optometrist
- Physiotherapist
- Nurse
- Health worker
- Social Worker/welfare worker
- Naturopath
- Other \_\_\_\_\_

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---

Q41 Would you like to learn more about your kidney health?

- |                          |                          |
|--------------------------|--------------------------|
| Yes                      | No                       |
| <input type="checkbox"/> | <input type="checkbox"/> |

Could you describe why you chose this option: \_\_\_\_\_

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Q42 Have you ever missed kidney dialysis treatment?

Yes

No

Please describe why you chose this option: \_\_\_\_\_

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Q43 How do you feel about kidney transplants?

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**PART E: OTHER MEDICAL CONDITIONS**

This section asks about other medical conditions.

Q44 Do you suffer from any other medical conditions?

Yes

No

If yes, please list below: \_\_\_\_\_

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Q45 What types of medication are you currently on?

Please list: \_\_\_\_\_

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Q46 Have you ever gone without medication?

Yes                  No  
                     

Could you describe why you chose this option: \_\_\_\_\_

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**PART F : HEALTH SERVICE UTILISATION**

The set of questions asks about using other health services.

Q47 Do you attend any of the following health services?  
(Please tick as many as apply)

- Aboriginal and Islander Community Health Services
- Hospital/Queensland Health Services
- Private Health Services
- None of these
- Other \_\_\_\_\_

Q48 In the last 12 months how often did you see your local doctor?

- Daily
- Weekly
- Fortnightly
- Monthly
- Other \_\_\_\_\_

Q49 In the last 12 months how often did you see your kidney specialist?

- Weekly
- Fortnightly
- Monthly

Other \_\_\_\_\_

Q50 In the past 12 months how often did you see the following professionals in regard to your kidney health? (Tick as many that apply)

(Please circle which one applies)

- |                          |                              |     |      |                    |
|--------------------------|------------------------------|-----|------|--------------------|
| <input type="checkbox"/> | General Practitioner(GP)     | 1-5 | 6-10 | more than 10 times |
| <input type="checkbox"/> | Dietitian/nutritionist       | 1-5 | 6-10 | more than 10 times |
| <input type="checkbox"/> | Diabetes educator            | 1-5 | 6-10 | more than 10 times |
| <input type="checkbox"/> | Podiatrist                   | 1-5 | 6-10 | more than 10 times |
| <input type="checkbox"/> | Optometrist                  | 1-5 | 6-10 | more than 10 times |
| <input type="checkbox"/> | Physiotherapist              | 1-5 | 6-10 | more than 10 times |
| <input type="checkbox"/> | Nurse                        | 1-5 | 6-10 | more than 10 times |
| <input type="checkbox"/> | Health worker                | 1-5 | 6-10 | more than 10 times |
| <input type="checkbox"/> | Social Worker/welfare worker | 1-5 | 6-10 | more than 10 times |
| <input type="checkbox"/> | Naturopath                   | 1-5 | 6-10 | more than 10 times |
| <input type="checkbox"/> | Other                        |     |      |                    |

Q51 Where did you see the above professionals? (Tick as many that apply)

- Aboriginal and Islander Community Health Services  
 Hospital/Queensland Health Services  
 At both of the above  
 Private Health Service  
 None of these  
 Other \_\_\_\_\_

Q52 Did someone accompany you on any of these visits?

- Yes                  No

If yes, who \_\_\_\_\_

Q53 Do you have any problems attending these appointments?

- Yes                  No

If yes, please list \_\_\_\_\_

Q54 Do you have any suggestions that could help improve life on dialysis for you ?

Please list anything you can think of: \_\_\_\_\_

**PART G: BACKGROUND**

The last set of questions ask about some of your personal characteristics

Q55 Where do you come from?

Q56 How long have you lived in Brisbane?

Years..... Months.....

Q57 How old are you ?.....

Q58 Gender:

- Male
- Female

Q59 Which of the following best describes your highest education level?

- Primary School
- Junior High School (Grade 8-10)
- Senior High School (Grade 11-12)
- Trade course
- TAFE course
- University degree
- Other (please specify) \_\_\_\_\_

Q60 Which of the following best describes your usual work situation?  
(Tick as many that apply)

- Home duties
- Retired
- Self-employed
- Employed
- Unemployed
- Physically unable due to medical reasons
- Other (please specify) \_\_\_\_\_

Q61 How do you identify?

- Aboriginal
- Torres Strait Islander
- Both Aboriginal and Torres Strait Islander
- Other (please specify) \_\_\_\_\_

**THANK YOU FOR YOUR TIME**

## Appendix 3 Information Sheet



Faculty of Health

ABN 63 781 724 622  
CRICOS No. 00213J

Appendix: 3

### *Model of Care Kidney Study ~Information Sheet~*

**Project:**

Developing a model of care to improve the health and well-being for Aboriginal and Torres Strait Islander people receiving kidney dialysis treatment

**Purpose of the Study:**

Being on kidney dialysis treatment affects people in many different ways. The purpose of this study is to look at your experiences while you have been on kidney dialysis treatment. Self care management is very important. You will be asked to talk about your background, surrounding environment, family support, social and cultural well-being and your life in general.

As a result of the information we collect we hope to better understand how kidney disease affects Aboriginal and Torres Strait Islander people and be able to provide a suitable system to support and prevent further complications of the disease. You will also be asked about what impact kidney dialysis treatment has had on your life and your family life.

**Duration of the participants Involvement:**

The overall study will be conducted over a one-year time frame. I will be speaking to you about the study, answer any questions that you may have and gain your consent. I will be visiting you twice during the study.

Participant's involvement will include the following-:

- the first interview time I will be asking you about your experiences whilst receiving kidney dialysis treatment and what support you have received;
- the second visit will be to show you the information that you have provided and to make sure that it is correct.

This may also be time to discuss any issues which have come out of the information collected from you. Results from the research will be given back to the participants in the form of a research report but also in the form of a plain language version. Participants will be given every opportunity to discuss the findings. Interviews will be for 40 minutes to an hour. I will ask your permission to record the interview with a tape recorder or to take notes about the interview. If you do not wish the tape recorder to be used, I will take notes only

PLEASE TURN OVER THE PAGE

**Voluntary participation:**

Participation in this study is entirely voluntary. You are free to withdraw your consent before or after any of the interviews or at any time during the study, without comment or penalty. Under no circumstances will your treatment or care be affected by your decision.

**Risks and discomforts:**

Although there is no danger of physical stress to you, there is the risk that you may remember some personal experiences which have happened to you whilst being on kidney dialysis treatment. If this occurs, I will ask you how I can help or whether you want to be involved in the study still. If you want me to arrange counselling, with your permission I will arrange this through the Aboriginal and Islander Community Health service at Woolloongabba or at a service that is convenient to you. I will assist with transportation to and from the selected service.

**Confidentiality:**

Only I will know your identity. I will not use your name or any identifying words to link you to the study in the finished report or any publications. All records kept on the computer will only be available via a password and therefore restricted to myself. All study material will be kept in a locked filing cabinet for the duration of the study and for the required five-year period after completion on the study. Information from this study will not be used for any other purpose unless you give your permission. If a tape recorder is used with the permission by the participant, after data has been transcribed the tape will be destroyed so that no one will be voice recognised.

**Questions and concerns:**

Questions regarding this study are welcome at any time. If you have any questions please direct them to either Cilla Preece on 3864 9629 or my supervisor Dr Elizabeth Parker on 3864 3371. If you have any concerns in relation to the ethical conduct of this study, you may contact the Secretary, Gary Allen of the Queensland University of Technology's Ethics Committee on 3864 2902.

**Acknowledgment:**

Thank you for your consideration of participation in this study, your help is greatly appreciated. Please ensure that you have read (or have had it read to me) and understood the previous information.

~~PLEASE RETAIN FOR YOUR RECORDS~~

## Appendix 4 Consent Form



Faculty of Health

ABN: 89 791 724 622  
CRICOS No. 00213J

Appendix: 4

### *Model of Care Kidney Study ~Consent Form~*

The researcher conducting this study stands by the principles governing ethical conduct of research and, at all times, promises to protect the interests, comfort and safety of all the participants. This form along with the Information Sheet has been given to you for your own protection. They include an outline of the research study and possible risks. This study will be conducted in the Brisbane area only.

If I sign below it will mean that:

- I have read (or had it read to me) the information in the Information Sheet and the Consent Form, and I understand the degree of my involvement in the research;
- I understand that before the research begins the person completing the research will talk to me about what's in the Information Sheet, and all the information I provide will be confidential; also all of the information will be stored in a locked cabinet where only the researcher has access;
- I understand what the research is about and what might be risks to me if I am involved;
- I have been informed that my involvement in the research is voluntary. I am free to withdraw from the research at any time, without comment or penalty; and I will be given the opportunity to ask any questions regarding this research and my involvement;
- I understand that if I do not participate in this research it will not affect the treatment or care I receive;
- I can direct any inquiries and further questions to either Cilla Preece on 3864 9629 or Dr Elizabeth Parker on 3864 3371. If I have any other complaints or concerns regarding ethical conduct of this research study I can contact the Secretary, Gary Allen of Queensland University of Technology Ethics Committee on 3864 2902;
- I agree to be involved in the research as set out in the Information Sheet for the study entitled "*Developing a model of care to improve health and well-being for Aboriginal and Torres Strait Islander people receiving kidney dialysis*";

**I consent to participate in this study:**

Name:..... Signed:.....

Witnessed:..... Signed:.....

Date:.....



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## QUEENSLAND ABORIGINAL & ISLANDER HEALTH FORUM

*A member of the National Aboriginal Health Community Controlled Organisation*

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PO Box 8200  
WOOLLOONGABBA Q 4102

Telephone: (07) 3255 3604  
Facsimile: (07) 3255 3602  
Mobile: 04381 17763  
ABN: 99584975865

### TO WHOM IT MAY CONCERN

This letter is to confirm that the Queensland Aboriginal and Islander Health Forum (QAIHF) lends support for Ms Cilla Preece to undertake further studies to complete a Master of Applied Science-Research.

QAIHF believes that the intended subject of study would be an important aspect in health research. In particular, contributing towards establishing best practice models for renal health care.

Please do not hesitate to contact me on 07 32553604 if you should require any further information.

Yours faithfully,

A handwritten signature in black ink, appearing to read 'Mick Adams', written over a horizontal line.

Mick Adams  
Chief Executive Officer

17<sup>th</sup> September 2001

## Appendix 6

## AICHS Support Letter



The Aboriginal & Islander Community Health Service Brisbane Limited

10 Hubert St Woolloongabba  
Old 4102 PO Box 8112  
Woolloongabba Old 4102

Ph: (07) 3393 0055  
Fax: (07) 3391 6196

### TO WHOM IT MAY CONCERN

The Aboriginal and Islander Community Health Service Brisbane Ltd support Ms Cilla Preece's research on developing a model of care for Aboriginal and Torres Strait Islander people at our Health Service.

Ms Preece's research will benefit the community and also help improve the health and well-being for indigenous people who are receiving renal dialysis.

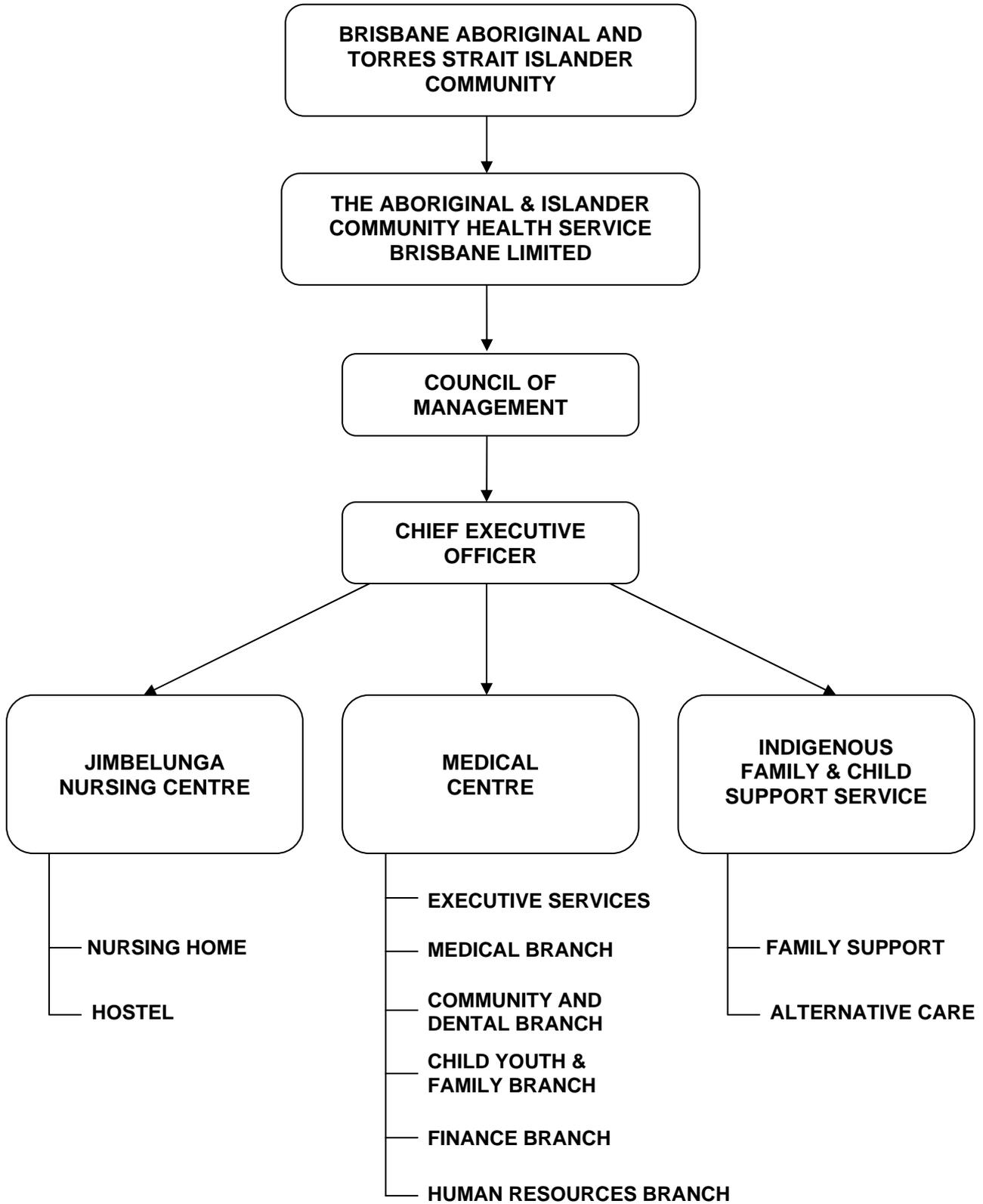
Ms Preece is an active member of our organisation and has only recently been elected by the Indigenous community to serve as a Board of Director for the next three years at our organisation. She holds the Executive position of Treasurer on this Board.

Please feel free to contact me on 33030055 if you have any queries.

Yours faithfully,

Mark Moore  
Chief Executive Officer

All donations \$2 and over are tax deductible"ABN 40 084 136 508 ACN 009 943435





Faculty of Health

ABN 83 191 724 822  
CRICOS No 002133

30<sup>th</sup> August 2002

Mr William Gorham  
Chairperson  
Aboriginal and Islander Community Health Service (AICHS)  
PO Box 8112  
Woolloongabba QLD 4102

Dear William and Board of Directors,

**Re: Recruitment for study**

I am currently a National Health and Medical Research Council Indigenous trainee studying at Queensland University of Technology (QUT) situated at Kelvin Grove. My topic is "*Developing a model of care to improve health and well-being for Aboriginal and Torres Strait Islander people receiving renal dialysis treatment*".

I have attached a brief summary of the research proposal I am currently undertaking and I am seeking permission from the Council of Management to recruit participants from your organisation.

Also attached are support letters from the Queensland Aboriginal and Islander Health Forum and the Australian Kidney Foundation Queensland branch. Without the support letters my application would not have been successful. In appreciation of your ongoing support a long term goal would be to involve the Aboriginal and Islander Community Health Service to help deliver the model of care. This would involve no costs and would be supported by the work I am currently developing.

Some of my background includes experience as a health worker at Wuchopperen for 8 years looking after the Diabetes program and working in a voluntary role after hours at the Cairns Base Hospital supporting Indigenous renal patients coming down from the Cape communities and Torres Strait Islands.

I would be happy to discuss this further with the Chairperson and the Board of Directors. My contact phone number 3864 9629. Thank you for your time on this important health area.

Yours sincerely,

Cilla Preece



**The Aboriginal & Islander Community Health Service Brisbane Limited**

10 Hubert St Woolloongabba Qld 4102  
PO Box 8112 Woolloongabba Qld 4102

Ph: (07) 3393 0055  
Fax: (07) 3391 6196

19<sup>th</sup> September 2002

Ms Cilla Preece  
Senior Research Assistant  
Queensland University of Technology (QUT)  
Faculty of Health  
Victoria Park Road  
Kelvin Grove Qld 4059

Dear Cilla,

**Re: Recruitment for study**

Following up from your letter dated 30<sup>th</sup> August 2002, the Aboriginal and Islander Community Health Service Council of Management have approved for you to recruit participants through this organisation for your study called "Developing a model of care to improve the health and well being for Aboriginal and Torres Strait Islander people receiving renal dialysis treatment".

Please contact me on 3393 0055 so we can arrange a convenient time to discuss the recruiting plan for your study in further detail.

Yours sincerely,

.....  
Mark Moore  
Chief Executive Officer  
AICHS

**All donations \$2 and over are tax deductible ABN 40 084 136 508 ACN 009 943 435**

## Appendix 10AICHS Confirmation of Counselling Support



**The Aboriginal & Islander Community Health Service Brisbane Limited**

10 Hubert St Woolloongabba Qld 4102  
PO Box 8112 Woolloongabba Qld 4102

Ph: (07) 3393 0055  
Fax: (07) 3391 6196

23<sup>rd</sup> October 2002

Mr Gary Allen  
Secretary University Human Research Ethics Committee  
QUT Secretariat  
GPO Box 2434  
BRISBANE QLD 4001

**COPY**

Dear Gary,

**Re: Confirmation of Counselling Support**

On behalf of the Aboriginal and Islander Community Health Service (AICHS) I would like to confirm that counselling support is available and is free should any participants from Ms Cilla Preece's study require this service. Ms Preece has indicated that she will arrange transportation if required by the participant.

If you have any further queries please do not hesitate to call me on 3393 0055.

Yours sincerely,

Mark Moore  
Chief Executive Officer  
The Aboriginal and Islander Community Health Service Brisbane Ltd

All donations \$2 and over are tax deductible A.C.N. 009 943 435



**The Aboriginal & Islander Community Health Service Brisbane Limited**

10 Hubert St Woolloongabba Qld 4102  
PO Box 8112 Woolloongabba Qld 4102

Ph: (07) 3393 0055  
Fax: (07) 3391 6196

.....  
.....  
.....

Dear

I am writing to see if you would like to participate in a study being conducted by Ms Cilia Preece from the Queensland University of Technology (QUT). This study has been supported by the Aboriginal and Islander Community Health Service (AICHS), Queensland Aboriginal and Islander Health Forum (QAIHF) and the Queensland branch of the Australian Kidney Foundation (AKF).

- The overall aim of the study is to develop a best practice model of care to improve health outcomes for Indigenous people on kidney dialysis treatment.

**Some info about Cilia Preece**

Cilia is from Cairns and has a background in health. Cilia has worked in a voluntary role at the Cairns Base Hospital with Indigenous people coming down from the Cape communities and Torres Strait Islands to begin kidney dialysis treatment. Since moving to Brisbane Cilia has been working at Queensland University of Technology (QUT) on a number of Indigenous health promotion projects. Cilia also is a member of the Australian Kidney Foundation as a Kidney Care volunteer.

Cilia is an active member of our organisation and has only recently been elected by the Indigenous community to serve as a Board of Director for the next three years.

**What's involved**

A couple of interviews. In the first interview, Cilia will ask you about your experiences while being on kidney dialysis treatment and the second interview will be feedback to you from your first interview.

**Your rights**

All information collected will be confidential and your participation is totally voluntary.

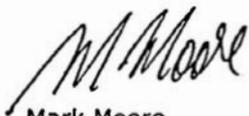
**All donations \$2 and over are tax deductible ABN 40 084 136 508 ACN 009 943 435**

**What's next**

If you decide that you would like to be a part of this study please tick the appropriate box on the form provided and post back with your reply envelope. We will then provide your details to Cilla who will call /write to you to make suitable arrangements for your interview.

If you have any queries or would like more information on the study please call Cilla Preece on (07) 3864 9629. Thank you for your time

Yours sincerely,



Mark Moore  
Chief Executive Officer  
16<sup>th</sup> December 2002

**~POST BACK ONLY THIS PAGE IN THE RETURNED  
ENVELOPE BY THE END OF JANUARY 2003~**

**~PLEASE TICK A BOX BELOW~**

I AM INTERESTED IN BEING INVOLVED IN THE STUDY.

Name: \_\_\_\_\_

Contact number: \_\_\_\_\_

Suitable time to call: \_\_\_\_\_

I AM NOT INTERESTED IN BEING INVOLVED IN THE STUDY.

Name: \_\_\_\_\_

**~THANK YOU FOR YOUR TIME~**

## Appendix 12      Qualitative Coding Guide

### Codes for Social Support Theme

#### **Theme 1: Left community pre dialysis (only)**

- *Label:* Left before renal failure diagnosed
- *Definition:* Participants describe leaving community well before ESRF established.
- *Example Indicators:* Coded when participants says, “We moved to Brisbane well before I got sick”, “I was not sick at that stage”, “I was not suffering with kidney failure when I moved to Brisbane with my boyfriend and his family”, “I did not have kidney failure”.

#### **Theme 2: Left community for employment opportunities**

- *Label:* Seeking job prospects
- *Definition:* Participants describe leaving community for employment reasons.
- *Example Indicators:* Coded when participants says, “Because I wanted to leave my community anyway and get a job”, “My husband and me came down here to look for work”, “I travelled to Brisbane from south of the boarder and came up here to look for employment opportunities”.

#### **Theme 3: Left community for medical/renal dialysis treatment**

- *Label:* Left specifically for medical/renal treatment
- *Definition:* Participants describe leaving community to commence renal treatment.
- *Example Indicators:* Coded when participants says, “When I left my community I was really sick. My kidneys were bad. I was all puffed up and I could not walk properly”, “Where I was living had no modern kidney dialysis treatment. I really had no choice, I had to move”.

#### **Theme 4: Left community for family reasons**

- *Label:* Support from family members
- *Definition:* Participants describe influence of family members influence to Brisbane for support

- *Example Indicators:* Coded when participants says, “Although I could get excellent treatment in Sydney where I was first diagnosed with ESRF I wanted to come back home to Brisbane for family support as I have no family support in Sydney”, “My first option was to go to Cairns but I had family down here in Brisbane. I decided on moving to Brisbane to be closer to my family”.

#### **Theme 5: Brisbane resident already**

- *Label:* Living in Brisbane
- *Definition:* Participants established as Brisbane residents
- *Example Indicators:* Coded when participants says, “I was already living in Brisbane”, “I was with my first family and we were already living in Brisbane, but did have to move closer to my family and closer to my local doctor”, “I was already living here in Brisbane”, “My family and I were already living in Brisbane”, “I was with my first family and we were already living here in Brisbane”.

#### **Theme 6: Family relocated to Brisbane**

- *Label:* Family members moved to Brisbane
- *Definition:* Participants family members moved to Brisbane
- *Example Indicators:* Coded when participants says, “Yes, I left the community only with my daughter who was one and a half”, “My husband and daughter came to Brisbane”, “My wife and son moved here to Brisbane”, “I moved to Brisbane with my boyfriend and his family”.

#### **Theme 7: Family support already in Brisbane**

- *Label:* Family support already in Brisbane
- *Definition:* Family support established in Brisbane
- *Example Indicators:* Coded when participants says, “Apart from my hubby and me the only family members we had down here in Brisbane was my brother, his wife and their three children”, “My family were already in Brisbane ready to help me with my ESRF”, “I moved closer to my family and they help with a lot of things. They only live two streets away and they help me cope”, “My family were here with me”, “My family and I were already

living in Brisbane”, “My first family were here already. My second wife is very supportive and has helped me cope with the shock of it all”.

#### **Theme 8: No family support in Brisbane**

- *Label:* No family support identified in Brisbane
- *Definition:* Participants describe how no family support is present in Brisbane
- *Example Indicators:* Coded when participants says, “None of my family moved to Brisbane, they are all out at the community”.

#### **Theme 9: Relocated to Brisbane**

- *Label:* Moved to Brisbane independently
- *Definition:* Participants describe how they moved to Brisbane
- *Example Indicators:* Coded when participants’ says, “I came by myself”, “I relocated from up north by myself”.

#### **Theme 10: Self**

- *Label:* When not on renal dialysis treatment what support
- *Definition:* Participants describe how they manage independently when not on renal dialysis treatment
- *Example Indicators:* Coded when participants’ indicate self as an option.

#### **Theme 11: Husband/wife/partner**

- *Label:* When not on renal dialysis treatment what support
- *Definition:* Participants describe how either their husband/wife/partner support them when not on renal dialysis treatment
- *Example Indicators:* Coded when participants indicate either husband/wife/partner as an option.

#### **Theme 12: Carer/s**

- *Label:* When not on renal dialysis treatment what support
- *Definition:* Participants describe how carer/s help support them when not on renal dialysis treatment
- *Example Indicators:* Coded when participants indicate carer/s as an option.

**Theme 13: Friend/s**

- *Label:* When not on renal dialysis treatment what support
- *Definition:* Participants describe how friend/s help support them when not on renal dialysis treatment
- *Example Indicators:* Coded when participants' indicate friend/s as an option.

**Theme 14: Family members**

- *Label:* When not on renal dialysis treatment what support
- *Definition:* Participants describe how family members help support them when not on renal dialysis treatment
- *Example Indicators:* Coded when participants' indicate family members as an option.

**Theme 15: Organisation**

- *Label:* When not on renal dialysis treatment what support
- *Definition:* Participants' describe how an organisation helps support them when not on renal dialysis treatment
- *Example Indicators:* Coded when participants' indicate organisation as an option.

**Theme 16: Medical team**

- *Label:* When not on renal dialysis treatment what support
- *Definition:* Participants' describe how an medical team helps support them when not on renal dialysis treatment
- *Example Indicators:* Coded when participants' indicate medical team as an option.

**Theme 17: Assistance by family members**

- *Label:* What support from family to help manage daily routine?
- *Definition:* Participants' describe who helps with daily routine when not on renal dialysis treatment

- *Example Indicators:* Coded when participants' says, "When I go shopping my daughter usually helps me", "My husband cooks and cleans the unit", "Family support in various ways with meals, washing, transport, regular household cleaners, I find it hard to clean the unit", "My little grand-daughter helps me sometimes with my shopping", "My partner helps with the housework and cooking", "My family assist me with my daily routine only when I need them", "My wife does all the shopping, getting my tablets".

#### **Theme 18: Assistance by friend/s, carers and neighbours**

- *Label:* What support from friend/s, carers or neighbours to help manage daily routine?
- *Definition:* Participants' describe how friend/s, carers or neighbours help with daily routine when not on renal dialysis treatment
- *Example Indicators:* Coded when participants' says, "My carer looks after my shopping, cleaning and get some of my tablets ready", "My friend/s help the housework and cooking", "My carer attends to all my daily routine needs, scripts ,shopping paying bills etc".

#### **Theme 19: Self-assistance with daily routine**

- *Label:* Managing independently with daily routine
- *Definition:* Participants' describe they can manage independently with daily routine when not on renal dialysis treatment
- *Example Indicators:* Coded when participants' says, " I can eat by myself", "I manage when I am OK", "I go shopping and do things by myself", "I do everything myself like shopping, cleaning and cooking", "I manage most things daily like shopping if I need anything. I take myself to appointments", " I managed mostly on my own".

#### **Theme 20: Assisted by external medical staff**

- *Label:* Helped by outside medical staff
- *Definition:* Participants' describe they can manage independently with daily routine when not on renal dialysis treatment

- *Example Indicators:* Coded when participants' says, "I get support from the hospital when I need it", "All care is provided through the nursing home", "An outside pharmacy delivers my medication weekly".

#### **Theme 19: Self assistance with daily routine**

- *Label:* Managing independently with daily routine
- *Definition:* Participants' describe they can manage independently with daily routine when not on renal dialysis treatment
- *Example Indicators:* Coded when participants' says, " I can eat by myself", "I manage when I am OK", "I go shopping and do things by myself", "I do everything myself like shopping, cleaning and cooking", "I manage most things daily like shopping if I need anything. I take myself to appointments", " I managed mostly on my own".

#### **Theme 20: Self care on dialysis treatment**

- *Label:* When receiving renal dialysis treatment what support
- *Definition:* Participants' describe how they manage independently when receiving renal dialysis treatment
- *Example Indicators:* Coded when participants' indicate self as an option.

#### **Theme 21: Husband/wife/partner**

- *Label:* When receiving renal dialysis treatment what support
- *Definition:* Participants' describe how either their husband/wife/partner support them when on renal dialysis treatment
- *Example Indicators:* Coded when participants' indicate either husband/wife/partner as an option.

#### **Theme 22: Carer/s**

- *Label:* When receiving renal dialysis treatment what support
- *Definition:* Participants' describe how carer/s support them when on renal dialysis treatment
- *Example Indicators:* Coded when participants' indicate carer/s as an option.

**Theme 23: Friend/s**

- *Label:* When receiving renal dialysis treatment what support
- *Definition:* Participants' describe how friend/s help support them when on renal dialysis treatment
- *Example Indicators:* Coded when participants' indicate friend/s as an option.

**Theme 24: Family members**

- *Label:* When receiving renal dialysis treatment what support
- *Definition:* Participants' describe how family members help support them when on renal dialysis treatment
- *Example Indicators:* Coded when participants' indicate family members as an option.

**Theme 25: Organisation**

- *Label:* When receiving renal dialysis treatment what support
- *Definition:* Participants' describe how organisational helps support them when on renal dialysis treatment
- *Example Indicators:* Coded when participants indicate organisation as an option.

**Theme 26: Medical team**

- *Label:* When receiving renal dialysis treatment what support
- *Definition:* Participants' describe how an medical team helps support them when on renal dialysis treatment
- *Example Indicators:* Coded when participants indicate medical team as an option.

**Theme 27: Other assistance**

- *Label:* Other assistance when receiving renal dialysis treatment
- *Definition:* Participants' describe how an other assistance is required to support them when on renal dialysis treatment
- *Example Indicators:* Coded when participants indicated other as an option.

**Theme 28: Family burn-out**

- *Label:* Family members help participants' but get tired/drained
- *Definition:* Participants describe how exhausting it is being a full-time carer for participants' on renal dialysis treatment
- *Example Indicators:* Coded when participants says: "I know my daughter gets burnt out".

**Theme 29: Extra general support needed**

- *Label:* Extra outside support needed
- *Definition:* Participants describe how extra general support would assist them while on renal dialysis treatment
- *Example Indicators:* Coded when participants says, "I need some help with getting my muscles strong again, I use to get this with the physio", "Assistance with exercising", "Medication could be sorted a lot better", "A car for transport", "With transport".

**Theme 30: Satisfied with family support**

- *Label:* Satisfied with family support
- *Definition:* Participants describe how satisfied they are with family support while on renal dialysis treatment
- *Example Indicators:* Coded when participants says, "Always there for me when I need them", "My husband does a lot of support for me and when my children are in town they all help and support me", "Parents go out of their way to help me", "My wife does everything for me, she is very organised and my only main support", "My family come over and ask me what I need doing around the house and outside in the yard", "My son understands what I have to go through and is supportive when I need things done", "My boyfriend is really great support", "A lot of love from my family. Sometimes they will ring me at the hospital and check if I'm OK. Very supportive. My partner is always there for me", "My family support is great. I get enough love from my family and that keeps me going strong", "My wife, children, brothers and sisters are great support for me. We all talk and support each other", "When I need help my family and partner are here for me".

### **Theme 31: Not satisfied with family support**

- *Label:* Not satisfied with family support
- *Definition:* Participants describe how they are not satisfied with family support while on renal dialysis treatment
- *Example Indicators:* Coded when participants says, “I don’t rely on them as they don’t live close to me. They visit me every now and then. I am really happy when they visit”, “I would like more contact with them but it’s a long way for them to travel”.

### **Theme 32: Extra medical support needed**

- *Label:* Extra medical support needed
- *Definition:* Participants describe how extra medical support would assist them while on renal dialysis treatment
- *Example Indicators:* Coded when participants says, “Medical appointments to suit my dialysis days”, “I would like to purchase a PD machine that operates at night so I would have the day free”.

### **Theme 33: Satisfied with medical support**

- *Label:* Satisfaction with medical support
- *Definition:* Participants’ describe satisfaction with medical support while on renal dialysis treatment
- *Example Indicators:* Coded when participants says, “The medical team are very good”, “The team are good”, “Because they look after me good”, “PD unit staff always available”, “The doctors and nurses are good”, Both at the hospital and down at my local community health service, the medical support is very efficient”, “My medical support is very good down here. I have been to a couple of hospitals up north and they do not compare with the standard down here”, “The medical team are very good to me. They assist me when I need things done”, “The nurses mainly have helped me get over some very rough patches by telling me exactly what is going on with my dialysis and medical condition. The little things are important to me. The more knowledge or information I have on my condition I am more relaxed and that really helps

with my surrounding environment”, “The team is very good to me. I get on better with the nurses than the doctors”.

#### **Theme 34: Not satisfied with medical support**

- *Label:* Not satisfied with medical support
- *Definition:* Participants describe how they are not satisfied with medical support while on renal dialysis treatment
- *Example Indicators:* Coded when participants says, “Only two nurses at the unit who are set in their ways make dialysis treatment uncomfortable”, “Sometimes the RN’s greet you sometimes they don’t. Attitudes are not good. RN’s lack cultural understanding. It’s a shame that there are no Indigenous RN’s at the unit”.

#### **Theme 35: Not satisfied with allied health support**

- *Label:* Not satisfied with allied health support
- *Definition:* Participants describe how they are not satisfied with allied health support while on renal dialysis treatment
- *Example Indicators:* Coded when participants says, “The liaison officers at the hospitals do not have the time of day for us”.

### **Codes for Lifestyle Theme**

#### **Theme 1: Accommodation**

- *Label:* Accommodation
- *Definition:* Participants describe their accommodation while receiving renal dialysis treatment.
- *Example Indicators:* Coded when participants describe “Self contained house”, “Flat/unit”, “Hostel”, “Nursing home”, “Duplex”.

#### **Theme 2: Being on dialysis treatment affects finances moderately**

- *Label:* Finances affect moderately
- *Definition:* Participants discuss how being on dialysis treatment affects their financial situation moderately

- *Example Indicators:* Coded when participants says, “All the bills seem to come at once. I find it hard to pay the toll if I have to travel to Inala”, “This has come down to being organised”.

### **Theme 3: Being on dialysis treatment affects finances quite abit**

- *Label:* Finances affect quite abit
- *Definition:* Participants discuss how being on dialysis treatment affects their financial situation quite a bit
- *Example Indicators:* Coded when participants says, “If I keep things under control I am OK. I struggle from time to time”, “We pay all our bills on time with a little extra left over”, “Although we plan our bills we learn to live with what we have”, “It’s hard to come with my current income”, “With the little income I receive I pay most of that on bills. On top of that I have to try and find employment which is difficult for me as I am tired constantly from dialysis treatment”.

### **Theme 4: Being on dialysis treatment affects finances very much**

- *Label:* Finances affect very much
- *Definition:* Participants discuss how being on dialysis treatment affects their financial situation very much
- *Example Indicators:* Coded when participants says, “I would like to go shopping but I can’t do that I’m always broke”, “It reduces my work hours which reduces my pay. I’m struggling abit”, “I am always broke. Being on dialysis and on a pension is hard”, “Its only whin I need to get a taxi my budget blows out”, “We struggle and try to keep to a budget”, “I use to work part- time and managed my finances well before I become sick. Now I can not work and have to rely on the disability pension and I try to cope by paying my bills on time”, “When I was working full-time and getting an income I really did not care but now that I’m on a pension I watch every cent. It’s hard at times but we manage”.

### **Theme 5: Alcohol and Tobacco**

- *Label:* Alcohol and tobacco

- *Definition:* Participants talk about alcohol and tobacco use before ESRF and while receiving renal dialysis treatment.
- *Example Indicators:* Smoking cigarettes and consuming alcohol affects participants' health" and well being.

#### **Theme 6: Physical activity**

- *Label:* Physical activity
- *Definition:* Participants discuss any type of physical activity while receiving renal dialysis treatment.
- *Example Indicators:* Coded when participants says, "Walking", "Cleaning", "Housework", "Gardening/hosing", "Washing clothes", "Moving in wheel chair", "Shopping".

### **Codes for health and renal well being**

#### **Theme 1: Happy with type of renal dialysis treatment**

- *Label:* Type of renal treatment
- *Definition:* Participants discuss if they are happy with their choice of treatment
- *Example Indicators:* Coded when participants says "I just feel a lot better", "CAPD did not suit me. I am happy on HD. After dialysis treatment I get up from the chair and I feel really good", "My freedom fits better with an independent lifestyle", "Its keeping me alive", "This treatment keeps me going so I have to be happy", "HD is much easier for me and as well I feel that HD is a better treatment option for me. I get more time for myself", "I find it a better treatment for me but everyone is different hey, that will do me", "HD makes me fel 100% better. You also get a 2 day break", "CAPD really suits me because as I do not have to be near the hospital and I do not like the sight of blood pumping through the HD machines", "I have control over my dialysis which is very good for me", "I prefer CAPD as it gives me some freedom", "I feel good on this one until I get a transplant".

#### **Theme 2: Not happy with type of renal dialysis treatment**

- *Label:* Type of renal treatment

- *Definition:* Participant discusses why they are not happy with type of treatment.
- *Example Indicators:* Coded when participants says, “Because all I do is sit on my arse. I would like to move positions abit while I’m on HD. I get cramps in the reclining chairs and I would rather like on the bed than sit in the chair. My head aches while I’m on the recliner chair. I like to sit on my good side”.

### **Theme 3: Maximum understand of own renal health situation**

- *Label:* Understand renal health situation
- *Definition:* Participants describe how they best understand their own renal health
- *Example Indicators:* Coded when participants says, “Its like I have kidney failure which lead to this. I wasn’t probably drinking enough water. Diabetes is a killer disease and its all connected to each other”, “1gA nephropathy following a post streptococcal glomerulonephritis, which lead to progressive scarring of my kidneys resulting eventually to ESRF”, “Over the years I’ve had leaky kidneys which is not good. My sugar made things worse and now I have no kidney function at all”, “My local doctor picked up that I my kidneys were not functioning properly and I had kidney failure not so long after that”, “When I was living in the bush working in the railways I did not have any water plus I suffer from high blood pressure and diabetes. All this has to do with my kidney health now”, “My kidney problem started from a kidney infection and they do not work”, “I think my kidneys were not working for a long time before they packed it in. I did not have the knowledge to maintain my diabetes and I did not even know I had diabetes. If I would have been educated better about my sugar I would have been right. My sugar is very well controlled”, “I am on dialysis because I had hypertension for a very long time and that in the end affected my kidneys. My doctors have told me that my kidneys have shrunk”, “How I understand my kidney problem is I had two large kidney stones that damaged my kidneys. When I finally got medical help I was in kidney failure and more or less started treatment after a couple of operations”.

#### **Theme 4: Minimum understanding of own renal health situation**

- *Label:* Minimum understanding of renal health situation
- *Definition:* Participants describe how they do not really understand their own renal health situation

*Example Indicators:* Coded when participants says, “Its all been explained to me but at the time it was all a major shock”, “I was feeling sick my urine had blood in it and my kidneys do not work”, “I only know the surface stuff. I do not know the in depth stuff about dialysis and my kidney health”, “Along time ago the doctor told me I had an infection in one of my kidneys and it spread to the other one. Now my kidneys are stuffed”.

#### **Codes for other medical conditions**

##### **Theme 1: Medication compliance**

- *Label:* Medication compliant
- *Definition:* Participants describe why have never have gone without their medication
- *Example Indicators:* Coded when participants says, “At the nursing home all my tablets are organised for me”, “I never go without tablets because the pharmacy provides them”, “I really try my best not to. If I can see my medication is running low I get a script at my local doctor and get my medication”, “My scripts are available through the hospital system and some through my GP. Inconvenient at times”, “All of my tablets are organised for me usually with the help of my wife who is my carer. I know through experience that it is important to your health to take your tablets”, “My tablets are organised through the local chemist so I do not miss them”, “I have never gone with my tablets. My tablets help keep everything under control which makes me happy”.

##### **Theme 2: Medication non compliant**

- *Label:* Medication non-compliant
- *Definition:* Participants describe why they have gone without their medication
- *Example Indicators:* Coded when participants says “When I was younger I thought I could go without them. I was strong but it all caught up with me. Its

hard because sometimes I can not get my scripts filled”, “Sometimes I just get fed up with the whole routine”, “Sometimes I forget to get my scripts at the hospital and at times I have no money to buy them so I go without”, “I’ve forget at times to fill the scripts. And the cost. I’ve felt sick so I missed taking them”, “Although my tablets are in this container and its all over the place I know when they are running out”.

## Appendix 13UHREC Approval Letter



UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE

Ms Cecelia Preece  
School of Public Health  
QUT Kelvin Grove

April 17, 2002

Dear Ms Preece

At its 16 April 2002 meeting, the University Human Research Ethics Committee considered the additional information / revisions you provided in relation to your project "Developing a model of care to improve health and wellbeing for Aboriginal and Torres Strait Islander people receiving renal dialysis" (Ref No QUT 2513H).

The Committee is satisfied that the information provided addresses its concerns, and has confirmed the full ethical clearance status of this project.

Please do not hesitate to contact me if you have any further queries in relation to this matter.

Yours sincerely

A handwritten signature in black ink, appearing to be 'G. Allen', written over the typed name.

Gary Allen  
Secretary, University Human Research Ethics Committee  
QUT Secretariat  
Telephone: (07) 3864 2902  
Facsimile: (07) 3864 1818  
Email: [gx.allen@qut.edu.au](mailto:gx.allen@qut.edu.au)  
<http://www.qut.edu.au/draa/or/ethics/human/index.html>

Cc: Prof B Meiklejohn, School of Public Health

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