

**School of Public Health
Faculty of Health Sciences**

**Health Beliefs and Behaviour of a Population
Screened for Chronic Kidney Disease in Sarawak:
A Mixed Methods Study**

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**This thesis is presented for the degree of
Doctor of Philosophy
of
Curtin University**

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007), updated March 2014. The study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Protocol Approval HR 07/2009.

Signature:



Date: March, 2016

Dedication

*A further sign of health is that we don't become undone by fear and trembling ...
but take it as a message that it's time to stop struggling and look ...
directly at what's threatening us.*

Pema Chödrön

Whenever I needed assistance, my friends were so obliging, helping me during the taxing recruitment, translation and rigorous data collection phases. I especially want to thank Caleena, Susan, Margaret and Ashleigh for your smiles and compassionate demeanour. Thank you to Dr Anand for helping me cope with some difficult medical complications during that time.

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I believe that this legacy of work I leave will be of value to them, and to my Kelabit extended family, as they endeavour to maintain a healthy lifestyle.

***Plaba doo pian kadi muyuh nengan kinah tah mare tubut ngan narih.
Repat ngan Tuhan ngeberakat tauh lem adto nuk pema'un.***

For I know the plans I have for you, declares the Lord, they are plans for good and not for disaster, to give you a future and a hope. (Jeremiah 29:11. NLT)

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The doctor of the future will give no medicines, but will interest his patients in the ... care of the human frame, in diet, and in the causes and prevention of disease.

Thomas A Edison

Many times I reflected on the fortitude and resilience to overcome the numerous challenges the dialysis patients encountered. The courage and acceptance of end-stage renal disease patients; the non-acceptance and trepidation of the first degree relatives and their spouses who care for them; the frustration of those with metabolic syndrome and chronic diseases, all prompted me to pursue this research area.

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This legacy of work I leave will be of value to those with metabolic syndrome, chronic kidney disease and end-stage renal disease, their families and members of the Miri community, as they transition towards a healthy urban lifestyle.

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And work for the peace and prosperity of the city ... Pray to the Lord for it, for its welfare will determine your welfare. (Jeremiah 29:7. NLT)



Photograph 0.1 Orang Ulu Youth performing at Miri City celebrations

Photograph by researcher's husband.

Abstract

Research evidence suggests that first degree relatives of patients with end-stage renal disease, particular ethnic groups and multiple components of metabolic syndrome may contribute to the development and exacerbation of chronic kidney disease. The study setting is Miri, in Sarawak, Malaysia. The participants were from a variety of ethnic and socio-demographic backgrounds.

The aim of this study is to synthesise a coherent explanation of health-related beliefs, behaviours and knowledge contributing to abnormal clinical parameters that may predict the development of chronic disease in participants. The quantitative objectives are to determine what socio-demographic, biochemical and lifestyle factors are associated with the risk of chronic kidney disease and metabolic syndrome. The qualitative objectives are to analyse the health-related beliefs, behaviours, knowledge, barriers, cultural practices and lifestyle choices that may be potential predictors of chronic kidney disease and metabolic syndrome.

This study employs a two-phased Mixed Methods sequential explanatory design. Phase One, a case-control study, involves the collection and analysis of statistical data by which to screen participants (n = 270) for chronic kidney disease and metabolic syndrome. An intermediate stage connects the two methodologies and determines what exposures of interest warrant further investigation. The Phase Two interview participants (n = 32) are a purposefully selected subset of Phase One.

The Phase One cases (n = 135) are the first degree relatives of end-stage renal disease patients at three Miri haemodialysis centres. The controls (n = 135) are the unaffected, non-genetic relatives of the first degree relatives' spouses, pair-matched by age and gender. Quantitative data from anthropometric measurements, laboratory results and a self-administered questionnaire was analysed using descriptive statistics. Multivariable logistic regression, with adjustment for potential confounders, was then applied to identify key associated risk factors. The adjusted odds ratios with 95% confidence interval for chronic kidney disease revealed that although alcohol was found to be protective (0.401 [0.179, 0.898]), being of Malay (5.666 [1.935, 16.593]) or Indigenous (2.347 [1.021, 5.395]) ethnicity, increasing age (1.048 [1.020, 1.076]) and having

metabolic syndrome (3.063 [1.527, 6.142]) predispose participants to developing chronic kidney disease. The adjusted odds ratios with 95% confidence interval for metabolic syndrome revealed significant markers being a first degree relative (2.409* [1.303, 4.454]) and having a family history of cardiovascular disease (2.650# [1.146, 6.130]). The odds of developing metabolic syndrome increase with age (1.027# [1.005, 1.049]), with living in low-cost housing (5.084* [2.301, 11.234]), with a personal history of smoking (3.163* [1.344, 7.442]) and with increasing glucose intolerance: for impaired fasting glucose / impaired glucose tolerance (3.568* [1.790, 7.110]) and being diabetic (14.308* [4.662, 43.915]) (* $p < 0.01$, # $p < 0.05$).

The qualitative data gathered from thirty-two in-depth semi-structured interviews was analysed and framework matrices created to explore the intersections between the participants and the themes that emerged. Qualitative themes derived from the interviews, identified lifestyle transitions, health beliefs surrounding traditional practices and herbal medicine, health behaviours including compliance with modern medical regimes, and environmental concerns. Many of those owning gardens or working in plantations hold mistaken beliefs and behaviours that expose them to multiple applications of potentially harmful agrochemicals. Food safety awareness and education in occupational health are needed, particularly among agriculture and plantation workers.

This study identifies associated factors, beliefs and behaviours that in all probability contribute to chronic kidney disease in Sarawak. It is recommended that development of screening and intervention programs aimed at preventing the onset and progression of chronic kidney disease target first degree relatives of end-stage renal disease patients and persons with metabolic syndrome. Strategies implemented must include addressing erroneous beliefs, healthy lifestyle management practises and the control of chronic non-communicable diseases associated with metabolic syndrome.

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Terminology

There are a number of terms frequently used throughout this submission. The list below gives a brief explanation of terms used in Sarawak to help the reader to better understand the context of the terminology in this study.

<i>Bumiputra</i>	Malaysian term meaning ‘Sons of the Earth’. The term refers to Malay, Orang Asli and Dayak people of Malaysia.
<i>Dayak</i>	Sarawak term for Indigenous person originally from Sarawak.
<i>Desa Klinik</i>	Rural / remote outpost clinic.
<i>Indigenous</i>	An Aboriginal person.
<i>Kampung</i>	An organised community often containing related members of one’s family or ethnic group (Malay, Chinese, Indian or Indigenous). A small village-like community. Used (slang) to enquire where one comes from or grew up.
<i>Kedai</i>	Small stall or shop
<i>Longhouse</i>	A long building, between 10 and 100 doors or families, housing related members of a Dayak tribe. Sometimes one storey, sometimes two storeys. Usually built off the ground and underneath may be left open or enclosed.
<i>Native</i>	Indigenous. An original inhabitant of the land.
<i>Orang Asli</i>	Peninsular Malaysian term for the Indigenous tribal people originally from Malaya.
<i>Orang Puteh</i>	Europid. Caucasian. Foreigner with European heritage.
<i>Penan</i>	The only nomadic / semi-nomadic tribal people remaining in Sarawak today.
<i>Poliklinik</i>	Government out-patients clinic.
<i>Tribal</i>	Belonging to an Indigenous tribe.
<i>Tuai Rumah</i>	Longhouse headman / chief

Abbreviations

There are abbreviations used, especially in the equations, tables and figures, throughout this submission.

The list below will help the reader identify the abbreviations used in this study.

ACR	Urine Albumin : Creatinine Ratio (mg Alb/mmol Cr)
BMI	Body Mass Index defined by (WHO-WPR 2007)
CKD	Chronic Kidney Disease defined by (KHA 2007)
CNCD	Chronic Non-Communicable Diseases
CVD	Cardiovascular Disease
eGFR	Estimate Glomerular Filtration Rate (mL/min/1.73m ²)
ESRD	End-Stage Renal Disease
FDR	First Degree Relative
FH	Family History
GFR	Glomerular Filtration Rate
HbA1C	Haemoglobin A1C Assay
HDL-C	High Density Lipoprotein Cholesterol
HT	Hypertension / High Blood Pressure
IFG	Impaired Fasting Glucose / Glycemia
IGT	Impaired Glucose Tolerance
LDL-C	Low Density Lipoprotein Cholesterol
MetS	Metabolic Syndrome defined by (Alberti, Eckel et al., 2009)
OGTT	Oral Glucose Tolerance Test 2hrs post 75g glucose challenge
SCG	Spousal Control Group
TC:HDL-CR	Total Cholesterol : High Density Lipoprotein-Cholesterol Ratio
T2D	Type 2 Diabetes

Chapter 1 Introduction

This introductory chapter provides the background and delves into the reasons underpinning this research. It explains the selection of the topic and the participants, describes the study setting, identifies the research questions, and outlines the aim, objectives and study focus. Finally a brief overview of the organisation of this thesis is presented.

1.1 The Background

Our kidneys are designed to function efficiently throughout our lifetime. Unfortunately for many people their kidneys become damaged to the point where they cease functioning. When this happens, and if a person does not receive medical intervention, they will die within two weeks (NKF [National Kidney Foundation US], 2013; NKF, 2008). Chronic kidney disease (CKD) is progressive, and deteriorates to end-stage renal disease (ESRD) and premature death (Levy, Morgan, & Brown, 2001; Levey, Eckardt, Tsukamoto, Levin, Coresh, Rossert et al., 2005). Chronic kidney disease often develops undetected as patients are asymptomatic until the disease is advanced and the kidneys have almost failed (Gaw, Murphy, Cowan, O'Reilly, Stewart, & Shepherd, 2008). If recognised early however, with appropriate clinical management, the rate of chronic kidney disease progression can be slowed (Mahon, 2001; Tonelli, Wiebe, Culleton, House, Rabbat, Fok et al., 2006).

The incidence of chronic kidney disease is increasing globally, and there is as yet no known cure for end-stage renal disease (Levy et al., 2001; Levey, Eckardt et al., 2005; Jha, Garcia-Garcia, Iseki, Li, Naicker, Plattner et al. 2013). This study investigates adverse health determinants and abnormal clinical parameters that may predispose to chronic kidney disease in an at risk population, and then considers the health beliefs and behaviours of a sample from a Malaysian population in Miri, Sarawak. Its findings may be valid for other states as well as other developing countries in South East Asia.

The leading risk factors of chronic kidney disease for all ethnicities includes being a first degree relatives (FDR) of a patient with end-stage renal disease, having diabetes mellitus, high blood pressure, and being over 50 years of age (KHA [Kidney Health Australia], 2006b). Having multiple risk factors increases the probability of developing

chronic kidney disease (KHA, 2006d), regardless of age or ethnicity (KHA, 2006a). Studies show that the first degree relatives of end-stage renal disease patients (Goldfarb-Rumyantzev, Cheung, Habib, Wang, Lin, Baird et al., 2006) and particular ethnic groups (Feehally, 2005) are at enhanced risk of chronic kidney disease as there is a significant and independent familial component, from shared environment and heredity (Freedman, Volkova, Satko, Krisher, Jurkovitz, Soucie et al., 2005). Population screening aimed at family members of end-stage renal disease patients has been recommended (Ramirez, Hsu, & McClellan, 2003; Hamer & El Nahas, 2006), but in Malaysia funding is unavailable for screening.

The incidence of chronic kidney disease and the two leading risk factors, type 2 diabetes (T2D) and hypertension (HT), are rapidly increasing in the developing world (ISN [International Society of Nephrology], 2006) and closely mimics trends in economically developed countries. Other reasons for the development of chronic kidney disease include aging, injury, disease, inheritance, congenital conditions, inflammation of the kidney glomeruli, infections of the urinary tract, medications, drugs, toxins, pesticides, pain relievers, traditional herbs, and illegal substances (NKF, 2013). Reasons that cannot be identified at the time of diagnosis are labelled as 'unknown causes or aetiology'. The renal morbidity statistics from various registries worldwide note that for persons with chronic kidney disease (Rashidi, Ghanbarian, Azizi, & Adler, 2007b) and those with end-stage renal disease (Levey, Bosch, Lewis, Greene, Rogers, & Roth, 1999; Bakris, Sarafidis, Weir, Dahlöf, Pitt, Jamerson et al., 2010), cardiovascular events are responsible for more than 50% of reported deaths. In Malaysia death from complications of cardiovascular disease (CVD) are reported at 36% while sepsis is 24% (MSN [Malaysian Society of Nephrology], 2014). Similar data for Miri is unavailable because of confidentiality issues.

Chronic non-communicable diseases (CNCD) are usually progressive, degenerating to disability, poor quality of life and untimely death (NCCDPHP [National Centre for Chronic Disease Prevention and Health Promotion], 2009). Globally, 60% of all deaths are attributed to chronic non-communicable diseases (Alwan, MacLean, Riley, d'Espaignet, Mathers, Stevens et al., 2010) with 80% of these deaths recorded in developing countries (Abegunde, Mathers, Adam, Ortegón, & Strong, 2007). This statistic is expected to increase by 17% over the next decade (WHO [World Health

Organization], 2013a). Apart from the genetic component, chronic non-communicable diseases can be prevented or modified by addressing the social, economic and physical environments, and behavioural aspects, such as smoking, alcohol, diet and physical activity (WHO, 2013a). Obesity is a common denominator and predictor of many nutrition-related chronic non-communicable diseases (Grundy, 2004). As developing countries become urbanised, obesity correlates with their industrialisation (Noor, 2002; L. Rampal, S. Rampal, Khor, Zain, Ooyub, Rahmat et al. 2007) and economic prosperity (Misra & Khurana, 2008). Obesity is independently associated with each of a combination of metabolic abnormalities that are often observed to cluster, referred to as the metabolic syndrome (MetS) (Alberti, Zimmet, & Shaw, 2005). Two metabolic syndrome components, type 2 diabetes and hypertension, mechanistically link obesity to chronic kidney disease (Abrass, 2004; Guarnieri, Zanetti, Vinci, Cattin, Pirulli, & Barazzoni, 2010). A person with multiple components of metabolic syndrome criteria has an increased likelihood of developing and exacerbating chronic kidney disease (Lea, 2006). Likewise, if a person has chronic kidney disease there is the likelihood of having multiple components of metabolic syndrome and obesity (Sowers, 2005), which in turn increase the risk of cardiovascular disease complications (CDCP [Centers for Disease Control and Prevention], 2010). In this study, this interplay between chronic non-communicable diseases in the participants is explored.

In many of the world's low-resource countries people die from end-stage renal disease because haemodialysis is unavailable, inaccessible and unaffordable (WHO [World Health Organization], 2003; Arogundade, Sanusi, Okunola, Soyinka, Ojo, & Akinsola, 2006). Malaysia reported that at the end of December 2012 there were 28,725 end-stage renal disease patients dialysing at 40 dialysis centres (government public, non-government organization (NGO), private, university or armed forces), a treatment rate of 979 persons per million (MSN, 2014). Those receiving haemodialysis therapy are assessed on a sliding scale according to their family income, and a government subsidy may be granted. The average cost for one dialysis session in Malaysia is between RM150 and RM250 and, with thirteen treatments per month needed, this amounts to RM3,250 per month (Loh & Shagar, 2013). That is equal to the entry monthly wage of full-time general staff at university in Sarawak and is more than many people's monthly income. Although they depend upon subsidies and donations, these may not cover costs, and family members have to meet the shortfall or raise funds from the

public. The number of persons on haemodialysis is currently doubling every six years, and it is predicted that this exponential escalation of end-stage renal disease in Malaysia will significantly increase the economic impact of kidney disease on the national healthcare system (Hooi, 2006).

Apart from such economic costs, identifying causal risk factors and preventing the progression of chronic kidney disease to end-stage renal disease has immediate and long-term benefits for the patient, the family and the community, especially in developing countries (Khwaja, El Kossi, Floege, & El Nahas, 2007). Health behaviour modification can affect the onset and progression of chronic diseases through prevention (avoiding disease), detection (screening), control of risk factors, self-management and control of the progression of the disease (Berwick, 2004; Bandura, 2011). A symptom of illness may trigger health behaviour changes (Rosenstock, 1974; Bowling, 2004; Rosenstock, 2005). Screening people with hypertension and type 2 diabetes is an effective strategy to detect persons at risk of chronic kidney disease (Hallan, Dahl, Oien, Grootendorst, Aasberg, Holmen et al., 2006), and taking a community public health approach delays its development and progression (Ramirez, Hsu et al., 2003; Hamer & El Nahas, 2006).

In Malaysia only opportunistic screening is available. This means that a person may only be incidentally screened and diagnosed for a disease when they visit their doctor. However, this only applies to a small percentage of the population as the conditions may be asymptomatic for many years before an individual presents with complications. Sponsored community health campaigns are sometimes organised in shopping centres but are not always well advertised or attended. Basch (1999) suggests that poor participation in community health screening may be due to a wariness of finding out if one has a medical condition as this accelerates the process of becoming a patient. Bowling (2014) comments that there may be a social stigma attached to being labelled sick if it is seen as a form of social deviance and a breach of society's norm. In this study, reasons why participants were reluctant to visit the doctor were explored.

Traditional practitioners from various ethnic groups in Sarawak dispense traditional herbs and medicine, some to maintain health, some to cure. Communities with strongly ingrained belief systems share similar values and ideas about health and illness, and

such culturally influenced behaviours have health consequences (Basch, 1999; Rosenstock, 2005). Strategies for chronic kidney disease health promotion, screening and intervention programs need to include local knowledge regarding health behaviour and practices if they are to be successful (Wilson, Jungner, & WHO, 1968; KHA, 2006c).

Malaysia has limited social welfare for persons in extreme poverty, and only those working for large multi-national companies have health-care insurance. Healthy lifestyle choices depends on each person's personal financial situation, and health is often a low priority (Bowling, 2004; Arogundade, 2006; Bowling, 2014), especially if abnormal clinical findings for a chronic non-communicable disease are in an asymptomatic stage. Response to illness by persons who are of low socio-economic status may be one of fatalism or powerlessness (Bowling, 2004; Bowling, 2014), denial and 'the will of God'. There is limited data published on the health status of first degree relatives of Malaysian end-stage renal disease patients. This study aims to address some aspects including their knowledge of and predisposition for chronic kidney disease, and the impact their beliefs and behaviours may have on their health. This will garner insightful information regarding first degree relatives in Sarawak.

1.2 Research Questions Arising

- How prevalent is chronic kidney disease among first degree relatives and their spousal family members?
- How prevalent is metabolic syndrome among the participants and is it a predictor of chronic kidney disease?
- Are there socio-demographic or socio-economic risk factors that may contribute to developing chronic kidney disease / metabolic syndrome?
- Are there behavioural or environmental risk factors that may contribute to developing chronic kidney disease / metabolic syndrome?
- How knowledgeable are the participants in this study with regard to preventing and coping with chronic non-communicable diseases?
- Are there traditional or culturally influenced beliefs and barriers preventing participants from seeing a medical doctor or heeding his advice?

- Is there evidence to support the need for targeted, rather than opportunistic, population screening and awareness campaigns for chronic kidney disease / metabolic syndrome in Miri?

1.3 The Study

This study was conducted in Miri, the second largest city in the state of Sarawak, Malaysia, situated on the central west coast of the island of Borneo. All the patients from all three haemodialysis centres that are operational in Miri were invited to participate in recruiting their first degree relatives and spousal families. Participants were from a variety of ethnic, demographic and socio-economic backgrounds.

Staff shortages and financial constraints at the dialysis centres in Miri demand that every end-stage renal disease patient attending dialysis must be accompanied by a family member who assists during the session: four hours, every second day, for the remainder of the patient's life. This creates inconceivable stress on patients and also places financial, physical and emotional anxiety on the carers who accompany them to dialysis sessions.

Prior to commencing this study, my work brought her into direct contact with end-stage renal disease patients and their carers, most often members of their immediate family. A significant number of these family members expressed apprehension that they too might develop the disease. This thesis seeks to better understand the local situation, in order to facilitate knowledge transfer with the purpose of empowering family members to make wise decisions regarding their health and lifestyle, to reduce their risk of chronic kidney disease and to help allay their fears and trepidation.



Photograph 1.1 Connecting to the dialysing machine

Photograph by researcher

1.4 Rationale of the Study

1.4.1 Aim

The aim of this study is to synthesise a coherent explanation of health-related beliefs, behaviours and knowledge contributing to abnormal clinical parameters that may predict the development of chronic disease in participants at risk.

1.4.2 Objectives

1. Identify the socio-demographic characteristics associated with the abnormal clinical findings among the participants.
2. Ascertain the behavioural lifestyle factors associated with the abnormal clinical findings among the participants.
3. Describe the housing and environmental features associated with the abnormal clinical findings among the participants.
4. Establish the abnormal clinical parameters for chronic kidney disease in the participants.
5. Determine the abnormal clinical parameters for metabolic syndrome and associated chronic metabolic disease comorbidities in the participants.
6. Analyse the health related beliefs, behaviours and stress factors of the participants with specific regard to determinants compounding the development of chronic kidney disease and metabolic syndrome.
7. Enquire into health-related attitudes, barriers and cultural practices delaying early recognition of the precursors of, and diagnosis of, clinical chronic non-communicable diseases in participants.
8. Develop an account of traditional beliefs and customs, as opposed to modern medical and health preferences, influencing the self-management of chronic non-communicable diseases in participants.
9. Document the modern myths, marketing and health knowledge that impinge on participants' health-related lifestyle choices and behaviours that may play a role in the development of chronic kidney disease and metabolic syndrome.
10. Provide evidence regarding high risk locales, vulnerable groups and topics identified, in order to develop targeted intervention strategies and programs.

1.5 Structure of the Thesis

Drawing on the literature review and employing a mixed methods research design, this study focuses on: (1) the first degree relatives of end-stage renal disease patients (cases) and the spousal control group (SCG) (controls); (2) screening for the main risk factors and causes of end-stage renal disease in Malaysia: chronic kidney disease, type 2 diabetes, hypertension and cardiovascular disease - all chronic metabolic diseases; (3) determining the abnormal clinical parameters for metabolic syndrome; (4) identifying socio-demographic and lifestyle exposures of interest; (5) considering the role of beliefs, behaviours and health-related lifestyle choices with regard to risk factors for chronic kidney disease and metabolic syndrome.



Photograph 1.2 End of dialysis session

Photograph by researcher

This thesis follows a sequential framework. A brief overview and description for each of the chapters of this thesis follows.

Chapter 1: Introduction delves into the background and reasons underpinning the research. It explains the selection of the topic, the participants and study setting, identifies the research questions and outlines the aim and objectives of the study.

Chapter 2: Context examines the major geographical, historical, political, economic, socio-demographic and health components that have shaped Sarawak. It highlights the country's health status in transitioning from infectious to chronic diseases.

Chapter 3: Literature Review explores the views of other researchers, what is known regarding chronic kidney disease and its interconnectedness with metabolic syndrome.

Risk factors, prevention and progression of chronic kidney disease, metabolic syndrome, and management are discussed.

Chapter 4: Research Methodology gives an overview of the benefits of using Mixed Methods and outlines the study design and ethical issues considered. The quantitative Phase One methods for the data collection and analysis are presented.

Chapter 5: Results – Quantitative Phase One presents the quantitative outcomes following analysis using SPSS software. It determines if participants can be classified as having chronic kidney disease or metabolic syndrome.

Chapter 6: Intermediate Connecting Stage draws on the results of the quantitative Phase One, identifies concerns of interest to investigate further, and determines the protocols for purposefully selecting participants for Phase Two. The qualitative Phase Two methods for the interview data collection are outlined.

Chapter 7: Findings – Qualitative Phase Two presents the outcomes of the qualitative analysis using the NVivo program. The qualitative data gathered from the interviews is organised into sub-themes which reveal the major theme.

Chapter 8: Discussion individually examines both the quantitative results and the qualitative findings. Each section concludes with a summary of the study outcomes for the relevant objectives and notes the associated risky behaviours of the participants.

Chapter 9: Integration of the Two Data Sets brings together the quantitative and qualitative outcomes from this study. It presents a coherent interpretation and understanding of the lifestyle aspects revealed from the qualitative findings that endorse and may impact and influence the quantitative results.

Chapter 10: Conclusion presents the study conclusions and insights into the reasons why some participants may have developed chronic kidney disease and metabolic syndrome. It closes with the study strengths, limitations and suggested future practice and research directions.

Appendices include copies of all relevant emails requesting permission to conduct the study, the recruitment letter and information sheets, informed consent forms, data collection sheets and other associated documents and diagrams.

1.6 Conclusion

Chapter 1 sets the scene for this dissertation. The background introduces end-stage renal disease, chronic kidney disease and the chronic non-communicable disease comorbidities of metabolic syndrome as the focus of this study and outlined why these conditions are creating a public health dilemma for developing countries such as Malaysia. The key contributing risk factors for chronic kidney disease, the reasons why urbanisation amplifies the problem and the reasons why the health-care systems of low-resource countries are unable to cope, was examined. This chapter defined the rationale for the study including the focus, research questions, aim and objectives. An overview of the scope and organisation of the thesis has been presented.

This chapter has established the framework for the thesis and shows how the study flows with continuity. The next chapter summarises the major events leading to the development of modern Malaysia and Sarawak, where this study was conducted.



Photograph 1.3 A dialysing hall

Photograph by researcher

Chapter 2 Context

This chapter positions the study in the context of governance, demographics, environment, socio-economic development and health attributes that have shaped Sarawak, distinct from yet comparable with Malaysia's development in recent times. It highlights the shift in emphasis as the country's health status transitions from having to contend with infectious diseases to tackling chronic diseases. It compares the country's health indicators with other South East Asian countries and notes the disparities between Sarawak, the focus of this study, and Peninsular Malaysia.

Where in the world is Borneo? Australia is the smallest continent in the world and any land mass smaller is considered an island. The island of Borneo (740,000 square kilometres) is the third largest island in the world after Greenland and New Guinea (J. Payne, Cubitt, & Lau, 1994) and is surrounded by Indonesia to the south and east, Philippines to the north and Peninsular Malaysia to the west (*Figure 2.1*). It comprises of three countries: the Sultanate of Brunei; Kalimantan, Indonesia; and the eastern territories of Malaysia, Sarawak and Sabah. Sarawak (124,449.5 square kilometres) lies along 800 kilometres of the west coast of Borneo, north of the equator between latitude $0^{\circ} 50'$ and $5^{\circ}N$, and longitude $109^{\circ} 36'$ and $115^{\circ} 40'$ E (Sarawak Government, 2011).

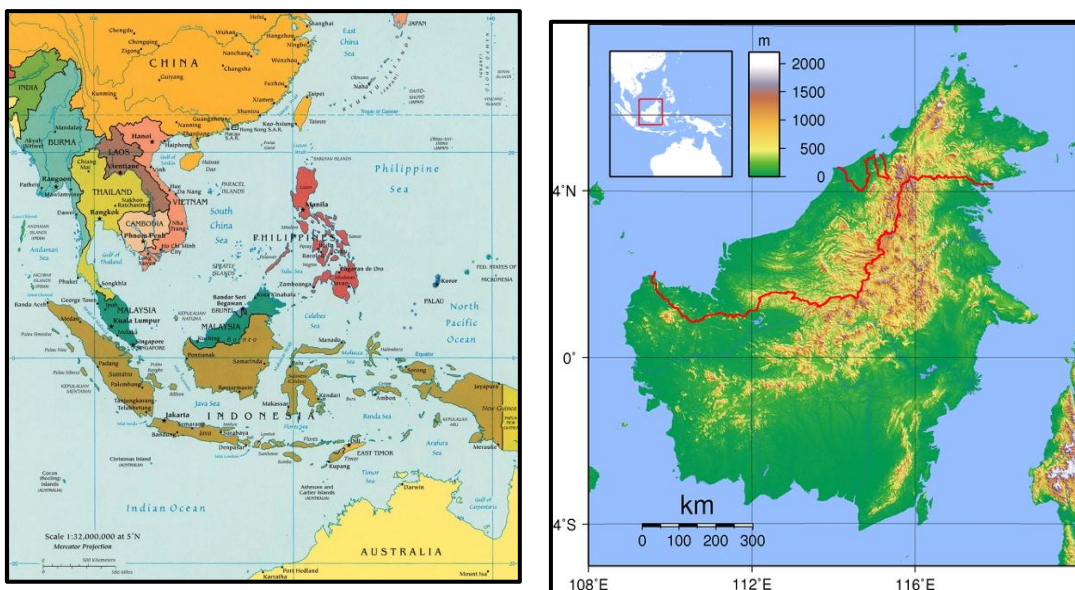


Figure 2.1 Maps of South East Asia and Borneo

Source: Creative Commons Map: South East Asia, 2014; Borneo, 2007

2.1 Governance

Malaysia. The Federation of Malaysia consists of Sabah ('Land Below the Wind') and Sarawak ('Land of the Hornbills') on the island of Borneo; eleven states on Peninsular Malaysia; the three federal territories of Kuala Lumpur, Petra Jaya and Labuan; plus numerous islands. Dividing Peninsular Malaysia from Sabah and Sarawak, by a distance of 600 kilometres, is the South China Sea. Figure 2.2 shows the Malaysian states (white), with Sarawak highlighted (dark).

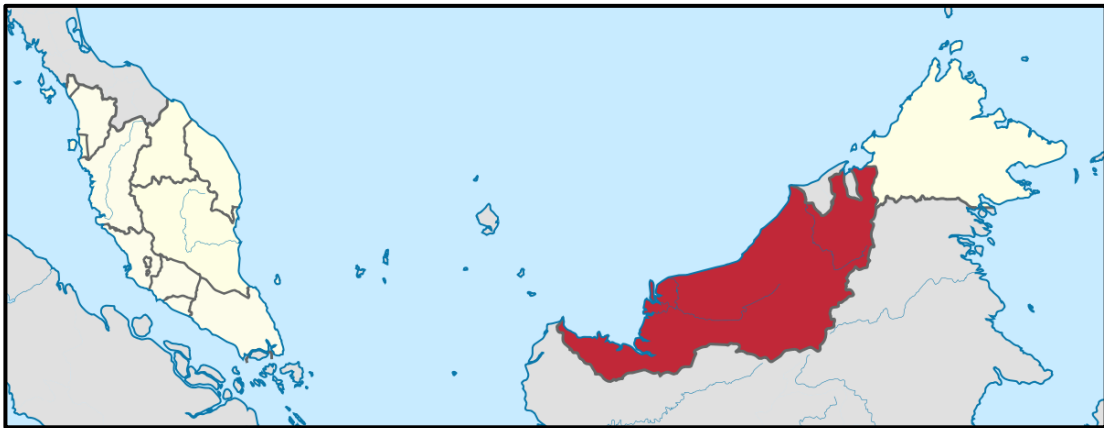


Figure 2.2 Malaysian states (Sarawak highlighted)

Malaysian States, 2009. Source: Creative Commons Map:

The capital city of Malaysia is Kuala Lumpur and Putrajaya, where Parliament meets, is the administrative centre (Tourism Malaysia, 2013). The Malaysian government is a democracy modelled on the Westminster parliamentary system and has a constitutional monarch (Sarawak Government, 2012; Tourism Malaysia, 2013). In Peninsular Malaysia the sultans are the heads of state but in Sabah and Sarawak the head of state is appointed by the Malaysian king (Rowthorn, Benson, Kerr, & Niven, 2001). The chief minister of each state government is appointed from the majority party of the state legislative assembly (Rowthorn et al., 2001). The legal system in Malaysia is based on English common law and there is a Syariah court for Muslims who breach Islamic law (Tourism Malaysia, 2013). Islam is by constitution the state religion, however, freedom of religion is allowed for non-Malays (Tourism Malaysia, 2013).

Sarawak. English law was established in Borneo in 1867, the oldest legislature in Malaysia (Miller, 1914; *History of Malaysia*, 2012). The British Colonial Government

(1946-1963) adopted the natural watershed running through central Borneo as the boundary between Sabah and Sarawak, Malaysia, and Kalimantan, Indonesia (Porrirt, 1997). Many Indigenous tribal families living along the political line were separated, and Bala (2001) notes that social, health and economic disparities have developed. By the time the Japanese occupation and World War Two ended, headhunting among the Indigenous tribes of Borneo had been suppressed (Rowthorn et al., 2001). Sarawak joined the newly formed Federation of Malaysia in 1963 (Rowthorn et al., 2001). With the conclusion of the 1962–1966 ‘confrontation’ along the Sarawak-Kalimantan border, backed by the Indonesian Communist Party and disaffected Malaysian Chinese (Rowthorn et al., 2001), Sarawak experienced rapid urban growth and the beginning of a widespread rural to urban migration (Bala, 2001).

The state of Sarawak is divided into six divisions for administrative and political purposes. All the participants in this study live in the Miri and Baram District. Figure 2.3 illustrates the Miri and Baram District boundary extending to the Kalimantan, Indonesian border.

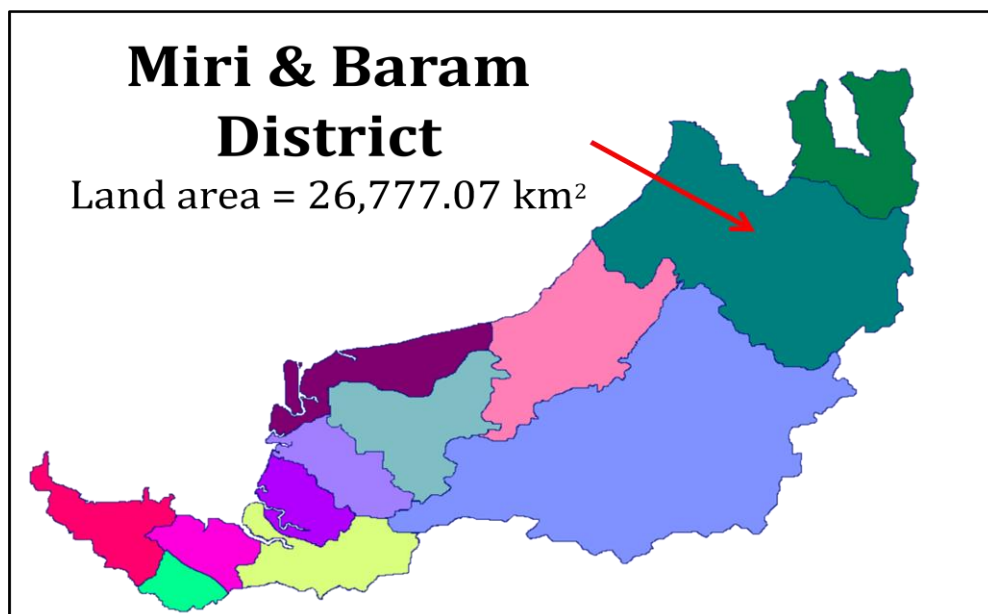


Figure 2.3 Map of Sarawak districts

Division of Sarawak. 2012 Source: commons.wikimedia.org

2.2 Demographics

Malaysia. The nation of Malaysia is multi-racial, multi-ethnic/tribal, multi-religious, multi-cultural and multi-lingual. In 2014 Malaysia had an estimated population of 31.7 million, broken down into ethnic groups as Malay and Indigenous (Bumiputra) (67.4%), Chinese (24.6%) and Indian (7.3%) (MDOS [Malaysian Department of Statistics], 2014). The predominant group in Peninsular Malaysia are the Malays (63.1%), in Sabah the Kadazan/Dusun (24.5%) and in Sarawak the Ibans (30.3%) (MDOS, 2014). The religious breakdown for Malaysia is Islam (61.3%), Buddhism (19.8%), Christianity (9.2%) and Hinduism (6.3%); the remainder includes other religions, including traditional, unknown or no religion (MDOS, 2014). Malaysian government statistics are kept to track intra-state, inter-state and international population movements (MDOS, 2011) and it shows that population diasporas has not led to cultural assimilation and each ethnic group continue to practice their traditions. Beng (2006) suggests that Malaysians identify with their own family's cultural roots and if of mixed parentage will celebrate both parents' cultural heritage. Most Malaysians appreciate each other's traditions and visit friends of different ethnicity for 'open house' during festivals. Of the 137 languages spoken in Malaysia, the official language is Bahasa Melayu (MDOS, 2011) however, most Malaysians speak two or more languages or dialects fluently.

Sarawak. In Sarawak there are 27 main ethnic groups and many sub-ethnic/tribal groups, each with discrete cultural identities and dialects (Sarawak Government, 2011). In total there are 78 Land Dayak, Malayic and North Borneo language families in distinct communities throughout Sarawak (SIL [Summer Institute of Linguistics], 2015). Many of the Indigenous people do not have a written language and until recently their family trees, history and legends were only passed down orally from one generation to the next, often in the form of songs about family exploits, especially from the headhunting days. The major languages spoken and taught in Sarawak schools are Malay, Mandarin, English and Iban (Sarawak Government, 2011).

The religious breakdown for Sarawak is Christian (1,052,986) Islamic (796,239) Buddhist (332,883) Traditional (148,645) and Hindu (4,049); the remainder includes other, unknown, or no religion (MDOS, 2014). Sarawak is the only state in Malaysia

with a Christian majority however, all live together respectfully, harmoniously and with tolerance for each other's beliefs. There are numerous cultural celebrations throughout the year and Sarawak is a favourite destination for tourists to experience the vast array of traditional music, costumes, dances, foods, crafts and customs of the different ethnicities and religions.

Sarawak has a population of 2.66 million with the highest concentration found in the capital Kuching (681,901), followed by Miri (358,020); the state's annual population growth rate is 0.8% (Sarawak Government, 2014). Sarawak is the largest state in Malaysia yet has a population density of 20 people per square kilometre, the lowest density of any Malaysian state (Sarawak Government, 2012). Comparing all the Malaysian states, Sarawak and Sabah have the lowest percentage of nuclear family households (53.1%) and the highest percentage of extended family households (31.4%) (MDOS, 2014). Records from the last two government censuses show that Sarawak has the lowest literacy rate, the lowest computer literacy rates for both urban and rural populations, and together with Sabah is the least urbanised of all of the Malaysian states (MDOS, 2014).

2.3 Environment

Malaysia. Sabah, Sarawak and Peninsular Malaysia are all fairly sheltered from typhoons, unlike Vietnam and the Philippines, and unlike neighbouring Indonesia have no active volcanoes, fewer earthquakes and tsunamis. Therefore Malaysia has had fewer natural disasters affecting the health and well-being of its citizens. The climate of Malaysia is equatorial (25–35° C) and humid (80–90%) with monsoon seasons however, the coastal areas are hotter and drier (Sarawak Government, 2014). The temperature in the highland areas above 1,200 metres can be as low as 10° at night and on the highest mountain in South East Asia, Mount Kinabalu (4,095 meters) in Sabah, can drop as low as 4° at night (*Sabah, Sarawak & Brunei*, 1993).

Sarawak. The steamy Borneo climate, which evenly receives between 2,000 mm and 4,500 mm of rain annually, feeds a rich and diverse tropical rainforest (Christensen, 2002; Sarawak Government, 2012) in which new animal and vegetable species are still being identified (Bruno Manser Foundation, 2014). Sarawak has established a number of national parks to preserve some of the pristine rainforest and the primeval limestone

caves of the Gunung Mulu National Park, said to be 140 million years old, have UNESCO World Heritage Site status (Sarawak Government, 2014).

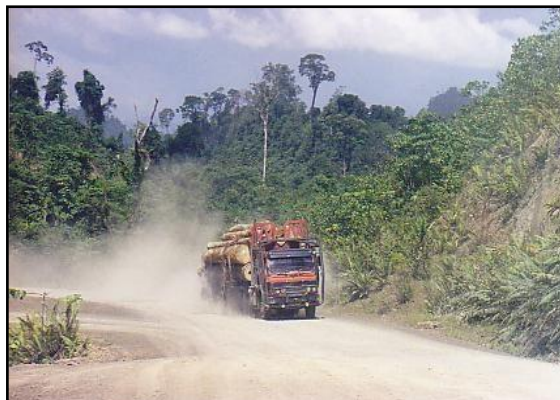
The tropical rainforest has been intensively logged over the past few decades and replaced with oil palm plantations (Hansen, Potapov, Moore, Hancher, Turubanova, Tyukavina et al., 2013). The copious amounts of agrochemicals used and machinery discharge threaten river ecosystems. The World Bank estimates that in Malaysia the timber and oil palm industries are cutting down the rainforest trees at four times the sustainable rate (Colchester, 1994). Christensen (2002) cautions that rapid ethnobotanical loss is likely over the next ten to twenty years unless steps are taken to preserve the unique species-rich ecosystems of Sarawak and in 2007 UNESCO urged the preservation and conservation of the Borneo rainforests (Thiessen, 2012). The Indigenous people supplement their diet by hunting animals, catching fish and gathering fruits, nuts and vegetables from the rainforest (Janowski, 1991). Wild vegetables are eaten at almost every meal in the longhouses (Christensen, 2002) and the nomadic Penan depend totally upon the rainforest for their food and shelter needs (Rowthorn et al., 2001). The consequences of deforestation are catastrophic and include the extinction of endemic species; polluted rivers, landslides and flooding; the loss of traditional foods and medicines; and the displacement of Indigenous people from their native customary homelands (Colchester, 1993).

2.4 Socio-economic Development

Malaysia. Strategically placed for trade, Peninsular Malaysia is linked to the island of Singapore by a bridge and a causeway, has a land border with Thailand, a maritime boundary with Vietnam and the Philippines, and is separated from Sumatra Indonesia by the Straits of Malacca (Miller, 1914; *History of Malaysia*, 2012). From colonial trading outpost to industrialisation, Malaysia is now ranked as the third leading economy of South East Asia (MDOS, 2014). From the 1980s Malaysia has seen rapid economic growth and urbanisation and has a GDP growth rate of 6.3% per annum (Tourism Malaysia, 2013). The currency differences for the Malaysian Ringgit (RM) hovers around (Australian) AUD\$1:RM3.03; (United States) US\$1:RM3.22; (European) EURO1:4.26; (Great Britain Pound) GBP1:5.46.

Sarawak. Borneo was considered an inhospitable land inhabited by fierce headhunting tribes (Lo, 1986) however, artefacts dating from the fourth century AD indicate early barter trade with India, China and other Middle-eastern and Asian countries (J. Payne et al., 1994). Trade ships also brought explorers, archaeologists and missionaries (J. Payne et al., 1994). As coastal security improved the villages of Borneo, once terrorised by pirates and slave-traders (Cunningham, 2002; Lo, 1986; Tate, 1988), grew and developed independently from Malaya (Adelaar, 1995).

The main export commodities for Sarawak are crude petroleum, liquefied natural gas, timber and agricultural products including pepper, palm oil, rubber and coconut oil (Sarawak Government, 2012). To accelerate economic growth and transform Sarawak into a developed state, the Sarawak Corridor of Renewable Energy development, which sanctions the construction of 50 hydroelectric dams, was launched in 2008 (Sarawak Government, 2014). Opposition to this initiative cites large-scale environmental destruction, little recompense and no equity for the affected communities, the displacement of tens of thousands of Indigenous people from the fertile river valleys (Colchester, 1993) and the demise of their tribal lifestyle forever (S. Osman, 2000).



Photograph 2.1 Dry season

Photograph by researcher's family members.

Sarawak's road network between major towns and cities are well developed with good standard airports, sealed roads, electricity, treated water supply, telecommunication systems, shopping centres and housing. However the Pan-Borneo Highway linking the west coastline from Pontianak in Kalimantan Indonesia through Sarawak and Brunei to Kota Kinabalu, Sabah is incomplete and would contribute to the eastern states'

infrastructure and development but it is in dire need of completion, repair and maintenance (J. Fernandez, 2014). Many interior areas of Sarawak are still inaccessible and only the larger population centres have small plane runways. The timber companies have opened up most of the interior areas but their roads are dangerous to use and, depending upon the season, can be feet deep in dust or mud.



Photograph 2.2 Monsoon season

Photograph by researcher's family members.

Miri and Baram District. The sparsely populated interior of Sarawak often depends upon rivers as the main means of transport between rural communities (Sarawak Government, 2014). The Baram River (466 kilometres long) is the second longest river in Sarawak and enters into the South China Sea just north of Miri (Hoebel & Hoon, 1986; *Sabah, Sarawak & Brunei*, 1993). Miri is the major urban centre for the Miri and Baram District and many of the participants in this study originate from small towns and longhouses situated along the Baram River system (Figure 2.4).

Miri has developed rapidly to city status, spurred on by the oil, timber and oil palm industries (Hutton, 1993; Sarawak Government, 2011). Curtin University Sarawak branch opened in Miri fifteen years ago and this has elevated Miri to an intellectual hub, especially in engineering and commerce. The current population of the city of Miri and of Miri Division is expected to rise, from natural increase and the migration of tribal folk from rural to urban areas in search of work or education (Sarawak Government, 2011). Statistics for Miri indicate the population is Iban (105,036)

Chinese (81,977) other Bumiputra tribes such as Kenyah, Kayan, and Kelabit (60,574) Malay (57,627) Melanau (9,285) Bidayuh (4,100) and Indian (1,271) (MDOS, 2014).



Figure 2.4 Map of Miri district and Baram River basin

Baram River Basin Sarawak. 2012. Source: commons.wikimedia.org

2.5 Health Indicators for Malaysia

Numerous waves of invasion and immigration saw various ethnicities, dissimilar to the Indigenous locals, settle in Malaysia and Borneo, bringing their culture and religion with them (Kamarudin, 2010). History records that many invaders and immigrants died from malaria, typhoid and cholera (Miller, 1914; Rowthorn et al., 2001). While the local Indigenous population had adapted to endemic diseases due to natural selection (Baer, 2000) many succumbed to newer introduced diseases.

When examining a country's principal causes of death one can deduce how developed a country is by the degree to which its' health problems have transitioned from infectious diseases towards chronic diseases. It is a reflection of a country's economic and industrial status and progress. Singapore is compared to as it is the most developed country of the South East Asian region (SMOH [Singapore Ministry of Health], 2014).

Table 2.1 shows the ten principle causes of death for Malaysia, Singapore and Myanmar.

Table 2.1 The ten principal causes of death – medically certified

	Malaysia (MDOS, 2014)	Singapore (SMOH, 2014)	Myanmar (MOHM, 2011)
1	Ischaemic heart disease	Cancer	Human immunodeficiency virus (HIV)
2	Pneumonia	Ischaemic heart disease	Septicaemia
3	Cerebrovascular disease (incl. stroke)	Pneumonia	Other diseases of respiratory system
4	Septicaemia	Cerebrovascular disease (incl. stroke)	Respiratory tuberculosis
5	Transport accident	Accidents, poisoning and violence	Other diseases of the liver
6	Chronic lower respiratory disease	Other heart diseases	Foetal malnutrition/slow growth, disorders of short gestation and low birth weight
7	Malignant neoplasm of trachea, bronchus and lung	Urinary tract infection	Stroke, not specified as haemorrhage
8	Diabetes mellitus	Chronic obstructive lung disease	Heart failure
9	Conditions of peri-natal period	Nephritis, nephrotic syndrome and nephrosis	Malaria
10	Diseases of the liver	Diabetes mellitus	Other heart diseases

Sources: (MDOS, 2014) (SMOH, 2014) (MOHM, 2011)

Table 2.1 shows the ranking differing widely between Malaysia, Singapore and Myanmar. From the ten principal causes of death, it can be seen that Myanmar still struggles with the effects of infectious diseases (MOHM [Ministry of Health Myanmar], 2011). The situation in Malaysia on the other hand, is shifting towards that of industrialized and developed countries, from infectious diseases to having more chronic non-communicable diseases as the main causes of death in the population.

Save the Children International and its 30 member organisations annually compile a world ranking order and report on the best to the worst country to live in, if a mother or a child, by evaluating their well-being and the availability of resources (Save the

Children, 2014). There are 178 countries on the list (1 being the best) and highlights those countries assessed to be in a ‘fragile’ state.

Table 2.2 shows the Save the Children 2014 mothers’ index ranking for some South East Asian countries and Australia, the developed country closest to Malaysia.

Australia has a ranking of 9, Singapore 15 and Malaysia is ranked number 68, in the better half of the list. Myanmar has the worst Save the Children 2014 Mothers’ Index Ranking of any South East Asian country. It is ranked at 157 and listed as ‘fragile’ and in need of aid and improvement (Save the Children, 2014).

Table 2.2 Save the Children 2014 mothers’ index ranking

	Malaysia	Singapore	Brunei	Indonesia	Thailand	Myanmar	Philippines	Australia
Lifetime risk of maternal death	1:1,300	1:25,300	1:1,900	1:1:210	1:1,400	1:250	1:300	1:8,100
Under-5 mortality rate (per 1,000 live births)	8.5	2.9	8.0	31.0	13.2	52.3	29.8	4.9
Expected number of years of schooling	12.7	14.4	14.5	12.7	13.1	8.7	11.3	19.9
Gross national income per capita (US\$)	9,820	47,210	31,590	3,420	5,210	1,130	2,500	59,360
Participation of women % govt seats	13.9	25.3	–	18.6	15.7	4.3	27.2	31.1
Mother’s Index Rank (out of 178 countries)	68	15	–	113	72	157	105	9

Source: Save the Children, 2014

The health indicator figures for Malaysia and Sarawak were obtained from the official Malaysian government department of statistics website. The data for 2014 was updated and published online in July 2016. The years 2015 and 2016 are yet to be published at the time of writing.

Table 2.3 presents demographic statistical comparisons given for Malaysia, Sarawak and Singapore. This is to identify the statistical differences for Sarawak as compared with Malaysia as a whole and compared with Singapore the most developed of all South East Asian countries.

Table 2.3 Demographic statistical comparison

	Malaysia (MDOS, 2014)	Sarawak (S'wak Govt, 2014)	Singapore (SDOS, 2014)
Population (millions)	31.7	2.66	5.54
Gender ratio (males : females)	107 : 100	107 : 100	965 : 1000
Annual population growth	1.5%	0.8%	1.0%
Crude birth rate (per 1,000)	13.1	14.9	9.8
Total fertility rate	2.0	1.9	1.25
Crude death rate (per 1,000)	4.8	4.3	4.7
Infant mortality rate (per 1,000 live births)	6.6	7.1	1.8
Male life expectancy (years)	72.5	75.2	80.5
Female life expectancy (years)	77.4	78.3	84.9

Sources: (MDOS, 2014) (Sarawak Govt, 2014) (SMOH, 2014)

From Table 2.3 it can be seen that for 2014 Sarawak has the least annual population growth (0.8%) which the ministry suggests may be due to movement of people to Peninsular Malaysia for education and in search of work (Sarawak Govt, 2014). Compared to Malaysia and Sarawak, Singapore has the lowest total fertility rate (1.25%) due to a decline in the average family size. The difference in infant mortality rates per 1,000 live births is glaring: Singapore (1.8) to Malaysia (6.6) and Sarawak (7.1). This figure reduces as a country develops and the health system improves.

Summarised verbal information for various statistics were also given by the Malaysian department of statistics for 2014, however, the charts were not available to view. Malaysia's rapid urban development and rural to urban migration has increased the urban population to 71.0%, up 10% in one decade from 2004 (MDOS, 2014). The Malaysian all mortality indicators declined in the two years prior to 2014 and crude birth rates also decreased (MDOS, 2014). There is a difference in birth rates when divided into the major ethnic groups: Malay (20.7) Indigenous (19.0) Chinese (12.7) and Indian (12.6) (MDOS, 2014). The Malaysian annual population growth decrease correlates with the decline in fertility rates, international migration and as the country becomes an aging population (MDOS, 2014).

2.6 Health Transition in Sarawak

Education. Education and health advanced jointly together in Sarawak. The first schools were set up by the Christian missionaries and followed a standardised English education system which helped to unify a multi-lingual society (J. H. Tan, 2012). The Christian mission schools were handed over to district councils to administer in 1954 (J. H. Tan, 2012). From 1950 to 1970, in response to the devastation of Asian countries from the second world war, Australia sponsored more than 40,000 Asian students to study in tertiary institutions in Australia under the Colombo Plan (Downer, 2005). My husband was one of these students. The then Australian prime minister Robert Menzies believed that ‘improved living standards would foster political stability and counter the spread of communism in the region’ (Downer, 2005, p. 2). Other countries also sent volunteer workers and teachers to the rural and remote areas to establish schools and give health instruction to the Indigenous Dayak tribes (Toynbee, 1997).

Health. Books documenting the early settlement of Europeans in Borneo note that many succumbed to malaria, cholera (Lo, 1986), typhoid fever (Cunningham, 2002), dysentery (Leong, 2011), plague brought in with the rats from the trading ships and unknown fevers (R. Payne, 1960). Westerners exploring Borneo introduced pneumonia, tuberculosis, diphtheria, sexually transmitted diseases and measles and, as the Indigenous people had no immunity from these, at least 50% of their number succumbed and many tribes were expected to die out (Lees, 1979). A number of the missionaries were qualified medical and health personnel who set up clinics near longhouses and the medical care they provided earned the respect of the animist Dayaks (Cunningham, 2002). Hygiene training for mothers, children’s health instruction and home cleanliness (Cunningham, 2002) helped to raise the standard of living, particularly in the longhouses and remote areas (Southwell, 1999) and tribal population numbers began to increase again from around 1952. The Borneo Evangelical Mission planes supplemented the limited government planes and opened up many airstrips in the central interior areas and were used to fly sick people to hospitals in the major towns (C. L. Tan, 2006). By 1980 the Sarawak Health Department Flying Doctors Service took over the role.

Today Sarawak, like the rest of Malaysia, has seen rapid development and most urban centres have good hospital facilities offering adequate medical services. Patients come from a wide radius that includes many smaller outlying villages, and if a needed service is not available they are referred to a government or private specialist clinic in Miri, Kuching or Kuala Lumpur. However, for those who live in Sarawak's interior, the scenario is quite different. In remote areas people sometimes have to walk a number of days through thick rainforest carrying a sick person on a stretcher, or navigate the rapids of the upper Rejang and Baram rivers in longboats to get to a *desa klinik* (district clinic). In rural districts closer to urban centres, it may take three or more hours' driving on rough, boggy roads to reach a clinic, sometimes to find there is no doctor or nurse there. Indigenous women of the highlands and interior of Sarawak usually deliver their babies in their longhouses, and if there are complications it is too late to get medical help, resulting in maternal death rates for Sarawak and Sabah Dayaks being much higher than for Peninsular Malaysian ethnicities (Jegasothy, 2002).

It is ironic that Sarawak, the richest natural resources state in Malaysia, spends RM422 (AUD\$140) per person on the health care budget (Sarawak Government, 2011) compared to Peninsular Malaysia, where the World Health Organization (WHO) recorded the annual average health budget per person as RM1,800 (AUD\$597) ('Sarawak's Hidden Health Scandal', 2011). The doctor-to-population ratio (including private) for Malaysia is 1:758 (MDOS, 2014) and for Sarawak is 1:918 (MDOS, 2014). In Australia it is 1:320 (ABS [Australian Bureau of Statistics], 2013) including urban and remote areas, general practitioners and specialist doctors. There is still an acute shortage of doctors and nurses in the rural government service in Sarawak and nurses and assistant medical officers (medics) run most of the small rural and remote clinics. This sometimes leads to imprecise medical diagnoses and mistakes. For example, erroneous epidemiological data and lack of information systems and registries has led the International Agency for Research on Cancer (IARC) to use comparative estimates, or data from major cities, to assess South East Asia's cancer burden, presented in *Global Cancer Statistics 2008* (Jemal, Bray, Center, Ferlay, Ward, & Forman, 2011). Basch (1999) notes various reasons why accurate health statistics are lacking in developing countries, including lack of knowledge, understaffing and the inaccessibility of registry offices to people in isolated rural and remote areas. This is

still true for the remote interior of Sarawak. However, lifestyle changes bring different medical challenges once the rural folk migrate to the urban areas of Sarawak.

2.7 Why This Study?

Living in Miri over four decades, I have been a subjective observer of many of my husband's relatives as their lives have transitioned from a remote subsistence agricultural community to an urban western lifestyle. I have seen relatives become obese, grapple with diabetes, hypertension and stroke, and unfortunately some who have died from untimely cancer, heart disease and kidney failure. With a rising number of end-stage renal disease patients, haemodialysis therapy centres were set up by the Sarawak state government in collaboration with non-government organisations (Hooi, 2006). Currently there are three haemodialysis centres in Miri. At the time of writing, the Miri Hospital serves 160 patients and is solely government funded and usually reserved for the very sick or poor. The privately run Miri City Medical Centre serves 20 patients whose therapy is self-funded or funded from employers' benefits. The Malaysian Red Crescent Kidney Dialysis Centre serves 313 patients and is funded by the patients' family, public donations and employers' benefits (MRC [Malaysian Red Crescent], 2014). All the patients on haemodialysis from all three centres were invited to enlist their family members to participate in this study on a 'first come, first recruited basis'. Sadly, a number of end-stage kidney disease patients from all ethnicities lamented how being on dialysis has depleted their savings and burdened their family. It was my work with renal dialysis centre patients and their families that drew my attention to their difficult circumstances and their incessant need to raise funds for their dialysis fees. Of concern to me were the patients' immediate family members and of interest to me, were their transitional lifestyles, the fallacies and misinformation that surround beliefs on the causes of end-stage kidney disease and the contradiction of their practices and behaviours.

There are no mass population screening programs in Malaysia, but hospitals, clinics, private doctors and voluntary organisations provide opportunistic screening services for cervical pap smears, diabetes, hypertension and proteinuria, incidentally for people who may have turned up for another reason. Those recorded as having infectious diseases or non-communicable diseases represent the tip of the proverbial iceberg. This study will

benefit the individuals participating in a number of ways. The clinical and biochemical screening tests conducted will identify those persons who are at higher risk for developing a chronic non-communicable disease, metabolic syndrome or chronic kidney disease. These tests were done free of charge for the participants. All laboratory reports were issued to each participant for them to take to their doctor for advice and follow-up. If detected early, intervention measures to slow the progression of and reduce complications from the disease can be initiated. The participants will be given the summary, conclusions and recommendations of the study, to share with their family and friends. This study will also be of value to the general Miri community. Analysis of the results will identify if there are local factors that may be associated with an increased risk for the development of chronic kidney disease in the Miri population. Appropriate intervention programs and strategies should be developed to target, screen and educate high risk groups identified from the study. This will contribute to health awareness, improve chronic non-communicable disease forecast and bring economic benefits for the community.

2.8 Conclusion

Over the last half century Malaysia has reaped huge profits from natural resources and developing industries, has created a yearning for wealth and education in the younger generations and progressed towards developed-nation status. Sarawak has also evolved within Malaysia and all ethnic groups, Malay, Chinese, Indian and Indigenous, are caught up in a transition from their traditional heritage to a modern lifestyle. Parallel to this lifestyle exchange is a corresponding health and medical transition from infectious diseases to chronic non-communicable diseases.

This chapter has discussed both the development of and the divide between Sarawak with Peninsular Malaysia and how health statistics quoted as Malaysian do not always reflect the reality of the situation in Sarawak. Researchers are gradually building up a repertoire relevant to Sabah and Sarawak and perhaps, as these territories develop, the statistical gap will also close.

The resultant physical and medical problems related to chronic kidney disease and metabolic syndrome and the consequences to effected individuals as well as the local community will be discussed in the next chapter.



Photograph 2.3 Mulu Tourism cultural dancers: Malay, Iban, Orang Ulu male, Orang Ulu female and Bidayuh dancers. Photograph by researcher.

Chapter 3 Literature Review

This literature review explores chronic kidney disease and its interconnectedness with the metabolic syndrome as a potential risk factor for chronic kidney disease. This literature review specifically focuses on chronic non-communicable diseases and environmental factors that may predict and advance the development of chronic kidney disease. It discusses the aetiology of chronic kidney disease and the progression to end-stage renal disease. The review includes discussion of the metabolic syndrome chronic comorbidities of type 2 diabetes, hypertension and cardiovascular disease. Written from the perspective of public health and lifestyle medicine, special reference is made regarding developing countries to help provide further context for this study. The chapter concludes with best public health management practices for chronic kidney disease and metabolic syndrome and uncovers research gaps in knowledge and information.

3.1 Literature Review Methods

3.1.1 Aims for the background, context and literature review

In order to underpin the research, the aims for the chapter 1 background, chapter 2 context and chapter 3 literature review of this study was to investigate fully:

- those areas determined to be relevant from the study's research questions;
- areas pertinent to achieving the aims and objectives of the study;
- research gaps and a niche in order to position this thesis for future directions when planning community education awareness and intervention programmes.

Prerequisite guidelines included the following:

- directly relating to the topics under research and applicable to this study;
- immersed in the medical and health knowledge surrounding the topics;
- assessing conflicting research to determine the best study plans;
- evaluating this intended study against other research study designs;
- appraising this study's methodology and approach in light of other research.

3.1.2 Selection of peer-reviewed studies

A contents outline was established in order to keep the background, context and literature review within the confines of the aims. The context chapter 2 explored factors contributing to the current public health challenges faced by the participant population source. This chapter relied heavily upon hard-cover books from the museum and libraries for factual information; government websites for demographic and health statistics; and local newspaper articles filled in gaps of knowledge that were unavailable on the websites. The background chapter 1 gave an overview of the study areas of concern and guided the literature review in defining those areas in more detail.

A detailed search strategy was employed for the selection of appropriate studies to consider for the background and literature review.

1. The source for retrieving reference material was through the online Curtin University library website. The electronic databases most often used for the literature search included Pubmed, Medline (Ovid), Medline (Proquest), Cochrane Library Database (updated 2011) and Google Scholar. Journal articles were also sought after from specific journal websites. Academic hard-copy books and journal magazines were also sourced as reference material.
2. A thorough key-word Boolean search approach using 'and' 'not' 'or' 'near' was conducted. The key words and various combinations that were searched included end-stage renal disease, chronic kidney disease, metabolic syndrome, chronic non-communicable diseases, type 2 diabetes mellitus, hypertension, cardiovascular disease, obesity, immediate family members, first degree relatives and other associated topics.
3. Peer-reviewed Google Books, journal reviews and journal abstracts relevant to the background and literature review contents outline were inspected. Those that fell within the inclusion and exclusion parameters had the full-text retrieved and read. Historical and significant references found in the reference lists of pertinent journal articles were also retrieved and read. After reading, relevant sections were marked and filed according to the contents category.

4. During the literature writing process the relevant sections were reviewed again and if suitable the idea was used and referenced in-text. Due care was taken to ensure literature research integrity by the proper citing of references. These were imported into the bibliography manager EndNote reference database and over five hundred references were found to be relevant.

3.1.3 Journal article inclusion and exclusion criteria

Throughout the thesis quantitative, mixed-methods and qualitative research studies were referenced. In searching for appropriate reference material, a pre-determined inclusion exclusion criteria list and a trials summary review table was followed. The limitations placed on the inclusion exclusion criteria list included being in English language; dates greater than 2000, although this was difficult for historical references; core clinical books and journals and peer-reviewed full-text articles only.

Quantitative studies were evaluated according to The Newcastle Critical Appraisal Worksheet which was originally sourced from Darzins, Smith & Heller, (1992). Updated versions were acknowledged and incorporated into the review table (Young & Solomon, 2009; van Raan, 2013). To ensure evidence-based research was optimal, aspects pertaining to validity, reliability and how research bias was minimised, were appraised (NHMRC, 1999; Cochrane Handbook, updated 2011). Checklists from different study designs were consulted, including for random control trials (CONSORT, 2010) and for cohort, case-control trials and cross-sectional observational studies (STROBE, 2000). The Singapore-Statement on Research Integrity (Resnik & Shamoo, 2011) and clinical and best practice guidelines for chronic kidney disease for Malaysia (MMOH, 2006a) and Australian (AIHW [Australian Institute of Health and Welfare], 2014) were also referred to. The Mixed-Methods studies were evaluated by assessing the methods used, forms of coding and analysis used, interpretation of the findings, mechanisms used in designing a conceptual framework and generalizability (Tashakkori & Teddlie, 2010; Creswell & Plano Clarke, 2007). Criterion examined for review or discussion of qualitative studies included recruitment method, sample size and trustworthiness. The trustworthiness of the study was assessed according to its credibility, transferability, dependability and confirmability (Patton, 2002; Lincoln, Lynham & Guba, 2011; Lincoln & Guba, 1985).

The different methodologies, the expansive range of topics reviewed in the literature search and the paucity of available literature in some areas, meant that it was not feasible to follow a systematic review approach as that would have led to the exclusion of numerous historic and pertinent references. Therefore, some decisions for the inclusion of the literature was based on relevance and not always on research rigor, however, every endeavour to correctly document the literature search in line with recognized protocol on reporting these studies ensued.

3.2 End-Stage Renal Disease and Chronic Kidney Disease

3.2.1 International perspective and magnitude of end-stage renal disease and chronic kidney disease

Adverse health determinants may lead to chronic kidney disease, which is progressive and may deteriorate to end-stage renal disease and premature death (Levy et al., 2001; Levey, Eckardt et al., 2005; Anderson, Halter, Hazzard, Himmelfarb, Horne, Kaysen et al., 2009). Worldwide more than 1.1 million patients with end-stage renal disease require dialysis to survive (Lysaght, 2002; WHO, 2015). This figure excludes many people in the world's low-resource countries, who are unable to receive therapy because dialysis is inaccessible, unavailable or unaffordable, the nearest centre has limited machines, or they are deemed too old to receive treatment (WHO, 2003; Ayodele & Alebiosu, 2010). Various international registries indicate that the incidence of kidney failure is increasing in all countries (Levy et al., 2001; Levey, Eckardt et al., 2005; Jha et al, 2013). In the United States end-stage renal disease has climbed from 150 new cases per million population to 287 in ten years (United States Renal Data System, 1999), a rate of 5% per year, an incidence similar to that of AIDS (Reikes, 2000) and representing a prevalence rate of more than one in every 1,000 persons. In the United Kingdom in 2004 there were 101 new patients per million population (PMP), and the incidence of end-stage renal disease had doubled over the past 10 years (1994-2004), but it was still below the European figure of 135 PMP (Renal Association, 2004). In developed countries the number of patients with end-stage renal disease is increasing at a yearly rate of 7% (Lysaght, 2002). In Malaysia there are no community-based studies of the incidence of end-stage renal disease, but in 1991 it has been estimated at 86 per million population (PMP) and prevalence rates at 46 PMP (Hooi, 1993). By 2005 the prevalence rate had increased to 497 PMP and globally,

Malaysia had one of the highest percentages for incident haemodialysis patients with type 2 diabetes (Hooi, 2006). In 2013 the vice-chairman of the NKFM [National Kidney Foundation Malaysia] announced there were 4,000 Malaysians diagnosed with kidney failure every year and that 14 of every 100,000 people in Malaysia have kidney failure (NKFM, 2013b; Cheng, 2013). This means there has been an exponential escalation of rates over twenty years.

The burden of disease is disproportionate between richer and poorer countries, and there is a double burden for developing countries as they move from coping with infectious diseases to chronic diseases (WHO, 2003; WHO, 2015). In many of the lowest-resource countries the majority of people with kidney disease do not receive renal replacement therapy and die (Moosa & Kidd, 2006). Without renal replacement therapy, or if a person with end-stage renal disease decides to discontinue dialysis, death is caused by the toxic waste products accumulating in the blood, causing electrolyte imbalances (National Service Framework for Renal Services, 2005) and leading to a rapid decline in physical and mental functions. For every person with end-stage renal disease there are a significantly greater number with chronic kidney disease (Levey, Eckardt et al., 2005).

Worldwide there are approximately 250,000 new cases of chronic kidney disease diagnosed per year in developed countries alone (Collins, Couser, Dirks, Kopple, Reiser, Riella et al., 2006). The National Health and Nutrition Examination Surveys determined the prevalence of chronic kidney disease is 13.1% in the United States (Coresh, Selvin, Stevens, Manzi, Kusek, Eggers et al., 2007) and affects one in nine Americans regardless of age or ethnicity (Langman, 2006), meaning up to 10% of the population suffer from some degree of kidney disease. Of other developed countries, the Netherlands has the same percentage (Collins et al., 2006). In Australia there was a prevalence of chronic kidney disease of 11.2% (Chadban, Briganti, Kerr, Dunstan, Welborn, Zimmet et al., 2003; AIHW, 2014) and one in seven persons has at least one indicator of kidney damage (KHA, 2006c; KHA, 2015) and therefore is at increased risk of developing end-stage renal disease and cardiovascular disease. In Singapore, the most developed of South East Asian countries, the prevalence for chronic kidney disease is 12.8%; the Chinese have lower rates than the Malay or Indian groups (Sabanayagam, Lim, Wong, Lee, Shankar, & Tai et al., 2010).

In a sample of 876 persons, taken from the National Health and Morbidity Survey 2011 in Peninsular Malaysia, the prevalence was 9.07% for chronic kidney disease (Hooi, Ong, Ahmad, Bavanandan, Ahmad, Naidu et al., 2013). Of particular concern is that only 4% of those diagnosed were aware that they had the disease (Hooi, Ong et al., 2013). It is estimated that 4.2 million Malaysians have chronic kidney disease, many of them unaware ('Malaysian patients spend \$286mil', 2011). In response to the pandemic of kidney and associated cardiovascular disease throughout the world, the International Federation of Kidney Foundations and the International Society of Nephrology established World Kidney Day in an attempt to increase global public awareness of kidney disease (Collins et al., 2006; ISN, 2006).

As a country develops and its per capita GNP increases to about US\$3,000 per year, studies show that the poor especially face an increased risk of obesity and type 2 diabetes which may lead to chronic kidney disease then end-stage renal disease (Hossain, Kavar, & El Nahas, 2007). This phenomenon is also being observed in Malaysia. In 1966 centres were set up to cater for the increasing number needing renal replacement therapy, and since 1990 the new haemodialysis acceptance rate has grown exponentially, in line with the economic development of the country (Hooi, Wong, & Morad, 2005). As well as between countries, inequality also exists within countries and inequality in Malaysia corresponds to the economic development of each state. Sabah and Kelantan have fewer than 300 PMP; Pahang, Terengganu, Kedah, Perlis and Sarawak have between 300 and 600; and the remaining six states have a prevalence of more than 600, with Penang the highest at 787 PMP (Hooi, Lim, Ghazali, Wong, Tan, Ahmad et al., 2005).

The direct and indirect costs to governments and societies are incalculable. In Australia in 2013 there were almost 12,000 people receiving haemodialysis and 15% of all hospitalisations were related to kidney disease; it is the third most common reason for palliative care (ABS, 2014). In Malaysia it is estimated that there are 30,000 people on dialysis, and the number increases by approximately 6,000 per year (Cruetz, 2014) which costs the government around RM700 million per year, or RM33,000 per year per patient ('Malaysian patients spend \$286mil', 2011). In 2005 patients were being dialysed in units run by the government (37%), private centres (31%) and non-government organisations (32%), and were funded by the government (51%), self-

funded (23%), charity (12%) or other means (14%) (Hooi, 2006). At one Miri non-government organisation run haemodialysis centre the normal charge per dialysis session is RM150, but ninety per cent of the patients are subsidised and pay between RM1 and RM80 per session depending upon their individual financial situation ('MRC Miri to build kidney dialysis substation', 2015). The average monthly running costs for this haemodialysis centre is RM200,000.00 and this is mostly raised through donations from the public, corporate bodies and non-governmental organisations ('MRC Miri to build kidney dialysis substation', 2015). As the number of patients entering haemodialysis therapy escalates, both the government and the private healthcare systems become overstressed (Hooi, Lim, et al., 2005). For this reason halting the progression of chronic kidney disease to end-stage renal disease is beneficial, as well as being financially better for the family and more economical for the community at large (Khwaja et al., 2007).

3.2.2 Mortality of end-stage renal disease

Patients undergoing end-stage renal disease treatment have a higher mortality rate, even when adjusted, than the general population and are at increased risk for atherosclerotic disease, left ventricular hypertrophy, malnutrition and infection (Reikes, 2000; CDCP [Centers for Disease Control and Prevention], 2007). Once a person has established end-stage renal disease, the underlying cause of the disease, usually determines the survival outcome (Reikes, 2000). In the United States end-stage renal disease mortality rates are highest in the elderly, those with type 2 diabetes, and European Americans with cardiovascular disease, accounting for about 50% of these deaths; infections are the second main cause of death (United States Renal Data System, 1999). Other developed countries are similar. In Malaysia, the demand for renal transplant is high but due to the shortage of donor kidneys the transplant rate remains at 5–7 per million population per year (Hooi, Lim et al., 2005). Ten per cent of patients on haemodialysis die while waiting for a donor organ (Cruetz, 2014). There is little difference in mortality between haemodialysis and peritoneal dialysis patients in the United States (Vonesh & Moran, 1999), but mortality is lower in kidney transplant patients (United States Renal Data System, 1999), especially those receiving kidneys from live donors (Reikes, 2000). In Malaysia the annual average death rate in end-stage renal disease patients for haemodialysis is 10%, comparable to other countries, and in the chronic ambulatory

peritoneal dialysis (CAPD) group it is 15% (Lim, Lim, Lee, Wong, Ong, Shaariah et al., 2008).

3.2.3 Morbidity of end-stage renal disease and chronic kidney disease

There are many causes of kidney failure, and when patients first present for haemodialysis their primary underlying renal disease is recorded. In Malaysia there has been little fluctuation over the last ten years and the recorded causes for end-stage renal disease are type 2 diabetes (58%), hypertension (11%), glomerulonephritis and systemic lupus erythematosus (4%), polycystic kidney (1%) and obstructive nephropathy (1%); the remaining 25% are registered as of unknown cause (MSN, 2013). In most countries the two leading causes of end-stage renal disease are hypertension and type 2 diabetes (Reikes, 2000; Hallan, Coresh, Astor, Asberg, Powe, Romundstad et al., 2006). WHO has forecast that by 2030 the highest number of type 2 diabetes patients will be in Asia (Wild, Roglic, Green, Sicree, & King, 2004). All Peninsular Malaysians commencing haemodialysis have hypertension (9%) and type 2 diabetes (58%) (Cruetz, 2014; Lim, Ong, & Goh, 2011; MSN, 2014), but the leading causes of end-stage renal disease in Miri are hypertension (32.5%) and type 2 diabetes (30.4%) (MRC, 2014). Why there is this discrepancy is not presently known.

In addition to complications arising from type 2 diabetes and hypertension, there is a high degree of morbidity from other causes in persons with end-stage renal disease. Haemodialysis complications (e.g., infection, haemorrhage, arteriovenous access thrombosis); peritoneal dialysis infection (e.g., peritonitis); and kidney transplant problems (e.g., infection and cancer due to long-term immunosuppression) are complications intrinsic to end-stage renal disease therapy modes (Reikes, 2000). Haemodialysis has limitations and cannot completely compensate for the kidneys, and toxins may accumulate (e.g., beta-2-microglobulin-associated amyloidosis, poor urea and acidic by-products of metabolism clearance) (Reikes, 2000). Nutritional consequences of end-stage renal disease include osteodystrophy, malnutrition and anaemia, although treatment with recombinant human erythropoietin for anaemia (Mallick & Gokal, 1999) and improved dialysis membrane technology to clear nitrogenous solutes (Krivitski & Depner, 1998) have improved patient outcomes (Mallick & Gokal, 1999; Reikes, 2000).

As with chronic kidney disease, other chronic non-communicable diseases are asymptomatic and may go undetected for many years until the person presents with an advanced disorder (Hooi, Ong et al., 2013). As well as in combination with kidney disease, type 2 diabetes, hypertension and cardiovascular disease individually have major morbidity and mortality consequences that contribute to society's economic costs (ISN, 2006). Type 2 diabetes and hypertension predispose patients to atherosclerotic disease and renal failure, and type 2 diabetes can also affect a person's sight, neuropathy leading to limb amputations and susceptibility to infection (Reikes, 2000; ISN, 2006). Global comorbidity statistics on renal failure show that 34% of patients with chronic kidney disease have heart failure and 25% have coronary artery disease (Levy et al., 2001; Jha et al, 2013). More than half of reported end-stage renal disease deaths (Levy et al., 2001; Jha et al, 2013) and half of chronic kidney disease deaths (Rashidi, Ghanbarian, Azizi & Adler, 2007b; McCullough, Li, Jurkovitz, Stevens, Wang, Collins et al., 2008) are caused by cardiac events. Whether these percentages are similar in Miri is yet to be determined.

Disease complications, income and address can influence quality of life. Malaysian women on dialysis experience a lower quality of life than men and all genders with advanced chronic non-communicable diseases had a lower quality of life (Liu, Chew, Chiu, Zaki, 2005). There was inequality in availability and facilities available to rich and poor patients receiving dialysis, and those especially at risk were unemployed elderly patients without medical insurance (Liu et al., 2006). Where a patient lives can affect quality of life as well. In Australia it was found necessary to set up modern community-based satellite dialysis centres when there were clusters of patients in an area living a great distance from metropolitan centres (Kneipp, 2002). Following the Australian example, a non-government organisation in Miri is intending to set up a new kidney haemodialysis substation on the outskirts of Miri city to relieve the demand currently faced at the main centre ('MRC Miri to build kidney dialysis substation', 2015). This will be near a bus stop and close to a large area of low-cost housing so will make it easier for poorer people needing the haemodialysis services.

3.2.4 Clinical diagnosis and prognosis of chronic kidney disease

3.2.4.1 Anatomy and function of the kidneys

Weighing approximately 150 grams each, the kidneys contain around one million tiny filters called nephrons, each comprising a glomerulus encased in a Bowman's capsule and a renal tubule (Lamb, Tomson, & Roderick, 2005) (*Figures 3.1 and 3.2*). Each day the kidneys process approximately 200 litres of blood, and excrete 1–2 litres of metabolic waste products and excess water as urine every day (Wills & Savory, 1981; KHA, 2015). The process of ultrafiltration occurs at the barrier between the blood and the filtrate in the glomerulus (Paulev & Zubietta-Calleja, 2004). An osmotic pressure gradient called the Starling forces compels small molecules including water, glucose, sodium, chloride, amino acids and urea through the filtration barrier (Paulev & Zubietta-Calleja, 2004); larger substances cannot cross. The kidneys regulate the blood volume and electrolyte balance, and some minerals such as sodium, potassium and phosphorus that seep through the glomerulus membrane into the tubules are reabsorbed into the bloodstream (NIDDK [National Institute of Diabetes and Digestive and Kidney Diseases], 2014).

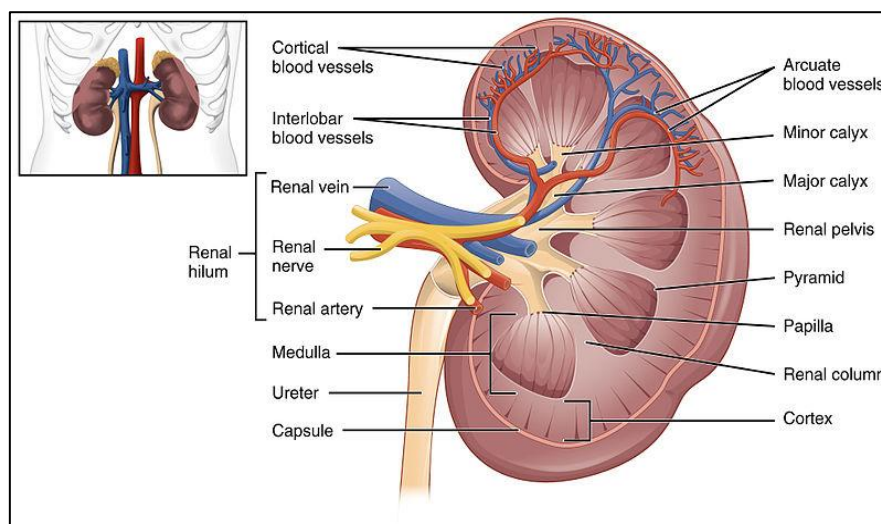


Figure 3.1 The physiology of the kidney

Source: Creative Commons. Open Stax College, 2013a

The physiology of the kidney is shown in Figure 3.1 and the route of blood flow through the kidneys and nephrons in Figure 3.2.

The kidneys also produce and regulate three important hormones: erythropoietin (EPO), vital for red blood cell production in the bone marrow; rennin to regulate and control blood pressure; and the active form of vitamin D, calcitriol, that promotes calcium absorption of the bone structure (NKF, 2013; NIDDK, 2014).

3.2.4.2 Pathophysiology of the kidney

Pathophysiology describes the biochemical and functional changes associated with a disease, as an organ, in this case the kidney, deteriorates. Irrespective of the disease aetiology of the chronic kidney disease, the end result is progressive renal damage through loss of functioning nephrons (Remington, Brownson, & Wegner, 2010). If this occurs over a few hours or days it is called acute renal failure and may or may not be reversible (Gaw et al., 2004; KHA, 2006b). Chronic kidney disease is the destruction of the kidney tissue by disease and develops over many months even years, is irreversible in the later stages, and eventually leads to end-stage renal disease (Gaw et al., 2004; KHA, 2006a).

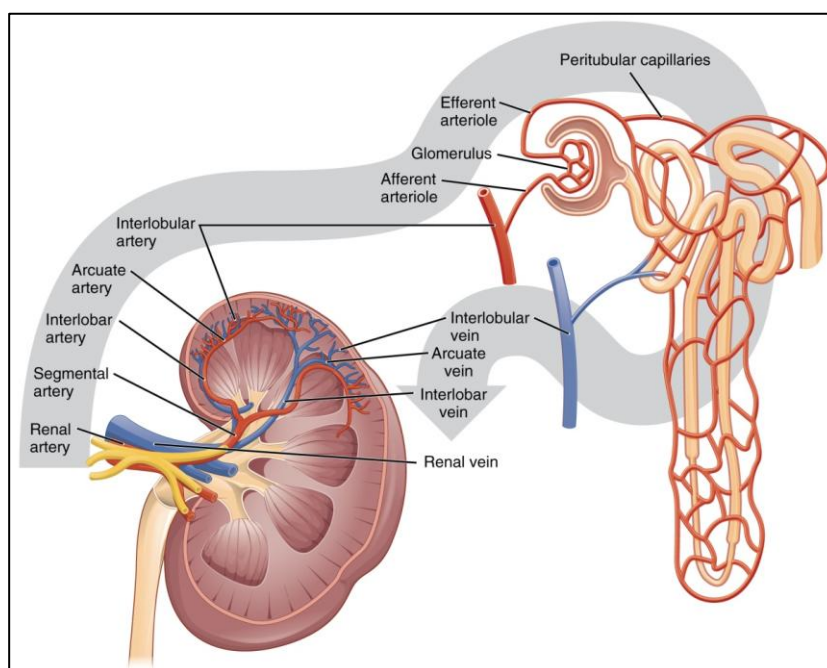


Figure 3.2 Blood flow in the kidney and nephrons

Source: Ketchum & Bright, 2013a. Creative Commons.

Abnormal mineral metabolism (Levin, Bakris, Molitch, Smulders, Tian, Williams et al., 2006) and biochemical disturbances commence with about 50% of kidney function

deterioration (Brocklebank & Wolfe, 1993; Kopple, 2001). Up to 90% of kidney function may be damaged before some people experience any signs or symptoms of disease (Levey, Coresh, Balk, Kausz, Levin, Steffes et al., 2003; KHA, 2015). In Australia 10% of people with chronic kidney disease do not know they have the disease (KHA, 2015). If diagnosed early, and with good clinical management, the rate of nephron loss may be slowed (Schieppati & Remuzzi, 2004; Stevens, Coresh, Greene, & Levey, 2006). Unfortunately even if the original cause of deterioration no longer exists, further deterioration is inevitable, as kidney damage has occurred and is irreversible (Brocklebank & Wolfe, 1993; Chadban et al, 2003).

3.2.4.3 Assessing kidney function and kidney damage

When less than 50% of the kidneys are functioning, the rate of deterioration declines substantially but symptoms such as tiredness, itchy skin and decreased urine output are often dismissed (KHA, 2006a) or associated with another chronic disease that the person may have. As the kidneys further deteriorate to 25% changes in the urine volume and colour, blood and/or pus in the urine, nausea, vomiting, loss of appetite, oedema and numbness in the hands and feet, a metallic taste and bad breath, darkening of the skin and cramping muscles may, or may not, begin to be noticed (KHA, 2006a). Anaemia, hyperthyroidism and cardiovascular disease also accompany kidney decline (Lamb et al., 2005).

Once suspected of kidney disease, a person will be sent for blood and urine tests. Normally the kidneys remove potassium from the blood; however, if they are damaged the potassium remains and can cause irregular heartbeat (KHA, 2007). Red blood cells leaking into the urine, known as haematuria, is a sign of urinary tract infection, kidney or bladder disease (KHA, 2007). Early in chronic kidney disease the protein albumin leaks into the urine in micro amounts and is a good marker of kidney damage. Creatinine is a waste product from body muscle breakdown and repair. Urea, the main nitrogenous waste from dietary protein, is formed in the liver and is the final stage, via the Krebs' cycle, of the protein catabolic process (Wills & Savory, 1981; NIDDK, 2014).

If the kidneys are functioning inadequately, these metabolites and other organic substances accumulate in the blood, become toxic, and may inhibit enzyme and

hormone activity in the body (Wills & Savory, 1981; NIDDK, 2014). Both urea and creatinine are concentrated in the blood as the kidneys lose their function. Urea may be reabsorbed but urine creatinine is not reabsorbed once it crosses the ultrafiltration barrier, and is a good indicator of kidney function (KHA, 2006b). The rate of ultrafiltration, called the glomerular filtration rate (GFR), is 140 mL/min in a normal healthy individual (Lamb et al., 2005); when this rate decreases and only 10% of the normal kidney function remains, the person needs to make preparations to commence renal replacement therapy before there is little or no more urine produced (Gaw et al., 2004; KHA, 2007). This is a major life-changing event.

In 2002 The National Kidney Foundation in the United States defined chronic kidney disease using glomerular filtration rate and stratified it into stages (Hooi, Lim et al., 2005) (*Table 3.1*).

Table 3.1 Categories and staging of chronic kidney disease using the glomerular filtration rate

Stage	GFR	Description
1	>90 ml/min/1.73m ² *	Kidney damage with normal GFR
2	60-89 ml/min/1.73m ² *	Kidney damage with mildly reduced GFR
3	30-59 ml/min/1.73m ²	Moderately reduced GFR
4	15-29 ml/min/1.73m ²	Severely reduced GFR
5	<15 ml/min/1.73m ²	Kidney failure (end-stage renal disease)

* To classify as stage 1 or 2 chronic kidney disease, there must be evidence of chronic kidney damage (present for at least three months); for example, structural or functional abnormalities of the kidney such as proteinuria and haematuria.

Source: (KDIGO, 2012; KHA-CARI, 2012; NKF, 2008)

When the glomerular filtration rate drops below 15 ml/min/1.73m² it is referred to as end-stage renal disease and renal replacement therapy is commenced.

A survey and series of international controversies conferences organised by the Kidney Dialysis Outcomes Quality Initiative (KDOQI) programme, provided evidence-based clinical practice guidelines which gained international acceptance and improved diagnosis and management of chronic kidney disease, providing a consistent definition and classification of kidney disease (Levey, Eckardt et al., 2005).

The initiative defines chronic kidney disease as

“... kidney damage or Glomerular Filtration Rate of <60 mL/min/1.73m² for 3 months or more, irrespective of cause ... Kidney damage in many kidney diseases can be ascertained by the presence of albuminuria, defined as albumin-to-creatinine ratio >30 mg/g in two of three spot urine specimens.” (Levey, Eckardt et al., 2005, p. 2091)

The original conceptual model depicting the stages of chronic kidney disease deterioration, modified and published by Levey, Eckardt et al. (2005), was designed to clarify the five stages to lay-people so they might better understand the deterioration of chronic kidney disease to end-stage renal disease. In the conceptual model, this deterioration is shown to produce more severe complications with progression over time, until death occurs.

3.2.4.4 Estimate of the glomerular filtration rate

Creatinine, a waste product produced by the muscles, is removed from the blood by the kidneys (KHA, 2006b). There is a reciprocal correlation between the serum creatinine and glomerular filtration rate, and different equations have been devised to interpret the results using creatinine plus age, gender, ethnicity, or body size of the person (ACCWG [Australasian Creatinine Consensus Working Group], 2005). The results are reported in mL/min/1.73 m² and are corrected for an average person's body surface area (Gribbles, 2007). Serum creatinine concentration is a common measure used to determine kidney function, but the blood test measurements alter with age, gender, muscle mass and diet, and measurements may vary by up to 20% (KHA, 2006d). Glomerular filtration rate is an accurate measure of creatinine clearance (KHA, 2006d), but it is cumbersome for an individual to save the 24 hours of timed urine output that it requires. A number of predictive equations to estimate glomerular filtration rate (eGFR) has been developed that do not require a weight measurement, are more accurate in calculating the level of kidney function, and enhance the ability to determine the extent of kidney damage at an early stage (KHA, 2006d). The eGFR formula only requires the person's age and ethnicity in order to determine the kidney function (Langman, 2006). It requires stable serum creatinine for its predictive accuracy therefore is not suitable for use with acute renal failure patients (Lamb et al., 2005). For chronic kidney disease it is accepted by

both KDOQI (Levey, Eckardt et al, 2005) and the later revised Kidney Disease: Improving Global Outcomes (KDIGO, 2012; Inker, Astor, Fox, Isakova, Lash, Peralta et al. 2014). The eGFR method is now preferred, as it facilitates early diagnosis and management of the disease (Stevens, Manzi, Levey, Chen, Deysher, Greene et al., 2007) when the individual is still asymptomatic (Mathew, Johnson, & Jones, 2007). The same staging as glomerular filtration rate is used when presenting eGFR formula results to determine the kidney function: stage 1 is normal; stages 2, 3 and 4 gauge the deterioration of chronic kidney disease, and stage 5 is end-stage renal disease (Langman, 2006).

Table 3.2 shows the equations for estimating renal function validated for a multi-ethnic Malaysian population (NKFM [National Kidney Foundation Malaysia], 2013a). The Cockcroft–Gault Creatinine Clearance method still uses the 24 hour urine collection sample as well as serum creatinine in the equation, and therefore is not the preferred estimate formula in Australia (ACCWG, 2005) but still accepted in Malaysia.

Table 3.2 Equations for estimation of renal function

1.	4-variable MDRD eGFR = 186 x standardised sCr ^{-1.154} x age ^{-0.203} x 1.212 [if black] x 0.742 [if female], where GFR is expressed as ml/min/1.73m ² of body surface area and sCr is expressed in mg/dl.	(Levey, Bosch et al., 1999)
2.	CKD-epi eGFR = 141 x min (sCr /k,1) ^α x max (sCr /k,1) ^{-1.209} x 0.993 ^{Age} x 1.018 [if female] x 1.159 [if black], k = 0.7 (females) and 0.9 (males), α = -0.329 (females) and -0.411 (males); min indicates the minimum of sCr /k or 1, and max indicates the maximum of sCr /k or 1.	(Levey, Stevens et al., 2009; Stevens, Schmid, et al., 2010)
3.	Cockcroft–Gault Creatinine Clearance = CrCl (ml/min) = (140 – age (yrs)) x body weight (kg)/ sCr (μmol/l) x constant (1.23 for males; 1.04 for females).	(Cockcroft & Gault, 1976).

Note. sCr = Serum Creatinine; CrCl = Creatinine Clearance; MDRD = Modification of Diet in Renal Disease; chronic kidney disease-epi = chronic kidney disease-epidemiology

Source: (National Kidney Foundation Malaysia, 2013a)

Although convenient, results using eGFR have limitations and may lack

- generalisability from one population group to another without evaluation and testing (Stevens, Manzi et al., 2007)
- inaccuracies in precision of the various formulas when measuring different populations such as those with diabetes mellitus (Beauvieux, Moigne, Lasseur, Raffaitin, Perlemoine, Barthe et al., 2007)

- or with those of a different ethnicity (Maple-Brown, Lawton, Hughes, Sharma, Jones, Ellis et al., 2010)
- or in populations without chronic kidney disease (Stevens, Coresh et al., 2006)
- calibration consistency of the creatinine assay (Stevens, Manzi et al., 2007)
- reliability in persons under 18 years of age (ACCWG, 2005)
- reliability for those on dialysis (ACCWG, 2005)
- nor is it suitable to use in cases of acute renal failure (Lamb et al., 2005)

Obesity has been validated for the MDRD formula (ACCWG, 2005). A number of other conditions may also affect the eGFR result using the MDRD estimate formula, and a change in 15% glomerular filtration rate result may indicate one of the following and require further testing to confirm (ACCWG, 2005):

- extreme diets such as vegetarian or high protein
- extreme exercise regimes
- pregnancy
- severe liver disease
- variation with drug dosage
- amputation (ACCWG, 2005)

In 2007 changes to reduce the range of variability, recommended by the Australasian Creatinine Consensus Working Group (2005), were adopted by all Australian laboratories (Matthew, Johnson et al, 2007). Notably this included a revised equation (*Table 3.3*) based on a different assay measurement and calibration of the serum creatinine, published as the Modification of Diet in Renal Disease revised '175' formula (rMDRD '175'), to align with international reference methods recommended by the National Kidney Disease Education Program in the United States (Levey, Coresh, Greene, Stevens, Zhang, Hendriksen et al., 2006) (Mathew, Johnson et al, 2007). Gribbles Pathology Malaysia, who handled the urine and blood collection and laboratory assessments for this study, follow the Australasian Creatinine Consensus working Group (2005) and provide automatic reporting whenever a serum creatinine test is requested (Gribbles, 2007).

Table 3.3 Revised equation for MDRD estimation of renal function

4. rMDRD '175 formula' =

$$eGFR = 175 \times (sCr \times 0.0113) - 1.154 \times (\text{age}) - 0.203 \times (0.742 [\text{if female}])$$

where MDRD = Modification of diet in renal disease (the name of the study where this formula was developed)

eGFR = estimate glomerular filtration rate (ml/min/1.73m²)

sCr = serum creatinine concentration (μmol/l)

age is expressed in years.

Source: (The Australasian Creatinine Consensus Working Group, 2005; Levey, Coresh, Green et al., 2006; Mathew, Johnson et al, 2007).

3.2.4.5 Urinary albumin to creatinine ratio If the kidneys are damaged, protein leaks into the urine along with waste products filtered from the blood (KHA, 2006a).

An increase in albumin and other water-soluble serum proteins (total proteins) in the urine is referred to as proteinuria and is an early marker for kidney damage from diabetes mellitus, high blood pressure and glomerular diseases in adults (KHA, 2006a) and a risk factor for early mortality (KHA-CARI [Kidney Health Australia - Caring for Australians with Renal Impairment], 2013). A number of factors can temporarily increase proteinuria including urinary tract infection, exercise stress, high muscle mass, fever and heart failure, ketosis and hyperglycaemia (KHA, 2006a).

Albuminuria and haematuria are indicators of kidney disease progressing to end-stage renal disease, whatever the cause of chronic kidney disease. Proteinuria is a good indicator of progressive renal disease but it is already in an advanced stage before it is detected. Traditional screening for proteinuria using urine dipsticks in patients without diabetes mellitus has been debated with regard to the sensitivity and specificity of the test, and high screening costs to low detection rates of end-stage renal disease (Johnson, Jones, Matthew, Ludlow, Chadban, Usherwood et al., 2012). The lower threshold for most reagent strips is set at 150 mg albumin per litre, a macroalbumin level, whereas if there is diabetic glomerular leakage the concentration of albumin in the urine is 20–100 mg per litre, which is a microalbumin level (Gribbles, 2007). Urine dipsticks do not adequately pick up microalbuminuria; a high proportion five false-positive results requiring recall of patients; and importantly, only they address end-stage renal disease and not cardiovascular disease; they are no longer recommended in Australia (KHA-CARI, 2013).

Based on the Kidney Disease, Improving Global Outcomes (KDIGO) position Statement in 2006, The Australasian Proteinuria Consensus Working Group recommend that a urinary albumin-to-creatinine ratio (ACR) should be used as it is a suitable measure for both those with diabetic nephropathy and those without diabetes mellitus, is more reliable than total protein tests, and is predictive of both end-stage renal disease and cardiovascular disease (APCWG [Australasian Proteinuria Consensus Working Group], 2012). Persons with risk factors for chronic kidney disease, including hypertension and cardiovascular disease, should be tested using ACR annually if they have diabetes mellitus, and those without diabetes mellitus bi-yearly (APCWG, 2012). Persons with type 2 diabetes and hypertension of Asian ethnicity should be tested for microalbuminuria to prevent complications from chronic kidney disease and cardiovascular disease developing (Wu, Kong, De Leon, Pan, Tai, Yeung et al., 2005). It is also recommended that all pathology laboratories follow standard definitions and sex-specific cut-off points for albuminuria (APCWG, 2011). Gribbles Pathology Malaysia (2007) confirm they follow this.

The ACR Range for kidney damage (*Table 3.4*) is shown below.

Table 3.4 Ratio of albumin to creatinine: range for kidney damage

	Urine albumin / creatinine ratio (mg/mmol)	
	Males	Females
Normal	<2.6 mg	<3.6 mg
Microalbuminuria (trace protein)	2.6–25.0 mg/mmol	3.6–35.0 mg/mmol
Macroalbuminuria (overt proteinuria)	>25.0 mg/mmol	>35.0 mg/mmol

Source: (KHA-CARI, 2012; Gribbles, 2007)

Cut-off points for increased levels of albumin in the urine are in two stages. Microalbuminuria has an albumin excretion rate of 20–200 ug/min and may be an early predictor of chronic kidney disease (Gribbles, 2007; KHA, 2007). It is referred to as incipient diabetic nephropathy. If type 2 diabetes is well controlled this may be reversible; however, macroalbuminuria is irreversible and has an AER of >200 ug/min (Gribbles, 2007).

Females have a higher threshold for microalbuminuria than males (APCWG, 2011). A first morning void is the preferred sample (APCWG, 2011), but if a random spot urine

sample is taken the patient must rest one hour first as exercise, even normal daily activity, increases the albumin excretion rate (Gribbles, 2007).

3.2.4.6 Classification and staging of chronic kidney disease

A large, multiracial study from Singapore, a relatively small but rich nation, advocates nation-wide screening to identify persons at risk of chronic kidney disease (Ramirez, McClellan, Port, Stephen, & Hsu, 2002), but screening the whole population is not considered cost effective or suitable for most countries (Mathew, Corso, Ludlow, Boyle, Cass, Chadban et al, 2010). The conclusion from The AusDiab Kidney Study, using data from the 1999 to 2000 Australian Diabetes, Obesity and Lifestyle Study, recommends screening all persons with hypertension and/or abnormal plasma glucose levels for microalbuminuria and macroalbuminuria (Atkins, Polkinghorne, Briganti, Shaw, Zimmet, & Chadban, 2004).

A study using the results from NHANES III suggests that screening for albuminuria and eGFR at the same time identifies a greater percentage of persons with kidney disease from different population sectors (Garg, Kiberd, Clark, Haynes, & Clase, 2002) and predicts cardiovascular disease (Johnson, Jones, et al., 2012). This is now the benchmark. Kidney function is determined by the glomerular filtration rate or eGFR result and kidney damage is indicated by the ACR result (KDIGO, 2012; KHA 2007; KHA-CARI, 2013).

Combining both eGFR and ACR enhances the detection and risk stratification of chronic kidney disease and cardiovascular disease (Johnson, Jones, et al., 2012). The matrix allows for easy assessment and plotting of chronic kidney disease progress and aids health workers in explaining to patients the two variables, glomerular filtration rate/eGFR and ACR involved in chronic kidney disease. This initiative to enhance the classification of chronic kidney disease by KDIGO (2012) has been adopted internationally.

Table 3.5 presents this as it is adapted and used by Kidney Health Australia (KHA-CARI, 2012).

Table 3.5 Stages of chronic kidney disease by glomerular filtration rate and albumin to creatinine ratio

		Albuminuria stage		
Kidney function stage	GFR (mL/min/1.73m ²)	Normal (urine ACR mg/mmol) Male: < 2.5 Female: < 3.5	Microalbuminuria (urine ACR mg/mmol) Male: < 2.5-25 Female: < 3.5-35	Macroalbuminuria (urine ACR mg/mmol) Male: > 25 Female: > 35
1	≥90	Not chronic kidney disease unless haematuria, structural or pathological abnormalities present	Yellow	Red
2	60-89			
3a	45-59	Yellow	Orange	
3b	30-44	Orange		
4	15-29	Red	Red	
5	<15 or on dialysis	Red		

Key: Green - Low Risk Yellow - Moderate Risk Orange - High Risk Red - Very High Risk

Note. Conversion factor for ACR is 10 for converting Metric Units (g/dl) to SI Units (g/l) (NKFM, 2013b)
Source: (KHA-CARI, 2012) Reproduced with permission (*see Appendix.G*).

Different clinical action plans are needed for each stage of chronic kidney disease, and management needs to be individualised for each patient as the lower the glomerular filtration rate the greater the metabolic consequences and thus the more complicated the disease management (Lamb et al., 2005; Mathew & Corso, 2009). In the early stages of chronic kidney disease greater than 60 mL/min/1.73 m², clinical intervention focuses on diagnosing and treating comorbidities, especially hypertension and proteinuria (Lamb et al., 2005). As the glomerular filtration rate declines further cardiovascular disease risk factors are addressed and lifestyle modification, especially smoking cessation, emphasised (Mathew & Corso, 2009). Although symptoms are still sub-clinical, stage three, less than 60 mL/min/1.73 m² to 30 mL/min/1.73 m², is the commencement of metabolic disturbances such as hypertension ↑, parathyroid hormone ↑, calcium absorption ↓, phosphate excretion ↓, anaemia (erythropoietin deficiency) ↓, nutritional status ↓, and left ventricular hypertrophy onset (KHA-CARI, 2013; Lamb et al., 2005). Anti-proteinuric drugs (ACE angiotensin converting enzyme inhibitor or ARB angiotensin receptor blockers) are commenced (Mathew & Corso, 2009). In

stages four to five, 30 mL/min/1.73 m² to 15 mL/min/1.73 m², glomerular filtration rate is severely decreased, the patient starts experiencing symptoms as metabolic disturbances effect whole body systems including triglycerides ↑, hyperphosphataemia, metabolic acidosis, hyperkalaemia and decreased libido (Lamb et al., 2005; NKF, 2008) and the patient is referred to a nephrologist and prepared for RRT or kidney transplant (Mathew & Corso, 2009). Stage five, less than 15 mL/min/1.73 m², presents with anorexia, vomiting, pruritus, saline retention and often heart failure (Lamb et al., 2005) and once uraemia occurs, RRT must be commenced (Mathew & Corso, 2009).

When developing an algorithm framework outlining the procedures for detecting chronic kidney disease, a health department or hospital must take into consideration the budget and the local state of affairs of that country. The Malaysian Ministry of Health algorithms for the management of chronic kidney disease (NKFM, 2013a) are different from those of the Australasian Proteinuria Consensus Working Group (Johnson, Jones, et al., 2012). The algorithms for both, however, enable medical staff to properly assess the patient, monitor deterioration of the kidneys, and determine the time at which to commence haemodialysis therapy (KHA-CARI, 2013; MMOH [Malaysian Ministry of Health], 2006a).

3.2.5 Selected risk factors of chronic kidney disease and end-stage renal disease

The aetiology of chronic kidney disease is not well understood and nor is the rate of progression and development of chronic kidney disease to end-stage renal disease, but a number of contributing risk factors are known. One seventh of the Australian population have a chronic non-communicable disease which increases their risk of developing kidney disease (KHA, 2015). Although most countries have the same contributing risk factors there may be local variation and anomalies. Apart from aging, being a first degree relative, type 2 diabetes and hypertension, Malaysia lists other possible risk factors for kidney failure as obesity and metabolic syndrome, cardiovascular disease, glomerulonephritis, abuse of non-steroidal antiinflammatory drugs (NSAIDs) and analgesic pain killers, smoking, anaemia, herbs including those containing aristolochic acid, and physical trauma (MMOH, 2006a). Biomedical risk factors include infectious and genetic diseases that may initiate kidney disease (KHA, 2006d). Lack of basic knowledge about diagnosing and treating disease-initiated kidney

problems can lead to unnecessary morbidity and mortality in some countries (ISN, 2006). Poor clinical management can accelerate kidney damage and hasten end-stage renal disease; and conversely, kidney damage can exacerbate these diseases (KHA, 2006d). Discussion of these diseases are outside the parameters of this literature review, and the discussion of risk factors of chronic kidney disease will focus on chronic non-communicable diseases, socio-demographic and environmental factors.

3.2.5.1 Predisposing factors

The distribution of the causes of end-stage renal failure may vary between different socio-demographic and population clusters. In Miri distribution differences for age, gender, ethnicity and inherited predisposing factors need to be determined before intervention programs can be planned for specific target groups.

Age. Chronic kidney disease diagnosis is multi-factorial, but the rise in incidence is associated with an aging population (Mahon, 2001; Zhang, Zuo, Xu, Wang, Wang, Wang et al., 2007). It was once thought that a mildly increased serum creatinine level was a normal feature of ageing, but new research shows that in fact it is chronic kidney disease as there is also a reduction in the glomerular filtering function of the kidney (Langman, 2006). In Australia 42% of new patients on renal dialysis are 65 or older (Kneipp, 2002). In the United States one in every 770 people aged over 65 has end-stage renal disease (United States Renal Data System, 1999). The incidence of end-stage renal disease increases with age, especially the median age, but this could be in response to other factors such as more efficient diagnosis, an increase in type 2 diabetes incidence with age, or a greater acceptance of undergoing haemodialysis (Reikes, 2000) however the risk of death is greater than the risk of end-stage renal disease in the aged (O'Hare, Choi, Bertenthal, Bacchetti, Garg, Kaufman, & McClellan, 2007). In Malaysia the number of younger patients starting dialysis remains static, but the incidence continues to rise in those over 65 years of age, who often have comorbid conditions including cardiovascular disease (Hooi, Lim et al., 2005).

Gender. In Australia 57% of new patients entering renal dialysis treatment are men and 43% women (Kneipp, 2002). In the United States 54% of end-stage renal disease patients are men (Reikes, 2000). The disparity between gender in Malaysia is similar to that of Australia, with 56% men and 44% women commencing dialysis in 2005 (Hooi,

Lim et al., 2005). Premenopausal women have a much less pronounced incidence of heart and kidney disease, but in diabetic women heart and kidney disease incidence equals or exceeds that of age-matched men (Maric, 2010).

Ethnicity. Populations of non-European origin have higher susceptibility to renal disease, and the prevalence of chronic kidney disease and end-stage renal disease will continue to increase more rapidly in other ethnic communities than European-descended populations (Feehally, 2005). The prevalence of chronic kidney disease and end-stage renal disease also varies significantly between different ethnic groups (Feehally, 2005; Mau, West, Shara, Efird, Alimineti, Saito et al., 2007). In the United Kingdom, for example, there is a higher incidence of diabetes mellitus in people from South Asia but a higher incidence of hypertension in people of Africa and Afro-Caribbean ethnicity; both these conditions are linked with a greater risk of chronic kidney disease (Mahon, 2001). In the United States end-stage renal disease is four times more common in African-Americans (3.6 cases per 1,000 population) than among European-descended Americans (0.8 cases per 1,000) (Reikes, 2000; Norris, Tareen, Martins, & Vaziri, 2008). The Pima American Indians have 20 times the rate of new cases of kidney failure than the general US population (Cho, Burrows, Roberts, Bullock, & Toedt et al., 2014). It was found that mortality for American Indians and Alaskan natives was different from European Americans and influenced by type 2 diabetes, smoking, alcohol and social determinants (Esprey, Jim, Cobb, Bartholomew, Becker, Haverkamp et al., 2014). Another study found that American Indians and Alaskan natives had longer survival rates than European-descended people with type 2 diabetes and attributed it to hereditary factors (Burrows, Cho, McKeever Bullard, Narva, & Eggers, 2014).

Comparing the diverse ethnic groups of the Asian and Pacific Islanders of Hawaii to mainland United States revealed a number of disparities which are likely due to cultural factors, language barriers, and health access factors (Mau, West, Sugihara, Kamaka, Mikami, Cheng, 2003): higher rates of diabetes mellitus, glomerulonephritis and hypertension are reported. In the National Kidney Early Evaluation Program (KEEP-2), a community screening program found that chronic kidney disease was four times greater in the Hawaiian population than in mainland Americans (Mau, West, Shara et al., 2007). Each ethnic group was also found to have different risk factors for chronic

kidney disease (Mau, West, Shara et al., 2007). Hypertension was the main risk factor for Japanese, Caucasians, native Hawaiians and Filipinos; diabetes and lower educational attainment for the native Hawaiians; diabetes and being over the age of 65 years for Filipinos. The Chinese were found to have no significant risk factors for chronic kidney disease (Mau, West, Sugihara et al., 2003).

The cause of end-stage renal disease can vary within the same ethnic group if residents live in different environments. Since migrating to London, Punjabi Indians have had a greater risk of coronary heart disease, including a greater body mass index (BMI), than their siblings in India (Patel, Winterbotham, Britt, Sutton, Bhatnagar, Mackness et al., 1995). It was found that Aborigines in New South Wales had different patterns of cause, incidence and outcomes than Aborigines in the Northern Territory (Feehally, 2005). From a racial perspective, in Australia 81% of new patients on renal dialysis to date were Caucasoid, 8% Aboriginal, 7% Asian, 2% Pacific Islander, and 2% other (Kneipp, 2002); the incidence of end-stage renal disease in the Australian Aboriginal population is greater than that of non-Aboriginal people for many reasons (White, Wong, Sureshkumar, & Singh, 2010; Jha et al. 2013).

Family Medical History. Ethnicity and family history (FH) go hand in hand, and it is not easy to distinguish ethnic links from family history. There are many genetic diseases affecting the kidney, such as polycystic kidney disease, a genetic abnormality that runs in families (ISN, 2006). Some diseases affect whole communities: for example, it is thought that the high rate of nephritis in some Australian Aboriginal communities may indicate a family trait of increasing susceptibility to post-streptococcal glomerulonephritis (PSGN) known to contribute to renal disease (A. White, Wong et al., 2010).

Chronic non-communicable diseases are also thought to be heritable. Diabetes mellitus and hypertension, the two leading causes of kidney disease, may have familiar genetic linkages (ISN, 2006). Diabetic nephropathy clusters in families and there is a considerable genetic component of kidney complications in type 1 diabetes with a high mortality among this group (Savage & Maxwell, 2008). The Reasons for Geographic and Racial Differences in Stroke (REGARDS) cohort concluded that the first degree relatives of end-stage renal disease patients were more likely to be obese and have type

2 diabetes and should be targeted for chronic kidney disease detection and intervention programs (McClellan, Speckman, McClure, Howard, Campbell, Cushman et al., 2007). End-stage renal disease patients and their families also tend to have increased cardiovascular disease complications and death, suggesting a genetic component is involved (Naiman, Cheung, Goldfarb-Rumyantzev, Naiman, Cheung, & Goldfarb-Rumyantzev 2009).

There are ongoing studies to find genetic markers and there appears to be a genetic link between chronic kidney disease and hypertension (Drawz & Sedor, 2011), and a variant in a gene on chromosome 10 has been identified as a marker for type 2 diabetes (Ng, Tam, Lam, So, Ma, & Chan, 2007), and there are a number of studies linking albuminuria to various chromosomes (Freedman et al., 2005). In the future there may be routine genetic tests available for high-risk persons.

3.2.5.2 Socio-demographic and socio-economic factors

A number of socio-demographic and socio-economic factors are associated with chronic kidney disease, although whether these factors directly contribute to its development is still under appraisal. Socio-economic factors such as environment and low income were found to contribute more in elderly African-Americans (Peralta, Ziv, Katz, Reiner, Burchard, Fried et al., 2006). Swedish, US and UK studies all show that in deprived areas there is a higher incidence of chronic kidney disease (Mahon, 2001; Levey, Atkins, Coresh, Cohen, Collins, Eckardt, & Powe, 2007). There is also a higher prevalence of chronic kidney disease in those with lower levels of education (CDCP, 2007; W. Y. Lee, Jung, Park, Rhee, & Kim, 2004; Levey, Atkins et al, 2007), in minority or disenfranchised population groups (Remington et al., 2010) and in developing countries and areas of developed countries where living standards and hygiene are lacking (Atkins et al., 2004). As well as infectious diseases, there is also evidence that many chronic non-communicable diseases are associated with inadequate housing and environmental conditions (Braubach, Jacobs, & Ormandy, 2011).

Housing. Poor housing and environmental conditions are related to socio-economic status and ultimately can affect the health of an individual (Braubach et al., 2011). Studies associating socio-economic status to chronic kidney disease have had mixed outcomes. The socio-economic status of 1,657 patients at the Sheffield Kidney Institute

(Sheffield, UK) was determined and the association between it and chronic kidney disease assessed (Bello, Peters, Rigby, Rahman, & El Nahas, 2008). This retrospective cross-sectional study used the British Index of Multiple Deprivation score and the National Kidney Foundation K-DOQI classification of chronic kidney disease to compare socio-economic status with estimated glomerular filtration rate (eGFR) (Bello et al., 2008). Adjusted logistic regression models determined that a low socio-economic status correlated with lower chronic kidney disease scores at presentation, supporting the view that it is associated with the development and progression of chronic kidney disease (Bello et al., 2008). Conversely, in a large US case-control study of almost 24,000 end-stage renal disease dialysis patients and controls, after adjustments for demographics, no statistically significant association was found for family history and socio-economic status (Song, McClellan, McClellan, Gadi, Hadley, Krisher et al., 2009). Indicators employed for socio-economic status included 'median household income, percentage high school graduates, percentage vacant housing units or ethnic composition' (Song et al., 2009, p. 1). Familial clustering in lower socio-economic areas was attributed to the patient no longer being able to work and moving to cheaper housing, and not to other socio-economic factors; inherited factors for type 2 diabetes, hypertension and chronic glomerular disorders had a greater effect on familial clustering, and the study recommended earlier screening for chronic kidney disease for family members (Song et al., 2009).

Comparing the prevalence of physical, mental and cognitive diseases and impairments among elderly persons in the United States and the Dominican Republic, it was found that chronic non-communicable disease prevalence and possibly cardiovascular disease were associated with a higher socio-economic status, but higher education was not; however, physical disabilities were inversely associated with affluence and higher education (Acosta, Rottbeck, Rodriguez, Gonzalez, Almanzar, Minaya et al., 2010) . An aging population requires that health inequalities be monitored and as economically disadvantaged communities become more affluent there is a need for chronic non-communicable disease prevention programs (Acosta et al., 2010). There are many studies of socio-economic status and chronic non-communicable diseases but few of the association with chronic kidney disease. The correlation is not known for the Sarawak end-stage renal disease and their first degree relatives. WHO is encouraging more research into socio-economic status and health transition in developing countries.

3.2.5.3 *Lifestyle behavioural factors*

Tobacco smoking. A negative lifestyle behaviour that appears to be escalating in Malaysia is tobacco smoking. It is well established that smoking, and passive smoking to a lesser extent, have a detrimental effect on coronary heart disease, which is now a leading cause of death in many countries (J. He, Vupputuri, Allen, Prerost, Hughes, & Whelton, 1999). The findings of the International Tobacco Control Southeast Asia survey revealed that 23% of Malaysian male teenagers are daily smokers, with the majority commencing the habit at the mean age of 13.7 (SD = 1.8), a 67% rise in teenage smoking over ten years (Hammond, Kin, Prohmmo, Kungskulniti, Lian, Sharma et al. 2008). The relationship between smoking and chronic kidney disease in older Malaysians is unknown.

Although the mechanism for the effect of smoking on kidney function is unclear, a study of 11,247 healthy Australian adults tested for indicators of renal damage showed smoking to be associated with the prevalence, development and progression of kidney disease in men but not in women (Briganti, Branley, Chadban, Shaw, McNeil, Welborn et al., 2002). In both type 1 diabetes and type 2 diabetes smoking affects renal haemodynamics and protein excretion and promotes the development of chronic kidney disease (Ritz, Ogata, & Orth, 2000). Orth (2000) emphasises that if a person has diabetes, smoking increases risk of development of nephropathy threefold. Smoking often plays an unrecognised role in chronic kidney disease (Ejerblad, Fored, Lindblad, Fryzek, Dickman, Elinder et al., 2004) with or without diabetes or hypertension (Orth & Hallan, 2008), regardless of blood pressure control with medication (Chuahirun, Simoni, Hudson, Seipel, Khanna, Harrist et al., 2004) and even in people who appear healthy (Ritz et al., 2000). Cardiovascular risk factors, including smoking, augments atherosclerosis of the kidney (Baggio, Budakovic, Casara, Gambaro, Saladini, Piccoli, et al., 2001), and even moderate chronic smoking may result in a person being susceptible for irreversible proteinuria (Halimi, Giraudeau, Vol, Caces, Nivet, Lebranchu et al., 2000; Remington et al., 2010). Smoking also hastens the progression of chronic kidney disease to end-stage renal disease in addition to increasing cardiovascular disease risk (Orth & Hallan, 2008); however, as soon as a person quits smoking, progression to end-stage renal disease decelerates and outcomes for the kidney immediately improve (Ritz et al., 2000).

Diet and physical activity. There are often health consequences when developing countries modernise. Adopting a modern lifestyle brings increasing economic affluence and status while lack of dietary restraint and of physical activity often accompanies the transition and leads to obesity and lifestyle diseases (Forouhi & Sattar, 2006). Poor nutrition increases the risk of obesity, which increases the risk of developing type 2 diabetes, a primary cause of kidney failure (KHA, 2006d). Simultaneous malnutrition and over-nutrition is a paradox many developing countries face today. A study using anthropometric measurements and three 24-hour diet recalls from the mothers and children of 182 households of the Indigenous Orang Asli of Selangor, Peninsular Malaysia, found that in 25.8% of households the mother was overweight (31%) or obese (20%) while the children were underweight (58%) and stunted (64%); only 14.8% of households had both a mother and child of normal weight (Saibul, Shariff, Lin, Kandiah, Ghani, & Rahman, 2009). Processed food, urbanisation and transitional lifestyles are the drivers of the shift towards unhealthy diets and sedentary lifestyles (WHO [World Health Organization], 2013b).

Protein diets and the amount of protein in a diet have mixed reviews. There is currently no firm evidence to suggest that a high protein intake can damage the kidneys in a normal healthy individual, as the kidneys respond by increasing the rate of filtration (Martin, Armstrong, & Rodriguez, 2005). There are conflicting study results for persons with chronic kidney disease. One study concludes that low-protein diets have not been shown to significantly slow chronic kidney disease deterioration and may instead increase the risk of malnutrition (Locatelli, Del Vecchio, & Pozzoni, 2002). Mandayam and Mitch (2006) do not agree that low-protein diets lead to malnutrition, arguing that, if compliant with dietary planning, people should be able to maintain body weight, serum albumin and electrolyte levels. Other studies offer evidence that for persons who have confirmed chronic kidney disease, protein restriction retards the progress of the disease (Fouque & Laville, 2009) although children and teenagers on renal replacement therapy need protein for growth (Brocklebank & Wolfe, 1993; Srivaths, Wong, & Goldstein, 2009). A study of 1,585 participants found that it took four months on a low protein diet for only small benefits to be seen in chronic kidney disease patients (Klahr, Levey, Beck, Caggiula, Hunsicker, Kusek et al., 1994). There was no significant benefit in following a low or very low protein diet for those with severe chronic kidney disease with no delay in reaching end-stage renal disease or

death (Klahr et al., 1994). Fouque and Laville (2009) in their review of low protein diets found that the more restricted the diet, the stronger the relative risk reduction in renal death. It is known that limiting dietary protein decreases creatinine production to a limit which ultimately lowers glomerular filtration rate and creatinine clearance, but more studies are required to determine the optimal threshold needed to halt the forming of lesions and the deterioration of the kidney in different stages of chronic kidney disease (Fouque & Laville, 2009). A vegetarian diet was found to lead to lower serum phosphorus levels and higher excretion of phosphorus compared with a meat diet, suggesting that the source of protein may be an important consideration (Moe, Zidehsarai, Chambers, Jackman, Radcliffe, Trevino et al., 2011). In Malaysia, a low-protein diet is not advised until the patient is established on haemodialysis therapy.

Traditional herbal medicine. In Malaysia traditional Malay, Chinese and Hindu Ayurvedic herbal medicines and many Indigenous herbal products are available from traditional practitioners. In Miri little information is available as to the identification of herbs and the quantities of traditional herbs consumed by the local population. To complicate matters, some tribal ethnic groups call particular herbs, vegetables, which makes identification confusing. Malay, Indian and Chinese traditional herbal medicine is much more organised but no better researched, and it is not known if the products used in Sarawak contain nephrotoxic substances.

Alternative and Indigenous medicines from poorer rural communities in developing countries are now being used in urban areas and in developed countries (Jha, 2010). The source, composition and toxicity of the herbs are neither tested nor controlled, and if unavailable a more noxious one may be substituted (Jha, 2010) or undisclosed drugs, hormones and glandular extracts added (Colson & De Broe, 2005). Traditional Chinese prescription herbal medicine is more potent than over-the-counter herbal soups and teas, but there is little standardisation (A. Lee, Chui, Aun, Lau, & Gin, 2006). Pesticides and heavy metals have been found in herbal preparations, and drug interactions with these substances may cause acute and chronic kidney toxicity (Colson & De Broe, 2005). Researchers from the Chinese University of Hong Kong found that traditional Chinese herbal medicine can cause complications if taken prior to anaesthesia and surgery, with patients twice as likely to have complications from low levels of potassium or impaired clotting (Chiu, Yau, & Epstein, 2009). The traditional

herbs liquorice, rehmannia, astragalus, atractylodes and eucommia have been named as potentially harmful if taken before surgery as they can cause arrhythmia (A. Lee, Chui et al., 2006).

There are some promising ongoing studies of the efficacy of traditional Chinese herbal medicine for the treatment of adverse outcomes of chronic kidney disease (Li & Wang, 2005). Large randomised trials are needed to test for active ingredients, toxicity, and effectiveness for use in chronic kidney disease (Zhong, Deng, Chen, Chuang, & He, 2013). WHO acknowledges the use of traditional herbal medicine. The Malaysian National Health and Morbidity Survey II 1996 reported that 2.3% of Malaysians visited traditional medical practitioners and 3.8% used both Western and traditional medicines, often concurrently (Hasan, Ahmed, Bukhari, & Loon, 2009). Since 2006 the Malaysian Government Ministry of Health, Traditional and Complementary Medicine Division has supported a number of hospitals, including one in Sarawak, as pilot projects using traditional practices that are evidence-based and proven to be safe and effective (Hasan et al., 2009).

3.2.5.4 Environmental factors

Agrochemicals. There is growing worldwide concern regarding excessive use of agrochemicals and the potential for kidney disease and kidney failure from long-term exposure in those using the chemicals. A number of studies based in under-developed tropical countries suggest that excessive, indiscriminate use of agrochemicals in plantations, combined with a lack of protective gear for workers, is linked to chronic kidney disease and end-stage renal disease (Almaguer, Herrera, & Orantes, 2014; Correa-Rotter, Wesseling, & Johnson, 2014; Wimalawansa & Wimalawansa, 2014). Common multi-factorial denominators have been uncovered in data from Sri Lanka, India and Central America, including hot humid conditions, occupational safety hazards, and the presence of chronic kidney disease without diabetes mellitus or hypertension (Chavkin, 2013; Herrera, Orantes, Almaguer, Alfonso, Bayarre, Leiva et al., 2014; Orantes, Herrera, Almaguer, Brizuela, Hernandez, Bayarre et al., 2009; Trabanino, Aguilar, Silva, Mercado, & Merino, 2002).

Most studies examine the association of multiple chemical exposure with chronic kidney disease, but some studies and reviews target particular individual chemicals or

chemical groups. A case-control study of the effect of the herbicide paraquat on Peninsular Malaysian plantation workers found no significant difference in health effects for those who had been spraying for less than five years, although it was projected that they would suffer long-term health effects (Howard, Sabapathy, & Whitehead, 1981). Reviews or fact sheets on paraquat (Bairaktari, Katopodis, Siamopoulos, & Tsolas, 1998; Watts, 2011), glyphosate (Cox, 1995) and 2,4-D herbicide (Azman, 1997; Cox, 1999) all conclude that these chemicals have toxic effects on the kidney. In Malaysia there are 30 registered pesticide manufacturing companies whose products may contain 250 active ingredients ('The Different Types of Pesticides Available', 2014), and 3,000 pesticide packaging outlets (I. Fernandez, Joshi, & Network, 2002). Surfactants and solvents, used to assist plants absorb the chemicals, are not required to be listed among the ingredients and may also contribute to organ dysfunction (Azman, 1997). The Ministry of Health Sri Lanka has recommended that fertilisers and pesticides containing heavy metals, if proven to cause chronic kidney disease, be banned (Weeraratna, 2012).

The National Health and Examination Survey 1999–2002 (NHANES), using a cross-sectional study design, found that organochlorine and Dioxin-like polychlorinated biphenyls pesticides were most strongly and consistently associated with five components of metabolic syndrome, suggesting that cardiovascular and diabetes risk factors relate to a background exposure to these pesticide chemicals (D. H. Lee, Song, Steffes, Toscano, Baker et al., 2006). The US National Toxicological Program workshop in 2011 found and reviewed 29 articles that had found a positive association between some environmental chemicals and diabetes (D. H. Lee, Lee et al., 2006): although there was insufficient evidence to conclude causality, the workshop recommended future studies including research into dose-response and joint exposure (C. C. Kuo, Moon, Thayer, & Navas-Acien, 2013). A study of type 2 diabetes among the Indigenous people of Canada concluded that obesity may be linked to toxic chemicals in the food chain, called endocrine disruptors, that interfere with the endocrine system, and may factor into the development of diabetes (Sharp, 2009).

Malaysia's small-scale farmers and cash crop plantation companies, in efforts to reduce crop damage and food loss, use multiple applications of agricultural pesticides, insecticides, herbicides and fungicides produced and distributed by over 30 companies

(‘Pesticides—a double-edged sword’, 2014). There are 1,600 pesticide products (I. Fernandez et al., 2002) and hundreds of different herbicides (Azman, 1997) distributed throughout Malaysia, and different names are often used for one substance or product. Many of the agrochemicals available and used in Sarawak are banned in Europe and the United States—including paraquat, which, following recommendations by the Chemical Review Committee of the Rotterdam Convention on Prior Informed Consent, has been banned by 36 countries including Malaysia (Watts, 2011). Its ban in Malaysia was reversed in 2006 after pressure from the manufacturing and plantation industries (Krishnamoorthy, 2006). In 2006 Brunei banned all vegetables from Miri because the pesticide content was excessive (‘More and Younger Patients Starting Dialysis’, 2006) and almost ten years later the ban is still in force. The increasing demand for agrochemicals is not being matched by health and safety awareness and education campaigns (Lum, Mamat, Cheah, Castaneda, Rola, & Sinhaseni et al., 1993) or government regulations (Watts, 2012).

‘Pesticides—a double-edged sword’ (2014) reported that the Sarawak Dayak Iban Association and the Pesticide Action Network Asia and the Pacific conducted a survey of pesticide applicators in the Suai District, one to two hours drive from Miri, and found that agrochemicals, mostly paraquat dichloride, glyphosate, d-phenothrin, cypermethrin, palletehrin and chlorpyrifos, were extensively used throughout Sarawak. Pesticide applicators and sprayers complained of ‘excessive sweating, dizziness, blurred vision, headache, narrowed pupils and excessive salivation’ (‘Pesticides—a double-edged sword’, 2014). The National Poison Centre of Malaysia reported that the largest proportion (47.2%) of the 3,057 reported poisoning exposures from Peninsular Malaysia were unintentional agrochemical poisoning of adult males working as agrochemical applicators; 84.2% of these needed hospital admission (Haslina, Fathelrahman, Rahman, Shalihin, Razak, Rahmat et al., 2007). As a method of suicide, ingestion of agrochemicals, such as paraquat, is common because of its availability (Haslina et al., 2007). In 2002 the Drug Information Unit, Hospital Universiti Sains Malaysia, reported on the disturbing number of farmers admitted with accidental pesticide poisoning (A. F. Ab. Rahman, 2002). A study of the health of Malaysian plantation sprayers found that, at the concentrations used, long-term paraquat spraying was harmful to their health (Howard et al., 1981). A Malaysian article, written on possible ways to reduce health risk among farmers in developing countries from

excessive use of pesticides, does not use any examples of or make reference to Malaysia (Rathinam, Kota, & Thiyagar, 2005), but infers the need for regulations and enforcement of regulations there. In Sarawak there is scant research on the agricultural use of pesticides, consequences for sprayers, or the impact on the environment including the rivers and water supply; such studies are urgently needed. A quarter of patients admitted for haemodialysis in Miri are recorded as have an unknown cause of chronic kidney disease / end-stage renal disease (MRC, 2014; 'MRC Miri to build kidney dialysis substation', 2015). Agrochemical poisoning may well be one.

3.2.6 Screening and intervention for chronic kidney disease

There are few kidney donors in Malaysia (Cruetz, 2014), and other than undergoing a kidney transplant there is no known cure for end-stage renal disease. As finances and resources improve, developing countries may lift restrictions on age and comorbid conditions, essentially allowing anyone with end-stage renal disease access to haemodialysis but this has profound logistic and economic repercussions (Reikes, 2000; Bello et al., 2008). The most effective way to contain the escalation of end-stage renal disease cases is to prevent or delay the development of chronic kidney disease (Ayodele & Alebiosu, 2010; Locatelli et al., 2002). In 1986 WHO published guidelines for screening for diseases, which are still relevant today and can be adjusted and applied to different diseases and countries. These guidelines suggest how to assess and justify setting up a screening program, address the disease condition, choose which detection tests to use, determine treatment options, and deal with program details such as facilities, policy, budget and continuity plans (Mathew & Corso, 2009).

3.2.6.1 Community strategies to detect chronic kidney disease

Screening Programmes. The intention of medical screening is to detect a disease in the early stage of development and refer the person to an appropriate place for diagnosis and intervention (Jaar, Khatib, Plantinga, Boulware, & Powe, 2008). Due to its sub-clinical nature, the only way chronic kidney disease can be detected is to undertake a protein dipstick test or a urine and blood test. In Malaysia most clinics and public screening campaigns only use a protein dipstick to save costs; and, as explained previously, only those with advanced proteinuria are detected. Laboratory testing can be costly for poorer people, and sponsorship for organised screening programs that

include eGFR and ACR are scarce. Public screening campaigns in Malaysia are often organised by politically motivated groups sometimes using non-medical staff. It is recommended that those running screening programs have to have a good knowledge of the tests performed and assessment skills (de Jong & Gansevoort, 2005).

Large screening programs for chronic kidney disease are impractical: they are not cost-effective (Mathew & Corso, 2009) and the incidence of end-stage renal disease in the general population is low (Garg et al., 2002; Hallan, Dahl et al., 2006). Even in a developed country such as Australia, screening for early kidney disease in the total population is not pursued (KHA, 2006d) and focus has been on targeting individuals who are deemed 'high risk' for developing chronic kidney disease (AIHW, 2014). In Australia it is recommended that all high risk persons, with and without diabetes, also have a urine ACR assessment to detect microalbuminuria (KHA-CARI, 2013).

Microalbuminuria has been detected in 58% of type 2 diabetes and hypertension participants (n = 6,482) from multiple ethnic groups throughout ten Asian countries: a worrying result requiring urgent targeted intervention to avert chronic kidney disease and cardiovascular disease complications (Wu et al., 2005). China is becoming more affluent and urgently needs to formulate strategies (N. Chen, Wang, Huang, Shen, Pei, Yu et al., 2009) and interventions to limit the surge of chronic kidney disease (Zhang et al., 2007). Chronic kidney disease in Peninsular Malaysia is common, and early detection is considered the best way to reduce the economic impact of end-stage renal disease (Hooi, Ong et al., 2013), but population-based screening is left to health clinics or public programs, who run opportunistic screenings on people who randomly appear (Hooi, Wong, et al., 2005). The Malaysian healthcare system recommends testing for proteinuria using urine dipsticks (Hooi, Lim et al., 2005), followed, if positive, by a referral for an eGFR using serum creatinine measurement by medical personnel (Hooi, 2006).

Early diagnosis. There are no randomised controlled trials for this area, but retrospective and prospective studies conclude that screening for early chronic kidney disease provides the best intervention opportunities and improves outcomes (KHA-CARI, 2013) and the yield detected must be sufficient to have a cost benefit (Jaar et al., 2008). The Kidney Early Evaluation Program (KEEP) concludes that targeting family members of end-stage renal disease, especially African-Americans (Laville, Juillard,

Deleaval, Fave, Charlois, Touzet et al., 2007) who have hypertension or type 2 diabetes is an effective means of detecting previously unidentified persons with chronic kidney disease (Brown, Peters, Ohmit, Keane, Collins, Chen et al., 2003). Persons at risk of developing chronic kidney disease in most countries include those of certain ethnicity (Feehally, 2005; Forouhi & Sattar, 2006), those who have a chronic non-communicable disease and those with a family history or other genetic predisposition for kidney problems (Ong, Punithavathi, Thurairatnam, Zainal, Beh, Morad et al., 2013). First degree relatives are usually motivated to undergo target screening as they know first-hand the outcomes of a disease and are often compliant to interventions (Jaar et al., 2008). Screening limited to those with a family history of end-stage renal disease and chronic non-communicable diseases finds that 93% of those screened have chronic kidney disease (Hallan, Coresh, et al., 2006). Opportunistic screening targeting high-risk populations (Feehally, 2005; Hallan, Coresh, et al., 2006), by physicians (KHA-CARI, 2013) or in combination with other community screening programs (Mathew, Corso, Ludlow, et al., 2010) such as cardiovascular disease (Rakhit, Armstrong, Beller, Isbel, Marwick, Rakhit et al., 2006), are evidence-based and recommended.

3.2.6.2 Medical intervention and barriers to screening

Interventions and management. Early diagnosis of chronic kidney disease is vital as it extends a person's life span and saves money (James, Hemmelgarn, & Tonelli, 2010) and facilitates a less distressing transition to haemodialysis therapy (Mathew, Corso, Ludlow, et al., 2010). Late referral to a nephrologist and commencing dialysis as an emergency affects future independence and quality of life (Laville et al., 2007). Early therapeutic interventions can ameliorate complications (Jaar et al., 2008; Levey, Eckardt et al., 2005). Those who are detected as having chronic kidney disease in community or opportunistic screening must be followed up in order for any benefits to be gained, and their high risk factors must be intensively managed in order to prevent end-stage renal disease and cardiovascular disease (Mathew, Corso, Ludlow et al, 2010; M. V. Rao, Qiu, Wang, & Bakris, 2008). Chronic kidney disease accelerates cardiovascular disease through unknown mechanisms (McCullough, Li, Jurkovitz, Stevens, Collins, Chen et al., 2008) and the person's life-span is shortened (McCullough, Li, Jurkovitz, Stevens, Wang, Collins et al., 2008) unless early referral to

a nephrologist (Locatelli et al., 2002; Johnson, 2012) and optimal management is given (Rossert & Wauters, 2002; Johnson, Atai et al., 2013).

With better medication, greater compliance in taking medication, and greater acceptance of dialysis, the overall survival of patients with end-stage renal disease is improving (Reikes, 2000; Jaar et al., 2008). In certain populations the incidence rates for chronic kidney disease / end-stage renal disease is slowing down, consistent with rigorous blood pressure and glucose control, lipid lowering and kidney-protective medications (ISN, 2006; James et al., 2010). Interventions for chronic kidney disease should also include correction of calcium-phosphate disorders and anaemia, cessation of smoking (Locatelli et al., 2002) and healthy lifestyle management (Egger, Binns, & Rossner, 2009). When developing a mass screening initiative, death, suffering, economic and social costs need to be considered in the program (Council of Europe, 1994). Pain often accompanies chronic non-communicable diseases and pain relief is a basic human right. In poor countries with limited resources, given the affordability and availability of analgesic medications, WHO (2007) has recommended that interventions should only be instigated if there is a high probability of a cure rate and pain relief against cost effectiveness.

Barriers to screening. A US review found that among health care workers including physicians, awareness of chronic kidney disease was low, resulting in incorrect and delayed diagnosis, missed treatment, unprepared entry into RRT (Jha et al., 2013) and under-reporting of kidney disease (WHO, 2015). A review of the NHANES data determined that high-risk groups were more likely to be unaware of having chronic kidney disease, even with good health care available to them (Crook, Washington, Flack, Crook, Washington & Flack, 2002; Nickolas, Frisch, Opatowsky, Arons, & Radhakrishnan, 2004). Media attention, community awareness programs and professional education are all needed to change public attitudes and behaviours towards chronic kidney disease (ISN, 2006) and is fundamental to improving health outcomes in the community (Johnson, Jones, et al., 2012) (Jaar et al., 2008).

A study of why people refused health screening found that non-participants thought the screening limited, were worried the results would be made public, did not want to know if they had an illness, felt they had good health, felt it was their responsibility to go to

the doctor if ill, and did not want to have their feeling of enjoying good health disturbed (Crook et al., 2002). Identifying causal risk factors for the local population and making chronic kidney disease a health education priority will help lessen the economic burden of end-stage renal disease in developing countries (Khwaja et al., 2007). Programmes must be culturally sensitive and appropriate for the whole community (Hostetter & Lising, 2003). Effective morbidity outcomes depend upon early interventions to delay the progression of chronic kidney disease to end-stage renal disease and to prevent the development of cardiovascular disease. Ways to motivate the target community to become involved should be considered when planning screening strategies. If persons with chronic kidney disease miss the opportunity for early intervention their quality of life is greatly reduced (Locatelli et al., 2002) and they are more likely to die from cardiovascular disease events than to survive long enough to start renal replacement therapy (KHA-CARI, 2013).

3.3 Metabolic Syndrome

3.3.1 Epidemiology of metabolic syndrome

A chronic non-communicable disease is a non-infectious medical condition that usually is of long duration. Chronic non-communicable diseases include autoimmune diseases, heart diseases, cancers, respiratory disease, diabetes mellitus, and others. It is not to be mistaken for a 'chronic disease', which may be infectious, such as HIV/AIDS. WHO (2014) estimates that 38 million people die from a chronic non-communicable disease each year, almost three quarters from low and middle income countries, and 82% under the age of seventy. Chronic non-communicable disease morbidity and mortality affect working aged adults who should be productive (Unwin & Alberti, 2006). Unhealthy diets, physical inactivity, drinking alcohol, and smoking, correlate with rapid urbanisation in developing countries and contribute to an increased risk of death from a chronic non-communicable disease (WHO, 2014), although these risk factors can often be prevented or reversed (Unwin & Alberti, 2006). Total global mortality from chronic non-communicable diseases includes cardiovascular disease (30%), cancer (13%), chronic respiratory disease (7%) and diabetes (2%) (Unwin & Alberti, 2006). Unhealthy lifestyles, environmental factors and genetics may contribute to the development of chronic non-communicable diseases (Bagby, 2004; Abegunde et al., 2007) but obesity, high blood pressure, high blood glucose levels and high blood lipid

levels are the four main metabolic risk factors (WHO, 2014). These are also the contributing risk factors for metabolic syndrome.

Metabolic syndrome is defined as a set of comorbid metabolic abnormalities found to increase a person's risk for heart disease, stroke and diabetes (Alberti, Zimmet, & Shaw, 2006). Epidemiological data show that chronic non-communicable diseases (WHO, 2014) and metabolic syndrome are escalating problems worldwide (Alberti et al., 2006) and Asian developing countries' prevalence statistics resemble those of Western nations (Nestel, Lyu, Low, Sheu, Nitiyanant, Saito & Tan, 2007).

3.3.2 Historical timeline

Following is a timeline for the development and interpretation differences of the metabolic syndrome.

1923. A Swedish physician, Eskil Kylin, first made the association between risk factors (Kumar, Chitra, & Reddy, 2013). A combination of metabolic disturbances was observed to cluster together especially in patients with type 2 diabetes and cardiovascular disease (Alberti et al., 2006).

1947. A study by J. Vague mentioned that people with diabetes tended to have abdominal obesity (Kumar et al., 2013).

1965. P. Avogaro and G. Crepaldi described a syndrome with hypertension, hyperglycaemia and obesity, all metabolic syndrome criteria (Kumar et al., 2013).

1981. The phrase 'metabolic syndrome' was first used by Hanefield and Leonhardt to describe chronic non-communicable diseases associated with cardiovascular disease (Kumar et al., 2013).

1988. Reaven (1988) described the relationship between insulin resistance and glucose intolerance in patients with non-insulin dependent diabetes mellitus and was the first to use the term 'syndrome X' (Bagby, 2004; Grundy, Brewer, Cleeman, Smith, & Lenfant, 2004).

- 1989.** Kaplan (1989) described upper body obesity, glucose intolerance, hypertriglyceridemia, and hypertension as ‘the deadly quartet’ that precedes cardiovascular disease (Kumar et al., 2013). He noted that ‘obesity, hypertension, hypertriglyceridemia, and glucose intolerance are common and they often coexist’.
- 1992.** The San Antonio Heart Study on diabetes and cardiovascular disease, renamed metabolic disorders ‘insulin-resistance syndrome’ due to the hyperinsulinemia that was observed prior to their development (Haffner, Valdez, Hazuda, Mitchell, Morales, & Stern et al. 1992).
- 1998.** WHO published position statements for the definition and diagnostic criteria for metabolic syndrome that included impaired glucose tolerance or type 2 diabetes and/or insulin resistance as prerequisites and used body mass index and waist-hip ratio as the measures of obesity; they also included microalbuminuria (Alberti & Zimmet, 1998; IDF [International Diabetes Federation], 2006; Kassi, Pervanidou, Kaltsas, & Chrousos, 2011). There was some criticism regarding the combination of components and criteria, and debate over whether microalbuminuria was a syndrome or an underlying cause (Alberti et al., 2006).
- 1999.** The European Group for the Study of Insulin Resistance (EGIR) recommended modifications be made to include measurement for non-diabetic persons and to exclude microalbuminuria (Balkau & Charles, 1999; Kassi et al., 2011). The EGIR version depended on fasting insulin levels in place of impaired fasting glucose (IDF, 2006)
- 2000.** It was suggested that visceral fat as a measurement of waist circumference and fasting triglyceride was an inexpensive screening tool to identify men at high risk of heart disease (Lemieux, Pascot, Couillard, Lamarche, Tchernof, Almeras et al., 2000), which has been termed cardiometabolic risk (Kassi et al., 2011).
- 2001.** The US National Cholesterol Education Program: Adult Treatment Panel III (NCEP-ATPIII) was the first to identify cardiovascular disease risk as the main focus of metabolic syndrome (NCEP, 2002). Their approach was to diagnose

three or more metabolic syndrome criteria, and insulin resistance (was not considered compulsory (Kassi et al., 2011).

- 2003.** The American Association of Clinical Endocrinologists (AACE) proposed a hybrid of the 1998 WHO and the 2001 NCEP-ATPIII definitions (Einhorn, 2003), but this was found to be vague in diagnosis and outcomes (Kumar et al., 2013). Differences in definitions and variations in obesity cut-off marks made it difficult to compare studies, especially of people of various ethnicities (Kumar et al., 2013). The Australian Diabetes, Obesity and Lifestyle Study (AusDiab) noted a wide variation across the population in the assessment of metabolic syndrome, using the three different criteria of WHO, EGIR and NCEP-ATPIII (Dunstan, Zimmet, Welborn, de Courten, Cameron, Sicree, et al., 2002).
- 2004.** The American Heart Association/National Heart, Lung and Blood Institute (AHA/NHLBI) organised a symposium to examine the scientific evidence and discuss issues related to metabolic syndrome (Grundy, Brewer et al., 2004). Most WHO criteria were adopted without any prerequisite criteria such as abdominal obesity (Grundy, Cleeman, Daniels, Donato, Eckel, Franklin et al., 2005).
- 2005.** All metabolic syndrome definitions failed to predict clinical endpoints. To eliminate the measurement variations when comparing different population groups, the International Diabetes Federation provided a new definition in collaboration with EGIR and NCEP, including ethnic-specific waist circumference measurements as an obligatory prerequisite plus any two of the other risk factor criteria (Alberti et al., 2006; IDF, 2006; Kassi et al., 2011; Kumar et al., 2013).
- 2007.** An International Diabetes Federation consensus report on metabolic syndrome in children and adolescents (IDF, 2007) stressed the point that the syndrome pathway should be prevented, and halted if already commenced, to reduce adult complications (Zimmet, Alberti, Kaufman, Tajima, Silink, Arslanian, 2007). Although simplified the criteria remain basically the same as the adult version except for waist measurement (WHO, 2007). This will facilitate studies to plot growth patterns, define values for younger people and determine predictors for

adult metabolic syndrome, cardiovascular disease and type 2 diabetes (Zimmet, Alberti et al., 2007).

2009. To refine and unify the metabolic syndrome definition further, the International Diabetes Federation, AHA/NHLBI and the International Association for the Study of Obesity published a joint statement outlining a new consensus definition; this is currently widely accepted (Alberti, Eckel, Grundy, Zimmet, Cleeman, Donato et al., 2009). There was agreement to eliminate all compulsory elements such as abdominal obesity; a person is diagnosed with metabolic syndrome if they have three abnormal findings of the five criteria; the set cut-off points are all unified except for an ethnic-specific waist circumference.

3.3.3 Clinical criteria and rationale

According to the International Diabetes Federation workshop, 'A syndrome is defined as a recognisable complex of symptoms and physical or bio-chemical findings for which a direct cause is not understood ... When causal mechanisms are identified, the syndrome becomes a disease' (as cited in Alberti, Zimmet, & Shaw, 2006, p. 473).

Having a cohesive metabolic syndrome diagnostic criteria to determine the abnormal clinical parameters for all ages helps validate metabolic syndrome as a useful screening and clinical tool for health professionals in all countries (Zimmet, Magliano, Matsuzawa, Alberti, & Shaw, 2005) and allows valid comparison of data between different populations and ethnicities (Alberti et al., 2006). Any three of the five risk factors of the criteria constitute a diagnosis of metabolic syndrome. These medical conditions, under the umbrella of metabolic syndrome, are driving the rampant global pervasiveness of type 2 diabetes and cardiovascular disease (Dunstan et al., 2002; Misra & Khurana, 2008).

Table 3.6 sets out the metabolic syndrome criteria. A clinical diagnosis is based on three of the five factors being present in the individual.

Table 3.6 Criteria for clinical diagnosis of the metabolic syndrome

<i>Measure</i>	<i>Categorical Cut Points</i>	
Elevated waist circumference	Population and country specific definitions*	
	<u>Male</u>	<u>Female</u>
*Causasian (Australian of European decent)	≥ 94 cm (increased risk)	≥ 80 cm
	≥ 102 cm (still higher risk)	≥ 88 cm
*Asian (including Malaysian)	≥ 90 cm	≥ 80 cm
Elevated triglycerides	≥ 150 mg/dL (1.7 mmol/L)	
(Alternate indicator: drug treatment for elevated triglycerides)		
Reduced HDL-C	<u>Males</u> < 40 mg/dL (1.0 mmol/L)	
	<u>Females</u> < 50 mg/dL (1.3 mmol/L)	
(Alternate indicator: drug treatment for reduced HDL-C)		
Elevated blood pressure	Systolic ≥ 130 mm Hg and/or	
	Diastolic ≥ 85 mm Hg	
(Alternate indicator: antihypertensive drug treatment with a history of hypertension)		
Elevated fasting glucose	≥ 100 mg/dL (5.5 mmol/L)	
(Alternate indicator: drug treatment for elevated glucose levels)		

“Any 3 of 5 risk factors constitutes a diagnosis of metabolic syndrome”.

Source: (International Diabetes Federation, 2006; Alberti, Eckel et al., 2009)

Table 3.7 is a schematic presentation of risk factors, pathogenesis, outcomes and interventions for metabolic syndrome. There are a number of other metabolic criteria that appear to correlate with metabolic syndrome and have systemic consequences, outside the scope of this literature review. The bolded areas are those addressed in the following section, and the focus is on chronic non-communicable diseases that contribute to the pathogenesis or outcomes of metabolic syndrome.

Table 3.7 Risk factors, pathogenesis, outcomes and interventions for metabolic syndrome

Genetic and Environmental	Pathogenesis of metabolic syndrome	Outcomes of metabolic syndrome	Interventions and Management
Thrifty genotype	Abdominal obesity	Type 2 Diabetes	Screening for metabolic syndrome
Thrifty phenotype	Hyperglycaemia		
In utero environment	Atherogenic	Cardiovascular Disease	Lifestyle Intervention
Energy dense foods	Dyslipidaemia		
Physical inactivity	Hypertension		
Smoking	Proinflammatory state	Chronic kidney disease	Pharmacological Intervention
Stress	Prothrombotic state	and	
	Microalbuminuria	End-stage renal disease	

3.3.4 A summary of the pathogenesis of the metabolic syndrome

Genetic and environmental factors, obesity and inactivity all influence the development of metabolic syndrome (Kaur, 2014; NCEP, 2002). The pathogenesis of metabolic syndrome is complex, with no direct route but a network of ‘interconnected pathways that mediate interactions among multiple organs and ... impair energy homeostasis in multiple organs simultaneously’ (Bagby, 2004, p. 2). Environmental and genetic factors may influence a positive energy balance and contribute to abdominal adipose tissue deposits, eventually making a person obese (Kaur, 2014). This initiates mechanisms that alter both the free fatty acid metabolism and the release of adipokines, resulting in dysfunctional conditions that escalate in severity and lead to disease (Kaur, 2014). Metabolic syndrome can present in a variety of ways, depending upon a person’s susceptibility to the combination of components (Eckel, Grundy, & Zimmet, 2005); and questions about its underlying pathogenesis remain unanswered (Unwin, 2006).

3.3.4.1 *Abnormal body fat distribution (abdominal obesity)*

Obesity increases the risk of a chronic non-communicable disease and the International Diabetes Federation considers the obesity escalation in many countries as driving

metabolic syndrome (IDF, 2005). The metabolic complications associated with obesity are now referred to as metabolic syndrome. Although the pathogenesis of the metabolic syndrome is not entirely understood, abnormal fat distribution (abdominal obesity) is recognised as a significant causal factor (Alberti et al., 2006). Although obesity is a predictor of the metabolic syndrome, the risk can be mitigated by reducing one's weight (Alberti, Zimmet, & Shaw, 2007). Adipose tissue affects the endocrine system and promotes the development of metabolic syndrome (Bagby, 2004; Després & Lemieux, 2006) and the multiple components of the metabolic syndrome interact to cause chronic low-grade systemic inflammation generated from obesity-related comorbidities (Kaur, 2014) and may exacerbate metabolic syndrome (Grundy, Cleeman et al., 2005). Obesity-initiated metabolic syndrome is characterised by large quantities of circulating free fatty acids, increased inter-cellular lipid content and insulin resistance, but reduced levels of adiponectin and leptin (Bagby, 2004), both insulin-sensitising adipokines that promote metabolism and free fatty acid oxidation (Eckel et al., 2005). Hyperglycaemia, hypertension, high serum triglycerides, low HDL-C and insulin resistance are all influenced by obesity, and it is associated with a greater type 2 diabetes and cardiovascular disease risk (Alberti et al., 2006).

Epidemiological studies show that with an increasing body mass index there is a greater prevalence of type 2 diabetes, dyslipidaemia and cardiovascular disease, but that an increasing excess of visceral adipose tissue adversely alters the metabolic risk profile of a person independent of body mass index (Alberti et al., 2006). Central abdominal obesity and insulin resistance are constant features of the metabolic syndrome; waist circumference is a more predictive measure of central abdominal obesity, and correlates with insulin resistance; both are predictive of metabolic syndrome (Alberti et al., 2005). It has been found that once body mass index is greater than 30, the majority of people will have a waist circumference above gender and ethnic-specific cut-off points (Alberti et al., 2006). Data from Asian population studies shows that the risk of developing metabolic syndrome is greater at waist circumference cut-off point values below those of Europeans (Alberti et al., 2006). The International Diabetes Federation therefore, have allowed for population specific cut-off points for waist circumference which vary by gender and ethnic group, regardless of the country a person resides in (IDF, 2005).

3.3.4.2 *Insulin resistance (and hyperglycaemia)*

The second potential causal factor in the pathogenesis of the metabolic syndrome is insulin resistance, which is almost always present when correlated with the various metabolic syndrome components (Alberti et al., 2006). Insulin resistance (IR) or its related hyperinsulinaemia is associated weakly with hypertension and prothrombotic state, but strongly with atherogenic dyslipidaemia and proinflammatory state; the link with cardiovascular disease needs further research (Alberti et al., 2006) even though all the metabolic syndrome components are associated with insulin resistance (Kahn, Buse, Ferrannini, & Stern, 2005). Normally free fatty acids can stimulate the secretion of insulin, but this secretion declines if there is protracted exposure (Eckel et al., 2005). When defective, the insulin hormone is unable to suppress glucose metabolism by the liver and kidney and unable to control the muscle and adipose tissue from glucose uptake (Eckel et al., 2005), eventually resulting in hyperglycaemia. Abdominal fat uniquely contains more triglyceride, displays more insulin resistance, and secretes less leptin than other fat deposits (Bagby, 2004). Individuals with insulin resistance will have impaired glucose tolerance (IGT) and/or hyperglycaemia and a decrease in insulin response; they will also have an obese abdomen (Kaur, 2014) and all these factors invariably lead to type 2 diabetes (Stern, 1994; Després & Lemieux, 2006). If a person's fasting plasma glucose is between 5.6–6.9 mmol/L (100 – 125 mg/dL) it is recommended they have an Oral Glucose Tolerance Test (OGTT) to identify impaired glucose tolerance or undiagnosed type 2 diabetes (Alberti et al., 2006). The clinical criteria for hyperglycaemia includes either Impaired Fasting Glucose (IFG), impaired glucose tolerance or type 2 diabetes (Alberti et al., 2006). Insulin resistance can be determined using the homeostasis model assessment (HOMA) (Chitturi, Abeygunasekera, Farrell, Holmes-Walker, Hui, Fung et al., 2002).

3.3.4.3 *Atherogenic dyslipidaemia*

Insulin resistance, through a number of pathways, results in atherogenic dyslipidaemia (Kaur, 2014) and 'consists of abnormal levels of triglycerides and apolipoprotein B (apoB), small Low Density Lipoprotein–Cholesterol (LDL–C) particles, and low High Density Lipoprotein–Cholesterol (HDL–C)' (Grundy, Cleeman et al., 2005, p. 2742). Metabolic syndrome patients usually present with these abnormal laboratory lipid results (Alberti et al., 2006). In the liver free fatty acid increases, synthesis and storage

of triglyceride increases and triglyceride and apoB is secreted as very low density lipoprotein (Lewis & Steiner, 1996; Grundy, Cleeman et al., 2005). Treatment needs to target LDL-C even in the metabolic syndrome (Grundy, Cleeman et al., 2005). Persons with hepatic steatosis or non-alcoholic fatty liver disease (NAFLD) have been found to be insulin resistant (Angelico, Del Ben, Conti, Francioso, Freole, Fiorello et al. 2005) and those with metabolic syndrome are more severely resistant. Chitturi et al. (2002), however, found that non-alcoholic fatty liver disease is associated with insulin resistance irrespective of obesity. In hypertriglycidaemia, HDL-C decreases while triglyceride and LDL-C increases, and the particles become small and dense and atherogenic (Eckel et al., 2005). A person has dyslipidaemia if the triglyceride level is ≥ 1.7 mmol/L (150 mg/dL), or low HDL-C, measured as < 0.9 mmol/L (40 mg/dl) for men and < 1.29 mmol/L (50 mg/dL) for women; or if they have previously been diagnosed with hypertriglycidaemia (Alberti et al., 2006).

3.3.4.4 Elevated blood pressure (hypertension)

High blood pressure is found in close association with obesity and type 2 diabetes (Eckel et al., 2005). In a study to test if insulin resistance was associated with hypertension independent of obesity and type 2 diabetes, it was found that glucose uptake was inversely correlated to hypertension but insulin resistance directly correlated with hypertension (Ferrannini, Buzzigoli, Bonadonna, Giorico, Oleggini, Graziadei et al., 1987). Elevated blood pressure found in persons with obesity, glucose intolerance and insulin resistance (Alberti et al., 2006) is exacerbated by type 2 diabetes, smoking, excessive salt intake, obesity and kidney disease. A study noted that type 2 diabetes and insulin resistant patients with metabolic syndrome retain more sodium than those without (Barbato, Cappuccio, Folkard, Stazzullo, Sampson, Cook et al., 2004). Their results showed that sodium re-absorption was increased in people of European descent (Europids) but not in African or South Asian patients (Barbato et al., 2004). They argued that their results endorsed another study showing that in severe cases, when insulin resistance increases so does sodium retention (Nosadini, Sambataro, Thomasset, Pacini, Cipollina, Brocco et al., 1993) and may indicate inherent renal abnormality in Europid people with insulin resistance (Barbato et al., 2004). Whether this is also the case with South East Asian and Chinese persons is not known. Increased sodium re-absorption affects the cardiac output which causes the

arteries to respond with vasoconstriction, leading to hypertension; endothelial dysfunction hastens atherosclerosis (Kaur, 2014).

The clinical criteria for metabolic syndrome for a person with a raised blood pressure is over ≥ 130 mmHg systolic and ≥ 85 mmHg diastolic, or being on antihypertensive treatment (Alberti et al., 2006). An English study ($n = 4,801$) found that for every 10 mmHg systolic blood pressure decrease there was a 12% statistically significant risk reduction of complications from diabetes and 15% for diabetes deaths, 11% for myocardial infarction and 13% for microvascular complications, with the lowest risk reduction being for those who had less than 120 mmHg systolic blood pressure (Adler, Stratton, Neil, Yudkin, Matthews, Cull, et al., 2000). Patients with hypertension have a 2.5 greater risk of developing type 2 diabetes (Gress, Nieto, Shahar, Wofford, & Brancati, 2000; Bakris, Ritz & World Kidney Day Steering Committee, 2009) and researchers have found that Pima American Indians who have hypertension are more likely to get diabetic kidney disease (Cho et al., 2014).

It is advised that patients with diabetes mellitus keep their blood pressure below $>130/>80$ mmHg using antihypertensive drugs to protect from cardiac and renal damage (Alberti et al., 2006).

3.3.4.5 Proinflammatory state

There are a number of hypotheses regarding the association of the metabolic syndrome and chronic inflammation although obesity appears to activate the mechanism contributing to the proinflammatory state of the metabolic syndrome (Monteiro & Azevedo, 2010). Proinflammatory cytokines, including C-reactive protein (CRP) and tumour necrosis factor α (TNF α), overproduced by excess adipose tissue (Eckel et al., 2005), may in turn stimulate the production of hepatic C-reactive protein in the liver (Sutherland, McKinley, & Eckel, 2004). Ethnic differences and fitness can affect C-reactive protein levels. C-reactive protein has been found to be higher in South Asian Indians than to European people because of greater abdominal obesity and insulin resistance in Indians (Stern, 1994; Mohan, Deepa, Velmurugan, & Premalatha, 2005). As the level of C-reactive protein rises, the level of adiponectin, an anti-inflammatory cytokine, inversely declines (Eckel et al., 2005; Sutherland et al., 2004). It is suggested that adiponectin may be the link between intra-abdominal fat with reduced insulin

sensitivity, increased insulin resistance and inflammation (Calton, Miller, & Soares, 2013; Cnop, Havel, Utzschneider, Carr, Sinha, Boyko et al., 2003). In addition, there is an associated decrease in HDL-C levels and an increase in free fatty acids and LDL-C particles (Eckel et al., 2005). A proinflammatory state is recognised in people with the metabolic syndrome by a raised C-reactive protein (≥ 3 mg/L), which rises with an increase in number of metabolic syndrome components; and a significant association is found between plasma C-reactive protein levels, adiposity and insulin resistance (Alberti et al., 2006). Studies show that genetics, a proinflammatory state and hormonal dysregulation may well vary between different ethnic populations (Alberti et al., 2006).

3.3.4.6 Prothrombotic state

A proinflammatory state may be metabolically linked to the prothrombotic state as there is a corresponding increase in procoagulant factors such as fibrinogen, and also endothelial dysfunctions, and lead to a hypercoagulable state (Kaur, 2014). Fibrinogen is a prothrombotic marker that rises when cytokine levels increase (Sutherland et al., 2004). A prothrombotic state refers to the association between components of the metabolic syndrome with both coagulation and fibrinolytic proteins (Alberti et al., 2006), reactant anomalies that increase with rising cytokine levels (Kaur, 2014). Persons with atherogenic dyslipidemia, elevated hypertension and elevated plasma glucose will usually also have a prothrombotic state and a proinflammatory state (Alberti, Eckel et al., 2009).

3.3.5 Microalbuminuria

There is a question whether microalbuminuria can be considered an integral part of the pathogenesis of metabolic syndrome. This study follows the International Diabetes Federation Joint Scientific Statement listing microalbuminuria as an area requiring more research (Alberti, Eckel et al., 2009). WHO, however, is the only organisation to include microalbuminuria in the definition of metabolic syndrome (Kaur, 2014). Microalbuminuria is defined as having a 'urinary excretion rate of >20 mg/min or albumin : creatinine ratio of >30 mg/g' (Kaur, 2014, p. 2) and is part of the new assessment diagnosis algorithm for chronic kidney disease (KDIGO, 2012).

Association of microalbuminuria with individual metabolic syndrome components.

Studies have looked at the mechanism to understand how microalbuminuria is involved in the development of chronic kidney disease. A study using a pre-existing Electronic Health Record-based chronic kidney disease registry from Cleveland, Ohio, found that the metabolic syndrome was associated with end-stage renal disease but not death, and that 60% of chronic kidney disease patients had metabolic syndrome, although when adjusted for proteinuria the association was less; they suggested that metabolic syndrome leads to kidney damage (Navaneethan, Schold, Kirwan, Arrigain, Jolly, Poggio et al., 2013). Many studies suggest a link but the causal mechanisms remain hidden. Study results often indicate the presence of microalbuminuria with metabolic syndrome diagnosis (Palaniappan, Carnethon, & Fortmann, 2003; Hao, Konta, Takasaki, Abiko, Ishikawa, Takahashi, ... & Kubota, 2007) but an association is not always found between microalbuminuria and the individual comorbidities of the metabolic syndrome.

Obesity, Hyperglycaemia, Insulin Resistance. Obesity-initiated metabolic syndrome glomerular hypertrophy in morbid obesity is thought to induce macroproteinuria (Kambham, Markowitz, Valeri, Lin, & D'Agati, 2001). A large number of studies associate microalbuminuria with hyperglycaemia, usually via type 2 diabetes; one such study is the MicroAlbuminuria Prevalence (MAP) Study (Wu, Kong, De Leon, Pan, Tai, Yeung et al., 2005). A Korean study of 1006 subjects, however, found that those who had microalbuminuria had a higher body mass index and waist-to-hip circumference ratio irrespective of having type 2 diabetes or not (Kim, Kim, Choi, Chung, Lee, Lee et al., 2001). Following multiple logistic regression analysis, microalbuminuria has been shown to be associated with hyperinsulinemia and central obesity, independent of hypertension or type 2 diabetes, and that it is a feature of insulin resistance, at least in a Korean population (Kim et al., 2001). A study of Indigenous Australians found that ACR was associated with waist-hip ratio but not body mass index; there was also an ACR association with insulin resistance and worsening microalbuminuria (Rowley, O'Dea, & Best, 2003). This study concluded that among Australian Aboriginal people type 2 diabetes, hypertension and abdominal obesity contribute to the high rates of albuminuria (Rowley et al., 2003).

Dyslipidaemia. Findings for dyslipidaemia vary with different studies. During a nephrology forum, conflicting evidence of the association between lipids and microalbuminuria was discussed, with the conclusion that it was unclear whether dyslipidemia contributed solely to cardiovascular disease or was also implicated in progressive chronic kidney disease (Keane, 1994). More up-to-date data now suggests increasing albumin is an independent risk for cardiovascular disease morbidity and mortality as well as a marker for progressive chronic kidney disease independent of renal function, blood pressure and dyslipidemia (Keane, 2000). In a review Maclsaac, Jerums and Cooper (2004) were more cautious about microalbuminuria and its direct association with chronic kidney disease progression, suggesting that it is an independent risk factor for cardiovascular disease morbidity and mortality in both diabetes mellitus and non-diabetes mellitus.

Hypertension. A cross-sectional study using the data of 5,659 men and women from the NHANES III: 1988–1994 found that 7.8% of women and 5.0% of men had microalbuminuria and that it was more common in those with metabolic syndrome (Palaniappan et al., 2003). When broken down into the metabolic syndrome components, hypertension was found to have the strongest association with microalbuminuria (Palaniappan et al., 2003). In a population-based cohort of 517 type 1 diabetes participants, it was found that ‘microalbuminuria and hypertension are infrequent in the first nine years of diabetes. Microalbuminuria is less frequent than expected’ (Allen, Pulta, Lecaie, Huang, Brazy, D'Alessio, 2002, p. 1). Redon and Pascual (2006) recommend that microalbuminuria in essential hypertension should be addressed to preserve the kidney and guard against cardiovascular disease.

Proinflammatory and Prothrombotic State. Microalbuminuria may be a risk marker for chronic kidney disease and coronary heart disease, and although the mechanism is still unclear, microalbuminuria in metabolic syndrome may be a sign of renin-angiotensin system activation and subsequent oxidant stress and inflammation through a common pathway (Gobal, Deshmukh, Shah, & Mehta, 2011). These eventually leads to endothelial impairment and cardiac and renal fibrosis (Gobal et al., 2011).

Association of microalbuminuria to metabolic syndrome outcomes. As described in Section 3.1.3.5, microalbuminuria is predictive of both end-stage renal disease and cardiovascular disease (APCWG, 2011). It was found that as the number of the

metabolic syndrome components increased, and elevated blood pressure and plasma glucose levels increased, the odds of developing chronic kidney disease and/or microalbuminuria became significantly greater (J. Chen, Munter, Hamm, Jones, Batuman, Fonseca et al., 2004). Gobal et al. (2011) have suggested that microalbuminuria may be a reliable predictive marker for chronic kidney disease and coronary heart disease.

Type two diabetes outcome. Strongly associated with insulin resistance and a warning sign of diabetic nephropathy, having microalbuminuria signifies endothelial damage (Pistrosch, Herbrig, Kindel, Passauer, Fischer & Gross, 2005). For people with type 2 diabetes, microalbuminuria compounds the risk for cardiovascular disease and related death, and increases the risk of chronic kidney disease (Hossain et al., 2007).

Cardiovascular disease outcome. Metabolic syndrome has been found to be an independent risk factor for cardiovascular disease and to increase the risk of microalbuminuria, moderately in the early stages and more strongly later (Thorn, Forsblom, Waden, Saraheimo, Tolonen, Hietala, et al., 2009). There is wide variation between study results and no one individual metabolic syndrome component can be indicated as solely or directly associated with microalbuminuria. Mechanisms for insulin resistance, hypertension, dyslipidemia and inflammation may cause renal fibrosis (Singh & Kari, 2013). Changes in glucose metabolism (Redon & Pascual, 2006), insulin resistance and hypertension are the clinical factors most associated with microalbuminuria (Redon & Pascual, 2006; Ruan & Guan, 2009) but are not yet included in the International Diabetes Federation definition of the metabolic syndrome. The question is if proteinuria intervenes consequentially between the metabolic syndrome and the progression of chronic kidney disease, or if microalbuminuria should be considered as a entity separate from the metabolic syndrome.

3.4 Association between Metabolic Syndrome and Chronic Kidney Disease

3.4.1 Metabolic syndrome complex implicated in both chronic kidney disease and microalbuminuria

The benchmark for gauging chronic kidney disease deterioration is glomerular filtration rate for kidney function and ACR for kidney damage. Studies have attempted to link the metabolic syndrome to microalbuminuria independently as well as within the

context of chronic kidney disease however, the outcomes, as seen especially in a number of different subset studies taken from NHANES III 1988–1994, vary widely.

Microalbuminuria but not glomerular filtration rate. Sometimes microalbuminuria is detected before chronic kidney disease begins to appear and progress (Hostetter & Lising, 2003). Sometimes, especially in persons with diabetes, non-diabetic hypertensives or the elderly, there may be microalbuminuria without any indication of glomerular filtration rate (Garg et al., 2002).

Glomerular filtration rate but not microalbuminuria. Not all persons with stages 3-5 glomerular filtration rate also have microalbuminuria. A cross-sectional type 2 diabetes subset of NHANES III 1988–1994, adults with type 2 diabetes, found that one third who had an eGFR <60 mL/min per 1.73 m² did not have microalbuminuria (Kramer, Nguyen, Curhan, & Hsu, 2003).

Both chronic kidney disease and microalbuminuria. In one study, following the APTIII definition, a large subsample from NHANES III was used to determine if the metabolic syndrome was a risk factor for chronic kidney disease, using the two measures eGFR and microalbuminuria ACR, and found that 24.7% were classified as having metabolic syndrome and that there was a graded relationship between chronic kidney disease or microalbuminuria (J. Chen, Munter et al., 2004).

Ethnicities. It has been found that different ethnicities, other than European and with or without diabetes mellitus, are more likely to have microalbuminuria especially if they have stages 3–5 chronic kidney disease (Bryson, Ross, Boyko, & Young, 2006). In a study of 213 Japanese participants metabolic syndrome was associated with, and albuminuria was independently associated with, the progression of chronic kidney disease (Saito, Mochizuki, Uchida, Tsuchiya, & Nitta, 2013). Asian ethnicities have an increased risk of developing end-stage renal disease and different epidemiologic features compared to Caucasians; their risk for microalbuminuria may also be different (Ramirez, McClellan et al., 2002; Hamer & El Nahas, 2006).

There is a strong, positive and significant association between the metabolic syndrome and chronic kidney disease and an independent two-fold risk of having microalbuminuria, but no causal relationship has been uncovered (Singh & Kari, 2013).

J. Chen, Munter et al. (2004) found that with about three to five metabolic syndrome components there was an increased risk for chronic kidney disease and microalbuminuria, independent of age, sex, ethnicity, NSAID use, education, physical activity or smoking. It is recommended that both glomerular filtration rate and ACR be assessed in the determination of chronic kidney disease so that the whole spectrum within a population are screened (Hostetter & Lising, 2003; KDIGO, 2012).

3.4.2 Clinical consequences and outcomes of both chronic kidney disease and metabolic syndrome

Chronic non-communicable diseases, in particular diabetes mellitus, hypertension and cardiovascular disease, interact in a complicated way. The people most at risk for chronic kidney disease, who have a higher rate of kidney sequelae, complications and cardiovascular disease, are those with diabetes mellitus and/or hypertension (National Service Framework for Renal Services, 2005).

3.4.2.1 Type 2 diabetes There are a number of different types of diabetes. Diabetes insipidus is due to the malfunctioning of the hormone vasopressin in adequately controlling the blood water levels resulting in dehydration and electrolyte imbalance (IDF, 2007). Diabetes mellitus is a chronic disease involving blood sugar levels and insulin imbalance and includes a number of different types (IDF, 2007). Two forms of diabetes mellitus auto-immune diseases are type 1 diabetes, also called insulin-dependant diabetes, which attacks the insulin producing cells (insulin deficiency) and adult-onset latent autoimmune diabetes (LADA) (Li, Liao, Yan, Huang, Lin, Lei et al., 2009). Gestational diabetes mellitus is a complication of pregnant women having high blood glucose levels and may or may not revert to normal after delivery (IDF, 2007).

Type 2 diabetes is three times more prevalent than type 1 diabetes; both often present with similar symptoms, have similar outcomes and there is no cure for either although following healthy lifestyle habits improves glycaemic control (Reikes, 2000). The major focus of this review is on the unhealthy lifestyle-initiated type 2 diabetes, also called non-insulin dependant diabetes, adult-onset diabetes or simply diabetes. The hormone insulin, produced by the beta cells in the pancreas, facilitates glucose to be absorbed by the body's cells; but when the liver, muscles and adipose tissue become

less sensitive more insulin is needed, leading to hyperinsulinaemia (IDF, 2006). If a person persistently consumes a high glycaemic diet the beta cells eventually cease producing enough insulin and the blood becomes saturated with glucose; over time the person becomes hyperglycaemic and will be diagnosed as having type 2 diabetes (IDF, 2006). Obesity is associated with insulin resistance, and as triglycerides also build up with hyperglycaemia this further impairs insulin sensitivity (IDF, 2007).

The link between increasing blood glucose levels associated with diabetes mellitus and end-stage renal disease is still unclear, but current research links a pathway between a protein modified by hyperglycaemia and the initiation of kidney damage (Levey, Eckardt et al., 2005). Postprandial hyperglycaemia is one of the main causes of both macrovascular and microvascular damage and cardiovascular disease risk, but the risk of vascular disease decreases with a reduction in oxidative stress and improved glycaemic control (Bavenholm & Efendic, 2006) optimal blood glucose and lipid levels, a lowering of blood pressure and maintenance of a healthy weight (Beeharry, Joseph, Ewins, & Nair, 2014).

Obesity-initiated metabolic syndrome has the potential to cause chronic kidney disease via abdominal obesity, and independently through insulin resistance (Bagby, 2004). Impaired Fasting Glucose or Impaired Glucose Tolerance and hypertension are associated with an increased risk for type 2 diabetes (Alberti et al., 2005) and end-stage renal disease (Navaneethan et al., 2013). Research using the data from the Finnish Diabetic Nephropathy (FinnDiane) study found that persons with type 1 diabetes who have metabolic syndrome have an increased risk of diabetic nephropathy (Thorn et al, 2009). Those persons with metabolic syndrome and diabetes mellitus have three to four times greater risk of developing cardiovascular disease and stroke (Alberti et al., 2006; Eckel et al., 2005; Thorn et al, 2009; Verdecchia, Reboldi, Angeli, Borgioni, Gattobigio, Filippucci, et al., 2004). Studies have shown that impaired fasting glucose / impaired glucose tolerance is also often present in non-diabetic people with metabolic syndrome, putting them at five times a higher risk for developing type 2 diabetes than non-diabetic people without impaired fasting glucose / impaired glucose tolerance (Alberti et al., 2006; Eckel et al., 2005).

An Australasian position statement was presented in response to the new updated classification of and criteria for diabetes mellitus (Colman, Thomas, Zimmet, Welborn,

Garcia-Webb, Moore et al., 1999; WHO, 2006). The Australasian Working Party on Diagnostic Criteria recommended accepting (1) the new criteria proposed for diagnosing diabetes mellitus; (2) the new category impaired fasting glucose in addition to the category of impaired glucose tolerance; (3) the use of oral glucose tolerance test, as some cases of diabetes might be missed if not performed on suspect persons. The Australian Diabetes Society give the parameters for the 75 g oral glucose tolerance test as fasting glucose ≥ 7.0 mmol/L and 2 hour glucose as ≥ 11.1 mmol/L; the oral glucose tolerance test cut-off points are < 5.6 mmol/L normoglycaemic, 5.6-7.8 mmol/L impaired fasting glucose, ≥ 7.8 mmol/L impaired glucose tolerance and ≥ 11.1 mmol/L diabetes mellitus (ADS [Australian Diabetes Society], 2014). The International Diabetes Federation recommends oral glucose tolerance test as the gold standard for diagnosing persons with diabetes and defining impaired glucose tolerance (IDF, 2006), and this is followed in this study. The Royal Australian College of General Practitioners advise all doctors on proper guidelines for administering the oral glucose tolerance test (Phillips, 2012).

Haemoglobin A1C (HbA1C) assay is the measurement for assessing whether a person has their diabetes under control: it is a three-month average glucose assessment measuring glycated haemoglobin (Hicks, Muller, Panteghini, & Garry, 2007). It was noted that HbA1C had an acceptable specificity and sensitivity for diagnosing diabetes (Saudek, Herman, Sacks, Bergenstal, Edelman and Davidson, 2008). The American Diabetes Association's International Expert Committee reported on the role of HbA1C in diagnosing diabetes, emphasising that it is a precise laboratory measurement and should be reported as a percentage rather than mmol/mol (ADA [American Diabetes Association], 2009). There was much debate and the International Diabetes Federation Chairman, who was from Cameroon, Africa, expressed concern that it might be too expensive for poorer countries with few good laboratories, compared with using the glucometer. HbA1C is now recognised generally as a diagnostic criterion for type 2 diabetes with the percentage of $> 6.5\%$ (48 mmol/mol) as the cut-off point for diabetes mellitus; however, using the HbA1C does not exclude using other methods to diagnosis the disease (ADS, 2014; WHO, 2011).

It is estimated that by 2030 the number of persons with type 2 diabetes will increase to 360 million, with at least 40% of these persons developing chronic kidney disease and

more than 10% developing end-stage renal disease (ISN, 2006). A review of cause-of-death certificates of the Pima American Indian people found that the highest cause of death listed was diabetes-related (Cho et al., 2014). The Pima have the highest rates of diabetes of any ethnicity in the world, with the average age of onset 36 years, compared with 60 for Europeans (Cho et al., 2014). Despite this, Burrows et al. (2014) found that American Indians and Alaskan Natives with type 2 diabetes lived longer and better than European Americans with type 2 diabetes. The incidence of diabetic end-stage renal disease in Malaysia increased from 30% in 1996 to 54% of the population in 2005 (Ong, Punithavathi, Thurairatnam, Zainal, Beh, Morad et al., 2013). In the UK it is 11%, Australia 26%, Pakistan 42%, Japan 37% and United States 14.8% (Mahon, 2001). In Malaysia the prevalence of type 2 diabetes prevalence is 8.2%, and the country is listed by WHO as having the highest percentage of haemodialysis patients with diabetes in the world (Hooi, Lim et al., 2005).

3.4.2.2 Cardiovascular disease and coronary heart disease

Diabetes is the driving force behind escalating rates of cardiovascular disease in all developing and developed countries. Even before type 2 diabetes is diagnosed an increase in triglyceride and a decrease in HDL-C increases a person's risk of cardiovascular disease (IDF, 2006). Cardiovascular disease is an umbrella for a number of cardiac conditions including coronary heart disease, angina, heart attack, cerebrovascular disease including stroke and transient ischaemic attack, all having an impact on the circulatory system or heart (Parfrey & Foley, 1999). Atherosclerosis, the narrowing of the arteries by fatty deposits, is often the cause of all of these conditions. Associated with hypertension, dyslipidemia and insulin resistance, atherosclerosis is a chronic process developing over a number of years and directly contributes to coronary heart disease; Global et al. (2011, p. 1) have suggested that 'microalbuminuria, chronic kidney disease, and coronary heart disease share common pathways involving inflammation and oxidative stress'.

Cardiovascular disease rises exponentially as chronic kidney disease worsens (Langman, 2006), and many chronic kidney disease patients die of their heart disease before they reach the stage of requiring renal replacement therapy (C. S. Fox, Muntner, Chen, Alexander, Roe, Cannon et al., 2010). Cardiovascular disease deaths account for half of all deaths on haemodialysis (Parfrey & Foley, 1999). Among the end-stage renal

disease population in the United States, 25% have hypertension; 40% of haemodialysis patients have coronary artery disease (US Renal Data System, 1999) and 75% have ventricular hypertrophy (R. Foley, Parfrey, Harnett, Kent, Martin, Murray et al., 1995). If a person has both chronic kidney disease and metabolic syndrome the risk of cardiovascular disease mortality is higher (Prasad, 2014), and as the number of metabolic syndrome components increases, the higher and sooner the risk of cardiovascular disease mortality (Grundy, 2004; IDF, 2006). A number of components of the metabolic syndrome are independent risk factors for cardiovascular disease and therefore metabolic syndrome is a strong (Alberti et al., 2006), but not an absolute, risk predictor (IDF, 2006). Persons with the metabolic syndrome but no diabetes mellitus have up to three times the risk of coronary heart disease (Eckel et al., 2005). The Framingham Offspring Study found that men (34%) had a greater risk of coronary heart disease than women (16%) (Rutter, Meigs, Sullivan, D'Agostino, & Wilson, 2005) and men (62%) also had a greater risk of type 2 diabetes than women (47%) (Eckel et al., 2005). Both the metabolic syndrome and insulin resistance have been related to incident cardiovascular disease, and a study of 2,898 people without diabetes mellitus or cardiovascular disease, found that the metabolic syndrome and insulin resistance were individually associated with cardiovascular disease ($P < 0.007$ in both), pointing out that the metabolic syndrome may not identify all persons associated with risk of insulin resistance-cardiovascular disease (Rutter et al., 2005). Different ethnicities also have risk variation: for example, South Asians tend to have more coronary heart disease and cardiovascular disease than European-British, African-Americans have more coronary heart disease and stroke than European-British and Africans-Caribbeans have lower coronary heart disease but higher stroke rates than European British (Forouhi & Sattar, 2006).

The underlying major risk factor for cardiovascular disease is obesity, which also raises the risk factors for hypercholesterolemia, hypertension and hyperglycaemia and is presumed to be a risk for atherogenic dyslipidemia, insulin resistance, proinflammatory state and prothrombotic state (Grundy, 2004). 'Inflammation, hemodynamic effects, and imbalanced adipokine secretion' are thought to be mechanisms linking the metabolic syndrome with the risk of chronic kidney disease (Nitta, 2010, p. 4). Insulin sensitivity decreases with the accumulation of excessive saturated fatty acids (J. S. Lee, Pinnamaneni, Eo, Cho, Pyo, Kim et al., 2006c) eventually resulting in insulin resistance

and insulin dysfunction in the liver and skeletal muscles (Boden, 2003) and changing the ‘insulin-mediated glucose transport and metabolism’ mechanism of the metabolic syndrome and many other manifestations not included in the metabolic syndrome criteria, such as microalbuminuria (Eckel et al., 2005, p. 1418). Insulin resistance is strongly associated with cardiovascular disease, type 2 diabetes (Eckel et al., 2005) and all the metabolic syndrome diagnostic criteria except for hypertension, which only has a mild to moderate association (Hanley, Karter, Festa, D’Agostino, Wagenknecht, Savage et al., 2002).

3.4.3 Best public health practices for the management of chronic kidney disease and metabolic syndrome

The chronic low-grade inflammation of the metabolic syndrome has grave systemic consequences on various body systems and organs, renal, hepatic, skin, ocular, sleep, reproductive and cardiovascular, and is linked with certain cancers (Kaur, 2014). The only way to improve one’s quality of life and longevity is to address the causes and commence a combination of lifestyle intervention programs and pharmacological management if needed, with the aim of preventing or slowing the progression of the particular chronic non-communicable disease condition.

3.4.3.1 Risk assessment

Risk assessment should include anthropometric measurements, laboratory investigations and a basic questionnaire survey noting family history, diet and exercise habits, and other general information. A Canadian study using the revised National Cholesterol Education Program data found that half of those studied had one or two metabolic syndrome risk markers and, although not diagnosed with the metabolic syndrome, every metabolic syndrome risk factor a person has becomes an increased risk for developing some chronic non-communicable disease and inflammation (D. Rao, Dai, Lagace, & Krewski, 2014). Before commencing an intervention program, medical and health personnel need to first give patients a risk assessment and medical examination, especially for those over 50 years of age. There is some discussion regarding the best risk score to assess a person’s risk of a chronic non-communicable disease and end-points, and the Framingham Risk Score is often compared with the metabolic syndrome assessment. In a prospective study (n = 5,128) of men with no

history of cardiovascular disease, CHD or stroke and using the Framingham Risk Score, Wannamethee, Shaper, Lennon and Morris (2005) established that it was a better predictor of coronary heart disease and stroke than metabolic syndrome however metabolic syndrome was still a strong predictor of cardiovascular disease and type 2 diabetes. The National Kidney Foundation Kidney Early Evaluation Program (KEEP) concluded that chronic kidney disease is independently associated with myocardial infarction or stroke, noting that cardiovascular disease was associated with hastened death in chronic kidney disease (McCullough, Li, Jurkowitz, Stevens, Wang et al., 2008). At the present no one risk assessment covers all areas; and more research is needed on lifestyle and pharmacological intervention outcomes in order to recommend the best combinations for treating chronic kidney disease patients with metabolic syndrome (Nitta, 2010). It also depends upon who is doing the assessment: whether a doctor or health personnel are assessing and instructing the person (both are required for optimal management). The metabolic syndrome was developed as an education and diagnostic tool to help identify people at high risk for type 2 diabetes and cardiovascular disease (Alberti et al., 2006) and may well be easier to use in the absence of a medical doctor.

3.4.3.2 Genetic factors: chronic non-communicable diseases

A South Carolina, USA study found that a low birth weight increased the risk of end-stage renal disease suggesting that adverse in-utero conditions may impair kidney development (Lackland, Bendall, Osmond, Egan, & Barker, 2000). Gene-environment interaction may result in obesity, even in-utero (Monasta, Batty, Cattaneo, Lutje, Ronfani, Van Lenthe et al., 2010) and if overweight babies are overweight at seven years of age they tend to become obese adults (Valerio, D'Amico, Adinolfi, Munciguerra, D'Amico, & Franzese et al., 2006). Another study has found that infants who had a low birth weight and were thin at two years of age but rapidly put on weight as children, gaining a higher than average body mass index by 11 years old, were more likely to have insulin resistance and heart problems as adults (Barker, Osmond, Forsen, Kajantie, & Eriksson, 2005). As Malaysia's health status transitions to economic development and affluence the incidence of type 2 diabetes and diabetic nephropathy will continue to increase (Jha et al., 2013). Poor environmental factors contribute to low birth weight (A. White et al., 2010) and overweight children, and it is of utmost

importance to educate young women and pregnant mothers in healthy lifestyle tactics as ‘prenatal undernourishment makes a person permanently at higher risk for developing diabetes’ (Barker et al., 2005). A variant in a gene on chromosome 10 has been identified as a reliable marker for type 2 diabetes and may be used in the future as a genetic test to determine persons of high risk (Ng et al., 2007).

Metabolic syndrome could also have a genetic aspect (Grundy, Cleeman et al., 2005), and diabetes mellitus and hypertension, the two leading causes of chronic kidney disease, tend to have familiar genetic linkages (ISN, 2006). In the United States, of those persons with end-stage renal disease, African–Americans are more likely to have hypertension but Native Americans are more likely to have type 2 diabetes (Reikes, 2000; Esprey et al., 2014). The *Genetics of Kidneys in Diabetes* study notes that diabetic nephropathy clusters in families, and there is a considerable genetic component of kidney complications and a high mortality in those with type 1 diabetes (Mueller, Rogus, Cleary, Zhao, Smiles, Steffes, et al., 2006).

3.4.3.3 Pharmacological management

If a person is diagnosed early, in the mild beginning stages of a chronic non-communicable disease, lifestyle intervention measures are usually the first line of treatment. Medication is added if the individual is uncompliant or if the condition is unstable or has advanced. Insulin resistance, hypertension and dyslipidemia are often found together but need to be treated separately from each other until such time as drug therapies targeting the whole metabolic syndrome multi-component cluster are developed (Alberti et al., 2006). (Medical and drug intervention measures are outside the parameter of this review.)

High blood pressure (hypertension). Hypertension is both a cause and an outcome of chronic kidney disease. The Malaysian Clinical Practice Guideline Working Group determined that 61% of the population had undiagnosed high blood pressure and only 35% of those being treated for hypertension were well controlled (A. R. Ab. Rahman, 2014). Suboptimal treatment for hypertension increases the risk of cardiovascular, cerebrovascular and renal morbidity and mortality (A. R. Ab. Rahman, 2014). Risk of diabetic complications is reduced further with tight blood pressure control (144/82 mm Hg) as compared with less tight control (154/87 mm HG), and to gain tight control

there is a need to combine antihypertensives, tailored to suit the individual's needs (Mustafa, Kamarudin, Ismail, Khir, Ismail, Musa et al., 2011).

Blood glucose control, hyperglycaemia and insulin resistance. It is vital for persons with metabolic syndrome, especially if diabetic, to attain optimal glycaemic control, and interventions by medical therapy and lifestyle modification will improve diastolic dysfunction and help prevent heart failure (Von Bibra & Sutton, 2010). Drugs that reduce insulin resistance in persons with metabolic syndrome are thought to delay the onset of type 2 diabetes and reduce the risk of cardiovascular disease (Alberti et al., 2006). Insulin resistance and atherogenic dyslipidaemia worsens with high doses of diuretics and β -blockers in people with diabetes (Alberti et al., 2006), so it is necessary for knowledgeable medical management to be given patients with a chronic non-communicable disease.

Dyslipidaemia (cholesterol). Patients with metabolic syndrome and elevated LDL-C levels are at extreme risk of cardiovascular disease and may require drug therapy to lower levels to within the acceptable range (Alberti et al., 2006). The Framingham Heart Study ($n = 2,471$) examined the chronic kidney disease and cardiovascular disease shared risk factors and found that there is a higher cardiovascular disease risk in chronic kidney disease if the person also has a low HDL-C (N. I. Parikh, Hwang, Larson, Levy, & Fox, 2008). One study has highlighted the fact that few patients reach an acceptable lipid level quickly enough and therefore dosage needs to be aggressive (K. Foley, Simpson, Crouse, Weiss, Markson, Alexander, 2003).

Chronic kidney disease. Many patients presenting with chronic kidney disease have had undiagnosed type 2 diabetes and hypertension for some time (Reikes, 2000; Xue, Ma, Louis, & Collins, 2001). The minority groups in the United States have higher end-stage renal disease rates due to type 2 diabetes and hypertension (Xue et al., 2001) and metabolic syndrome (Lea, 2013). Strict control of blood glucose, blood pressure and HbA1C and medication is recommended by the American Diabetes Association, to prevent complications and progression to end-stage renal disease (American Telemedicine, 2005). Patients undergoing end-stage renal disease treatment have a higher mortality rate, even when adjusted, than to the general population and are at increased risk for atherosclerotic disease, left ventricular hypertrophy, malnutrition and infection (Reikes, 2000). The survival of a person with established end-stage renal

disease is correlated with the underlying cause of their renal disease (Reikes, 2000), but, as described, the management of one condition often has a positive effect on another inter-related one. Metabolic syndrome can be modified to delay progression of chronic kidney disease (Lea, 2013) and with good medication control for hypertension and type 2 diabetes, compliance in taking medication and acceptance of renal replacement therapy, survival time of end-stage renal replacement patients should improve (Reikes, 2000; Lea, 2013).

3.4.3.4 Lifestyle factors: diet and nutrition

In all cultures there is a trend to eat foods high in energy, fats, sugar and salt, and less fruit, vegetables and whole grains; and this, coupled with inactivity, increases the risk of death from a chronic non-communicable disease, especially cardiovascular disease (WHO, 2013b). For those who are obese a moderate calorie restriction aiming for 5–10% weight reduction in the first year should be pursued by changing the composition of the diet to reduce saturated fat, sugar and salt and to increase fibre intake (Alberti, et al., 2006). If an obese person loses weight, inflammation and insulin sensitivity improve (Monteiro & Azevedo, 2010).

Kidney organisations have different food and protein dietary guidelines for different countries. KDOQI has detailed guidelines for adults with chronic kidney disease, but often patients will not accept a rigid protein diet once they commence renal replacement therapy (Kopple, 2001). Other patients go into starvation mode, drastically reducing their protein and energy intake and becoming malnourished when they are diagnosed with end-stage renal disease and commence haemodialysis. Good dietary advice, intervention and control, good hypertension control, patient motivation and compliance and a good working relationship with the doctor and the dietitian should be available to every person diagnosed with chronic kidney disease (Kopple, 2001).

3.4.3.5 Lifestyle factors: physical activities and exercise

Genetic, environmental and psychosocial factors interact, and when lifestyle stress, low-quality excessive energy food intake and little exercise dominate, the body reacts negatively (Monteiro & Azevedo, 2010). Physical inactivity coupled with obesity modifies muscle insulin sensitivity (Alberti et al., 2006). Interestingly it is known that

some non-obese people have insulin resistance and some who are obese have a benign form that does not lead to a chronic non-communicable disease or metabolic syndrome (Monteiro & Azevedo, 2010). More research is needed to link insulin resistance with the metabolic syndrome in all of its components (Unwin, 2006), but it appears that aging, accompanied by muscle mass loss and an increase in abdominal body fat, can increase insulin resistance and influence the development of metabolic syndrome (Alberti et al., 2006). Weight loss and increased physical activity can improve insulin sensitivity along with blood pressure and blood glucose levels (Monteiro & Azevedo, 2010).

To reduce weight, moderate increases in physical activity, including muscle strengthening, are encouraged with the long-term aim of achieving a normal body mass index and/or waist circumference (Alberti et al., 2006). With the escalation in obesity in children, the Commission on Ending Childhood Obesity has been established, to find ways to counter this problem (WHO, 2013b). Persons with chronic kidney disease should engage in proper exercise, even walking, every day to prevent or reduce obesity and improve their comorbidities, and patients with end-stage renal disease on dialysis should be encouraged to lead active and fulfilling lives (Ong et al., 2013) as this also helps mental health.

3.4.3.6 Lifestyle behavioural changes: smoking, alcohol and drugs

Many chronic non-communicable diseases are considered preventable because the condition can be greatly improved if the individual ceases at-risk lifestyle behaviour. The best example of this is cigarette smoking. Cigarette smoking exacerbates glomerular filtration rate decline in persons with macroalbuminuria and type 2 diabetes, but as soon as a person stops smoking, kidney injury improves (Chuahirun et al., 2004; Ritz et al., 2000; Xue et al., 2001). Smoking is highly addictive and it is a difficult challenge to stop, so patients need to be motivated (Chuahirun et al., 2004) and educated about helpful tools and techniques such as nicotine patches, gum or hypnosis. A study using data from NHANES II 1976 through 1980 found no association between chronic kidney disease and alcohol consumption, although smoking, physical inactivity and morbid obesity were risk factors (Stengel, Tarver-Carr, Powe, Eberhardt, & Brancati, 2003). A Singapore study found that compared with non-smokers, people exposed to smoking and who more than four alcoholic drinks per day had almost five

times the odds of developing chronic kidney disease (odds ratio = 4.93, 95% CI: 2.45, 9.94). (Shankar, Klein & Klein, 2006). A US study of 647 veterans at a hypertension clinic found that there was a significant, positive, and independent association between illicit drug use and risk for mild kidney function decline in hypertensive men (Vupputuri, Batuman, Muntner, Bazzano, Lefante, Whelton, et al., 2004). Persons engaging in negative lifestyle behaviours need to be advised appropriately regarding their risk of developing and progressing chronic kidney disease and given help to overcome their bad habits if they ask.

A healthy lifestyle is essential for preventing and treating chronic non-communicable diseases. Those persons with metabolic syndrome need to undertake lifestyle behaviour modification to control their risk of chronic kidney disease, cardiovascular disease and coronary heart disease (Gobal et al., 2011). It is important for people who have a chronic non-communicable disease to endeavour to improve their longevity, and they need the support of both medical and health professionals to achieve a better quality of life. Both preventable and non-preventable risk factors need to be recognised. For example, it has been found that overeating and under-exercising has different vascular and metabolic dysfunctional effects on different ethnicities (Faruhi & Sattar, 2006). Environmental and economic development, and changes in lifestyle and diet, have led to metabolic syndrome being highly concentrated in urban areas of China but not in rural areas (Y. He, Jiang, Wang, Feng, Chang, Fan et al., 2006). It is necessary for organisers to understand that, before commencing any intervention program, they must be familiar with the ethnic groups who are participating, their circumstances and propensity to develop a chronic non-communicable disease.

3.5 Research Gaps Identified

From the literature review a number of gaps in knowledge and information have been uncovered, with particular reference to chronic kidney disease, metabolic syndrome and outcomes, in Miri, Sarawak.

There is a scarcity of epidemiological studies from Malaysia on

- chronic kidney disease and metabolic syndrome in Malaysia that include data on the Malay, Chinese and Borneo Indigenous peoples from the Eastern Malaysian states of Sarawak and Sabah
- socio-demographic and socio-economic risk factors for chronic kidney disease / metabolic syndrome for the different ethnic groups of Sarawak
- lifestyle behavioural and environmental risk factors for chronic kidney disease / metabolic syndrome for the different ethnic groups of Sarawak
- whether Miri end-stage renal disease patient's household members have metabolic syndrome components or microalbuminuria which may indicate undiagnosed chronic kidney disease.

No research studies in Sarawak have determined if there is clustering within

- ethnic and family groups susceptible to chronic kidney disease / metabolic syndrome.
- socio-demographic and socio-economic groups susceptible to chronic kidney disease / metabolic syndrome.
- groups living in particular housing and environments that make them more susceptible to chronic kidney disease / metabolic syndrome.

There are currently no published studies for Sarawak reporting on

- abnormal clinical parameters for diabetes mellitus, hypertension, chronic kidney disease and cardiovascular disease in the first degree relatives of patients with end-stage renal disease.
- whether the first degree relatives are predisposed to a family history of chronic non-communicable diseases implicated in the development of chronic kidney disease or metabolic syndrome and outcomes.

- the health status of the first degree relatives or spousal family relatives of end-stage renal disease patients on haemodialysis.

Only limited studies of chronic kidney disease / metabolic syndrome risk factors address

- a predisposition for chronic non-communicable diseases in end-stage renal disease patients; households.
- social determinants such as home environment, in the Miri community.
- health determinants such as obesity, type 2 diabetes, smoking, alcohol drinking.
- whether metabolic syndrome is a risk factor for chronic kidney disease and whether chronic kidney disease is a risk factor for metabolic syndrome in Miri.

There are no Sarawak qualitative investigations regarding the

- health-related beliefs and behaviours of the Malay, Chinese and Borneo Indigenous ethnic groups
- decision-making processes involved in choosing a modern medical doctor or a traditional practitioner
- cognitive process of choosing modern medicine or traditional herbal medicines.
- barriers preventing persons from seeking medical attention for chronic non-communicable diseases.

There are no published Sarawak research recommendations for

- using the metabolic syndrome criteria as a diagnostic tool for chronic kidney disease / metabolic syndrome.
- public health awareness and education promotion, to recognise and prevent chronic non-communicable diseases, in the community
- identifying at-risk population groups for targeted for chronic kidney disease screening and intervention programs
- future public health intervention strategies and programs for chronic kidney disease / metabolic syndrome in the community with the intention of delaying the progression of chronic non-communicable diseases.

In summary, there is a need for

- research on chronic kidney disease, metabolic syndrome and chronic non-communicable disease comorbidities, cardiovascular disease and outcomes
- information on chronic non-communicable diseases in this multi-ethnic population
- high risk factors and clustering for chronic kidney disease / metabolic syndrome to be documented for end-stage renal disease patients' families
- information on the family history and health status of the participants
- information on the social and health determinants of the participants
- information on participants' health-related beliefs and behaviours
- recommendations for chronic kidney disease / metabolic syndrome screening and intervention programs.

3.6 Conclusion

This literature review was divided into two areas, end-stage renal disease / chronic kidney disease and metabolic syndrome, in order to fully understand each area before reviewing the connections between them. Chronic kidney disease is asymptomatic in the pre-clinical stage, and if detected early may be prevented from progressing to end-stage renal disease; this may also reduce mortality from cardiovascular disease.

Community strategies and barriers to screening for chronic kidney disease were discussed, including the cost of screening for a disease with a low pick-up rate such as end-stage renal disease. It addresses some ethnic, social and economic disparities found between populations. Studies show that it is cost-effective to screen for chronic kidney disease using the ACR in high-risk persons with a family history of end-stage renal disease and who have type 2 diabetes and hypertension, but not for others.

The metabolic syndrome is not a disease in itself but a number of different chronic disorders that contribute to this syndrome. There is an intricate relationship and type 2 diabetes and cardiovascular disease may be both a cause of and an outcome of chronic kidney disease and metabolic syndrome.

Evidence-based best public health lifestyle practices for the prevention and management of chronic kidney disease and metabolic syndrome was discussed.

This literature review has identified a niche in which to locate the research and bridge a gap between the existing knowledge regarding chronic kidney disease and the metabolic syndrome with the intention of informing future lifestyle intervention programmes in Sarawak.

The following chapter focuses on the Phase One methodology used in this study.

Chapter 4 Research Methodology

The Mixed Methods methodology is the design that underpins this thesis. A brief overview of the benefits of using a Mixed Methods approach and the value it brings to health research is presented. Ethical issues and the protocol for the data collection and analysis are detailed.

4.1 Mixed Methods

Mixed Methods research has advanced significantly and is now an established methodology in its own right (Teddlie & Tashakkori, 2010). The data for this research was drawn from both quantitative and qualitative phases, analysed separately then combined (Creswell & Plano Clarke, 2007). The rationale for using this approach was to facilitate a deeper understanding of the local nuances and health beliefs among the Miri population. Saks and Allsop (2013) have suggested that Mixed Methods is a suitable methodology to follow when investigating people of different ethnicities, languages and cultures as I can decipher information from a number of different angles.

The Mixed Methods design can be of a number of different sequence combinations ,and the methods used can vary in emphasis, depending on what is considered the most appropriate way to address the research questions and produce trustworthy results (Saks & Allsop, 2013). In this study, an explanatory quantitative to qualitative sequence was chosen. The Phase One quantitative data collection identified those at risk for chronic diseases like chronic kidney disease and metabolic syndrome and the analysis identified phenomena for follow-up. The Phase Two qualitative collection explored and clarified these phenomena in more depth and also investigated the participants' beliefs and behaviours with regard to chronic kidney disease and metabolic syndrome risk factors.

A scheme for the Mixed Methods sequential explanatory design is presented below (*Figure 4.1*). Equal emphasis and precedence was given to both the quantitative and qualitative phases.

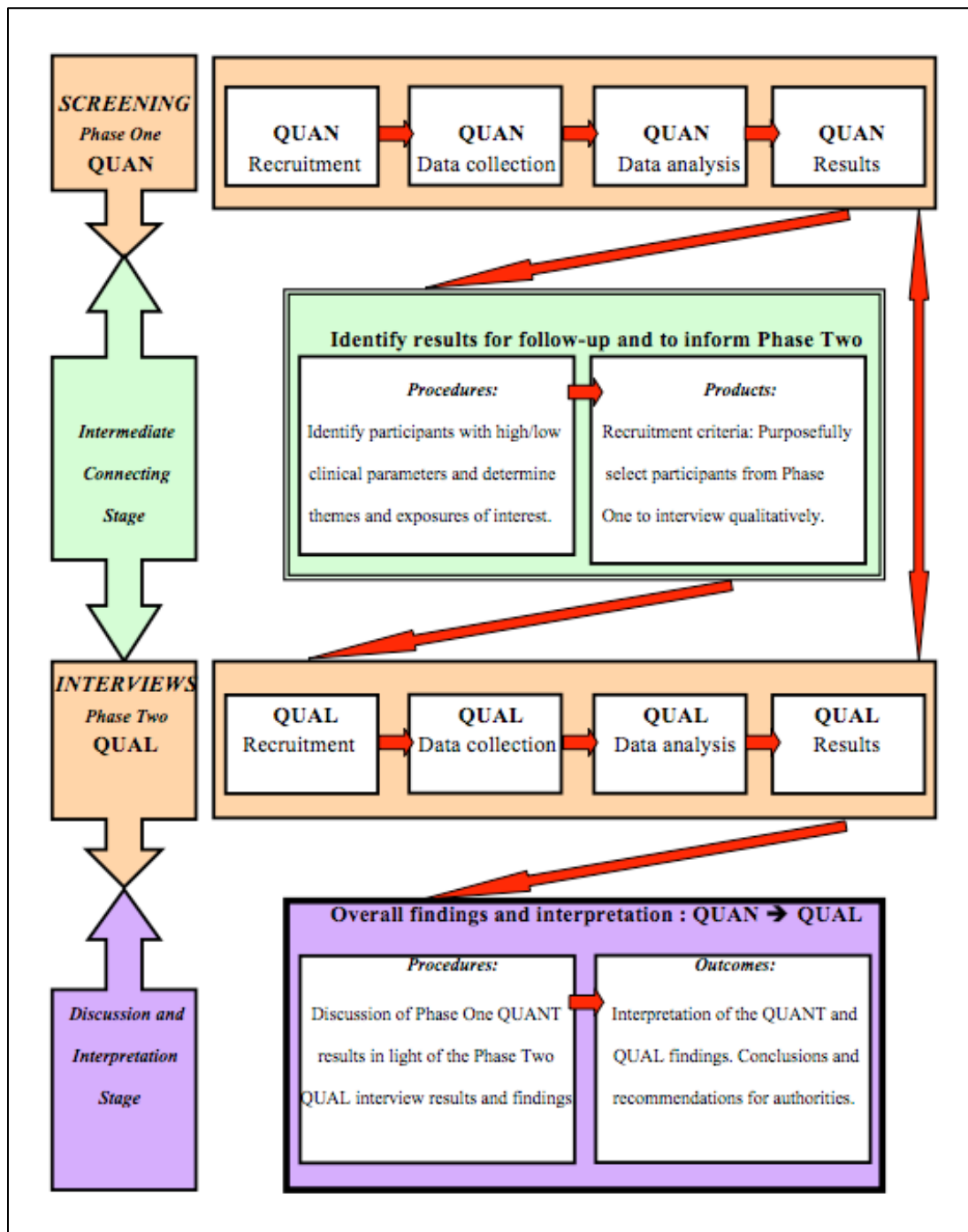


Figure 4.1 Mixed methods sequential explanatory design: participant selection model

Adapted from Creswell and Plano Clarke (2007, 71-75; 119)

Certain quality standards unique to Mixed Methods, as discussed in Creswell and Plano Clarke (2007), Saks and Allsop (2013), Tashakkori and Treddlie (2009) and Treddlie and Yu (2007), were addressed in this study.

- With respect to the weighting of the quantitative to qualitative components, the study design was intended to have an equal balance.

- Being a sequential design, with the Phase Two recruitment of participants dependent upon the Phase One results, inevitably meant more expense and a lengthy study time frame.
- The rationale for the selection of the participants for both phases was explicitly stated in the proposal and participant information sheets. This ensured the study had rigour as it intentionally and deliberately gathered both the quantitative Phase One and the qualitative Phase Two data from the same set of participants.
- A number of procedures have enhanced the confidence and validity of the research. In addition to expounding the quantitative results, in Phase Two meaningful information was extracted by guiding the dialogue towards known predictors of chronic kidney disease. The quantitative outcomes were also compared and contrasted with the qualitative findings, similar to Triangulation Design methods, to corroborate or contradict results. All aspects of the study process were rigorous and systematic, in accordance with Mixed Methods quality standards.

4.1.1 Explanatory design purpose statement

This research undertook to investigate significant risk factors, beliefs and behaviours that might contribute to the development of chronic kidney disease in the household family members of end-stage renal disease patients. It had two phases, with the outcome of Phase One framing Phase Two; an intermediate stage connected the two methodologies and an interpretation stage synthesised the results and findings to draw coherent conclusions. Phase One was a matched case-control study in which quantitative data regarding the participants' socio-demographic, anthropometric and biomedical information was gathered. In the intermediate stage significant results from this data were identified, and these formed the basis of the Phase Two interview schedule. Participants from Phase One who were determined to have both high and low clinical parameters for chronic kidney disease were purposefully selected for follow-up in Phase Two, which gathered qualitative data through in-depth semi-structured interviews. The qualitative data expounded the quantitative results and contributed to new knowledge and understanding of health-related beliefs and behaviours that could be contributing factors for chronic kidney disease in the household members of end-stage renal disease patients.

4.2 Ethical Considerations

Information set out in the National Statement and Guidelines for Research has been referred to (NHMRC [National Health and Medical Research Centre], 2007a,b,e) and pertinent issues addressed. In addition, guidelines set out by the World Medical Association Declaration of Helsinki, *Ethical Principles for Medical Research Involving Human Subjects*, have been consulted and addressed in this study (World Medical Association 2013). The Curtin Human Research Ethics Committee (HREC) guidelines approved the study via protocol approval number HR 07/2009 (*see Appendix H*).

I obtained permission from the Malaysian Ministry of Health (MMOH) to use the Malaysia Non Communicable Disease Surveillance 2006 questionnaire (MMOH, 2006b). This questionnaire was standardised following the WHO STEPS Instrument (WHO, 2005; WHO, 2008) and had already been used by the Malaysian Ministry of Health (MMOH, 2006b) and validated for a mixed ethnic Malaysian population. I was granted permission to use this by both WHO Geneva and the Malaysian Ministry of Health, Putra Jaya, Kuala Lumpur (*see Appendixes I; J*).

The Divisional Medical Officer for 4th Division of the Sarawak Health Department, the Miri General Hospital Haemodialysis Unit and the Miri City Medical Centre Dialysis Centre approved verbally based upon the above mentioned approval letters (*see Appendixes H; I; J*). The Malaysian Red Crescent Kidney Dialysis Centre gave a letter of approval (*see Appendix K*). Once the three dialysis centres had sanctioned this study and allowed access to the end-stage renal disease patients, recruitment of the family members commenced.

Sarawak Shell Berhad made a financial contribution toward the conduct of the study and the analysis of the urine and blood. No other financial assistance was received, and additional costs were borne by me. Columbia Hospital, Miri, provided a double hospital ward for the Phase One anthropometric and questionnaire data collection. Gribbles Pathology Laboratory Malaysia conducted the laboratory data collection and provided a discount on all clinical chemistry measurements; and Dr Roland Mattu allowed the use of his clinic for the Phase Two interviews.

As far as possible, gender-appropriate assistants and translators were used to address cultural gender sensitivities. There was no coercion of anyone to participate and those approached had the right to refuse without explanation. There was no remuneration given. The laboratory tests were conducted without charge to the participants, and packet drinks and biscuits were provided in Phase One. In Phase Two a bottle of water and petrol money, based on mileage from each participant's home, was provided to those who were interviewed. Invitations were given each phase (*see Appendixes L; M*).

In order for everyone to understand fully and respond appropriately, every person who was selected and agreed to participate in Phase One and Phase Two had their mother tongue noted for this study. A translator in the language they preferred was made available to them during data collection, for the questionnaire, and during the interview sessions.

Translation of the information sheets, consent form and the interview guide involved testing for cultural equivalence and sensitivity, following the procedure outlined by Bowling (2004). The interview guide was reviewed by the reference group, four persons not involved in the study, to ensure it was accurate and appropriate. All information from the questionnaire and interviews in a language other than English was transcribed into English text before analysis.

During recruitment all participants were given information sheets outlining the purpose of the research, the data collection procedures, and the risks and benefits of participation in the study. Prior to the Phase One data collection session, the participants were given a consent form and the questionnaire. Prior to the Phase Two interview session the participants were given another consent form and a brief outline of the purpose of the interview. Questions the participants had regarding the study was explained verbally in their language and also in an information sheet (*see Appendix N*).

Consent forms were signed by participants prior to both Phase One and Phase Two data collection sessions. When they signed the Phase One Consent form they were asked to consider participating in the Phase Two interviews, which required allowing me to identify and contact them. Those who did not agree were excluded from Phase Two. Participants were also asked for consent to record the qualitative interviews (*see Appendixes O; P*).

Confidentiality and privacy issues were stressed to all nurse assistants and translators helping during the study. Privacy during data collection sessions was respected. The anthropometric measurements were taken in a private cubical in the hospital ward. Blood was collected in a separated private area at the laboratory. The participants filled out the questionnaire on their own, although translators were present to help if they didn't understand the questions or couldn't read or write. All participants were protected through anonymity. Malaysians hold identification cards, and the card number and a sequence number were used rather than names. No names, identity card numbers or identifying features were used in any papers or publications, and only anonymous group results have been, or will be, released.

In accordance with the Joint NHMRC/AVCC Statement (2007e,c,d), original data is retained in the research office. All data files were coded so that participants could not be identified directly from the data sheets. The recruitment sheets holding the code numbers and matching participant names, identity card numbers, address, particulars, contact information and signed informed consent form, were kept in a separate file and locked in a cabinet at the office. This was only consulted to identify persons from their identity card numbers for the Phase Two interviews. All research data and test results were entered onto a password-protected computer. All data sheets have been stored in a locked cabinet in an alarm-monitored office, including a backup hard drive of the data, the data analysis and results, the questionnaires and interviews, the laboratory reports, and the anthropometric measurements. I am the only one with access to this cabinet. All hard data and an electronic copy of results have been handed to the main supervisor for safe upload on Curtin R drive.

All clinical measurements and laboratory tests were handled with strict medical confidentiality. The Malaysian Ministry of Health requires laboratory reports to be issued to patients personally. The assessment and medical reports were made available to the participants to take to their personal doctor for follow-up, and a copy of their laboratory report and clinical information sheets were retained in the locked cabinet at the research office.

A number of factors contribute to 'research fatigue'. One such problem, occurring in situations of unique interest, when participants are not fed back information from the study outcomes, they refuse to cooperate with researchers another time (Clark, 2008).

Information from this research will be distributed to all participants, end-stage renal disease patients, their families and the community. Clark (2008) remarks that over-researching a social group, without any evidence of change for the better occurring, may lead to annoyance in the participants. A summary of the results and suggestions for future practice improvements will be given to Sarawak Shell Berhad, the participating haemodialysis centres and the Government Health Department. Local newspapers circulate public health announcements, and public seminars will be organised to disseminate information relating to this study. Already a number of community health awareness talks have been presented by me, including interactive workshops where participants take responsibility for lifestyle behaviour changes to improve their health.

4.3 Quantitative Overview

From the literature review, a number of determinants that may lead to the risk of developing chronic kidney disease were identified. The exposures of interest included:

- socio-demographic – predisposing factors: age; gender; ethnicity; level of education; place of residence; socio-economic status; personal and family medical history
- lifestyle – behavioural risk factors: tobacco smoking; alcohol / drug consumption; physical activity / inactivity; diet – Western / traditional; medication – Western / traditional; use of agrochemicals
- metabolic syndrome comorbidities – metabolic disorders: obesity; diabetes; hypertension; dyslipidaemia; cardiovascular disease; chronic kidney disease.

The quantitative methods used to investigate the exposures of interest and to screen the participants for chronic kidney disease and the metabolic syndrome included:

- a standardised self-administered questionnaire on participants' background: socio-demographic, lifestyle, diet and physical activity
- anthropometric measurements to determine participants' physical characteristics: height; weight; waist circumference; waist–hip ratio; body mass index; skinfold fat; blood pressure

- laboratory investigations for biomarkers of chronic kidney disease and metabolic syndrome components contributing to chronic non-communicable diseases and chronic kidney disease: central obesity; triglycerides; HDL-C; LDL-C; plasma glucose; microalbuminuria.

From this data, significant local factors associated with chronic kidney disease were determined and trends contributing to abnormal clinical parameters among the participants identified.

4.4 Quantitative Phase One Research Methods

To achieve the study objectives, 270 participants were recruited. The socio-demographic questionnaire, the anthropometric measurements and the laboratory investigations gave a range of results relating to chronic metabolic disorders that came under the auspices of contributing to associated risk factors for chronic kidney disease and the metabolic syndrome.

4.4.1 Recruitment of participants and selection criteria

The three major racial groups residing in Miri are Malay, Chinese and Indigenous people. The recruitment population was all the end-stage renal disease patients being treated at all three haemodialysis units in Miri; they were invited to enlist their first degree relatives and in-laws to participate in the study. The first degree relatives and their spousal in-laws were provided with an information sheet. Those who wished to participate contacted me for an appointment date, providing their name, age, gender, relationship to the patient, preferred language and mobile phone number. Only those fitting the selection profile were invited to participate. The inclusion criteria were being a first degree relative (parent, sibling or child) of the end-stage renal disease patient and over the age of eighteen. The spousal control group inclusion criteria were being a non-affected, non-genetic relative of the patient's spouse, or a spouse of a patient's sibling or child, with no family history of end-stage renal disease.

4.4.2 Matching cases with controls

One hundred and thirty-five first degree relatives of end-stage renal disease patients were compared with the same number of controls. The reason for using spousal groups

as controls was that they often shared a similar environment, diet and socio-economic status as the case group, but not the genetic component of being closely related to someone with end-stage renal disease.

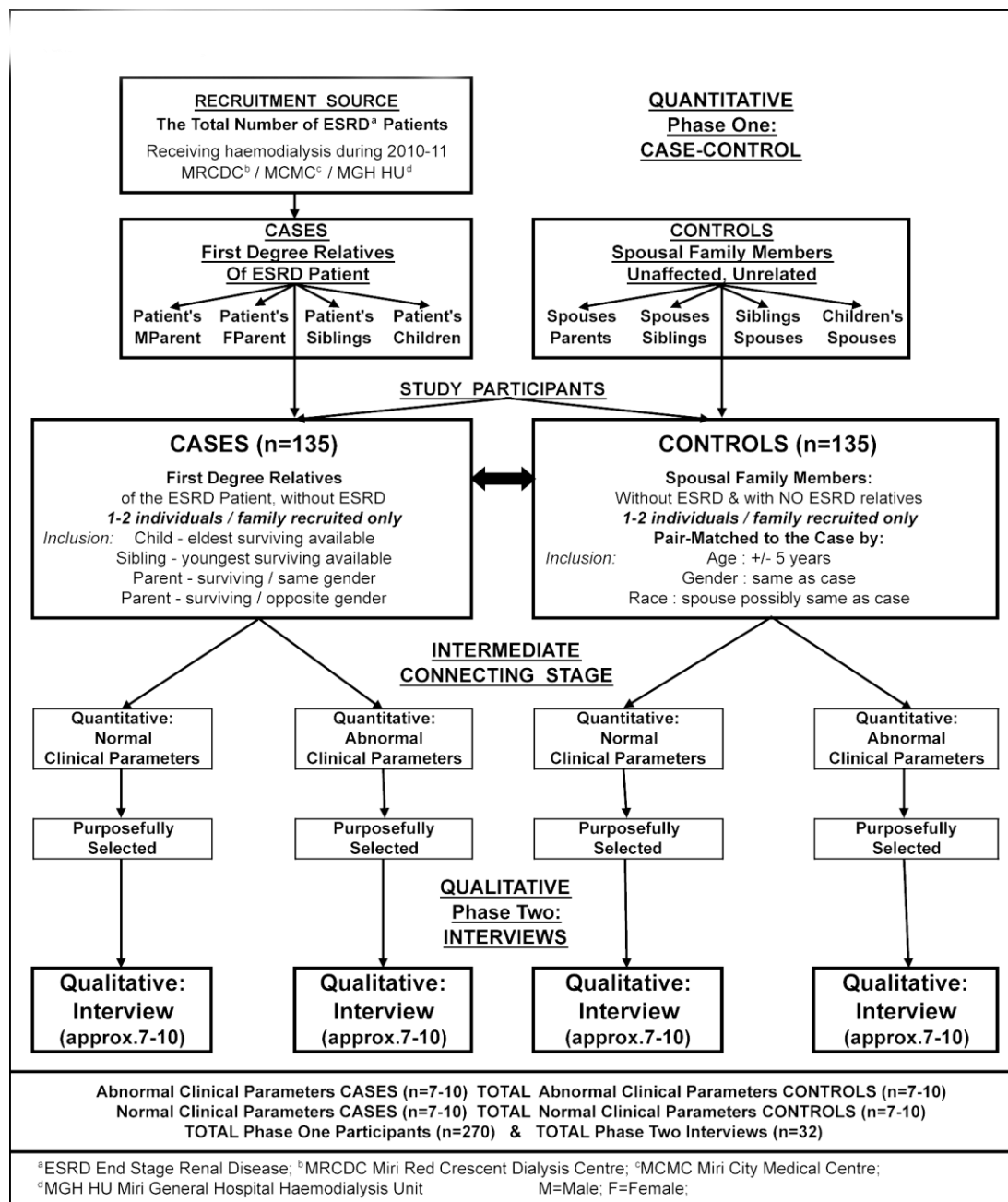


Figure 4.2 Study recruitment diagram

4.5 Sample Size

The sample size was based on an abnormal kidney function indicating chronic kidney disease as eGFR (less than) $<60 \text{ mL/min/1.73m}^2$ versus normal / not indicated chronic kidney disease as eGFR (greater than) $\geq 60 \text{ mL/min/1.73m}^2$.

To detect an odds ratio of 2.0 with type 1 error at 5%, and equal proportions of cases and controls a study sample size of 270 is needed: i.e., 135 cases and 135 controls.

The sample size number was calculated to include drop-outs, however this was a highly motivated group (n=272) and only two recruits dropped out before data collection commenced, because of off-shore work commitments, and these were replaced.

4.6 Validity and Reliability

Validity is addressed in both the quantitative and qualitative sections (Chapters 4 and 6). Although validity is interpreted differently, 'in both approaches it serves the purpose of checking on the quality of the data and the results' (Creswell & Plano Clarke, 2007, pp. 133). In this study, potential threats to validity were identified (Creswell & Plano Clarke, 2007) and minimised during the data collection sessions by ensuring that all techniques and the instruments used were standardised (Golafshani, 2003). Validity was also reinforced in the intermediate connecting stage by using the significant predictors for chronic kidney disease and metabolic syndrome, identified from the analysis of the quantitative Phase One, to inform the qualitative Phase Two; and drawing a small sub-set of the same participants from the Phase One large sample for follow-up in Phase Two.

In Phase One of this study research reliability, being able to replicate or repeat the results (Golafshani, 2003), was ensured in a number of ways. The research assistants and the translators were briefed by on aspects of the study and how they should assist. I trained the assistants in the correct techniques for gathering the anthropometric measurements and blood pressure readings. To avoid errors of measurement, I insisted on consistency and monitored accuracy during all data collection sessions. The anthropometric measurements followed standardised procedure. The procedures were written up and kept in an operations manual. The questionnaire had been validated by the Ministry of Health Malaysia for a Malaysian population.

4.6.1 Quantitative data collection protocol

Standardised protocol following international guidelines was used for all anthropometric measurements and the clinical data collection. The metabolic syndrome set cut-off points were used to identify abnormal clinical parameters for central obesity,

HDL, LDL, triglycerides, blood pressure, plasma glucose and microalbuminuria. The metabolic syndrome diagnostic criteria followed the set cut-off points outlined in *Harmonizing the Metabolic Syndrome* (Alberti, Eckel et al., 2009) (*see Appendixes Q*). These were meticulously adhered to, ensuring the validity and reliability of the results.

International measurements, standardisation and calibration were used for all the clinical tests, performed by Gribbles Pathology. The machinery used and the validity and reliability of test results are outlined on their comprehensive website (Gribbles Pathology Malaysia, 2008). The validity and reliability of the equipment used, the anthropometric measurements and the clinical assessments are displayed in the appendices (*see Appendixes R; S*). The oral glucose tolerance test was administered and the samples collected by laboratory technicians who follow strict laboratory guidelines set by Gribbles Pathology Malaysia (*see Appendixes R; S*). To ensure validity and reliability of the clinical samples, the participants were given a detailed instruction sheet and informed on how to correctly fast overnight, in order to obtain optimal clinical results (*see Appendix T*).

4.6.2 Research tools, instruments and data collection

The tools used during the quantitative Phase One included Microsoft Office 2007 Excel and Word, Endnote X1 Referencing Manager and SPSS 16.0. The instruments used for this phase, including information sheets, consent forms and data collection sheets, were tested prior to the quantitative data collection.

For logistic reasons, all participants were asked to report to Columbia Hospital, Miri, where they were asked to read and sign a consent form (*see Appendix N*) before having their details, height and weight recorded. The signed consent also asked for agreement to participate in Phase Two if selected. Participants then proceeded to the adjoining Gribbles pathology laboratory where fasting urine and fasting plasma blood samples were taken and the oral glucose drink given. An instruction sheet on how to fast the night before and the procedure order during the data collection day was given to each participant during the recruitment (*see Appendix T*).

The questionnaire was completed and anthropometric measurements taken while waiting for the second urine and blood sample collection two hours later. Including

time for registration, the data collection session took approximately two and a half hours, and upon completion refreshments were given to all participants. All the participants were informed when their clinical results were available for collection. They personally received their copy from me at Dr Mattu's clinic, and were advised to take the results to their family doctor for discussion and advice.

4.6.2.1 Questionnaire

A standardised self-administered questionnaire was used to address socio-demographic, lifestyle, diet and physical activity issues. Local doctors and nurses who attended the end-stage renal disease patients reviewed the questionnaire to ensure it covered all areas relevant to the research and that it was locally and ethnically sensitive. It was pilot tested on five volunteers and informed consent was sought prior to the administration of the trial questionnaire. This data was not used in the actual study data collection. The questionnaire was assessed for content validity and then modified where necessary (see Appendix U).

The Phase One questionnaire was specifically to gather socio-demographic information to combine with the anthropometric and clinical data, using the SPSS programme. The participants were graded according to their CKD and MetS results then screened for selection for the Phase Two interviews. Data on a wide range of exposures of interest were obtained and the outcomes from these, highlighted in the multivariable logistic regression, were identified for further enquiry in the interviews.

The intra-observer variability check for the questionnaire was through having two questions, rephrased differently and on different pages of the questionnaire. The answers were then compared and if different, the participant was questioned regarding this. Inter-observer variability check was done through comparing the same question in the questionnaire responses to the interview responses.

4.6.2.2 Anthropometric measurements

The equipment for taking anthropometric and blood pressure measurements was supplied by me and calibrated against the Columbia Hospital, Miri, apparatus and equipment.

Age. The participants' current age was calculated at the time of the questionnaire and data collection date.

Height. Wearing only light clothing and no shoes, participants stood with their back and heels to a fixed wall, eyes facing forward. A right-angle triangle was placed flat to the wall and a gauge used to ensure the crown of the participant's head was correctly marked against a measuring tape secured to the wall. Height was taken to the nearest centimetre.

Weight. Wearing light clothing and no shoes or items in their pockets, the participants stood on a digital Salter spring balance scales, placed on a hard horizontal tiled floor, to record their weights. This scale was regularly tested for accuracy against a weighing machine using weights at the Columbia Asia Hospital, Miri. Two measurements in succession were taken to ensure accuracy, and the result recorded to the nearest half kilogram.

Abdominal obesity is one of the risk factors for metabolic syndrome and has specific values for different gender and ethnic groups, not country of residence (Alberti, Eckel et al., 2009; WHO-WPR [World Health Organization-Western Pacific Region], 2007).

Waist circumference. Participants were asked to stand erect, heels together and relaxed. The waist was measured on the horizontal, midway between the iliac crest and the lower ribs, without compressing the participants' skin (Welborn & Dhaliwal, 2007; WHO-WPR 2007). To ensure it did not stretch in the tropical heat, a metal measuring tape was used, and the nearest one centimetre was recorded.

Hip circumference. Participants were asked to stand erect, heels together and relaxed. The hips were measured on the horizontal plane at the maximum extension point of the buttocks when viewed from the side (Welborn, Dhaliwal, & Bennett, 2003). A metal measuring tape was used without compressing the participants' skin, to take a measurement to the nearest centimetre.

Waist-hip ratio was calculated by dividing the waist circumference (cm) by the hip circumference (cm) (Welborn, Dhaliwal & Bennett, 2003).

Body mass index was calculated using the participant's height and weight following WHO clinical criteria (Weight (Kg) divided by the height squared (m²)). Obesity for an Asian population was defined using the WHO Asia Pacific guidelines (Obesity >25kg/m².) (WHO–WPR 2007).

The intra-observer variability check for the anthropometric measurements involved having the same participant measured twice, once before they went to the laboratory then once after they returned, by the same assistant. Inter-observer variability check was by having two different assistants take the same person's measurements and then compare them. If the measurements differed then the assistants were instructed in the proper techniques again. This was done regularly.

4.6.2.3 Blood pressure

The auto-inflate digital electronic 'Omron HEM7322 Ultimate Premium Blood Pressure Monitor was used. A standard adult-size cuff (9–12.5 inch circumference) delivered a cuff pressure of 0-300 mm Hg (+3 mm Hg). This was checked regularly against a mercury sphygmomanometer (Diamond Delux BP apparatus, Pune, India) used at Columbia Hospital, Miri,. The cuff was placed on the right arm of the seated and rested participant. Blood pressure readings were taken after at least 15 minutes of rest. In this study, high blood pressure is considered as greater than 130 mm Hg systolic over greater than 85 diastolic mm Hg (Alberti, Eckel et al., 2009).

4.6.2.4 Laboratory investigations

The study participants were instructed to fast for 8–12 hours overnight and not to eat or drink anything prior to arriving at the laboratory. The laboratory technicians drew a fasting blood, administered the oral glucose solution, then collected the two-hour sample and labelled the blood. A spot urine sample was collected for testing. The blood was analysed for fasting glucose, creatinine, total cholesterol, HDL-C, LDL-C and triglycerides. The two-hour sample was assessed for glucose. The urine specimen was used to determine the urine ACR and creatinine excretion.

The eGFR for kidney function was calculated using four different formulae: Cockcroft-Gault (Cockcroft & Gault, 1976), Modification of Diet in Renal Disease MDRD (Levey, Bosch et al., 1999), Revised rMDRD (Levey, Coresh, Green et al., 2006)

(Mathew, Johnson, et al., 2007), and CKD-epi eGFR (Levey, Stevens, Schmid, Zhang, Castro, Feldman et al., 2009) (Stevens, Schmid, Zhang, Coresh, Manzi, Landis, & Poggio et al., 2010). These formulae are provided and discussed in the literature review (Chapter 3, Tables 3.2 and 3.3).

4.6.2.5 Chronic kidney disease and metabolic syndrome definitions for abnormal parameters

The quantitative phase of this study screened the participants for chronic kidney disease and metabolic syndrome using a one cut-off point to determine their risk for chronic non-communicable diseases.

Chronic kidney disease. *Chronic kidney disease* was determined taking into account both estimated glomerular filtration rate and urine Albumin : creatinine ratio results and staging (*Table 3.5*), following Kidney Health Australia recommendations; (KHA-CARI, 2013).

ACR. *Albumin : creatinine ratio* was considered abnormal if ≥ 2.5 mg Alb/mmol Cr for males or ≥ 3.5 mg Alb/mmol Cr for females (KHA-CARI 2006).

eGFR. *estimated Glomerular Filtration Rate* for kidney function, using a person's age and ethnicity and plasma creatinine, was calculated following the Modification of Diet in Renal Disease revised '175' formula (rMDRD) (Mathew, Johnson, et al., 2007). An eGFR of <60 mL/min/1.73m² was considered to indicate kidney deterioration.

Metabolic Syndrome. *Metabolic syndrome* was determined using set cut-off points (*Table 3.6*) to identify abnormal clinical and biochemical results of the component risk factors (Alberti, Eckel et al., 2009).

Blood pressure was considered elevated if the systolic BP ≥ 130 mm Hg or diastolic BP ≥ 85 mm Hg or the participant was receiving treatment for hypertension (IDF 2006) (Alberti, Eckel et al., 2009).

Waist circumference was considered elevated for a Malaysian participant if ≥ 90 cm for males and ≥ 80 cm for females. The values used were for a South Asian (Indian,

Malay and Chinese) reference population (Alberti, Eckel et al., 2009; IDF 2006; WHO–WPR 2007)

Triglycerides were considered raised if ≥ 150 mg/dL (1.7 mmol/L), for males and females, or if the participant was receiving treatment for lipid abnormality (Alberti, Eckel et al., 2009; IDF 2006).

HDL cholesterol was considered reduced if ≤ 40 mg/dL (1.0 mmol/L) in males or ≤ 50 mg/dL (1.3 mmol/L) in females or if the participant was receiving treatment for this lipid abnormality (Alberti, Eckel et al., 2009; IDF 2006).

LDL cholesterol was considered abnormal if ≥ 100 mg/dL (2.58 mmol/L) (Tonkin, Barter, Best, Boyden, Furler, Hossack, et al., 2005).

TC:HDL-CR. *Total cholesterol : HDL-cholesterol ratio* was considered raised if ≥ 200 mg/dL (≥ 4.5 mmol/L) for males and females (Tonkin et al., 2005).

FPG. *Fasting plasma glucose* was considered raised if ≥ 100 mg/dL (5.6 mmol/L) or if the participant was receiving treatment for type 2 diabetes and under drug treatment (Alberti, Eckel et al., 2009; IDF 2006).

OGTT. *The oral glucose tolerance test* was used to determine the fasting plasma glucose for metabolic syndrome. The study ascertained the blood glucose results from the participants including impaired fasting glucose, impaired glucose tolerance and type 2 diabetes (Alberti, Eckel et al., 2009; IDF 2006). The parameters of determining fasting plasma glucose is shown in the following Table 4.1.

Table 4.1 Fasting plasma glucose and oral glucose tolerance test cut-off points

Level	Minimum	Maximum	Time
Normal	<6.1 mmol/L FPG	<7.0 mmol/L	2 hours OGTT
Impaired fasting glucose	>6.1 – <6.9 mmol/L FPG	7.8 mmol/L	2 hours OGTT
Impaired glucose tolerance.	<7.0 mmol/L FPG	<7.8– 11.0 mmol/L	2 hours OGTT
Diabetes mellitus	>7.0 mmol/L FPG	and/or >11.1 mmol/L	2 hours OGTT

Source: (Colman, Zimmet, Welborn, Garcia-Webb, & Moore, 1999; Gribbles Pathology Malaysia Sdn. Bhd., 2007; Schneider, 2003; Twigg, Kamp, Davis, Neylon, & Flack, 2007).

4.6.3 Quantitative data analysis procedure

Three forms were used for recording the quantitative data collected from the participants: the anthropometric measurement sheet which included the blood pressure readings, the laboratory report on the urine and blood samples tested, and the questionnaire survey (*see Appendix V*). The Statistical Package of Social Sciences (SPSS) Version 22 statistical computer software program was used to facilitate the analysis of all the statistical data.

Comparisons of the socio-demographic and anthropometric characteristics of the first degree relatives and the spousal control group were made using descriptive statistics and cross-tabulations. The metabolic syndrome diagnostic criteria were used as a benchmark for assessing the clinical outcomes. Characteristics of the cases and estimates of the strength of the association between each predictor variable and the presence or absence of the disease (Hulley, Cummings, Browner, Grady, & Newman, 2007) was performed by screening for clinical risk markers of chronic kidney disease and components of the metabolic syndrome in the study participants. Data was expressed as a number and percentage for the categorical variables and as mean \pm standard deviation for the continuous variables. A *p*-value of less than 0.05 indicated statistical significance. The crude odds ratio (with 95% confidence interval) then later the adjusted ratio, after adjustment of potential confounders, was calculated for all the variables of interest that might contribute to developing chronic kidney disease and the metabolic syndrome.

Multiple logistic regression analysis was performed to determine associated risk factors for the dependent variables, firstly chronic kidney disease then for the metabolic syndrome. Potential confounders, variables found to be statistically insignificant, were removed to moderate their interaction or effect on the analysis. A *p*-value of less than 0.05 indicated statistical significance. The adjustment on the model was both a forward and a backward stepwise procedure, but the backward elimination method best suited the objectives of determining the predictor variables.

The significant expected outcomes, and the strategies and instruments employed to achieve the quantitative results, are presented in Table 4.2.

Table 4.2 Quantitative objective rationales, strategies and expected outcomes

Objective	Rationale	Strategies and instruments	Expected outcomes
1	Chronic kidney disease assessment including eGFR and ACR	Urine and blood laboratory tests and formulae used	All participants have eGFR and ACR results verified and their chronic kidney disease staging calculated
2	Metabolic syndrome assessment ,including chronic metabolic disorders associated with metabolic syndrome.	Anthropometric results; blood pressure results; urine and blood laboratory tests; OGTT; questionnaire.	All the participants have their metabolic syndrome score calculated from results of their central waist measurement, abnormal clinical parameters and medication self-reports
3	Socio-demographic factors, including age, ethnicity, employment, qualification, and income	Questionnaire	SPSS quantitative analysis identifies socio-demographic characteristics in first degree relatives and spousal control group
4	Lifestyle factors, including physical activity habits, dietary habits, taking herbs, taking supplements, smoking and drinking alcohol	Questionnaire	SPSS quantitative analysis identifies lifestyle behaviours of first degree relatives and spousal control group
5	Housing and environment factors, including origins, type of housing, gardens, chemical exposure, parks nearby	Questionnaire	SPSS quantitative analysis identifies housing and environment factors experienced by first degree relatives and spousal control group.

4.7 Conclusion

The rationale behind the choice of utilizing a mixed methods methodology and study design to address the study objectives was outlined. Ethical and confidential considerations relevant to the study were discussed and issues regarding language, translation and local sensitivities, were highlighted. The recruitment of participants and the selection criteria were described. The Phase One research methods employed for the quantitative data collection were described in detail.

The chapter concluded with the quantitative data analysis procedures used. Guided by the Mixed Methods sequential explanatory design, the qualitative Phase Two research methods are outlined in chapter 6.3 and the qualitative interview findings in chapter 7. The Phase One quantitative results are presented in the following chapter.

Chapter 5 Results: Quantitative

Chapter 5 presents the quantitative results. The appropriate variables obtained from the questionnaire survey, anthropometric and clinical results and recorded in the SPSS program were used to determine if participants could be classified as having chronic kidney disease or metabolic syndrome. The socio-demographic characteristics, family history and medical history, anthropometric, clinical and biochemical results of the first degree relatives and the spousal control group were compared. Multiple logistic regression analysis, after adjustment for confounding variables, was then performed to ascertain what variables were associated with having chronic kidney disease or the metabolic syndrome.

5.1 Socio-demographic Characteristics

The participant's socio-demographic profiles (study objective 1) are presented in Table 5.1. The first degree relatives case group (n = 135) were compared to a spousal control group (n = 135) consisting of 108 males and 162 females of the same ethnicity: 37 Malay (13.7%), 108 Chinese (40.0%) and 125 Indigenous (46.3%) ($p = 0.424$), with no statistically significant difference between groups.

The gender distribution between the first degree relatives (M 55 (40.7%) / F 80 (59.3%)) and the spousal control group (M 53 (39.3%) / F 82 (60.7%)) ($p = 0.804$) was similar, as was age (first degree relatives 40.8 ± 15.5 / 42.1 ± 14.6 v's spousal control group 44.7 ± 14.9 / 44.1 ± 12.0 ; $p = 0.101$).

When comparing the lifestyle habits of current smokers, alcohol drinkers or betel nut users (study objective 2), there was no statistically significant difference between the first degree relatives and the spousal control group. The percentage of current smokers for the first degree relatives was 17.0% and for the spousal control group was 12.6%; 37.0% of the first degree relatives and 38.5% of the spousal control group had drunk alcohol and the rest never had; and betel nut use was limited to five persons (3.7%) among the first degree relatives and four (3.0%) among the spousal control group (Table 5.1).

Table 5.1 Socio-demographic characteristics of participants in study (n=270).

	FDR ^a (n=135)	SCG ^b (n=135)	<i>p</i> -value
Age			0.101
male	40.8 ± 15.5	44.7 ± 14.9	
female	42.1 ± 14.6	44.1 ± 12.0	
Gender			0.804
male	55 (40.7)	53 (39.3)	
female	80 (59.3)	82 (60.7)	
Ethnicity			0.424
Malay	22 (16.3)	15 (11.1)	
Chinese	54 (40.0)	54 (40.0)	
Indigenous	59 (43.7)	66 (48.9)	
Origin of Birth			0.517
urban	77 (57.0)	84 (62.2)	
semi-urban	21 (15.6)	15 (11.1)	
rural / remote	37 (27.4)	36 (26.7)	
Employment			0.664
government /NGO ^c	12 (8.9)	13 (9.6)	
private company	42 (31.1)	51 (37.8)	
self-employed	28 (20.7)	24 (17.8)	
unemployed	53 (39.3)	47 (34.8)	
Education Level			0.139
no schooling	13 (9.6)	10 (7.4)	
primary only	15 (11.1)	25 (18.5)	
secondary only	81 (60.0)	66 (48.9)	
tertiary	26 (19.3)	34 (25.2)	
Income (RM^d)			0.308
below rm1,999	94 (69.6)	86 (63.7)	
rm 2,000-3,999	29 (21.5)	29 (21.5)	
rm 4,000 and above	12 (8.9)	20 (14.8)	
Housing			0.185
detached / semi-detached	64 (47.4)	56 (41.5)	
terraced low-cost	36 (26.7)	50 (37.0)	
self-built / longhouse	35 (25.9)	29 (21.5)	
Current Smoker			0.304
(ever vs. never)	23 (17.0)	17 (12.6)	
Alcohol Drinker			0.802
(ever vs. never)	50 (37.0)	52 (38.5)	
Betel Nut			0.735
(ever vs. never)	5 (3.7)	4 (3.0)	

Note: Data is expressed as number (percentage) for categorical variables or as mean ± standard deviation for continuous variables. Statistically significant at 5% level.

^aFDR = first degree relative; ^bSCG = spousal control group; ^cNGO = non-government organisation;

^dRM = ringgit Malaysia.

5.2 Family and Medical History

The participant's family history and personal medical history were self-reported in the questionnaire. Comparing the first degree relatives group with the spousal control group, a family history of hypertension (102 (75.6%) vs. 87 (64.4%) $p = 0.135$) was not significantly different however, having a family history of diabetes (71 (52.6%) vs. 47 (34.8%) $p = 0.007$) or of high cholesterol (58 (43.0%) vs. 45 (33.3%) $p = 0.014$) were statistically significantly different for the first degree relatives (*Table 5.2*). There was no statistically significant difference in the reporting of their medical history.

Table 5.2 Self reported family history and medical history of participants (n=270)

	FDR ^a (n=135)	SCG ^b (n=135)	<i>p</i> -value
Family history ^c (FH) of diabetes (vs. no)			0.007
yes	71 (52.6)	47 (34.8)	
not sure	19 (14.1)	19 (14.1)	
FH of hypertension (vs. no)			0.135
yes	102 (75.6)	87 (64.4)	
not sure	11 (8.1)	15 (11.1)	
FH of high cholesterol (vs. no)			0.014
yes	58 (43.0)	45 (33.3)	
not sure	40 (29.6)	30 (22.2)	
FH of cardiovascular disease (vs. no)			0.298
yes	22 (16.3)	20 (14.8)	
not sure	29 (21.5)	20 (14.8)	
Diabetes (vs. no)			0.520
yes	8 (5.9)	10 (7.4)	
not sure	29 (21.5)	22 (16.3)	
Hypertension (vs. no)			0.836
yes	35 (25.9)	31 (23.0)	
not sure	21 (15.6)	23 (17.0)	

Note: Data is expressed as number (percentage) for categorical variables.
Statistically significant at 5% level.

^aFDR = first degree relative; ^bSCG = spousal control group; ^cFH = family history.

5.3 Anthropometric Measurements

The anthropometric characteristics (*Table 5.3*) of the first degree relatives and spousal control group were compared, contributing to Objective 5 of the study. There were anthropometric differences between the genders of first degree relatives and spousal control group. Male first degree relatives on average were 1.8 centimetres taller than males in the spousal control group. First degree relatives scored statistically greater for weight (81.4 ± 17.6 vs. 69.8 ± 13.5 ; $p = <0.001$), body mass index (28.6 ± 5.4 vs. 25.1 ± 4.3 ; $p = <0.001$), waist circumference (94.8 ± 13.8 vs. 87.5 ± 10.4 ; $p = 0.002$), and waist-hip ratio (0.94 ± 0.05 vs. 0.9 ± 0.06 ; $p = 0.010$) (*Table 5.3*). There was no statistically significant difference between the females of the two groups on any of the variables measured (*Table 5.3*).

Table 5.3 Anthropometric measurements of the participants in the study (n=270)

	FDR ^a (n=135)	SCG ^b (n=135)	p-value
Male			
height (cm)	168.4 ± 6.6	166.6 ± 5.9	0.151
weight (kg)	81.4 ± 17.6	69.8 ± 13.5	<0.001
body mass index ^c (kg/m ²)	28.6 ± 5.4	25.1 ± 4.3	<0.001
waist circumference ^d (cm)	94.8 ± 13.8	87.5 ± 10.4	0.002
hip circumference ^e (cm)	100.6 ± 10.5	97.9 ± 12.9	0.231
waist-hip ratio ^f (cm)	0.94 ± 0.05	0.9 ± 0.06	0.010
Female			
height (cm)	155.1 ± 6.1	155.7 ± 6.5	0.581
weight (kg)	61.4 ± 15.0	65.1 ± 15.3	0.127
body mass index ^c (kg/m ²)	25.4 ± 5.6	26.7 ± 5.6	0.135
waist circumference ^d (cm)	82.5 ± 11.8	84.0 ± 13.6	0.444
hip circumference ^e (cm)	98.5 ± 10.7	100.9 ± 16.4	0.263
waist-hip ratio ^f (cm)	0.83 ± 0.07	0.83 ± 0.09	0.773

Note: Data is expressed as mean ± standard deviation for continuous variables.

Statistically significant at 5% level.

^aFDR = first degree relative; ^bSCG = spousal control group; ^cBMI = body mass index defined by WHO-WPR (2007); ^dwaist circumference defined by WHO-WPR (2007); ^ehip circumference defined by Welborn et al. (2003); ^fwaist-hip ratio defined by Welborn et al. (2003).

5.4 Clinical and Biochemical Results

The clinical and biochemical results for the participants are presented in Table 5.4. These results include the components that make up the metabolic syndrome and contribute to study Objective 5. There were very little differences between the first degree relatives and the spousal control group in the clinical measurements for the systolic blood pressure (129 ± 16.4 vs. 127 ± 18.6 ; $p = 0.258$) and diastolic blood pressure (81 ± 12.0 vs. 80 ± 11.8 ; $p = 0.459$) (Table 5.4).

Table 5.4 Clinical and biochemical results and components of metabolic syndrome in the study participants (n=270)

		FDR ^a (n=135)	SCG ^b (n=135)	<i>p</i> -value
Metabolic syndrome (MetS) ^c				0.012
	present (3 of 5)	50 (37.0)	31 (23.0)	
	Absent (<3)	85 (63.0)	104 (77.0)	
Chronic kidney disease (CKD) ^d				0.776
	present (<60)	7 (5.2)	6 (4.4)	
	absent (>60)	128 (94.8)	129 (95.6)	
Blood pressure	systolic (mm Hg)	129 ± 16.4	127 ± 18.6	0.258
	diastolic (mm Hg)	81 ± 12.0	80 ± 11.8	0.459
Fasting plasma glucose (mmol/L)		5.0 ± 1.0	4.9 ± 0.8	0.363
OGTT ^e 2-hour glucose (mmol/L)		7.1 ± 3.1	6.7 ± 2.8	0.242
Total cholesterol (mmol/L)		5.2 ± 1.1	5.2 ± 1.0	0.876
Triglycerides (mmol/L)		1.8 ± 1.2	1.4 ± 1.1	0.012
HDL ^f cholesterol (mmol/L)		1.3 ± 0.3	1.4 ± 0.4	0.092
LDL ^g cholesterol (mmol/L)		2.9 ± 1.2	3.1 ± 1.1	0.188
TC : HDL-C Ratio ^h (mmol/L)		4.1 ± 1.2	3.8 ± 1.1	0.025
ACR ⁱ (mg Alb/mmol Cr)		6.9 ± 23.8	2.3 ± 7.5	0.030
eGFR ^j (mL/min/1.73m ²)		81.6 ± 13.2	82.4 ± 11.5	0.620

Note: Data is expressed as number (percentage) for categorical variables or as mean \pm standard deviation for continuous variables. Statistically significant at 5% level.

^aFDR First Degree Relative; ^bSCG = spousal control group; ^cMetS Metabolic Syndrome defined by (Alberti, Eckel et al., 2009); ^dCKD Chronic Kidney Disease defined by (KHA 2007); ^eOGTT Oral Glucose Tolerance Test at 2 hours post glucose (75g) challenge (Twigg et al 2007); ^fHDL High Density Lipoprotein Cholesterol (Alberti, Eckel et al., 2009); ^gLDL Low Density Lipoprotein Cholesterol (Tonkin et al., 2005); ^hTC : HDL-C R Total Cholesterol : High Density Lipoprotein - Cholesterol Ratio (Tonkin et al., 2005); ⁱACR Urine Albumin : Creatinine Ratio (mg Alb/mmol Cr) (KHA 2007); ^jeGFR estimated Glomerular Filtration Rate (mL/min/1.73m²) based on adjusted_rMDRD revised '175' formula (Mathew et al 2007).

In the biochemical results there were no statistically significant differences between the first degree relatives and the spousal control group for fasting blood glucose (5.0 ± 1.0 vs. 4.9 ± 0.8 ; $p = 0.363$), two hour blood glucose (7.1 ± 3.1 vs. 6.7 ± 2.8 ; $p = 0.242$), total cholesterol (5.2 ± 1.1 vs. 5.2 ± 1.0 ; $p = 0.876$), HDL-C (1.3 ± 0.3 vs. 1.4 ± 0.4 ; $p = 0.092$), LDL-C (2.9 ± 1.2 vs. 3.1 ± 1.0 ; $p = 0.188$) or eGFR (81.6 ± 13.2 vs. 82.4 ± 11.5 ; $p = 0.620$) (*Table 5.4*). There were statistical differences between the groups in the laboratory results recorded for triglycerides (1.8 ± 1.2 vs. 1.4 ± 1.1 ; $p = 0.012$), Total Cholesterol : High Density Lipoprotein-Cholesterol Ratio (TC:HDL-C R) (4.1 ± 1.2 vs. 3.8 ± 1.1 ; $p = 0.025$), and ACR (mg Alb/mmol Cr) (6.9 ± 23.8 vs. 2.3 ± 7.5 ; $p = 0.030$) (*Table 5.4*).

The chronic kidney disease score as defined by KHA (2007) and the metabolic syndrome score as defined by Alberti, Eckel et al. (2009) was calculated for each participant. The first degree relatives (5.2%) showed no statistically significantly greater association with having chronic kidney disease less than $<60 \text{ mL/min/1.73m}^2$ than the spousal control group (4.4%) (*Table 5.4*). There was however, a statistically significant difference with 50 (37%) of the first degree relatives compared with 31 (23%) of the spousal control group ($p=0.012$) being assessed as having metabolic syndrome (*Table 5.4*).

5.5 Probability for Chronic Kidney Disease

Since there was no statistically significant difference between first degree relatives and the spousal control group for chronic kidney disease, analysis proceeded to multiple logistic regression to determine the variables associated with the probability for chronic kidney disease, analysing all participants together.

The probability and results, after adjustment for potential confounders, are shown in Table 5.5 (study Objective 4).

Table 5.5 Multiple logistic regression analysis of associated risk factors for chronic kidney disease in all participants after adjustment for potential confounders* (n=270)

Variable	No.	Crude OR [†] (95% CI [‡])	Adjusted OR [†] (95% CI [‡])	p-value
Age (years)	270	1.076 (1.051, 1.101)	1.048 (1.020, 1.076)	0.001*
Alcohol	no, never	1	1	
	yes, consumed	102	1.025 (0.614, 1.710)	0.401 (0.179, 0.898) 0.026*
MetS ^a	no, absent	189	1	
	yes, present	81	1.764 (0.998, 3.119)	3.063 (1.527, 6.142) 0.002*
Ethnicity	Chinese	108	1	
	Malay	37	1.97 (0.562, 2.552)	5.666 (1.935, 16.593) 0.002*
	Indigenous	125	1.680 (0.792, 3.566)	2.347 (1.021, 5.395) 0.045*

-2 log likelihood = 269.344, d.f =9.

All variables of interest were included in the full model in the initial step and backward elimination procedure was applied to obtain the final model, using 5% critical value of χ^2 test for the appropriate degrees of freedom.

*Non-significant variables were gender, BMI body mass index, chewing betel nuts, smoking status, chewing tobacco status, family history of diabetes, family history of high cholesterol, family history of hypertension, hypertension, the status of FDR of patients with ESRD and SCG, TC : HDL-C R, HDL, LDL, Triglycerides, IFG/IGT, diabetes, salty food intake, and sugary food intake.

[†]OR =Odds Ratio; [‡]CI= Confidence interval;

* $p < 0.01$, # $p < 0.05$.

^aMetS = Metabolic Syndrome defined by (Alberti, Eckel et al., 2009).

Table 5.5 leads to the following conclusions:

- Age is a significant factor of having chronic kidney disease: with one year older, the association with having chronic kidney disease is increased by almost 5% (95% CI [2%, 7.6%]), after controlling for ethnicity, alcohol consumption, and the metabolic syndrome.
- Drinking alcohol is found to be a protective factor against developing chronic kidney disease. Compared to people who reported never having consumed alcohol, the adjusted OR for chronic kidney disease is lower at 40% (95% CI [18%, 90%]). For those who have consumed alcohol the association with chronic kidney disease is estimated to decrease after controlling for ethnicity, age and metabolic syndrome status. There was no data on the amount of alcohol consumed [standard drinks per day or duration]; nor was adjustment for energy intake possible.
- As expected, people with metabolic syndrome have a significant higher association for having chronic kidney disease. Compared to healthy people,

having metabolic syndrome was estimated to be 306 (95% CI [1.53, 6.14]) times greater after controlling for ethnicity, age and alcohol consumption.

- Ethnicity is also found to be positively associated with having chronic kidney disease. Compared to Chinese people, having chronic kidney disease was estimated to be 5.67 (95% CI [1.94, 16.59]) times higher for Malays and 2.35 (95% CI [1.02, 5.40]) times higher for Indigenous people after controlling for age, metabolic syndrome and alcohol consumption.

5.6 Probability for Metabolic Syndrome

The metabolic syndrome is a composite of metabolic abnormalities (Alberti, Eckel et al., 2009; R. M. Parikh & Mohan, 2012) therefore further multiple logistic regression analysis was performed to determine the associated risk factors for metabolic syndrome in the participants. The initial analysis included all of the dietary variables recorded in the Phase One questionnaire return (*Appendix W*) that was based on WHO Steps and validated by the Malaysian Ministry of Health (MMOH, 2006b; WHO, 2005). It is suggested that dietary questions regarding salt can be attached to the WHO STEPwise survey (L'Abbé, Legetic, Legowski, Claro & Levy, 2010) therefore, some questions were added to the sparse food section of the questionnaire.

In the recommendations, the WHO/PAHO Regional Expert Group for Cardiovascular Disease Prevention through Population-wide Dietary Salt Reduction state that to accurately assess salt in the diet, the methods used need to be precise (L'Abbé et al., 2010). The questionnaire was not a standard Food Frequency Questionnaire therefore, to eliminate any suggestion regarding the precision of the salt and dietary questions, multiple logistic regression analysis of risk factors associated with the metabolic syndrome was performed again with the exclusion of all the dietary variables (*Table 5.6*).

There were two differences between the initial analysis (*Appendix W*) and *Table 5.6*: First, salt is missing and second, family history of hypertension (*Appendix W*) is replaced by family history of cardiovascular disease (*Table 5.6*). Apart from these, all the other significant variables remained the same after adjustment for potential confounders, and this current study follows *Table 5.6*.

The variables of interest, after the adjustment for potential confounders, and the results, are shown in Tables 5.6 below (study Objective 5).

Table 5.6 Multiple logistic regression analysis of risk factors associated with metabolic syndrome excluding dietary factors* (n=270)

Variable	No.	Crude OR [†] (95% CI [‡])	Adjusted OR [†] (95% CI [‡])
FDR ^a			
no	135	1	1
yes	135	1.932 (1.135, 3.287)	2.409* (1.303, 4.454)
FH of CVD ^b			
no	179	1	1
unknown	49	1.362 (0.687, 2.698)	0.835 (0.374, 1.864)
yes	42	2.106 (1.050, 4.224)	2.650[#] (1.146, 6.130)
Age (years)	270	1.026 (1.007, 1.045)	1.027 [#] (1.005, 1.049)
House			
detached	120	1	1
terraced / low cost	86	2.038 (1.098, 3.782)	5.084* (2.301, 11.234)
self-built / longhouse	64	2.169 (1.113, 4.226)	3.772* (1.680, 8.468)
Smoking			
no	230	1	1
yes	40	1.692 (0.845, 3.390)	3.163* (1.344, 7.442)
Diabetes			
normal	130	1	1
IFG ^c /IGT ^d	116	2.296 (1.287, 4.096)	3.568* (1.790, 7.110)
diabetic	24	7.000 (2.750, 17.820)	14.308* (4.662, 43.915)

-2 log likelihood = 269.344, d.f =9.

All variables of interest were included in the full model in the initial step and then forward selection procedure was applied to obtain the final model, using 5% critical value of χ^2 test for the appropriate degrees of freedom.

*Non-significant variables were gender, ethnicity, income, alcohol drinking status, chewing betel nuts, chewing tobacco, family history of diabetes, family history of high cholesterol, family history of stroke, fitness status, times doing moderate/vigorous activities per week, Urine_ACR and eGFR (adjusted_rMDRD).

†OR =Odds Ratio; ‡CI= Confidence interval;

* $p < 0.01$, # $p < 0.05$.

^aFDR = first degree relative; ^bFH of CVD = family history of cardiovascular disease (self-reported); ^cIFG = impaired fasting glucose or glycaemia defined by (Twigg et al., 2007); ^dIGT = impaired glucose tolerance defined by (Twigg et al., 2007).

Conclusions from Table 5.6 follow:

- The first degree relatives group has a significantly higher association with having metabolic syndrome than the control group. The odds of having metabolic syndrome for the first degree relatives group are 2.41 (95% CI: [1.30, 4.45]) times higher than for the control group.

- Compared to those people without a family history of cardiovascular disease, the odds of having metabolic syndrome for those with a family history of cardiovascular disease are 2.65 times higher (95% CI: [1.15, 6.13]).
- The odds of having metabolic syndrome increase by 2.7% for every one year increase in age, after controlling for other covariates. The population odds of having metabolic syndrome are estimated with 95% certainty to increase by between 0.5% and 4.9% with every year's increase in age.
- Compared to people living in detached houses, those who live in terraced or low cost houses (OR = 5.08, 95% CI=[2.30, 11.23]) or in self-built and longhouses (OR = 3.77, 95% CI=[1.68, 8.47]) have a significantly higher association with having metabolic syndrome.
- Current smokers are more likely to have metabolic syndrome than non-smokers. The odds of having metabolic syndrome for smokers are 3.16 (95% CI [1.34, 7.44]) times higher than for non-smokers.
- Compared to people with a normal result, those with impaired fasting glucose / impaired glucose tolerance (OR = 3.57, 95% CI = [1.79, 7.11]) and those with type 2 diabetes (OR = 14.31, 95% CI = [4.66, 43.92]) have a significant higher correlation with having metabolic syndrome.

5.7 Key Results of the Quantitative Phase One

5.7.1 Summary of factors associated with chronic kidney disease in Sarawak

Four factors were found to be associated with chronic kidney disease. The adjusted odds ratios (AOR) (95% confidence interval) found to be of increasing significance were:

- age (1.048 (1.020, 1.076) $p = 0.001$)
- metabolic syndrome (3.063 (1.527, 6.142) $p = 0.002$).
- alcohol was found to be protective (0.401 [0.179, 0.898] $p = 0.026$).
- those of Malay ethnicity (5.666 [1.935, 16.593] $p = 0.002$), followed by those of Indigenous ethnicity (2.347, [1.021, 5.395] $p = 0.045$), compared to Chinese.

5.7.2 Summary of factors associated with metabolic syndrome in Sarawak

Six factors were found to be associated with having metabolic syndrome. The adjusted odds ratios (AOR) (95% confidence interval) found to be of increasing significance and markers associated for developing metabolic syndrome were:

- age (1.027 (1.005, 1.049) $p = <0.05$)
- first degree relatives of an end-stage renal disease patient (2.409 (1.303, 4.454) $p = < 0.01$)
- family history of cardiovascular disease (2.65 (1.146, 6.130) $p = <0.05$).
- living in terraced or low-cost housing (5.084 [2.301, 11.234] $p = <0.01$), followed by those living in self-built or longhouses (3.772, [1.680, 8.468] $p = <0.01$), compared to those living in detached houses.
- smoking (3.163 (1.344, 7.442) $p = <0.01$).
- diabetes (14.308 (4.662, 43.915) $p = <0.01$), followed by those having impaired fasting glucose and/or impaired glucose tolerance (3.568, (1.790, 7.110) $p = <0.01$), compared to those with normal blood glucose levels.

Consistent with the Mixed Methods sequential study design for this thesis, the Phase One results were carried forward to inform the next chapter; the discussion of these results appears in Chapter 8.

Chapter 6 Intermediate Connecting Stage

In this study the intermediate connecting stage draws on the results of Phase One and determines the criteria for purposefully selecting a sub-set of participants for the qualitative Phase Two of the study. The Phase Two protocol for data collection during the interview sessions are outlined here.

6.1 Intermediate Connecting Stage

Mixed Methods research requires the integration of quantitative and qualitative data sets (Teddlie & Tashakkori, 2010). The intermediate connecting stage is the interface where the methodologies intentionally link and the data is connected (Creswell & Plano Clarke, 2007).

In this study three steps were taken to facilitate the flow from the quantitative to the qualitative phase. The first step was to determine the direct links between the phases by scrutinising the key Phase One findings for factors that might contribute to chronic kidney disease in the participants.

Table 6.1 Key Phase One results identified for exploration in Phase Two

Age	Probability of getting CKD increases 5% with each passing year.
Alcohol	Maybe a protective factor of getting CKD.
Metabolic syndrome	Those with metabolic syndrome have a 306% higher probability of getting CKD as they age.
Ethnicity	5.67% Malay and 2.35% Indigenous people are more likely than Chinese to get CKD.

Note: Summary of data presented in Table 5.5

Multiple logistic regression identified four key factors associated with chronic kidney disease. Although alcohol was found to be protective, three factors were found to predispose participants to developing chronic kidney disease: age, metabolic syndrome and ethnicity.

6.1.1 Connecting Phase One to Phase Two

Figure 6.1 illustrates the determinants of chronic kidney disease linking to the interconnecting stage of the study design and informing Phase Two.

6.1.2 Key Phase One categories identified for Phase Two exploration

The second step was to identify questions arising from, and local peculiarities encountered in, Phase One that required explanation. These issues provided a connection between the phases. Concerns of interest were identified and grouped into four categories that formed and informed the major broad topics outlined in the interview schedule and identified for further exploration in Phase Two. They were also used as labels for the free nodes in the initial coding in the NVivo software.

Table 6.2 Phase One concerns of interest identified for exploration

Transitional changes	Including migration, education and vocation
Environment	Including lifestyle, home surroundings and activities
Health beliefs	Including the influence of traditional practices; medicine
Health behaviours	Including ignorance and detrimental behaviour

Constructing the interview schedule in this manner followed a deductive ‘top-down’ approach (Creswell & Plano Clarke, 2007), with the findings of Phase One determining the interview schedule. Later, during the interviews, an inductive ‘bottom-up’ approach was used to build upon the information received (Laverack, 2004) and the interview schedule was continually revised or expanded to accommodate new findings. This ‘cyclical’ research process allowed ideas to be built upon and tested as more interviews were undertaken, until such time as the participants’ responses were similar, with reoccurring themes and patterns, and saturation of information was considered to have been reached (Saks & Allsop, 2013).

6.1.3 Purposeful selection of participants for Phase Two

The third step in the intermediate connecting stage entailed purposefully selecting a sub-set of the participants from Phase One, in accordance with the Mixed Methods explanatory design (Creswell & Plano Clarke, 2007). The participants for Phase Two were specifically taken from those who had participated in the initial data collection phase. A maximum variation sampling approach (Patton, 2002) is the best fit for this study as the participants are diverse in terms of socio-economic, educational and demographic characteristics, and ethnicity. There are, however, aspects that also identify with other sampling techniques set out by Patton (2002), including extreme

sampling (comparing extreme outliers to equate experiences) and criterion sampling (selected from pre-determined criteria considered significant).

Patton (2002, p. 230) writes that ‘the logic and power of purposeful sampling lies in selecting *information-rich cases* for study in depth ... information-rich cases whose study will illuminate the questions under study.’, Phase Two recruitment criteria purposefully selected participants from both cases and controls, and included representatives who had low or high likelihoods of developing chronic kidney disease. Comparing the responses from participants who had the best and worse chronic kidney disease scores was considered the best way to inform the qualitative study.

As metabolic syndrome was found to be associated with chronic kidney disease in Phase One, participants were also sorted by their metabolic syndrome score then compared with the chronic kidney disease. It was found that, as expected, many who were most likely to develop chronic kidney disease also had the greatest number of metabolic syndrome components. Curiously, there was a subset of normal and underweight people who also had lower eGFR and chronic kidney disease scores; this was noted for further exploration during the interviews.

6.2 Qualitative Overview

The findings and questions arising from the Phase One survey formed the basis for the development of the interview schedule. Observations of frequency distribution from the quantitative descriptive statistics triggered some curiosity, and a number of special interest questions were identified and developed in more detail in the interview schedule.

Table 6.3 Phase Two interview topics and questions arising from Phase One

Transitional changes	Including their past history and whether they moved from where they were born and grew up. If yes, do they still maintain connections / visit their family / ethnic home? How did the transition affect them?
Environmental	Has the change of environment altered their lifestyle / diet / activities / health status? Do they have a house with a garden / own a garden? Do they grow / eat fruit and vegetables? Is there a green space to go for walks nearby?
Health beliefs	How do they view traditional practices? Medicines? If a Western doctor gives them medicine are they compliant? If not, why not?
Health behaviours	Are they or family members obese? Do they smoke / drink alcohol / take herbs / exercise? Have they made healthy lifestyle changes?

The research areas selected were chosen in order to explore possible influences that might have an effect on the development of chronic kidney disease and metabolic syndrome in the participants. Questions and prompts were developed to aid the interview process. The detailed interview schedule was photocopied, and each participant's responses were transcribed and recorded into it. It was hoped that further information and an explanation for the Phase One results would be forthcoming through the interview enquiry of the participants in Phase Two.

6.3 Qualitative Phase Two Research Methods

The selection parameters for the qualitative phase included the total number of participants (n=270) who completed the quantitative phase of the study and had consented to be included in the follow-up interviews. The best participants to interview are those who will deliver the richest information (Patton, 2002). By purposefully selecting participants for the semi-structured interviews, it was anticipated that a deeper understanding and comprehension regarding the situation in Miri might be gleaned.

6.3.1 Recruitment of participants for the interviews

A matrix was arranged to ensure that male and female participants with the worst and best scores among the first degree relatives and spousal control group were recruited. All ethnic groups were represented and it was hoped that commonalities and differences between ethnicities would be revealed through the qualitative interviews (*see Appendix X*).

SPSS code numbers were used to access the master file and retrieve the names and contact mobile numbers of participants who had agreed to participate in Phase Two. They were contacted by telephone and provided with information regarding the qualitative study. If they declined to take part, the next outlier person on the list was invited. If they agreed to partake, an appointment date and time was made. This was repeated until the matrix for the interviews was completed. No money or compensation was offered to participants during recruitment. All those who participated in Phase Two were thanked for volunteering and told that their participation was a valued contribution to this community study.

6.3.2 Sample size

The final sample size for the qualitative interviews was 32 persons. A matrix was designed by ethnicity, grouped as Malay, Chinese, Indigenous Orang Ulu and Indigenous Iban and Bidayu on the vertical. The horizontal indicated male or female, case or control participant. These participants were grouped for interviews according to whether they had a low or high score for chronic kidney disease. Sixteen persons were interviewed from among the cases and 16 from the controls, meaning eight persons each from the low and the high score groups were conducted. Men and women were equally represented (*see Appendix X*).

6.3.3 Trustworthiness

The qualitative primarily adhered to the criteria, terminology and techniques set out by Lincoln and Guba (1985). Appropriate and efficient strategies to deal with validity threats (Maxwell, 2008) was considered for this study, including research design focus, participant selection, and choosing the most appropriate data gathering methods (Graneheim & Lundman, 2004). Reliability and validity are treated as one entity in qualitative research (Golafshani, 2003) and the trustworthiness of the study can be gauged by its credibility, transferability, dependability and conformability (Lincoln & Guba, 1985).

6.3.3.1 Credibility

Credibility is the confidence a researcher has that the findings regarding the phenomena of interest are truthful (Lincoln & Guba, 1985). Lincoln and Guba (1985) have the viewpoint that prolonged engagement and persistent observation is beneficial in the collection of credible data. Having lived and worked in the community from which the participants were drawn means that over the years I gained an understanding and insight into the various ethnic cultures. A relationship with the participants was established during the quantitative data collection and questionnaire sessions, and this aided trust in the interview sessions. In this study, triangulation was carried out by comparing the questionnaire answers of a participant with their interview statements (Shenton, 2004). If there was a contradiction that particular participant was contacted and asked again what they meant and to clarify.

Peer debriefing with members of the reference group and peer review of the database, coding and themes, was conducted by persons unfamiliar with the research. Feedback given during a poster presentation at a national conference provided some objective insight into the research. Due to transportation logistics, only member checking of the transcription with participants living in Miri was carried out only by mobile phone; each confirmed that their transcription was accurate.

6.3.3.2 *Transferability*

This is the first time research in this field of study has been made in East Malaysia, and for this reason, to facilitate transferability, a ‘thick description’ of the contextual factors and the phenomena under investigation (Lincoln & Guba, 1985; Shenton, 2004) was carried out in order to give ‘generalisability’ to other geographical and cultural situations. (Graneheim & Lundman, 2004).

6.3.3.3 *Dependability*

Dependability refers to the data gathered and whether similar results would be produced if repeated (Shenton, 2004). In order to gather reliable data, the participants must be honest. In this study, before they signed the consent form, they were asked to be truthful; however, if they felt uncomfortable answering they could decline and were free to leave. Two reliability methods were employed to check on their honesty: another similar prompting question regarding suspect information was asked later on in the interview schedule; and answers given in each participant’s questionnaire paper were compared with their interview responses. No participant’s response was excluded.

In order to maintain consistency during data collection (Graneheim & Lundman, 2004) the broad areas within the semi-structured interview schedule did not change significantly, although because of the ‘evolving process’ of the interviews there was flexibility within these areas. An inquiry audit was kept, detailing alterations and when changes in inquiry direction were made to the interview schedule.

To ensure dependability and trustworthiness of the translation, a group of professional and lay linguistic translators living in Miri checked the transcribed material against the recordings to ensure accuracy in content and interpretation.

6.3.3.4 Confirmability

Confirmability is the concept of neutrality and other issues regarding researcher bias. An 'audit trail' was maintained throughout this study, sequential, sufficiently detailed to outline the methods, and transparent enough that the study and findings may be reproduced. A reflexive journal was kept to address progressive study and researcher issues.

Researcher influence and lack of trust produced during the research process (Denzin & Lincoln, 2009) and acknowledgment and disclosure of researcher bias (Miles & Huberman, 1994) was considered. I was sensitive of being objective even though I was immersed in the culture. Berger (2013) lists a number of studies showing how having a 'dual identity' especially when studying minority groups, brings the possibility of overlaying one's own experiences onto the data. From personal experience, Berger (2013, p. 6) explains, it requires 'a constant deliberate effort to maintain the separation'. I felt this, and in the interview sessions had to continually control myself from interjecting with my experience, and to focus on each participant's story and point of view only.

6.3.3.5 Overview of trustworthiness of the study

In assessing Cohen & Crabtree's (2008) 'paradigms in health care research', although simplified, I found myself aligning with the 'realism' paradigm although I also agreed with parts of the 'positivism' and 'interpretivism' paradigms. They emphasised that our perspective, our training and our beliefs affect our research, and researchers need to be impartial in their approach. This study also addressed the criteria advocated by Saks and Allsop (2013). There appears to be some disagreement but a lot of crossover between different qualitative authors, and the general consensus is that different problems require different methodological approaches (Patton, 2002) and that there is no single standard for qualitative research (Denzin & Lincoln, 2009). Merriam (1995, p. 51) stated that 'rigor is needed in all kinds of research to ensure that findings are to be trusted and believed'. Ultimately trustworthiness depends upon telling the truth and being truthful, in order for the truth to be revealed. This applies equally to participants and researchers.

Discussion with a few select persons participating as the reference group monitored trustworthiness, questioned my biases and provided insight for me regarding peculiarities. They noted inaccuracies they felt were present in the translations and in my interpretation of the interview data, in accordance with Mixed Methods guidelines (Berger, 2013; Miles & Huberman, 1994; Tashakkori & Teddlie, 2009).

6.3.4 Qualitative data collection protocol

The pilot questionnaire tested language and the comprehensibility of the questions, and the pilot interviews tested the interview schedule. Minor changes were made after participants' feedback. The ethics, consent and protocol were the same as for the main data collection sessions. When requested, a translator in the participant's mother tongue was present to interpret for me when conducting interviews. The translators had been instructed in aspects of qualitative interview data collection techniques.

Cultural sensitivity is of importance to this research. The interview question guide was tested with a culturally and linguistically appropriate reference group from the administrative staff and nursing pool at Columbia Hospital, Miri. Informed consent was sought prior to these sessions. The data gathered in these sessions was excluded from the actual study. Adjustments were made to the interview guide where indicated.



Photograph 6.1 An Iban longhouse

Photograph by researcher

6.3.5 Translators, transcripts and translation

A number of translation issues were addressed in Phase Two. My researcher notes during Phase One were detailed, and any language and translation problems encountered then were noted in the planning and preparation of the Phase Two interviews. Temple and Young (2010, p. 164) note that ‘language is power’: when a researcher has to rely upon translators, this gives power to the translators who control the flow of questions, ideas and responses across the divide. Consideration of how translators fitted into the study led me to deliver all the interviews myself, to ensure consistency. If a participant did not understand English, the appointed translator translated into their dialect directly from my words.

Language cannot be translated verbatim, as context needs to be transferred. Since language is ‘value-laden ... differences in power between languages also influence the translation of meaning’ (Temple & Young, 2010, pp. 167). The translators were not always literal and had their own cultural biases and this also had to be continually checked. I have a basic knowledge of Malay and Kelabit so could generally follow what the translators said, but a number of times, after realising a translator was taking liberties, I organised briefing sessions to ensure the translators and she had a collaborative relationship.

Malaysians live in a multilingual society and almost everyone speaks more than one language and a few dialects. When people need to communicate but do not understand each other, ‘Pasar Malay’, a very simple common Malay idiom, is used throughout Sarawak (Kenyalang, 2010). Living in such a rich language medium has produced a uniquely Malaysian form of code-switching where Malay, Chinese, English and Indigenous jargon are frequently mixed within a sentence. To extract deep meaningful information and to avoid translation errors, as far as possible the translators came from the same ethnic group and used the same dialect as the participant, and actively used code-switching in that dialect.

Following the interview the translator transcribed the interview from the recording into English onto the interview schedule, using Microsoft Word. A second translator who spoke the relevant dialect then listened to the recording of the participant’s interview and read the translated transcript to ensure accuracy. All of the translators in this study

had experience in language translation skills, having worked as teachers, nurses, Bible translators, government servants and other professionals.

Translation errors can occur from misunderstandings. If the translators disagreed about the English version, or unknown words or names were used or the language was vague or unclear, this was discussed and if necessary the participant was contacted to clarify what had been meant. Sometimes I had also to consider language in a social and cultural context (Nilep, 2006) but this was aided by my having lived in Sarawak for more than three decades.

Cultural prejudice and bias may affect researchers in their assessment and expectation of others (Gumperz, 1970). My ability to chat in Malay helped establish a rapport, and having an understanding and appreciation of both urban and remote rural Sarawakian way of life has given me insight into the ethnographic effects on local language. This helped me adapt my methods, change communication strategies, and acknowledge overt bias and perceived subvert biases I might otherwise have brought to the study.

6.3.6 Research dilemmas

It is common in Sarawak to be requested to sponsor or contribute to community events. ‘Community empowerment can be viewed as both a process ... and an outcome ... an interactive process’ (Laverack, 2004, p. 12) and there is always an ethical debate as to whether sponsorship promotes community empowerment or hinders it. To avoid this ‘expected donor-sponsor mentality’ it was stated explicitly in the information sheets that no compensation would be given for participating in the study. Even so I was continually asked, ‘what is available for me?’ and some people refused to be recruited in both phases when they learned there was no recompense.

I did not want to be seen in a position of power, authority or expertise, and tried to keep a humble profile. I never used official details or letterheads on any information sheets, consent forms or the questionnaire. I consciously dressed ‘smart local’ and did not wear make-up or jewellery, and asked translators and assistants to do likewise. I wanted to be approachable and I wanted the poorer participants to feel worthwhile, and that their voices were being heard, with the data collection sessions being purely about the participants. At the end of the sessions, however, any health questions were answered

and they were given pamphlets about hypertension, diabetes and kidney health education. When they collected their clinical results they were advised to see their doctor for medical advice.

6.3.7 Reflexivity

Although I have lived in Sarawak for two thirds of my life, I am Western raised and educated. As a European woman married to a professional local man I have certain status within Sarawak as well as personal biases that are different from the status quo. Berger (2013) has argued that the positionality of the researcher can have both positive and negative influences on the research and all researchers need to consider how their social position can affect reflexivity. As I shifted between insider and outsider roles during the study I experienced some conflict, both internally and externally. It has been noted that research should include continuous reflection, acknowledgement and critique during all stages (Saks & Allsop, 2013) in order to reduce subjectivity (Corbin & Strauss, 2008) and increase validity (Creswell & Miller, 2000). In the planning stages of this study, the benefits and constraints that might affect insider research (Teusner, 2010) were contemplated and I was made aware of areas needing particular attention and adjustment.



Photograph 6.2 A Kelabit longhouse

Photograph by researcher

It is important for researchers to acknowledge their own social values and prejudices, to reduce unwarranted influence (Hall & Callery, 2001) and an unintentional impact on the study (Patton, 2002) and it is especially important to develop a respectful relationship when doing Indigenous research (S. Wilson, 2001). Half of the participants were Indigenous but with the Chinese and Malay participants too, some topics, taboos and sensitivities had to be treated cautiously. I was very aware that if local mores are questioned by someone who has not established a respectful rapport, people become defensive. I can identify with many research aspects outlined by Kanuha (2000) and understand how being a member of the community under study can be both advantageous and challenging. Being aware of cultural missteps, who to contact, and how to negotiate tricky situations and protocol dilemmas, was an asset to me.

I have membership with three ways of life: Australian (born in Tasmania), local Malaysian urban (Malay, Chinese, Indian, Indigenous and expatriates) and tribal Indigenous (through my husband and from our close personal ties with other Indigenous groups). I see things from both community subjective and objective perspectives, which makes it easier for me to pick up on local nuances, be insightful and innovative without offending. As one of the assistants said, 'you see things differently to me, I never thought of it that way and I've lived here all of my life'. Although I am an 'insider' aware of the broader social consciousness, I am also an 'outsider' to both a first degree relative and a spousal control group family member. Even though I have worked for years at a dialysis centre and have sympathy, I do not have empathy as I do not live within their frame of reference and cannot truly understand their situation. In this particular study it did not appear to affect the research negatively and helped me to be impartial; so in that respect I am not so close and so similar to those under study as to jeopardise objectivity (Kanuha, 2000).

Local Miri citizens who know me treat me differently from a visitor or tourist. I have never not felt accepted as part of the community. I have pondered over the argument that 'the researcher's perceptions might be clouded by his or her personal experience and that as a member of the group he or she will have difficulty separating it from that of the participants' (Dwyer & Buckle, 2009, pp. 58). From a researcher's perspective I am in a unique position as I am neither a total 'insider' nor a total 'outsider', but both. So long as I remained aware of my bias and preconceptions I found that being both was

beneficial (Dwyer & Buckle, 2009), especially in ‘breaking the ice’ in the quantitative sessions and in the interviewing and analysis of the qualitative phase.

Berger (2013, pp. 2) has said that researchers have to ‘carefully self monitor the impact of their biases, beliefs, and personal experiences on their research; and maintain the balance’. I am forward-looking, inquisitive, equitable and tolerant; but a few things overtly challenged my world-view. Of most fascination to me was the variety of religious and ethnic subtleties, and social undercurrents I am not often privy to. Milner (2007) has written about a filtering that occurs in researchers when faced with conflicting views emanating from racial and cultural issues: that introspection (reflexivity) is required before one can build a relationship, understand, and represent participants with integrity. The researcher plays a role ‘in the construction of knowledge at all stages of the research process’ (Saks & Allsop, 2013, pp. 449), and it is important to maintain its quality through reflexivity (Berger, 2013). From the conception of this project, I kept a reflective journal describing cultural issues that arose, the impact participants’ stories had on me, the effect of their beliefs and knowledge on my own attitudes, and how my assumptions and perceptions changed through the course of the study. This continuous process of reflexivity kept me aware of my own subjectivity and made me pay more attention to my decision-making throughout the research.

6.3.8 Research tools, instruments and data collection procedure

The tools used in Phase Two included Microsoft Office 2007 Excel and Word, Endnote X1 Referencing Manager, and NVivo 12. Instruments included an information sheet and a semi-structured interview schedule, was pre-tested prior to the qualitative data collection.

The Phase Two interviews took place in Dr Mattu’s clinic next to Columbia Hospital, Miri, as the participants were familiar with the place from Phase One. The furthest any participant travelled from their residence for the interview was two hours by road. Signed consent was obtained before the interviews commenced. The participants had their weight and blood pressure taken to compare against their Phase One data. They were asked if they had taken their clinical results to their doctor for discussion, and if they had not, were advised to do so.

6.3.8.1 Interviews

A semi-structured in-depth interview was chosen as the best approach to gather the qualitative data from the participants. The interviews were conducted in such a way as to encourage and provide ‘the opportunity for participants to impact the process and outcome of the research’ (Berger, 2013, pp. 12). Flexibility was permissible, so participants could digress from the question topic (*see Appendixes Y, Z*).

6.3.9 Analysis of the data

The qualitative data analysis followed the procedure set out by Creswell and Plano Clarke (2007). The processes conducted in this research were:

- **preparing the data for analysis**; translating and transcribing the interviews; preparing and entering the data into the computer software program
- **exploring the data**; reading through the interview transcripts and researcher’s notes; developing a codebook, coding the data and assigning labels
- **analysing the data**; grouping the codes into themes; collapsing the number of themes
- **representing the data analysis**; using narrative and visual models to discuss and present the findings
- **using validation strategies**, as discussed previously.

The remainder of this chapter, details aspects of these steps as applied to this study.

6.3.9.1 Transcription of the interviews sessions

I conducted all the interview sessions; a translator was available to translate into and back from the participants’ dialect when needed. All data obtained from the interviews was transcribed into English, verbatim if the responses were in English, or in as close meaning as possible if translated, before analysis. Immediately following each interview I reflected on the session. I transcribed the recording into English at the soonest possible time. Translators transcribed all the sessions not conducted in English, then we discussed the translation and revised the interview guide if necessary. Being involved in both the interviews and their transcriptions allowed me to become immersed in the data and gave me a better understanding of participants’ perspectives.

It was a dynamic process, and the schedule was continuously refined in order to improve its appropriateness and flow, and enhance data collection. The participants were not asked to check the transcripts of their interviews for logistical reasons, but were asked to contact me if they had any questions. They were told they would receive information on the outcomes of the study upon its completion.

6.3.9.2 Notation used in the transcriptions

Being a purposive sample, the findings are not fully applicable to the broader Miri community: they are representative of the Phase One first degree relatives and spousal control group. Thirty-two people were invited to participate in the qualitative interviews. The number of participants and the languages the interviews were conducted in were: 13 English, 6 Malay, 2 Mandarin, 4 Iban, 3 Kayan, 2 Kelabit, 1 Hokkian and 1 Fuchau.

The advantage of qualitative methodology is that it can candidly record, interpret and report what a participant has to say about a particular matter (Patton, 2002). In these Phase Two interviews, the intention was to hear their voices and to record their views. The participants' words are reported as spoken with colloquial jargon, or as the interpreter transcribed it. They may not be grammatically correct, but are included in the following chapters without alteration. There were many responses to choose from in every area. Each participant's quote is indented in italics, followed by an identification label: P (Participant, followed by a number indicating which participant); I (Indigenous); C (Chinese); M (Malay); B (Best CKD score) or W (Worst CKD score); M (Male); F (Female); R (Relative FDR) or); S (Spousal control group).

6.3.9.3 Entering the data into NVivo 12 for analysis

QSR NVivo 12 software program was used to facilitate the evaluation and interpretation of all the qualitative data. Following the determination of the semi-structured interview questions, the survey sheet was formatted in the same font and style as the auto-coding for NVivo, to aid in transferring and coding. Once all the interviews had been completed, translated and typed into Microsoft Word, the documents were exported into NVivo 12 under 'Internals – Interviews' and auto-coded.

6.3.9.4 Exploring and coding the data

A 'memo link' was made for each participant, containing my notes and initial thoughts during each interview, as well as my later reflections. A codebook was set up, so that the steps in setting up the database could be repeated, in case it is needed in the future. Node classifications for attributes, such as code number, ethnicity, chronic kidney disease status, gender, case or control, metabolic syndrome status and age were made for all participants.

Initial 'nodes', 'child nodes' and 'baby nodes' were set up, based on the semi-structured divisions of the interviews. The interview process was dynamic, so as the various texts were coded, various nodes were collapsed or added to. The qualitative data gathered and the knowledge gleaned from the interviews, once categorised into nodes, were organised in a hierarchy. Once this stage was completed, a word frequency search was performed to see if all avenues of thought from participants had been captured. For example, two nodes, labelled 'Changes' and 'Stress' were added as both terms appeared many times in the interviews. Different terms with similar meanings were searched by adjusting the slider on the word frequency tab; no further words or concepts of interest appeared. A text search query was run on a few outstanding words from the word search, such as 'chemical' and 'garden'. A query was also performed on these words and the results depicted in a word tree, in order to understand the context and meaning given them by participants. One word that was particularly enlightening and informative about its use by participants was 'traditional'. For this term, the interpretation was complex, and a number of child nodes were added to accommodate its various meanings. A baby node was added to the child node if there was a need to expand.

6.3.9.5 Establishing themes and analysing the data

Following this broad-brush coding, a closer coding-on analysis was performed on each interview, and labels were assigned, some derived from the exact words of the participants (in vivo coding) (Creswell & Plano Clarke, 2007). This step assists in exploring and refining the coding to the nodes. The codes or categories were grouped into major themes; then, after reflection, the themes too were collapsed and reduced to be more manageable. The major themes identified followed thematic content analysis,

and a matrix analysis grid was constructed (Miles & Huberman, 1994). As the qualitative data was being gathered the analytical process began, and the ongoing interview inquiry was constantly discussed with the reference group members and adjusted. There was continual comparison of the participants' responses, from both phases and between different participant groups.

6.3.9.6 Representing the data through narrative and visual models

Using QSR NVivo 12, Framework Matrices were constructed so that tables showing the intersections between different themes and nodes could be viewed. Displaying data this way aided understanding of different relationships and facilitated the comparison analysis. Of interest were the intersections between the X and Y axes in the NVivo matrix. The X axis included ethnicity, gender, first degree relatives and spousal control group, and whether the participant had chronic kidney disease and/or metabolic syndrome. The Y axis included answers from interviewees. The intersections recorded the number of responses made by participants, and were an indication of the strength of verbalisation on that particular subject. The most numerous responses were checked against the participants' verbal recordings to expose patterns.

The matrices were first organised in two dimensions; later, meta-matrices were attempted. A record of decisions made in the development of the matrices was kept in the codebook so that they could be repeated or modified. The two-dimensional matrix gives an idea of the categories arising from the data (Miles & Huberman, 1994). These were then expanded to meta-matrices, conclusions written up and visual models of the results shown and validated (see 6.3.3).

Although the circumstances and experiences revealed by the participants were diverse, common categories or codes emerged across all ethnic divides. With continual reflection and refinement, these codes were reduced and re-grouped (analytical coding). Using the NVivo Matrix Query, coding patterns were identified then checked against the written transcripts, which had been sorted into four categories for comparison. This led to the development of more complex sub-themes and the identification of the major theme which guided the presentation of the findings in Chapter 7.

6.3.10 Research methods employed to achieve the qualitative outcomes

The significant expected outcomes, and the strategies and instruments employed to achieve the qualitative findings, are presented in Table 6.4.

Table 6.4 Qualitative objective rationales, strategies and expected outcomes

Objective	Rationale	Strategies and instruments	Expected outcomes
6	Determinants including diet and physical activities, education and employment changes, medical and health changes: all contributing to transitional life changes.	Interviews	Identify beliefs, behaviours and stress factors of participants with regard to identified determinants compounding the development of chronic kidney disease and metabolic syndrome .
7	Attitudes, barriers and practices including environmental issues such as housing, parks, surroundings, gardening, farming, agrochemical usage and land concerns.	Interviews	Identify attitudes, barriers and practices impeding the early recognition of precursors and diagnosis of clinical diseases in the participants.
8	Health beliefs including traditional practices, medical preferences, traditional herbs and modern medicines, medical beliefs and health information, herbal supplements.	Interviews	Identify contributing health beliefs and behaviours having an effect on participants' self-management of chronic metabolic diseases.
9	Health behaviours including compliance with doctor's orders, compliance with medication, mixing herbs, supplements and modern medicines, health habits and behavioural change.	Interviews	Report on reasons contributing to non-compliance with doctor's orders; taking prescription medication; and how myths, marketing and knowledge affect one's choices of medication.
10	Evidence including specific locales that are hazardous to health, topics of concern identified, at-risk population groups needing Government or NGO health promotion programs.	Interviews	Compile a list of the high-risk locales, topics and risk groups emerging from quantitative and qualitative analysis to set up a task group to develop targeted intervention programs.

6.4 Conclusion

The intermediate connecting stage is where Phase One connects with and informs Phase two of this study. The key findings and concerns of interest identified from Phase One guided the development of the interview schedule. The issues of trustworthiness and translators were discussed. A sub-set of both high and low chronic kidney disease, from both the first degree relatives and the spousal control group and from all of the major ethnic groups, were chosen as participants for Phase two. The research methods and the qualitative data analysis procedures employed for the Phase Two data collection were described.

The Phase Two findings are presented in the following chapter.



Photograph 6.3 Longhouse fireplaces

Photograph by researcher

Chapter 7 Findings: Qualitative Phase Two

Chapter 7 introduces the accurately recorded ‘voices’ of the participants, and the patterns that emerged are presented as the qualitative findings. I used the NVivo program matrix intersections to determine the initial categories from the qualitative data gathered during the interview sessions. As recruitment for Phase Two was multi-layered (*Appendix X*), the findings compared and contrasted responses between ethnicities, the first degree relatives and the spousal control group, the best/worst chronic kidney disease scores and the best/worst metabolic syndrome scores in order to discern differences in the beliefs and lifestyles of the participants. This data was then organised into sub-themes which, when analysed, revealed the major theme.

7.1 Transitional Changes

Of the 32 participants recruited for Phase Two, surprisingly, only one first degree relative and one spousal control group were first-generation Miri. Three participants were born overseas, in China, Indonesia and Brunei. The remaining 27 participants were all born and raised elsewhere in Sarawak, split evenly between urban and rural, and over six divisions of Sarawak. Some participants lived one to two hours’ drive from Miri city.

7.1.1 Majority views

Relocation issue. There were many reasons why participants moved to Miri. Some had lived there previously and moved away, only to return because of life circumstances:

Mid 1984 I moved to Miri then in 1986 I came back and stayed at the longhouse to do some farming work. Last three years now 2009–2013 we moved to Miri for youngest schooling. (P2 IWMR)

The participant’s comments below are representative and show the significance all ethnicities hold regarding festivities wherever their kampung is, even if they are unable to go:

My parents still live in Bario. My mother still plant paddy. I go back at Christmas times. (P12 IBFS)

I return to my home village at least once a year at Hari Raya but sometimes other times if we can arrange it. (P32 MBFR)

When I was in Sibu my home place is at Sungei Merah a bit country outside Sibu. I only go back twice a year to Sibu, during Chinese New Year and Ching Ming Festival. (P20 CBFR)

They face difficulties in going back:

Occasionally I would go back to visit the longhouse, 2–3 times per year. My transport back to kampung is by express boat [with outboard engines] from Kuala Baram and the journey takes about eight hours to destination. (P16 IBMR)

Kampung happenings were of high importance to those who had moved to Miri. Some participants were able to return regularly:

I have just come back from Pa Ukat two weeks ago as just finished rani [harvesting the rice]. I go at least twice every year to plant rice then to harvest the rice. (P4 IWMS)

Some are apprehensive of possible future responsibilities:

My dad and mum are fairly healthy except my dad has hypertension. They also have their longhouse at Betong so go back to visit sometimes. He still has land there and still looks after it and has fruit trees there. I don't go back with them as working. When my father passes on I will have to look after his land for him. I very seldom go back to the kampung. (P10 IWMS)

7.1.2 Disparities between groups

First degree relatives vs. spousal control group. The biggest difference between the first degree relatives and the spousal control group, of course, are the horror stories about family members with end-stage renal disease. Most often the one receiving renal replacement therapy passes away from cardiovascular disease, type 2 diabetes or hypertension complications:

My eldest brother, the one on dialysis, was suspect to have diabetes. By the time when he took the medicine the sickness become worse and he stop taking the medicine, and do not follow-up check-up after stop taking the medicine and died. (P2 IWMMR)

Others spoke of incidents related to dialysis:

My mother was on dialysis but already pass away about two year ago [2011] because of bleeding a lot after surgery. (P13 MWMMR)

Sadly, some who wanted to have renal replacement therapy were unable to because the family couldn't afford the treatment:

The doctor didn't say anything about my mother's kidney failure, but I know my mother had diabetes and hypertension ... the doctor advised her to do dialysis but last time ... we were told we would have to buy a machine and be trained and all that but we couldn't do anything about that ... and then ten days later she passed away. (P28 CWFR)

Some patients are known to refuse renal replacement therapy, fully aware that they will die:

Last year, my mother who had hypertension and diabetes was told by the doctor that she had kidney failure and must go for dialysis, but she refused to go because she said, she old already and didn't need to go for dialysis. She was 77 years old when she died. (P30 CWFR)

All family member caretakers have their lives changed for as long as the one on renal replacement therapy remains alive:

My wife started dialysis ten years ago and she is 41 years old. She is still active but adjusting and I'm coping ok with it now too. My daughters help a lot. I take her to dialysis every time. My wife is suffering from migraine and she keep on taking Panadol and Ponstan and we believed that could cause her kidney failure. We asked around and this is what we found out. (P27 CWMS)

Worst vs. best chronic kidney disease / metabolic syndrome. In both the first degree relatives and spousal control group, those who were classified as having the worst score for chronic kidney disease or metabolic syndrome were more likely to report having medical and health fears for themselves:

My father is still alive but not really healthy. My mum was not well and she was put on kidney dialysis for two years. My mum she found out she had kidney problem after she do your blood test and scared. She died now. (P5 IBFR)

A number of participants expressed their concern that they might be the next in their family to be struck down with chronic kidney disease:

One of my brothers already passed away because of kidney failure, and my sister is on dialysis at Miri General Hospital, she's now aged 52. I worry ... (P18 MBMR)

Or hypertension or diabetes:

My father has been injecting himself with insulin for the last 50 years. That's why I want to avoid that and I'm very worried about having to do that. I've never had a hypo but I've seen my father pass out from that. (P25 CBMS)

My mother is very big size and having arthritis and diabetes. I have seven siblings, and two of them having hypertension like me and one of my brother is big size. I having hypertension and cholesterol, now I on medication. No diabetes. (P14 MBFS)

My grandfather and father both have diabetes, this is why I'm scared and because of this, I have to control my food ... Last my mother got kidney problem also from diabetes. As I have so many of my family are diabetic I have to be very careful with my health (P27 CWMS)

Oddly, the best scorers for chronic kidney disease / metabolic syndrome, both in the first degree relatives and spousal control group, were twice as likely to return to their kampungs during the year and to be care-giver, than the worst scorers:

My mother was from Long Atip and my father from Long Bemang. My father already passed away ten years ago, now my mother stays with me. (P11 IBMS)



Photograph 7.1 Iban longhouse veranda

Photograph by researcher

Male vs. female. The reasons for relocating to Miri were varied but diverse between men and women. Some of the men's comments follow:

I am now able to sponsor and support my family with money. (P3 MWMS)

I was born in Siburan, Kuching and I move to Miri because of my job. (P21 CWMR)

Some of the women's comments follow:

I don't stay at kampung but stay with my daughter in Miri now. With the daughter who's been ten years plus at Miri Hospital dialysis. (P6 IWFR)

I didn't go to school, because we didn't know how to speak Malay and anyway our family very poor and could not afford to send us to school. Since young when I married until old, I work as a farmer but now I cannot do any more farming because I am always sick and admitted to Miri Hospital. (P22 IBFR)

Both genders wanted the best for their children:

Coming to live in town means I can pay for my children to go on in school. If my children don't have education they just stay in kampung at home on farm. (P2 IWMR)

Ethnicities. Across all groups the biggest difference between the ethnicities in this section is the returning to kampung of origin, especially if the family still owns land there, such as this Melanau participant:

My grandfather on my father's side is a farmer. My dad has passed away but my mum is still living in Daulat so I take my family back twice a year, we are going this weekend. (P31 MBMS)

This Chinese participant laments that they no longer have land or a reason to return to visit the land of their parents:

My great-grandparents ... had a big plot of land and grew fruit trees and vegetables. My parents are already passed away ... We have no other land for farming now. (P20 CBF)

Older Indigenous participants voiced their dissatisfaction with living in Miri, like this man now staying with his daughter:

In the kampung we have a lot of interesting places to walk around and it makes me feel less stressed ... I feel better at kampung than in Miri because I really love my kampung as I can meet other people in the longhouse. (P16 IBMR)

7.1.3 Conclusions

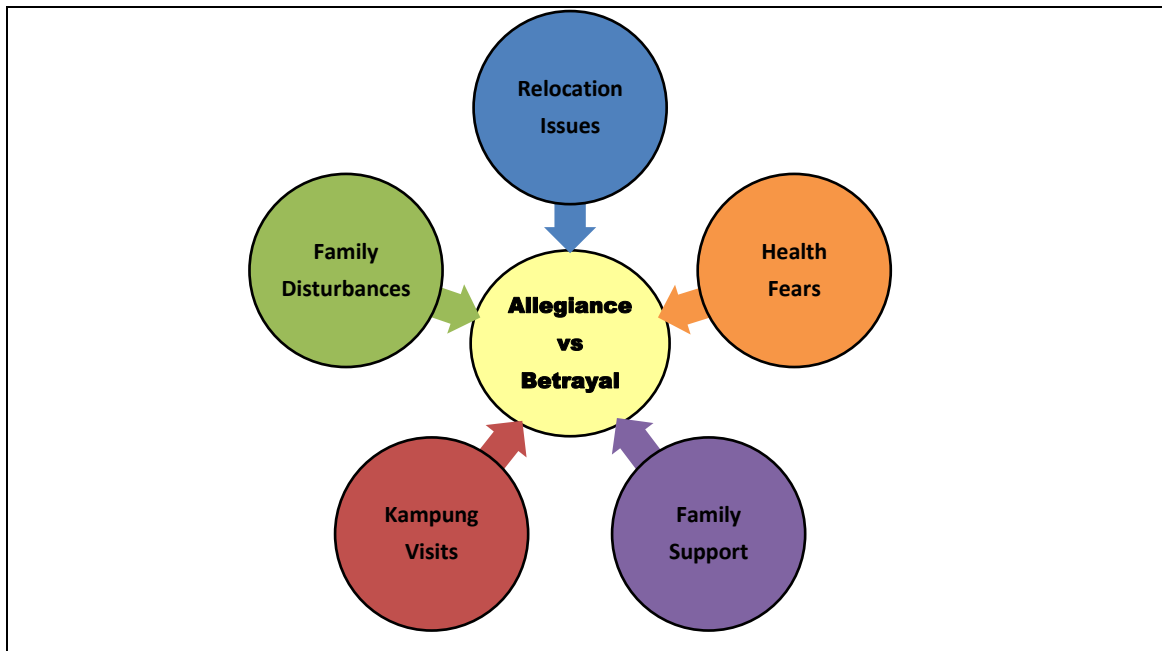


Figure 7.1 Summary of sub-theme 1: allegiance vs betrayal

7.1.4 Main differences seen between groups:

- First degree relatives are disturbed, and have their lives disturbed, by a family member on dialysis. They are often the care-takers and providers, and this causes stress and fears for their own health.
- The worst scorers for chronic kidney disease / metabolic syndrome group, whether first degree relatives or spousal control group, express more fears regarding getting a chronic non-communicable disease like their parents, or if they have one themselves, regarding their own future.
- Males relocate to Miri because of work or money, females more often because of medical concerns for their dependants or themselves, or to follow their husbands.
- The Orang Ulu ethnic groups are the ones most likely to want to return to their kampungs of origin in the remote highlands and Baram River areas of Sarawak. The Indigenous population was more likely to mention they experienced health problems and stress since moving to Miri.

7.2 Health Beliefs and Behaviours

In this section the dominant sub-theme running through all areas of enquiry was the difference between parents' and children's health practices.

7.2.1 Majority views

Different approaches acceptable. The replies given by the participants to the prompt 'do you still follow traditional ways?' was overwhelming; however on closer inspection there were a number of degrees of obligation. The first group followed ethnic and religious lines. Following are Iban, Melanau, Chinese participants' comments:

I'm not Christian but traditional religion practice. I am still a pagan we still practise the Spiritual Miring [Iban, Sacrifice]. (P24 IBMR)

My grandparents and the rest of my family still actively practise traditional Melanau ways. (P31 MBMS)

My brothers and sister, all of them, still follow our parent traditional way. Very traditional practices and lifestyle like my parents. I only take herbs when I am having fever, and see the sinseh [Chinese traditional doctor] and get the medicine from him when I'm sick. (P21 CWMR)

In Raja Brooke times different denominations were given different areas to work amongst the Dayaks. These two Orang Ulu are from different areas of the Baram River:

Only my grandparents follow the adat [old way] but we follow Christian way. My parents were RC Christian and I become Christian since I was born. (P16 IBMR)

My parents became Christian in 1953. Now with SIB [Sidang Injil Borneo or Borneo Evangelical Church] and don't follow Bungan [Orang Ulu, traditional religion] any more. (P1 IWFS)

Some participants who had strong traditional parental backgrounds were more likely to continue those traditions:

As my parents were from China they stayed very true to the traditional way of living. My father and mother never liked to take Western medicine especially as they knew a bit about Chinese medicine so preferred to take the traditional Chinese herbs and also small round Chinese pills. (P28 CWFR)

I cannot compare the sinseh to a Western doctor. Umm I always get better so believe it works better than Western medicine. (P21 CWMR)

In the next group the parents still practise the traditional way while the children do often mix traditions with modern ways:

For traditional practices, my father was a Chinese sinseh ... But when I am sick I would prefer to see Western doctor as I trust the Western doctor to Chinese traditional medicine. I'm not sick often, nor my children. I don't have a regular doctor I see. (P20 CBFRR)

My grandfather on my mother's side is a traditional Melanau medicine sharman. When I was growing up my parents used the sharman for traditional medicines if we were sick and for ceremonies until I left home for school... We now go to the company panel clinic if we need to see the doctor. (P31 MBMS)

Last time my parents follow the traditional way, they practised Chinese lifestyle, follow the real Buddhist way and go to the temple. I practise Buddhism but it's like this, since it's inherited from my parents we just follow on. We don't burn incense at home. I don't practise Tai Chi. (P26 CBMR)

My parents still go to traditional man. I don't see a traditional healer now but go to the doctor at the poliklinik when sick. (P21 CWMR)

My family is modern but my mum still believes in the traditional way... I see the work panel doctor. (P27 CWMS)

Numerous participants visited both a traditional healer and a medical doctor. Some followed their own set of guidelines about whom to see:

If I have fever, flu and cough I would prefer to see sinseh to a Western doctor. I only go to the government hospital for hypertension, diabetes and cholesterol medicine or if I need injection. (P21 CWMR)

I am still a pagan [animist]. We follow traditional belief and practices, but I never take herbs for my hypertension, and if I am sick I see the government doctor. (P22 IBFR)

I am a Christian, RC [Roman Catholic]. Traditional practices, we still believe in the Chinese traditional doctor. We see the Chinese sinseh regularly ... unless have a problem inside the body, or when the children are really ill. Maybe if really sick we'd go to hospital. (P19 CBFS)

Sometimes I see a traditional Malay bomoh. If I sick with fever or pain I always go to see Dr M and I only go to poliklinik to get hypertension and cholesterol medicine. I only got tablets after I took your results to doctor when you asked me to. (P14 MBFS)

If I am having hypertension I would prefer to see the Chinese sinseh for Chinese herbs and see the Western doctor for other problems. (P19 CBFS)

Some participants only consulted doctors trained in Western medicine, and gave their reasons for doing so:

My belief in Chinese medicine has changed a little, maybe with education ... When I am sick I would prefer to see Western doctor as I trust the Western doctor more than Chinese traditional medicine man. (P20 CBFR)

My wife doesn't believe in traditional Chinese practice or herbs even though she's from a Chinese school, she's Western in her medicine taking. I'm the same. (P25 CBMS)

I'm not really traditional, maybe because of education we are aware of how to help prevent of diabetes and hypertension and also the medicine has improved more and helps the kidney also. (P28 CWFR)



Photograph 7.2 Chinese ginseng

Photograph by researcher

7.2.2 Disparities between groups

First degree relatives vs. spousal control group. When comparing the first degree relatives to the spousal control group a number of issues arose. The first degree relatives recorded the most suspicion towards doctors and Western medicine:

I try not to be given medicine and if I'm given by the doctor I try to bargain with the doctor. I know nothing about medical things but I try to avoid too much medicine and sometimes I notice that doctors here really like to over prescribe medicine even when we don't need it. (P32 MBFR)

One doctor at Poliklinik Tudan wanted to give me tablets for my blood pressure but I don't want to take it for rest of life so he said I need to exercise more. (P5 IBFR)

Sometimes the participants, mostly first degree relatives, decide they know better than their doctor:

On hypertension medicine but ran out of BP tablets many days now. I feel a bit pusing pusing [giddy] today. (P7 IWMR)

Now about three months been eating new hypertension tablet ... but I feel sicker and it doesn't do good. I stop eating. (P22 CWMR)

Medicine I stop to take if I feeling better ... I don't finish it. (P5 IBFR)

I stop, the medicine is very bad, very strong for me, my stomach rots. (P3 MWMS)

The spousal control group were more likely to complain about costs:

I do take medicine prescript from doctor but when I feel better I will stop to take the medicine and save for next time. (P12 IBFS)

20 years already got tablets from the doctor. Doctor said to keep taking the tablets even when feel better. So take the doctors Western medicine from the poliklinik so it's not so expensive. (P1 IWFS)

First degree relatives noted a number of barriers to seeing the doctor that were not mentioned by the spousal control group. The first group of participants complained about the pharmacies. One in particular had a bad experience with drugs he bought from the pharmacist:

Now I go to Tudan clinic and they give me good very expensive medicine, advised by the kidney doctor. Last time I bought medicine from outside but later doctor tested me and found I had high blood pressure and also I had kidney problem and my legs were all swollen. I don't take the medicine from pharmacies now but just what the doctor gives me. (P28 CWFR)

The poliklinik is the government outpatient clinic. The majority of all the complaints were by the first degree relatives. These women sum it up:

If I'm sick I always go see doctor at Poliklinik Tudan and he checks my blood pressure, my blood sugar, then after that they give me vitamins and only that. There's always a different doctor every time I go there. If I go to see a doctor they only give me vitamins, so no need go-lah. (P5 IBFR)

I see a different doctor every time I go to poliklinik. (P4 IWMS).

Another barrier, which again was only noted by first degree relatives, in particular of Indigenous participants, is summarised by this comment:

No government doctor comes to our longhouse, only when we see the doctor in poliklinik in Miri, that only when we can have information but they don't say anything. Why they don't come and see us so they know how we are and about us. It takes too long a time for us to go to Miri much [two hours' travel by road, then back again]. (P22 IBFR).

A disturbing barrier was described by a daughter translating for her mother:

We don't know why she now no taking any medicine and getting sicker. Doctor at hospital said she don't need to take the medication and only to monitor the blood sugar at Klinik Desa [government outstation clinic] near the longhouse. Doctor said to go to Klinik Desa for check and monitor next time and if diabetes and hypertension bad again can continue medicine again but he never said when to go and there is never any doctor there anyway – so we never been yet. (P23 IWFR)

Worst vs. best chronic kidney disease / metabolic syndrome. This section deals with alternative medicine: herbs, supplements, special foods and drinks, and vitamins and minerals. Some people only consulted a Chinese herbalist when ill, to receive herbal medicine:

When I am sick with cough or flu, I will buy the Chinese herb from the sinseh at back of Chinese Chamber of Commerce and the main Miri market. You boil the herbs then drink it like tea. (P19 CBFS)

Some had Chinese herbs regularly:

We always take Chinese herbal teas. I frequently do take herbs. (P20 CBFR)

Others appear to have experimented with them once in a while:

Except for cinnamon and misia kuching drinks, because people said it was good for diabetics, I don't take much Chinese herbs. I also take misia kuching [a type of Chinese herb] to drink, and even cinnamon and all sorts of things, I have all these formulas and I've tried them at various times but it's how to be consistent to continue using it. (P25 CBMS)

For the next section, supplements, the participants gave a host of names connected with direct sales and marketing and also pharmaceutical offerings. One particular product was mentioned by eleven of the worst chronic kidney disease and metabolic syndrome score participants from both the first degree relatives and the spousal control group, not mentioned at all by the best score group. The following participant is on blood pressure, diabetes and cholesterol medication, and also taking these supplements:

I don't take traditional herbs but I am taking supplement, spirulina elken product, the lady said it is necessary for good health, but so expensive. I also did take flaxseed oil tablets because they say it is good for the skin but makes me burp and get gastric. I also take monavie. But my body don't feel any different effect from taking it. I buy it for RM145 [AUD48] for one small bottle of monavie, very expensive ... doctor said that monavie is not suitable for diabetes patients as due to high sugar level it contain. (P15 IWFS)

The next group for special foods and drinks mentioned products such as spirulina, ginseng, primrose oil, colonic water, flaxseed oil and gamat, again direct sales and pharmacy products. This man with metabolic syndrome refused to take medication for blood pressure and type 2 diabetes, and outlined what he took instead:

My routine at home, I always take supplement like; gamat [sea cucumber] worth RM400 per month, spirulina calcium, salmon omega3 to reduce cholesterol, garlic tablet. RM200 per month of Amway product and gamat emas [golden sea cucumber]. It is not I alone that take the supplement but my wife and kids also take the same as mine. It costs a lot. (P18 MBMR)

Comparing the best and worst scorers revealed strangely that only the best scorers, in both the first degree relatives and the spousal control group, took vitamin and mineral supplements:

I take omega 3 and vitamin B complex daily. (P26 CBMR)

I do take supplements such as vitamin E shakley fish oil and vitamin B complex every day. (P31 MBMS)

My family still eat traditional herbs for when not well and pain. And I take monavie, a supplement herbal tea if I have headache or not well. And Amway supplements. Supplements, vitamins and minerals, are very good and should use them every day. (P8 IBFS)



Photograph 7.3 Supplements all taken daily by one type 2 diabetes participant in study

Photograph by researcher

Sometimes a little knowledge may be dangerous:

The gurana tea is good for my children also because I believe when I use the product, I can treat my son's asthma and the asthma become good since primary school now they big enough already. Now I also do the same thing for my grandchild who gets asthma every week. I give him half of a capsule a day. Hopefully it helps. (P5 IBFR)

Male vs. female. Interestingly, males and females held different preferences for traditional practices. Only males mentioned having massages; only females mentioned acupuncture' other practices mentioned by both were iridology and foot reflexology:

Traditional practice, I went to urut [massage], but now hard to find someone who can really massage, and only can be found in village like Bekenu. I did go

to Brunei last year for massage ... because Brunei still got old people who can do Malay traditional massage. I think it's a skill. (P3 MWMS)

When I went home last, I complained about not being able to lose weight, so my mother and sister-in-law dragged me to the acupuncturist, so I had to go there every day for one whole week. The acupuncturist was very good actually. He poked my tummy with needles, it hurt, he said I had problem with metabolism. I don't know whether it works or not, probably not. (P32 MBFR)

Two very popular herbs were one marketed for women instead of hormone replacement and one for men's virility:

I also take supplement such as primrose oil and omega 3 which I purchase from the local pharmacy ... I don't know if it works and it costs money. (P20 CBF)

I only eat Malay traditional jamu [herbal] products. Some people say not to take tongkat ali every day as it can affect your kidney. Not sure if it actually works or all in the head. Gamat is for cleaning the colon after eating food. (P10 IWMS)



Photograph 7.4 Penan medicine

Photograph by researcher

Ethnicities. There were distinct differences in the type of traditional herb taken by the ethnicities. Following are quotes from a Chinese man, a Malay woman and an Indigenous Orang Ulu man:

Chinese herbal leaf teas to drink. I only take the Chinese herbs. (P27 CWMS)

My father was a professor in Pharmacy but his research was in traditional Malay medical herbs. He is evidence based medicine as he tested them in the lab. So I grew up with my parents boiling up herbs but I can't stand the smell or taste. (P32 MBFR)

I do take herb, because my brother always brings from the kampung, and there get the herb from the Orang Penan at Long Sait. I feel better when I eat it but I don't want to mix it if I'm on doctor's tablets. (P7 IWMMR)

I take herbs called sabah snake grass and the price is 15 leaves for RM30 very expensive, to reduce my blood pressure. We also take the herbs from ulu [remote, upper reaches] Baram from the Penan but don't know where it comes from. Function of those herbs is to reduce the blood pressure, cholesterol, diabetes and blood poisoning – cures everything. (P16 IBMR)



Photograph 7.5 Snake grass.

Source: advertisement

When taking prescribed Western medicines, Indigenous participants were the least compliant group:

My blood pressure is high today because I didn't take tablets as have run out and not gone to get more. Actually I doesn't punctually take medicine. (P15 IWFS)

I don't like to go to the doctor and if he gives me some tablets I don't like to eat it. Sometimes I do but I stop eating the tablets when I'm feeling better. (P1 IWFS)

Before doctor gave me tablets for my high blood pressure and told me to take it forever. But after a few months I stopped as I didn't think I need it. (P31 MBMS)

A number of participants mentioned that they do not mix traditional with modern medicine. Upon enquiry it transpired that

Normally I will separate taking Western medicine and herbs, I mean I take the tablets at breakfast and the herbs at lunch ... I'm not sure if the herbs work as sometimes good for the body but sometimes the doctor's medicine is better. (P16 IBMR)

I take medication but don't mind mixing it with herbal medicine. (P21 CWMR).

Mixing medication I take – but Dr R doesn't know I taking mixed medicine. (P3 MWMS).

I still take medicine if doctor gives me as well as herbs and supplements. If I do see doctor I always take all the medicine the doctor gives me. (P8 IBFS)

The surreptitious nature of all chronic non-communicable diseases is seen in this comment:

I not sure why my results so bad. I don't feel ill so can't get off work and not much time to go to see a doctor. (P10 IWMS)

7.2.3 Conclusions

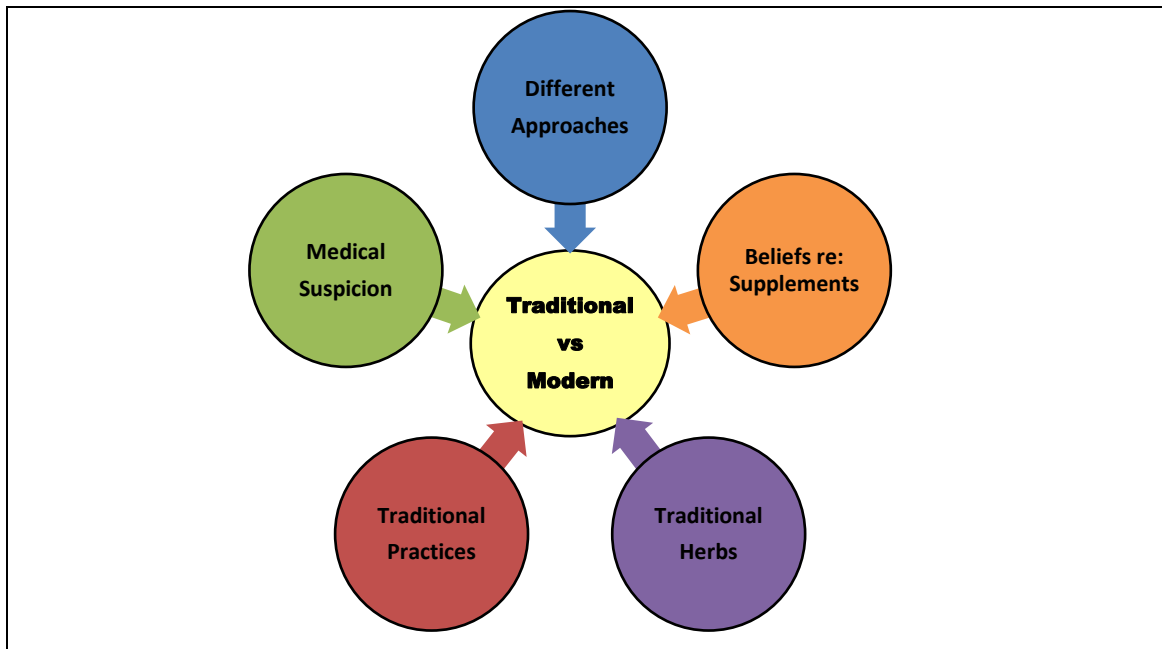


Figure 7.2 Summary of sub-theme 2: traditional vs modern

7.2.4 Main differences seen between groups:

- The first degree relatives are the more suspicious of doctors and Western medicine and more likely to try anything they think might help their chronic non-communicable disease conditions.
- The worst-scoring group for chronic kidney disease / metabolic syndrome appears willing to try multiple supplements they deem may help their chronic non-communicable disease, even at great expense.
- Both males and females are likely to try traditional practices and take herbal products, especially those specifically for their gender.
- People visit traditional herbalists and take traditional herbs peculiar to their ethnic group; however, all ethnicities tend to revere Chinese herbs. There are ethnic differences in compliance to doctor's advice.

7.3 Attitudes and Barriers

Contradictions surfaced in all areas of this section, with many of the participants telling what they should do although they were not able to achieve their expectations and had

to compromise on standards. This made many feel disloyal toward themselves and their families, and because of this they felt uncomfortable talking about their lifestyle habits and laughed off their excuses.

7.3.1 Majority views

Life Stresses and Maintaining Health. In Malaysia, if one does not work there is no social support system as backup. Private haemodialysis centres have to fund-raise. Government hospitals and clinics provide limited subsidised rates and medicines for hard-core poor, poor, mentally and physically challenged, and older citizens:

Last time when all my brothers and I were still working, we actually could afford to buy the medicine from the hospital, but now we can't because both of my brother passed away and I'm retired and also now we need support from the government to help us to reduce the burden to buy the medicine. (P21 CWMR)

This man is under tremendous stress, working long hours, looking after a spouse with end-stage renal disease and their children, and ignoring his own health decline from two chronic non-communicable diseases:

My wife is not working now due to her failing health and she gets depressed ... I still can cope because I'm still working but once I stop working I'm scared. If anything happens, everything depends on me, if I stop working we stop eating, very stressful. (P27 CWMS)

A number of participants offered advice on how to relieve stress:

For me when I take the supplement, it was effective, why? Because I felt that it reduce my stress ... but when I didn't take the supplement, my blood pressure can be high. (P18 MBMR)

If I am stressed I will share the problem ... Positive thinking and sharing with friends and family help lift the burden and problems we experiences. (P19 CBFS)

I control stress in my life through religion and through the reading. Some readings helps you put down your stress, sorrow or trauma. You come to the

point where it gives you a way out instead of being backed into a corner. (P28 CWFR)

When I stressed then only I smoking as it makes me calm down. (P18 MBMR)

Sometimes medical staff do not offer medicine if they think the patient cannot afford it, especially if needed over the long term:

I did go to polyclinic for further medical checkup but the medical officer says there is no need to as I am only suffering from too much wind in my body, they only advised me to reduce on my coffee and tea intake. I always have backache, sometimes I cannot stand the pain, but don't want to see a doctor so just tough it out because they only say its wind or gastric problem. I asked for investigation but they said no need just cut down on coffee and tea. (P15 IWFS)

There is a lot of confusion and misguided advice given by health staff, sales people pitching products, the media, and well-intentioned family and friends:

When I get up I drink colonic water before breakfast. I take advice from Madam M, at the Diabetes Association. (P27 CWMS)

I only drink monavie, and after I started drinking it my blood pressure reduced, I feel less tired. (P29 MWFS)

Supplement I take monavie but for me not much changes after I take monavie, I still feel the same. (P29 IBFS)

A lot of marketing of supplements makes me feel I need to buy it to be healthy. (P27 CWMS)

I normally buy vitamins and medicine direct from the 'V' Pharmacy but sometimes I get constipated with them. (P15 IWFS)

I read one of newspaper article say that 'spinach not good for kidney' ... I don't drink soya bean. [Her daughter-in-law translating said 'she misunderstanding/confused about the newspaper article she was believe for

person having kidney pain but the reality of article was meant for person already long-time on kidney dialysis’]. (P15 IWFS)

There are those who ignore professional advice anyway:

The nurse at poliklinik gave me some diet information about the foods I should eat for diabetes. They checked me last time after the New Year’s celebration and I had eaten a lot of food and had a lot of beer with friends. They increased my dose [metformin] as my blood sugar was too high. (P2 IWMR)

My biggest hindrance to following a healthy diet is my will power, or should I say won’t power [laughs], and all the distractions from my colleagues at work, we all feed each other. (P32 MBFR)

7.3.2 Disparities between groups

First degree relatives vs. spousal control group. Upon examining the transcripts it appears that a higher percentage of the spousal control group smoke than of the first degree relatives group. Many of the first degree relatives declared that they used to smoke but gave up years ago:

My brother used to smoke and drink ... I also used to drink alcohol socially before but now I stopped drinking also. (P26 CBMR)

Some first degree relatives with the worst chronic kidney disease / metabolic syndrome scores, said they stopped smoking on advice from their doctor:

No smoking now but last time yes. I was told to stop when doctor said I had high blood pressure. (P10 IWMS)

There were many comments relating to family members who smoke even though there is plenty of evidence why they should give up. For example, this female Iban lady said:

Today I headache. I can’t sleep last night. I attend special occasion and did drink too much alcohol... I no smoking anymore but I still drink tuak [rice wine] with my friends at Gawai and for special functions. For me, my five brothers should be scared and stop smoking because my mother pass away caused from

lung infection due to heavy smoking but they are still heavy smokers, they can't stop smoking ... My mother was a heavy smoker. (P15 IWFS)

Some participants gave up smoking but consume other addictive substances such as alcohol:

I don't smoke now but did when younger. Doctor advised me to quit smoking when I got high blood pressure. I often drink alcohol, like beer. Less now as I get gout sometimes, very painful toes. (P10 IWMS)

I no smoking but I do drink alcohol but I had gout problem, so drink less now. Too much meat, too much alcohol, too much good food. (P9 IBMS)

Or tobacco chewing and betel nuts:

Once upon a time I smoked but no smoking now. Last time I also did drink too much alcohol but not now. I eat sepa [betel nuts] and sirih leaves put with tobacco and with betel nuts [they add lime and chew it with either betel nut or tobacco]. (P7 IWMR)

I also take sugi [chewing tobacco] and smoking rokok lutang but I have stopped smoking cigarettes for many years already. (P16 IBMR)

Some lament the fact that their children will not listen to their advice. This participant is one of the worst first degree relatives, who had a stent operation recently:

Previously I do smoke and drink alcohol but now everything changed and now I stopped the habits. I have two children, one of my children follow me to become a vegetarian, and second child is drinking alcohol, smoking a lot and a very stubborn child, not listening to my advice. I advise everyone who smokes to stop smoking. I also stopped drinking alcohol and now I feel more health than before. (P21 CWMR)

Worst vs. best chronic kidney disease/ metabolic syndrome. Paradoxically, those who had the best chronic kidney disease scores and those with the worst metabolic syndrome scores were most likely to talk about experiencing stress in their lives. A

number of different areas causing stress were identified, including fears about one's health:

I took your results as asked, to Dr R and he explained them to me. Doctor said my blood pressure was very high 189/125!! He said I could have had a stroke then! He put me on strong drugs to bring it down and I have to see him every week now. My sister took me to the doctor because I was scared I was going to die like my brother! (P3 MWMS)

Some Indigenous participants experienced stress caused from relocating to Miri:

I had stress in my younger days. When I first come to Miri, I have big problem with the food, as I didn't know where to get the food from; I didn't have very much money to buy; the food here was different and I didn't know how it tasted or how to cook it. (P6 IWFR)

At first I stay together with my sister in-law and brother-in-law [husband's brother] who was working ... That was a difficult time until my husband got a job and we got somewhere to live on our own, but now we're old, we live with my daughter. (P6 IWFR)

I stay with my brother-in-law about two years, I feel pressure stress because we stay with other people and it's not my own house. (P7 IWMR)

Life has changed since all the children have left home. I so stressed living in terrace housing in Senadin. I want to work, my husband didn't give me permission to, because we keep getting our house robbed a lot when we go out. Even if at home it's not safe as one old lady against two or three robbers is no match. So now very disturbing and a lot of stress. (P15 IWFS)

The men were more likely to experience stress from responsibilities at work:

Now my job I'm doing procurement for offshore and has big pressure and if anything goes wrong it's my head. Am having too much stress. (P10 IWMS)

I worked with civil aviation as a traffic controller in the tower for almost 20 years. I've been all around. Very stressful job. (P26 CBMR)

And women from long hours at work:

I now work at FA at Permy Mall. I work from 9am – 10 pm, very long hard hours with no breaks except for lunch hour. (P12 IBFS)

Unforeseen circumstances also caused stress:

It's been very difficult adjusting at beginning when my husband started dialysis seven years ago. We are coping better now. (P14 MBFS)

My husband died last year aged 53 years. When he was alive, he doesn't take care of his health... The doctor said that he had kidney failure... Starting from that moment, our lifestyle changed drastically. (P29 MWFS)

It is difficult for young people and people with young families to go on holiday:

I always go out with my friends every day last time. We always go to Miri to eat but now very seldom because of work and I have to look after my mum. (P24 IBMR)

Very difficult when we go for holidays – we have to organise for dialysis for my wife at other cities before we go. (P27 CWMS)

Participants with the worst metabolic syndrome scores spoke the most about information or lack of information and misinformation. Participants first searched for information from a wide range of sources including friends, siblings, parents, nurses, doctors, medical assistants, newspapers, magazines, leaflets, books, television, radio and internet. For some,

I not really believe everything advertised on internet. (P8 IBFS)

Others were more gullible and blindly followed misinformation and sales pitches:

Datuk L said it [kidney disease] was because of the chemicals in the water, but I don't think so it's just an excuse but the hypertension part I think it's caused from the fresh milk because it contains sawit from the oil palm so I always take

the UHT although sometimes when I'm out I cannot help it when I drink local coffee. (P25 CBMS)

For health information always get from my friends and the person I get the supplements from. (P18 MBR)

Those very desperate may chase the elusive 'cure' and 'good health':

I read about this diet in the newspapers, this Chinese lady from West Malaysia doing her Master degree in Nutrition in the UK, tried it on 100 patients and 60% was cured from diabetes. The headline was 'Possible Cure for Diabetes' so I read about it in the newspaper then later on it came out in the Nature Magazine. So I put it together and did what I think she was doing for months... I almost died... Dr S was worried that I could have damaged myself... worried about my heart and my brain... I was thinking that I could cure myself. (P25 CBMS)

There were many comments on the need for authoritative information for the community:

There are a lot of seminars on diabetes and hypertension in the community but mostly organised to sell supplements and such but doesn't really help us to learn how to change our lifestyles like what foods to eat or not. Doctors should do more free talks for the community. I taught myself about diabetes and the changes you need to do in lifestyle in order to control it. For me it's very difficult to advise others and have to give them time to change their diet and lifestyle. (P21 CWMR)

And the disappointment they feel regarding the medical and health fraternity:

The doctors and nurses at the dialysis centre never discussed or advised us our family about kidney disease when my sister was there and I think they should support us more. (P20 CBFR)

Even end-stage renal disease patients had to organise their own information support groups. I spoke to Mr. L a few months before he passed away, and he expressed

frustration with the lack of professional support and information given to patients and families. His friend during the interview said:

Not much information from the dialysis centre so now my wife teaches others on the machines as she's been there eight years already so knows things. It's very hard seeing your good friends pass away every day. She also gets advice from her friends and she gets a lot of support from our good friend Mr. L, you know him from Red Crescent Blood Recruitment Committee, he's very scared about being on dialysis machine so he organises a support gathering every two months so they can discuss things. (P27 CWMS)

More camps need to be organised for Miri people as it is expensive for many to go to Kuching:

I'm always careful when I take food for my diabetes program. I have attended the diabetes camp organised by government in Kuching and from that program I learn a lot about diabetes and how to control my diet. I try to control most of my food but hard to though. I still try to watch my food. (P2 IWMR)

They should include the spouses and carers:

I don't cook any different for my husband since he started dialysis. A dietician sometimes advises my husband but not me yet I'm the cook. Sometimes difficult to get protein and water balance right. My husband likes to eat chilli, and my husband doesn't control the food he eats. (P14 MBFS)

However if the doctor spends a little time with the patient they are less confused and more likely to be compliant about taking medication:

Last time I confused about the medicine the doctor gave me and didn't know it was for my hypertension so didn't take it, but not now, as the doctor explained it to me. (P7 IWMR)

Last time I always buy the painkiller from pharmacy but I notice I not sure of the content of the drug until Dr R ask me to stop buy drug from pharmacy due to high content of steroid. (P3 MWMS)

Some participants suggested the government do more:

I recommend that government can advertise more about health information on television and newspaper because, like me, I only get information about diabetes by reading books or magazines. (P21 CWMR)

I think the government should tell the children in schools how to live more healthy and have more sport, and promote not just at Sukma level [state and national level], so everyone have chance to do. (P3 MWMS)



Photograph 7.6 Rainforest food

Photograph by family member of researcher

Male vs. female. Food habits which are work-related, and socialising, are the biggest differences seen between men and women in this section.

Five men worked offshore:

Offshore I eat on the rigs and the food mostly cooked is Chinese fried food, rice and noodles. Food offshore is mostly heavy food. (P4 IWMS)

Half of my time I'm offshore. The food they provide there is very rich. After very physical work all day I get hungry and eat a lot. (P31 MBMS)

Three men worked in restaurants. One summed it up:

I like my job. I like to eat the hotel cakes and banquet pastry at the end of the meal but worry I'll put on weight. Because I work in hospitality line, there's a lot of salt and MSG and oil. Quite delicious and some time can make you ill or fat or gout. Mostly I don't like to eat meat, for me eating a lot of meat can make people sick, like bad heart and blood pressure problems. (P9 IBMS)

Work stress played havoc for a few men, such as for this overweight participant:

My job covers both Sarawak and Sabah so a lot of travelling and I eat out a lot and skip meals often. (P27 CWMS)

Although there is little control over ingredients when eating out, many men are considerate to their working wives:

At home my wife cook, not every day, maybe just at weekend and because she is working and have not enough time to cook after come back from work, I will bring my family to eat outside or she will buy in from outside. (P18 MBMR)

Gout is a big complaint among the men:

Recently not well because of gout. I don't drink beer but like to eat buri [intestines]. But I'm getting better at controlling what I eat now days. (P7 IWMMR)

This pragmatic Chinese man made an astute observation:

I have two friends on dialysis and one has just died. I don't have an answer for why so many people in Miri are getting kidney disease. The one who just died he thinks it was because he drank so much arak [45%+ alcohol] when he was among the Penan in Mulu. But the other guy had a kidney problem I think because he just didn't bother with controlling his diabetes. Also another guy who died ate really badly like samboi, chips, preserved black plum from China every day he snacks on that type of food ... We have a lot of natives who are educated, hard working and very knowledgeable and live a healthy life but too

many others eat, drink and smoke too much and don't look after their diabetes and hypertension, then end up on dialysis. (P25 CBMS)

Women are more likely to complain of 'gastric':

I can't control my food, because I having bad gastric and I'm hungry all the time. When I do housekeeping, I having gastric, it's hard for me to do my work. (P15 IWFS)

Women are more likely to diet and regain:

I have tried several 'fad' diets including the low carb. I don't take sugar usually, although yesterday I did drink barley. I have switched to red rice but one thing I cannot help, I do love carbs you know to chew on and I like deep fried stuff, that is my weakness. I don't eat much sugar, much meat and fat, like I don't eat nasi lemak, mee goreng and foods like that. After I went off the fad diets I bounced back fairly quickly afterwards. Once I went on the low carb diet and I lost lots of kilos of weight but gradually I gained again and I put on more than when I started the diet. (P32 MBFR)

A number of retired women are looking after their grandchildren, busy and bored:

Last time I did exercise walking I got down to 70 kilograms once because no one disturb me so I am free but after I got grandchildren to care for and no time I gained it all back again and some more because my exercise is different. When I exercised I got tired but a different tired. And different diet, I make cakes for my grandchildren and eat some too because I like it. (P5 IBFR)

Festivals seemed to factor in gaining or losing weight with men saying they gain:

I have tried to lose weight in the past ... but because we have a lot of Chinese New Year's functions and gatherings I gained back a bit more weight. (P26 CBMR)

Some Malay women use the fasting month to try and lose weight:

My mother has diabetes tendencies so she exercises and watches her diet. She is almost 75, small size and very active. During Ramadan she lost 7 kgs while I only lost 2 kgs. She is very particular – around her we are not to eat any sweets. (P32 MBFR)

A number mentioned that they ate differently when they had less money:

Normal diet, seldom change our diet, only when we are poorer our diet changes. (P3 MWMS)

We grew a lot of vegetables and ate kampong food. Meat and fish were a treat for the family. However when we move town and our life changed as we have a monthly earning and we can afford foods that we never could afford before thus our eating habit changed and we no more cook like my mother and grandmother used to. We go for fast food and desserts like cakes and sweets that we had not had before and many choices of food at the supermarket. (P15 IWFS)

There was a big difference between the types of food the men and women wanted. The men wanted spicy foods, at home and when eating out:

At first I followed a diet after the doctor advised me to cut out fat, salt and sugar in my food but I got tired of it and it didn't last long as I wanted to eat more tasty foods. So I stopped and nowadays I not really worry about my diet at all. (P4 IWMS)

I take a lot of noodles, I love noodles very much sometimes I can even take two bowls at one time. I don't like soup noodles, I prefer fried. I don't like Kentucky much, I prefer noodles and rice meals. (P27 CWMS)

Others admitted they could not control themselves, especially around durian:

I was on Avandamet [Metformin] because of the durian season in November, because when it comes to durian there is no stopping me, there was no lunch also only durian ... trouble is with me anyway it is difficult to be consistent. (P25 CBMS)

During fruit season, because I like durian did eat some durian, cempedak and langsung, but I just control myself and take little only, hard to though. (P2 IWMR)

While the women mentioned they like to eat fast foods when they eat out:

I like to eat fast food like KFC and local food also. Only eat curry when we attend special occasion. Even my husband on dialysis, 7 years already, the way I cooked still the same like before this. I don't worry to follow healthy diet strictly as I think we are healthy. (P14 MBFS)

The youngest lady in the study:

I seldom cook at home and always go to Sugarbun or KFC, two or three times a week. I eat the meat [fried chicken] and rice at Sugarbun during lunch and dinner because it's close to where I work. I get to eat some FA biscuits at work, that's probably why I've gained weight. (P12 IBFS.)

The vegetarians found it the hardest to eat outside the home:

Myself, I'm a vegetarian for 10 years now and always cooked and eat at home as it is difficult to find a vegetarian café in Miri. (P21 CWMR)

I changed my diet to vegetarian ... I don't really feel healthier but you must know how to eat in a way but at least eating a lot of vegetables you avoid eating a lot of meat and that temptation can help you to control your diet better. (P28 CWFR)

The older people found it difficult when they had to live with their children and they or their spouse were not doing the cooking any more. The older folk were very vocal about changes in their diet:

Last time I did take food cooked by my sister but she uses a lot of salt and viching [monosodium glutamate or umami], until I realise one day I had pain at the back of my head. I remember before my brother pass away because of stroke, two or three day before, he was complaining back head pain ... Doctors

said it was from high blood pressure problem. So now mostly my food I cook myself. (P3 MWMS)

Food changes from kampung to town ... I like to eat umai [Melanau traditional raw fish or prawn dish]. Then different kampung food to now. Then kampung food, we always boil and fish was cooked with kunyit [turmeric] and was less eating of sugaring food and drinks. (P17 MWFR)

Different the kampung food compared to town. Changes in lifestyles... Living in town with my daughter, my diet changed and I eat what my children eat and they always eat fried food, seldom boil, and in a month we would go to eat outside two to three times at the kedai ... My diet at home, I always eat vegetables, seldom fruit, sometimes meat like chicken, often eat fish, we eat only a little pork sometimes. (P16 IBMR)

My diet food at town is different from kampong food. But I used to cook like kampong style because I like to eat kampong food but couldn't properly in Miri ... I don't like sweet drinks. (P5 IBFR)

The Orang Ulu often mentioned Bario or Kelabit salt:

Cooking at home less using MSG [monosodium glutamate] but we use the Bario spring salt. No one in the kampung has goitre. (P16 IBMR)

I always eat at home, and very seldom eat outside. I also seldom use vicin [monosodium glutamate]. I do use salt, it's iodine salt and also Kelabit salt. (P5 IBFR)

Town people often chose the cheaper non-iodised salt and probably got their iodine from eating prawns and prawn paste:

I don't use a lot of MSG but I take some ingredient without MSG which can enhance the flavour. I do use the raw salt for cooking, ordinary RMI/packet [local Chinese non-iodised salt]. But I don't like too salty. (P28 CWFR)

I avoid salt, I use the pink Himalaya salt now. It's not iodised like Saxa although they say there are minerals in it. They say it's the same as Bario salt. I

don't use MSG at all. People use too much MSG here it's in every type of food.
(P32 MBFR)



Photograph 7.7 Cinnamon, Bario Salt

Photographs by family member of researcher

Ethnicities. Activity transition was greatest for the Indigenous participants who relocated to Miri from rural or remote areas:

Since living in Miri the worst thing is I don't have hard work to do, like lack of sweating, because I seldom do heavy work like farming. Because of responsibility, it's finding time to exercise a problem. (P2 IWMR)

Across all ethnicities, religions and genders there was a unanimous dislike for exercise with a wide variety of excuses such as these Chinese ladies':

No exercise because we have no time to do it, we get home then have to cook for the children, plus I have to send my kids for tuition and other activities. At work I walk around. (P19 CBFS)

I'm not really exercising much. My exercise is my housework ... I sometimes watch TV and I read books ... I'm too lazy to do exercise because after I finish my housework I'm too tired and need to rest and sit down, then I have to cook, and all sorts of excuses not to! We don't have this kind of habit so don't. (P28 CWFR)

Both worst and best Malay ladies:

I don't exercise I feel demam [fever] when I do. Last time I used to go for exercise three times a week but now no more because I have no friend to go with. Also now no time as looking after my grandchildren. (P17 MWFR)

Honestly, I very lazy do exercise for me when I do housekeeping work at home, it enough from doing the exercise. No exercise in a week [laughing] I have time if I want to go for exercise, but I too lazy to do it. I did exercise last time, three times a week. The doctor told me I should be exercising especially as I get older. (P14 MBFS)

An Indigenous Orang Ulu grandmother:

Now I take care of my grandchild I become don't like to go exercise. I always do move a lot, maybe that's why my hands feel painful [arthritis] some time now. I feel now because if we look after our grandchildren so I don't have time to move so much, I don't have time to walk around and put on weight. I don't know how to control myself. (P5 IBFR)

Men usually used work as their excuse for not exercising, such as these Chinese men:

I'm getting older now so life has changed a little bit now, now less exercise activity. I seldom go to exercise now as I am being lazy. I'm retired now. I now prefer to watch television and read the newspaper. I don't like tai chi to do and no group doing it anyway near my place. My son also doesn't do exercise because he working morning till night. (P21 CWMR)

I do very little exercise, not for a year, because I am very busy and travel a lot. When I travel and stay at hotels there are facilities like gym and swimming pool but I can't use it as ... I am too busy writing reports. I guess I have to managed my time more and fit the exercise in the between the busy schedule ... last few years I've gained quite a bit. (P27 CWMS)

And the largest, youngest male Malay participant:

At home I will do some housekeeping work and I seldom do exercise. Other activity at home I like to play are computer games. (P13 MWMR)

Miri is extremely hot between 10.00 am and 4.00 pm, sometimes 40 degrees Celsius, and on the equator it is pitch black everyday by 7.00 pm, so for office workers returning home late there is not much time for outdoor exercise:

I feel healthy at moment. But before I was 105.4 kg only and now increase to 116.9 kg. Wow that's 11.5 kilograms ... I was big also in secondary school. Now I don't go to exercise, because I my work time till 6 pm, get back home around 7.00 pm. (P13 MWMR)

Only eight out of 32 said they exercise regularly. Of those who did, the Chinese were the most regimented:

I think the most important thing for health is exercise. I do morning walk every day except Sunday. I walk about 40 minutes which covers about 5 km... If I don't go for my routine exercise every morning I feel that something is missing. I look forward to going and meet up with a group of my friends as well [laughs]. (P26 CBMR)

The Malay and Indigenous men were most likely to exercise with their children:

I'm not allowed to use gym at work, just do my own program. I exercise only sometime, when I get time. My house is not far from the Jemu Padang and sometime when I have time I exercise there together with my children. I want to be a role model for them, that's why I'm always keen for exercise. (P9 IBMS)

I occasionally use the gym offshore ... When I'm onshore I still stay active. Sometimes I go jogging, on bike, or go swimming with the children. (P31 MBMS)

The Indigenous men felt the most frustrated in Miri:

No, I don't exercise, only when I balik kampung [return to village] then I do heavy work on the farm ... When I stay in Miri I have only the house to move around and we go by car a lot when we go to shopping malls and Emart. I

prefer to stay in the kampung so I can walk around the farm gardens and do the padi [rice] farming work. (P16 IBMR)

Illness and disability prevented some from exercising:

After my leg become worse and worse I stop to do my activities. Very hard to exercise when something wrong with you and you can't because of pain. (P3 MWMS)

Others who exercised two to three times per week were concerned by the need to control a chronic non-communicable disease:

When I stop exercise my blood pressure goes high. (P18 MBMR)

Exercise is important to me because I old age already and because some of my family have diabetes and I don't want high sugar and become diabetic. I feel better also after I do. (P20 CBFR)

If there was encouragement and accountability the participants were more likely to exercise:

I bring my evidence here [recent blood workup] instead of just telling you, I want to show you that I am improved since I saw you for tests. I lost weight and my cholesterol, hypertension and blood sugar is better. (P28 CWFR)

My blood pressure is high and Dr A advice me, to do regular exercise rather than buying and taking supplement that cost a lot of my money. Now you say the same thing so I better take notice. Ok I've changed my mind I'll now go to the gym and exercise more to get fit. At least at weekends. (P18 MBMR)

The regular Shell check up every six months is good as the doctor may tell you that your blood sugar is too high or tell you to do more exercise so it motives you. (P25 CBMS)

One lady did not follow advice:

I'm on medication for hypertension and cholesterol only I don't have diabetes. Doctor did advice me go for exercise but I don't follow his advice. (P14 MBFS)

Those who did exercise regularly were eager to say how they felt afterwards:

After I exercise I feel refreshed and feel relieved of stress. I also problem solve when jogging and sometimes I can think of the solution – either I solve it or it becomes a very small problem. (P31 MBMS)

The hardest thing about trying to lose weight is that I feel my body is tired and my feet hurt. The best thing about losing weight is that I feel more energy, I can do more work, less sleepy. I feel sleepy after meals before I lose some weight. (P1 IWFS)

Some expressed frustration that their family members did not listen to them:

I did advise my brother and sister to exercise and control their food habits but it's hard for them to listen when they don't want ... so what you going to say. (P28 CWFR)

I try to keep my same weight. I have three sisters ... very big size ... They don't have children. I as brother try to get them to go for walks and lose weight and not eat so much – but not happening yet! (P9 IBMS)

Difference between me and my mum is that my mum was having diabetes and arthritis and she also very big size. My brother also in big size. I tell him to go jogging but he doesn't want to exercise or to control the food he eats. (P14 MBFS)

7.3.3 Conclusions

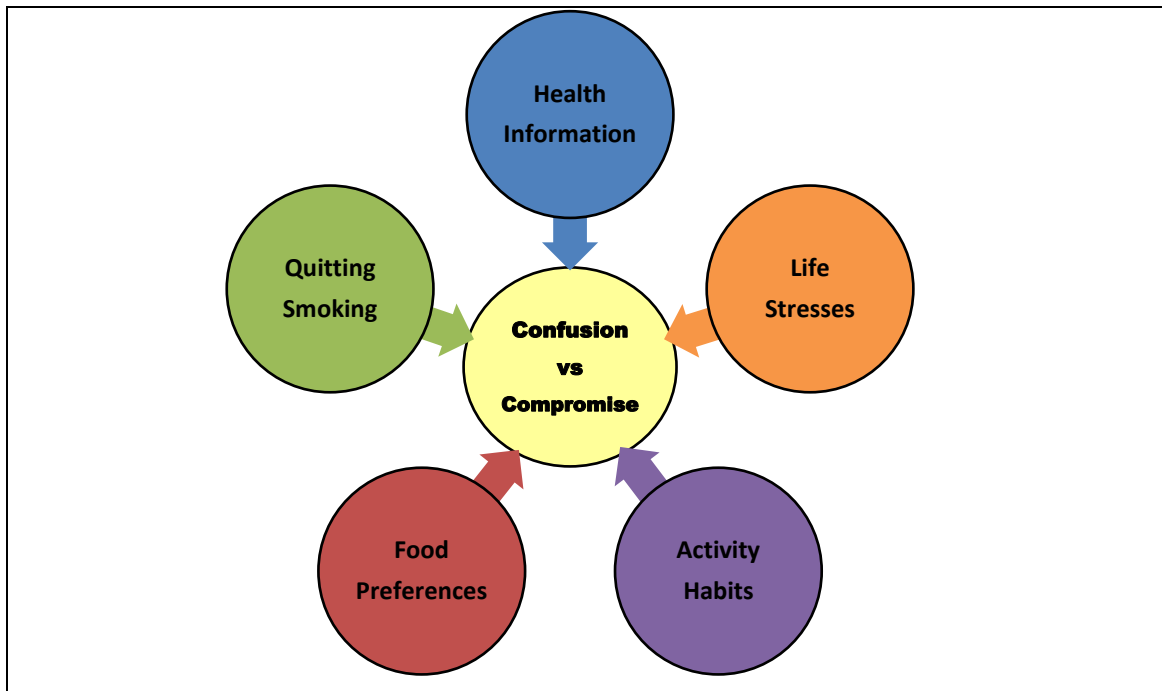


Figure 7.3 Summary of sub-theme 3: confusion vs compromise

7.3.4 Main differences seen between groups:

- The spousal control group smoked more than the first degree relatives, who were more likely to say they had given up when diagnosed with a chronic non-communicable disease.
- Lifestyle stress factors for the best chronic kidney disease group revolved around keeping themselves healthy so they could continue to support and look after their dependants. The worst metabolic syndrome group talked of the stress caused by trying to control their chronic non-communicable diseases. There were only patient gatherings and no support groups for first degree relatives or their families.
- There were many food preference differences between men and women participants but the outcome was the same – frustration with weight matters.
- Different ethnic groups showed divergent activity habits often related to their work. The majority of the participants preferred taking a tablet from their doctor

or a herb or supplement rather than using time, effort or energy to exercise on a regular basis.

7.4 An Aging Population

The quantitative Phase One multiple logistic regression analysis determined that age was a risk factor for both chronic kidney disease and metabolic syndrome. When the actual responses of the qualitative interviews were inspected it was noted that there were double the number of participants in Phase Two in the 40–49 age group and only two above 70. Quotes are selected from the groups with the highest percentage of responses and are based on pertinence to the topic.

7.4.1 Majority views

Life Adjustments. Those in their 40–50s were the majority in this subset. The older group showed most distress at relocating to Miri; for example, this 60-year-old lady and 50-year-old man:

Last time I do work some farming. After coming to Miri we no longer make farms. When I was living in the kampong I felt healthy then first time come to Miri I felt lemah [not strong] but I recovered from sickness, then I did do some farming at Riam Miri for a while. Now I cannot make garden as old and weak. I miss gardens. (P6 IWFR)

In the kampong my wife cooks the food I grow from our garden and we eat at home most of the time. When I moved to Miri Town my life and my food changed also ... I'm bored, have nothing to do in spare time in Miri but to go to coffee shops and eat a lot with friends. (P2 IWMR)

Many of the older participants took the chance to comment on their siblings' and children's habits, as did these 64- and 56-year-old men:

I'm getting older now so life has changed a little bit now, now less exercise activity. I seldom go to exercise now as I am being lazy. I'm retired now. I now prefer to watch television and read the newspaper. I don't like tai chi to do and

no group doing it anyway near my place. My son also doesn't do exercise because he working morning till night. (P21 CWMR)

My brother and sister... are concerned about their diabetes but you never know what they eat outside the home, they never listen to what you say. (P28 CWFR)

There were some differences between the decades: the transitional changes lessened with age and time living in Miri.

7.4.2 Disparities between groups

30–39 Age Bracket. Those who had relocated to Miri in their teenage and young adult years still held a strong attachment to their kampungs but lacked the money to return as often as the older groups due to having a mortgage; however, they were more flexible and able to adjust to urban living better than older groups:

I feel stronger in the ulu and weaker when I stay in town. I still got land in my kampong I wish I could farm. (P7 IWMR)

If I were still living in the kampong I'd be farming padi [rice] and lada [pepper]. Most of my cousins and friends are now living in towns, mostly Miri. When I first came to Miri it took half a day by boat and then a day by 4-wheel drive. Kampong is very difficult to get money. Many jobs in town that can do. Life is easier in town if you have a job. My life has changed and I'm more happy. Now we own a house, having a car, radio, watching TV, going to church, like that lah. (P1 IWFS)

The biggest difference for me to my parents in Bario is that I have money and I live and can go shopping in Miri. (P12 IBFS)

40-49 Age Bracket. By 40 years of age most of the participants were married and the realities of providing for a growing family had set in. Activities for women tended to be more family orientated, and a number commented that it was different from how they were raised:

My mum never worked and she had one amah and one gardener to help her with all the work around the house whereas I work, raise my sons, feed my

family and do all the housework myself, except for the ironing I get a lady to do for me. Compared to my parents, I move and travel more ... IT these days keep me constantly in touch. (P32 MBFR)

The men were work and promotion orientated:

Very seldom go for exercise, no time now. Last time I always play football. Now I just watch it on TV. I think my blood pressure better when I'm on holiday and when I jog regularly but no time now - work. (P10 IWMS)

I seldom go for exercise now, because I always come home late from work. I stop exercise my blood pressure goes high. (P18 MBMR)

Some had health issues or the added responsibility of family members relying on them like these 40+ year-old men:

I was responsible for my mum and brothers after dad passed on. That was hard when I was younger. (P24 IBMR)

Yes now I get treatment and have my leg checked also. The lowest I can get is 125/95 for my blood pressure, if I not take tablets maybe higher than this then after two days I'll have trouble again. I asked doctor if I get 125/80 can I give up my medicine but Doctor said no no no you need medicine for the rest of your life, so be it. (P3 MWMS)

This is the age when first degree relatives said they stopped smoking cigarettes and many started to get hypertension, like this 43-year-old:

I have been on hypertension medication since your blood test. I was sent back off-shore last week for high blood pressure and I cannot go off-shore again till it is lower and stable. (P31 MBMS)

50-59 Age Bracket. The 50- to 60-year-olds had the most concerns regarding nutrition and lack of activity and had started reining in excesses:

Actually it was last 10 years ago when things began to go haywire I think partly because of age, 51, but the other thing was my lifestyle changed and... through overeating everything went haywire. (P25 CBMS)

Many participants in this age bracket were looking after their sickly parents or spouses:

It's been very difficult adjusting at beginning when my husband started dialysis seven years ago. We are coping better now. (P14 MBFS)

Now my mum-in-law live with us because she has high blood pressure and kidney problem, and she's been on dialysis ... Very hard, my wife is upset about her mum. Mum in law cannot go home anymore to long house as too far and no dialysis there. (P9 IBMS)

Almost without exception, for both the first degree relatives and the spousal control group, participants over 55 years of age mentioned they had a chronic non-communicable disease or cardiovascular disease but many did not take it as life-threatening. This participant was assessed as chronic kidney disease low stage 3 in this study:

My next appointment to see doctor is at poliklinik in April. I go for follow-up every three months. I've never had my urine for kidneys checked for long time, not since you did for me. (P7 IWMR)

Those who joined their children later in life could get very homesick for their kampung and friends at this age, like these 57-year-old men:

I feel better at kampung than in Miri because I really love my kampung as I can meet other people in the longhouse. (P16 IBMR)

The problem I cannot sleep at night, I think too much. If I in kampong I go early to bed because I'm happy seeing my friends. Then we get up early in the morning to talk around the fire. I feel happier in the kampung but cannot go back often because the transportation is very expensive and it is such a long way, many hours [16 hours by rough timber road]. (P7 IWMR)

60+ Age Bracket. During this decade a number of participants had heart problems, like this 70-year-old, and some mentioned they had friends who had died from heart complications:

In fact I feel that if you have some health problem we must not hide it, go and see the doctor early as we do not know our self. Like my, this balloon, in fact I don't feel anything, it was just my children said I'm now quite old I should go for medical check-up. So I went to HSBC KL and doctor found that one of my vessel was 75% blocked so I either have to take medicine or have the balloon, so I chose the balloon. If I didn't go for check-up I wouldn't have known and it might be too late ... I've been healthy lately but it was frightening then. (P26 CBMR)

Some reflected on their parents' health and how they were better controlled with knowledge and medication:

Last time we were less informed about the content of coka-cola, and my brother always buy big amounts for mom. We found out my mother started having kidney failure when her sugar level was very high. (P21 CWMR)

And later from the same 64-year-old Chinese man:

My diabetes is under control now. I changed my eating diet because for me being a vegetarian was healthier. Being a vegetarian has improved my life yes. Not much different about my lifestyle. Some of my relatives ask me why I am a vegetarian ... When I still drank alcohol, I always was not feeling well but after I became vegetarian, I feel better. I always ask my friends around us to follow our diet [vegetarian] to live a healthier life. (P21 CWMR)

7.4.3 Conclusions

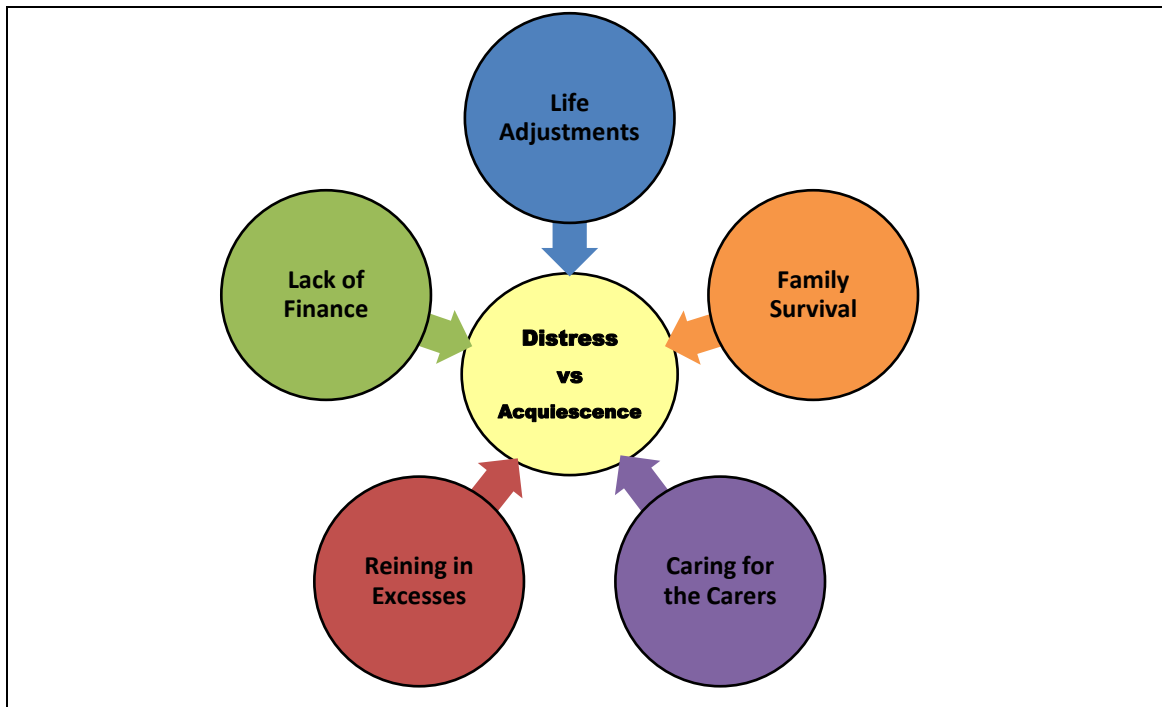


Figure 7.4 Summary of sub-theme 4: distress vs acquiescence

7.4.4 Main Differences seen Between Groups:

- The older participants showed maturity and wisdom from their years of experience but complained that the younger ones never listened to them.
- Often it was the diagnosis of their own chronic non-communicable disease or cardiovascular disease that shocked participants to take action and change their own bad health habits.



Photograph 7.8 Low-cost corner house

Photograph by family member of researcher

7.5 Environmental Concerns

7.5.1 Majority views

Housing environment. This section, more than any other, showed the inequalities and difficulties the less wealthy participants struggled with daily:

I like living here as we can jog around the complex or can walk across the road to the beach. (P32 MBFR)

My house is at Piasau Garden [development of detached houses with large gardens]. A lovely area. (P26 CBMR)

My house is a corner one and I have a garden at house. (P9 IBMS)

I live in a detached house. My wife and I are on our own now that our children have grown up and married. (P26 CBMR)

The Indigenous Iban preferred to live in their longhouses even if they needed to travel to Miri for work or their children's schooling, rather than relocate to Miri:

All my extended family live together in the longhouse. (P23 IWFR)

The land we built the longhouse on now is my brother's land, its NCR Land and all my brothers and sisters and I and their children all live together in the same long house. (P22 IBFR)

Living in a longhouse in a rural area is so very green around and lots of space and no traffic. (T3-P24 IBMR)

I stay my own house at Taman Tunku [low-cost housing at Miri outskirts]. I live in Miri and manage to look for transportation for my youngest child to go to school, and when I have time I go back to longhouse to see my missus about two times every week. My own kampong land is near Sui [1½–2 hours' drive from Miri]. (P2 IWMR)

Many of the Indigenous Orang Ulu had relocated to Miri years before:

Before we moved to our new terrace house at Permy Jaya, we stayed at Pujut Padang Kerbau for about 22 years. (P13 MWMR)

Before I have my own house, I was renting a house at Kampung Wireless ... Now about 12 year stay at my own house at Senadin [terrace housing]. Just my husband, children and myself in our very small house. (P14 MBFS)

I have a low cost terrace house in Senadin. My wife and I share the mortgage. (P18 MBMR)

We own our own house in Senadin by Naim Candra [low-cost]. My husband and I share the repayments. (P1 IWFS)

Often when children got married the new couple moved in with the parents who had a house and space, until they got a place of their own. Sometimes, if the child had a good job and a house, the parent moved in with them, especially if the grandmother could look after the children:

I have a house at Sungei Adong Pujut but I am now living with one of my daughters to help her look after the grandchildren. (P4 IBFR)

I living at my own house, my children are stay with me, two daughter, my son and my two grandchilids. Her son I take care of now but her husband work still in Kuching. (P5 IBFR)

Now I only stay at home living together with my daughter at Permy Jaya [terrace house]. (P16 IBMR)

Many participants who lived in low-cost housing complained about the few children's playgrounds:

There was no playground near our house and dangerous as too many cars along the road there ... We community hope and want to build a padang nearby in future. The government could build the playground near to our house as there in an empty land available in front of my house. At the moment it is used by the neighbourhood for gardening. The people around there go plant banana, tapioca etc. so now children cannot use. (P21 CWMR)

There were few padang (playing fields), although some were lucky:

No padang around just terrace housing. (P27 CWMS)

I will walk around the housing area on the road. (P7 IWMR)

There is no padang nearby to walk to exercise. I just walk around the house or sometimes along the road scary. (P1 IWFS)

The padang near to my house only take 3 minute walking to the place but a jungle and can't go jogging there now. Before could walk and jog there but not now, not cared for by council. (P14 MBFS)

There's a padang not far from my house. My children go there to play football with their friends. (P10 IWMS)

There were few parks in new low-cost housing areas:

I have my own house and a small garden. I live at Permy Jaya area, for about 3 years already. We live in a new area but no park close around for exercising. (P21 CWMR)

Nowhere to walk around near where I live. (P30 CWFS)

My house is in the kampung at Lutong so more open space than housing developments. (P31 MBMS)

When asked the question about gardens, one lady couldn't stop laughing:

Now I am staying at Kampung Wireless [her house is on stilts in the river water village]. My activity at home is fishing in the river [people there literally throw a line out of the window to catch dinner]. (P17 MWFR)

Even though some people were close to the beach or a park, this did not mean they exercised there:

There is a park within walking distance from my house but I don't bother to go there. (P14 MBFS)

The kampung is between the river and the sea [on the peninsula]. It is close to the beach so I can walk there, but don't. (P29 MWFS)



Photograph 7.9 Two low-cost houses

Photograph by family member of researcher

7.5.2 Disparities between groups

First degree relatives vs. spousal control group. The most comments concerning land were made by the first degree relatives, those with metabolic syndrome, and Indigenous from rural or remote regions. In the Indigenous community, family members quite often shuttle between their urban family and their rural farms:

I am first in my family to be living in a town. My parents are still in the kampong, still in Long Terang. I go back to the kampong to see them maybe two three times a year to help with harvest and fruit seasons. (P1 IWFS)

Malay and Melanau landowners on the outskirts of Miri had their land taken if they had no title:

Last time we had land in Kuala Baram near the pottery factory there and we always plant something to eat there. Our land had no title papers so the government took all our land and gave it to someone else ... So all the families had to leave about 10–15 years ago. My father and mother were very upset. (P3 MWMS)

The land that we were living on was NCR village land starting from my grandfather until my generations. Mostly the land is seaside land and has oil

palm further away from beach area. The Government offered us compensation for the land when they wanted to do a fish processing factory in the village. A lot of changes ... even our daily expense is hardly enough. (P15 IWFS)

A number of participants said they had relocated to Miri due to one of the multiple dams being built by the government:

When they made the Ulu Baram dam all the land at Long Sunyei was flooded and we cannot go there anymore. I miss there. (P6 IWFR)

Long Ikang kampung is ... below the dam and my kampung will have to lose their farms when the dam floods. (P16 IBMR)

My village is from Long Keses, Baram. My mum and dad inherited land from their parents there. The Murum Dam is above our kampung we are just below it, we will have to get out of the way. Don't know what's going to happen. (P5 IBFR)

Many traditional tribal lands have been taken over by large timber and oil palm companies. There were a number of mentions of this; one lady described the frustration:

The oil palm company, Greenwood / IOI already come into my kampong Patah. They are causing problems for the old folk left there like when my mum and dad were forced off their traditional land. So we went by timber roads from Patah [Baram River] to Long Terang [Tinjar River] as the land in between the rivers were taken by other Kayan longhouses. So now my mum and dad have to live in Long Terang to rent land to grow rice but it's not on their own land anymore. Now our land at Patah, we took them to high court, 4 years already. The oil palm company keeps postponing it, every time go to high-court appeal. So many delays, so much money to pay the lawyer. (P1 IWFS)

Some of the small farmers and longhouses planted oil palm to sell to the plantation companies, to supplement their income:

Both of my brothers are on dialysis, that's why, the expenses are tough to cover the dialysis charges, luckily we have planted oil palm and this helps to get money. They were still healthy, during the blood test for your research, and still doing some kebun [gardening] then. (P23 IWFR)

Worst vs. Best chronic kidney disease / metabolic syndrome. The NVivo matrix intersections showed that most comments on gardens were by these with the best chronic kidney disease scores and the worst metabolic syndrome scores. Most of the participants with the worst scores had gardens elsewhere outside Miri. Some went by motorbike or car and some by longboat with an outboard motor up the river:

The land is just near the back [Taman Tunku], and can use motorbike to go to my garden. At Kampung Lusut and do gardening there, I plant some vegetable and fruit. (P2 IWMR)

At my garden, I plant some vegetable and fruit. My garden at Batu Niah area it takes more than one hour to reach the area of my garden. When my husband has off-day we two together do gardening. (P5 IBFR)

In the past all ethnicities grew their own food. Many living in town felt disconnected from not having a garden:

In the kampung I liked to grow our own food but in Miri I have no kebun [garden] to grow vegetables, fruit even flowers. I have to buy all our food at the kedai [market] ... In front of the house is only just enough cement to park a car. (P1 IWFS)

We have a small garden at back of the house where we plant vegetables but we have to grow fruit trees at Bakum [one hour's drive away]. (P4 IWMS)

It transpired that those living in low-cost housing did not have enough garden area to grow fruit or vegetables. There were many more complaints than the few that follow:

At my place has no room for a garden, so small only, just a cement carport, then the house, then at the back a small 3'x 6' cement section. I dry my clothes inside the house as not enough room outside. At back outside entrance is the

toilet, the plumbing, before fence and the 2' longkang [drain]. Then the neighbours house backs on to mine, the same design. There are three small bedrooms and one toilet only. My house is so small but so expensive! (P1 IWFS)

I didn't do gardening due to only limited area, just got a fence and parit [drain] at the back of my house. (P3 MWMS)

We have no garden around our house, at the back just a very small space then parit [drain]. My mum used to have garden at her place last time planted vegetables and fruits but now she has stopped gardening due to her heart problem and old age. (P27 CWMS)

Now usually we plant in pots as not enough room for a garden. (P20 CBF)

My house is a terrace house with no garden just rubbish in Senadin. (P10 IWMS)

I always do some gardening but near the house [on the reserve area by road]. I also plant some kangkuk manis, sawi and daun ubi [local green, leafy vegetables]. (P5 IBFR)

In front of my house on the reserve, I plant some fruit trees. (P18 MBMR)

In my garden I have planted logan and mango at back and in front of the house on reserve have planted banana. My children help in the garden. (P9 IBMS)

Male vs. Female. There were no great differences in the comments made by female and male participants except that a number of women raised curious issues of concern:

No smoking and no drinking tuak [rice wine] no betal nut, only drink coffee. I don't know why my sister get diabetes, I get high blood pressure or my brothers get kidney failure. We are all skinny and have worked hard on the farm all our lives. (P22 IBFR)

While I still farming, I felt healthier, because I moved and sweat a lot ... Last time I used to garden and sell vegetables and fruit to Miri but now I can't

because I always sick ... I feel sick now, because of no gardening, but I don't want to manja [whine like a spoilt child] ... Now since I got sick I could not go out to the farm, I feel sick and the children asked me to stay at home. All I do is just sitting on the ruai [veranda] and I feel so bored. (P22 IBFR)

On health information, I do not know anything. The only thing I noticed is that so many of the longhouse folks are suffering from kidney dialysis but we do not know what causes it. (P23 IBFR)

My brothers, one 40 and one 44 years old, saw the doctor for medical checkup when they wanted to work offshore, but they were told have to do dialysis already, we also don't know what is the reason of their kidney failure. The doctor never gave information to us. Now in the other long houses like ours in the Bekenu area also having a lot of people on kidney dialysis. (P22 IBFR)

I don't know the reason why my mom has kidney problem, but doctors says it's because of her smoking – but so far she don't smoke since she was a teen. Other doctors say using the spray, always this gardening spray that what they suspect my mother using the weedicide causing the kidney problem. But she's the only one in my family with it, how can? (P5 IBFR)

Others expressed similar concerns to these, and this prompted an adjustment of the qualitative interview schedule to include this line of questioning.

Ethnicities. The qualitative interviews identified a number concerns with regard to agrochemicals. DDT [dichlorodiphenyltrichloroethane] was used to reduce mosquitoes causing malaria and dengue fever:

When I was younger until the middle of the 1980s the government also did come to our long house every year to spray the longhouse with DDT for eradication of mosquitoes. (P16 IBMR)

I sometimes use pesticide - gastrofed at my oil palm and they use it in the kampong too and before that we used DDT. I also sometimes use weedicide to get rid of the lalang [strong, resistant weeds]. (P2 IWMR)

*The council does fogging around the kampung and my house for mosquitoes.
(P31 MBMS)*

The council fogs around our area for mosquitoes. (P19 CBFS)

My wife got dengue fever it's not nice, very sick, and don't want the children to get it. (P18 MBMR)

My children seldom go outside and we only use air-conditioners in our house so have less mosquitoes. (P19 CBFS)

A range of herbicides and pesticides were mixed and sprayed by participants, including named products:

As a farmer, I did used weedicides Gramazone [paraquat] and Roundup [glyphosate]. I prefer gramazone because it's stronger and I want the grass to die quickly. It's called Gramazone and Spark. The government gives a free subsidy for racun [poisons - including herbicides, fertiliser, pesticides] but sometimes if finished I buy for myself at the shop. It is easily available. (P16 IBMR)

Sometimes I do use the pesticide for the bugs, a lot of these insects, but not always to use it. The brand I use is Malathion. I like it because other brands are not effective. Sometimes we spray the weeds. We use the Roundup and Gramazone. We use Gramazone around the edges for the lalang [tough variety of weed] grass there it gets rid of it better, Roundup not the same, not so good. (P5 IBFR)

Majority all of other longhouse folk also use the same weedicide called gramazone, plus now they plant the oil palm so mostly will use the gramazone as very effective. It's sold to all the kampungs. Sometimes they will cover their face and hands, but sometimes they don't bother to cover up. They got information that if not cover up it is racun [poison] to them. They don't have a choice because if they don't use it the weeds grow too fast and thick. (P22 IBFR)

Some use coveralls and face masks when spraying, some do not:

My daily routine work is planting, harvesting and spraying the weed around the oil palm trees. The weedicide I always use is Supermore... I cover up dress when I do spraying. (P24 IBMR)

I always cover up and use a mask now. In my younger days on my father's farm I never did. Gramazone is what I use as very popular to use in Sarawak and it's so easy to get in the kampungs and the oil palm companies use it. (P31 MBMS)

I do contract work, when the area needs to spray with ant poison, around the walls of the house. I did use cover up dress when I use pesticide but sometimes hard for me to avoid from breathing the poison, because the smell is too strong. I did use the mask but still can breathe it in. (P18 MBMR)

Some of the reasons given for not covering up when using agrochemicals:

I am a farmer since young and I do farming on my own land, but now I not doing any farming because of my present condition ... I do not use cover-up or boots during using the poison as too hot and I sweat a lot. (P23 IWFR)

I frequently pee, very annoying so I don't drink water much [daughter said, 'very annoying when you are spraying']. (P22 IBFR)

The agrochemicals are also used on home gardens:

I use herbicide most places, around the paddy field before the paddy is planted, the vegetable garden and I use around the pepper plants and I also use pesticide at my pepper plants area, can't remember the name of the pesticide. I also use it at home. (P23 IWFR).

We grow vegetables and eat cendawan [mushrooms] and midin [fern tips] that grow around the plantation trees [which have been sprayed with agrochemicals]. (P15 IWFS)

And on their children:

Every time I came home from boarding school for holidays mum would rub spray chemicals in my hair and hands to kill kutu rambut [hair lice] and kudis buta [scabies] and it worked. (P12 IBFS)

For suicide:

A girl from my kampung drank it when she upset over something. So painful way to die. No one should die like that. (P1 IWFS)

Longhouses are almost without exception built beside a large river, for water for the longhouse and for transport:

Normally the kebun is far from the longhouse and now mostly children are at school or sit in the longhouse watching television. Cannot swim in river or they get itchy skin. Cannot go fishing as no more fish live in river any more. (P22 IBFR)

The following comments are by those who never used agrochemicals:

When we grew up my parents had a large garden and my mum used fertilisers but the herbicides were only used by the gardener. Here people always look for the easy way out so like they would prefer to use strong chemicals to kill the lalang rather than cut or pull them out. (P32 MBFR)

We have some fruits in the garden, like longan and we use not the artificial fertiliser but the hormone enzyme to make it fruit three months later. We never use the racun rumput [herbicide], we don't even spray for mosquitoes and now even to clean the floor we don't use strong chemicals. (P28 CWFR)

There were many comments on the vegetables the participants chose to eat:

I have a big garden at my house and I grow my own vegetables, quite a few types. I never use chemicals in my garden. It's all organic, 100%. In the 80's Brunei refused to buy vegetables from Miri because of too much chemicals used when growing vegetables. (P26 CBMR)

In our garden at the house in Sungei Adong Pujut we don't use weedicide or pesticides. I don't mind holes in the leaves of the vegetables. (P4 IWMS)

My wife washes the vegetables many times to get rid of the pesticides on the leaves. (P25 CBMS)

I grow some vegetables that don't take up much rook in the garden so we don't have to buy so much vege from the kedai. I prefer vegetables with holes in it as I know it's got not poison on it. (P21 CWMR)

I read one article it said that once a vegetable has a lot of holes it is already very weak, it's a very weak vegetable and when you eat it you don't get a lot of nutrition from it. (P28 CWFR)

7.5.3 Conclusions

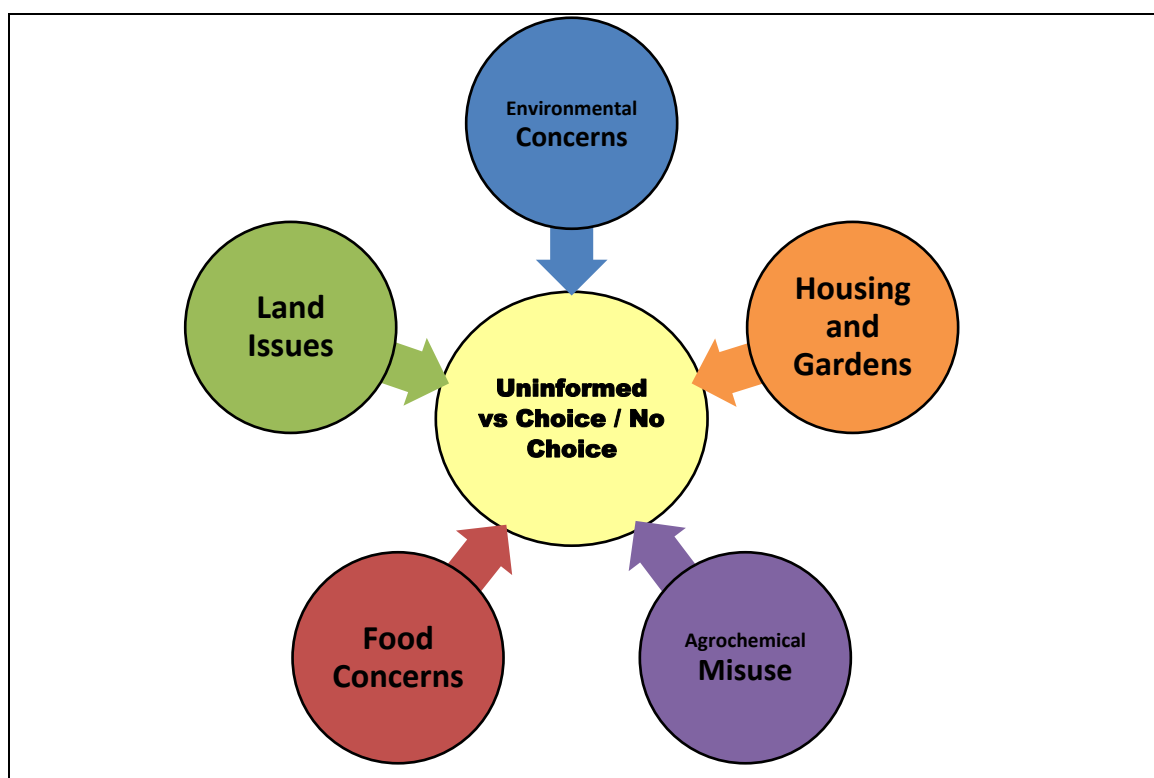


Figure 7.5 Summary of sub-theme 5: uninformed vs choice / no choice

7.5.4 Main Differences seen Between Groups:

- The first degree relatives group, the metabolic syndrome worst scores and the Indigenous voiced the most frustration with land issues that were out of their control.
- The worst metabolic syndrome scores are those who live in the low-cost housing and do not have a garden. Many grow vegetables and fruit on the council verge or on a farm one or more hours outside Miri.
- The Iban ladies made comment about the health of some in their longhouses which prompted further enquiry.
- Indigenous ethnicities used agrochemicals much more than the Malay or the Chinese. Although knowing the agrochemicals are poisonous, many do not cover up when using it because of the sweltering tropical climate.

7.6 Summary of Key Findings in Qualitative Phase Two

7.6.1 Sub-themes identified

Five sub-themes emerged from the interviews and one major theme was identified.

Allegiance Versus Betrayal: Transitional changes in their kampungs of origin had generated torn loyalties in participants of all ethnicities, usually those with land or parents still living there. They endeavoured to maintain ties with their kampung.

Traditional Versus Modern: Participants were conflicted about whether to follow the traditional system of health beliefs and behaviours of their parents and culture, or to mix cultures, or solely to follow the modern system.

Confusion Versus Compromise: Transitioning generations living in the ‘new urban’ found themselves confused about correct health information. They often had to make health compromises in order to look after their extended families and dependants.

Distress Versus Acquiescence: There was evidence of an aging population for whom longevity did not necessarily correlate with a good quality of life. Participants found that by their 50s they were starting to develop a chronic non-communicable disease and at the same time were having to look after sickly aging spouses or parents.

Uninformed Versus Choice / No Choice: Environmental concerns, were predominantly voiced by the Indigenous participants, many who are mourning the loss of their homelands and their health. They feel disempowered and have no self determination.

7.6.2 Major theme identified

Health-seeking anxiety best describes the participants' trepidation concerning their and their family's health conditions. Figure 7.6 illustrates the complex interactions of the sub-themes with the major theme.

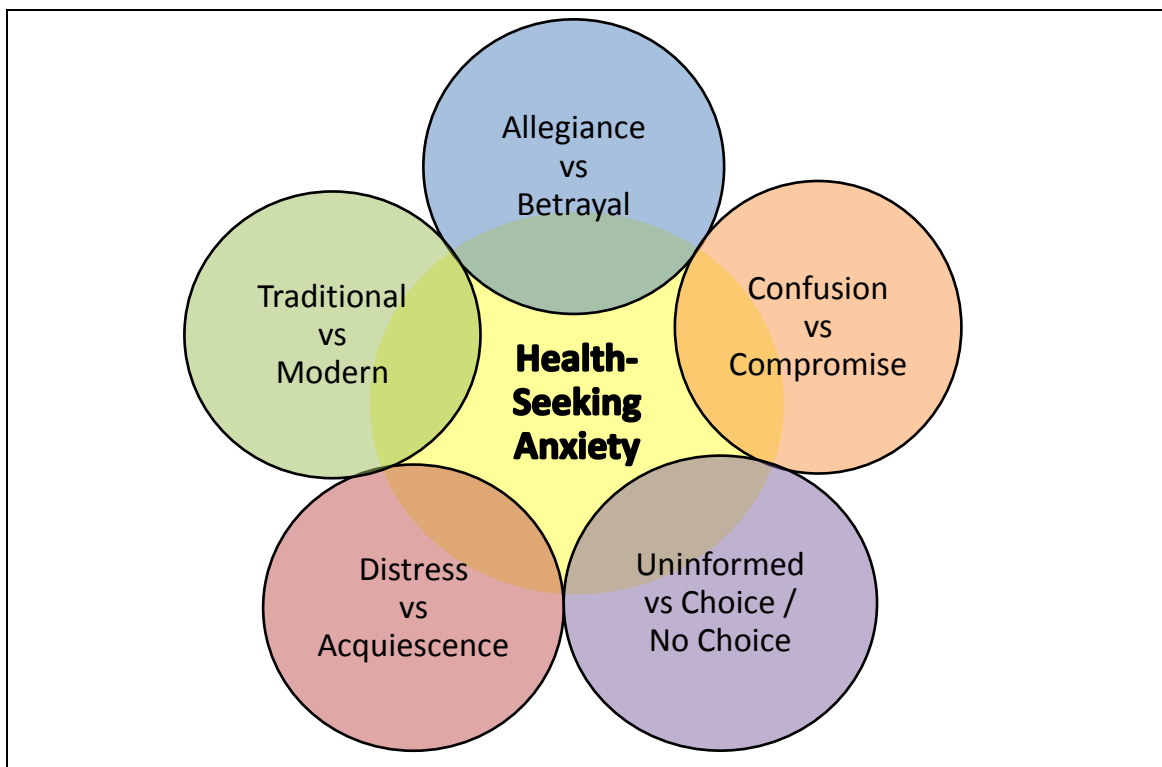


Figure 7.6 Health-seeking anxiety model

To alleviate their anxiety they need to be given accurate information, understanding and support to cope with their health circumstances. People who comprehend their medical condition are more likely to exercise autonomy in its management and this may prevent, or if already present, delay its progress. People who are empowered to take responsibility are more likely to make life-long changes and to be better able to control health-related behaviour. The next chapter discusses the integration of the two data sets and how the qualitative influences the quantitative information.

Chapter 8 Discussion and Integration of the Two Data Sets

Mixed methods is distinctive in that it chooses the most appropriate study design, involving both quantitative and qualitative data gathering and analysis, to conduct a research study (Teddlie & Tashakkori, 2010). The methodology is pre-planned and deliberately integrates the data sets to investigate thoroughly a ‘phenomenon of interest’ (Teddlie & Tashakkori, 2010).

The headings for the quantitative results, found in Chapter 5, guide this discussion and are explained, supported or rejected by the qualitative findings, the headings found in Chapter 7. The quantitative results are presented as tables (*Tables 5.1 –5.6*). The qualitative findings, information and quotes are presented by participant number.

The quantitative discussion outlines the statistically significant differences between the first degree relatives’ and the spousal control group’s socio-demographic characteristics, anthropometric results, behavioural lifestyle factors and socio-economic factors. The participants’ chronic kidney disease biochemical results and the metabolic syndrome clinical and biochemical results are highlighted. The multiple logistic regression analysis identifies a number of factors associated with chronic kidney disease and the metabolic syndrome, and the reported links between metabolic syndrome and early kidney deterioration are discussed.

The qualitative discussion is wrapped around the quantitative discussion in order for the two phases to be truly integrated in accordance with a Mixed Methods design. The thread that ran through all of the participant interviews was that of being in a transitional dilemma that caused emotional conflict and often resulted in a personal identity crisis. A number of sub-themes that emerged from the interviews can be seen to have a direct relationship with and influence on the quantitative results. The interviews revealed the participants’ desire to comprehend their medical condition in order to make rational health decisions, although most portrayed a state of bewilderment and anxiety when asked about their health. The major theme identified, relating to all the sub-themes, is ‘health-seeking anxiety’ concerning their lifestyle and medical circumstances. The chapter concludes with a summary of the outcomes for the quantitative and qualitative objectives.

8.1 Discussion

8.1.1 Beliefs, attitudes, behaviours and barriers

A number of beliefs, attitudes, behaviours and barriers were identified from the Phase Two interviews and will be addressed throughout the discussion as some may influence the health and behaviour of participants. These barriers may be erected by the participants themselves or be hindrances outside their control that are ignored, neglected or imposed on them by others. A review of Canadian haemodialysis centres listed the following barriers to patient-centred care and patient engagement: ‘conflict with other priorities; lack of training and fear of change; the unequal balance of power between patients and providers; physician culture and behaviour; the fee-for-service model of physician compensation; slow implementation of electronic health records; and fear of accountability’ (Bear & Stockie, 2014, p. 5). Many of these can be identified in Miri. Bear and Stockie (2014) noted that there is inadequate consideration given to this area. There is even less consideration given to the first degree relatives and their spouses, who sacrifice so much as providers, carers and supporters of a family member with end-stage renal disease. Phase One of this study determined that the first degree relatives are associated with the metabolic syndrome (*Table 5.6*), which may well be an important factor driving chronic kidney disease in Miri. In this study the NVivo intersections indicated that participants from both the first degree relatives and the spousal control group had the worst scores for chronic kidney disease and metabolic syndrome; many expressed their frustration at the number of obstacles impeding them from maintaining good health.

8.1.2 Allegiance versus betrayal

In this study were three major racial groups, Malay, Chinese and Indigenous, each comprising many minor ethnic groups. For instance, six different Chinese dialects and more than twelve different Indigenous ethnic groups with individual dialects were represented by the participants in Phase One. Of the 32 participants recruited for Phase Two, only two were ‘generation 1’, and thirty were ‘generation 0’ living in Miri. Most came to Miri as young adults. For men the main reasons for moving to Miri were to search for employment, make more money, or because their company transferred them there; many of the women, followed their husbands to Miri or moved because they, or their parent or child, needed medical attention not available in the kampung.

A Malaysian kampung does not have the same connotation as a Western country's village or town where one lives an independent nuclear family lifestyle. In a kampung everyone is known, often are related and have in-laws, live in extended family groups and share equipment and responsibilities, including difficult agricultural work. There is an intrinsic support and survival system. Many participants felt they had betrayed their home, and were torn between their kampung of origin and their assimilation into Miri as their home. On their identity cards they had their kampung of birth registered as 'home' and never changed the address even if they had no intention of returning to live there. In fact, the former Sarawak Director of Immigration Datuk Robert Lian-Saging advised young people who were not born in the kampung but had parents from there, to register the kampung as their home. This was to ensure that links to the community continued for posterity. In addition, unless people have an officially recognised link with the community they have no voice in how the community land is used. This is a contentious issue as those who have moved to cities are often dismissed by politicians, community leaders and persons with ulterior motives as having no authority or right to speak on kampung matters.

The Indigenous Iban are likely to live in a longhouse within one or two hours' drive of Miri. The Indigenous Orang Ulu, however, in an attempt to stay involved in the community and hold onto their kampung land, shuttle between two homes even though the journey is arduous (*Ch.7 P16*), causes financial strain (*Ch.7 P15*) or are very busy with work (*Ch.7 P10*). If a longhouse household (one door) does not light a fire in their fireplace at least once a month, the Iban custom is for a penalty to be paid to the kampung head; if the fire remains unlit for an extended time, the household loses 'membership' in the community (Soda, 2007a). In the Orang Ulu community, for example the Kelabit tribe, persons who have abandoned their household and land must return it to the kampung land committee so it can be utilised by someone resident in the community in need of land to feed his family members (R. D. Mattu, 2014).

Urban centres have been the focus of development in Sarawak and rural communities have been sidelined, as demonstrated by studies showing the economic benefits small-holder farmers receive when good roads are connected to large towns and cities (Windle & Cramb, 1997). Timber roads, the basis of road transport in rural areas, are not maintained once the timber is extracted, and become impassable. In the guise of

development, oil palm plantation conglomerates have replaced timber companies, often taking over 'idle' Native Customary Rights land and not involving the local communities in executive decision making (Cooke, 2002). These land grabs often go unchallenged in an expensive, protected legal system whereby Dayaks have to prove the land was theirs prior to 1958 (Cramb, 2007b).

There are approximately 2.3 million documented foreign workers and 4 million undocumented foreign workers in Malaysia, and Home Minister Datuk Seri Ahmad Zahid Hamidi has announced that 1.5 million more will be brought into Malaysia to meet demands in oil palm plantations in Sabah and Sarawak (Teh, 2015). Isolation from lack of adequate, safe roads means that people in remote areas cannot get their goods and agricultural produce, including rice, to market. It takes 16 hours on dangerous timber roads over mountainous terrain to drive the 310 kilometers from Bario to Miri. Inadequate rural development, cheap foreign labour and not wishing to work hard for large oil palm companies on their own land (Cramb, 2007a) has driven young Dayaks to the cities for work. This modern-day exodus of Indigenous people has created a new order whereby rural-to-urban migrants endeavour to retain their membership of both kampung and city life (Soda, 2007b). The study by Soda (2007b) is based on the Iban of the Rejang River and Sibuh, but this current study too supports this observation, true of all Indigenous participants from the Baram River and tributaries and Miri. A new concept of 'double belonging' has developed, whereby membership of both urban and rural communities (Soda, 2007b) can be generalised to all Indigenous ethnicities of Sarawak and possibly also Sabah.

The Malay and Chinese participants in this study whose families own, or once owned, land in their kampung or town of origin, or whose parent or parents still live there, also hold a strong attachment, do not sever their community ties, and return as often as they are able. All the participants in this study held their ethnic and religious ceremonies in deep respect and devotion, and many endeavoured to return to their village of origin for celebrations. Miri has many active Malay, Chinese and Indigenous ethnic associations, set up to support clans who have relocated to the city from a common geographical area and share mutual dialects and background. These associations provide an avenue for those dislocated from their kampung to still participate in community discussion and activities. They are also used as a political means for two-way interaction with

government officials. Government funds are channelled through these associations for community development, often apparently as a reward for voting loyalty to the ruling party (Soda, 2007a).

The perception is that life is easier living in the city:

Kampung is very difficult to get money ... Life is easier in town if you have a job. (Ch.7 P1).

Physically this may be true, but psychosocially it takes a toll, especially on those who are unable to return to their kampungs. A cross-sectional survey of 1,000 rural-to-urban migrants in Beijing found that psychological distress negatively influenced their quality of life (Wang, Li, Stanton, & Fang, 2010). The survey found that pre-migration preparation was important as migrants were better able to cope, had real expectations, better quality of life and good mental health (Wang et al, 2010). Some participants in this study expressed regret, and some felt they would betray their parents and community if they did not go back regularly (Ch.7 P15). A longitudinal study, the Indonesian Family Life Survey, compared urban migrants' health with that of those who remained in the rural village and found that rural-to-urban migration had an economic gain but no physical health benefits and a high psychological cost in stress and depression (Lu, 2010). Large amounts of urban migrants' earnings were remitted to their villages (Lu, 2010); in this study also many participants admitted to this, like one Malay migrant:

I am now able to sponsor and support my family with money. (Ch.7 P3).

Both males and females were unanimous in wanting to have their children attend better schools than were available in their kampung:

Coming to live in town means I can pay for my children to go on in school. If my children don't have education they just stay in kampung at home on farm. (Ch.7 P2)

Their connection to the land is so strong that many Indigenous participants mentioned they planned to return to their kampung when they retired and their children were independent. A number who had already retired, however, were unable to return

because they no longer had kampung land (*Ch.7 P20; Ch.7 P3*), were caretakers of sick relatives (*Ch.7 P6, P11; Ch.7 P9*), had children still living with them (*Ch.7 P5*), lived with their children to help with the grandchildren (*Ch.7 P4*) or were ill themselves (*Ch.7 P22*). One participant expressed the dilemma facing him:

I don't go back with them [family] as [I am] working. When my father passes on I will have to look after his land for him. I seldom go back to the kampung.
(*Ch.7 P10*)

The regular two-way flow of Miri city-dwellers returning to their kampung or town of origin keeps open marriage opportunities with those still residing there; in time these new partners and family are likely to migrate to urban areas. Inter-marriage with other ethnic groups is also common in Sarawak, and the desire to spend money on the kampung and to return there every holiday may not be fully understood by the spouse and their urban-raised children. This creates further conflict and the sense of a two-way betrayal: to the family in the kampung, and to the urban family.

8.1.3 Socio-demographic characteristics

The quantitative results of the socio-demographics of participants were statistically similar (*Table 5.1*) so it can be surmised that the socio-demographic profiles for both the first degree relative cases and the spousal control group are alike. Altman (1991) remarked that groups being compared should be similar apart from the study concern. The introduction of bias and over-matching, however, also needs to be considered and addressed (Wacholder, Silverman, McLaughlin, & Mandel, 1992). In this study a spousal control group excluding the spouse was recruited, the rationale being that these often share a similar ethnicity, culture and environment as the case group without having the genetic component. The first degree relatives of those with end-stage renal disease and on dialysis were matched with a non-genetic member of their in-law family. The participants all had knowledge of the difficulties experienced by their family or in-law member having dialysis and thus were highly motivated to participate in this study.

A number of studies have investigated the link between end-stage renal disease patients and their first degree relatives. One large case-control study in the United States

concluded that the risk of developing end-stage renal disease increased within families (Lei, Perneger, Klag, Whelton, & Coresh, 1998). Following a population-based sample of incident end-stage renal disease cases in the United States, Freedman et al. (2005) cautioned physicians that there is a marked familial aggregation of end-stage renal disease in patients with chronic kidney disease. Another American population study found that a familial component for chronic kidney disease or end-stage renal disease was not significant amongst second degree relatives (Goldfarb-Rumyantzev et al., 2006), although a cross-sectional study in Taiwan found that first and second degree relatives and their spouses had a significantly higher prevalence of chronic kidney disease (albuminuria or low estimated glomerular filtration rate) than two sex- and age-matched controls (Tsai, Chen, & Hwang, 2010), suggesting that in households where there is a person with end-stage renal disease, shared environmental and health behaviours may be a causal risk factor in non-genetic relatives developing chronic kidney disease. This is reflected in the current study, where the proportion of chronic kidney disease was similar in both cases and controls (*Table 5.4*). The socio-demographic results show similarities within all categories, and no factor is significantly different between the first degree relatives and the spousal control group (*Table 5.1*).

A recent study of 1,062 first degree relatives and 450 spouses of end-stage renal disease patients on dialysis in four Chinese cities, sex- and age-matched with general population controls from Beijing found that the first degree relatives had a higher prevalence of albuminuria (X. Kong, Liu, Zuo, Yuan, Li, Li et al., 2013). This was also found in the Taiwan study (Tsai et al., 2010) and in the Kidney Early Evaluation Program (KEEP) study (Brown et al., 2003). This current study also shows first degree relatives to have a high albumin-to-creatinine ratio compared with the spousal control group ($p=0.030$), but not of the estimated glomerular filtration rate or chronic kidney disease (*Table 5.4*). It has been suggested that findings like this may be due to familial susceptibility to hypertension, type 2 diabetes and other known renal risk factors of albuminuria as well as to shared environmental factors (Lei et al., 1998; X. Kong et al., 2013). Familial clustering through metabolic disorders may be applicable to the Miri first degree relatives as well, but this study design cannot prove a causal link, and can only suggest a correlation. Microalbuminuria is not included in the metabolic syndrome assessment, and more research in this area is needed.

In the Phase One questionnaire, the participants gave a self-reported family history and a personal medical history (*Table 5.2*). There were limitations to this as many did not know what diseases their parents and grandparents had had; nor did they know what medications their parents and grandparents were taking and whether they were compliant. The family history (*Table 5.2*), when compared to that of the spousal control group (34.8%), revealed that a significant number of first degree relatives (52.6%) had a family history of diabetes ($p=0.007$) (*Table 5.2*). Although more than half of the first degree relatives and a third of the spousal control group knew they had a family history of diabetes, 21.5% of the first degree relatives and 16.3% of the spousal control group had not been tested themselves and were ‘not sure’ if they had diabetes (*Table 5.2*). There was no statistically significant difference between the first degree relatives and the spousal control group for a family history of hypertension (*Table 5.2*) or for a self-reported personal high blood pressure (*Table 5.4*). It should be noted that 75.6% of the first degree relatives and 64.4% of the spousal control group acknowledged their parents had hypertension, yet 15.6% of the relatives and 17.0% of the control group were ‘not sure’ if they had it themselves (*Table 5.2*). This study shows the first degree relatives (43%) have a significantly greater probability of having a family history of high cholesterol ($p=0.014$) compared with the spousal control group (33.3%) (*Table 5.2*). The multiple logistic regression analysis of factors associated with metabolic syndrome found that compared with those without a family history of cardiovascular disease, those with a family history of the disease were 2.65 times more likely to have metabolic syndrome (*Table 5.6*). To have a family history for any chronic disease increases the first degree relatives’ risk of inheriting that disease (Yoon, Scheuner, & Khoury, 2003) so knowing the family’s medical history can forewarn an individual to take measures. The issue of not knowing, or not wanting to know, one’s risk of a chronic non-communicable disease emerged from the qualitative interviews and will be discussed later in this chapter.

The multiple logistic regression to determine factors associated with the metabolic syndrome (*Table 5.6*) showed that the first degree relatives were 2.41 times more likely to have metabolic syndrome than the spousal control group (*Table 5.6*). McClellan et al. (2007), in a cross-sectional study of participants in the Stroke (REGARDS) Renal Cohort Study, found that with an increasing number of components for the metabolic syndrome there was a strong positive trend for having a family history of end-stage

renal disease. This study concurs with these conclusions, as the socio-demographic and socio-economic factors of both groups were similar, with no differences for chronic kidney disease. It may be deduced that there is a genetic factor involving metabolic disturbances as the metabolic syndrome was greater among the first degree relatives.

Age is a predisposing factor for many chronic non-communicable diseases, and this was reflected in the multiple logistic regression analysis. Age was found to be significant for both chronic kidney disease and the metabolic syndrome. It was also found to be a significant factor of chronic kidney disease: with every year older, having chronic kidney disease increased by almost 5% (*Table 5.5*). As the combined mean age of all participants in this study was 42.94 ± 14 years (*Table 5.1*), the development of kidney disease and the worsening of chronic kidney disease may become greater with age (CDCP, 2010). Although not entirely understood, both aging and having chronic kidney disease independently increase the risk of death from cardiovascular disease (Parfrey & Foley, 1999). For the multiple logistic regression analysis of the metabolic syndrome, the odds of having metabolic syndrome increased by between 0.5% and 4.9% for every one year increase in age (*Table 5.6*); thus the metabolic syndrome and its associated chronic non-communicable disease comorbidities are likely to deteriorate further as susceptible individuals grow older.

8.1.4 Distress versus acquiescence

In the qualitative interviews, participants revealed degrees of adjustment depending upon their age, length of time living in Miri, family life, work stage or retirement, and the condition of their health. In Sarawak 'retirement' in the Western sense is virtually non-existent. There are very few old-age homes and no retirement villages in Sarawak. In Miri there is one private Chinese old-age home, for those without family. All ethnicities look after their older folks in an extended household; if they are Indigenous with family still living in the longhouse, the aged prefer to live the remainder of their life there with their friends. For all ethnicities it is almost inconceivable, and considered shameful, to allow and pay for, their parents to live in an aged-care facility; yet many cannot cope with their family situation. The participants in this study highlighted the impact on the family when their aged parents were on dialysis or had an advanced chronic non-communicable disease or cardiovascular disease:

Now my mum-in-law live with us because she has high blood pressure and kidney problem, and she's been on dialysis ... Very hard, my wife is upset about her mum. Mum-in-law cannot go home anymore to longhouse as too far and no dialysis there. (Ch.7 P9)

This problem will only get worse as the population ages.

Most participants had been living in Miri for many years when interviewed. The exception were older Indigenous folk who had only recently joined their children in Miri: because their spouse died, their land had been sold, they were looking after their grandchildren while their children worked, or they were too old to live on their own in the kampung. The older Indigenous participants were obviously homesick for their kampung, lonely after living in an atmosphere as vibrant as a longhouse, and out of their 'comfort zone' in town (*Ch.7 P6; P7*). People in the kampung are grateful for modern appliances and if there is electricity from a micro-hydro or solar panel they use washing machines, rice cookers and even have hot water to shower in. These facilities are usually supplied by their children who work in the city. The younger generations appreciate the comforts of modern material items, fashion items and nice vehicles and houses. Sadly the infrastructure-building days of the Miri oil industry are over, and during the 1990 recession years many who had a car and a house loan, were laid off. There was a reverse migration to the kampungs as there was no work to be found in Miri. Suicides took place when older folk who considered this a failure taunted their children for returning to the villages. A second wave of rural to urban migration began again in the early 2000s and has lasted to the present, as off-shore platform contract jobs become available and young Indigenous people began to earn large wages again. There were also plenty of timber camp and oil palm plantation managerial jobs available for those who enjoyed working in the rural areas and the interior.

Most participants were somewhere along the age continuum between recognition and acceptance of their situation. When the participants first came to Miri to live there was an adjustment phase during which they found a place to live, took on work, found schools and established contacts (*Ch.7 P6; P1; P7*). The middle-aged participants were more settled, but voiced anxiety about their busy lives and having to consider measures to avoid a chronic non-communicable disease from worsening (*Ch.7 P18; P10; P3*), especially when their work was affected:

I was sent back off-shore last week for high blood pressure and I cannot go off-shore again till it is lower and stable. (Ch.7 P31).

Being in their fifties for many coincided with being diagnosed with a chronic non-communicable disease and also with having to care for aging, sometimes sickly, spouses and parents. Participants expressed distress when their parents or spouse commenced dialysis (*Ch.7 P14; P9; P27*) and they had to become both providers and carers. Some of the over-60 participants clung to their independence (*Ch.7 P15; P26*) while others were frustrated with their health and with having to live with their children (*Ch.7 P15*) although most accepted their situation, and turned their energies to improving their diet and starting an exercise program—although some admitted to laziness (*Ch.7 P21*). Sometimes this happened after a health scare, as for the gentleman who had a heart operation (*Ch.7 P26*). The older age group mentioned annoyance that their adult children did not take health and lifestyle advice from them (*Ch.7 P21; P26*), but most expressed a sense of resignation rather than passion or anger about their situation.

In the quantitative results of this study, ethnicity was found to be positively associated with chronic kidney disease but not with the metabolic syndrome. Compared with the Chinese people, having chronic kidney disease was 5.67 times higher for Malay people and 2.35 times higher for Indigenous people (*Table 5.5*). In a multi-ethnic national cross-sectional population-based survey ($n=17,211$) it was found that Indigenous Sarawakians have a higher prevalence of metabolic syndrome at a younger age than other ethnic groups (S. Rampal, Mahadeva, Guallar, Bulgiba, Mohamed, Rahmat et al., 2004). The current study reflects this anomaly for Malay and Indigenous ethnicities (*Table 5.5*) and forecasts that if obesity, metabolic syndrome and type 2 diabetes develops before middle age, individuals will be at high risk of cardiovascular disease, chronic kidney disease and consequently end-stage renal disease in their retirement years. Disturbingly, one third of those in this study were already classified as having metabolic syndrome (*Table 5.4; Table 5.5*), meaning they had at least three metabolic abnormalities.

Freedman et al. (2005) has stated that darker coloured ethnicities show more susceptibility to renal disease, although other studies show no such relationship: for example, a case-control study from Brazil finds a familial risk for first degree relatives

of end-stage renal disease patients but no association with ethnicity (Madeira, Santos, Santos, daSilva, MacIntyre Innocenzi & Santoro-Lopes, 2002). An article from Johore Bahru, Peninsular Malaysia, found that Malays have a much higher incidence of end-stage renal disease than Chinese or Indian ethnicities (Liu & Hooi, 2007); however, a descriptive study from Penang found similar percentages of end-stage renal disease patients for Malays (47.0%) and Chinese (48.7%) (Shaza, Rozina, Izham, & Azhar, 2005). The majority of Malaysia's Indian community resides in West Malaysia and only one person of Indian heritage was on dialysis in Miri at the time of this study (MRC, 2010).

8.1.5 Anthropometric results

The Westernisation of Asian-Pacific countries including Malaysia, has brought with it the escalation of obesity and obesity-related diseases (comorbidities for the metabolic syndrome) has escalated. Of peculiar concern is that these comorbidities occur at a much lower body mass index than for European ethnicities (WHO-WPR, 2007). This has implications for Miri, as it means that the onset of chronic non-communicable diseases may occur before the individual appears to be excessively overweight or obese. A New Zealand study has found ethnic differences for body fat, muscularity, bone mass and leg length between European, Maori, Pacific Island and Asian Indian adults (Rush, Freitas, & Plank, 2009). Rush et al. (2009) found that Asian Indian people had more abdominal fat but less skeletal muscle and lower bone density. This means that two people with the same body size may have different proportions of fat, muscle and bone. It is not known what proportional differences Malaysian Indian, Malay, Chinese and Indigenous ethnicities have, but if they carry a normal-looking body size they may not be offered tests for type 2 diabetes and hypertension by the very busy poliklinik doctors. This may be one reason why a number of participants in this study, who did not look over-weight to a Western eye, had advanced type 2 diabetes and/or hypertension but did not know it.

In the anthropometric measurement for metabolic syndrome (*Table 5.3*) the female groups were similar but the male first degree relatives had a significantly larger waist circumference than the men in the spousal control group ($p=0.002$) (*Table 5.3*), and there was a greater percentage of obesity and morbid obesity among the male first degree relatives. They had a statistically significant greater weight ($p<0.001$) and

body mass index ($p < 0.001$) (Table 5.3) than the spousal control group. Of concern is that in both groups, most of the men and women participants were above the normal cut-off points for abdominal obesity (90 cm for Asian men and 80 cm for Asian women) (Table 5.3). These three factors, waist circumference, weight and body mass index, may suggest an increased likelihood for the development of cardiovascular disease in the first degree relatives if they also have abdominal obesity. It was non-significant however, when all participants were combined in the multiple logistic regression analysis for metabolic syndrome.

8.1.6 Chronic non-communicable diseases and food transition

When they meet people for the first time, Sarawakians instinctively know their general ethnic family by their facial features, body proportions and vocal cadences. They can identify whether people are Malay or Melanau, which Chinese clan they belong to, whether Indigenous people are from highland, lowland, interior or coastal areas. There are variations between ethnic groups in their *adat* (communal laws) as well. Native customary land includes uncultivated community rainforest, vital for the hunting and gathering of food (Bulan & Locklear, 2008), but the *adat* controlling these areas can differ. For example, although both the Iban and the Kelabit *adat* dictate that all land is communal, the Iban practice of slash and burn allows individuals to cultivate land they clear from virgin jungle (Bulan & Locklear, 2008), while among the Kelabit native land is distributed to community members by a *kampung* land committee, to ensure that all families have enough to grow fruit trees, rice and vegetables, and rear domestic animals (R. D. Mattu, 2012). To supplement their subsistence living, many Indigenous people bring the wild meats, fruits, nuts and herbs they have sourced from the rainforest and the excess food they have grown on their farms to the town markets to sell (Soda, 2007b). The dilemma many Borneo Indigenous tribes people face today involves inadequate infrastructure in remote areas, such as efficient transportation of products into and out of rural and remote areas. During the last general election the government made marketing of rural products a priority, but improvements have yet to be seen and many rural folk continue to move into towns because they cannot transport their products to market. There are also decisions to address such as whether to convert to modern farming techniques, often at the expense of ancient methods; for example, with rice production decisions have to be made about whether to continue using buffalo or to

mechanise, which requires using agrochemicals. Should they open their land for agricultural and pastoral development, or sell their land to large plantation corporations? With a better communication and transport infrastructure, modern work opportunities including industries that are eco-friendly, sustainable, profitable and micro-hydro electricity, perhaps more Dayaks would stay in the villages and make a good living, and be healthier (R. D. Mattu, 2012).

Borneo is a very rugged island, and physical barriers and weather play a part in rural people being unable to see a doctor, especially those living in remote interior areas. The Flying Doctor service is irregular and usually only in a crisis. The plight of rural women in labour is well documented (Jegasothy, 2002), and emergency situations often end in tragedy. Rural people do not have the money or time to travel to Miri for hypertension or diabetes medication especially if they feel fine. One lady knew she had hypertension and diabetes that needed medication, but was told to see the doctor at the Desa Klinik near her longhouse. There was no doctor located there (Ch.7 P23). The poliklinik is subsidised by the government, as this lady noted:

20 years already got tablets from the doctor ... from the poliklinik so it's not so expensive. (Ch.7 P1).

The long travel time to Miri and a long waiting time at the poliklinik (Ch.7 P22) mean that many people do not bother to go. Private doctors' fees and pharmacy medication are too expensive for poor people (Ch.7 P1), especially for women who have lost a wage-earning partner (Ch.7 P21; P29).

There are also establishment barriers. Government clinics and NGO dialysis centres are understaffed and their doctors, medics and nurses overworked, but generally they are efficient and committed to providing good patient care. However, there were a number of complaints from participants regarding the service or advice they had been given. Participants who were less educated and poorer were often treated in a condescending manner by medical staff:

Sometimes I cannot stand the pain, but don't want to see a doctor so just tough it out because they only say its wind or gastric problem. I asked for investigation but they said no need just cut down on coffee and tea. (Ch.7 P15)

One lady never goes to the clinic to see a doctor because

If I go to see a doctor they only give me vitamins, so no need go-lah. (Ch. 7 P5)

Some of the participants in this study felt patronised when ignored and their medical problems were not explained to them:

The doctors and nurses at the dialysis centre never discussed or advised us our family about kidney disease when my sister was there and I think they should support us more. (Ch.7 P20)

All haemodialysis centres have a duty of care to their patients, but it should not be difficult for the centres to extend support in the form of advice to those who help staff in the dialysis hall to tend to their relatives with end-stage renal disease.

A common complaint from those who attend the poliklinik was that every time they went they saw a different doctor (*Ch.7 P5; P4*), and because there was no relationship with the doctor it made them feel awkward. A number of first degree relatives noted that, although their parent was on dialysis, this study was the only time they had had their kidneys or blood glucose tested (*Ch.7 P14; P18*).

For a variety of reasons many Indigenous people are transferring from rural living to an urban lifestyle (Sarawak Government, 2011). In fact, all people who have relocated and set up family life in Miri have had to adjust in many aspects of their lives, including having to modify the kinds of food they eat. A number of Orang Ulu mentioned that they return to their kampung to harvest their rice and to collect fruits and vegetables from their farms (*Ch.7 P4; P1*), and a number of Indigenous, Malay and Chinese noted that they have gardens outside Miri to grow food (*Ch.7 P2; P5; P9*). Of particular interest were those who commented on how their food had changed over the last generation, a Malay man (*Ch.7 P3*), a Malay woman (*Ch.7 P17*), an Indigenous man (*Ch.7 P5*), an Indigenous woman (*Ch.7 P15*), a Chinese man (*Ch.7 P21*), and a Chinese woman (*Ch.7 P28*).

A food transition occurs as people exchange home-grown farm and rainforest foods for urban fast-fried foods. Many participants described how their food composition and intake had changed since living in Miri, because they were faced with heavy offshore

food (*Ch.7 P4*), worked in the hospitality industry (*Ch.7 P9*), often travelled (*Ch.7 P27*), cooked and looked after others (*Ch.7 P5; P15*), dieted (*Ch.7 P32*), changed diet in response to a medical condition (*Ch.7 P21; P28*), ate out in the market too much (*Ch.7 P27; P25*), attended too many functions and celebrations (*Ch.7 P26; P32*) and enjoyed fried fast foods (*Ch.7 P14; P12*).

Rapid, unplanned urbanisation and changing lifestyles has led people to consume processed foods containing high-energy fats, sugars, and salt, and to have inadequate servings of vegetables and fruits (WHO, 2013b). Lukito and Wahlqvist (2006) postulate that with regard to food transition in a different environment, it takes a number of factors, including time, before body composition disorders become manifest in those who have migrated compared to those of the same ethnic group remaining in their geographical origins. This may explain this study's quantitative results. This study identified those in low-cost housing as having the greatest association with the metabolic syndrome (*Table 5.6*). Those who had come from country areas usually lived a number of years in the lower socio-economic housing areas (Huu, Abd Latif, & Nasir, 1999) until they became established. The quantitative results in this study agree with this: by the time the participants moved from self-build or shanty areas to low-cost housing, their diet and food had transitioned from kampong to city style and they might also have become obese.

Lipoeto, Geok Lin & Angeles-Agdeppa (2004) commented that in Malaysia, although traditional food patterns remain the same, the composition of recipes has changed with the addition of more animal products, palm oil and sugar, and that this is probably contributing to increasing obesity rates. Interestingly, he concludes that in Indonesia, the Philippines and Malaysia, rapid food transition and obesity are more due to increasing availability, variety and the purchasing power of people than a shift to Western fast food preferences. This is supported in the qualitative findings of this study: many participants said they preferred kampong food or spicy local food (*Ch.7 P17; P16; P5; P4*) rather than fried fast foods.

It is now established that urbanisation and an improved economic outlook in developing countries corresponds with increasing obesity and metabolic syndrome (Misra & Khurana, 2008). One can speculate from this current study that by the time people living in Miri reach middle age, they have a stable job, are upgrading their

home, have more disposable income, have an established social life which includes eating out more, but are busy working often offshore or travelling, don't exercise as much as they used to or should, and have developed a chronic non-communicable disease.

8.1.7 Chronic kidney disease biochemical results

To assess the status of chronic kidney disease in Phase One, all participants had their urine and blood taken and their estimated glomerular filtration rate (*Table 3.3*) and ACR (*Table 3.4*) calculated using the formulae described in Chapter 3, then their chronic kidney disease (*Table 3.5*) staging calculated (as described in Chapter 3.3.3). chronic kidney disease was determined by taking into account the ACR and the eGFR results; and the staging followed Kidney Health Australia (KHA-CARI, 2006) (KHA, 2007) and KDIGO (2012) recommendations. Many of those recruited, in particular the first degree relatives, mentioned that they had never been tested for any chronic non-communicable diseases, for chronic kidney disease, or for microalbuminuria even though their relatives were undergoing haemodialysis.

The glomerular filtration rate / estimated glomerular filtration rate was calculated to determine kidney insufficiency. Initially results derived from four different methods, namely 4-variable MDRD eGFR, CKD-epi eGFR, Cockcroft-Gault Creatinine Clearance and rMDRD '175', were calculated and compared. Those participants who had a true normal kidney function were determined so they could be considered for selection for Phase Two, separate from those who had some kidney function deterioration but were still above $>60 \text{ mL/min/1.73m}^2$. The rMDRD '175' formula (Mathew et al., 2007) had the greatest number separation for stages 1 and 2, 4 and 5 chronic kidney disease; therefore this formula was chosen. When reviewed against other studies in the region (Mathew, Corso, Ludlow, et al., 2010; Mau, West, Shara et al., 2007; O'Dea, 2005; Tsai et al., 2010) this formula was deemed best suited to the Miri population group and the purposes of this study, especially as it included Chinese and Indigenous ethnicities. For the chronic kidney disease biochemical results (*Table 5.4*), a present or absent one cut-off point was used at $>/<60 \text{ mL/min/1.73m}^2$ to screen participants for any association with chronic kidney disease. Comparing the first degree relatives to the spousal control group found no significant difference in glomerular filtration rate or chronic kidney disease (*Table 5.4*).

The urine ACR was used to calculate kidney damage (KHA-CARI, 2006) in the participants. Studies show that inadequately controlled diabetes mellitus and hypertension exacerbate chronic kidney disease and increase the risk of progression to end-stage renal disease (CDCP, 2010). In a study from Kuching, Sarawak that considers a similar demographic profile as this one, 48% of the diabetic patients had proteinuria or microalbuminuria and were at risk of developing diabetic nephropathy (Wong, 2005). Investigators for the Microalbuminuria Prevalence (MAP) study in Malaysia have recommended that all hypertensive type 2 diabetics be routinely screened for microalbuminuria to safeguard against cardiovascular disease complications and retard progression to end-stage renal disease due to diabetic nephropathy (N. Kong, Chia, Khalid, Juwita, Samiah Yasmin, Yap et al., 2006); however, this is not regularly practised. Freedman et al. (2005) have advised that screening the first degree relatives of end-stage renal disease patients will help pick up clinically silent proteinuria or chronic kidney disease. In this study there was a statistically significant difference between the first degree relatives and the spousal control group in the ACRn results (*Table 5.4*). The first degree relatives were more likely to have microalbuminuria than the spousal control group, and this reinforces the need for the first degree relatives to be screened for microalbuminuria, especially if they have type 2 diabetes. If these relatives are only being screened for macroalbuminuria using a dipstick, valuable time may be wasted instead of delaying their progress to end-stage renal disease. The ACRn can also be used as an indicator or marker of treatment adequacy and patient compliance. In a study including different ethnicities in the USA found that a single random ACRn measurement of men with higher muscle mass and in certain ethnic groups may underestimate microalbuminuria (Mattix, Hsu, Shaykevich & Curhan et al., 2002). Many Indigenous people in this study were physically active in their villages before they moved to Miri and many now work in manual jobs, so Mattix et al.'s finding may also be valid for this study, and suggests a direction for future research.

There were a number of possible risk factors leading to the development of chronic kidney disease. It was projected that the first degree relatives would have a greater association with developing chronic kidney disease (less than $<60 \text{ mL/min/1.73m}^2$) (*Table 5.4*) than the spousal control group. The results, however, show that both groups have a similar low percentage. As the mean age of participants was the early 40s (*Table*

5.1), the participants may not have been old enough for chronic kidney disease to have progressed to stages 3, 4 or 5. It would be useful to follow up these participants in ten years' time. As the groups are not statistically significantly different to each other, the question is whether environmental factors are coming into play. Death may also play a part for the over-50s and over-60s. For adults with chronic kidney disease, death from cardiovascular disease is actually more common than reaching end-stage renal disease (Alebiosu & Ayodele, 2005) and more prevalent than in the general population (Rashidi, Ghanbarian, Azizi & Adler, 2007b), creating much debate on whether the causation for cardiovascular disease is chronic kidney disease or its sequelae, especially type 2 diabetes and hypertension.

Proceeding to the multiple logistic regression analysis to determine if there were any factors contributing to a predisposition for chronic kidney disease, it was determined that neither group was associated as a risk factor for chronic kidney disease (*Table 5.5*). Of the four factors associated with chronic kidney disease, the first three, age, ethnicity and alcohol, which was suggestive of being protective (*Table 5.5*), have already been discussed. The fourth factor, metabolic syndrome, was identified among this population group. There are also non-diabetic factors leading to the development of chronic kidney disease and end-stage renal disease in tropical countries (Almaguer et al., 2014; Weeraratna, 2012).

8.1.8 Uninformed versus choice / no choice

Each Dayak ethnic community of Sarawak and Sabah follows its respective adat, born out of their tribal history, cultural and religious traditions (Bulan & Locklear, 2008). These customs are the basis of 'territorial domains' which connect the tribes people to their ancestral lands (Bulan & Locklear, 2008). If an Orang Ulu family moves to another location it must be with permission of the receiving kampung, who gives them an area to cultivate (Talla, 1979). Indigenous land is traditionally not allowed to be sold but is inherited by subsequent generations as long as members of that family reside in the kampung (R. D. Mattu, 2011). However, younger generations now have begun to petition for permission to sell their family land, and this is being supported by the new chief minister of Sarawak, Tan Sri Adenan Satem (Bernama, 2014), much to the dismay of tribal elders. When this occurs there is no returning to the kampung for the petitioners, and their migration to town becomes irrevocable.

A number of seemingly irreversible predicaments face the Baram population, some by choice and some by situations forced upon them. There are three reasons for the displacement of peoples in the Baram area. First is the declaration of forest reserves in the name of conservation, only to have timber concessions for some of these areas awarded to timber companies. Second is the building and impoundment of twelve hydroelectric dams to be developed along the Baram River by 2020. Between 25,000 and 30,000 Indigenous people are expected to lose their ancestral lands when the next phase of the Baram dams is undertaken. Even among the small sample of people in Phase Two of this study, a number of the Orang Ulu declared their anguish over their families' impending displacement. Some have already had their lands flooded (*Ch.7 P6*) and others are from kampungs that will be displaced when new dams commence impoundment (*Ch.7 P16; P5*). Third, the rapid advancement of vast monoculture oil palm estates is likely to escalate rural migration to Miri and other towns in Sarawak. Temporary occupation licences on native customary lands are awarded by the State Government Land and Survey Department to these companies (Sarawak Government, 1996; State Attorney-Generals Chambers, 1999; Fong, 2001). In the past few years this has caused clashes between longhouses and company workers. Villagers who take the court route find it frustrating:

The oil palm company ... my mum and dad were forced off their traditional land ... we took them to high court, 4 years already. The oil palm company keeps postponing it, every time go to high-court appeal. So many delays so much money to pay the lawyer. (Ch.7 P1)

In the past among Indigenous tribes of Sarawak, headhunting was often associated with the advancement of tribal territorial claims (Ritchie & Langgu, 2009, p 35) and the protection of ancestral land, but now these people are disenfranchised (Colchester, 1993) because their native customary land is not recognised. One Malay participant (*Ch.7 P3*) and one Melanau participant (*Ch.7 P15*) also had their family lands annexed by the Land and Survey Department and given to large companies to develop. The qualitative interview transcripts and the NVivo intersections reveal that the majority of those disenfranchised in Phase Two were the first degree relatives or those who had the worst chronic kidney disease and metabolic syndrome scores.

Comments by some Indigenous Iban ladies in Phase Two prompted a deeper exploration of agrochemicals in the interviews. This is in keeping with the methods of qualitative semi-structured interviews, which are flexible and allow questions to be adjusted as they progress to better uncover the living experiences of the participants (Saks & Allsop, 2013). These ladies spoke of an apparently large number of people from the longhouses in their area suffering from kidney disease and on dialysis (*Ch.7 P22; P23*); another participant mentioned that a doctor suggested her kidney problem could have been from the spray she had been using (*Ch.7 P5*). One lady noted,

I don't know why ... my brothers get kidney failure. We are all skinny and have worked hard on the farm all our lives. (Ch.7 P22).

Agrochemicals used in tropical developing countries have been linked with chronic renal failure. Called chronic kidney disease of Unknown Aetiology in Sri Lanka, it is associated with not having diabetes, heavy metals, fertilisers and pesticides that promote the growth of blue-green algae toxins (Weeraratna, 2012). and drinking contaminated water and engaging in harmful toxic agrochemical practices, such as not wearing protective clothing, are implicated (Wimalawansa & Wimalawansa, 2014). These detrimental factors have also been identified in Central America named Mesoamerican nephropathy; it is most often seen in young male agricultural workers (Almaguer et al., 2014; Trabanino et al., 2002).

Three quarters of the participants interviewed in Phase Two used multiple chemicals on a regular basis. The NVivo intersections showed that those participants who had the best chronic kidney disease scores knew how to handle agrochemicals properly (*Ch.7 P22; P31*), followed safety precautions (*Ch.7 P18; P24*), or hired gardeners to use the agrochemicals (*Ch.7 P32*). A number of negative findings arising from the interviews, however, need to be followed up with more research so they may be properly addressed.

Indigenous Iban, Kenyah and Kayan are the ethnic groups who predominantly work in the agriculture and plantation sectors and who were most often exposed to agrochemicals (S. Mattu, Lewis, & Soares, 2014; 'The Different Types of Pesticides Available', 2014). A number of Iban participants in this study were from longhouses in the Sui District; they disclosed that they were mixing and spraying a variety of

fertilisers, pesticides and herbicides (*Ch.7 P2; P5; P16; P22; P24; P31*). Participants noted that agrochemicals, banned by WHO, are readily available at shops throughout Sarawak (*Ch.7 P16*). One study of the oil palm plantations in Sarawak ('The Different Types of Pesticides Available', 2014) confirmed that a cocktail of agrochemicals is being used regularly in the Sui District.

It was found that a number of participants using agrochemicals were not following standard safety procedures. This meant that they had direct exposure to the agrochemicals, and even if they used protection, it was not total protection (*Ch.7 P18*). They held risky beliefs; some were unaware of the toxicity of the agrochemicals, while others who knew still did not use protective gear (*Ch.7 P23*). The sprayers drank very little water while working and become very dehydrated (*Ch.7 P22*). A number of studies agree that pesticides are more readily absorbed through damp, sweaty skin (I. Fernandez et al., 2002) especially if the sprayer is severely dehydrated (Chavkin, 2013; Correa-Rotter et al., 2014), facilitating the absorption of the chemicals through the skin.

Multiple applications of agrochemicals are widely used on and around the gardens and farms supplying fruit, rice, corn and vegetables destined to the Miri market. (*Ch.7 P23*). Herbicides are sprayed around oil palm trees to keep them free of weeds; then the mushrooms and ferns that grow around the base of the trees are eaten (*Ch.7 P15*) or sold as favourite local foods to Miri restaurants. More medical research is needed to determine the dose-response of agrochemicals (C. C. Kuo et al., 2013) and whether it is the agrochemicals or the 'inert additives', such as the solvents and surfactants used with the product, that lead to kidney disease over time (Azman, 1997). More research is needed in Sarawak on agriculture and plantation workers' habits. Education programs targeting those who use agrochemicals, and food safety awareness, intervention and enforcement (Watts, 2012) (Howard et al., 1981) are fundamental to ensure safe food consumption for the people of the Miri district.

One older longhouse participant lamented that the children

cannot swim in river or they get itchy skin. Cannot go fishing as no more fish live in river any more. (Ch.7 P22)

This is supported by the Sui District study ('The Different Types of Pesticides Available', 2014). The agrochemical surplus is washed off into rivers during heavy rain, where it has polluted the waters and poisoned the fish. Drinking water has to be trucked in. For special guests the longhouse folk supply bottled water, an expensive gesture from people earning a minimum wage. Paradoxically, sugary soda drinks and beer are less expensive than bottled water and more commonly consumed in the longhouses. The virgin rainforests and rivers destroyed by timber and oil palm companies' activities are no longer a source of nuts, vines, fruits, wild animal meat and fish for longhouse folk. Their rich natural food stores depleted, they turn to less nutritious, cheaper foods purchased at the kedais. Many of the kampung children have rotten teeth from eating sweet foods such as *kropok* and *gula batu* and drinking soft drinks. Fatty, cheaper cuts of farmed meat bought at market have replaced the protein-dense meat of wild animals and kampung chickens. In the longhouse kitchens, instead of boiling food as in the past, the womenfolk nowadays deep-fry meat and vegetables in cheap palm cooking oil.

In this study the quantitative results showed that Malays, followed by Indigenous participants, had the greatest association with chronic kidney disease (*Table 5.5*) and that those participants living in self-build or longhouse accommodation had a greater likelihood of developing metabolic syndrome than Chinese participants living in urban areas (*Table 5.1*). Independent of and discrete from the toxic route agrochemicals may have on the body's end-organs, environmental challenges imposed on longhouse occupants that forced a transition in food choices and cooking methods may be at the root of metabolic changes initiating obesity and chronic non-communicable diseases. Age and migration to an urban centre may ultimately promote the development of metabolic syndrome, as the participants living in low-cost housing, many of whom originally come from rural and remote areas, had the greatest probability of developing metabolic syndrome (*Table 5.6*).

8.1.9 Behavioural lifestyle factors

Smoking is top of the list as a self-sabotaging barrier to health and a known risk factor for chronic kidney disease (Briganti et al., 2002; Ejerblad et al., 2004). In this study 17.0% of the cases and 12.6% of the controls were current smokers ($p=304$) (*Table 5.1*). Hammond et al. (2008) have found that Malaysian teenagers who are daily

smokers are mostly male; 7% smoke Indonesian brands but the majority smoke Western brands, and there are no observable rural, urban or ethnic differences. This is not typical of the general Malaysian population, but early initiation predicts long-term dependency and use (Hammond et al., 2008) and is particularly damaging to the heart and kidneys (Orth & Hallan, 2008). In the qualitative portion of this study, although they admitted to smoking in the past, fewer first degree relatives still smoked. Many of those who smoked commented in the interviews that they commenced as young teenagers; the damage may now be starting to reveal itself.

Obesity, smoking, and physical inactivity are significantly associated with risk of chronic kidney disease (Hallan, Mutsert, Carlsen, Dekker, Aasarød, & Holmen, 2006) and cardiovascular disease (Orth & Hallan, 2008). Smoking is potentially within one's control and if smoking ceases some of the risks of chronic kidney disease are mitigated or even reversed (Halimi et al., 2000) and damage from macroalbuminuria in persons with type 2 diabetes may be lessened (Chuahirun et al., 2004). A population based survey of Asians living in Singapore found that although smoking was slightly higher amongst non-diabetics, there was no significant increase in cardiovascular disease risk for those with type 2 diabetes even though there were metabolic syndrome factors present (Hughes, Choo, Kuperan, Ong, & Aw, 1998). Although women are far less likely to smoke than men (Hammond et al., 2008) a Norway study has found that the risk factors for chronic kidney disease, obesity, smoking and physical inactivity are the same for men and women (Hallan, Mutsert et al., 2006). Clearly there are wide variations in study results. In the multiple logistic regression analysis of this study, smoking was found to be a factor associated with obesity and metabolic syndrome in the participants, and current smokers were 3.16 times more likely to develop this than non-smokers (*Table 5.6*). This result appears to be in contradiction to studies indicating that obesity is significantly higher in non-smokers in Peninsular Malaysia (L. Rampal, Rampal et al., 2007; Tan, Dunn, Samad, & Feisul, 2010), but concurs with a Korean study (Oh, Yoon, Lee, Kim, Park, Lee et al., 2005). Two major factors were persuasive in participants' giving up cigarettes: first, if a sibling or parent died of smoking-related lung infection or cancer (*Ch7 P15*), but second, and more significant, if they had been diagnosed with or experienced symptoms of a chronic non-communicable disease such as hypertension or type 2 diabetes and the doctor advised them to quit smoking (*Ch7 P10*).

There are a number of conflicting studies of the risk of chronic kidney disease from smoking or smoking and alcohol consumption. In a 2003 study of data from the second National Health and Nutrition Examination Survey (NHANES II), it was found that smoking contributed to the risk of chronic kidney disease but alcohol did not (Stengel et al., 2003). A 2006 study, however, found that heavy drinking was associated with chronic kidney disease and increased almost five-fold the odds of developing chronic kidney disease if the person was also a current smoker (Shankar, Klein, & Klein, 2006). The urge to smoke a cigarette is often triggered by an event such as eating a meal, having a cup of coffee or drinking alcohol (Benowitz, 2010). Surprisingly, in this study drinking alcohol was found to be a protective factor against developing chronic kidney disease, compared with people who never consumed alcohol (*Table 5.5*). No data was collected on the quantity of alcohol consumed, so although alcohol was suggestive of being protective in this study, this is not conclusive. It was suggested in one study that alcohol consumption, although not directly associated with chronic kidney disease, may contribute to morbid obesity and that this together with physical inactivity contributes to the risk of chronic kidney disease (Stengel et al., 2003). More research is needed into this topic; for even if alcohol is protective to the kidneys it may still contribute to liver disease.

Miri has the most pubs of any town or city in Borneo, encouraging young people to spend their money on alcohol and pub food. As their wallets get lighter their bodies gain weight. A senior Chinese gentleman made an incisive social observation:

We have a lot of natives who are educated, hard working and very knowledgeable and live a healthy life but too many others eat, drink and smoke too much and don't look after their diabetes and hypertension, then end up on dialysis. (Ch.7 P25)

Negative behavioural lifestyle factors may activate the development of type 2 diabetes and hypertension. As discussed in Chapter 3, obesity, which is often initiated by negative behavioural factors, may lead to the development of type 2 diabetes. The results of the oral glucose tolerance test were statistically similar for both the first degree relatives and the spousal control group (*Table 5.4*) and it is expected that the incidence of developing type 2 diabetes will increase as both groups age.

Inconsistencies have been found in glucose readings using venous plasma blood or

capillary whole blood (Colagiuri, Sandbæk, Carstensen, Christensen, Glumer, Lauritzen et al., 2003) and the glucose in whole blood, as measured by a glucose meter, is unstable (Tonyushkina & Nichols, 2009). In this study a fasting plasma glucose and a two-hour post-glucose load of venous plasma (an oral glucose tolerance test) was taken to provide a definitive diagnosis of type 2 diabetes and hyperglycaemia, as recommended by the Australian Diabetes Society (Colman, 1999) and WHO (WHO, 2006).

For the multiple logistic regression analysis, the impaired fasting glucose and impaired glucose tolerance categories were combined using the cut-off point of ≥ 7.8 mmol/L. Compared with participants with normoglycaemia, those with impaired fasting glucose or impaired glucose tolerance, or type 2 diabetes, had a greater likelihood of having metabolic syndrome (*Table 5.6*). The deterioration of glucose tolerance corresponded with an increased probability of having metabolic syndrome in participants who had an estimated 3.57 times higher probability for impaired fasting glucose and impaired glucose tolerance and a 14.31 times higher probability for type 2 diabetes (*Table 5.6*) after controlling for and adjustment of potential confounders. This result is comparable to increasing abnormal glucose tolerance prevalence rates in Australia (Dunstan et al., 2002) and in Kuala Lumpur, Peninsular Malaysia (Mustafa et al., 2011).

The role of hypertension in chronic kidney disease is complicated as it is both a cause and an effect of chronic kidney disease (M. V. Rao, Qui et al., 2008) and is also associated with other chronic diseases linked with chronic kidney disease, particularly diabetes mellitus and coronary heart disease (Bakris et al., 2009). This study found no statistically significant difference between the first degree relatives and the spousal control group blood pressure readings (*Table 5.4*): both groups had poor readings although the Phase One questionnaire revealed that many were on medication for hypertension - meaning they had uncontrolled hypertension. In the literature review (Chapter 3.3.2.2) it was noted that the leading cause of end-stage renal disease in Peninsular Malaysia was type 2 diabetes (58%) by a large margin (hypertension scored 9%) (Y. N. Lim et al., 2011), while in Miri the leading cause of end-stage renal disease was hypertension (32.5%) then type 2 diabetes (30.4%) (MRC, 2010). There is need for a study to determine why there is such a difference in percentages, although a number of reasons may be postulated: for instance, there is a better doctor to population ratio in

the large urban cities of Peninsular Malaysia (MDOS, 2014) and the doctors may have more opportunities to test for and diagnose hypertension. Rural and remote people in Sarawak may not be screened for hypertension or type 2 diabetes and so are not given medication to impede progression of chronic kidney disease. Or perhaps those living in Miri who are diagnosed with hypertension are not compliant in taking their medication.

8.1.10 Chronic disease and nutritional marketing

In this study the patience, resilience and love shown by the first degree relatives who were caretakers of family members with end-stage renal disease is exemplary. This does not exempt them from the fear that one day this will be their destiny too. This was the biggest difference in concerns articulated by the spousal control group and the first degree relatives of all ethnicities, Malay (*Ch.7 P18*), Chinese (*Ch.7 P25*) and Indigenous (*Ch.7 P5*). No other studies have been found expressing the first degree relatives' fears of developing the disease, although in a study of diabetic patients, the participants expressed a personal fear of developing diabetes mellitus complications and a fear that their children would also develop type 2 diabetes (Rafique & Shaikh, 2006). The first degree relatives have the experience of living with a close relative on haemodialysis. Their perspectives on end-stage renal disease and the family disturbance created by this unfortunate circumstance are telling. In public they display fortitude and hide the trauma of coping with end-stage renal disease in the family, and anxiety about their own health. The confidential interviews in this study gave them permission to let down their guard, allowing them to expose their grief, distress and despair. Many of these men and women cried.

In this study, members of both groups in Phase One who scored poorly for both kidney disease and metabolic syndrome reported feeling unnerved when they found out they had an advanced chronic non-communicable disease. Had the blood tests not been sponsored they might never have known, for they had never been offered the tests and were unable to afford them. A qualitative study of end-stage renal disease patients and their partners' experience of dialysis found that the couples went through a number of stages: 'anger, depression and hopelessness were evident in the patients, whilst a pervasive sadness, resentment, guilt and loss were prevalent in the partners', White and Grenyer (1999, p. 1312) exposing the emotional impact dialysis has on families as they adjust to the upheaval in their lives. A study reported that even five years after a renal

transplant, patients who had been on dialysis still held significant fears, prompting the authors to recommend interventions to be designed to promote quality of life for those on renal replacement (Fallen, Gould, & Wainwright, 1997). In the qualitative portion of this current study, those from both groups who had the best chronic kidney disease and metabolic syndrome scores appeared to have better jobs, more money, were not encumbered looking after a relative, were able to return to their kampung of origin regularly, and were happier. Those with poor scores wanted to understand ‘why me?’.

Stress is a significant barrier that affects one’s health and quality of life. The difficulties of recent arrivals to Miri in adjusting to urban life, or of those dealing with family dynamics complicated by end-stage renal disease, coupled with stress at work, have been previously discussed. Responsibilities generating stress may be a barrier to participants’ seeing a doctor and being diagnosed: participants most often cited ‘lack of time’ or ‘too busy at work’ as an excuse not to see a doctor. Sometimes a little misinformation or knowledge led participants to decide that they knew better than the doctor (*Ch.7 P3; P32*), and this obstructed diagnosis and timely treatment for a chronic non-communicable disease. Other self-imposed barriers included non-compliance (*Ch.7 P22; P15; P12*), discontinuation of medication (*Ch.7 P31; P5; P1*) and buying medicine from a pharmacy without seeing a doctor first, as in this case:

Last time I bought medicine from outside but later doctor tested me and found I had high blood pressure and also I had kidney problem and my legs were all swollen. I don’t take the medicine from pharmacies now but just what the doctor gives me. (Ch.7 P28)

Early recognition, diagnosis and treatment depend upon seeing the doctor. One man, assessed as having metabolic syndrome, knew his blood and urine results indicated he needed to be followed up medically, but

I don’t feel ill so can’t get off work and not much time to go to see a doctor. (Ch.7 P10)

This illustrates the insidious nature of type 2 diabetes, hypertension and chronic kidney disease in the early stages. The quantitative results of this study show that those with the poorest metabolic syndrome results (*Table 5.5*) are 3.06 times more likely to be

associated with chronic kidney disease; the first degree relatives are 2.4 times more likely to be associated with metabolic syndrome (*Table 5.5*). These are the people the qualitative NVivo intersections identified as the ones most influenced by nutritional supplement sales companies and marketing. This may be an important area to investigate further.

Many participants fully believed the nutritional information provided by nutritional products. The companies marketing these supplements, and the pharmacies promoting them, are tapping into the fear that many people, including relatives of ill people and those with a chronic non-communicable disease, have for their health. Some pharmacies in Miri hire young form 5/6 (year 11/12) girls of different ethnicities, dressed in white medical coats, to persuade customers to buy nutritional supplements. Their sales pitch is very convincing and the market is fertile. One particular product was mentioned by eleven of the participants with the worst chronic kidney disease and metabolic syndrome scores from both groups, but not mentioned at all by the best scorers. Upon investigation it was found that the product, Monavie, was being promoted as a protein shake and supplement for weight loss. One participant with type 2 diabetes said,

Monavie, very expensive ... doctor said that Monavie is not suitable for diabetes patients due to high sugar level it contains. (Ch.7 P15)

Participants on hypertension, diabetes or cholesterol medication were trying to lose weight by taking this supplement rather than following an exercise and diet program. As this first degree relative participant said,

There are a lot of seminars on diabetes and hypertension in the community but mostly organised to sell supplements and such but doesn't really help us to learn how to change our lifestyles like what foods to eat or not. (Ch.7 P21).

There are few dietitians in Sarawak, and public nutrition seminars in Miri are often organised to promote and sell nutritional supplements backed by claims based on half-truths. More rigorous research is needed to endorse or disprove their claims.

8.1.11 Traditional versus modern

The use of traditional (Malay, Chinese and Indigenous) doctors and medicines contrasted with participants' attitudes towards Western doctors and medicine, leading to complex and profound contradictions. In Malaysia each ethnicity has its own particular traditional medical system, and although Western-style clinics and health centres have been established, both urban and rural people still look to traditional practitioners as either a sole or complementary medical provider (P. C. Y. Chen, 1975). The participants in this study were not shy about talking about their family practices even when they appeared to be torn between the heritage of their parents and, especially in the under 50s, a more Western world approach to medicine. Traditional medical knowledge is passed down through the generations, is often mystical as well as empirical, and is deeply rooted in the cultural practices of each ethnic group (P. C. Y. Chen, 1975;) no two systems are the same (P. C. Y. Chen, 1981b). This is evidenced by the spiritual attachment many participants in this study had for traditional practices, described differently by Iban (*Ch.7 P24*), Melanau (*Ch.7 P31*) and Chinese (*Ch.7 P21*). The groups least likely to follow traditional methods and consult traditional practitioners was the Orang Ulu whose parents had converted to Protestant Christianity during colonial rule (*Ch.7 P1; P16*), and those whose parents and themselves had attained higher education (*Ch.7 P20, P25; P28*).

Some participants were purists:

I only eat Malay traditional jamu (herbal) products. (Ch.7 P10)

I only take the Chinese herbs. (Ch.7 P27)

It was more common for participants to mix medical systems. One Chinese lady said,

I am a Christian (RC). Traditional practices, we still believe in the Chinese traditional doctor [Sinseh] ... Maybe if really sick we'd go to hospital. (Ch.7 P19)

Many participants fence-sat like this, not sure which way to fall: not wanting to offend their parents and ethnic traditions but wanting to show they were truly modern and educated.

In Peninsular Malaysia an ill individual may seek treatment from one or a combination of the Western doctor, the Malay *bomoh*, the Chinese *sinseh*, the Indian or the Orang Asli medicine men. It is not uncommon for a person, not satisfied with the advice given them by one medical practitioner, to seek treatment from another from a different racial group and medical system (P. C. Y. Chen, 1981b). In Borneo there are many Indigenous medicine systems as well, providing different modalities. In this small study sample participants had parents or grandparents who were a Chinese *sinseh* (Ch.7 P20), a Malay *bomoh* (Ch.7 P14) and a Melanau medicine *sharman* (Ch.7 P31). The participants in this study appeared to separate the spiritual side of traditional medicine from traditional practices and the taking of traditional herbs. For instance, an Iban lady said,

I am still a pagan [Animist]. We follow traditional belief and practices, but I never take herbs for my hypertension, and if I am sick I see the government doctor. (Ch.7 P22)

There is a sense of hedging one's bets by counterbalancing one method with another - if one method doesn't work, maybe the other will.

Some Western-trained doctors combine systems: for example, a Chinese physician may use acupuncture (Heggenhougen, 1980); this is common practice in Miri. Apart from cultural forces, political and economic forces created by a two-tiered poor-public rich-private system (Chan, 2014) may influence a person to choose a traditional practitioner in preference to a Western doctor (P. C. Y. Chen, 1981b). Medical pluralism in Malaysia is unlikely to change in the near future although there are calls to incorporate traditional healers into the government health-care system (Heggenhougen, 1980). A Chinese participant best articulated the path that most followed:

I practise Buddhism but it's like this, since it's inherited from my parents we just follow on. We don't burn incense at home. I don't practise Tai Chi. (Ch.7 P26)

Most participants declared loyalties divided between their ethnic, religious or parental practices and what they considered more modern. Higher education and many years

living in the city appear to be the ‘deal breakers’ for switching exclusively to Western trained doctors and Western medicine.

Traditional, complementary and alternative medicine have received much press attention, both positive and negative, in recent years. There are more than 12,000 registered traditional and complementary medicine practitioners in Malaysia (Abuduli, Ezat, & Aljunid, 2011). Six universities and colleges are now running traditional and complementary medicine programs. Political and public interest has led the Traditional Complementary Medicine (TCM) Division of the Malaysian Ministry of Health to establish integrated hospitals in 2006, allowing herbal preparation, acupuncture and traditional massage to be practised in the hospitals (Abuduli et al., 2011). Kuching Hospital is the only one with a traditional and complementary medical unit in Sarawak. A survey found that 69.4% of the Malaysian population had used traditional and complementary medicine (P Y Lee, Taha, Bennett, Lin, Ghazali, Almashoor et al., 2007). A survey conducted in primary care clinics in Kuching, Sarawak noted that 51.4% patients had used traditional and complementary medicine with 47.8% of those patients had used multiple medicines (Siti, Tahir, Farah, Fazlin, Sondi, Azman, et al., 2009). The participants in this current study demonstrate that traditional and complementary medicines are widely used across all ethnicities, ages and socio-economic stratum in Miri as well.

Abuduli et al. (2011, p. 2) make the claim that ‘T&CM has been proven to be successful in treating numerous diseases and conditions with less side effects. For example HIV/AIDS, certain kind of cancer, malaria, SARS, hepatitis B, insomnia, anxiety, depression and some chronic diseases and conditions’ (Abuduli et al., 2011, p. 2), but offer no evidence except to say that more research is needed in these areas. This claim sounds similar to the Orang Ulu participant in this study who said

I take herbs called Sabah Snake Grass... also take the herbs from ulu (remote, upper reaches) Baram from the Penan but don't know where it comes from. Function of those herbs is to reduce the blood pressure, cholesterol, diabetes and blood poisoning—cures everything. (Ch.7 P16)

One bottle of Sabah Snake Grass costs RM78.00 for 60 capsules from a direct salesperson. The label says that it will ‘help: overcoming constipation, anti-cancer,

remove toxin, reduces uric acid, reduce exhausted, keep kidney, reduces cholesterol, drop in a sugar, overcome the inflammation of the prostate, launch her period' and 'it has been approved by the bureau pharmaceutical Malaysia'. Local knowledge and observation often align traditional herbs with certain diseases and cures but there has been very little evidence-based research conducted to prove an association so far.

Chinese herbs, mostly boiled and drunk as a tea, were commonly consumed by almost all Chinese participants and by many of the other ethnicities in this study. Food prepared with local herbs and spices is prized, and all ethnicities promote their unique dishes and flavours throughout Sarawak. Three examples are Ka Ca Ma, a Chinese chicken and herb dish eaten during the post-natal period, bamboo stuffed with chicken and herbs then smoked over an open fire by Iban persons, and Kikid Kering, a Kelabit speciality herb porridge. There are more than 1,000 types of Malay, Chinese and Indigenous traditional herbs regularly consumed by Sarawak locals, and 50,000 wild herbs with commercial value identified in Malaysia's rainforests ('Gain knowledge of herbs,' 2015).

A Malaysian survey found that 70% of the population accept traditional herbal medicine because they believe that it will not bring about side-effects and is comparable to Western medicine ('Gain knowledge of herbs,' 2015). The reasons most often mentioned by the participants in this study were that it had no side-effects and was comparable to Western medicine; in fact, there was a strong belief that it was better (*Ch.7 P28*) (*Ch.7 P21*).

A little disconcerting is the statement that 'although great numbers of people use T&CM recently, many people are not aware of the side effects of T&CM. Some people hesitate in using T&CM concurrently with conventional medicine or as alternative therapies' (Abuduli et al., 2011, p. 2). A number of participants in this study said they mixed herbal with Western medicine (*Ch.7 P16*) (*Ch.7 P21*) and most said they never informed their doctor of this (*Ch.7 P3*). When queried they said they were never taken together; but this did not mean that they were not consumed within a few hours of each other. High steroid content is known to be present in some herbal products in Miri (*Ch.7 P3*) and can interact with Western medicine given to patients. Overdosing can occur if patients consume both herbal and Western medicines containing steroids, or if women take herbal supplements containing phytoestrogens and hormone replacement

therapy at the same time. Chui et al. (2009) warn that toxicity and interactions with anti-cancer drugs can occur in cancer patients taking traditional and complementary medicines at the same time as receiving chemotherapy. They too found that few patients of Asian ethnicity actually informed their doctors that they were taking traditional or complementary medications (Chiu et al., 2009). If medical pluralism is going to be accepted and herbal medicine is to be integrated into the general hospital system in Malaysia, research and dissemination of results is urgently needed on herbal pharmacologic dosages, the contents and active ingredients in the traditional and complementary medications, the washout period, contraindications, and their interaction with Western medicines.

The first degree relatives recorded the most suspicion towards Western doctors and Western medicine. A few of the more educated participants suspected that traditional and complementary medications and supplements had a placebo effect (*Ch.7 P32*) (*Ch.7 P10*). In the interviews the women never mentioned having massages and the men never mentioned having acupuncture, but from observation in Miri these practices are common among both genders. Some of the participants mentioned Bario salt (*Ch.7 P5*) (*Ch.7 P16*), which has a high potassium to sodium ratio and a high iodine content; the rural or remote communities who eat this spring salt do not get iodine deficiency goitre or children with cretinism (P. C. Y. Chen, 1981a; A. Osman, 2003). A number said they cooked with cheap non-iodised salt in Miri. Miri is on the coast, and seafood, prawns and shrimp, made into a paste (*belacan*), are common foods and a good source of iodine. *Ikan bilis* (anchovies), a high purine food, is enjoyed by all Sarawakians. Indigenous and Chinese people love to eat pork organ meats, and the Malay people eat a lot of beef and lamb red meat—also high in purine. Many of the men mentioned they drank alcohol. If they experience gout, they change their diet radically and stop drinking alcohol (*Ch.7 P10*) as this participant said:

Recently not well because of gout ... But I getting better at controlling what I eat now days. (Ch.7 P7)

For those with chronic non-communicable diseases, there may not be pain or another reminder to alter ones' lifestyle; so motivation and desire have to be factored into intervention strategies or it is difficult to sustain change. An elderly participant noted that

doctors should do more free talks for the community. I taught myself about diabetes and the changes you need to do in lifestyle in order to control it. For me it's very difficult to advise others and have to give them time to change their diet and lifestyle. (Ch.7 P21)

8.1.12 Metabolic syndrome clinical and biochemical results

Metabolic syndrome is perplexing. Rather than a single component of the syndrome leading to chronic kidney disease, it is more likely that a cluster of factors all contribute (Rashidi, Ghanbarian and Azizi, 2007a). In this study, for the multiple logistic regression analysis to determine the associated factors for chronic kidney disease, it was found that people with metabolic syndrome have a 306% (*Table 5.5*) increased likelihood of developing chronic kidney disease compared with the healthy participants. Metabolic syndrome also forewarns of the risk of cardiovascular disease in those with chronic kidney disease (Prasad, 2014). Further multiple logistic regression analysis was performed to determine what factors contributed to metabolic syndrome in the participants.

In the multiple logistic regression analysis in this study there were a number of possibilities leading to an association with having metabolic syndrome, after adjustment for potential confounders. Significant factors associated with metabolic syndrome in the participants (*Table 5.6*) which have already been discussed, include aging, being a first degree relative of an end-stage renal disease patient, having a family history of cardiovascular disease, being a current smoker, and having type 2 diabetes. The final factor, living in terraced or low-cost housing, can also be said to incorporate socio-economic and environmental aspects.

The benchmark for screening was the International Diabetes Federation metabolic syndrome clinical parameters with South East Asian ethnic-specific measurements for abdominal obesity (Alberti, Eckel et al., 2009). In this study the metabolic syndrome, waist circumference, clinical and biochemical results were calculated for each participant and their likelihood of developing metabolic syndrome determined. Metabolic syndrome was more likely to be present in the first degree relatives group (37%) than the spousal control group (23%) ($p=0.012$) (*Table 5.4*). The clinical and biochemical results revealed no statistically significant difference between the first

degree relatives and the spousal control group for their systolic or diastolic blood pressure readings (*Table 5.4*). Waist circumference (determining abdominal obesity) predisposes a person to multiple chronic non-communicable diseases (IDF, 2006) and contributes to high triglycerides and low HDL-C in persons at risk for cardiovascular disease (Alberti, et al., 2005). The first degree relatives had significantly higher levels than normal for triglycerides ($p=0.012$) and for TC : HDL-C Ratio ($p=0.025$) (*Table 5.4*). These results translate to an increased associated likelihood for the development of cardiovascular disease in the first degree relatives with abdominal obesity and metabolic syndrome.

A study found that in Asian Chinese populations, this study's reference group, metabolic syndrome is an important risk factor for chronic kidney disease (J. Chen, Gu et al., 2007). Although the debate as to what element, or group of elements, initiates chronic kidney disease first continues, it is increasingly clear that components of the metabolic syndrome are implicated (Ritz, 2007), and that multiple components of the metabolic syndrome lead to or exacerbate the development of chronic kidney disease (Rashidi, Ghanbarian & Azizi, 2007a). One unifying underlying causal factor for the metabolic syndrome has not been identified, although insulin resistance, to which obesity contributes, is often associated with metabolic syndrome and predicts type 2 diabetes and cardiovascular disease (Alberti et al., 2005). As described in Chapter 3.4.4.2, persons with insulin resistance often have abdominal obesity and impaired glucose tolerance or hyperglycaemia (Kaur, 2014). Metabolic syndrome is a risk factor for both chronic kidney disease and cardiovascular disease (J. Chen, Gu et al., 2004), independent of diabetes and hypertension; and in a vicious spiral, chronic kidney disease may aggravate insulin resistance and hypertension (Guarnieri et al., 2010). Ritz (2007) cites a number of international studies linking metabolic syndrome to early kidney deterioration. The juxtaposition of obesity, insulin resistance and metabolic syndrome associated with chronic kidney disease and end-stage renal disease may be a clue why renal deterioration and microalbuminuria commence before hypertension and diabetes become apparent (Iseki, 2008); they may even be a trigger for renal dysfunction (Wahba & Mak, 2007). This is a strong reason to promote having first degree relatives with metabolic syndrome screened for chronic kidney disease and microalbuminuria, and indicates the need for regular community public health awareness campaigns to promote maintaining a healthy weight, controlling type 2

diabetes and hypertension, complying with medical intervention, and preventing or reverting metabolic syndrome.

8.1.13 Aging and compliance

Malaysia is becoming an aging population. The population of Malaysia is projected to reach 32.4 million by 2020, with one million more men than women, and 10% will be over the age of 60 (MDOS, 2014). The Malaysian government conducts a nation-wide census every ten years, and the last one in 2010 found that the average life expectancy has risen to 71.05 years for men and 76.73 years for women (MDOS, 2014). This is largely due to health-care improvements and the outreach of medical clinics, an increase in medical staff, widespread vaccination of infants and children, and control and medication for infectious diseases; all of these have contributed to the improved health of the nation. Unfortunately, longevity does not always bring good quality of life, and over the past few decades the incidence of chronic non-communicable diseases has been steadily mounting. Malaysia has no medical insurance or social welfare old-age pension, and when people retire it is stressful and expensive if they become ill or have a chronic illness, especially if they have limited savings. For the elderly who become sick in Malaysia, the burden of their medical expenses usually falls on their family. Apart from one Chinese nursing home, there is no fall-back support of nursing homes or retirement villages for other ethnicities in Miri. The supporting family members and, as this study has shown, the spousal control group are also affected, need the tools of knowledge and skill to help them cope with their circumstances. It is essential that local and state governments consider health awareness, education and prevention strategies in the under-50 age groups to avoid the ramifications of an aging population with chronic non-communicable diseases and cardiovascular disease which will place stress on the health care system in the future. Rafique and Shaikh (2006, p. 347) have asserted that ‘understanding needs and expectations of people with diabetes is essential in initiating and improving the outcomes of education program for diabetes self care’.

A number of compliance issues were divulged by the participants. Some felt that Miri doctors over-prescribed and said they did not take the medicine (*Ch.7 P32*), a number said they stopped taking medication as soon as they started to feel better (*Ch.7 P12; P5*), some said they keep some medicine for ‘next time’ (*Ch.7 P1*) and some felt the

medicine was no good or made them worse and so stopped taking it (Ch.7 P22; P3). Most participants resisted the idea of taking medicine for the rest of their lives, yet were not compliant with exercising:

Doctor did advise me go for exercise but I didn't follow his advice. (Ch.7 P14)

or choosing healthy food options:

At first I followed a diet after the doctor advised me to cut out fat, salt and sugar in my food but I got tired of it and it didn't last long as I wanted to eat more tasty foods. So I stopped and now days I not really worry about my diet at all. (Ch.7 P4)

It is important for persons with a chronic non-communicable disease to make changes with the aim that they will be life-long. Unless they commit to a lifestyle paradigm shift there will be no health gain, and this needs to be factored into intervention programs. It is easy to assume that 'people know', but the reality is that unless they are told and shown - unless they comprehend why they need to change, they will never change. For instance, recently at an Iban longhouse, where some of the participants in this study who have hypertension lived, many ladies attended a cooking session organised to demonstrate how to cook healthy versions of local dishes. One lady commented after the session,

When the doctor told me to cut out fat and salt in my diet I did. I now use oil instead of lard and replaced salt with pati ayam (stock cubes). I never knew salt, sugar and fat hides in food. I cook and eat kicap, chilli sauce and soy sauce with everything!

This sentiment was echoed by a number of participants with spouses who had type 2 diabetes and two whose spouses had commenced dialysis since Phase One:

A dietitian sometimes advises my husband but not me yet I'm the cook. Sometimes difficult to get protein and water balance right. (Ch.7 P14)

It is recommended that Malaysia start preparing for the consequences that come with an aging population. High rates of chronic non-communicable diseases, chronic kidney

disease and cardiovascular disease will have an impact on the national economy, and in particular the health care system. The qualitative intersections in this study identified a lack of compliance by participants across all age groups. This area of convergence may be an important contribution to the quantitative results for diabetes and metabolic syndrome (*Table 5.6*). Rates will not improve unless pharmacological compliance by patients is achieved. Health awareness and education programs need to address this issue, emphasising the importance of a life-long program of diet, exercise and medication to help slow the progression of all chronic non-communicable diseases.

8.1.14 Confusion versus compromise

This study identified many beliefs and fears of those who have, or who are supporting family members with, a life-impacting chronic non-communicable disease, chronic kidney disease or cardiovascular disease.

The Indigenous groups were more likely to mention health changes they had experienced since moving to Miri:

When I was living in the kampong I felt healthy then first time come to Miri I felt weak. (Ch.7 P6)

The Chinese participants were the most vocal on the subject of stress. There is implicit pressure on the family provider, and often they sacrifice their health for the benefit of their family. A stressful job with responsibility, long hours and time away from home takes a toll on family life and personal health, but unless the provider is able to provide for the family, they literally go hungry, go without medical care and go without material things. It is hard on older members of a family when a provider or those sharing financial responsibilities die, and they themselves are too old or sick to work (*Ch.7 P21*). Participants from younger generations also expressed fear of this happening (*Ch.7 P27*).

In Malaysia there is still a stigma connected with mental health, and mentioning that a family member has a mental issue is deemed to bring shame and disgrace to the family. Only those with severe mental health problems are provided for by the government health system, and psychiatrists, psychotherapists and psychologists are few in Sarawak. Doctors are the first point of contact for many, as at present there are no

private counselling services available. Counselling services for relationship, stress and addiction problems are most often run by volunteer or religious groups. Interestingly there were a number of suggestions offered by the participants to reduce stress, including using supplements (Ch.7 P18), sharing with family (Ch.7 P19), religion and reading (Ch.7 P28), smoking (Ch.7 P18) and exercise (Ch.7 P31). It has been reported that for some people, stress amplifies abdominal obesity (L. E. Kuo, Kitlinska, Tilan, Li, Baker, Johnson et al., 2007), and a prospective cohort study of 10,308 participants in London concluded that chronic work stress can lead to metabolic syndrome (Chandola, Brunner, & Marmot, 2006). It is important that carers of end-stage renal disease dependants, especially, are supported by their families and, if they do not have family living in Miri, by the dialysis centre staff.

All the participants knew the main reasons for obesity are lack of exercise or activity and eating an unbalanced diet high in fats and carbohydrates. Unfortunately, knowledge does not always lead to healthy behaviour. Many participants had tried fad diets and supplements to lose weight, only to regain it and more. As one participant noted,

My biggest hindrance to following a healthy diet is my will power, or should I say won't power [laughs] and all the distractions from my colleagues at work, we all feed each other. (Ch.7 P32)

The participants often felt they were letting themselves and their family down. The replies given by one particular participant during the interview exemplified this and underscored the desperation and despondency felt in response to uncontrollable circumstances:

I still can cope because I'm still working but once I stop working I'm scared. If anything happens, everything depends on me, if I stop working we stop eating, very stressful. (Ch.7 P27)

My job covers both Sarawak and Sabah so a lot of travelling and I eat out a lot and skip meals often. (Ch.7 P27)

I take a lot of noodles ... I prefer fried ... I prefer noodles and rice meals. (Ch.7 P27)

I do very little exercise, not for a year, because I am very busy and travel a lot ... I am too busy writing reports. I guess I have to manage my time more and fit the exercise in there between the busy schedule ... last few years I've gained quite a bit. (Ch.7 P27)

No padang around just terrace housing. (Ch.7 P27)

This 40 year old is on medication for hypertension and has been assessed as having metabolic syndrome. If he does not stop compromising on his health now, his prognosis is not good. He was not the only participant to show this behaviour pattern.

Lack of health information is a barrier which needs to be addressed through public health awareness and intervention strategies. Participants with a chronic non-communicable disease requested more information regarding their particular medical condition and how to implement dietary and lifestyle changes (Ch.7 P21). Some said they were confused by the advice given to them (Ch.7 P7). The first degree relatives and spouses helping their in-laws wish for encouragement from the medical staff (Ch.7 P20) and support groups run by medical professionals need to be established (Ch.7 P27). The government organises a diabetes camp in Kuching once a year, and one man who had attended one said

I learn a lot about diabetes and how to control my diet. (Ch.7 P2)

More need to be organised for citizens in Miri. Health-related barriers impeding early recognition and diagnosis of a chronic non-communicable disease, in particular chronic kidney disease, should be acknowledged by health authorities and dialysis centres. Health awareness and intervention programs and strategies need to match the level of education, health literacy and circumstances of the target audience and solicit their involvement and participation. With good investment and policy making these can make a difference to the lives of anyone with a chronic non-communicable disease. It is difficult setting up long-term programs for end-stage renal disease patients and their families, but the problems can be overcome with committed leadership and the development of information-based implementation plans (Bear & Stockie, 2014). The aim should be to improve each person's comprehension of their medical condition in

order to empower them to implement lifestyle changes and to be compliant with their doctor's instructions.

8.1.15 Socio-economic factors

In Sarawak the towns are predominantly populated by the Chinese and Malays while the majority of people living in the rural and remote areas are Indigenous (Sarawak Government, 2003); for them treatment for end-stage renal disease remains impossible unless they relocate to towns where there are dialysis centres and family members with better paying jobs. Participants in this study comprised urban-born Chinese, urban and urban fringe-born Malay, and Indigenous ethnicities (*Table 5.1*), more than half of whom had been born and raised in remote longhouses (*Table 5.1*) and migrated to Miri as adults. Rural to urban migration initiates an often irreversible transition for a family and engenders a host of positive and negative psychosocial and behavioural changes.

The category self-build / longhouse (*Table 5.1; 5.6*), necessitates some explanation. Self-build includes rural farm houses, houses built by their inhabitants on a free-settlement lot allocated by the local council, and those who have built in an illegal urban shanty area. In this study there was no statistically significant difference between the first degree relatives and the spousal control group in the type of housing they lived in (*Table 5.1*). Many people moving from rural areas to the city initially stay with extended family members who have already settled in the city, until they find work and their own accommodation. There is the possibility that they will crowd into poorly built or rented shanties in the lower socio-economic areas and remain there for many years. In this study those born in urban areas were more likely to own a detached house, and those born in the rural/remote areas were more likely to live in a terrace, low-cost house, or a self-build or longhouse (*Table 5.1; Table 5.6*). Those participants listed as 'semi urban' lived in longhouses, farm houses and low-cost houses, between one and two hours' drive from the Miri city centre.

The development of low-cost housing estates has been encouraged by the government (Huu et al., 1999) and this allows the middle-income earner, or two relatives who combine their income, the opportunity to own their own homes, although it is still more common to rent them from wealthier businessmen. The multiple logistic regression analysis for this study shows that compared with people living in detached houses,

those living in terraced or low-cost houses were 5.08 times more likely to have metabolic syndrome, and those who lived in the self-build / longhouses were 3.77 times more likely (*Table 5.6*). This brings into question the food quantity and quality, and the levels of physical activity, of those living in lower socio-economic housing groups.

Shariff and Khor (2005) found that in West Malaysia overweight and obesity in rural women correlated with food insecurity and low income and socio-economic status. Conversely, this study reveals that the middle-income group, living in terraced and low-cost houses, had the greatest probability of having metabolic syndrome (*Table 5.6*). Only a few studies have been found that consider the socio-economic trends of the Indigenous people of Sarawak and Malaysian, and none on their housing demographics. Freedman et al. (2005) have noted that although heredity and non-socio-economic factors appear to predominate, lower socio-economic status and associated familial clustering may be more important with regard to kidney disease. Income equates with the affordability of items such as food, cars, medical treatment, tuition, furniture and the like, whereas housing is indicative of environmental and living conditions. Being able to afford a bank loan to purchase a semi-detached or detached house is a clear indicator of one's employment type and level of income: a person needs to have high-paying work to afford a detached house mortgage. In this study the multiple logistic regression analysis showed that income and housing followed the same trend (*Table 5.1*); therefore, housing may be considered a surrogate marker for income and the probability of developing metabolic syndrome (*Table 5.6*). Perhaps by using housing and location as a socio-economic indicator for standard of living, the data collected is more trustworthy as it circumnavigates the discomfort, even embarrassment, some people feel at having to reveal their income, and better describes their circumstances and the environment they live in.

8.1.16 Environmental constraints

The qualitative interviews revealed some reasons why the quantitative results show metabolic syndrome as significantly greater among participants living in terraced and low-cost housing estates (*Table 5.6*). This study found that those persons with professional or managerial jobs and higher wages, and who were more established in Miri, were more likely to live in a detached or semi-detached house with a large garden and to hire gardeners to look after the grounds. A few participants with high wages said

they lived in condominiums and had nice, managed facilities to enjoy. Government incentives to contractors to build low-cost housing so people can own their own home are good, but such houses provide the bare minimum most do not have a garden (*Ch.7 P6; P1; P27; P20; P3*); if there is a little back garden it is often full of contractors' building rubbish (*Ch.7 P10*). People are fortunate if they own a corner house (*Ch.7 P9*). There are very few children's playgrounds, *padang* or parks to exercise in; there are no footpaths, and the roads are dangerous to walk along (*Ch.7 P30; P1; P7*). From the interview intersections, those who do not have chronic kidney disease / metabolic syndrome were more likely to have an attached garden with their house. The poorer scoring participants grew fruit and vegetables in a garden elsewhere, sometimes over an hour from their houses (*Ch.7 P2; P5*). The Indigenous Iban shuttle between their longhouse and their work in Miri, but many families relocate to town when their children attend secondary school (*Ch.7 P2*). This study confirms that those who have moved to Miri from the rural and remote areas often initially stay in the free settlement or slum areas (*Ch.7 P6*), renting, building their own place or sometimes living with relatives already settled in Miri (*Ch.7 P6; P7*). After some years they secure regular work and, maybe with a spouse who is also working, are able to get a mortgage and move into low-cost housing (*Ch.7 P18; P1*). There are compromises to make, such as room size and garden space - and yet this is the population most likely to have a large extended family living together.

A Cameroon study of 999 women and 727 men concluded that the recent migration history and exposure to poor urban environmental conditions lead to decreased physical activity, dietary changes and psychological stress (Sobngwi, Mbanya, Unwin, Porcher, Kengne, Fezeu, et al., 2004). These factors, over time, contribute to the development of type 2 diabetes and hypertension (Sobngwi et al., 2004). One participant in the present study, living in a low-cost housing estate, was so scared of being burgled she never left her house (*Ch.7 P15*). WHO (2013b) has listed several urban environmental factors that are unfavourable to people being more active, including fear of violence, high-density traffic, and the lack of parks, sidewalks and sports and recreation facilities. These factors were spoken of by the participants in Phase Two as barriers preventing them from exercising regularly. Fenton (2005) has emphasised that 30 minutes of physical activity is needed every day in order to reduce the risk of a chronic non-communicable disease morbidity and early death. He advocated healthy environments

that promote physical activity to counteract a sedentary lifestyle (Fenton, 2005). In promoting better town planning, footpaths, bicycle tracks, safer streets, more parks, and more trees and shrubs are recommended for healthier living environments, and preferably include sustainable development and be culturally sensitive (Burden, 2001). Adequate house environments are very important in promoting mental and physical health in the population and public health is a priority. Every low-cost housing estate in Miri should include a garden with every house, or at the very least a community vegetable garden, footpaths, playgrounds, sports ovals and facilities within easy reach of all.

A Peninsular Malaysian study (n=17,392) found that higher wages, city living and physical inactivity brought on by lifestyle changes was highly prevalent amongst urban adults and contributed to glucose intolerance, hypertension and obesity in Malaysia (T. O. Lim, Ding, Zaki, Merican, Kew, Hamid et al., 2000) and this current Sarawak study concurs with their results. Metabolic syndrome and obesity-related diabetes and hypertension are preventable diseases and potentially treatable (Iseki, 2006). A number of mechanisms whereby the metabolic syndrome may contribute to chronic kidney disease have been identified (Prasad, 2014), and Bagby (2004), in a review of the effect of obesity-initiated metabolic syndrome on the kidney, notes that intensive exercise and weight loss especially in the earliest stages of obesity-initiated metabolic syndrome may be renal protective if undertaken before kidney damage becomes permanent.

Oddly, participants who did have somewhere to go to exercise, or who lived near the beach, often did not use the advantage (*Ch.7 P32*):

all sorts of excuses not to! We don't have this kind of habit so don't. (Ch.7 P28)

Older people worked hard on their farms and in their gardens, but for those in towns it was considered inelegant and undignified to exercise or run. Malaysia is a Muslim majority nation and even non-Muslims tend to wear long trousers, long skirts and long sleeves in this tropical country. Older obese women especially are embarrassed about their weight, worry about modesty, and their clothing makes exercising uncomfortable. The Chinese and Indigenous younger generations may change the status quo for their ethnicities, but media fashion reports suggest that young Malay female adults are using the *tudung* (female Muslim veil or headscarf) and full cover at all times in public now,

and not just for official wear as in the past. The Malay participants in this study were 5.67 times more likely to be associated with chronic kidney disease (*Table 5.5*), many with a family history of a chronic non-communicable disease and themselves having metabolic syndrome. Current research on health issues concerning Muslim women who wear the *burka* (coat covering a woman except for her eyes and hands) have revealed that they are at significant risk for Vitamin D deficiency (Masood & Iqbal, 2008), obesity and metabolic syndrome (Reyaz & Islam, 2012), hypertension and cardiovascular disease (Stroope, 2015). Malay female politicians and community leaders have a role to play in persuading young Muslim women to start an exercise routine for health benefits now and when they are older. All Malaysian females need to be encouraged to exercise regularly; possibly by forming groups will help overcome shyness and will persuade them to.

This study has indicated that middle income earners with terrace and low-cost housing are at greater risk of metabolic syndrome (*Table 5.6*) and need to have more exercise parks and facilities. Lack of physical activity is the part of the health equation most often neglected, but without exercise it is very difficult to reduce weight and maintain healthy body proportions throughout life. Lifestyle intervention studies point out the difficulty people have in losing weight and keeping it off. Goldstein (1992) has argued that even with a weight reduction of 10% or less, chronic non-communicable diseases and metabolic syndrome would lessen, increasing longevity and reducing the risk of cardiovascular disease. Obese persons who are able to achieve a weight loss of only 5% still gain health and emotional benefits (Blackburn, 1995). For obese people with type 2 diabetes the degree of weight loss at one year is strongly ($P < 0.0001$) associated with improvements in their risk for cardiovascular disease; those who lose greater than 10–15% of their body weight reap greater benefits (Wing, Lang, Wadden, Safford, Knowler, Bertoni et al., 2011). A number of participants in the current study said that their doctor had asked them to exercise and lose weight to reduce their hypertension (*Ch.7 P5*) and type 2 diabetes (*Ch.7 P21*), but as previously noted, participants were not always compliant (*Ch.7 P14*).

There is some debate on whether exercise without diet is useful for long-term weight loss and improvement of hypertension and type 2 diabetes in the obese. In this study some participants noticed the effect exercise had on their hypertension (*Ch.7 P1; P28*).

It has been found that 60 minutes of moderately intense exercise five times a week, without weight loss, reduced visceral fat and lipids in skeletal muscle in both obese and type 2 diabetic men (S. Lee, Kuk, Davidson, Hudson, Kilpatrick, Graham et al., 2005). Another study of 52 obese men with waist circumferences of 110.1 ± 5.8 cm found that weight loss from daily exercise without dieting could reduce obesity and insulin resistance, decrease abdominal fat, and prevent weight regain (Ross, Dagnone, Jones, Smith, Paddags, Hudson, et al., 2000). A study of eleven obese women, using walking as exercise and with no dietary restrictions, found that weight loss only occurred when walking exceeded 30 minutes a day; the weight loss was slow and graded to the amount of time taken (Gwinup, 1975). Another study found that diet alone produces a greater weight loss than exercise alone, but much of the loss was from lean body mass; it recommended combining dietary restrictions with exercise for a weight loss that promoted better body fat distribution (Blair, 1993). A meta-analysis of diet and exercise interventions compared with diet alone found that at one year follow-up participants had regained half their initial weight loss; diet with exercise gave a better long-term outcome (Curioni & Lourenco, 2005).

One Chinese participant (*Ch.7 P26*) commenced an exercise program after heart surgery. He commented that he was frightened at the beginning but felt well now. Heart surgery should not prevent a person from exercising, even if only gently, but this does underscore the need for doctors to monitor and encourage those with advanced chronic non-communicable diseases and cardiovascular disease when they embark on an exercise program. The results of a study to determine the best way to reduce cardiovascular disease risk in obese women ($n=40$) found that an increase in daily physical activity, a structured aerobic exercise program and a low-fat diet of 1,200 kilocalories per day was best (Andersen, Wadden, Bartlett, Zemel, Verde, & Franckowiak, 1999). Another study found that for obese individuals, diet and exercise counselling combined with behavioural interventions and motivation resulted in 3–5 kilograms of sustained weight loss after one year (USPSTF [United States Preventive Services Task Force], 2003). Moderate weight loss gives health benefits such as improved blood pressure and lower blood glucose and lipid levels, but intensive counselling and support is needed to sustain long-term weight loss in the obese (USPSTF, 2003). A multiple risk factors approach to intervention and medication (T. O.

Lim et al., 2000) and recommendations for intensive exercise and weight loss (Bagby, 2004) especially targeting those at high risk for chronic kidney disease is required for obese and type 2 diabetes patients. For the best lifestyle intervention results a program must be individualised and intense enough to allow the person to achieve and allow the adhere to long-term outcomes (DPPR [Diabetes Prevention Program Research Group], 2002). The Diabetes Prevention Program Research Group recommend that the program be structured and should address ethnically diverse people, and especially their food and cooking methods (DPPR, 2002). To maintain a 7% weight loss and to improve type 2 diabetes, 700 calories (\pm 30,000 kilojoules) per week of physical activity is recommended (DPPR, 2002). Anderson, Wadden, Bartlett, Zemel, Verde and Franckowiak (1999) advocated enough physical activity to derive health benefits, recommending at least 30 minutes of exercise most days of the week: even short episodes of moderately intense activity, such as using the stairs instead of the elevator, could counteract a sedentary lifestyle and help avert weight gain. Active and fit overweight men and women appear to have lower morbidity and mortality rates than unfit overweight persons; therefore, even if one does not lose weight exercise is beneficial (Blair, 1993). Regular walking, or swimming if there is joint pain, is worthwhile. Handicapped people should also be encouraged to exercise within their limitations. For muscle and joint injuries a professional fitness instructor is invaluable in showing how to continue exercising while allowing the injury to recover.

Some of the participants in this study merely needed encouraging and convincing that a regular exercise program would do them good (*Ch.7 P18*). Having a reliable social support system is very important. Weight loss is greater and maintained longer if there is a 'buddy-system' of friends or family members also participating (Wing & Jeffery, 1999). Aids such as pedometers, computer programs and mobile phone applications have been found to help obese persons with type 2 diabetes feel empowered, and self-controlled, and help their management of their chronic non-communicable disease (Piette, 2007). It takes determination and often a life-changing personal crisis to initiate and maintain weight loss. Lifestyle counsellors need to be sensitive and if clients do not lose weight, they should be supported and encouraged to continue to comply with medication, eat healthy foods, and exercise regularly for the positive physical and mental effects these bring, and to help control hypertension and type 2 diabetes and prevent these conditions from deteriorating. Even for end-stage renal disease patients,

regular gentle daily exercise helps prevent muscle atrophy, strengthens the heart, averts constipation, and improves one's mood and outlook on life. In Asian societies where there is fast-paced socio-economic change, Lukito and Wahlqvist (2006) have warned that in order to reverse obesity and diabetes trends, weight management must not narrowly focus on energy balance but should span generations and encompass the nutritional status of mothers at pre-conception, during inter-uterine growth, and later in maternal and child health programs; life-long public health strategies which address adverse living conditions should also be designed. Community nutrition and health advocacy is needed to address and correct inadequacies and inequalities, particularly in the areas contributing to the development of obesity, type 2 diabetes and cardiovascular disease, and government health policies need to be planned to cover decades if they are to succeed in the long term (Wahlqvist, 2008).

There were many excuses from participants, and it often took a medical crisis in a family member (*Ch.7 P9; P14; P26*), or themselves (*Ch.7 P18; P31*) before they would begin a regular exercise program. For many participants there was confusion (*Ch.7 P7*) misunderstanding and exasperation as they gained, lost, then regained their weight (*Ch.7 P26; P15; P13*). Women in this study were more likely to admit to laziness (*Ch.7 P17; P14*). Men especially wanted to be good role models for their children (*Ch.7 P9; P31*) but were thwarted by work commitments. A number of participants had out-of-control situations to deal with, like this lady:

I don't have time to walk around and have put on weight. I don't know how to control myself. (Ch.7 P5)

Those who are exercising regularly appear healthier and happier (*Ch.7 P26; P20*). There are plenty of gyms (with expensive membership) in Miri but for those not wanting to use a gym the two barriers inhibiting exercise are lack of facilities such as footpaths and parks near their homes, and lack of time or bad time management. Some participants expressed anxiety regarding their health. Some said that they knew what to do, but were unable to do it for many reasons and therefore had to make compromises with own health and fitness (*Ch.7 P27*). This should not be the case; they need to be advised appropriately to eliminate any confusion they may have, and encouraged not to compromise their health but to follow a holistic lifestyle management program for life.

8.2 Conclusion

In accordance with Mixed Methods protocol, the two data sets were integrated in order to explain cohesively those aspects of the qualitative Phase Two that converged with, and might influence, aspects of the quantitative Phase One.

The quantitative analysis of this study identified many participants, from both the first degree relatives and the spousal control group, as having a modifiable chronic non-communicable disease. Some had three or more chronic non-communicable diseases and were classified as having metabolic syndrome; a few had chronic kidney disease. Metabolic syndrome was the only modifiable factor found to be strongly associated with chronic kidney disease.

Many participants did not know they had a chronic non-communicable disease until they received their Phase One laboratory reports. A dominant concern raised in the interviews was that they had never been screened for a chronic non-communicable disease or for chronic kidney disease before this study. The first degree relatives in particular were anxious that they might end up like their parent on dialysis, but most participants were confused about the correct course of action to take to prevent or delay progression of a chronic non-communicable disease or chronic kidney disease. The major theme emerging from the sub-themes of the qualitative data analysis was 'health-seeking anxiety', as the participants were anxious about their health, confused about the causes of chronic non-communicable diseases and chronic kidney disease, and unsure of the best practice for the prevention of and treatment for their disease.

The qualitative findings of this study exposed poor health literacy, non-compliance, environmental constraints, incorrect health beliefs and attitudes, barriers to seeking medical treatment and unhealthy lifestyle behaviour among the participants. These factors intersected or converged with, and might have contributed to, the poor results identified in the quantitative analysis. The integration of the two data sets has revealed negative beliefs, behaviours and attitudes that are likely to be detrimental to long-term health and good quality of life. The participants' beliefs, behaviours, attitudes and barriers to seeking medical treatment are significant intersections where the Phase One quantitative results and the Phase Two qualitative findings integrate and require more investigation. These are areas that should be targeted by government policy review and

lifestyle intervention strategies, and if addressed will benefit the health and welfare of all living in the Miri and Baram communities. Local knowledge, cultural sensitivity, self-monitoring by the participants, empowerment of communities, and focusing on the positive, progressive aspects illuminated in this study will enhance participation and aid in achieving the objectives of health awareness and intervention programs. Individual counselling and public health awareness campaigns involving medical professionals will ensure the delivery of truthful, accurate information regarding chronic kidney disease and the metabolic syndrome.



Photograph 8.1 Batu Lawi, Pulong Tau National Park, central Borneo
Photograph by researcher's husband (from helicopter)

Chapter 9 Conclusions and Future Directions

This, the concluding chapter for this thesis, presents the significant study conclusions including insights into the reasons why some of the participants may have developed metabolic syndrome and chronic kidney disease. The outcomes for the study objectives, the strengths and limitations of this study are summarised. The chapter concludes with some recommendations for various community stakeholders about future directions for public health practice and future research challenges.

9.1 Study Conclusions

In this study, a Mixed Methods sequential design was chosen to investigate health related beliefs, behaviour and knowledge contributing to the metabolic syndrome comorbidities that might initiate the development of chronic kidney disease in participants at risk. The integration of the quantitative and qualitative phases is unique to Mixed Methods and the interface or convergence point between the two methods are of particular interest (Teddlie & Tashakkori, 2010).

In Phase One the non-modifiable factors associated with chronic kidney disease were identified as age and ethnicity. Metabolic syndrome, with its chronic non-communicable disease comorbidities, was found to be the modifiable factor for chronic kidney disease. The non-modifiable factors associated with the metabolic syndrome were identified as age, a family history of cardiovascular disease, and being a first degree relative of someone with end-stage renal disease. The modifiable factors for the metabolic syndrome were smoking, living in a low-cost house and having type 2 diabetes. This study found that persons of Malay and Indigenous ethnicity who are diagnosed with metabolic syndrome have a greater possibility of developing or having chronic kidney disease with age than someone without metabolic syndrome who is of Chinese ethnicity. Such high-risk ethnic populations should be made aware of a possible genetic propensity to chronic kidney disease, especially if they have metabolic syndrome, and should be offered health awareness education. Lifestyle changes amongst urban Malaysian adults contribute to glucose intolerance, hypertension and obesity (Khambalia & Seen, 2010; T. O. Lim et al., 2000; Mustafa et al, 2011), and this study has identified the first degree relatives as having a greater association with these factors and with metabolic syndrome than shown by the spousal control group. As the

metabolic syndrome, or its chronic disease components, may lead to chronic kidney disease, it is recommended that all first degree relatives of end-stage renal disease patients be screened for type 2 diabetes, hypertension and chronic kidney disease.

Phase Two provided an opportunity for selected participants to voice their opinions, beliefs, behaviours and frustrations; they gave me a deep appreciation of their lived experience. This facilitated a better understanding of the key drivers behind the Phase One results. The integration of the quantitative and qualitative data was strongly correlated in the areas of food transition and obesity, nutritional marketing companies targeting those with chronic non-communicable diseases, and non-compliance in taking medication. Differences in attitudes and opinions were noted for different age groups. There were also a number of beliefs, behaviours and environment constraints identified as contributing to the nutritional and physical activity inadequacies of the participants. Of concern was participants' meagre knowledge of occupational health and safety issues when handling agrochemicals. A number of barriers, both self-sabotaging such as being too busy to see a doctor, and from the establishment for example no doctors being available at the rural clinics, identified in the qualitative interviews, may influence the quantitative results. The participants' beliefs and attitudes may also be barriers to their following a healthy lifestyle, attending a clinic or seeing a doctor. These barriers need to be addressed by government authorities, health officials, medical personnel and dialysis centre staff in order to identify the first degree relatives with a chronic non-communicable disease in order to delay its development and the progression to metabolic syndrome and chronic kidney disease. If these obstacles, or some of these obstacles, are overcome the community will benefit and it will also, in the long-term, alleviate pressure and expense on the health department.

Marginalised groups, including the dialysis community, need to be given an opportunity to express themselves and to be part of political decision-making processes in matters that concern them (Clark, 2008). It is imperative that this thesis be used as an indispensable avenue for their voices to be heard and for protocols to be reviewed and changed. Future intervention campaigns need to be devised that will persevere with the goal of empowering end-stage renal disease patients and their families to gain more control over their circumstances. This study has uncovered evidence to show that if the first degree relatives in particular, are not screened and do not know they have a

chronic non-communicable disease, they cannot perceive nor consider feasible their risk of needing dialysis in the future. If they are identified early, before symptoms appear, they can be counselled to modify their behaviour before it becomes too late to mitigate the disease.

Having a family member commence dialysis is a traumatic and life-changing event for all in the immediate family. Parallel with population growth and urbanisation, end-stage renal disease in Malaysia is increasing exponentially and is forecast to greatly increase the economic impact on the healthcare system (Hooi, Wong et al., 2005). Based on this study's outcomes, screening of end-stage renal disease patients' extended family members and those with type 2 diabetes, using the ACR and the estimated glomerular filtration rate, is recommended. Community health awareness campaigns by non-doctors, using the metabolic syndrome criteria as a marker, to detect those at high risk of developing a chronic non-communicable disease which may develop into chronic kidney disease, is recommended.

Chronic non-communicable diseases are usually degenerative, resulting in a poor quality of life; however, apart from the genetic aspect, most can be prevented or improved with lifestyle changes (NCCDPHP, 2009). The major chronic non-communicable diseases are cardiovascular disease, cancer, chronic respiratory diseases and diabetes (WHO, 2013a). With unhealthy lifestyles, aging populations are exacerbating the problem (WHO, 2014), and unless all countries address the burden created by these chronic non-communicable diseases, health-care costs will continue to soar (WHO, 2013a).

Government health care policies and management need to be coherent and consistent, and to span all generations. Intervention programs with advice on nutrition, exercise and weight loss can be initiated from the outcomes of this study. Best practices for chronic kidney disease and metabolic syndrome management, has been discussed in the literature review, and these need to be incorporated into preventive intervention measures. Every person who can prevent and delay the onset and progression of a chronic non-communicable disease, metabolic syndrome or chronic kidney disease, by being compliant in taking medicine on a doctor's advice and following a healthy lifestyle program, can expect to increase their longevity and improve their quality of life.

9.2 Summary of the Outcomes for the Study Objectives

9.2.1 The quantitative objectives

A number of strategies and instruments were employed to achieve the forecast outcome for the objectives (*Table 4.3*). This was weighed against the actual outcomes achieved; all targets were met. We cannot control age, ethnicity or family history, but we can control other factors that place populations at risk of developing chronic kidney disease. The non-lifestyle predisposing factors of genetic susceptibility, age and ethnicity were discussed, and the socio-demographic characteristics identified. The lifestyle factors of smoking, drinking alcohol and having type 2 diabetes were discussed. Further exploration of other lifestyle and cultural behaviours and habits were carried forward to Phase Two; these were discussed in the qualitative section. The examination of housing had an interesting outcome, and this should be researched in more depth. Questions on the environment were carried forward for further exploration in the Phase Two semi-structured interviews, and a number of illuminating aspects emerged. Participants with chronic kidney disease were identified. Alcohol was found to be protective for chronic kidney disease in this study; however, it must be noted that the respondents who answered ‘yes’ to drinking alcohol admitted only to moderate alcohol consumption and the exact quantity consumed is not known.

The factor associated with chronic kidney disease, metabolic syndrome, is a composite of metabolic disorders which to a certain extent are lifestyle driven. Although challenging, making behavioural lifestyle changes in the early stages can mitigate complications and delay the progression of a chronic non-communicable disease. The metabolic syndrome and metabolic disturbances in participants were determined. Being a first degree relatives of a person with end-stage renal disease, having a family history of cardiovascular disease, and age are pre-disposing factors and cannot be altered. Smoking is an unhealthy lifestyle habit, and type 2 diabetes is a disease initiated by an unhealthy lifestyle; but both these risk factors for metabolic syndrome can be altered with lifestyle-altering behaviour changes. A number of unpleasant habits and unhealthy lifestyle choices and practices were found to be associated with metabolic syndrome and may be playing a role in its high prevalence rate in Miri. To better understand this, participants’ cultural and lifestyle behaviours were explored in the qualitative interviews.

9.2.2 The qualitative objectives

A number of strategies and instruments were employed to achieve the forecast outcome for the objectives (*Table 6.4*). This was weighed against the actual outcome achieved; all targets were met. The participants had diverse belief systems ranging from totally traditional to totally Western. Their behaviours were dictated by their belief systems. The many stress factors affecting participants, particularly those first degree relatives caring for a relative on dialysis, were discussed. Those from the kampung had conflicting loyalties. There were many barriers impeding them from seeing a Western doctor, from being diagnosed with a chronic non-communicable disease when they did see a doctor, and from being compliant with the doctors' instructions, medication and follow-up treatment. It was found that participants were anxious and confused about the correct medicine and treatment for their particular disease, often choosing to take both Western medicine and traditional herbal medicine at the same time. This could affect the progression of their non-communicable disease and, if they had it, of their chronic kidney disease. Many participants were swayed by modern marketing myths and spent large sums of money on nutritional supplements in preference to Western medicine prescribed by a doctor.

A number of high-risk localities and vulnerable groups were identified. Those in low-cost housing did not have an environment conducive to healthy living. Those using agrochemicals, at work or in their own gardens and farms, needed better health awareness and safety instructions on using toxic agrochemicals safely.

9.3 Strengths of this Study

This Mixed Methods study is ground-breaking and innovative. The advantages of using quantitative methods are that it is 'measurable, has rigour, holds internal validity, generalizability and replicability' (Saks & Allsop, 2013, p. 23). The data collected and analysed in Phase One gave rise to questions that could not be answered using quantitative methods alone. The advantages of using qualitative methods are that it has 'flexibility in thinking, flexibility in research process, has rich description, compensation and validity' (Saks & Allsop, 2013, p. 27). Had this study used only one method, the correlation of data would not have been possible.

Mixed Methods compensates for the weaknesses and draws on the strengths of each methodology; and by corroborating its findings a study is given greater validity (Saks & Allsop, 2013). This study greatly benefited from using Mixed Methods. The qualitative Phase Two supported and complemented the quantitative Phase One by allowing greater detail, such as about the beliefs, behaviours and lifestyle habits of the participants, to be revealed. These explained the reasons underlying the quantitative results and gave insight into aspects that need to be considered and targeted when planning health awareness and intervention programs.

9.4 Limitations of this Study

One limitation to this study is that it was not possible to include a random community control group for comparison with the first degree relative cases and the spousal control group. However, it is impractical to collect data and determine risk factors for rare medical conditions such as end-stage renal disease from the general population (Hulley et al., 2007).

Another limitation was that none of the participants had a medical background and may have been confused by the terminology in the Phase One questionnaire, especially if their mother tongue was a different dialect. In the areas of family and personal medical history, chronic non-communicable diseases and medication, the participants may have been unfamiliar with the medical words used.

This study is a screening study and the food questions in the Phase One questionnaire were not exact, and this may have compromised analysis of food items, food quantities consumed, cooking methods used in the home, eating out habits, changes in physical activity, exercise habits, and changes in medical health.

9.5 Future Directions for Public Health Practice

Based on this pioneering research, community stakeholders and key policy makers will be sent an executive summary outlining the important findings and study conclusions and indicating the suggested interventions and areas for change.

9.5.1 Informing the educators

All health-care providers, nurses and staff working in haemodialysis centres, and those who are caretakers of persons with end-stage renal disease need to be adequately trained. In-house training should be conducted by the centres to further ensure the best duty-of-care for all patients receiving haemodialysis.

An American study found that health care providers and primary care physicians had inadequate knowledge of early recognition of chronic kidney disease in their patients (Israni, Shea, Joffe, & Feldman, 2009) yet if the disease is picked up early the progression can be retarded (C. H. Fox, Brooks, Zayas, McClellan, & Murray, 2006). A mentoring system for all young medical doctors should be set up early in their careers, as often renal patients are not referred to nephrologists until they are quite advanced, in stage 4 or 5. If the patient is identified in stage 2 or 3, medication and lifestyle management may delay their progression to end-stage renal disease and dialysis.

In Sarawak doctors need to be aware that even though their patients pay for the medicine given to them for hypertension and type 2 diabetes, they may not take it, may mix it with traditional herbal medicine, may not renew their prescriptions, or may discard it and solely take traditional herbal medicine or supplements. They need to enquire into their patients' compliance history and to impress upon them the serious need to follow instructions, renew prescriptions and the need to regularly return for followup assessment. They need to make sure that their patients understand that even though they feel fine, if their diabetes or hypertension is not under control, kidney damage may be occurring.

9.5.2 Health awareness and education

Health awareness programs should focus on educating the first degree relatives and empowering individuals and families to make positive lifelong healthy behaviour changes in order to prevent or delay a chronic non-communicable disease or chronic kidney disease.

Diabetes and hypertension, the two main medical conditions leading to end-stage renal disease, may cluster in families, therefore children of parents who have type 2 diabetes or hypertension should be given advice on lifestyle factors influencing the development

of these diseases. According to the National Kidney Foundation, 2.5 million Malaysians suffer from kidney disease and 60% of these are diabetic (Cruetz, 2014). Schools could offer healthy lifestyle programs to instruct young people on the importance of maintaining an ideal body weight, following a healthy diet, and undertaking regular physical activity.

This study found that medical doctors held the most influence in persuading participants to change their lifestyles. Patients want clarification and comprehension of their medical condition so they can be more knowledgeable when addressing unhealthy lifestyle habits. The medical profession should take the lead in delivering health education, both by spending time with their patients and by using public forums, including television and public talks, to highlight the consequences of chronic kidney disease, chronic non-communicable diseases and metabolic syndrome. Registered dietitians, nutritionists and health educators should be employed by medical centres so that busy doctors can refer patients to them for lifestyle medicine as this will improve patient's outcomes and enhance their quality of life.

9.5.3 Intervention planning and programs

This study has identified the need for Miri citizens to change their risky lifestyle behaviours. I propose that, as a public community campaign, the Ministry of Health initiate intervention strategies to address this issue. Medical and health professionals, experts in the area of behavioural modification, and the media should be involved in raising awareness that chronic kidney disease and metabolic syndrome are lifestyle behaviour choices that can be prevented.

9.5.4 Clinical practice and screening programs

I suggest that the criteria for the metabolic syndrome be used as a screening tool to aid local health care (non-doctor) workers target and identify individuals at increased risk of a chronic non-communicable disease, in particular type 2 diabetes, hypertension, cardiovascular disease and chronic kidney disease, in Miri. The familial susceptibility of first degree relatives and the abnormal clinical parameters of the metabolic syndrome need to be recognised to prevent the progression of chronic kidney disease.

Barriers such as lack of staff or time to discuss their medical conditions with patients need to be acknowledged and overcome.

9.5.5 Participants, end-stage renal disease patients, first degree relatives and the spousal control group

Phase Two participants who were first degree relatives of people with end-stage renal disease were aware of the difficulty and stress of having a relative needing dialysis in order to survive. However, most had limited knowledge of the causes of kidney disease, or how to prevent chronic kidney disease or its progression to end-stage renal disease. This needs to be addressed. The best access to the first degree relatives is through the dialysis centre dealing with their end-stage renal disease relatives. First degree relatives and those with metabolic syndrome are potentially at risk and should be targeted for screening; intervention should commence before or in the early stages of a chronic non-communicable disease or chronic kidney disease.

9.5.6 Haemodialysis centres

Local politicians have said that Miri needs to increase its number of haemodialysis units, both government and private, launch satellite dialysis centres, and raise funds to meet the rising needs of those with end-stage renal disease (MRC, 2014). Supported by evidence from this study I advocate that efforts to screen, prevent and delay the development of end-stage renal disease should be part of every Miri haemodialysis centres' overall objective. Early detection of chronic kidney disease and metabolic syndrome will relieve the burden of disease in the future. Efficient screening programs for the first degree relatives specifically, and for anyone who is obese and has metabolic syndrome generally, is cost effective for families and the community in the long-term.

9.5.7 Local Miri community council

This study provides new information and insights into the difficulties experienced by participants in transferring to Miri, which are generalisable to the whole of Sarawak. Those relocating from rural or remote areas should not be neglected when they settle in poorer urban areas. They need proper facilities and health awareness to avert future chronic non-communicable health problems in their community. The World Health

Organization (2013a, p 19) notes that “the underlying determinants of non-communicable diseases often lie outside the health sector”. A paradigm shift in rural and urban development is obligatory for sustainable healthy environments to have priority over profits. Municipal councils should be able to moderate latent negative outcomes of rural to urban migration by innovative town planning aimed at preventing unhealthy lifestyle risks for all its citizens.

9.5.8 State departments

The economic burden of end-stage renal disease on the healthcare system is escalating and this study will make a significant contribution in aiding local health authorities to develop sound intervention strategies targeting high-risk groups. This study supports recommendations that the Sarawak Health Department screen all the first degree relatives of end-stage renal disease patients having type 2 diabetes by the ACR method for determining microalbuminuria. Macroalbuminuria, detected using a dipstick, indicates that kidney damage is advanced. If irreversible impairment to the kidneys have already occurred the chance of preventing end-stage renal disease by medication and lifestyle intervention is diminished. The ACR is also a measure of chronic kidney disease deterioration and useful for determining the progression of the disease.

It is advisable for the Agriculture Department to organise intensive agrochemical occupational safety and health campaigns aimed at rural longhouse folk working in agriculture and the oil palm plantations, as this study has identified them as likely to be exposed to agrochemicals and to not follow safety regulations. The agrochemicals they use may have direct or indirect toxic effects on end-organs such as the kidneys. The environmental impact of agrochemicals on the traditional food and water sources of communities is also of concern, and should be addressed by the department.

9.5.9 The federal ministry

In providing low cost housing for the people, healthy surroundings should be an important part of the planning. Plans should take into account provision of playgrounds, parks, footpaths and cycle paths in addition to all other necessary amenities. There are many developers who will ignore these aspects to reduce costs and increase profits. Conditions requiring adequate road parking spaces, gardens and

community parks should be established when the state gives contractors land to develop at low cost. It is proposed that all plans by developers comply with regulations; an independent body may be needed to enforce a high degree of compliance.

9.6 Future research challenges

I have created a chronological record of all proceedings, including data collection and analysis for future revisitation and planning of intervention strategies; this is available for use by other researchers.

A validated quantitative food frequency questionnaire and a physical activity questionnaire followed up by qualitative observation would give a more accurate assessment of participants' food and exercise behaviours. Quantitative research on the exact quantities of cigarettes and alcohol consumed by participants would be of value in determining the associated risk for chronic kidney disease.

Many of the participants who had medication prescribed for diabetes, high blood pressure and cholesterol by a medical physician did not take the medication as advised, but chose instead to mix it or solely to take traditional herbs and supplements. Studies are needed to understand barriers to compliance and the reasons for choosing between traditional and modern medication.

Many participants viewed traditional herbs and supplements as more natural and just as good as Western medicine; however, research shows this may not always be true. Rigorous scientific studies are needed to ascertain safety parameters for all who take these products.

Many questions arose from this study, particularly in the area of rapid food transition and consequential obesity, showing middle income earners with terrace and low-cost housing, to be at greater risk of metabolic syndrome-associated chronic disease comorbidities. This is contrary to Peninsular Malaysian studies showing lower income earners are at greater risk (Saibul et al., 2009). Further research is needed to investigate this anomaly.

Ideally a study with a random community control group is needed to determine whether the environment is masking genetic factors. Changes in lifestyle such as poor diet and

lack of exercise, plus new environmental factors such as lack of housing space, no available garden, no green space or recreation facilities nearby, and other modern factors are affecting everyone, both the cases and the controls. If all environmental factors were removed, alternatively if all environmental factors were ideal, would the genetic factors of ethnicity, family history predisposition to diabetes, dyslipidaemia or hypertension appear highly significant in the first degree relatives of those with end-stage renal disease? These questions need further investigation.

This study has uncovered health disparities and susceptibilities of an East Malaysian population and, of significance, emerged the impact of urbanization on health. The state and local governments have a responsibility to address all negative socio-economic and environmental determinants of health affecting its population. It is well-advised for the State Planning Unit to recurrently collaborate with local university researchers. Contemplation of evidence-based transformative research and evaluation studies, advocating health-promoting environmental policies, planning and management; contributes to progressive administration.

Concluding Thoughts

*We have the means and the capacity to deal with our problems,
if only we can find the political will.*

Kofi Annan

This study demonstrates that kidney disease encompasses all socio-demographic variables. The age of the participants in this study ranged over three generations and, during the interviews, all mentioned the challenges of adapting to various transitional changes in their lives and the stress of family responsibilities. This stress is amplified radically if one of their family members is receiving haemodialysis therapy. The first degree relatives of children, siblings, spouses or parents with end-stage renal disease, need dependable social support. These primary caregivers, silently apprehensive that they too may eventually end up needing renal replacement therapy like their loved ones; are also the people shown in this study to be the most susceptible for metabolic syndrome and for living in environmentally-unfriendly low-cost housing estates.

The tragic consequences chronic non-communicable diseases incur on individuals were highlighted by the participants throughout the interviews. As a whole, both the case and control groups showed a lack of elementary knowledge regarding metabolic syndrome and how to prevent or mitigate comorbid chronic non-communicable diseases, including chronic kidney disease. Malaysia is leading the region for obesity and type 2 diabetes therefore, medical, health and dietetic professionals, not marketing companies, should organize and provide recurrent health awareness seminars with the aim of empowering individuals to make positive behaviour changes and healthy choices. This study provides sufficiently strong evidence for the State Government in the Planning Unit to sanction only health-promoting environmental policies for residential planning. As society transitions, humanity, stewardship and virtuous political will are integral in creating healthier surroundings; conducive to practicing healthy lifestyles therefore improving the quality of life for all. The equality, dignity and wellbeing of all Sarawak citizens, free of health-seeking anxiety, will be a valuable legacy to leave for posterity.

***We will miss one more of our elders who had been in the unique position of
being in the transition period between the 'old way' and the modern era.***

(Medan, 2015) (Facebook: condolence from a cousin regarding my husband's uncle's passing).

Appendixes

OUTCOMES FROM THIS RESEARCH

Appendix A: Asian Pacific Academic Consortium for Public Health (APACPH) International Conference, Bali, Indonesia. Oral Presentation and Abstract in Conference Magazine, October 2010.

RISK FACTORS FOR CHRONIC DISEASE IN SARAWAK MALAYSIA: A MIXED METHODS STUDY.

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The aim of this study is to inform future intervention programs for the prevention of chronic disease. End-stage renal failure (ESRF) is a debilitating condition that accounts for significant morbidity and mortality. Immediate family members (IFM) of such patients are expected to be at greater risk for chronic kidney disease (CKD) and other lifestyle conditions. This study is being conducted in Miri, Sarawak Malaysia, to understand the ethnic, demographic and socio-economic influence on potential predictors of CKD and associated morbidity. The study employs a two-phase Mixed Methods Sequential Explanatory Design. Phase 1 involves a comparison between IFM of ESRF patients and a control group. Clinical and socio-demographic parameters for CKD, diabetes, hypertension and cardiovascular disease will be measured. This analysis will determine what exposures of interest warrant further exploration. Phase 2 will comprise of a qualitative, in-depth interviews of participants from Phase 1, chosen for low or high risk. This aspect will include examining the beliefs, behaviours, knowledge and their correlation to environmental and socio-demographic variables. The rationale for this mixed methods approach is to facilitate a deeper understanding into the local/ethnic nuances of disease aetiology.

Appendix B: Nutrition Society of Australia (NSA), Scientific Meeting, Perth, Western Australia. Poster Presentation. November 2010.

Determinants of risk of metabolic syndrome in first degree relatives of patients with end stage renal disease.

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Background

End stage renal disease (ESRD) is a debilitating outcome of poorly controlled diabetes and/or hypertension. First Degree Relatives (FDR) of these patients are known to be at greater risk of chronic disease. There is currently no information on familial aggregation, susceptibility and risk factors for MetS in Sarawak, Malaysia; a region with high prevalence of ESRD.

Aim

The aim was to understand the role of ethnic, socioeconomic, diet and lifestyle practices and glucose tolerance in the predisposition to metabolic syndrome (MetS) in FDR of ESRD patients.

Study Design

The overall program has a Mixed Methods Sequential Explanatory Design, and comprises a phase one (quantitative) followed by phase two (qualitative) arm. This paper reports on phase 1 outcomes.

Research Methods

One hundred and thirty five First Degree Relatives of End Stage Renal Disease dialysis patients being treated at three haemodialysis centres in Miri, Sarawak, Malaysia consented to participate, and were compared to a spousal control group (n= 135) of similar age, gender and race with no personal or family history of kidney disease.

All subjects underwent an oral glucose tolerance test, anthropometric measurements and completed a questionnaire in their local language that enquired about socioeconomic status, diet, lifestyle, personal and family medical history. The study had received human research ethics approval from Curtin University.

Data analysis

All data analyses were carried out using the Statistical Package for Social Science (SPSS), release 18.0 (SPSS Inc., Chicago, IL, USA). Multivariable logistic regression was applied to determine factors associated with the risk of MetS. All variables of interest were included in the full model in the initial step and then a backward elimination procedure was applied to obtain the final model by removing those variables with a non-significant effect, using 5% critical value of χ^2 test for the appropriate degrees of freedom.

Factors associated with presence of metabolic syndrome in FDR of ESRD patients.

Variable	Number	Adjusted OR	95% CI
Age	270	1.029	1.004, 1.055
Race			
Indigenous	125	1	
Malay	37	0.373	0.133, 1.052
Chinese	108	0.196	0.087, 0.44
Smoking			
No	230	1	
Yes	40	3.55	1.290, 9.79
Diabetes			
Normal	130	1	
IFG	79	3.61	1.62, 8.09
IGT	37	4.14	1.61, 10.64
DM	24	21.75	6.25, 75.69
Salt intake			
Never	39	1	
Sometimes	175	1.86	0.65, 5.36
Often	56	5.75	1.70, 19.31
FDR			
No	135	1	
Yes	135	2.27	1.19, 4.34
F/H of Hypertension			
No	55	1	
Unknown	26	2.14	0.53, 8.67
Yes	189	2.92	1.17, 7.25
F/H of CHD			
No	179	1	
Unknown	49	1.01	0.40, 2.57
Yes	42	2.72	1.07, 6.92

Non-significant variables were gender, alcohol drinking status, chewing betel nuts, chewing tobacco, family history of diabetes, family history of high cholesterol, family history of stroke, fried food intake, MSG intake, prawn/fish intake, preserved food intake, meat intake, sugar intake, supplement intake, total amount of vegetables and fruit intake, and times doing moderate/vigorous activities per week.

Conclusions

First degree relatives of ESRD patients, and indigenous Malaysians have significantly greater risk of MetS. Public health measures should target modifiable factors like smoking, salt intake and deterioration in glucose tolerance.



Appendix C: Mark Liveris Student Research Seminar Program, The Faculty of Health Sciences, Curtin University, Western Australia. Abstract, November 2014.

RISKY HEALTH BELIEFS AND BEHAVIOURS OF PERSONS USING AGROCHEMICALS: A QUALITATIVE STUDY IN SARAWAK, MALAYSIA.

Presented by: Sheryl Mattu, School of Public Health

Course: Doctor of Philosophy

Supervisor: A/Prof Mario Soares, School of Public Health

A/Supervisor: Dr JA Lewis

Background/Aims: There is increasing evidence linking the excessive use of synthetic agrochemicals with Chronic Kidney Disease (CKD) in tropical developing countries. The study aim was to explore and identify beliefs and behaviours of participants at risk of chronic kidney disease, with regard to chemical use.

Methods: Thirty-two participants were identified as the sixteen best and sixteen worst scores of a quantitative survey that screened for CKD. CKD was based on kidney function (estimated glomerular filtration rate $<60 \text{ mL/min/1.73 m}^2$) and/or kidney damage (Urine albumin : creatinine ratio $>25 \text{ mg/mmol}$). They were invited to participate in semi-structured qualitative interviews that enquired about the participant's home environment, work and gardening-related practices. Translators interviewed the participants in their preferred tongue. The data was analysed for themes by the NVivo software.

Results: Seventy-five per cent interviewed used multiple chemicals on a regular basis. The group with the best CKD scores had a greater knowledge of agrochemicals, were more likely to adhere to safety precautions or hired others to do the work. Our overall findings were as follows: Indigenous people predominately worked in the agriculture and plantation sectors; They mixed and sprayed an assortment of fertilisers, pesticides and herbicides; They mostly did not follow standardised safety regulations to minimise direct exposure to the chemicals; Many held mistaken beliefs or were unaware of the

toxicity of the agrochemicals; The crops they grew were subjected to multiple applications of agrochemicals.

Conclusions: Food safety awareness, occupational health and safety intervention and education campaigns are needed in Sarawak, Malaysia.

Funding source: Sarawak Shell.

Appendix D: Mark Liveris Student Research Seminar, The Faculty of Health Sciences, Curtin University, Western Australia. Oral Presentation and Static Slide, November 2014.

RISKY HEALTH BELIEFS AND BEHAVIOURS OF PERSONS USING AGROCHEMICALS: A QUALITATIVE STUDY IN SARAWAK, MALAYSIA



Three photographs showing people using agrochemicals in a plantation setting. The first shows a person in a blue shirt and hat spraying plants. The second shows a person in a white shirt spraying plants. The third shows a person in a white shirt and green pants kneeling and spraying a yellow container.

Recommendations: Food safety awareness, occupational health and safety intervention, and education campaigns need to target vulnerable groups in Sarawak, Malaysia.

Photos of plantation sprayers in Borneo.

Talk by:
Sheryl Joy Mattu
PhD candidate –
School of Public Health,
Curtin University, WA.



Two photographs showing people in protective gear using agrochemicals. The first shows two people in red protective suits and masks spraying plants. The second shows a person in a green protective suit and mask spraying a field.

Appendix E: Nutrition Society of Australia (NSA) 38th Annual Scientific Meeting, Hobart, Tasmania. Poster Presentation with Short Talk, November 2014.

RISKY HEALTH BELIEFS AND BEHAVIOURS OF PERSONS USING AGROCHEMICALS: A QUALITATIVE STUDY IN SARAWAK, MALAYSIA.



SJ Mattu, JA Lewis, MJ Soares.

Directorate of Nutrition, Dietetics & Food Technology, School of Public Health, Curtin University, Perth, Western Australia.

Introduction:

Miri, Sarawak, East Malaysia, is located on the equatorial island of Borneo and has an ethnic mix of Malay, Chinese, Indian and 27 main Indigenous Tribal groups¹.

Over the past few decades, after an area of rainforest is logged, it is replaced with oil palm plantations where various agrochemicals are used². In Malaysia, there are agrochemical regulations in place, however they are not always rigorously enforced.

In the hot, humid climate workers are sweaty, do not use protective clothing and gear and are dehydrated³. Herbicides and pesticides are readily absorbed through damp skin and dehydration increases the body's sensitivity to the chemicals³.

There is accumulating evidence linking the excessive use of synthetic agrochemicals with CKD in tropical developing countries⁴.



Figure 1: Monoculture Oil Palm plantations are being developed on thousands of hectares of land throughout Sarawak.

Aims:

The study aim was to explore and identify beliefs and behaviours of participants at risk of CKD, with regard to chemical use.

Recruitment:

This report is on phase two of a Mixed Methods Sequential Explanatory Design⁵.

Thirty-two participants were identified as the sixteen best and sixteen worst scores of a quantitative survey that screened for CKD.

CKD was based on kidney function (estimated glomerular filtration rate <60 mL/min/1.73 m²) and/or kidney damage (Urine albumin:creatinine ratio >25 mg/mmol)⁶.



Figure 5: 600 people live in this Indigenous longhouse. Workers use agrochemicals in the surrounding Oil Palm plantation.

Methods:

The participants were invited to participate in semi-structured qualitative interviews that enquired about their home environment, work place activities and gardening-related attitudes and practices.

Translators were given training in qualitative interview techniques and interviewed the participants in their preferred tongue.

They were blinded to the participant's disease condition, socio-demographic or economic profiles.

The data collected was analysed for themes using the NVivo software.

Results:

Seventy-five percent interviewed used multiple chemicals on a regular basis. The group with the healthiest CKD scores had

- a greater knowledge of agrochemicals,
- were more likely to adhere to safety precautions
- or hired others to do the work.



Figure 6: This Indigenous lady sprayer is not following safety regulations regarding toxic exposure to agrochemicals.

Results:

Findings that emerged from the interviews:

- Indigenous people predominately worked in the agriculture and plantation sectors;
- They mixed and sprayed an assortment of fertilizers, pesticides and herbicides;
- They mostly did not follow standardized safety regulations to minimize direct exposure to the chemicals;
- Many held mistaken beliefs or were unaware of the toxicity of the agrochemicals;
- The crops they grew were subjected to multiple applications of agrochemicals.

Conclusion

Food safety awareness, occupational health and safety intervention and education campaigns need to target vulnerable groups in Sarawak, Malaysia.

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Acknowledgements:

Sarawak Shell Berhad funded the study. We thank Dr RD Mattu, the translators and the study participants for their valuable contributions.

Contact:

sheryl_joy@hotmail.com

Appendix F: *European Journal of Clinical Nutrition (EJCN)*, article (pending acceptance). Abstract.

METABOLIC SYNDROME IN FIRST DEGREE RELATIVES OF PATIENTS WITH END-STAGE RENAL DISEASE: A CASE-CONTROL STUDY IN SARAWAK, MALAYSIA.

Background: Family members of patients with End-Stage Renal Disease (ESRD) have a higher risk of renal and other diseases. The metabolic Syndrome (MetS) is linked to deterioration of kidney function.

Objective: The objective was to investigate the role of socio-demographic, lifestyle factors and glucose intolerance in the predisposition to metabolic syndrome in First Degree Relatives (FDR) of ESRD patients.

Design: One hundred and thirty FDR relatives of ESRD patients from Miri in Sarawak, Malaysia were compared to a Spousal Control Group (SCG) (n= 135) of similar age, gender, ethnicity and without family history of kidney disease. All subjects underwent biochemical tests, anthropometric measurements and completed a medical history questionnaire in their local language. The study received approval from Curtin University Perth, Australia.

Results: First degree relatives had a significantly greater prevalence of MetS but were similar in ethnicity, socio-demographic characteristics and markers of Chronic Kidney Disease (CKD) to the spousal control group. Multiple logistic regression analysis indicated that (1) age, (2) being a first degree relative, (3) having a family history of hypertension, (4) smoking, (5) added salt intake, (6) glucose intolerance, and (7) residing in terraced or low-cost housing were independently associated with greater odds for MetS.

Conclusion: The study highlights tangible targets for the early detection and attenuation of MetS in this population group.

Key words: renal failure, metabolic syndrome, housing, first degree relatives, chronic kidney disease.

Appendix G: Permission to Reproduce Table 3.5

RE: Copyright Permission

SCHN-CHW-CARI (SCHN-CHW-CARI@health.nsw.gov.au)

To: Sheryl Mattu, SCHN-CHW-CARI

Hi Sheryl

That is fine considering your acknowledgement of the source.

Regards

David Tunnicliffe

David Tunnicliffe | KHA-CARI Research Officer | Centre for Kidney Research Clinical

t: (02) 9845 1470 | **f:** (02) 9845 1491

| **e:** david.tunnicliffe@health.nsw.gov.au | **w:** www.schn.health.nsw.gov.au

Cnr Hawkesbury Road and Hainsworth Street, Westmead, NSW Australia

Locked Bag 4001, Westmead 2145, NSW Australia

From: Sheryl Mattu [mailto:sheryl_joy@hotmail.com]

Sent: Tuesday, 3 November 2015 7:39 PM

To: SCHN-CHW-CARI

Subject: Copyright Permission

Dear Madam/Sir,

I am a PhD (Public health) student with Curtin University Perth Australia. My thesis focuses on Chronic Kidney Disease and metabolic Syndrome and is a case-control mixed methods study on end stage renal disease first degree relatives in Sarawak, Malaysia. I wish to ask permission to use the online KHA-CARI Guidelines, diagram b and c, duly acknowledged, of the Chronic Kidney Disease Guidelines 'Diagnosis, Classification and Staging of Chronic kidney Disease May 2013' Author David Johnston (written July 2012) in my thesis literature review chapter as it clearly illustrates staging in the diagnosis of chronic kidney disease. I look forward to hearing from you with regard to this soon. Thank you.

Yours sincerely,

Sheryl Joy Mattu sheryl_joy@hotmail.com

Appendix H: HREC Letter of Approval



Office of Research and Development
Human Research Ethics Committee

memorandum

To	Dr Janice A Lewis, Public Health
From	A/Professor Stephan Millett, Chair, Human Research Ethics Committee
Subject	Protocol Approval HR 07/2009
Copy	Sheryl Joy Mattu Public Health Graduate Studies Officer, Faculty of Health Sciences

Thank you for providing the additional information for the project titled "Health Beliefs and Behaviour of a Population Screened for Chronic Kidney Disease in Sarawak: A mixed Methods Study". The information you have provided has satisfactorily addressed the queries raised by the Committee. Your application is now **approved**.

- You are authorised to commence your research as stated in your proposal.
- The approval number for your project is **HR 07/2009**. Please quote this number in any future correspondence.
- Approval of this project is for a period of twelve months **31-03-2009 to 31-03-2010**. To renew this approval a completed Form B (attached) must be submitted before the expiry date **31-03-2010**.
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Divisional Graduate Studies Committee.
- The following standard statement **must be** included in the information sheet to participants:
This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 07/2009). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **FORM B** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development:

When the project has finished, or

- If at any time during the twelve months changes/amendments occur, or
- If a serious or unexpected adverse event occurs, or
- 14 days prior to the expiry date if renewal is required.
- An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Regards,

A/Professor Stephan Millett
Chair Human Research Ethics Committee

Appendix I: Permission to use STEPS Questionnaire: WHO

From: Guthold, Regina
To: mracs_hru@streamyx.com
Cc: Riley, Leanne ; Herren, Catherine E. ; Cowan, Melanie
Sent: Thursday, December 11, 2008 11:33 PM
Subject: RE: use of STEPS questionnaire

Dear Sheryl,

thank you very much for your message and interest in using the STEPS questionnaire. My name is Regina, and I work for the Surveillance team within the Department of Chronic Diseases and Health Promotion at WHO Geneva.

I cc Leanne Riley who is our team leader, as well as my colleagues Melanie Cowan and Catherine Herren (Catherine is our assistant). You are most welcome to use the STEPS instrument in your study. However, please note that this instrument has been developed for large population-based surveys that aim to determine levels of risk factors for chronic diseases, so it is fine to use it if you want to determine these levels in your population. The STEPS instrument (although capturing blood pressure and blood glucose values) has not been developed to diagnose individuals suffering from diabetes or hypertension.

Usually, we recommend countries to use sample sizes of several thousand individuals as STEPS data normally gets reported in 10-year age groups. For small sample sizes like yours, levels of risk factors should only be reported for the whole sample as otherwise sizes get too small.

I hope this information helps. It would be great if you could keep us up-to-date on how you are going with the instrument. Please note that programs are available to analyse STEPS data in EpiInfo, these are available at <http://www.who.int/chp/steps/resources/database/en/index.html>

All the best and good luck with the study!

Regina
Regina Guthold, MPH
STEPwise approach to surveillance
Chronic Diseases and Health Promotion
WHO Geneva

e-mail: gutholdr@who.int

Tel.: +41 (22) 791 1051

Appendix J: Permission to use NCD Questionnaire: MMOH

NCD Surveillance Questionnaire

From: **feisul mustapha** (dr.feisul@moh.gov.my)

Sent: Thursday, 4 December 2008 3:23:42 PM

To: sheryl_joy@hotmail.com

Dear Sheryl,

Please include the following text for your acknowledgement:

Questionnaire used for the "Malaysia NCD Surveillance 2006: NCD Risk Factors in Malaysia".

Non-Communicable Disease Section,
Disease Control Division
Ministry of Health, Malaysia
Putrajaya

Looking forward to reading your report once its completed. Feel free to drop by if you are ever around. In addition, if you would like a copy of the MyNCDS-1 report, give me your mailing address.

Feisul


--

Dr. Feisul Idzwan Mustapha
Public Health Physician
Cardiovascular Diseases & Diabetes Unit
Non-Communicable Disease Section
Disease Control Division
Ministry of Health, Malaysia
Level 6, Block E10, Complex E
Federal Government Administrative Centre
62590 PUTRAJAYA
Malaysia

Phone: +603-8883 4117

Fax: +603-8888 6277

Appendix K: MRCDC Letter of Approval

 **PERSATUAN BULAN SABIT MERAH MALAYSIA**
(MALAYSIAN RED CRESCENT SOCIETY, MIRI CHAPTER)
(馬來西亞紅新月會，美里區會)

Lot 312, Jalan Bulan Sabit, Krokop 1, P. O. Box 370, 98007 Miri, Sarawak.
Tel: 085-411121/428032/413346 Fax: 085-420479
Email: mrcsmi@po.jaring.my Website: www.sarawak.com.my/org/mrcs_miri
Sunflower Centre: Tel: 085-420722 / 425421 Kidney Dialysis Centre: Tel: 085-436862

18.07.2008

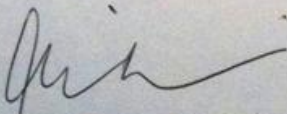
University Ethics Committee,
Curtin University of Technology,
Perth, Western Australia.

The Miri Red Crescent Dialysis Centre (MRCDC) Management Committee support Sheryl Mattu in the study undertaken at the MRCDC as outlined in the research proposal, while being under the supervision of Professor Paola Ferroni, Centre for International Health, Curtin University, Perth, WA.


The MRCDC Management Committee agree to allow Sheryl Mattu to collect data for her Doctorate as outlined in the Research Proposal, while being under the supervision of Professor Paola Ferroni, Centre for International Health, Curtin University, Perth, WA.

The MRCDC Health Research Committee has reviewed the study design, methodology and ethical issues pertaining to the Research Proposal and has agreed and recommended to the MRCDC Management Committee that this study be permitted to commence upon the approval from Curtin University Ethics Committee.

Yours truly,



YB Lee Kim Shin
The Chairman,
Miri Red Crescent Dialysis Centre Management Committee,
Malaysian Red Crescent, Miri Chapter.

Member of the International Federation of Red Cross & Red Crescent Societies 

ETHICS DOCUMENTS: PARTICIPANTS

Appendix L: Invitation letter given to end-stage renal disease patients

English, Malay, Mandarin and Iban

YOU are invited to Participate in a research study on Chronic Kidney Disease in Sarawak

An Invitation to All Family Members and Friends Of End Stage Renal Failure Patients

Are you:

- The father or mother; the brother or sister; or the son or daughter; of someone who has now, or had (prior to death), End Stage Renal Failure and on haemodialysis or peritoneal therapy?
- Over 18 years of age?
- Wish to be screened for your risk of developing Chronic Kidney Disease, which may lead to future End Stage Renal Failure?
- A friend or someone interested in knowing if you are at high risk for Chronic Kidney Disease?

This Case-Control study on Chronic Kidney Disease in Sarawak is now recruiting participant Cases and Controls for screening.

A case is anyone with a relative with End Stage Renal Failure and a Control is anyone without a relative with End Stage Renal Failure and who would like to participate in this study.

The data collection centre is at Gribbles Pathology Laboratory above the Columbia Asia Medical Centre, Miri.

Data Collection to commence in August 2009.

All tests are FREE for all the participants.

Limited number only. First come, first serve basis.

All information received will be kept strictly confidential.

Participants will receive their original results and reports.

To participate in this study, or for more information,
please telephone / SMS: 019-885 6233 and ask for Joy.
Or email: ckd.study@live.com

This study has been approved by Curtin University Perth,
Human Research Ethics Committee and the
Columbia Asia Medical Center, Medical Committee.

Sponsored By

COLUMBIA ASIA MEDICAL CENTER
GRIBBLES PATHOLOGY
CURTIN UNIVERSITY &
SARAWAK SHELL BERHAD

邀請參與在砂羅越慢性腎病 研究工作

特別邀請所有的末期腎衰竭 病患者的親朋戚友們來參與

以下的類型是有助於這探究:

如果您是:

- 認識病患者有末期腎衰竭或靠血液透析(洗腎)或靠腹膜透析治療的直系親屬
- 超過十八歲;
- 任何人對慢性腎病能導至末期腎衰竭的高風險感興趣或希望受檢查。

這慢性腎病的病例研究工作在砂羅越已經招募患者及抑制者來參與檢查。患者是任何人的親屬者有末期腎衰竭。抑制者是任何人的親屬有腎病但沒有末期腎衰竭而且有興趣參與這研究工作。

這病例資料收集中心是美里GRIBBLES PATHOLOGY

LABORATORY (在哥倫比亞亞洲醫院的樓上)。

- 病例資料在二零零九年八月開始收集。
- 所有檢驗免費於參與者。
- 參與者人數有限制, 先來者有優先。
- 所有提供的資料將會嚴格受保密。
- 原本的檢驗結果及報告會給予參與者。

如要參與或要知更多的資料, 請和JOY聯絡。

手機號碼/SMS: 019-885 6233 或 email: ckd.study@live.com

這研究工作是通過在伯斯(Perth)科廷(Curtin)理工大學的人, 類道德學研究委員會及美里的哥倫比亞亞洲醫院, 醫學道德學委員會批准的。

贊助者:

美里哥倫比亞亞洲醫院
GRIBBLE PATHOLOGY (MIRI)
科廷理工大學和砂羅越殼牌石油公司

Anda adalah dijemput untuk menyertai satu kaji selidik mengenai penyakit buah pinggang yang berlaku dengan serius di Sarawak.

Jemputan ini adalah terbuka kepada semua ahli keluarga dan kawan-kawan kepada seseorang yang mengalami penyakit buah pinggang yang sudah rosak.

Adakah Anda:

- Seorang bapa atau emak; seorang abang, kakak atau adik; atau seorang anak; kepada seseorang yang sekarang ini mengalami penyakit buah pinggang atau sudah meninggal dunia akibat penyakit buah pinggang, seseorang yang memiliki buah pinggang yang sudah rosak dan sekarang sedang dalam rawatan haemodialysis atau peritoneal?
- Adakah anda berumur 18 tahun ke atas?
- Ingin di skrining untuk mengetahui apakah anda berisiko kepada penyakit buah pinggang, di mana berkemungkinan pada masa depan buah pinggang anda akan rosak?
- Seorang kawan atau seseorang yang berminat ingin mengetahui kalau anda berkemungkinan berisiko kepada penyakit buah pinggang yang teruk?

Kajian kes-kawalan mengenai penyakit buah pinggang yang berlaku dengan serius di Sarawak sedang rekrut Kes dan Kawalan untuk diskinkan. Kes ialah seseorang yang ada sanak-saudaranya menghidap penyakit buah pinggang di peringkat akhir dan Kawalan ialah seseorang yang tidak ada sanak-saudaranya yang menghidap penyakit buah pinggang di peringkat akhir dan juga seseorang yang ingin terlibat dalam kajian ini. Pusat pengumpulan maklumat adalah di Gribbles Pathology Laboratory di atas Columbia Asia Medical Centre, Miri.

Pengumpulan maklumat akan bermula pada bulan Ogos 2009.

Pemeriksaan ke atas semua peserta adalah percuma.

Jumlah peserta adalah terhad, dasar Siapa cepat dia dapat.

Semua maklumat yang di terima akan disimpan sebagai maklumat sulit.

Peserta akan menerima keputusan dan laporan mereka yang asli.

Untuk menyertai kajian ini atau untuk maklumat lanjut, silalah.

Telefon / SMS: 019-885 6233 dan cari Joy.

Atau email: ckd.study@live.com

Kajian ini adalah diluluskan oleh Curtin University Perth,
Jawatankuasa Komiti Kajian Etika Sumber Manusia dan
Columbia Asia Medical Center, Medical Committee.

Diraja oleh:

COLUMBIA ASIA MEDICAL CENTER
GRIBBLES PATHOLOGY
CURTIN UNIVERSITY &
SARAWAK SHELL BERHAD

Nuan dikangau enggau dalam pansik pelajar pasal Penyakit Tungkul Sengayuh di Sarawak

Kangau tu nuju semua kita sebilik enggau pangan sida ti kala kena Penyakit Tungkul Sengayuh ti raya bendar

Kati nuan:

- Apal tauka indai; menyadi lelaki tauka menyadi indu; anak lelaki tauka anak indu; sida ti bisi kena penyakit tu, tauka (bala kita sebilik bisi udah mati ketegag penyakit tu), agi berubat ketegag penyakit tu?
- Be-umor 18 laun keatas?
- Deka minta diperesa pengeral nyangka bisi ngambilan Penyakit Tungkul Sengayuh, ti tau ngujung ka kena Penyakit Tungkul Sengayuh ti raya jemah ila?
- Pangan tauka nuan empu deka nemu nyangka diri empu tau kena Penyakit Tungkul Sengayuh?

Nyadi pansik pelajar pasal Penyakit Tungkul Sengayuh di Sarawak tu diatu benung ngau orang awak ke bisi diperesa sida. Orang ti deka diperesa dalam pansik tu lanya sebarang sapa ti bisi kaban-belayan ti bisi Penyakit Tungkul Sengayuh ti udah raya, lalu dibanding ka enggau sida kaban-belayan ti nadai kala kena Penyakit Tungkul Sengayuh sereta enggau sebarang sapa ti deka enggau dalam pelajar pansik pasal penyakit tu. Endor ngumpul pansik tu lanya ba Gribbles Pathology Laboratory diatas Columbia Asia Medical Centre, Miri.

Pengawa ngumpul pansik tu belabuh bulan Ogos 2009.

Semua pengawa maresa pengeral tu diberi pecuma

ngagal semua ti enggau dalam pansik tu.

Penyampau orang ti diterima bisi sekat. Sapa dulu,

orangnya meh ti deka diperesa pengeral enggau pecuma.

Semua informasi ti diterima dekan disimpan enggau cukup likun.

Sida ti enggau dalam pansik tu deka nerima pemutus

peresa enggau riopot pengeral ti asal.

Enti deka enggau dalam pengawa pansik tu, tauka deka nemu enggau lebih dalam agi, kita tau be-talipun / SMS ngagal: 019-885 6233 lalu minta bejaku enggau Joy. Tauka emel: ckd.study@live.com

Pelajar pasal pansik tu udah dikemendar ka ulih Curtin University, Perth,
Human Research Ethics Committee sereta enggau
Columbia Asia medical Center, Medical Committee.

Dibayar ulih:

COLUMBIA ASIA MEDICAL CENTER
GRIBBLES PATHOLOGY
CURTIN UNIVERSITY &
SARAWAK SHELL BERHAD

Appendix M: Invitation Letter: For the first degree relatives's and Spouses

AN INVITATION TO PARTICIPATE IN THE
MIRI KIDNEY RESEARCH STUDY

THE RESEARCH – I am researching the local risk factors associated with Chronic Kidney Disease (CKD) among First Degree Relatives (FDR) of End-Stage Renal Disease (ESRD) patients who are receiving dialysis at the Miri Red Crescent Dialysis Centre, the Haemodialysis Unit of the Miri General Hospital and the Miri City Medical Centre Dialysis Unit. The hope is that local information regarding socio-demographic, lifestyle and metabolic factors that increase risk for developing chronic kidney disease and ultimately end-stage renal disease, in the end-stage renal disease patient's first degree relatives in particular, will be identified. Please read the Information Sheet on this study and ask your family members to read it also.

THE STUDY DESIGN – This is a Case-Control study. I would like to invite you to participate as either a Case or a Control in this study. If you are over 18 years of age and willing to participate in this study, please fill out the attached CASE or CONTROL form.

Cases – Are the first degree relative's of the end-stage renal disease patient and includes being their parents, their siblings and their children.

Controls – Are the non-genetic relatives of the first degree relative's spouse, the first degree relatives's sibling's spouses, the first degree relatives's sibling's children's spouses and the first degree relatives's children's spouse's family and relatives. The Control needs to be matched by age, ethnicity and if possible by gender to the Case. For example, if the first degree relatives's brother aged 53 years is available to be a Case in this study then the spouse's families need to be asked to find a male aged around 53 years old and who is willing to participate as a Control in this study. If they agree, please fill out the attached CONTROL form. Likewise for your child or parent.

It is hoped that at least two (2) first degree relatives of the end-stage renal disease Patient and two (2) in-laws agree to participate as cases and controls in this study.

Please call, sms or email as soon as possible for an appointment for you to come for data collection. You must make an appointment in order to participate. All the assessments and laboratory blood and urine tests will be taken at Gribbles Pathology Laboratory, Miri. Both the case and control should come to the laboratory at the same time. All tests will be **free** of charge to participants. A limited number only. First come, first serve basis.

Please call, sms or email to make an appointment, if you request more information or have questions regarding this research:

The Health Researcher:

H/Ph : 0198856233 Fax : 085-653135

Email: ckd.study@live.com.

CASE AND CONTROL FORM

CASE No:..... First degree relative of the end stage renal disease patient, ie. parents, siblings and children. Must be over 18 years of age. Able to travel to Gribbles Pathology Laboratory (Columbia Asia) .

Name:..... New I.C. No:.....

Age:.....Gender:.....Ethnicity:.....

Language prefer to use in this study: Spoken.....Written.....

Contact numbers: House Phone.....Hand Phone.....

Where do you live?

Tests will only be done at the Gribbles Pathology Laboratory, in the mornings between 8.00-11.00am. Which days suit you best for an appointment? :.....

You will be contacted by either house phone or hand phone and an appointment date made.

Signature Thank you for participating in this worth-while project.

CONTROL No:..... The spouse's relatives. In-laws not genetically related to the end stage renal disease patient. Must be over 18 years of age. Matched by age, ethnicity and/or gender to the Case. Able to travel to Gribbles Pathology Laboratory (Columbia Asia).

Name:..... New I.C. No:.....

Age:.....Gender:.....Ethnicity:.....

Language prefer to use in this study: Spoken.....Written.....

Contact numbers: House Phone.....Hand Phone.....

Where do you live?

Tests will only be done at the Gribbles Pathology Laboratory, in the mornings between 8.00-11.00am. Which days suit you best for an appointment?:.....

You will be contacted by either house phone or hand phone and an appointment date made.

Signature Thank you for participating in this worth-while project.

JEMPUTAN UNTUK MENGAMBIL

BAHAGIAN DALAM KAJIAN PENYELIDIKAN

PENYAKIT BUAH PINGGANG MIRI.

PEYELIDIKKAN – Saya merupakan penyelidik yang menjalankan kajian mengenai risiko masalah penyakit buah pinggang yang sering kali berlaku di kalangan ahli keluarga bagi pesakit buah pinggang yang menerima rawatan di pusat dialisis bulan sabit merah, unit rawatan Haemodialisis hospital Miri dan Unit Dialisis Miri City Medical Centre. Ini berharap dengan maklumat yang diterima dapat membantu mengetahui mengenai socio-demographic, gaya-hidup, dan faktor metabolik peningkatan risiko perkembangan penyakit buah pinggang (chronic kidney disease) serta yang tahap kronik (end stage renal disease). Sila baca maklumat mengenai penyelidikkkan dan kongsi maklumat penyelidikkkan bersama ahli keluarga yang lain.

TUJUAN KAJIAN PEYELIDIKKAN – Penyelidikkkan ini adalah mengenai kajian kes-kawalan penyakit buah pinggang. Dengan ini, saya ingin mengajak anda untuk menjadi peserta dalam kajian penyelidikkkan ini. Jika anda berumur 18 tahun ke-atas dan berminat untuk mengambil bahagian dalam kajian penyelidikkkan ini, anda diminta untuk mengisi borang kes atau kawalan yang telah disediakan.

Kajian Kes – Terdiri dari dikalangan ahli keluarga (first degree relatives) pesakit buah pinggang tahap serius (end stage renal disease) dan termasuklah ibu/bapa, adik-beradik dan anak-anak pesakit sendiri.

Kajian Kawalan – Bukan terdiri dari dikalangan ahli keluarga, seperti ahli keluarga sebelah pihak suami/isteri, saudara-mara ataupun sahabat anda. Bagi kajian kawalan ini, persamaan umur, keturunan dan jantina, untuk dibandingkan dengan kajian kes adalah diperlukan, Mencontohi, jika abang kepada (first degree relatives) yang berumur 53 tahun berminat mengambil bahagian sebagai kajian kes, maka isteri kepada abang (first degree relatives) diminta untuk mencari individu dari ahli keluarga sebelahnya atau saudara-mara yang sama jantina, dan keturunan sekitar umur 53 tahun. Dimana ia juga berminat mengambil bahagian sebagai peserta dalam kajian kawalan ini.

Ini berharap peserta yang mengambil bahagian sekurang-kurangnya dua (2) first degree relatives bagi pesakit end stage renal disease dan dua (2) ahli saudara pihak suami/isteri ataupun sahabat yang bersetuju mengambil bahagian sebagai kes dan kawalan dalam penyelidikan ini. Sila hubungi, sms atau menghantar email kepada kami secepat mungkin untuk mendapatkan temujanji bagi mengumpul maklumat data anda dan sebagai peserta anda mestilah mendapatkan temujanji. Bagi semua sampel darah dan air kencing, ia akan diambil di Makmal Gribbles Pathology Miri. Bagi kedua-dua peserta kes dan kawalan, mereka dipinta datang pada masa yang sama. Semua ujian yang dilakukan adalah **percuma**. Penyertaan ini adalah terhad.

Sila menghubungi, sms atau menghantar email bagi membuat temujanji ataupun jika ada sebarang pertanyaan mengenai kajian. Dengan merujuk maklumat dibawah;

The Health Researcher

H/Ph : 0198856233 Fax : 085-653135

Email: ckd.study@live.com

BORANG KES ATAU KAWALAN

NO KES: : Ahli keluarga bagi pesakit buah pinggang tahap akhir (end stage renal disease), sprt. Ibu / bapa, adik-beradik serta anak yang berumur lebih daripada 18 tahun ke-atas. Dapat mengunjungi Makmal Pathologi Gribbles (Columbia Asia).

Nama Kes : No Kad Pengenalan (Baru):

Umur: Jantina: Bangsa:

Pilihan bahasa yang digunakan dalam kajian penyelidikan ini : Percakapan Tulisan.....

Hubungi nombor : Telefon Rumah Telefon Bimbit

Dimanakah tempat kediaman anda sekarang?

Ujian ini hanya akan dijalankan di Makmal Pathologi Gribbles, pada sebelah pagi dalam masa pukul 08:00 pg-11:00pg. Apakah masa terbaik sesuai bagi anda untuk temu janji?

Anda akan dihubungi ke nombor talian rumah atau telefon bimbit setelah temu janji dibuat.

TandatanganTerima kasih bagi penyertaan anda dalam menjayakan projek ini.

NO KAWALAN : : Saudara-mara sebelah suami/isteri, sebaiknya bukan terdiri daripada ahli keluarga pesakit buah pinggang tahap akhir (end stage renal disease). Semestinya berumur lebih daripada 18 tahun ke-atas. Dapat mengunjungi Makmal Pathologi Gribbles (Tingkat 2 Columbia Asia Specialist Clinic).

Nama Kes : No Kad Pengenalan (Baru):

Umur: Jantina: Bangsa:

Pilihan bahasa yang digunakan dalam kajian penyelidikan ini : Percakapan..... Tulisan.....

Hubungi nombor : Telefon Rumah Telefon Bimbit

Dimanakah tempat kediaman anda sekarang?

Ujian ini hanya akan dijalankan di Makmal Pathologi Gribbles, pada sebelah pagi dalam masa pukul 08:00 pg-11:00pg. Apakah masa terbaik sesuai bagi anda untuk temu janji?:.....

Anda akan dihubungi ke nombor talian rumah atau telefon bimbit setelah temu janji dibuat.

TandatanganTerima kasih bagi penyertaan anda dalam menjayakan projek ini.

Appendix N: Information sheet for participants

Study Focus

- The First Degree Relatives of End Stage Renal Disease patients.
- Screening for the main risk factors and causes of end stage renal disease in Malaysia: Chronic Kidney Disease, diabetes, hypertension and cardiovascular disease.
- Using the metabolic Syndrome set sup-off points to determine the abnormal clinical parameters for the risk factors.
- The socio-demographic and lifestyle exposures of interest.
- Beliefs, behaviour and health-related lifestyle choices with regard to risk factors for chronic kidney disease.

Quantitative Phase One Research Methods include the following:

- **Laboratory investigations:** the metabolic syndrome set cut-off points will be used to identify abnormal clinical parameters for central obesity; HDL; LDL; triglycerides; blood pressure; plasma glucose; endothelial function; and microalbuminuria.
- **Anthropometric measurements:** height; weight; waist circumference; waist-hip ratio; body mass index; skinfold fat.
- **A standardised self-administered questionnaire:** socio-demographic, lifestyle, medical history, diet and physical activity.

Data Collection will be undertaken at the Gribbles Pathology Laboratory Miri (Above Columbia Asia Hospital). If persons are unable to come, or have failed to fast overnight, they will be excluded from the study.

Qualitative Phase Two Research Methods requires a qualitative interview. Inclusion criteria for Phase Two will be participants selected from the low normal and high abnormal clinical parameters of both the cases and the controls as determined from Phase One.

ETHICAL CONSIDERATIONS

- **Voluntary Participation:** There will be no coercion to participate and those approached will have the right to refuse without explanation. There will be no remuneration given, however the laboratory tests (blood, urine and oral glucose tolerance test) will be free of charge to all the participants.
- **Informed Consent:** Forms will be signed by the participant prior to both data collection sessions.
- **Ethical Guidelines:** Ethical approval has been obtained from the Curtin Human Research Ethics Committee (HREC) and the guidelines (HREC, 2008) are acknowledged.
- **Confidentiality:** Clinical measurements and laboratory tests will be handled with strict confidentiality. Privacy will be respected and participants will be protected through anonymity. No names, IC numbers or any identifying features will be used in any publications. Only group anonymous results will be released.

The benefit to the individual participating in this study

The study participants will be asked to complete a series of screening tests conducted to identify those persons who are at higher risk for developing metabolic syndrome, cardiovascular disease, Type 2 diabetes, hypertension and chronic kidney disease. Following the Malaysian Ministry of Health guidelines, all laboratory reports for each patient will be issued to them personally.

The assessment of the anthropometric measurements and the laboratory / medical report on the participant's oral glucose tolerance test , urine and blood tests will be made available for them (only) to take to their own doctor for discussion and follow-up. These tests will be done free of charge to the participant however, should they withdraw from the study after the blood and urine tests have been conducted, the person will be asked to pay Gribbles Pathology Laboratory. At the completion of the research the participants will be given the summary, conclusions and recommendations of the study.

The value of this study to the general Miri community

Analysis of the results will identify if there are any predisposing local anomalies that may be associated with an increased risk for the development of chronic kidney disease, in Miri.

Appropriate community intervention programs and strategies may need to be developed to target, screen and educate high risk groups identified in the study. Measures of prevention will be devised to delay the onset and rate of progression of chronic kidney disease, and reduce the development of complications of chronic kidney disease and end stage renal disease.

INFORMASI

Fokus Kajian

- Ahli keluarga pesakit buah pinggang/ginjal tahap akhir.
- Mengkaji punca utama faktor risiko penyebab bagi berlakunya end stage renal disease (Penyakit Buah Pinggang/Ginjal tahap akhir) di Malaysia.
- Menggunakan Set pemotongan markah metabolic syndrome untuk menentukan abnormal parameter klinikal bagi faktor risiko penularan.
- Membuka minat dalam sosio-demographic dan gaya hidup yang sihat.
- Kepercayaan, tingkah-laku serta gaya-hidup yang sihat dan dapat membuat pilihan yang baik bagi mengindahkan faktor risiko masalah serius penyakit buah pinggang berlaku.

Kaedah penyelidikan secara kuantitatif bagi fasa pertama ini termasuklah seperti berikut:

- **Makmal Penyiasatan:** menggunakan set metabolic syndrome untuk mengenalpasti abnormal parameter klinikal bagi HDL; LDL; Triglycerides; tekanan darah tinggi; plasma glukosa; fungsi endothelium dan mikro-albuminuria.
- **Sukat anthropometric:** ketinggian, berat badan, BMI, lingkar pinggang, pinggang-hip ratio serta lapisan lemak.

- *Soalan yang ditanya telah ditetapkan mengenai:* sosio-demographic, gaya-hidup, latar belakang perubatan, diet dan aktiviti fizikal.

Pengumpulan Data. Bagi pengumpulan data, proses ini akan dilakukan di Makmal Pathologi Gribbles Miri. (Tingkat 2 Columbia Asia Sepecialist Clinic). Jika ahli peserta tidak dapat menghadiri diri dalam proses pengumpulan data, ataupun gagal berpuasa semalaman, mereka masih lagi termasuk sebagai peserta dalam kajian ini.

Kaedah Kajian Penyelidikan kuantitatif Fasa Kedua. Dalam kajian fasa kedua, temuduga secara kuantitatif akan dilakukannya, dengan bertujuan untuk mengetahui kategori yang berkaitan dengan kesihatan yang mempengaruhi gaya-hidup seharian dimana ia menjadi penyebab dalam pencegahan chronic kidney disease.

Kriteria Rekrut Fasa Kedua. Bagi kriteria rekrut fasa kedua, ia melibatkan peserta yang mempunyai daya ketahanan badan peringkat berisiko tinggi dan sederhana normal dalam parameter klinik, dengan menentukan kedua-dua kajian kes-kawalan, dari kajian fasa pertama.

Pengumpulan Data. Data akan dikumpulkan bagi proses penilaian, dengan membuat temuduga secara bergilir-gilir. Bagi kajian fasa kedua, temujanji akan dibuat untuk mengunjungi kediaman peserta yang mengambil bahagian.

PERTIMBANGAN DARI SEGI ETIKA

- *Penyertaan Sukarela* – Bagi mereka yang datang dengan penyertaan secara sukarela untuk mengambil bahagian, setelah memahami tujuan kajian dilakukan tanpa mendapat penerangan.
- *Persetujuan Informal* – Borang akan diberikan untuk ditandatangani bagi kedua-dua penyertaan kajian kes-kawalan semasa sesi pengumpulan data.
- *Garis Panduan Dalam Etika* – Etika kebenaran ini diperolehi dari Curtin Human Research Ethics Committee (HREC) serta panduan (HREC,2008) yang dibenarkan.
- *Kesulitan* – Keputusan ujian sukatan klinikal dan makmal akan dirahsiakan secara sulit/peribadi bagi menghormati peserta serta melindungi maklumat daripada pengetahuan umum.

Faedah bagi individu yang mengambil bahagian dalam kajian penyelidikan

Peserta kajian penyelidikan ini, akan diminta untuk mengemukakan siri ujian skrin bagi mengetahui individu yang berisiko tinggi dalam perkembangan sindrom metabolik, cardiovascular disease, Diabetes jenis kedua, tekanan darah tinggi dan chronic kidney disease (Penyakit buah pinggang tahap serius). Dengan berpandukan Kementerian Kesihatan Malaysia, kesemua keputusan ujian makmal akan diberikan secara sulit/peribadi kepada pesakit.

Bagi penilaian sukatan anthropometrik dan makmal, keputusan akan diberi kepada peserta oral glucose tolerance test , dimana sampel air kencing dan darah akan diambil untuk dibawa kepada doktor mereka sendiri untuk perbincangan dan rawatan selanjutnya. Ujian makmal ini akan diberikan secara percuma kepada peserta. Jikalau peserta ini menarik diri, setelah ujian dijalankan, mereka akan diminta untuk membayar-balik kesemua kos ujian makmal ke Makmal Pathologi Gribbles. Akhir sekali, ringkasan, kesimpulan, dan rujukan mengenai kajian penyelidikan ini akan diterangkan kepada peserta yang mengambil bahagian.

Nilai bagi kajian penyelidikan kepada komuniti umum Miri

Keputusan analisis akan dikenalpasti jika terdapat tanda-tanda jangkitan yang berkaitan dengan peningkatan risiko perkembangan penyakit buah pinggang di Miri.

Komuniti-komuniti perlu mengambil target dalam program dan strategi untuk mengetahui bagaimana cara mengalakkan kajian skrin dan mengenalpasti risiko pemulaan peningkatan penyakit ini berlaku dalam kelompok. langkah-langkah bagi mencegah penularan penyakit adalah diambil-kira bagi mengurangkan perkembangan komplikasi chronic kidney disease dan end stage renal disease.

Appendix O: Informed consent agreement for participants in Phase One

INFORMED CONSENT AGREEMENT : STUDY PARTICIPANTS – Phase One

My name is My I.C. number is

My home address is

- ❖ I have read (or had an interpreter read / explain) the information sheet regarding this research.
- ❖ I understand fully what this study is investigating and how I am involved in the data collection.
- ❖ I agree to attend the Gribbles Pathology Laboratory for the research study data collection at the agreed date and time.
 - I am willing to participate in the (please tick the box)
 - Self-administered written questionnaire of Phase One
 - The one on one interview session and, if selected Phase Two
 - I consent to having / giving an (please tick the box)
 - Oral Glucose Tolerance Test
 - Anthropometry measurements
 - Urine samples
 - Blood samples
 - I am willing for the principal investigator to (please tick the box)
 - Include me for selection for the Phase Two interview session.
 - Able to attend the interview at Dr Mattu Clinic.
 - I would like to receive the (please tick the box)
 - Laboratory / medical report on my urine and blood tests
 - Summary, conclusions and recommendations from this study.
- ❖ I understand that I am giving this information voluntarily and will not be paid in cash or given any kind of gift for my participation in this research study.
- ❖ I understand that I can ask questions regarding this research study at any time.
- ❖ I understand that all my questionnaire and interview answers will be kept confidential and that my identity will not be connected to my answers. Code numbers will be used on all forms other than this consent form.
- ❖ I agree for the principal investigator to use my questionnaire and interview answers in reports and publications so long as my name and answers will be anonymous.
- ❖ I understand that this research study relies on the participant in completing all segments of Phase One of the study.
- ❖ I understand that if I do not complete all of the data collection, my participation in this research study will be withdrawn.

- ❖ I understand that I may withdraw from this research study at any time without explanation.
- ❖ I understand that all clinical measurements and laboratory tests will be handled with strict medical confidentiality. These measurements and tests will be available for me (only) to take to my own doctor for discussion and follow-up.
- ❖ I agree for the principal investigator to use my clinical measurements and laboratory tests in reports and publications so long as my name and test results are anonymous.
- ❖ I understand that I may not be selected for, or may decline participation in Phase Two.

..... (Signature / Thumb Print) Date:.....

Please tick the box if you would like a photocopy of this form.

Thank you so much for your interest, time, help and cooperation.

PERJANJIAN MAKLUMAT PERSETUJUAN : PENYERTAAN KAJIAN

Nama saya No Kad.Pengenalan

Alamat Rumah

- ❖ Saya ada membaca ,borang maklumat mengenai kajian penyelidikan ini.
- ❖ Saya telah difahamkan mengenai kajian ini adalah dengan tujuan penyiasatan dan dengan ini saya sama sekali akan terlibat dengan pengumpulan data.
- ❖ Saya bersetuju untuk menghadirkan diri di pusat dialisis bulan sabit merah,Unit makmal penyelidikan untuk pengumpulan data bagi kajian penyelidikan dengan masa dan tarikh yang telah ditetapkan.
 - Saya bersetuju untuk menjadi peserta (Sila tandakan didalam kotak)
 - Menulis pertanyaan peribadi fasa pertama.
 - Membuat sesi temuduga bergilir-gilir di rumah sendiri,jika dipilih di fasa kedua.
 - Saya bersetuju mengambil/memberi (Sila tandakan didalam kotak)
 - Ujian lisan bagi mengetahui kandungan gula
 - sukatan anthropometri sample air kencing sample darah
 - Saya bersetuju dengan ketua penyiasat (Sila tandakan didalam kotak)
 - Memasukkan saya dalam temuduga sesi kedua.
 - Saya ingin mendapatkan (Sila tandakan didalam kotak)
 - Keputusan makmal bagi ujian air kencing dan darah yang telah dijalankan keatas saya.
 - Ringkasan,kesimpulan dan rujukkan mengenai kajian penyelidikan ini.
- ❖ Saya memahami bahawa maklumat yang saya bagi adalah sukarela dan tidak untuk dibayar mahupun menerima sebarang ganjaran dalam penglibatan saya dalam soal selidik ini.
- ❖ Saya faham bahawa saya boleh menanyakan sebarang soalan berkaitan dengan soal selidik ini pada bila bila masa.
- ❖ Saya faham bahawa semua soalan dan jawapan temu duga saya adalah sulit dan identiti saya tidak berkaitan dengan jawapan saya. Nombor kod akan digunakandalam semua borang selain dari borang persetujuan.
- ❖ Saya bersetuju dengan ketua penyiasatan untuk menggunakan soalan dan jawapan temu duga untuk laporan dan publisiti selagi nama saya tidak didedahkan dalam apa cara sekalipun. Jawapan saya akan dirahsiakan.
- ❖ Saya difahamkan bahawa kajian siasatan ini bergantung pada penglibatan pesakit dalam memenuhi semua sektor Fasa Pertama dalam kajian.
- ❖ Saya difahamkan bahawa jika saya tidak menghabiskan proses kesemuaan pengumpulan data, penglibatan saya dalam kajian ini akan ditarik balik.
- ❖ Saya difahamkan bahawa saya tidak boleh menarik diri dalam kajian ini pada bila- bila masa tanpa penjelasan.

- ❖ Saya difahamkan dimana kesemua sukatan klinikal dan ujian makmal akan dikendali dengan rahsia dan sulit. Sukatan dan ujian ini hanya dijalankan ke atas saya serta hanya saya seorang sahaja yang dapat membawa kesemua keputusan ujian kepada doctor untuk tujuan pembincangan dan rawatan selanjutnya.
- ❖ Saya bersetuju dengan ketua penyiasatan menggunakan sukatan klinikal dan keputusan ujian makmal dalam laporan dan publisiti selagi nama saya tidak didedahkan dalam apa jua keadaan. Sukatan dan keputusan ujian akan dirahsiakan dari pengetahuan umum.
- ❖ Saya difahamkan jika saya tidak terpilih atau penyertaan saya ditolak dlm temuduga sesi fasa2.

..... (Tandatangan / Cap jari) Tarikh:.....

Sila tandakan dalam kotak jika anda ingin mendapatkan salinan borang ini.

Terima kasih dengan minat, masa, pertolongan dan kerjasama daripada anda.

Appendix P: Informed Consent: Agreement for Participants in Phase Two

INFORMED CONSENT AGREEMENT: INTERVIEW – Phase Two

My name is My I.C. number is

My home address is

- ❖ I have read (or had an interpreter read and explain) the information sheet regarding this research study.
- ❖ I understand fully what this research study is investigating and how I am involved in the Phase Two interview.
- ❖ I agree to participate in this interview.

➤ I am willing to participate (please tick the box if you agree)
In the interview.

➤ I am willing for the principal investigator to (please tick the box)
Talk to anyone in my household who requests more information
on this study.

➤ I would like to receive the (please tick the box)
Summary, conclusions and recommendations from this study.

- ❖ I understand that I am giving this information voluntarily and will not be paid in cash or given any kind of gift for my participation in this interview.
- ❖ I understand that I can ask questions regarding this interview at any time.
- ❖ I understand that anything I say will be kept confidential and that my identity will not be disclosed.
- ❖ I understand that I may refuse to, or withdraw from, participating in this trial, without explanation.

..... (Signature / Thumb Print) Date:.....

Please tick the box if you would like a photocopy of this (signed and dated) form.

Thank you so much for your interest, time, help and cooperation.

PERJANJIAN MAKLUMAT PERSETUJUAN : SESI PERCUBAAN TEMUDUGA

Nama saya No. kad pengenalan

Alamat rumah

- ❖ Saya telah membaca kesemua borang maklumat berkaitan dengan kajian ini.
- ❖ Saya memahami sepenuhnya mengenai kajian penyelidikan adalah bertujuan untuk siasatan dan saya akan terlibat sekali dalam percubaan sesi temuduga.
- ❖ Saya bersetuju mengambil bahagian dalam percubaan sesi temuduga.
 - Saya bersetuju untuk mengambil bahagian (sila tandakan dalam kotak)
 - Dalam sesi percubaan temuduga.
 - Saya bersetuju dengan ketua penyiasatan untuk (sila tandakan dalam kotak)
 - Berbual dengan sesiapa sahaja dalam ahli keluarga yang ingin mendapatkan maklumat kajian ini.
 - Saya ingin mendapatkan (sila tandakan dalam kotak)
 - Ringkasan,kesimpulan dan rujukkan mengenai kajian penyelidikan ini,
- ❖ Saya telah difahamkan bahawa segala maklumat yang diberikan adalah dengan sukarela tanpa dipaksa, dibayar atau memberi ganjaran untuk penyertaan dalam sesi percubaan temuduga.
- ❖ Saya telah difahamkan bahawa saya boleh mengemukakan pertanyaan soalan mengenai sesi percubaan temuduga pada bila- bila masa.
- ❖ Saya telah difahamkan bahawa apa sahaja yang diperkatakan oleh saya adalah dirahsiakan dan segala identiti saya tidak akan didedahkan.
- ❖ Saya difahamkan bahawa saya tidak boleh menarik diri dalam mengambil bahagian bagi sesi percubaan ini tanpa penjelasan.

..... (Tandatangan / Cap jari) Tarikh:.....

- Sila tandakan dalam kotak jika anda ingin mendapatkan salinan borang ini.

Terima kasih dengan minat, masa, pertolongan dan kerjasama daripada anda.

CLINICAL INFORMATION

Appendix Q: Screening: Clinical Parameters for metabolic syndrome

Appendix Q : SCREENING: Clinical Parameters for MetS				
MetS	SCREENING FOR:		Normal / Low Risk SPSS variable 1	Abnormal / High Risk SPSS variable 2
* + Central Obesity	Ethnic Group:			
Waist Circumference	South Asians - Chinese/Malay/Indian	Men Women	< 90 cm < 80 cm	> 90 cm > 80 cm
BMI	Asian	Men & Asian Women	≤ 23 kg/m ²	≥ 23 kg/m ²
Waist - hip ratio		Men Women	< 0.90 cm < 0.85 cm	> 0.90 cm > 0.85 cm
Subcutaneous Fat assessment		Men Women	< 110 mm < 120 mm	> 110 mm > 120 mm
* Triglycerides		Men & Women	≤ 1.7 mmol/L	≥ 1.7 mmol/L
Raised TG level or Specific treatment for this lipid abnormality			No	Yes
* HDL Cholesterol		Men Women	≥ 1.03 mmol/L ≥ 1.29 mmol/L	≤ 1.03 mmol/L ≤ 1.29 mmol/L
Reduced HDL level or Specific treatment for this lipid abnormality			No	Yes
LDL Cholesterol		Men Women	≤ 2.5 mmol/L	≥ 2.5 mmol/L
Raised LDL level				
Total Cholesterol	Cholesterol, HDL, LDL, TG	Men	≤ 240 mg/dL	≥ 240 mg/dL
Raised ChL level or	UPIO	Women		
* Blood Pressure		Men & Women	systolic BP ≤ 130 mm Hg diastolic BP ≤ 85 mm Hg	systolic BP ≥ 130 mm Hg diastolic BP ≥ 85 mm Hg
Raised or Treatment of previously diagnosed hypertension	(0,1,2 Hrs) mean		No	Yes
* Plasma Glucose	Oral OGTT - Fasting, 1,2 hr	Men & Women	≤ 5.6 mmol/L	≥ 5.6 mmol/L
Raised Fasting PG or Previously diagnosed Type 2 diabetes	Glucose + HBA1C		No	Yes
* Vascular Dysregulation	Microalbuminuria - urine	Fasting	< 20 g/min	> 20 g/min
Beyond elevated BP	Albumin:Creatinine Ratio	Fasting	≥ 30 mg/g	≤ 30 mg/g
Previously diagnosed with CKD	Serum Creatinine - eGFR	Fasting	≥ 60 mL/min/1.73m ² No	< 60 mL/min/1.73m ² Yes
	Endothelial Function Trace		Normal	Abnormal
Anaemia		Men	< 13.3 g/dl	> 13.3 g/dl
Hb		Women	< 11.8 g/dl	> 11.8 g/dl
<p>Extreme ends of result range of normal and abnormal for waist circumference, blood pressure, plasma glucose and eGFR will be considered for purposefully selected participants to be interviewed in the qualitative Phase Two of the study.</p> <p>* Metabolic syndrome definition is abnormal clinical parameters for any three of the five components: Abdominal Obesity, Triglycerides, HDL Cholesterol, Blood Pressure, Plasma Glucose. Creatinine for vascular dysregulation research.</p>				

Appendix R: Data Collection: Techniques, Measurements, Standardisation

Appendix R :			
DATA COLLECTION TECHNIQUES, MEASUREMENTS & STANDARDIZATION			
DATA COLLECTION EQUIPMENT & CALIBRATION			
EXPOSURES OF INTEREST		MEASUREMENT	
		Quantitative	
<u>Socio-Demographics</u>			
<i>Predisposing Factors</i>			
	Age	Questionnaire	
	Gender	Questionnaire	
	Ethnicity	Questionnaire	
	Level of education	Questionnaire	
	Place of residence	Questionnaire	
	Socio-economic status	Questionnaire	
	Personal medical history	Questionnaire	
	Family medical history	Questionnaire	
<u>Lifestyle</u>			
<i>Behavioural Risk Factors</i>			
	Tobacco smoking	Questionnaire	
	Alcohol / drug consumption	Questionnaire	
	Physical activity / inactivity	Questionnaire	
	Poor diet: Western/Traditional	Questionnaire	
	Preserved foods	Questionnaire	
	Medication: Western- OCD	Questionnaire	
	Medication: Traditional- Herbs	Questionnaire	
	Use of herbicides / pesticides	Questionnaire	
		APPENDIX R	APPENDIX S
<u>Screening:</u>		TECHNIQUES /	EQUIPMENT /
<u>Clinical Parameters</u>		MEASUREMENTS	CALIBRATION
<i>Medical Risk Factors For:</i>			
<u>Anthropometry Measurements:</u>			
	Current Age	Questionnaire	
	Central Obesity:	See Page 296	See Page 300
	Waist Circumference	See Page 296	See Page 300
	Height measurements	See Page 296	See Page 300
	Weight measurements	See Page 296	See Page 300
	Body Mass Index	See Page 296	See Page 300
	Waist - Hip Ratio	See Page 297	See Page 300
	Skin-fold Calipers	See Page 297	See Page 300
	Hypertension:	See Page 297	See Page 300
	Blood Pressure reading	See Page 297	See Page 300
<i>Medical Risk Factors For:</i>			
<u>Laboratory Tests:</u>			
	Insulin Resistance	See Page 298	See Page 301
	Fasting PG; OGTT	See Page 298	See Page 301
	OGTT	See Page 298	See Page 301
	Atherogenic Dyslipidemia	See Page 298	See Page 301
	TG; HDL Cholesterol; LDL;	See Page 298	See Page 301
	Microalbuminuria	See Page 299	See Page 301
	Urinary Albumin	See Page 299	See Page 301
	Albumin : Creatinine Ratio	See Page 299	See Page 301
	Serum creatinine - eGFR	See Page 299	See Page 301
	Endothelial Function	See Page 299	See Page 301
	Haemoglobin	See Page 299	See Page 301

Appendix R : Continued page 2	
<u>DATA COLLECTION TECHNIQUES</u>	<u>MEASUREMENTS & STANDARDIZATION</u>
<u>Anthropometry Measurements</u>	<u>Anthropometry Measurements</u>
<u>Current Age</u>	
The participant will be asked their date of birth.	Current age will be calculated at the time of the interview and data collection date.
<u>Central Obesity</u>	
Central (abdominal) obesity is a pre-requisite risk factor for the Metabolic syndrome ² . Obesity is defined using the WHO Asia Pacific guidelines ³ .	The IDF Central obesity is assessed using waist circumference and has specific values for different gender and ethnic group (not the country of residence) ² .
<u>Waist Circumference</u>	
The IDF consensus definition for metabolic syndrome ² cutoff for waist circumference is...	Asian males = ≥ 90 cm Asian females = > 80 cm
Participants will be asked to stand erect, heels together and relaxed. Waist to be measured on the horizontal plane at the narrowest point between the ribs and the hips as viewed from the front after the participant has exhaled. This should be mid-way between the iliac crests and the lower lateral ribs ⁴ .	South Asians (Chinese, Malay and Asian Indian populations) ² Asian males = ≥ 90 cm Asian females = > 80 cm Europid males = ≥ 94 cm Europid females = > 80 cm
	Two waist measurements to be taken to the nearest 1 cm. The average value will be used.
<u>All height measurements:</u>	
Participant standing in bare feet, heels together, with back against a rigid, fixed wall. Eyes should be facing forward.	The height measurement is taken to the nearest centimetre.
<u>All weight measurements:</u>	
Participant standing in bare feet and in light street clothing. 0.5 kg deducted from the weight recorded as an allowance for the clothing worn by the participant.	Two measurements will be taken in succession and the result should be the same. The result taken will be to the nearest kilogram.
<u>Body Mass Index</u>	
BMI uses the height and weight measurements. WHO clinical criteria ³ .	BMI is calculated using the formula : $\text{weight (Kg)} / \text{height (m)}^2$. Weight (Kg) divided by the height squared (m ²). Obesity $>30\text{kg/m}^2$ White: BMI $> 25 \text{ kg/m}^2$ = overweight BMI $\geq 30 \text{ kg/m}^2$ = obese ³ . Asian: BMI $> 23 \text{ kg/m}^2$ = overweight BMI $\geq 25 \text{ kg/m}^2$ = obese ³ .

Appendix R : Continued page 3	
<u>DATA COLLECTION TECHNIQUES</u>	<u>MEASUREMENTS & STANDARDIZATION</u>
<u>Waist - Hip Ratio</u>	
Participants will be asked to stand erect, heels together and relaxed. Waist to be measured on the horizontal plane at the narrowest point between the ribs and the hips as viewed from the front after the participant has exhaled. This should be mid-way between the iliac crests and the lower lateral ribs. The hips will be measured on the horizontal plane at the maximum extension point of the buttocks (at the trochanter major points) when viewed from the side ⁵ .	Waist to Hip Ratio will be calculated by dividing the waist circumference (cm) by the hip circumference (cm) ⁵ . Waist/hip ratio > 0.90 cm males Waist/hip ratio > 0.85 cm females Two measurements to be taken to the nearest 1 cm. The average value is to be used.
<u>Skin-fold Caliper Measurement</u>	
Used to measure the subcutaneous fat (beneath skin). Participants are asked to stand upright. All measurements to be taken on the right side of the body.	The totals (in millimeters) of the four sights are noted. Sex and age categories on the Durin-Womersley chart noted. Body fat percentage calculated from the table.
Measurements are taken from four sights: Biceps: A vertical fold on the front of the arm over the biceps muscle, half way between the shoulder and the elbow. Triceps: A vertical fold on the back of the upper arm, with the arm relaxed and held freely at the side. This skin-fold should be taken halfway between the shoulder and the elbow. Subscapular: A 45-degree angle fold of 1-2 cm, below the inferior angle of the scapula. Iliac Crest: A 45-degree angle fold, taken just above the iliac crest and medial to the axillary line.	To calculate one's fat mass and lean body mass: first: Body fat % X scale weight = fat mass then: Scale weight - fat mass = lean body mass Internet calculations available. Average the four measurements in millimeters (MM) Excellent - Good - Average - Below Average - Poor Normal Male: 60-80 - 81-90 - 91-110 - 111-150 - 150+ Normal Female: 70-90 - 91-100 - 101-120 - 121-150 - 150+
<u>Hypertension</u>	
<u>Blood Pressure</u>	
The IDF consensus definition for metabolic syndrome ² cutoff for raised blood pressure is...	Systolic greater than ≥ 130 mm Hg Diastolic greater than ≥ 85 mm Hg OR treatment of previously diagnosed hypertension ² .
Blood pressure will be measured with the patient sitting relaxed. The cuff will be placed on the upper right arm opposite the heart. Three readings to the nearest 1 mm Hg will be taken for both the systolic and diastolic pressure, one hour apart and the mean of the three used ⁶ .	An average of three readings over three hours will be taken for the data collection.
Must determine if on Hypertension drugs or not. Hypertension will be diagnosed based on the past medical history as disclosed by the participant; drug treatment for hypertension; or if the blood pressure is greater than 130 mm Hg / 85 mm Hg as determined by the IDF criteria ² . However, the stage of hypertension will be noted following the diagnostic criteria of the Joint National Committee 7 (JNC VII) Criteria ⁶ .	

Appendix R : Continued page 4	
<u>DATA COLLECTION TECHNIQUES</u>	<u>MEASUREMENTS & STANDARDIZATION</u>
<u>Laboratory Tests</u>	<u>Laboratory Tests</u>
Hyperglycaemia	
<p>Insulin resistance The IDF consensus definition for metabolic syndrome ² cutoff for raised fasting plasma glucose is...</p> <p><i>All the participants will be given an OGTT test.</i></p> <p>Diabetes will be diagnosed based on the past medical history as disclosed by the participant; drug treatment for diabetes; and an OGTT result greater than 5.6 mmol/L as determined by the IDF criteria ². However, the stage of glucose tolerance will be noted following the diagnostic criteria of the Keep Guidelines ⁶.</p> <p>Must determine if on diabetes drugs or not - (insulin or oral hyperglycemic agents).</p>	<p>Fasting Plasma Glucose > 100 mg/dL (SIU 5.6 mmol/L) OR treatment of previously diagnosed type II diabetes ².</p> <p>Medical Files/History/diagnosis of Diabetes type II</p> <p><i>Gribbles Laboratory use Standard International Units SIU for reporting all their laboratory test results.</i></p> <p>Fasting and two hour post-load -Oral Glucose Tolerance Test (OGTT) plasma glucose concentrations will be done on all the participants. Those with FGP > 5.6mmol/L = prediabetes</p>
Atherogenic Dyslipidemia	
<p>Raised TG levels The IDF consensus definition for metabolic syndrome ² cutoff for raised TG levels is</p> <p>Reduced HDL Cholesterol levels The IDF consensus definition for metabolic syndrome ² cutoff for reduced HDL Cholesterol is</p> <p>Raised TG and Reduced HDL Cholesterol will be diagnosed based on the past medical history as disclosed by the participant; or specific treatment for these lipid abnormalities as determined by the IDF criteria ².</p> <p>Must determine if on lipid drugs or not.</p>	<p>Medical Files/History / diagnosis of dyslipidemia</p> <p>TG levels \geq 150 mg/dL (SIU 1.7 mmol/L) OR specific treatment for lipid abnormality ².</p> <p>HDL <103 mg/dL (1.03 mmol/L) M; <50 mg/dL (1.29 mmol/L) F OR specific treatment for lipid abnormality ².</p>

Appendix R : Continued page 5

<u>DATA COLLECTION TECHNIQUES</u>	<u>MEASUREMENTS & STANDARDIZATION</u>
<u>Vascular Dysregulation</u>	
<p>Microalbuminuria The WHO clinical criteria for metabolic syndrome ² cutoff for microalbuminuria is...</p> <p>Protein is not normally found in the urine. Increased levels of albuminuria in the urine may indicate kidney disease.</p> <p>Albumin : Creatinine Ratio estimates the amount of albumin (protein) in the urine in a day and avoids the need to collect a 24-hour urine sample.</p> <p><i>All the participants will be given an eGFR test.</i></p> <p>The Estimated Glomerular Filtration Rate (eGFR) test for kidney function is calculated using serum creatinine, race and gender of the person ^{1,7}.</p>	<p>Urinary albumin excretion rate > 20 g/min OR albumin:creatinine ration > 30 mg/g ².</p> <p>Urinary albumin excretion rate ⁶.</p> <p>less than ≥ 30 mg/L = Normal between 30 mg/L - 300 mg/L = Microalbuminuria greater than ≥ 300 mg/L = Macroalbuminuria</p> <p>Albumin : Creatinine Ratio ¹⁵</p> <p>less than ≥ 30 mg/g * random = Normal greater than ≤ 30 mg/g * random = Abnormal</p> <p>Individuals with an eGFR ^{1,7}</p> <p>≥ 90 mL/min/1.73m² = normal kidneys / no disease OR</p> <p>Stage 1 ≥ 90 mL/min/1.73m² = damage with normal kidney function</p> <p>Stage 2 60 - 89 mL/min/1.73m² = mild loss of kidney function</p> <p>Stage 3 30 - 59 mL/min/1.73m² = moderate loss of kidney function</p> <p>Stage 4 15 - 29 mL/min/1.73m² = severe loss of kidney function</p> <p>Stage 5 ≤ 15 mL/min/1.73m² = End-stage renal failure</p>
<p>Endothelial Function Trace to test for endothelial dysfunction - arterial stiffness ¹⁰</p> <p>A simple non-invasive test of endothelial function, a rapid assessment of arterial stiffness and endothelial function marker of developing arterial disease.</p>	<p>The Stiffness Index SI is a measure of the large artery stiffness. Reflex Index RI is the height of the second peak of the Digital Volume Pulse DVP expressed as a percentage and measures the tone of the small / medium arteries.</p>
<p>Haemoglobin Hb (for Anaemia) ⁷</p>	<p>Hb 13.3 g/dL = normal adult male Hb 11.8 g/dL = normal adult female</p>

Appendix S: Data Collection: Equipment and Calibration

Appendix S : DATA COLLECTION EQUIPMENT AND CALIBRATION	
<u>DATA COLLECTION EQUIPMENT</u>	<u>CALIBRATION</u>
<u>Anthropometry Measurements</u>	<u>Anthropometry Measurements</u>
<u>Central Obesity</u>	
<u>Waist Circumference</u> A metal measuring tape will be used without compressing the skin of the participant	The measuring tape must be metal as fibre measuring tapes tend to stretch in the tropical heat.
<u>Height measurements:</u> A 90° angle moveable gauge will be used to ensure the crown of the head of the participant is correctly marked against a metal measuring tape that has been secured to the rigid wall.	The right-angle triangle will be placed flat to the rigid wall to ensure the correct height of the participant is measured.
<u>All weight measurements:</u> A digital Salter spring balance weighing scales will be used. The weight will be measured with the scales sitting on a hard horizontal tiled or cement surface.	The spring balance will be tested for accuracy against a weighing machine at the international airport. The 'zero' will be checked regularly.
<u>Body Mass Index</u>	Weight (Kg) divided by the height squared (m ²). Obesity >30kg/m ²
<u>Waist - Hip Ratio</u> A metal measuring tape will be used without compressing the skin of the participant	The measuring tape must be metal as fibre measuring tapes tend to stretch in the tropical heat.
<u>Skin-fold Caliper Measurement</u> A Slimguide Caliper based on the Harpenden Caliper Jaw. Constant pressure design. Strong heavy duty ABS plastic. Direct reading analogue pointer.	Calibration set and tested in the factory. Spring close ensures constant pressure throughout procedure.
<u>Hypertension</u>	
<u>Blood Pressure</u> An auto-inflate digital electronic blood pressure monitor will be used. Model DS-145 powered by four "AA" alkaline batteries or AC- adapter. Standard adult size cuff for 9 - 12.5 inc; arm circumference. Cuff pressure 0 - 300 mm Hg (+ 3 mm Hg). Pulse measurement range from 40 to 150 pulse / min. (+- 5%)	This digital electronic blood pressure monitor will be calibrated against a mercury sphygmomanometer (Diamond Delux BP apparatus, Pune, India). The cuff will be put on the right arm of the seated participant.

Appendix S : Continued page 2

<u>DATA COLLECTION EQUIPMENT</u>	<u>CALIBRATION</u>
<u>Laboratory Tests</u>	<u>Laboratory Tests</u>
<u>Endothelial Dysfunction</u>	
<u>Pulse Trace - Pulse Contour Analysis PCA</u>	
All the analysis for the endothelial tests done in this study will be done on the Pulse Trace PCA 1000 ¹⁰ .	Calibrated by Micro Medical, U.K. http://www.micromedical.co.uk/ ¹⁰
Specifications for this machine include:	Calculates and displays SI, RI, heart rate, PPT, waveforms.
Description: A small table top system with printer and display	
Type: Precision photoplethysmographic finger probe	Normal SI range for subject age - based on
Parameters: 'Spot check' and automated x3 test protocol	national Vascular age estimate.
Throughput: Up to 10 complete tests / measurement session	
Transducer: Touch screen graphic LCD 240X160 pixels	
Display: Input 100-240V 50-60Hz, Output 12v 2.5A	
WxDxH: 25.5 x 12.0 x 3.5cm. Transducer 2.0 x 2.0 x 6.0 cm	
Weight: 630 g. excluding any transducer.	
More information regarding machine is available on-line at: http://www.micromedical.co.uk/ ¹⁰	
<u>Urine and Blood Sample Analysis</u>	
All the biochemical analysis for the tests done in this study will be done on the Dade Behring Dimension ® RXL MAX ¹¹ .	The laboratory tests that will be done at the Gribbles Laboratory in Miri include: the lipid profile; OGTT and CRT. The eGFR will be calculated from the CRT measured.
Specifications for this machine include:	
Description: An integrated chemistry system	
Type: Chemical Analyzer	The only laboratory test not done at the Miri Branch is the microalbumin. This will be done in Kuala Lumpur at the Gribbles Laboratory headquarters. This test is run daily and the turn-around for the report is the next day.
Parameters: 79 analytes	
Throughput: 740 samples / hour	
Method: Filter Photometric	
Open system: Yes	
WxDxH: 160x79x112 cm	Fasting blood samples are to be collected into fluoride tubes the samples will be maintained at 4°C and will be dispatched to the laboratory within 3 hours for analysis.
Weight: 273 kilos	
Features: All methods plasma-approved draw-spin-run	
Automatically loads and removes Flex ® Reagent Cartridges.	
Flat-panel 17" colour LCD digital touchscreen operating system.	For the Oral Glucose Tolerance Test the glucose formula used is a 75 gram of glucose monohydrate premixed with water, imported from Australia and supplied through the laboratory.
More information regarding machines by Dade Behring, Inc. US is available on-line at: http://www.dadebehring.com ¹¹	
	Now recommended to use the Modification of Diet in Renal Disease (MDRD) equation to estimate Glomerular Filtration Rate (eGFR) in adults ^{7,9} .
The Gribbles Pathology Malaysia ⁷ has a comprehensive website where details of their policies; international standard protocol; management system; services provided; quality controls; validity and reliability of test results; test information; etc. It is available on-line at: http://www.gribbles.com.my ⁷	Values of < 60 mL/min per 1.73 ² = moderate CKD ⁷ Values of < 30 mL/min per 1.73 ² = CKD declining to ESRF ⁷
<i>Gribbles Pathology Laboratory use Standard International Units SIU for reporting all their laboratory test results.</i>	

Appendix T: Data Collection: Procedure and Explanation

PHASE ONE DATA COLLECTION PROCEDURE AND EXPLANATION

(For Assistants' information. Assistants are to explain clearly to the participants, in their preferred dialect, the procedure, especially regarding fasting, prior to coming for data collection in Phase One. They are to follow-up all participants who registered.)

Prior To The Appointment:

1. Household family members identified by ESRF patients will be contacted and asked if they would be willing to participate in this research study.
2. If they agree to participate in the study a mobile phone contact number will be asked for and their age, gender and ethnicity will be noted. The language preferred will be noted and a translator, if needed, speaking that dialect will be allocated to assist during data collection sessions. As far as possible, gender appropriate assistants / translators will be used to eliminate cultural gender sensitivities.
3. An appointment date and time for the Phase One data collection to be taken at the Malaysian Red Crescent: Health Research Unit laboratory will be discussed and allocated to the study participants.
4. For those who are employed, a signed letter asking permission from their employer to allow them to participate in this research study without having to take annual leave on the morning of the data collection appointment, will be given to the study participants.
5. Data collection procedure is expected to take three hours, including registration and refreshments. Participants please be available for your appointment otherwise you may be excluded from the study as the laboratory technicians and translators are only available for certain time periods.
6. **The study participant must fast** overnight and refrain from eating or drinking breakfast on the morning of the data collection for the research study. If they have broken their fast they will be excluded from the study. They must bring with them a first-void morning urine sample in the container they were given.
7. **The study participant must be available for their appointment date** otherwise they may be excluded from the study as the laboratory technicians and translators will only be available for certain time periods.

On The Day Of The Appointment:

8. **The study participant must fast** overnight and refrain from eating or drinking breakfast on the morning of the data collection for the research study. If they have broken their fast they will be excluded from the study. They must bring with them their first-void morning urine sample in the container they were given.
7. **The study participant must arrive on time at the MRC,HRU laboratory** otherwise they may be excluded from the study as the laboratory technicians and translators will only be available for a certain time period.
8. They will read the Information Sheet. If they decide not to sign the Informed Consent Form they will be excluded from the study. The participant may withdraw from this research study at any time without explanation however, they will be asked to pay for any laboratory samples taken.
9. Once the Informed Consent Form is signed, a number will be given and they proceed to the laboratory to have their data collection session.
10. Food and drink will be given at the end of their data collection and the person thanked for their participation.

Please Note:

All clinical measurements and laboratory tests will be handled with strict medical confidentiality. These will be available for the study participant (only). No participant identity will be revealed in any report.

Measurements And Laboratory Screening Tests Explained

- Anthropometric measurements will be taken to determine the participant's body mass index (BMI) and waist circumference (WC). The measurements are used in calculating their risk of having metabolic syndrome.
- Blood pressure readings (the average of three) will be taken to establish the absence / presence of high blood pressure (hypertension) among the participants.
- A fasting blood sample is needed for the oral glucose tolerance test and laboratory tests. Participants please fast 8-12 hours overnight and please do not eat or drink anything on the morning of the data collection for the research study. If you break fast you will be excluded from the study. You will be given food and drink after completion of the data collection.

- The oral glucose tolerance test will take two hours to complete. While waiting the two hours the participant will be asked to complete the minimal questionnaire and have the anthropometric measurements and laboratory tests done.
- The Oral Glucose Tolerance Test will be administered to establish the absence / presence of Type 2 Diabetes among the selected participants. (oral glucose tolerance test and plasma glucose)
- Blood and urine tests will be carried out to establish the absence / presence of kidney disease among the selected participants. (Microalbuminuria, serum creatinine and estimated glomerular filtration rate)
- Blood tests will be carried out to establish the lipid profile of the selected participants. (Triglycerides, HDL, LDL and ratio, total Cholesterol)
- The oral glucose tolerance test will be administered, the urine sample collected and the blood samples will be drawn by properly trained laboratory technicians from Gribbles Laboratory Malaysia.

PHASE TWO INTERVIEW SESSION

Those selected from Phase One and invited to participate in Phase Two will be contacted and provided with an information sheet and have the qualitative study explained. A mobile phone contact number will be asked for and an appointment date and time made for the qualitative interview to be delivered. The participant's current place of residence is where the data collection for Phase Two will take place. Signed consent will be sort before commencing data collection.

In the second phase of the study, data will be gathered by in-depth, one on one semi-structured interviews. I will conduct all interview sessions. A translator, if needed, will interpret for me.

DATA COLLECTION INFORMATION

Appendix U: Phase One Self-administered Questionnaire

For reporting accuracy, a linguistic and culturally appropriate standardise self-administered questionnaire for Malaysia has been obtained from the Malaysian Ministry of Health.

The ‘Malaysian NCD Surveillance 2006: NCD Risk Factors in Malaysia’,

<http://www.who.int/chp/steps/MalaysiaSTEPSReport.pdf>

The questionnaire is standardised following the **WHO STEPS Instrument** (www.who.int/chp/steps)

<http://ghdx.healthdata.org/record/malaysia-steps-noncommunicable-disease-risk-factors-survey-2005-2006>

and is validated for a Malaysian population by the Disease Control Division, Malaysian Ministry of Health. It is available in English, Bahasa and Mandarin Languages.

The STEPS questionnaire can be viewed at the above websites.

WHO STEPS Instrument

Question-by-Question Guide

(Core and Expanded)



The WHO STEPwise approach to noncommunicable disease risk factor surveillance (STEPS)

World Health Organization

20 Avenue Appia, 1211 Geneva 27, Switzerland

For further information: www.who.int/chp/steps



Appendix U continued... NCD Malaysian Ministry of Health

MyNCDS - 1

Negeri Daerah bncal BP TK Subjek

PROGRAM SURVEILANS NCD KEMENTERIAN KESIHATAN MALAYSIA 2005

Assalamualaikum / Seiamat Pagi / Petang / Malam

Saya _____ dari Kementerian Kesihatan Malaysia (KKM).

Anda telah dipilih oleh Kementerian Kesihatan Malaysia untuk menjalani pemeriksaan kesihatan PERCUMA di bawah Program Perkhidmatan Kesihatan (Surveilans NCD), di dalam usaha untuk meningkatkan taraf kesihatan dan mencegah penyakit-penyakit tidak berjangkit.

Pihak kami ingin mengucapkan terimakasih di atas kerjasama dan sokongan anda dalam menjayakan program ini. Penyertaan anda akan dapat memberi sumbangan yang bernilai kepada program yang telah dirancang khususnya dan negara amnya.

Bagi melengkapkan pemeriksaan, anda perlu menjawab soal selidik ini. Semua maklumat yang diperolehi akan dirahsiakan dan hanya digunakan sebagai asas perancangan Program Kesihatan Negara

Appendix U continued... Participant's Personal Information Sheet

Appendix T : (In CAPITALS Please)

PERSONAL INFORMATION / MAKLUMAT PERIBADI

1 Name / Nama :

2 Home Phone / Telefon Rumah :

3 Office Phone / Telefon Pejabat :

4 Mobile Phone / Telefon Bimbit :

5 E-mail:

(Office Information) DATE:

PARTICIPANT'S RECRUITMENT CODE: Ca-Co No:

THIS PARTICIPANT IS A: CASE CONTROL

RECRUITMENT CODE FOR MATCH: Ca-Co No:

I wish to sincerely thank you for participating in this worth while study. You need to book an appointment to receive your laboratory test results. You will also be told by the researcher on whether you should see your family doctor for follow-up and advice.


You will receive a summary of results and the recommendations from this study in due time.

Once again, thank you very much for taking the time to participate in this study.

Saya ingin mengucapkan berbilang terima kasih ke atas luangan masa, yang dibenkan anda dalam menyertai kajian ini.

Appendix V: Clinical data collection forms

Lab use only



TRUSTED INTERNATIONALLY

GRIBBLES PATHOLOGY (M) SDN BHD 149031-W
 MAIN LABORATORY
 1st Floor, Bgn. Takafu Ikhlas
 (FORMERLY WISMA KT)
 No. 14 Jalan 19/1, 46300 Petaling Jaya
 Selangor Darul Ehsan Malaysia
 T +603 7957 7752
 F +603 7957 7732
 E enquiries@gribbles.com.my
 URL www.gribbles.com.my

Patient's Name (Block Letters) <input style="width: 100%; height: 20px;" type="text"/>		Referring Doctor's Name, Address & Doctor's Code Mrs. Sheryl Mattu CURTIN UNIV. PROJECT	
IC/Passport No. <input style="width: 100%; height: 20px;" type="text"/>		Note: This request form is NOT transferable.	
DOB (dd/mm/yyyy) Sex Your Ref. <input style="width: 100%; height: 20px;" type="text"/>		<input type="checkbox"/> URGENT <input type="checkbox"/> Phone <input type="checkbox"/> Fax <input type="checkbox"/> Cash	
Patient's Address <input style="width: 100%; height: 40px;" type="text"/>		Number <input style="width: 100%; height: 20px;" type="text"/>	
Specimen Type <input type="checkbox"/> Blood <input type="checkbox"/> Faeces <input type="checkbox"/> Urine <input type="checkbox"/> Sputum <input type="checkbox"/> Swab <input type="checkbox"/> Fluids <input type="checkbox"/> Tissue <input type="checkbox"/> Cytology <input type="checkbox"/> Others		Specimen Taken from Patient Date / / (dd/mm/yy) Time am/pm <input type="checkbox"/> Fasting <input type="checkbox"/> Non-Fasting	
Drug Therapy Last Dose Date / / Time am / pm		Copy to <input style="width: 100%; height: 20px;" type="text"/>	
CLINICAL HISTORY <input style="width: 100%; height: 80px;" type="text"/>		Cervical Cytology <input type="checkbox"/> Pap Smear <input type="checkbox"/> Thin Prep <input type="checkbox"/> HPV (DNA Testing) <input type="checkbox"/> Normal <input type="checkbox"/> Post - Meno Bleed <input type="checkbox"/> Susp Lesion <input type="checkbox"/> Other	
Site <input type="checkbox"/> Cervix <input type="checkbox"/> Endocx <input type="checkbox"/> Post Fornix <input type="checkbox"/> Vault <input type="checkbox"/> Lat. Vag. Wall <input type="checkbox"/> Other		Bill to SHENG	
LMP / / (dd/mm/yy) <input type="checkbox"/> Post - Menopausal <input type="checkbox"/> HRT (Hormone Replacement) <input type="checkbox"/> Other		Amount RM <input style="width: 100%; height: 20px;" type="text"/>	
Receipt No. <input style="width: 100%; height: 20px;" type="text"/>		Collected By <input style="width: 100%; height: 20px;" type="text"/>	
Profile Test <input type="checkbox"/> G2000 <input type="checkbox"/> DFS <input type="checkbox"/> G2000-X <input type="checkbox"/> LFT <input type="checkbox"/> GT9 <input type="checkbox"/> RFT <input type="checkbox"/> GT1 <input type="checkbox"/> TFT <input type="checkbox"/> NEO <input type="checkbox"/> MAC <input type="checkbox"/> ES <input type="checkbox"/> LGL <input type="checkbox"/> HB3 <input type="checkbox"/> LIP		Biochemistry <input type="checkbox"/> CEA <input type="checkbox"/> HIV 1 & 2 <input type="checkbox"/> CA 1 (CA 125) <input type="checkbox"/> HbA1c <input type="checkbox"/> CA 5 (CA15.3) <input type="checkbox"/> HBsAg <input type="checkbox"/> CA 9 (CA 19.9) <input type="checkbox"/> H.pylori <input type="checkbox"/> PSA <input type="checkbox"/> Uric Acid <input type="checkbox"/> AFP <input type="checkbox"/> Free T4 <input type="checkbox"/> Glucose	
Haematology <input type="checkbox"/> FBE (incl ESR) <input type="checkbox"/> FBC <input type="checkbox"/> Hb <input type="checkbox"/> TWDC <input type="checkbox"/> Platelets <input type="checkbox"/> ABO & Rh (D) <input type="checkbox"/> Malarial Parasite		Microbiology <input type="checkbox"/> Urine FEME <input type="checkbox"/> RPR (VDRL) <input type="checkbox"/> Microscopy/Culture/Sensitivity <input type="checkbox"/> AFB (ZN) Smear Only <input type="checkbox"/> AFB Smear & Culture	
Anatomical Pathology <input type="checkbox"/> Histology <input type="checkbox"/> Non-Gynae/FNA Site _____		ADDITIONAL TESTS Hb - LIP, GGT, MAC, CRT, eGFR ↓ ↓ ↓ ↓ ↓ O & 2 hrs Age =yrs ↓ ↓ Wt = kgs Race =	
Date / / (dd/mm/yy) Doctor's Signature		SH Mattu	

Appendix V continued... Anthropometric data collection form

<u>FLOW-CHART CHECK-LIST FOR PARTICIPANTS IN THE MIRI KIDNEY RESEARCH STUDY</u>				Date
(circle one)				
NAME: _____		CONTACT: _____		Case / Control/...../09
Registration <input type="checkbox"/>	Consent Form <input type="checkbox"/>	Fasted 8 hrs <input type="checkbox"/>		No.
Demographics <input type="checkbox"/>	Questionnaire <input type="checkbox"/>	Anthropometrics <input type="checkbox"/>		
Start Time of Tests: _____		Finish Time of Tests: _____		
1-2 min	1: Endothelial <input type="checkbox"/>	B P Reading <input type="checkbox"/>	Urine Sample <input type="checkbox"/>	Blood Sample <input type="checkbox"/>
30 min	2: Endothelial <input type="checkbox"/>	B P Reading <input type="checkbox"/>		
1hr	3: Endothelial <input type="checkbox"/>	B P Reading <input type="checkbox"/>		
2nd hr (if time)	4: Endothelial <input type="checkbox"/>	B P Reading <input type="checkbox"/>	Urine Sample <input type="checkbox"/>	Blood Sample <input type="checkbox"/>
				Code
Time	Test	Systolic / Diastolic		
1-2 mins	Baseline 1. Endothelial	RI: _____	SI: _____	/
Comments: _____				
30 mins	1st 2. Endothelial	RI: _____	SI: _____	/
Comments: _____				
1 hour	2nd 3. Endothelial	RI: _____	SI: _____	/
Comments: _____				
2nd hour	3rd 4. Endothelial	RI: _____	SI: _____	/
Comments: _____				
Room Temperature:	C	Age:	yrs	<u>Calipers</u>
Subject's Temperature:	C	Race:		Biceps:
Waist Circumference:	cm	Height:	cm	Subscapular:
Hip Measurement:	cm	Weight:	Kg	Iliac Crest:
Waist - Hip Ratio:	%	BMI :		AVG % :
Participant has had the Refreshments provided <input type="checkbox"/>				
Participant Received Results from Gribbles Pathology <input type="checkbox"/>				
Laboratory Results Reviewed with the Participant <input type="checkbox"/> Subject referred to a doctor <input type="checkbox"/>				
Accumulative Results Scored by Subject are : LOW <input type="checkbox"/> NORMAL <input type="checkbox"/> ABNORMAL <input type="checkbox"/> (tick one)				
Subject Selected <input type="checkbox"/> or Rejected <input type="checkbox"/> for Phase Two Qualitative Interview (tick one)				
Participant Agreed to Participate in Phase Two Qualitative Interview <input type="checkbox"/>				

Appendix V continued... Example of a participant's laboratory report

GRIBBLES PATHOLOGY
(MALAYSIA) SDN BHD
149031-W

2nd Floor, Wisma Techna
18A, Jalan 51A/223
46100 Petaling Jaya
Selangor Darul Ehsan
Malaysia

LABOUR 1300 88 9734
Fax -603 7957 2732
www.gribbles.com.my

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TRUSTED INTERNATIONALLY

Patient Details UR: Courier Run:
Doctor Details
MRS SHERYL MATRU
CURTIN UNIVERSITY OF TECHNOLOGY
CURTIN UNIVERSITY PROJECT LOGY
SARAWAK
MIRI 98000

MIRI
DOB : / /42 Sex: Female
IC No. : Age: 67 Years
Collected: 23/11/09
Referred : 23/11/09 Your Ref. : Lab No. : 09

GENERAL CHEMISTRY SPECIMEN: SERUM

ORAL GLUCOSE TOLERANCE TEST

Specimen collected 0945
Specimen type 75g load

Time	Plasma Glucose	Urine	
		Glucose	Ketones
Fasting	4.0 mmol/L	Nil	Nil
2 hour	11.5 mmol/L	++	Nil

Diagnostic Criteria

	2 hr Glucose
Impaired Glucose Tolerance	7.8 - 11.0
Diabetes Mellitus	>= 11.1
Gestational Diabetes	> 7.7

Specimen comment: Haemolysis + (Ref: + (mild) to +++ (severe).)

Fasting glucose estimation is lower due to fluoride sample haemolysis.
Advice repeat with a fresh specimen, if clinically indicated.
Validated by N.Mohanaraja B. Biomedical Sc. (Hons) UM, Dip MLT (USM).

3rd reading SP = 142/98

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Patient Details UR: Courier Run:
MIRI Doctor Details
DOB : / /42 Sex: Female MRS SHERYL MATTU
IC No.: Age: 67 Years CURTIN UNIVERSITY OF TECHNOLOGY
Collected: 23/11/09 MIRI 98000
Referred : 23/11/09 Your Ref. : Lab No. : 09-

SPECIAL CHEMISTRY SPECIMEN: URINE

RANDOM URINE ALBUMIN

ALBUMIN AND CREATININE RATIO (ACR)

Urine Albumin	1285	mg/L	(< 21)
Urine Creatinine	6.61	mmol/L	(4.00-25.00)

* ACR 194.4 mg Alb/mmol Cr (< 3.5)

Microalbuminuria is defined as ACR 3.5-25.0 mg/mmol for female and ACR 2.5-25.0 mg/mmol for male. Values greater than 25.0 are indicative of macroalbuminuria and probably overt proteinuria.

Validated by N.Mohanaraja B. BioMedical Sc. (Hons) UM, Dip MLT (USM).

HAE MATOLOGY SPECIMEN: WHOLE BLOOD

* Haemoglobin 111 g/L (115-165)

LIPID STUDIES SPECIMEN: SERUM

Total Cholesterol	4.4	mmol/L	(< 5.2)
* Triglyceride	2.30	mmol/L	(< 1.68)
* HDL Cholesterol	0.91	mmol/L	(> 1.03)
LDL Cholesterol	2.44	mmol/L	(< 2.58)

Total Cholesterol/HDL ratio 4.9 (< 5.0)

Ref. ranges for lipids are in accordance with NCEP ATP III guidelines for optimal lipid levels.

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Patient Details UR: Courier Run:
Doctor Details
MRS SHERYL MATTU
CURTIN UNIVERSITY OF TECHNOLOGY
CURTIN UNIVERSITY PROJECT LOGY
SARAWAK
MIRI 98000
MIRI
DOB : / /42 Sex: Female
IC No.: Age: 67 Years MIRI 98000
Collected: 23/11/09 Your Ref. : Lab No. : 09-
Referred : 23/11/09

BIOCHEMISTRY

SPECIMEN: SERUM

*** Creatinine	514	umol/L	(44-110)
* eGFR	7	mL/min/1.73m ²	

An eGFR ≤ 30 mL/min/1.73 m² usually indicates a need for referral for assessment and management of Chronic Renal Failure disease.
NOTE: eGFR is NOT VALID for pregnant women or dialysis patients.

"NOTE: RESULTS HAVE BEEN VERIFIED BY REPEAT ANALYSIS."
Validated by N.Mohanaraja B. BioMedical Sc.(Hons) UM, Dip MLT (USM).

REPORT COMPLETED PLEASE FILE

Tests Requested:
GLUCOSE TOLERANCE TEST, MICROALBUMIN SPOT, HAEMATOLOGY GENERAL, LIPID STUDIES,
MULTIPLE BIOCHEM ANALYSIS

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Appendix W: Multiple logistic regression analysis of factors associated with the metabolic syndrome including dietary factors

Variable		Number	Crude OR [†] (95% CI [‡])	Adjusted OR [†] (95% CI [‡])
First degree relatives	No	135	1	1
	Yes	135	1.932 (1.135, 3.287)	2.468 (1.313, 4.640)
Family history of hypertension	No	55	1	1
	Unknown	26	1.778 (0.614, 5.147)	1.643 (0.478, 5.649)
	Yes	189	1.953 (0.944, 4.041)	2.751 (1.183, 6.396)
Age (years)		270	1.026 (1.007, 1.045)	1.034 (1.011, 1.058)
House	Detached	120	1	1
	Terraced / low-cost	86	2.038 (1.098, 3.782)	4.380 (2.022, 9.489)
	Self-build / longhouse	64	2.169 (1.113, 4.226)	3.276 (1.432, 7.494)
Added salt intake	Never	39	1	1
	Sometimes	175	1.594 (0.686, 3.702)	1.602 (0.591, 4.344)
	Often	56	2.507 (0.975, 6.446)	4.270 (1.382, 13.198)
Smoking	No	230	1	1
	Yes	40	1.692 (0.845, 3.390)	3.467 (1.429, 8.413)
Diabetes	Normal	130	1	1
	IFG ^a /IGT ^b	116	2.296 (1.287, 4.096)	3.636 (1.809, 7.307)
	Diabetic	24	7.000 (2.750, 17.820)	17.103 (5.463, 53.545)

-2 log likelihood = 309.735, d.f = 11.

All variables of interest were included in the full model in the initial step and then forward selection procedure was applied to obtain the final model, using 5% critical value of χ^2 test for the appropriate degrees of freedom.

*Non-significant variables were gender, ethnicity, income, alcohol drinking status, chewing betel nuts, chewing tobacco, family history of diabetes, family history of high cholesterol, family history of stroke, fried food intake, MSG^c intake, prawn/fish intake, preserved food intake, meat intake, sugar intake, supplement intake, total amount of vegetables and fruit intake, fitness status, times doing moderate/vigorous activities per week, Urine_ACR and eGFR (adjusted_rMDRD).

[†]OR =Odds Ratio ; [‡]CI= Confidence interval;

^aIFG Impaired Fasting Glycaemia defined by (Twigg et al., 2007); ^bIGT Impaired Glucose Tolerance defined by (Twigg et al., 2007); ^cMSG Monosodium Glutamate.

Appendix X: Matrix for Phase Two Recruitment

Appendix X : 6.1 : Matrix for Phase Two Recruitment				
RACIAL GROUP	WORST CKD Male - FDR	WORST CKD Female - FDR	WORST CKD Male - SCG	WORST CKD Female - SCG
Chinese	Interview 21 78 / 64 Mon. 13th May. 2013 Recorded in - Mandarin	Interview 28 36 / 56 Thu. 6th Jun. 2013 Recorded in - English	Interview 27 45 / 39 Sat. 8th Jun. 2013 Recorded in - English	Interview 30 37 / 40 Sat. 8th Jun. 2013 Recorded in - English
Malay	Interview 13 250 / 24 Mon. 15th Apr. 2013 Recorded in - Malay	Interview 17 100 / 73 Thu. 9th May. 2013 Recorded in - Malay	Interview 3 247 / 44 Fri. 8th Feb. 2013 Recorded in - English	Interview 29 126 / 32 Sat. 8th Jun. 2013 Recorded in - Malay
Indigenous Orang Ulu	Interview 7 163 / 69 Sat. 16th Feb. 2013 Recorded in - Kayan	Interview 6 164 / 60 Sat. 16th Feb. 2013 Recorded in - Kayan	Interview 4 113 / 62 Fri. 15th Feb. 2013 Recorded in - Kelabit	Interview 1 42 / 32 Mon. 4th Feb. 2013 Recorded in - English
Indigenous Iban	Interview 2 156 / 49 Wed. 6th Feb. 2013 Recorded in - English	Interview 23 182 / 67 Mon. 13th May. 2013 Recorded in - Iban	Interview 10 239 / 41 Sun. 17th Feb. 2013 Recorded in - English	Interview 15 149 / 43 Sat. 27th Apr. 2013 Recorded in - Iban
RACIAL GROUP	BEST CKD Male - FDR	BEST CKD Female - FDR	BEST CKD Male - SCG	BEST CKD Female - SCG
Chinese	Interview 26 124 / 70 Thu. 9th May. 2013 Recorded in - Hokkian	Interview 20 59 / 44 Sun. 12th May. 2013 Recorded in - Fuchau	Interview 25 84 / 58 Thu. 6th Jun. 2013 Recorded in - English	Interview 19 218 / 42 Sat. 11th May. 2013 Recorded in - Mandarin
Malay	Interview 18 129 / 38 Thu. 9th May. 2013 Recorded in - Malay	Interview 32 199 / 42 Sat. 24th Aug. 2013 Recorded in - Malay	Interview 31 269 / 43 Thu. 8th Aug. 2013 Recorded in - English	Interview 14 132 / 44 Tue. 16th Apr. 2013 Recorded in - Malay
Indigenous Orang Ulu	Interview 16 158 / 57 Thu. 9th May. 2013 Recorded in - Kayan	Interview 5 94 / 49 Fri. 15th Feb. 2013 Recorded in - English	Interview 11 266 / 43 Fri. 5th Apr. 2013 Recorded in - English	Interview 12 160 / 36 Fri. 5th Apr. 2013 Recorded in - Kelabit
Indigenous Iban	Interview 24 189 / 41 Mon. 13th May. 2013 Recorded in - Iban	Interview 22 184 / 60 Mon. 13th May. 2013 Recorded in - Iban	Interview 9 240 / 38 Sun. 17th Feb. 2013 Recorded in - English	Interview 8 230 / 37 Sun. 17th Feb. 2013 Recorded in - English

Appendix X continued... Categories for matrix and codes

Appendix X : Continued. Categories for Matrix and Codes

1. WORST scores from the First Degree Relatives (FDR) CASES	4 MALES 1. Chinese 2. Malay 3. Orang Ulu 4. Iban	4 FEMALES 1. Chinese 2. Malay 3. Orang Ulu 4. Iban
2. WORST scores from the Spousal Control Group (SCG) CONTROLS	4 MALES 1. Chinese 2. Malay 3. Orang Ulu 4. Iban	4 FEMALES 1. Chinese 2. Malay 3. Orang Ulu 4. Iban
1. BEST scores from the First Degree Relatives (FDR) CASES	4 MALES 1. Chinese 2. Malay 3. Orang Ulu 4. Iban	4 FEMALES 1. Chinese 2. Malay 3. Orang Ulu 4. Iban
2. BEST scores from the Spousal Control Group (SCG) CONTROLS	4 MALES 1. Chinese 2. Malay 3. Orang Ulu 4. Iban	4 FEMALES 1. Chinese 2. Malay 3. Orang Ulu 4. Iban

RACIAL GROUP	INTERVIEW STRUCTURE : WORST CKD Scores			
	WORST Male - FDR	WORST Female - FDR	WORST Male - SCG	WORST Female - SCG
Chinese	(T-P21 CWMR)	(T-P28 CWFR)	(T-P27 CWMS)	(T-P30 CWFR)
Malay	(T-P13 MWMR)	(T-P17 MWFR)	(T-P3 MWMS)	(T-P29 MWFS)
Orang Ulu	(T-P7 IWMR)	(T-P6 IWFR)	(T-P4 IWMS)	(T-P1 IWFS)
Iban	(T-P2 IWMR)	(T-P23 IWFR)	(T-P10 IWMS)	(T-P15 IWFS)
RACIAL GROUP	INTERVIEW STRUCTURE : BEST CKD Scores			
	BEST Male - FDR	BEST Female - FDR	BEST Male - SCG	BEST Female - SCG
Chinese	(T-P26 CBMR)	(T-P20 CBF)	(T-P25 CBMS)	(T-P19 CBFS)
Malay	(T-P18 MBMR)	(T-P32 MBFR)	(T-P31 MBMS)	(T-P14 MBFS)
Orang Ulu	(T-P16 IBMR)	(T-P5 IBFR)	(T-P11 IBMS)	(T-P12 IBFS)
Iban	(T-P24 IBMR)	(T-P22 IBFR)	(T-P9 IBMS)	(T-P8 IBFS)

Appendix Y: Phase Two Semi-structured Interview Schedule

HEALTH BELIEFS AND BEHAVIOUR OF A POPULATION SCREENED FOR CHRONIC KIDNEY DISEASE IN SARAWAK: A MIXED METHODS STUDY

Topic : Open-ended questions to ask/prompt/enquire of the study participant

Thanks so much for coming. As you participated in the study, I want to follow-up with you, to see how you are now and to give you some information regarding the study outcomes. Also I'd like to ask a few questions regarding your lifestyle and beliefs.

Topic 1 Past History

Origins: *Where were you born? Which kampong / town are you / your parents / your grandparents from? Were your parents / grandparents born in Miri or did they migrate to Miri? Are your parents still living on traditional family land in the kampong? How many generations back living on your family land can your mother/father remember? Does your mum / dad remember their great-grandparents names?*

Schooling / Training / Education: *Where did you do your primary schooling? Secondary schooling? Where did you do your tertiary education / job training?*

Working Life: *Where have you worked in the past? Did they provide training for you? How long have you worked at your last job?*

Family Roots: *Where have you spent the longest time / most years living? How many generations of your family have been living in urban areas? Are your parents still living? in the Kampong? Where are your parents living now? How often do they visit you here in Miri? How often do you go back to your Kampong / town to visit? Are you still single or married? Do you have children? Aged? Do they get to see both sets of grandparents regularly?*

Topic 2 Transitional Changes

Changes in Lifestyle: *What do you think has changed most for your parents now compared to living in the kampong? For you? What would you be doing if you were still living in the kampong? Have you still got many cousins and friends living in the kampong? How has your life changed? What has changed the most in your life since your grandparents time? Over the past ten years? What do you think needs changing in the next ten years to make your life more satisfied / happy / fulfilled? Do you have someone to help you look after the children? Housework? Garden work?*

Changes in Health Status: *Do you have brothers and sisters? Is everyone of your siblings healthy? If not, why not? Does anyone in your family have kidney problem? on dialysis? Is there anyone in your family with high blood pressure, diabetes, or heart problem?*

Changes in Diet / Eating Habits: *Has your diet / food changed in the past ten years? Or do you still eat the same traditional foods prepared the same way as your mother and your grandmother used to cook when you were living with them? Has your eating habits changed? Do you mostly cook and eat at home or do you eat out a lot? Do you bring take-away food home to eat? If you go out, do you like to eat at McDonalds, Kentucky and Pizza or prefer local kedai / coffee shop food? When you cook do you use salt? MSG? Do you drink water? Or prefer other drinks? What hinders you from consistently following a healthy diet? How many times a day / week do you eat away from home?*

Changes in Exercise / Physical Activity Habits: *Are you as active as when you were in your twenties? Are you active at your work place or do you mostly sit at a desk? Are you sometimes too tired after work to exercise? Do you consider it important to exercise every day? How often do you exercise? Do you get your children / cousins / friends to play sport or go for a run with you? Do you sit at a desk more than five hours per day? Do you watch more than 3 hours (sitting down) of TV / films per day? How do you view exercise? Is there anything stopping you from exercising more? On a regular basis?*

Topic 3 Environmental

Housing Environment: *Do you own your own house? Or are you Sharing? Or Renting? Do you share the repayments? Or only your husband make the repayments? What type of house is it?*

Living Arrangements: *Do you have dependants (children, aged parents, etc) you provide for? Living with you? Do you like the area where you are living? Or hope to move again one day?*

Gardening Space: *Do you have a garden / kebun / and grow your own vegetables? Fruit? Do you grow or buy most of your food? Would you have a garden if you had time to make one? Any reason not to? Have you every regularly used pesticides or weedicides around your house compound?*

Surrounding Environment: *So how far is it for you to walk from your house to the nearest padang (green space) where you can go for relaxation / jog / exercise / sport / fish in a pond etc.? Close or far? How many minutes to walk to the padang? Where do your children go to play with their friends?*

Topic 4 Health Beliefs

Traditional Practices: *Are your grandparents / parents still following their traditional ways? Do you still practice your grandparents' / parents' traditions? For example, do you ever consult a traditional practitioner for massage? Herbs? Medicine? Advice?*

Alternative Medicines: *What age did you leave living with your mum and dad? Have your health beliefs changed from your mum and dad's? Like if you have a headache your mum might say 'take this herb' or if you have a backache you do this? Have those beliefs changed at all since coming to Miri? Or do you still follow your mum's practice / advice?*

Medical / Alternate Preferences: *If you are not well what is your first choice – a traditional herbal practitioner or a medical doctor at the hospital or a clinic? What do you believe is the best options for your health? The most expensive? Do you think supplements are necessary for good health? Do you do or take anything to improve your quality of life? Do you take supplements? HRT? Do they work? Improve your health?*

Belief in Medical / Health Information: *With regard to health advice, do you always believe what you read on the internet? Newspaper? Advertising? From your friend? A doctor? What do you think is causing kidney disease in your family? In Miri as a whole?*

Topic 5 Health Behaviours

History of Compliance to Doctors Orders: *Do you go to the same doctor every time you are not well? Or to a clinic and see different doctors every time? Do you have a good rapport / relationship with a family doctor? Do you find it easy to see and talk to a doctor? Or is it difficult for you? If you go to the doctor and he gives you some Western medicine or tablets, do you eat keep taking the tablets - even when you feel better? Stop when feeling better? Don't eat it? Would you rather take traditional herbs? If you see a medical doctor do you tell him if you are taking traditional herbal medicine? If you need a repeat dose / tablets where do you get it from? Doctor? Pharmacy? Over the counter? Drug store? Kedai?*

Health Habits: *Have you ever deliberately tried to change any of your health habits? Smoking? Drinking? Weight? Are you still trying? Have you lost any weight? What kind of problems did you face when trying to lose weight or get fit?*

Lifestyle Behaviour Changes: *Are you trying to lose weight (quit smoking) on your own? with anyone else? In a group? How are you doing it? Do you exercise more? Have you always been big size? When did you start to gain weight? What's the hardest thing about trying to lose weight? Do you worry about the heat with sweating? Do you get itchy skin? What's the best thing about losing weight? How do you feel? Do you feel sleepy after meals? What would help you most?*

(Are you trying to quit smoking on your own? with anyone else? In a group? How are you doing it? Using patches, etc?)

Life Aims: *What would you say would be three defining moments of your life? What are three things that have influenced your life, but which were out of your control? What are three critical (life changing) decisions you have made in your life? What are three goals (1 long term, 1 medium term and 1 short term) goals you are aiming to accomplish in the next ten years?*

Thanks so much for your time. Please feel free to email me if you want to know anything regarding the study or if you want some advice or information from me.

45 minutes.

Appendix Z: Observation, Comments and Notes Sheet

Notes from Quantitative Results:

Participant No:.....

- Age
- eGFR & ACR
- metabolic Syndrome
- Weight Changes
- Blood Pressure Changes Similar /
- Cholesterol Changes
- OGTT Oral glucose tolerance test Results

Notes from Qualitative Interview:

- Body Language Response
- Changes in Health
- Confirmation or Contradictions to Quantitative Questionnaire
 - 1.
 - 2.
 - 3.
 - 4.
- Other Points Noted and My Feelings
 - 5.
 - 6.

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