

**Understanding how individual, family and
societal influences impact on Indigenous
women's health and wellbeing**

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of Doctor of Philosophy in the School of Public Health**

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DECLARATION

This thesis is submitted to the University of Sydney in fulfilment of the requirements for the degree of Doctor of Philosophy. To the best of my knowledge, the work presented in this thesis is original except as acknowledged in the text.

I hereby declare that I have not submitted this material in either full or in part for a degree at this or any other institution.



3 March 2017

DEDICATION

I dedicate this thesis to my sister Christine Baker, a life taken far too early at the age of 54. If only you had taken as much care of yourself as you did of our family, perhaps we would be sharing this moment together.



3 March 2017

ABSTRACT

Introduction

This PhD study explores issues of stress, psychosocial health and chronic disease (CD) affecting Indigenous Australian women. It seeks to understand the impact of the roles and responsibilities Indigenous women have in their families and communities on their ability to manage their own health.

Background

In relation to the social determinants of health, Indigenous Australian women are the most socially and economically disadvantaged women in Australia. They face considerable disparity in relation to their health and wellbeing compared to other women in Australia. Indigenous Australian women are predominantly the sole care providers for close family members and are called upon to support family and community members through extended kinship networks. These women often experience limited educational and employment opportunities as a consequence. Women with such limited opportunities often face a lifelong trajectory of inadequate housing, reduced access to services and poverty. Under these circumstances, Indigenous Australian women suffer a heavy burden of CD and ill-health. Premature mortality due to diabetes, chronic kidney disease (CKD) and cardiovascular disease (CVD) contributes significantly to the gap in life expectancy (LE) for Indigenous women in Australia.

Despite the reality of the lived experiences of Indigenous women, positive stories of resilience, strength and outstanding leadership exist throughout the country. These stories are not only remarkable success stories in their own right, they are even more remarkable given that these stories of success and resilience were achieved within a society that had at its structural core, seemingly insurmountable impediments, often present from birth. For example, such impediments saw the author taken home to a tent on the outskirts of town from the hospital following her birth; and until the age of three, she was not counted as a person or citizen of this country. Laws such as the various Aboriginal Protectionist Acts that were in force across Australia from 1838 to the

1970s, reinforced oppression and thwarted the aspirations of many Aboriginal people (Sherwood, 2013). This reality continues to impact on Indigenous people today. As recent as 1980, the author's own aspirations to become a nurse were seriously eroded by career guidance officers who enthusiastically promoted early school departure and a career as a hospital domestic and cleaner instead of directing her towards further education or a professional career in health.

A particularly important focus of this thesis is the research study involving interviews with 72 Australian Indigenous women from four Aboriginal health services in Australia about their roles and responsibilities to their family and community. The author listened to stories of strength, resilience and cohesiveness underpinned by pride and a strong sense of identity and belonging. These women shared how they juggled hectic workplace responsibilities, with having to provide care and support for extended family. This was both a strongly positive factor in their lives, yet the research will also explore the potential impact of their caring roles upon their own health and wellbeing.

Methods

This study reviewed the published evidence exploring the impact on Indigenous women of living with a CD, and reports on the burden of stress and psychosocial issues for Indigenous women. A systematic review examined intervention programs to address CD and mental health. This review was focused on issues as they affected Indigenous women and highlighted interventions occurring within Aboriginal Medical Services (AMS).

Findings from two qualitative research projects are reported. In-depth interviews were undertaken with 21 Indigenous men and women and their healthcare providers as part of the process evaluation accompanying the Kanyini-GAP clinical trial, which aimed to improve health outcomes for people with high cardiovascular risk. In-depth qualitative interviews were also undertaken with 72 Indigenous women from four AMS around Australia to explore their experiences of living with CD and seeking to understand the factors that impacted on their ability to manage their own health.

Research findings

A review of the literature outlined the historical, social and economic factors that impact on Indigenous women's health. These social determinants result in a greater incidence and prevalence of CD and premature death. The review also explored the heavy burden of psychosocial stress faced by Indigenous women.

A systematic review explored evidence regarding programs addressing CD and mental health or social and emotional wellbeing (SEWB) for Indigenous people. We found a lack of high quality intervention studies, with poor delineation of key outcome measures and indicators of success, and a strong potential for bias in the reporting of results. We were unable to determine the efficacy, cost-effectiveness, or the potential for using programs beyond the original research setting.

The in-depth interviews of women from four AMS explored the roles and responsibilities that Indigenous women have in their family and community, and if these roles and responsibilities impacted on the women managing their CD. Women took on significant roles and responsibilities within extended family networks. These responsibilities affected the study participants' wellbeing and management of their CD was also affected by additional factors such as the incarceration of family members. The heavy burden of CD on the individual, family and wider community was highlighted. The impact of domestic violence is also highlighted, as was the grief related to repeated accounts of death and family members dying. Protective factors that promoted resilience included family support, cultural identity and belonging, education and health service access.

The impact upon the author as an Aboriginal woman undertaking this research and the potential for Indigenous researchers to suffer vicarious trauma (VT) through conducting such research is discussed in Chapter 6.

Implications of the research

The findings presented in this thesis have implications for service delivery, resource allocation and policy development. For Indigenous women to be better able to manage

their own health, to support earlier presentation with illness, health maintenance, improved self-management and enhanced quality of life, the extended family and community caring responsibilities of these women need to be taken into account. Better resources to support new mothers, culturally appropriate safe houses for women fleeing family and domestic violence, and flexible models of service delivery to more communities to better accommodate the competing demands placed upon Indigenous women are required to bring about improvements in health and wellbeing.

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I would like to acknowledge and thank the 72 women who shared their amazing journey of caring for their families, their communities and Country. Although some of the stories shocked me to the core, I never saw victims; instead, what I saw was strength, resilience and the will to hold a family together, with the women forgetting to care for themselves at times.

I would like to acknowledge the generosity of Wuchopperen Aboriginal Medical Services in Cairns, the Central Australian Aboriginal Health Congress, Geraldton Aboriginal Medical Services and Wirraka Maya Aboriginal Medical Services in South Hedland for allowing me access, for their hospitality, generosity and the patience shown to me as a researcher.

I would like to acknowledge the continued support and guidance of my supervisors Professor Alan Cass and Associate Professor Maree Hackett. During my data collection in Western Australia, Professor Juli Coffin also supported and guided me.

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To my family and friends, I would like to thank each of you for putting up with me when I was too busy to talk or listen, and anything else for that matter.

AUTHOR'S CONTRIBUTION

The work presented in this thesis has been conducted by the author under the supervision of Professor Alan Cass (Menzies School of Health Research, Charles Darwin University and The George Institute for Global Health, Sydney School of Public Health, University of Sydney), Associate Professor Maree Hackett (The George Institute for Global Health, Sydney School of Public Health, University of Sydney) and Associate Professor Juli Coffin (Notre Dame University, Broome)

The author led the planning of the research, design of the component studies, ethics committee submission, the collection, management, analysis and interpretation of the data, writing of the manuscripts for submission to peer-reviewed journals, and the writing of the thesis.

All co-authors were contacted to notify them of the inclusion of individual manuscripts related to Chapter 3 and Chapter 4 of this PhD thesis, as well as to seek their authorisation.

Data analyses in this thesis were undertaken from qualitative interviews with Indigenous women from four AMS within Australia. The information from these interviews was generated solely for the purpose of this body of work.

ETHICS CLEARANCE

Chapter 4 uses data generated as part of a pragmatic randomised controlled trial (RCT) for the *Kanyini Guidelines Adherence with the Polypill* study and was assessed as part of a process evaluation within the George Institute for Global Health. The author was part of the original process-evaluation planning team and a member of the qualitative team conducting interviews for this study. She was also part of the team of researchers interpreting and analysing the data, as well as the writing and editing of manuscripts published using these data.

Chapters 5, 6 and 7 contain data generated as part of a qualitative study with 72 Indigenous women from two states and one territory in Australia. This project received ethics clearances from the following committees: the Human Research Ethics Committee Cairns & Hinterland, Cape York, Torres Strait – Northern Peninsula Hospital & Health Services (December 2013; see Appendix 1); the Central Australian Human Research Ethics Committee, Centre for Remote Health, Alice Springs, Northern Territory (March 2014; see Appendix 2); and the Western Australian Aboriginal Health Ethics Committee, Perth, Western Australia (March 2014; see Appendix 3).

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LIST OF ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Service
AIHW	Australian Institute of Health and Welfare
AMS	Aboriginal Medical Service
CD	chronic disease(s)
CHD	coronary heart disease
CKD	chronic kidney disease
CTG	Close the Gap
CVD	cardiovascular disease
DoHA	Department of Health and Ageing
GFR	glomerular filtration rate
eGFR	estimated glomerular filtration rate
ESKD	end-stage kidney disease
GP	general practitioner
IPA	interpretive phenomenological analysis
KVC	Kanyini Vascular Collaboration
LE	life expectancy
NHMRC	National Health and Medical Research Council
NSW	New South Wales
NT	Northern Territory
RCT	randomised controlled trial
SEWB	social and emotional wellbeing
VT	vicarious trauma
WA	Western Australia
WDNWPT	Western Desert Nganampa Walytja Palyantjaku Tjutaku

The Team

AC	Supervisor
AE	Author
HL	Research fellow
JC	Secondary supervisor
MH	Secondary supervisor
SP	Review author

CHAPTER 1: INTRODUCTION

1.1 Introduction to the thesis

This thesis explores how the roles Australian Indigenous women play within their families and communities impact on the management of their chronic disease (CD). Through privileging their views and stories, it has explored the meaning of psychosocial health and wellbeing from the perspective of Indigenous women. It describes how stress and poor psychosocial health affect Indigenous women's ability to manage their health.

Mixed methods were used in the thesis. A systematic review explored the intersection of psychosocial and physical health interventions for Indigenous women. Secondary analysis was undertaken of interviews obtained as part of a process evaluation of the Kanyini-GAP pragmatic randomised controlled trial (RCT). Interviews were conducted with 72 Indigenous women living with CD, sourced from four Aboriginal medical services (AMS) around Australia.

1.2 Background and significance

The gap in life expectancy (LE) between Aboriginal and Torres Strait Islanders (from here on will now be referred to as 'Indigenous' in this thesis) and other Australians remains too wide, with current estimates at 12 years less for Indigenous men and 10 years less for women (Australian Institute of Health and Welfare [AIHW], 2010a). CD is the leading cause of death for Indigenous people aged between 35 and 74 years (AIHW, 2010b). Premature mortality due to diabetes, chronic kidney disease (CKD) and cardiovascular disease (CVD) contributes significantly to this gap in LE (George Institute for Global Health, 2011).

Indigenous women are more socially and economically disadvantaged when compared to other women in Australia. As highlighted in a report on progress addressing the LE gap, socio-economic disadvantage is associated strongly with poor health outcomes (Holland, 2015). Indigenous women born between 2010 and 2012 could expect to live to 73.7 years, four years and eight months more than Indigenous men, and ten years less than non-Indigenous women born in those same years (ABS, 2013). Undetected,

treatable and preventable chronic conditions are highlighted as having significant effects on LE for both Indigenous men and women, according to findings from the *National Aboriginal and Torres Strait Islander Health Measure Survey* (ABS, 2014e).

When planning for programs to improve Indigenous people's health, it is important to view their healthcare needs through a holistic framework and consider their social, emotional, spiritual and cultural wellbeing needs (Sherwood & Edwards, 2006). This approach accommodates people's feelings and coping mechanisms. It also incorporates how people function on a daily basis. In addition, people's SEWB extends to include their connection to land, family, community and tradition (Sherwood & Edwards, 2006; George Institute for Global Health, 2011). This is why, when caring for Indigenous Australians, we must explore how models of CD care provide them the best chance of returning to good health and to their homes and communities.

SEWB can be affected by many factors: historical events, discrimination, ill health, the death of a family member, drug abuse and legal issues (Gee et al., 2015). The 2008 *National Aboriginal Torres Strait Islander Social Survey* reported that 80 per cent of Indigenous survey participants had experienced at least one significant stressor in the 12 months prior to completing the survey (ABS, 2008). The impact of these stressors on Indigenous women's health is not well understood. The health of Indigenous women is poor when compared with non-Indigenous women from within Australia and other developed countries. Research suggests that late presentation for healthcare, resulting in diagnosis at advanced stages of a disease, influences the poor health status of Indigenous women in Australia (Burns et al., 2013).

Various suggestions have been made to explain Indigenous women's late presentation to services when they need medical care. This could be due to the multiple roles they hold within their communities; these roles extend beyond the women's immediate family structure, as do the expectations placed on them (Burns et al., 2013). Further, an expectation exists that women in Indigenous families look after sick members of their household, possibly at the expense of their own health (Burns et al., 2013; Thackrah & Scott, 2011). Such conflicting demands might contribute to the reported high levels of stressors among Indigenous women.

1.3 Research method

This study uses a mixed-methods approach to explore Indigenous women's experience of living with a CD, and how the roles women play within their family unit and community impact on the management of their own health. The exploration involved the following elements:

- A review of published evidence provided an overview of current knowledge regarding the impact of diabetes, CVD and CKD on Indigenous women.
- A systematic review of programs to address mental and physical health, with a focus on CD management, for Indigenous women.
- Exploration of the roles and responsibilities Indigenous women have in their families and communities.
- Discussion and reflection on the challenges emerging from these roles.
- Examination, through the words, views and perspectives of the Indigenous women, regarding how these challenges affected how Indigenous women managed their CD.

Interviews were conducted with Indigenous women living with CD. Prior to engagement with study participants, negotiations, consultation, agreement and ethics approval was sought and given at each of the AMSs where the research was conducted. The author provided information sessions to members of the executive committee and clinical teams at each of the four health services. The purpose of the information sessions was to request support from the leadership within each health service centre, along with guidance on and support with participant recruitment. An outcome of these information sessions was that the clinicians asked those clients attending the clinic if they would be interested in talking to the author about the study. In each health service centre, the author was allocated a clinical support staff member to help with recruitment.

To ensure that privacy and confidentiality were maintained for potential participants, the author was provided with a room in which to conduct interviews. An explanation of the study was given to health service clients who agreed to meet the author. This explanation included details about the purpose of the study and what would be required of participants.

A purposive sampling approach was used to select study participants. Potential participants were invited to participate if they met certain criteria: being an Indigenous woman with a CD – diabetes, CKD or CVD, and who might have issues affecting their SEWB. Potential participants fitting the study criteria were selected by each health service and were approached from amongst current clients of the AMS. Before being approached by the author, potential participants had read the *Notification to Inform Potential Participant Form* (Appendix 1) and had expressed an interest in being part of the study.

1.4 Research questions

RQ1: What is the chronic disease burden for Indigenous women?

Specific objectives

1. To discuss the prevalence and burden of diabetes, CVD, CKD and disorders of thought and thinking among Indigenous women.
2. To explore the lifestyle, environmental and biological factors that may or may not affect Indigenous women for each of these CDs.

RQ2: How do women's roles within their family and communities affect their health and wellbeing, and management of their chronic disease?

Specific objective

1. To explore the impact these women's roles have on CD management.

RQ3: What is the meaning of psychosocial health and wellbeing from the perspective of Indigenous women?

Specific objectives

1. To explore the views and understanding of Indigenous women regarding health and wellbeing.
2. To explore community-based models for health, stress and wellbeing.

RQ4: How does stress and poor psychosocial health in Indigenous women affect their ability to manage their chronic disease?

Specific objective

1. To explore the relationships between stress, psychosocial health and the management of CDs.

1.5 Methods

1.5.1 Research team and reflexivity

The research team consisted of the study's chief investigator (AE/author) who conducted qualitative interviews with the participants, a research fellow (HL) who assisted in the analysis and writing relating to some of the research findings and the author's PhD supervisors (AC and MH) who contributed to the study design, analysis and writing. HL, MH and AC are non-Indigenous investigators with medical and psychology backgrounds and have had significant health research-related experience working in collaboration with ACCHSs. JC is an Indigenous investigator with a Indigenous health research background and significant health research-related experience working in collaboration with ACCHSs. To ensure clarity for the reader of this thesis, the chief investigator (AE) is referred to as the 'author' from here on, and when referring to herself and others, will use the term 'the team'.

The qualitative interview study with Indigenous women formed the most significant part of the author's PhD program. The author was solely responsible for conducting the 72 interviews and focus groups with participants, who were accessed through four AMSs across Australia. The author is an Indigenous woman with a nursing background. She has completed a Master's in Nursing Research and is currently pursuing a PhD through the School of Public Health at Sydney University. The author combines experience and expertise in nursing practice and Indigenous health with a commitment to identifying preventative strategies for Indigenous people regarding CD. Her interest in the role of psychosocial factors in CD and building resilience in Indigenous health has resulted in the research undertaken towards this thesis.

The author had a previous professional or personal relationship with each AMS prior to the commencement of any negotiations, consultations or agreement to conduct research in that health service. However, no relationship existed with any of the participants prior to them reading the *Notification to Inform Potential Participant Form* (Appendix 1). Selection of potential participants was established when they were current clients of the AMS, had been selected by health service providers as potential participants fitting the criteria of the study and who may be interested in participating. This information included a brief introduction of the author, the research aims, the broad issues being explored, and what the author hoped might be achieved through conducting the study.

An overview of the research was included in Form 1, as was information relating to ethics approval for the study, assurance about the confidentiality of information collected, and contact information for the author, her supervisors and the ethics committee for any concerns or issues arising from the conduct of the research.

1.5.2 Study design

The methodological approach that underpins this study is interpretive phenomenological analysis (IPA). IPA is a qualitative research approach concerned with exploring and understanding the lived experiences of a specified phenomenon and involves a detailed examination of the world in which participants live through their experiences, and the meaning they attach to these experiences (Smith, 2004). Furthermore, this approach is relevant where multiple layers of complexities inform who the participants are and where they fit in society.

The only difference for this study, not normally consistent with IPA, is the sample size, which was greater than normally consistent in studies using this design, that is, 72 women were interviewed using this approach (Smith & Osborne, 2015). This methodological approach sees the participants as having the expertise to provide insight into beliefs, responsibilities and thoughts by sharing their accounts in a comprehensive way that can leave very little room for misinterpretation, and recruitment relates to knowledge of the research topic under study (Reid, Flowers, & Larkins, 2005).

This approach provides the author with a framework to understand what it would be like to undergo the experiences of Indigenous women within their families and communities. From the experiences reported here, the author has highlighted factors that might enhance or impede these women's management of their health and wellbeing (Streubert & Carpenter, 1999).

Phenomenology is both a philosophy and a research method: a phenomenological theoretical approach underpins this study's research as it is concerned with exploring and understanding human experience. Researchers use this method to uncover the meaning of an individual's experience of a specified phenomenon through focusing on a concrete experiential account grounded in everyday life (Langridge, 2007). Although the author is an Indigenous woman herself, she acknowledges the complexities associated with Indigenous culture and that not all lived experiences are the same.

1.6 Participant selection

1.6.1 Sampling strategy

A purposive sampling approach was used to select participants for this study. Potential participants were invited if they met the criteria of being an Indigenous woman with a CD that included diabetes, CKD or CVD, who was a current client of the AMS, and who had been selected by that service as a potential participant fitting the study's criteria. Potential participants read the *Notification to Inform Potential Participant Form* (Form 1) and expressed an interest in being part of the study. Initial negotiation, consultation, agreement and ethics approval was sought and given at each of the sites prior to engagement with participants from the AMS.

The author provided information sessions to members of the executive committee and clinical teams in each of the four health services. The purpose of the information sessions was to reiterate the approach for data collection and to request support and guidance on recruitment. An outcome of these information sessions was that health service providers asked those clients attending the clinic for appointments if they were interested in discussing the study with the author. In each of the health services, the author was allocated a clinical support staff member to help with recruitment and

provided with a room to ensure that privacy and confidentiality was maintained for potential participants. For those clients who agreed to meet with the author, the study was explained, with a description of what the study was about and what would be required of participants.

Interested parties were provided with a *Participant Information Statement* (see Appendix 4), reiterating what had just been discussed. After the participants had read this form, and understood what the author was asking of them, participants were then provided with a *Consent Form* (see Appendix 5), which was explained further. If participants agreed, the consent form was signed and a suitable time and place was established to conduct the interview. The author used a face-to-face approach to conduct participant interviews; these interviews were audio-recorded with participant permission. Seventy-two Indigenous women were interviewed.

1.6.2 Presence of non-participants

Interviews at the first and third health service only included study participants. At the second health service, as two participants wanted to be interviewed consecutively (at their request), each remained in the room while the other was being interviewed. With the fourth health service, the two participants being interviewed in another healthcare facility also wanted to be interviewed one after the other and with an Aboriginal liaison woman known to both women present.

1.6.3 Setting

The research was conducted in four AMSs in three Australian states. The services were located in urban, regional and remote settings. In the first health service, data were collected in the clinic. The author was provided with a private office away from the clinic to ensure privacy and confidentiality were maintained. In the second health service, the author was also provided with an office to conduct the interviews. However, on four occasions, the author met with participants at the hostel where they lived and were awaiting dialysis treatment. The third health service provided an office; however, the author interviewed three participants in their work place and one at the participant's home. The confidentiality and safety of both author and participants were maintained at

all times. Due to space constraints, the fourth health service was only able to provide the author with desk space. For this health service, the author conducted all but four of the interviews in participants' homes. Two of these interviews were conducted in another healthcare facility and two were conducted at the health service. The confidentiality and physical safety of both author and participants were maintained at all times.

1.6.4 Description of sample

Current AMS clients who were Indigenous women with at least one CD, including diabetes, CKD or CVD and disorders of thought and thinking, including depression, anxiety, stress or worry met the criteria for inclusion in the study. Females aged 0 to 17 years were excluded from this study, along with any woman diagnosed with dementia or as being at risk of not giving valid informed consent.

1.6.5 Ethical issues

There is a need to recognise the unique richness and diversity of Aboriginal culture in Australia (Holland, 2015; Zubrick et al., 2004). Although the author is an Indigenous woman, she is cognisant of the importance for adherence to the guiding values related to working with Indigenous people that is stated in the National Health and Medical Research Council Values and Ethics Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research. These values provide direction for researchers conducting studies within the Indigenous health space. This direction is underpinned by six guiding values: (i) reciprocity; (ii) respect; (iii) equality; (iv) responsibility; (v) survival and protection; and (vi) spirit and integrity (NHMRC, 2003). Guiding Value 1 (reciprocity) relates to the shared commitment among families and communities of Indigenous descent to achieve equity. This commitment broadens to include *the lands, animals and nature*' (NHMRC Values & Ethics, 2003, p. 10). Guiding Value 2 (respect) covers the maintenance of human dignity and its worth that characterises relationships among people, including how they behave within a functioning moral society. The third value (equality) ensures that Indigenous people see themselves and others within their communities as being equal. Survival and protection is the fourth value that bonds Indigenous Australians as guardians providing protection for the culture and identify of Indigenous society in Australia. Guiding Value 5 (survival and protection) must be

adhered to when conducting research with Indigenous Australians; the essential responsibilities in '*Aboriginal societies and cultures are to country, kinship bonds, caring for others and maintenance, harmony and balance within and between the physical and spiritual realm*' (NHMRC, 2003, p. 16). Finally, Guiding Value 6 (spirit and integrity) binds all these principles together to ensure past, current and future generations maintain the continuation of this culture. In addition, Aboriginal and Torres Strait Islander values and cultures can only be maintained with integrity if none of the other five values are not diminished during the conduct of conducting research with Aboriginal people (WHO, 1946).

This project excluded children and young people. All participants were Indigenous women. Women with CD, some of whom might be highly dependent on medical care, were recruited for this study. This author did not intend to recruit people whose primary language was other than English, pregnant woman, people in existing dependant or unequal relationships or people who may have been involved in illegal activity. Nevertheless, we recognise that some recruited participants might fall into these categories.

Ethics approval to conduct research in four Australian AMSs was obtained in March 2014. Amendments to the ethics applications were submitted and approved so that an additional researcher to assist with data analysis and write up, and to extend the research in one AMS, could be recruited. Between April and July 2014, the author conducted information sessions for the executive committee and clinical teams at each site. Qualitative interviews with participants from each site were conducted between May and October 2014.

The student and research team conducted this research seeking to contribute to, and not erode social and cultural bonds among Aboriginal and Torres Strait Islander participants or their communities. Initial negotiations, consultation, agreement and mutual understanding was established with the Aboriginal Medical Services (AMS) at each of the health service sites prior to engagement with participants. We worked to achieve best outcomes for all concerned, without compromise or harm to any of the participants, health services or researcher.

A mutual understanding of all consultation and negotiations to achieve best outcomes for all concerned, without compromise or harm to any of the participants, health services or researcher was cautioned for. The researcher took responsibility for ensuring ongoing consultation and negotiation throughout the conduct of the research.

The author was guided by a health worker in each of the AMS sites to ensure language barriers and cultural values and practices were not compromised during the conduct of the research. The researcher sought access to interpreters from the local community, with the permission of participants prior to engaging with the interpreters. Interviews were conducted at venues suitable to both the researcher and the participants.

Consent to participate in the study was informed with the assurance by the author that participants were free to withdraw without risk of penalty to themselves.

In accordance with NHMRC Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research Guiding Value 2 (respect) and Guiding Value 3 (equality), the author was guided by participants at all times to ensure that there was no power imbalance that may have compromised the participant's level of control and autonomy when disclosing personal information about themselves to the author. The author adhered to Guiding Value 4 (responsibility) by ensuring the participant's rights to maintain control in the protection and development of their cultural heritage, traditional knowledge, cultural expressions and other tangible heritage issues.

Guiding Value 4 (responsibility) was adhered in that rights in the traditional knowledge and cultural expressions were respected, protected and maintained throughout the conduct of the research. Although information collected belongs to participants of this study, it was and continues to be stored with the author at the George Institute for Global Health. Acknowledging ownership of the data is ongoing as the stories of the participants is repeated throughout the reports, presentations and publications. As per Guiding Value 5 (survival and protection), data collected during the interviews was transcribed, and where necessary, clarity was sought by the author to ensure that the information she reported was accurate.

Guiding Value 2 (respect) and Guiding Value 5 (survival and protection) were followed to ensure that rights in the traditional knowledge and cultural expressions were respected, protected and maintained throughout the conduct of the research. Although information collected belongs to participants of this study, it was and continues to be stored with the author at the George Institute for Global Health. Acknowledging ownership of the data is ongoing as the stories of the participants is repeated throughout reports, presentations and publications.

1.7 Data collection

1.7.1 Interview guide

Indigenous women with a CD were interviewed to explore the interplay between living with CD, their family and community and how they managed their health. The preferred data collection approach for this study was to use a semi-structured style of interviewing. This was seen as the best approach to provide participants with the flexibility to reflect, identify and interpret all-important information employed to gain significant worth. This approach sought to make sense of what the women were saying in relation to situations where their roles and responsibilities influenced on them managing their health. One-on-one interviews were used in this study because information sought by the author was of a very personal nature. When seeking this type of information from participants, the author needed to ensure a certain level of rapport had been developed with the participants. This is due to the participant's need to be feel secure enough to share thoughts and uncertainties she may have had with the author.

The interview guide was a set of questions based on where the participants were originally from, their family and household structure, and the women's roles in the home and community. The next set of questions focused on health, in particular who cared for family members when they became unwell, and who took care of the participants when and if they were sick. The final set of questions focused on SEWB and the impact of stress and worry on participants (see Appendix 6).

Due to the potentially stressful nature of the questions asked of the research participants, as a precautionary measure they were also asked to complete a

questionnaire related to depression. This form, the *Patient Health Questionnaire* (PHQ-9), measures the severity of depression (see Appendix 7). This tool can assist in the diagnosis and management of people with undetected depression. With the permission of participants, where concerns arose regarding the questionnaire results, participants were referred to a general practitioner (GP) at the AMS.

Although the interviews and questioning were not formally piloted with participants at each site, the questions were provided as part of an information package to health service executive staff and clinical teams prior to meeting with the health service. Guidance was also provided from the contact person at each site during the study's community engagement and collaborative phase. The feedback from each site suggested they were satisfied with the documents provided and no refinement of the interview guide was requested.

The first interview was conducted in May 2014 and the final interview was conducted in October 2014. As the author was initially less familiar with the program chosen to support the study's analysis, the author sought an amendment to the ethics application to add HL to the research team as a collaborator to ensure a rigorous process of thematic analysis. All interviews were audio-recorded with participant permission. The author took field notes during all stages of data collection. These field notes were a mechanism for the author to reflect on uncertainties. They were also taken when the author felt compelled to explore her own thoughts.

The duration of interviews with participants was between 15 and 60 minutes. The author clarified any uncertainties or apparent discrepancies with participants prior to leaving each site. Transcripts were not returned to participants for clarification, as any uncertainties had already been discussed with participants.

1.8 Thesis structure

Within the confines of this thesis, the author presents the stories and provides a voice for Indigenous Australian women. As an Indigenous author, she was concerned with exploring, understanding and presenting the lived experience of these women. Although

there is an abundance of data related to the health and wellbeing of Indigenous women, the causal pathway to the excess burden of CD is poorly understood.

1.8.1 Chapter 2: Indigenous women with chronic disease – A review of the literature

Specific objectives

1. To discuss the prevalence and burden of diabetes, CVD, CKD and disorders of thought and thinking among Indigenous women.
2. To explore the lifestyle, environmental and biological factors that may or may not affect Indigenous women for each of these CDs.

Chapter 2 establishes the scene for this thesis, highlighting that the research will be discussing Indigenous women from urban, rural and remote parts of Australia. This chapter also discusses the historical context for contemporary Indigenous Australia, and some of the common health issues faced by Indigenous people today. The chapter reports on what the literature identifies as the roles and responsibilities for Indigenous women in their family and communities.

1.8.2 Chapter 3: Systematic review

Chapter 3 systematically reviews programs addressing CD and SEWB for Indigenous people in Australia. This chapter highlights that not only is there a high burden of CD among Indigenous people, but limited programs are available to address that disease burden.

Specific objectives

1. To explore the views and understanding of Indigenous women regarding health and wellbeing.
2. To explore community-based models for health, stress and wellbeing.

1.8.3 Chapter 4: Exploring the views of Indigenous patients and their healthcare providers

Chapter 4 reports on the acceptability of a cardiovascular polypill strategy trialled in Indigenous communities within Australia. This chapter highlights the complexity of intervening to improve the management of CD.

Specific objective

1. To explore the relationships between stress, psychosocial health and the management of CDs.

1.8.4 Chapter 5: Roles and responsibilities of Indigenous women and their impact on health – Findings from a qualitative study

Specific objectives

1. To explore the impact these women's roles have on CD management.
2. To explore the relationships between stress, psychosocial health and the management of CDs.

This chapter comprises three sections relating to in-depth qualitative interviews conducted with 72 Indigenous women in four Indigenous communities within Australia. The chapter explores how the roles and responsibilities these women have within their families and communities affect how they manage their own CD. The chapter explores the possible relationship between stress, psychosocial health and the management of CD for these women. This chapter also reports findings related to domestic violence and the impact it has on the participants.

1.8.5 Chapter 6: Exploring the determinants of domestic violence in Indigenous communities

This chapter discusses the burden of ill health and the additional problem of generational and intergenerational trauma. Participants reported how daily stressors such as domestic violence, drug misuse, poverty and incarceration contribute to intergenerational trauma. In this chapter, the author reflects on the impact that this research had on her as an Indigenous woman engaging deeply in the lived experience of other Indigenous women.

1.8.6 Chapter 7: Vicarious trauma – Reflections of an Indigenous researcher

Through the course of my study it became obvious that there is a very real risk of an Indigenous female researcher experiencing vicarious trauma when undertaking research among Indigenous females with whom the author may have shared lived experiences. This research has led the author to recommend that supervisors should be particularly alert to these additional stressors faced by Indigenous researchers working in the Indigenous health space. Whilst on the one hand these shared commonalities enabled the author to better grasp the issues at play for these women in terms of their health, there was also the potential for research to be impeded by the author's emotional wellbeing.

1.8.7 Chapter 8: Discussion and conclusion

This chapter discusses the implications of the research findings for clinicians, the community, researchers and policy makers.

1.9 Summary

This chapter introduces the background and methodological approach for research conducted towards this thesis and provides a thesis outline. The author shares the development of her interest in this work, presents the research aims and questions, and outlines the research design and settings. In the next chapter, she explores the literature surrounding Indigenous women with CD.

CHAPTER 2: INDIGENOUS WOMEN WITH CHRONIC DISEASE – A REVIEW OF THE LITERATURE

2.1 Introduction

Indigenous women manage their own health in the context of their roles as providers and carers for their families and community members. The everyday reality for Indigenous women involves facing several challenges. These include greater rates of familial incarceration, attending a significant number of funerals in any given year and being subjected to higher levels of violence, racism and sexism; in addition, they die at a younger age than their non-Indigenous counterparts do (Fredericks, Adams, Angus, & Australian Women's Health Network Talking Circle, 2010).

Indigenous women are more likely than their male counterparts are to take on caring roles and responsibilities in the family. This was highlighted in a Centre for Aboriginal Economics Policy Research working paper that reported on gender-based perspectives on the costs and benefits of accessing an education (Baird et al., 2016). The study reported that Indigenous women enrolled in higher education who also had children sought child care to help balance their family responsibilities and study commitments. However, this was not the case for Indigenous men, who reported no need for child care, or for balancing study with caring responsibilities (Yap & Biddle, 2012).

This chapter focuses on the literature related to diabetes, CKD and CVD. It also explores the broader, yet related, issues of mental health, SEWB and their impact on Indigenous women. This literature review forms part of a research program exploring how Indigenous women's roles and responsibilities within their families and communities affect how they manage their own CD.

2.2 Setting the scene

The literature review focuses on Indigenous women living in urban, regional and remote Australian communities – places in which women experience the most diverse range of access to health, education, justice and other social services. It should be noted that, even in urban communities where resources are generally more widely available, they

are not necessarily located appropriately or designed to meet the needs of Indigenous women. Indigenous women across these communities also share similar social, cultural, economic and historical experiences in a common landscape that all Indigenous Australians inhabit.

2.3 Broader themes

2.3.1 Historical context for contemporary Indigenous Australians

The Australian socio-historical landscape is one where control is the predominant theme. The colonisation of Australia was the beginning of the destruction of Indigenous Australian lifestyles and culture (Fredericks et al., 2010). The massacres, removal of children and people from their land, and past government policies that led to the devastation of an entire culture, are thoroughly documented (Blainey, 1994; Evans, Cronin & Saunders, 1975; Zubrick et al., 2014). The impact of these historical events has been so significant on Indigenous Australians' way of life that the effects continue to feature in contemporary health and life outcomes for the Indigenous population (Walters & Saggars, 2007).

Many Indigenous people experienced racism from an early age (Department of Native Affairs, State of Western Australia [WA], 1936). For example, individuals or families were often refused education based on their being one of the few Indigenous people in an otherwise 'white' school (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2006). Refusal of education forced some Indigenous people into life trajectories with limited opportunities. Some Indigenous people required approval from authorities before they could marry (Haebich, 1992). Most Indigenous people in the early part of the twentieth century were forced off their land and onto reserves, in line with the segregation policy of the day (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2006; Haebich, 1992). Practices and policies such as these allowed Indigenous people to be policed and monitored. In WA, for example, policing and monitoring was enabled through the *Aborigines Act (1905) WA*, which governed the lives of Indigenous people in WA for nearly 60 years (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2006). In other parts of Australia, Indigenous women's historical experiences of colonisation included being exploited

sexually and economically. The opportunity to raise their own children or to form family bonds was denied of Indigenous women. Instead, they were put to work caring for others, typically non-Indigenous families, as domestic aids in line with the Aboriginal Protectionist Act in force across Australia from 1838 to the 1970s (Sherwood, 2013).

Against this backdrop of government guardianship, low expectations, low value and low self-worth were instilled in Indigenous people. The lived experiences of most Indigenous Australians were reinforced by legislation and policy, such as the 1936 *Native Welfare Act* that institutionalised Indigenous children. This policy was responsible for the Stolen Generations (Department of Native Affairs, State of Western Australia, 1936). This national landscape still, in 2017, sees Australia debating whether and how to recognise its first peoples in its constitution.

2.3.2 Social issues

Indigenous people endure inequitable access to healthcare, education and employment, which leads to social disadvantage and results in poorer health outcomes (AIHW, 2011a). The lack of services to support families today, particularly at times when Indigenous women and their family are vulnerable, risking their children to be removed, resulting in an overrepresentation of Aboriginal children and infants in child protection and out-of-home care in Australia [O'Donnell, Maclean, Sims, Brownell, & Gilbert, 2016; Bartels, 2010]. Indigenous women have frequent encounters with the justice system. Although they make up less than 3 per cent of the Australian adult female population, Indigenous women are the fastest growing population in Australian prisons, representing 34 per cent of the national female prisoner population (ABS, 2013c; MacGillivray & Baldry, 2015). The imprisonment of women places additional pressure on already over-burdened older Indigenous women, who must often take on the primary caregiver roles for children and other dependents of those who are incarcerated.

Limited educational opportunities have been experienced by many Indigenous women from an early age due to racism and the onset of family and community obligations. Missed educational opportunities often result in limited employment opportunities (Australian Indigenous HealthInfoNet, 2016c). However, there has been a slow but

definite improvement for Indigenous women's education and workforce opportunities (ABS, 2012). As Burns et al. (2013) reported, 22 per cent of Indigenous women aged 15 years or more had post-school qualifications. Further, 16 per cent of these women had attained a diploma or certificate level qualification, and 5.8 per cent had achieved a bachelor degree or above (Burns et al., 2013). The three main industries now employing Indigenous women include those in which post-school qualifications are necessary, for example, healthcare and social assistance, public administration and safety, and education and training (ABS, 2013a).

2.3.3 Economic and resource issues

Many political and economic issues affect Indigenous Australians' health status. Indigenous Australians suffer a greater burden of ill health compared to other Australians (AIHW, 2016b). Durie (1999), in reference to his model for Maori health promotion, explained that the poor health status of Indigenous people is due to economic disadvantage, limited resources and political oppression. For example, in relation to the 1905 *Aborigines Act*, in WA, Indigenous people came under the control of the chief protector as children of the state (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2006).

Protectionist policies have been in place in states other than Western Australia from the mid-1800s and continue today. Indigenous affairs represents a national priority for the Australian government and the Department of Prime Minister and Cabinet seeks to influence policy across the whole of government (Commonwealth of Australia, 2015). Contemporary examples of policies which give extensive control over the lives of Indigenous Australians include the Northern Territory Emergency Response (NTER), which since 2012 has been replaced by a similar program known as Stronger Futures (Australian Human Rights Commission, 2011); and the income management card, which quarantines a proportion of a person's welfare payments for essentials such as food, clothing, housing, gas, water and electricity.

Economic and resourcing issues facing Indigenous Australians, and particularly Indigenous women, affect individuals, families and communities. A 2011 AIHW report highlighted that of the 49 per cent of all Indigenous households that included families

with dependent children, more than one-third (39%) were one-parent families (Australian Indigenous HealthInfoNet, 2016c). In one-parent family situations, the parent is usually the mother of the children. Where the mother is also the sole income provider, she will likely earn less than Indigenous men, and much less than non-Indigenous women and men. The Australian median weekly income for an Indigenous woman is \$680, compared with \$718 for Indigenous men, \$791 for non-Indigenous women and \$941 for non-Indigenous men (Fredericks et al., 2010). This lower income is in the context of many Indigenous women in the workforce having more children, caring for parents, siblings or extended family, and experiencing a greater incidence of domestic or family violence than other women in Australia (AIHW, 2011a; Fredericks et al., 2010; Australian Indigenous HealthInfoNet, 2016c; Hill, Cass, Newton, & Valentine 2012; Carers Australia, 2006). Many Indigenous women also live with and manage at least one CD (AIHW, 2012).

The accumulation of these socio-economic factors, coupled with stretched and under-funded services, forces Indigenous women and their families to remain in a continuous cycle of disadvantage (Webster, 2016). For example, shelters for women experiencing family and domestic violence are not widely available (Tually, Faulkner, Cutler, & Slatter, 2008). An identifiable gap also exists in the availability of culturally safe drug and alcohol rehabilitation services for women (Jenner, Lee, Cameron, & Harney, 2014). Despite the high rate of incarceration for Indigenous women, government resourcing decisions – such as drastically reducing community re-entry programs for Indigenous women being released from prison and ongoing cuts to Aboriginal legal services – reinforce the cycle of disadvantage (MacGillivray & Baldry, 2015).

2.4 Roles and responsibilities of Indigenous women in their families and communities

Indigenous women play many roles within their families and communities (Hill et al., 2012; Tually et al., 2008). Fundamentally, these roles relate to caring and providing for their children, families and extended families (Fredericks et al., 2010; Hill et al., 2012). The roles that women have also extend beyond the family to their community. For instance, they provide for and participate in the ceremonial practices of Aboriginal law as well as caring for Country (Davis, 2007; Fredericks et al., 2010).

Commonly, Indigenous women have caring roles extending beyond their immediate family. From 2006 to 2011, the numbers of Indigenous Australians who reported taking on a caring role in their family or community increased by almost 13,000 (Carers Australia, 2006). More Indigenous women than men are carers, and mothers were the primary carer most frequently, followed by other female relatives (AIHW, 2011c). Many Indigenous women were not paid for their caring roles; this may be due to the women or their families seeing the care as being included in their daily responsibilities. Neither did the women do any paid work (AIHW, 2011a). This may be due to the increased hours spent in their caring role, leaving little time for paid employment opportunities.

In situations where extended family roles have broken down, the roles of some Indigenous women may include caring for their extended family's children, as well as their own (Tually et al., 2008). This is particularly the case where lives have been affected by incarceration, family violence or death and dying (Zubrick et al., 2014). Having to care for extended family poses many challenges for Indigenous women. For example, challenges occur where over-crowding exists in a house. Family numbers can be too great for the size of a house; this situation is more likely when Indigenous families live in public housing. Such over-crowding due to large family structures often leads to greater scrutiny by authorities, which is an additional pressure. Intrusions on time, exhaustion and continually carrying multiple responsibilities result in less priority being given to a woman's own health needs and this can often have serious health consequences (Monahan & Twining, 2007). For instance, when considering the burden of care for Indigenous women in relation to population distribution where more than half the population is under 25 years of age, profound health inequality in and of itself places a greater burden of care upon Indigenous women who tend to be the ones left carrying the load (ABS, 2016).

2.5 Chronic disease and their risk factors

Chronic conditions – manifesting and persisting over an extended period – are major contributors to Indigenous women's premature morbidity and mortality (Kidney Health Australia, 2015). These diseases are complex in terms of their impact on the individual,

that person's family and the community in which they live and require long-term management (Department of Health and Ageing [DoHA], 2015). Indigenous women experience a heavy burden of chronic health conditions, including respiratory diseases, disorders affecting eyesight, and cancer. This thesis will focus on non-communicable conditions including diabetes, CKD and CVD, which contribute substantially to premature mortality and disability (AIHW, 2012).

CDs have many causes. Some infectious conditions, such as skin infections and rheumatic fever, can contribute to the risk of developing chronic conditions (AIHW, 2009). People's genetic background, lifestyle and environment can determine if they are predisposed to CD (Tanamas et al., 2013). The broad array of factors that influence a person's health outcomes can be understood using a social determinants of a health framework. These determinants range from proximate biology, through to distal societal factors which might limit access to education, employment and other services. An Indigenous infant may be born into poverty, then experience food and housing insecurity, limited educational and employment opportunities, within an environment that promotes risk-taking behaviour.

The determinants of health are social and economic factors that can have either positive or negative effects on people's health outcomes or on whole communities (DoHA, 2013). To exemplify positive health outcomes would be to describe where an individual lives in a cohesive safe community surrounded by family, friends and work colleagues. This community would encompass culture, affluence, social cohesion, social inclusion and supportive political structures (Australian Indigenous HealthInfoNet, 2016c). Having these structures in place provides opportunities for education and employment that can then lead to higher incomes and wealth creation. An individual living in a safe community is more inclined to know their neighbours, live in comfortable and affordable housing, and have access to quality services. Therefore, such a person is less inclined to engage in risk-taking behaviours that may affect their health negatively (Gee, Dudgeon, Schultz, Hart, & Kelly, 2014).

Where an individual is marginalised within their community, has limited educational opportunities, is unemployed, unable to afford appropriate housing, or access affordable

and healthy food and appropriate healthcare, he or she may be more inclined to partake in risky behaviours. These can include smoking, consuming high levels of alcohol or illicit drugs, behaviours that can lead to high blood pressure, obesity and a weakened immune status. This can then lead to injury, morbidity and mortality (Reeve, Church, Haase, Bradford, & Viney, 2014). These behavioural risk factors are all associated with the common CDs affecting Indigenous people (Abbott, Davison, Moore & Rubinstein, 2010). Indigenous women also often experience low literacy levels, poor educational attainment, poorly maintained housing and/or over-crowding, homelessness and incarceration, which also can contribute to their CD susceptibility (Burns et al., 2013).

2.5.1 Contribution of chronic diseases to the gap in life expectancy for Indigenous women

Premature mortality due to certain chronic conditions contributes substantially to the gap in LE of Indigenous people aged between 35 and 74 years (ABS, 2014d). Indigenous women born from 2010 to 2012 can expect to live for 9.5 fewer years than non-Indigenous women (Commonwealth of Australia, 2015). The median age at death for Indigenous women ranges from 69 to 75 years, compared to other Australian women, where the median age at death is between 80 to 84 years (Walters & Siggers, 2007). In some remote areas of Australia, the median age at death indicates a LE gap of 14.4 years for Indigenous women (Tually et al., 2008).

The *Closing the Gap Prime Minister's Report 2015* highlighted that little progress has been made to date regarding government commitments to closing the gap in LE by 2031 (Commonwealth of Australia, 2015). However, over the past five years, the increase in LE for Indigenous people has been reported as being greater for Indigenous men, with an increase of 18 months, compared with a six-month increase for Indigenous women (Reeve et al., 2014). The slow pace at which LE is increasing for Indigenous women is a cause for concern, particularly given the demands placed on Indigenous women to manage their health, and take care of their families and extended families (Simmons, Khan, & Teale, 2005).

Some predominant contributors to early mortality for Indigenous women relate to CD (AIHW, 2016a). Findings from the *National Aboriginal and Torres Strait Islander*

Health Measures Survey conducted on Indigenous people to measure health status reported that large numbers of Indigenous people live with undetected, treatable and preventable chronic conditions such as diabetes, CKD and CVD, which affect their LE significantly (ABS, 2014a). For example, ischaemic heart disease continues to be the leading cause of death for Indigenous people (AIHW, 2010b). The prevalence rates for each of these chronic conditions rise at a much earlier age among Indigenous Australians. For Indigenous women, the relative burden of diabetes, CKD and CVD in young and middle-aged women is striking (Australian Indigenous HealthInfoNet, 2016a; AIHW, 2011b; Holland, 2015; Hoy, Kondalsamy-Chennakaesavan, Scheppingen, & Sharma, 2005).

2.5.2 Diabetes

Indigenous people are three times more likely to have diabetes than other Australians and Indigenous women are nearly twice as likely to develop gestational diabetes as non-Indigenous women (AIHW, 2010c). Diabetes is a complex metabolic condition where the body is unable to maintain healthy levels of glucose in the blood and the conversion of glucose to energy is impaired. The two main causes of this inability to convert glucose into energy are related to the inability to produce, or the ineffective use of, insulin (Australian Indigenous HealthInfoNet, 2016c). If diabetes is not adequately managed, it can also lead to coronary heart disease (CHD), stroke, kidney failure, peripheral arterial disease or blindness (ABS, 2014a).

There are three main types of diabetes. Type 1 diabetes is an autoimmune disease with onset generally during childhood or early adulthood; it is not commonly identified in Indigenous Australians (AIHW, 2011d). Type 2 diabetes is usually associated with lifestyle factors and is preventable with lifestyle changes, such as increased exercise and dietary modifications; it is frequently identified in the Indigenous population (Burrow & Ride, 2016). Gestational diabetes, the third type of diabetes, occurs during pregnancy (AIHW, 2014b).

Gestational diabetes is more common among Indigenous than among non-Indigenous women (AIHW, 2010c; Shih et al., 2013), but it can also be related to the presence of pre-existing type 2 diabetes before pregnancy (AIHW, 2010c). Women with pre-

existing diabetes are more likely to give birth before their due date, to develop hypertension during pregnancy, and are at high risk of caesarean sections and extended periods of stay in hospital post-delivery (AIHW, 2010c).

Risk factors for diabetes

Health risk factors increase an individual's chance of developing a disease (Burrow & Ride, 2016). Some risk factors – such as family history or age – are referred to as 'non-modifiable risk factors'. Non-modifiable risk factors cannot be manipulated or adapted to suit the individual and reduce their disease risk. Modifiable risk factors are those risk factors that can be modified or manipulated to achieve good health outcomes for an individual (AIHW, 2010a).

The main risk factors for type 2 diabetes and gestational diabetes are modifiable and include obesity, partaking in little or no exercise, a poor diet (such as one high in fat and sugar) and poor environmental conditions (Maple-Brown, Brimblecombe, Chisholm, & O'Dea, 2004).

A significant public health concern relates to the young age of onset in diabetes for Indigenous people, associated with an increase in CKD and CVD morbidity and mortality (Thompson, Bradshaw, Veroni, & Wilkes, 2003). Indigenous women are at an even greater risk of type 2 diabetes. Their predisposition for gestational diabetes also increases the risk of subsequently developing type 2 diabetes (ABS, 2014c).

Incidence and prevalence of diabetes

Type 2 diabetes is seen more in Indigenous people than type 1 diabetes (AIHW, 2010a). In 2011, more than 650 Indigenous people commenced insulin therapy for type 2 diabetes, and 118 Indigenous women commenced insulin therapy for gestational diabetes (AIHW, 2015b). Self-reported data relating to current diabetes status and HbA1c results (HbA1c is a screening and monitoring test for diabetes control), as reported by the Australian government in 2014, highlighted that approximately 5.4 per cent of people aged 18 years or more had diabetes in Australia (AIHW, 2014a). As reported in the 2012 to 2013 Australian Aboriginal and Torres Strait Islander Health

Survey, a larger proportion of Indigenous women reported having diabetes (10%) than did Indigenous men (8%) (ABS, 2014b).

During pregnancy, Indigenous women were more than three times as likely as non-Indigenous Australian women were to have had pre-existing diabetes. However, Indigenous mothers who had previously given birth were ten times more likely to have type 2 diabetes than non-Indigenous mothers who had previously given birth (AIHW, 2010c). A prospective cohort study in a remote NT community, measuring the incidence of diabetes among Indigenous Australians (to identify any association between obesity, impaired fasting glucose and impaired glucose tolerance), found that baseline impaired fasting glucose and impaired glucose tolerance, as well as obesity, contributed significantly to the high incidence of diabetes in Indigenous communities. In that remote community, two out of every three Indigenous women were living with diabetes (Wang, Hoy, & Si, 2010).

Effect on daily life of living with diabetes

A diagnosis of diabetes requires lifestyle changes that can include a change of diet to avoid sugar or foods high in saturated fat, and to include foods high in fibre (Australian Indigenous HealthInfoNet, 2016c). Diabetes management can also be enhanced with 30 minutes of daily exercise and by weight reduction. Monitoring blood sugar levels is also very important for self-management. Insulin-dependent diabetics must ensure that they have adequate supplies of insulin at all times, so they can administer it before each meal (Burrow & Ride, 2016).

The complications of diabetes can affect one's health-related quality of life and function profoundly. Diabetic retinopathy, where the small blood vessels in the eye are damaged, can lead to reduced vision and blindness (AIHW, 2012). Particular attention is also required to detecting and managing diabetic neuropathy (Dunstan et al., 2002); the affected patient's feet should be monitored for the presence of undetected foreign bodies or lesions that may become infected. Damage to nerve endings in the extremities can lead to breaks in the skin that can result in wounds under the feet, which if not treated, can lead to the debridement or amputation of extremities (Maple-Brown et al., 2004).

Diabetes morbidity and mortality

Although diabetes represents the underlying cause of death for 3 per cent of all Australians, this number understates the true impact, especially when combined with CKD and CVD (AIHW, 2014b). The 2015 ABS *Causes of Death, Australia, 2013* report identified type 2 diabetes as the second leading cause of death (202 deaths) for Indigenous people (ABS, 2015). Burrows and Ride (2016) further reported that death from diabetes was 10.5 times more likely for Indigenous women than for non-Indigenous Australian women.

2.5.3 Chronic kidney disease and end-stage kidney disease

CKD is a condition affecting a person's kidneys, where the effects last for a period of three months or more. The kidneys show evidence of damage, as well as a reduced capacity to function effectively (AIHW, 2009). Evidence of kidney damage is highlighted through the presence of protein (proteinuria), albumin (albuminuria) or blood in the urine (haematuria) (Maple-Brown et al., 2004).

Initial investigations of kidney function focus on measuring glomerular filtration rates (GFR). The GFR is measured by the amount of blood the kidney can filter in a one-minute period. It is difficult to obtain a direct measure of GFR, and so the current practice is to estimate GFR (eGFR) (AIHW, 2015a) using age, gender and creatinine levels in the blood (Johnson et al., 2013). Creatinine is a waste product filtered through the kidney and excreted via urine. Increased levels of creatinine in the blood are a sign of kidney damage due to poor filtration (AIHW, 2014c). As part of the general practice management of CKD, blood samples are taken to measure blood creatinine levels (Kidney Health Australia, 2015). Table 2.1 illustrates the different levels of kidney damage according to levels of filtration from the blood (eGFR).

As illustrated in this table, once kidney function reaches Stages 4 and 5 of kidney damage, kidney function is reduced significantly with little chance of improvement. Once eGFR is less than 15 mL/min, a range of symptoms develop and it is likely that people will progress to end-stage kidney disease (ESKD) (ABS, 2014a). People who

have ESKD normally require kidney replacement therapy in the form of regular dialysis or a kidney transplant to sustain life.

Table 2.1 Different levels of kidney damage according to eGFR

Stage of damage	Explanation
Stage 1 Kidney damage (eGFR at least 90 mL/min/1.73 m ²)	Evidence of kidney damage but without decreased GFR. Usually no symptoms.
Stage 2 Kidney damage (eGFR) 60–89 mL/min/1.73 m ²)	Evidence of kidney damage with some reduction in GFR. Most patients have no symptoms.
Stage 3 Kidney damage (GFR 30–59 mL/min/1.73 m ² *)	GFR significantly reduced. May show signs of kidney damage and often indications of dysfunction in other organs. Often asymptomatic, despite a reduction in kidney function of up to 70%.
Stage 4 Kidney damage (GFR 15–29 mL/min/1.73 m ² *)	Kidney function significantly reduced. Blood levels of urea and creatinine increase, and greater evidence of dysfunction exists in other organs. Usually only mild symptoms.
Stage 5 Kidney damage ESKD (GFR less than 15 mL/min/1.73 m ² *)	A range of symptoms and laboratory abnormalities in several organ systems, collectively referred to as ‘uraemia’. Kidney replacement therapy (dialysis or transplant) is required when kidney function is no longer sufficient to sustain life, typically at a GFR of around 7–8 mL/min/1.73 m ² .

* With or without other evidence of kidney damage, including proteinuria/albuminuria. Adapted from Obrador and Pereira (2002) (AIHW, 2011b)

Risk factors for chronic kidney disease

Non-modifiable factors have been identified as risk factors for CKD (AIHW, 2015a). These factors include family history and genetics, increasing age, previous kidney disease or injury and low birth-weight (AIHW, 2009). Behavioural risk factors that can be modified include tobacco smoking, low levels of physical activity and poor nutrition. Biomedical risk factors, also considered modifiable, include diabetes, high blood pressure, CVD, being overweight or obese and systemic kidney inflammation (AIHW, 2009). Having a greater understanding of what causes CKD can improve how patients adapt to and manage their disease. For example, differences in language, perceptions of health and illness and other cross-cultural barriers might further complicate self-

management for Indigenous Australians with CKD (Anderson, Devitt, Cunningham, Preece, & Cass, 2008).

Incidence and prevalence of chronic kidney disease and end-stage kidney disease

Biomedical signs of early stage CKD (Stages 1–3) were identified in 10 per cent of the Australian population in 2011 to 2012 (AIHW, 2014b). With appropriate management, however, disease progression can be reduced significantly, reducing the rate of kidney function deterioration. Very little difference existed in the prevalence of CKD for men (10.3%) and women (9.3%) in 2014 (AIHW, 2014c). From 2012 to 2013, of the 3300 Indigenous Australians who participated in the ABS *Health Measures Survey I*, 17 per cent had signs of CKD; fifty-three per cent of participants who had diabetes also showed signs of CKD (ABS, 2014a).

Between 2007 and 2008, despite only accounting for 2.5 per cent of the Australian population, Indigenous people made up 10 per cent of new ESKD cases (AIHW, 2011b). The rate of treated ESKD for Indigenous Australians increased with age. Of particular note is that the incidence rate for Indigenous women aged 45 to 49 years was 25 times that of non-Indigenous women (AIHW, 2011b). ESKD incidence is between six and 30 times higher for Indigenous Australians living in remote and very remote areas of Australia compared to non-Indigenous Australians (AIHW, 2014c). Treated ESKD prevalence increased at twice the rate in remote and very remote areas (163 and 183 cases per 100,000 population respectively) in comparison to urban and regional areas, with 85 cases per 100,000 population (Hoy et al., 2005). For Indigenous Australians, the high prevalence of ESKD in remote areas of Australia is related to risk factors that are shared with many other chronic conditions. Coupled with the poor social determinants of health, many Indigenous people are poorly positioned regarding their ability to maintain good health.

Effect of chronic kidney disease on daily life

Much of the literature about the impact of CKD on Indigenous people is either self-reported or captured via survey data from community-based studies and screening programs (Stumper & Thomson, 2013). There is a heavy burden of CKD among

Indigenous people (AIHW, 2009; Stumper & Thomson, 2013). A review of kidney disease among Indigenous people by Stumper and Thomson (2013) found that the significant prevalence of ESKD among Indigenous people resulted in considerable strain on patients and their families (Stumper & Thomson, 2013). Given the high incidence of ESKD for people living in remote parts of Australia (who generally need to relocate to major cities for renal treatment), the impact on patients, families and communities is profound (AIHW, 2014b; Stumper & Thomson, 2013). Many people living with CKD experience high levels of fatigue (which can be related to anaemia), fluid overload, lack of appetite, poor sleep and many other issues (AIHW, 2015a). In addition to strict treatment regimes – such as haemodialysis three times a week for up to five hours duration – fluid restrictions and strict monitoring to ensure a low-salt, low-potassium diet are also important for ensuring a better quality of life (AIHW, 2009). CKD can lead to inactivity, withdrawal from social gatherings and potential depression (Bonner, Wellard, & Caltabiano, 2010). In some remote areas of Australia, rates of ESKD are 30 times greater than the national average for Indigenous women and Indigenous men (Connors & Patel, 2010). Although some evidence suggests treated ESKD incidence rates might be stabilising for Indigenous women (Vos, Barker, Begg, Stanley, & Lopez, 2009), women constitute most of the Indigenous patients receiving ESKD treatment. As such, they live with the major challenges of dietary restriction, management of complex treatment regimens and frequent hospitalisation associated with this condition.

Morbidity and mortality for chronic kidney disease and end-stage kidney disease

CKD was the underlying cause of death for 2.1 per cent of all deaths recorded in Australia in 2011 (Holland, 2015). Overall, Indigenous women are 11 times more likely to die from CKD than are other Australians (AIHW, 2010c). From 2003 to 2007, Indigenous women aged between 35 and 39 years died from CKD-related causes at 28 times the rate of non-Indigenous women (AIHW, 2011b). However, there is a lack of evidence to explain the excess burden of ESKD among Indigenous women. No studies have been performed to explain whether Indigenous men are more likely to die before their disease progresses to the stage when they need dialysis, or whether Indigenous

women's kidney disease is more likely to progress. Further evidence is needed to guide the required intervention strategies.

2.5.4 Cardiovascular diseases

Cardiovascular disease (CVD) refers to a related group of disorders of the heart and blood vessels. Blood vessel diseases that fit the criteria of CVD include CHD, cerebrovascular disease, peripheral arterial disease, rheumatic heart disease, congenital heart disease, deep vein thrombosis and pulmonary embolism (AIHW, 2015a). Each of these diseases has different physiological impacts. This section will briefly describe CHD, cerebrovascular disease and rheumatic heart disease, each of which is experienced disproportionately amongst Indigenous Australians.

CHD concerns blood supply to the heart muscle being impaired due to the blockage of a blood vessel to the heart muscle (ABS, 2014c). CHD presents as two major clinical forms: acute myocardial infarction, which is a life-threatening blockage of the blood supply to part of the heart requiring aggressive treatment; the other is a chronic condition called angina. It is a temporary loss of or insufficient blood supply to the heart, causing episodes of chest pain (AIHW, 2016b).

Cerebrovascular disease is where the blood supply to the brain is compromised or suddenly becomes blocked, leading to infarction in sections of the brain. This can also cause paralysis of certain body parts, depending on the location of the affected brain tissue and what part of the body that tissue controls. This condition is also referred to as a 'stroke' (Vasant, Mathew, Burgess, Connor, & Bailie, 2016). Peripheral arterial disease compromises blood supply to the extremities. When this occurs, blood flow to the extremities is impaired; this can result in poor wound healing, the loss of toes or fingers, and in the worst cases, the loss of a limb (Henry et al., 2014).

Rheumatic fever is an inflammatory disease which typically develops several weeks after a throat infection. Rheumatic heart disease, usually occurring after repeated attacks of rheumatic fever, involves damage to the heart valves and may result in heart failure and arrhythmias (Bailie & Wayte, 2006).

Risk factors for cardiovascular disease

The non-modifiable risk factors associated with CVD include a family history of heart disease, ethnicity, age and genetic mutations (AIHW, 2014c). Modifiable risk factors include tobacco use or exposure, hypertension, high cholesterol, obesity, physical inactivity, diabetes, poor diet and high levels of alcohol use or abuse (AIHW, 2014c). A 2015 AIHW report highlighted that people diagnosed with CVD were 2.1 times more likely to have poorly managed blood pressure, 1.5 times more likely to be overweight and have poor control of their cholesterol levels (AIHW, 2014c). Eighty-four per cent of Australian adults reported having three or more risk factors for CVD (AIHW, 2015a). CVD was reported as 1.2 times more common for Indigenous people than non-Indigenous people (Australian Indigenous HealthInfoNet, 2016c).

Incidence and prevalence of cardiovascular disease

CVD is the most common cause of mortality and morbidity among all Australians, particularly among Indigenous Australians. However, CVD death rates are falling among Indigenous men and women (AIHW, 2014c; AIHW, 2016b). This could be related to pharmaceutical interventions, such as drugs to lower blood pressure and cholesterol, the use of antithrombotic medical interventions and reduced behavioural risk-taking behaviour (AIHW, 2014c). Of particular concern for Indigenous Australians is the impact of CHD on young and middle-aged adults who contribute 24 per cent of the gap in LE (World Health Organization [WHO], 2015). Indigenous women have greater rates of CVD than men do, according to the 2012 to 2013 Australian Aboriginal and Torres Strait Islander Health Survey (ABS, 2014b). The survey reported the rate of CVD for women at 14 per cent of all Indigenous Australians living with CVD, compared to 11 per cent for Indigenous men. Like many surveys that gather data on self-reported health status, the actual burden of CVD for Indigenous women may be greater than currently reported.

Effect on daily life of living with cardiovascular disease

The initial impact of a cardiovascular event can result in a loss of confidence in one's health and in feeling uncertain about the future, due to the life-threatening implications (AIHW, 2014c). However, the level of management and future health planning can

determine a person's outlook on life following such an event. Effective holistic care – where quality rehabilitation, nutrition and exercise regimes are established to support a person's journey to good health – can ensure that a person's confidence in his or her health is also regained. Where this does not occur, frequent hospitalisation and poor quality of life may result (ABS, 2012). Indigenous women are more likely to be hospitalised for CVD management than other Australians, and live with at least one CVD-related disability and at least one modifiable risk factor (Heeley et al., 2005). Culturally appropriate programs that target risk factors such as smoking, obesity and diabetes could reduce the rates of CVD in Indigenous communities, particularly among Indigenous women (Thompson et al., 2003). The introduction of absolute cardiovascular risk assessments into health services (as a continuous quality improvement initiative targeting Indigenous women with multiple risk factors who are asymptomatic for CVD) could be beneficial for identifying and treating undiagnosed CVD. This could ensure the effective management of modifiable risk factors, including changes to lifestyle, adherence to medication and improvements in CVD status, ultimately reducing the burden of CVD in Indigenous people (Vasant et al., 2016).

Morbidity and mortality of cardiovascular disease

CVD is the leading cause of death worldwide, with 17.5 million people dying from CVD globally in 2012 (WHO, 2015). In Australia from 2014 to 2015, CVD was the leading cause of death for all Australians (ABS, 2014c). The *Australia's Health in 2016* report identified that 3.6 per cent of all Australians had been diagnosed with CVD (AIHW, 2016b). The leading cause of death for Indigenous Australians is CVD, with Indigenous people dying from CVD at twice the rate of non-Indigenous Australians (Baker IDI Heart and Diabetes Institute, 2012). In 2014, 6,486 Indigenous women died from CVD (ABS, 2014c).

2.5.5 Mental illness, and social and emotional wellbeing

A state of wellbeing, where people have the capacity to realise their own capabilities, and can contribute to society in a meaningful way, describes good mental health (AIHW, 2016b). Mental health is fundamental to good overall health, and includes SEWB (WHO, 2013). The WHO (2006) states in their constitution that: 'health is a

state of complete physical, mental and SEWB and not merely the absence of disease or infirmity'. Factors that influence Indigenous people's SEWB relate to their connection to country, family history (which includes spirituality and ancestry), and kinship relationships (Australian Indigenous HealthInfoNet, 2016c). As is the case with other issues related to good health for Indigenous people, mental health can be affected by socio-economic factors that lead to mental illness or disorders (AIHW, 2016b).

Mental illness is a CD that accounts for 7 per cent of hospitalisations for Indigenous Australians, and is the leading cause of hospitalisation in the 25 to 44 age group (DoHA, 2013). Indigenous women are more than three times more likely than other Australians or Indigenous men to be diagnosed with mental illness due to psychoactive substance misuse, such as imbibing harmful levels of alcohol or other drug misuse, along with domestic or family abuse. Indigenous women are 2.5 times more likely than other Australians to be hospitalised for schizophrenia and related disorders (Pink & Albion, 2008).

The four most common types of mental disorders affecting Indigenous people are anxiety, depression, psychosis and personality disorders (Dudgeon, Milroy, & Walker, 2014). Mental illness is usually the result of multiple complex factors relating to the social determinants of health. For example, if a person is homeless, they may not be able to gain employment, which could affect their ability to seek adequate healthcare if needed. Such a situation could cause distress and difficulty in functioning, which can lead to psychological distress (ABS, 2014c). The level of psychological distress in the Australian population can be measured using an instrument referred to as the *Kessler Psychological Distress Scale (K10)* (AIHW, 2016b). Where a person is experiencing very high levels of distress in the four weeks leading up to the measurement, they are characterised as having significant psychological distress.

Risk factors for poor social and emotional wellbeing

The factors that negatively impact on SEWB for Indigenous people include unresolved grief and loss, trauma and abuse, domestic violence, removal from family, substance abuse, family breakdown, cultural dislocation, racism and discrimination, anxiety disorders and psychological distress (Social Reference Group for National Aboriginal

and Torres Strait Islander Council and National Mental Working Group, 2004). Other negative influences include physical ill health, child removals and unresolved trauma, family or domestic violence, death of a family member, substance abuse and socio-economic factors (Gee et al., 2014). Additionally, cumulative stress, chaos, social exclusion (which can include racism) and social inequality are contributors (Zubrick et al., 2014). Stress can be defined as any condition that is a threat to the psychological or biological capacity of a person (Grant, 2003). Chaos refers to instances of unsupervised peer groups or settings where children and young people spend extended periods with very little or no structure or organisation of that time (AIHW, 2016b). Issues of social exclusion during the early years of life and adulthood can significantly affect the capacity for socio-economic and civil opportunities or choice that would otherwise provide employment and social support in the workplace and other mainstream services (Gee et al., 2014).

Prevalence and incidence of mental illness, and social and emotional wellbeing

Mental illness was among the most common CDs reported in 2016, both as a stand-alone CD and as a comorbidity (AIHW, 2016b). Poor psychosocial stress can affect physical and mental health and wellbeing. Psychosocial stress can result from the loss of employment, poor educational qualifications, a lack of skills, having many caring responsibilities and kinship responsibilities, as well as experiencing frequent deaths among family members (Australian Indigenous HealthInfoNet, 2014). The cumulative impact of these elements causes high levels of psychosocial distress. During 2012 to 2013, Indigenous women reported higher levels of psychological distress in all age groups than Indigenous men (ABS, 2014a), except for those men in the 65 to 74 year age range (Australian Indigenous HealthInfoNet, 2016a). The same health survey found that approximately 30 per cent of Indigenous people experienced high and very high levels of psychological distress, twice the rate of non-Indigenous people (ABS, 2014b). Amongst those people who reported experiencing high to very high levels of psychological distress, Indigenous women reported experiencing high psychological distress at a rate of 36 per cent, compared with Indigenous men at 24 per cent (Australian Health Ministers' Advisory Council [AHMAC], 2015). The most common causes of psychological distress for Indigenous people were stressors such as the death

of a family member, serious illness, being unemployed, drug-related problems or mental illness (Dudgeon, Walker et al., 2014). The rates of hospital presentation for deliberate self-harm (cutting or tearing the skin, intentional pulling out hair and eyelashes and overdosing on medications) (Australian Indigenous HealthInfoNet, 2011) for Indigenous women in the 15 to 19 year age group was 5.9 times greater than that for non-Indigenous women from 2001 to 2010 (AIHW, 2014a). Between 2013 and 2014, Indigenous women were hospitalised at a greater rate than Indigenous men for domestic violence, at a rate of 3.4 and 0.5 per cent respectively (Australian Indigenous HealthInfoNet, 2016c).

Effect on daily life of living with mental illness

Mental disorders such as psychosis, although relatively uncommon, can have a significant impact on family and society, due to the ongoing demands that people with this disorder have as part of their management (AIHW, 2016b). Some people with mental disorders can function effectively and cope with normal levels of stress, while others require care from family and the community to live within broader society (Australian Indigenous HealthInfoNet, 2014). People living with mental illness may not be able to manage their thoughts, behaviour or interactions appropriately (WHO, 2013). If provided with adequate family, community and cultural support (ensuring a healthy lifestyle), many people living with mental illness who also adhere to prescribed medications can have a good quality of life; people experiencing mental illness can function and cope effectively with the stressors of daily life (Australian Indigenous HealthInfoNet, 2015).

As discussed, Indigenous women experience high levels of CD (Australian Indigenous HealthInfoNet, 2016a, 2016c; Vasant et al., 2016) and the effect on their mental health and SEWB is significant. Of particular concern are the high levels of stress, anxiety, psychological distress and/or depression that many of these women have to deal with while also managing their CD (AIHW, 2016b). Further effects on Indigenous women's mental health and SEWB result from the complexities surrounding their caring roles within their families and communities.

2.5.6 Morbidity and mortality for mental illness, and social and emotional wellbeing

During 2013 to 2014, hospitalisation rates for mental and behavioural disorders were 3.7 times higher for Indigenous Australians than for other Australians. Hospitalisation resulting from self-harm was 2.1 times greater for Indigenous women than it was for their non-Indigenous counterparts. Mortality due to mental health-related conditions was 1.3 times greater for Indigenous women than non-Indigenous women (Australian Indigenous HealthInfoNet, 2015). The *National Survey of Mental Health and Wellbeing* conducted in 2007 reported that 45 per cent of all Australians aged between 16 and 85 years would be exposed to mental disorders such as depression, anxiety and psychotic illnesses. It is estimated that one in nine Australians aged 16 to 85 have a CD and a mental illness (AIHW, 2014a, 2016b).

2.6 Conclusion

Indigenous Australians are affected by a heavy burden of chronic illness, psychosocial stress, historical and socio-economic disadvantage. Indigenous women are particularly affected. A greater occurrence of CD, early deaths and heavy caring burden and responsibilities impact Indigenous women, in addition to their relatively high exposure to domestic violence. This is the background in which these women contribute to their communities, care for their families, and ultimately manage their own health. This situation is highly challenging.

CHAPTER 3: SYSTEMATIC REVIEW

3.1 Introduction

There is a 10 to 12 year difference in LE for Indigenous Australians compared to their non-Indigenous counterparts (DoHA, 2013), with CD accounting for two-thirds of premature deaths (AHMAC, 2012). CVD, diabetes and CKD are two-to-four times more prevalent among Indigenous Australians than are non-Indigenous people, with this disparity being greater for remote-dwelling Indigenous Australians (Ware, 2013).

Mental illness is a CD that accounts for 7 per cent of Indigenous Australian hospitalisations, and is the leading cause of hospitalisation in the 25 to 44 age group (DoHA, 2013). Social determinants of health, including social exclusion, isolation, poverty, neglect, abuse, trauma, alcohol and other drug misuse, poor physical health and physical or intellectual disability are all known risk factors for mental illness (Council of Australian Governments [COAG], 2012). People with severe mental illness in the general population are more likely to receive lower quality care for physical health conditions and have more modifiable risk factors, such as smoking, physical inactivity, and obesity, which may also be a side effect of some psychiatric medication (WHO, 2013). Despite repeated calls for a holistic focus on SEWB for Indigenous Australians (Dudgeon, Walker et al., 2014); the predominant clinical focus is on physical health and illness, to the potential detriment of those with mental illness.

To address the excessive and inter-related burden of CD and mental illness, effective holistic approaches to healthcare for Indigenous Australians should be identified. We¹ have systematically reviewed programs focusing on CD and mental health and SEWB designed specifically for Indigenous Australians. This review aimed to describe the programs designed for CD and mental illness in Indigenous Australians and determine their efficacy, cost-effectiveness, potential for use beyond the original research, and enablers and barriers to their conduct and/or implementation.

¹ As this review was conducted by the author and others, the pronoun 'we' is deliberately used throughout this chapter when discussing the systematic review.

3.2 Methods

A systematic review of the published and ‘grey’ literature was conducted to determine the available CD and mental health programs designed specifically for Indigenous Australians, along with their effectiveness (including cost factors).

3.2.1 Criteria for the inclusion of programs in this review

We included all programs designed with explicit intentions to address the following:

- CD, which was limited to CVD, diabetes, and CKD (accepting the criteria for CD applied by the authors/owners of the program).
- Mental illness (depression, anxiety and stress) or SEWB (unresolved grief and loss, trauma and abuse, domestic violence, removal from family, substance misuse, family breakdown, cultural dislocation, racism, discrimination and social disadvantage).

We excluded programs with the following elements:

- A focus on either CD or mental illness alone.
- Inclusion in the publication/program of the incidence, prevalence, frequency or determinants of disease without an intervention component.
- A program that had been completed prior to 2002.
- Where all the criteria for inclusion were met, but no outcome or evaluation data were available (and such data were unavailable from the authors). These programs could not contribute to any estimate of effectiveness, the cost of implementation or the identification of enablers or barriers.

3.2.2 Types of participants

We included programs designed with the explicit intention to be used by, with, or for Indigenous Australians.

3.2.3 Search methods for identifying programs

We searched Medline [Ovid], AMED, Cinahl, Embase, Informit Online, PsychInfo, Scopus and Web of Science from 2002 to December 2014 with the following terms and keywords: ‘chronic disease’/ or ‘kidney disease’/ or ‘cardiovascular disease’/ or

‘diabetes mellitus’/ and ‘mental health’/ or ‘social adj2 wellbeing’/ or ‘grief or loss’/ or ‘stress’/ or ‘trauma’/ or ‘domestic violence’/ or ‘removal’/ or ‘racism’/ or ‘depress*’/ or ‘anxiety*’/ or ‘distress’. All references were collated into an Endnote [X7.1] database. In an effort to identify further programs, relevant government, non-government and research institute websites were searched to identify programs (full details are available on request).

Four review researchers (author, SF, SP and MH) scrutinised the titles and abstracts, and excluded obviously irrelevant articles. Where a program could possibly be relevant, we retrieved the full-length article or description for further assessment. Any two of the four review researcher (author, SF, SP and MH) independently scrutinised all reports against the inclusion and exclusion criteria. Disagreements were resolved by discussion, and MH confirmed the final list and adjudicated any persisting differences. The number of articles and programs identified at each stage are presented in Table 3.1. All articles were published in English.

We wrote to all authors requesting additional data or seeking clarification of ambiguous data in the published articles or grey literature. Twelve authors responded to our request for further information. Three authors provided additional references. One person directed us to an executive report published on the DoHA website that was not peer reviewed, another suggested we access their website, where all additional data related to the program had been placed.

Table 3.1 Programs included in the systematic review

Cardiovascular disease and mental health programs
ABCD Project (Bailie et al., 2011)
An integrated culturally competent approach to incorporating mental health into CD (Lowitja Institute, 2005)
Aunty Jean's good health program (Curtis, 2004)
Adult Health Checks (Spurling et al., 2009)
Clinical Services Redesign program (NSW Department of Health and Centre for Aboriginal Health, 2010)
Depression Screening Tool (Esler, Johnston, & Thomas, 2007)
Healthy Start, Healthy Life (Haswell-Elkin, Hunter, Nagel, Thompson, & Hall, 2005)
Heart Health for our people by our people (Katzenellenbogen et al., 2014)
The heart health project (J. Reilly et al., 2011)
The Home Study (Kanyini Vascular Collaboration [KVC], 2012)
Keeping Well Program (Maari Ma Health Aboriginal Corporation, 2011)
Sharing Health Care Initiatives (DoHA, 2005a)
Strengthening Cardiac Rehabilitation & Secondary Prevention for Aboriginal and Torres Strait Islanders (DoHA, 2005b)

Chronic kidney disease and mental health programs
ABCDE Project (Bailie et al., 2011)
Aunty Jean's Good Health Project (Curtis, 2004)
Clinical Services Redesign Program (NSW Department of Health and Centre for Aboriginal Health, 2010)
Healthy Start, Healthy Life (Haswell-Elkin, Hunter, Nagel, Thompson, & Hall, 2005)
The Home Study (KVC, 2012)
I'm Ok Project (Connors & Patel, 2010)
Keeping Well Program (Maari Ma Health Aboriginal Corporation, 2011)
Renal Primary Health Program (CAAC, 2014)
WDNWPT Program (Western Desert Nganampa Walytja Palyantjaku Tjutaku, 2009)

Diabetes and mental health programs

ABCDE Project (Bailie et al., 2011)

Aunty Jean's Good Health Project (Curtis, 2004)

Clinical Services Redesign Program (NSW Department of Health and Centre for Aboriginal Health, 2010)

Diabetes Cooking course (Abbott, Davison, Moore, & Rubinstein, 2012)

Healthy Start, Healthy Life (Haswell-Elkin, Hunter, Nagel, Thompson, & Hall, 2005)

The Home Study (KVC, 2012)

Keeping Well Program (Maari Ma Health Aboriginal Corporation, 2011)

Sharing Health Care Initiatives (DoHA, 2005a)

General chronic disease, and social and emotional wellbeing programs

Aboriginal Health Community Re-entry Program (Hart, 2012)

Bundap Marram Durn-Durn (Higgins et al., 2013)

Chronic Condition Management Strategies in Aboriginal communities (Harvey et al., 2013)

Daisy Petal Program (Derbarl Yerrigan Health Service, 2013)

Living Improvements for Everyone (LIFE) (Warren & Coulthard, 2005)

Mibbimbah (Men's Space) Men's Chronic Disease Program (Bulman & Hayes, 2011)

3.2.4 Data extraction

The review author (SP) commenced extraction of the 2012 data and the author finalised extraction of the 2012-2014 data and entered data independently on specially designed forms. There were two second review authors for the 2012 data and two second review authors for the 2012-2014 data (AE, SF, SP and MH) who independently cross-checked all extracted data. Any discrepancies in the data were discussed and resolved before inclusion in the review.

A standard form was used to extract the data. This included the following information:

1. The primary targets of the program (population, CD, SEWB area) and overall aims of the research.
2. The intervention components.
3. The quality and generalisability of the program (clearly defined objectives, program delivery, participants [included/consented, number assessed, use of control groups for comparison]), outcomes (including blinding of outcome assessors), efficacy and cost.
4. Enablers and barriers to the implementation or translation of the program.

3.3 Results

We identified 9888 references in the searches (see Figure 3.1) and ultimately included 101 articles, webpages and reports relating to 24 programs (see Table 3.1).

Of the 24 programs identified for this review, five were run in the NT (Central Australian Aboriginal Congress Aboriginal Corporation [CAAC], 2014; Connors & Patel, 2010; Entwistle, Entwistle, & Stothers, 2011; Esler, Johnston, & Thomas, 2007; Western Desert Nganampa Walytja Palyantjaku Tjutaku [WDNWPT], 2009). Five were run in NSW (Abbott et al., 2012; Curtis, 2004; Maari Ma Health Aboriginal Corporation, 2011; NSW Department of Health and Centre for Aboriginal Health, 2010; J. Reilly et al., 2011), three in WA (Derbarl Yerrigan Health Service, 2013; Hart, 2012;

Katzenellenbogen et al., 2014). Two were conducted in Queensland (Kanyini Vascular Collaboration [KVC], 2012; Spurling, Hayman & Cooney, 2009), two in South Australia (Harvey, Petkov, Kowanko, Helps, & Battersby, 2013; Warren & Coulthard, 2005) and one in Victoria (Higgins, Murphy & Jobling, 2013). Five programs were run in multiple sites in multiple states (DoHA, 2005a, 2005b; Bailie et al., 2011; Bulman & Hayes, 2011; Haswell-Elkin, Hunter, Nagel, Thompson, & Hall, 2005) and the location was unspecified in one program (Lowitja Institute, 2005). Thirteen programs targeted ACCHSs specifically (Abbott et al., 2012; Bailie et al., 2011; CAAC, 2014; Derbarl Yerrigan Health Service, 2013; Entwistle & Entwistle, 2012; Esler et al., 2007; Harvey et al., 2013; KVC, 2012; Katzenellenbogen et al., 2014; Maari Ma Health Aboriginal Corporation, 2011; J. Reilly et al., 2011; Spurling et al., 2009; Warren & Coulthard, 2005).

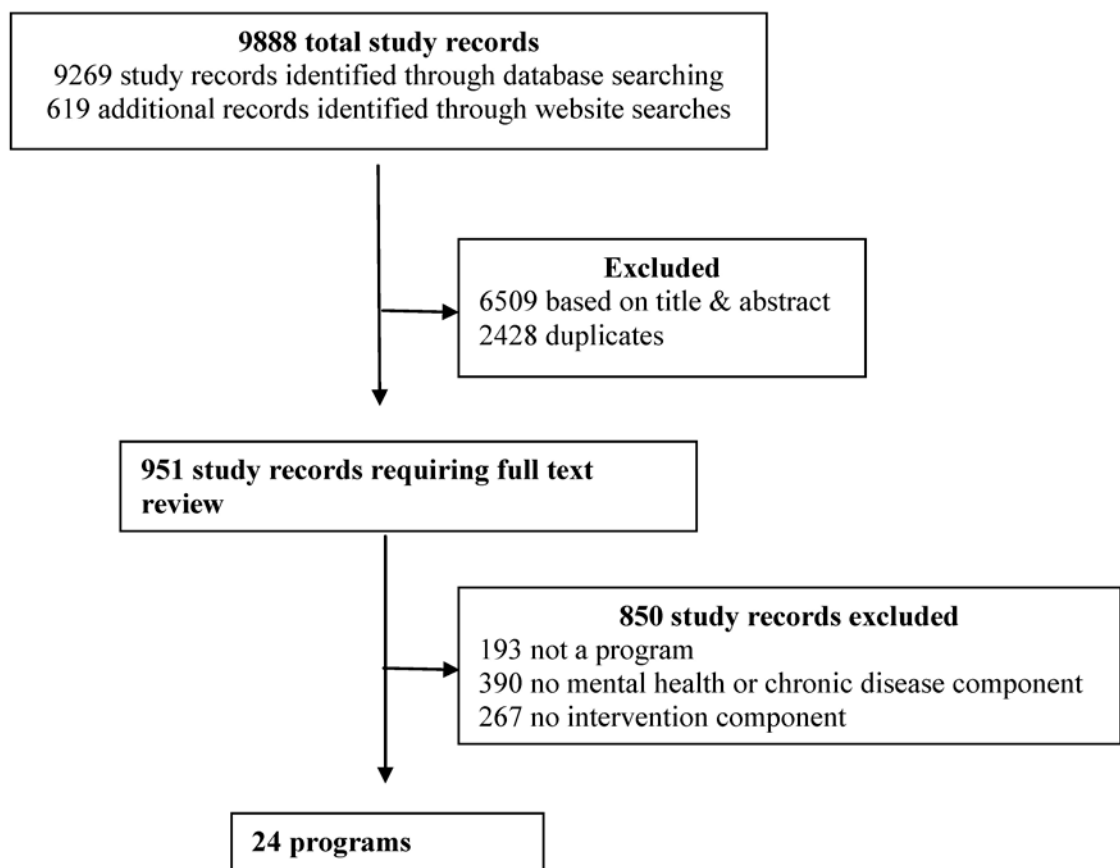


Figure 3.1 Systematic review flow diagram

3.3.1 Primary program targets

These programs were designed for people with (or for staff managing) the CDs listed in the rest of this paragraph. These CDs include CVD (DoHA, 2005b; Esler et al., 2007; Katzenellenbogen et al., 2014; J. Reilly et al., 2011; Spurling et al., 2009); CKD (CAAC, 2014; Connors & Patel, 2010; WDNWPT, 2009); diabetes (Abbott et al., 2012; Entwistle et al., 2011); and CD as a single unspecified category. Programs that targeted more than one CD were also included (DoHA, 2005a; Bailie et al., 2011; Bulman & Hayes, 2011; Curtis, 2004; Derbarl Yerrigan Health Service, 2013; Hart, 2012; Harvey et al., 2013; Haswell-Elkin et al., 2005; Higgins et al., 2013; KVC, 2012; Maari Ma Health Aboriginal Corporation, 2011; NSW Department of Health and Centre for Aboriginal Health, 2010; Warren & Coulthard, 2005). The following areas of mental health and SEWB were incorporated into programs targeting multiple mental health areas (Abbott et al., 2012; Bailie et al., 2011; Bulman & Hayes, 2011; CAAC, 2014; Connors & Patel, 2010; Curtis, 2004; DoHA, 2005b; Derbarl Yerrigan Health Service, 2013; Entwistle et al., 2011; Hart, 2012; Haswell-Elkin et al., 2005; KVC, 2012; Katzenellenbogen et al., 2014; Maari Ma Health Aboriginal Corporation, 2011; NSW Department of Health and Centre for Aboriginal Health, 2010; J. Reilly et al., 2011; Spurling et al., 2009; Warren & Coulthard, 2005; WDNWPT, 2009); SEWB not otherwise defined (Abbott et al., 2012; Bulman & Hayes, 2011; CAAC, 2014; Derbarl Yerrigan Health Service, 2013; Entwistle et al., 2011; WDNWPT, 2009); anxiety and/or depression (DoHA, 2005a; Esler et al., 2007; Harvey et al., 2013; Higgins et al., 2013); psychosocial factors not otherwise defined (Katzenellenbogen et al., 2014; Lowitja Institute, 2005; Spurling et al., 2009); mental wellbeing (Connors & Patel, 2010); and schizophrenia or drug-induced psychosis (Bailie et al., 2011). The target disorders were combined as follows: CVD and SEWB (DoHA, 2005b; Esler et al., 2007; Katzenellenbogen et al., 2014; Lowitja Institute, 2005; J. Reilly et al., 2011; Spurling et al., 2009); CKD and SEWB (CAAC, 2014; Connors & Patel, 2010; WDNWPT, 2009); and diabetes and SEWB (Abbott et al., 2012; Entwistle et al., 2011). Three programs specifically targeted multiple CDs and anxiety and/or depression (DoHA, 2005a; Harvey et al., 2013; Higgins et al., 2013). Ten programs targeted the broad concepts of CD and SEWB (Bailie et al., 2011; Bulman & Hayes, 2011; Curtis, 2004; Derbarl Yerrigan Health Service, 2013; Hart, 2012; Haswell-Elkin et al., 2005; KVC, 2012;

Maari Ma Health Aboriginal Corporation, 2011; NSW Department of Health and Centre for Aboriginal Health, 2010; Warren & Coulthard, 2005).

3.3.2 Intervention components

Some interventions were broad and difficult to categorise (Abbott et al., 2012; CAAC, 2014; Derbarl Yerrigan Health Service, 2013; Hart, 2012; Haswell-Elkin et al., 2005; Higgins et al., 2013; Katzenellenbogen et al., 2014; Lowitja Institute, 2005; Maari Ma Health Aboriginal Corporation, 2011; NSW Department of Health and Centre for Aboriginal Health, 2010; Warren & Coulthard, 2005). They can be grouped broadly as follows: education (Entwistle et al., 2011; Harvey et al., 2013; Katzenellenbogen et al., 2014); self-management (DoHA, 2005a; Hart, 2012; Warren & Coulthard, 2005); ‘models of care’ (CAAC, 2014; KVC, 2012; NSW Department of Health and Centre for Aboriginal Health, 2010); screening (Derbarl Yerrigan Health Service, 2013; Esler et al., 2007; Katzenellenbogen et al., 2014); capacity building (Curtis, 2004; Higgins et al., 2013; WDNWPT, 2009); providing a support person (Connors & Patel, 2010; Maari Ma Health Aboriginal Corporation, 2011); continuous quality improvements (Bailie et al., 2011); other resource provision (Bulman & Hayes, 2011); a cooking course (Abbott et al., 2012); screening, management and capacity building (Lowitja Institute, 2005); screening, management and education (Spurling et al., 2009); a risk factor prevention program (Lowitja Institute, 2005); and an education and capacity-building program (DoHA, 2005b). Twelve programs were ongoing (DoHA, 2005b; CAAC, 2014; Connors & Patel, 2010; Derbarl Yerrigan Health Service, 2013; Entwistle et al., 2011; Hart, 2012; KVC, 2012; Maari Ma Health Aboriginal Corporation, 2011; NSW Department of Health and Centre for Aboriginal Health, 2010; Warren & Coulthard, 2005; WDNWPT, 2009) with one running since 2004 (Curtis, 2004). Eleven programs had finished (Abbott et al., 2012; DoHA, 2005a; Bailie et al., 2011; Bulman & Hayes, 2011; Esler et al., 2007; Harvey et al., 2013; Higgins et al., 2013; Katzenellenbogen et al., 2014; Lowitja Institute, 2005; J. Reilly et al., 2011; Spurling et al., 2009) and it was difficult to determine the status of one program (Haswell-Elkin et al., 2005).

The five education interventions tended to focus on the provision of information in a group setting. In three programs, education was the sole intervention (Entwistle et al., 2011; Harvey et al., 2013; Katzenellenbogen et al., 2014). The other two interventions

incorporated practical support by facilitating access to transport (Connors & Patel, 2010), referrals to healthcare, and access to financial and legal support (Maari Ma Health Aboriginal Corporation, 2011). Adult health checks were conducted in the other program (Spurling et al., 2009).

A modified Stanford CD self-management course (Harvey et al., 2013) and an education, self-management and community capacity-building intervention (Warren & Coulthard, 2005) appeared to have a similar approach and content, although this was not explicitly stated as the intervention's theoretical basis. The Stanford model used two trained facilitators (one or both of whom were not health professionals) to cover techniques dealing with emotions, appropriate exercise, medication use, communication, nutrition and treatment evaluation. Focus was also placed on the following process skills: education and information; aged health assessment and care planning; and behaviour change, disease-related problem solving, decision-making and pharmacy review.

A resource intervention involved the provision of 'safe spaces' for men to meet (Bulman & Hayes, 2011). Interventions providing people-based support were focused on providing a person or persons who could liaise with healthcare providers (Connors & Patel, 2010), or facilitate access and referral services through coordinating care (Maari Ma Health Aboriginal Corporation, 2011). One 'model of care' included adult health checks in addition to transport services for clients on haemodialysis (CAAC, 2014).

Most interventions were chosen following stakeholder and community engagement and a review of the literature (Abbott et al., 2010; DoHA, 2005a; Bailie et al., 2011; CAAC, 2014; Connors & Patel, 2010; Curtis, 2004; Hart, 2012; NSW Department of Health and Centre for Aboriginal Health, 2010; Spurling et al., 2009). Two interventions modified existing interventions; these were chosen as they could be modified to suit the target population (Bailie et al., 2011; Esler, Johnston, Thomas & Davis, 2008). Four interventions were chosen because no culturally appropriate interventions were currently available (Abbott et al., 2010; Connors & Patel, 2010; Hart, 2012; NSW Department of Health and Centre for Aboriginal Health, 2010). With two of these, the need for a new program had been identified by researchers and the community

(Entwistle & Entwistle, 2012; Hart, 2012). The remaining reasons for selecting these interventions were ‘to further knowledge’ (Katzenellenbogen et al., 2014), because the current program was considered ineffective, or that particular area had already been identified by the National Health and Medical Research Council (NHMRC) as a priority (Haswell-Elkin et al., 2005). The reasons for selecting interventions were not clearly articulated in three programs (Entwistle et al., 2011; Higgins et al., 2013; Maari Ma Health Aboriginal Corporation, 2011).

3.3.3 Generalisability, efficacy and cost

Insufficient data were provided to determine the generalisability, efficacy or cost-effectiveness of 11 programs (Abbott et al., 2012; CAAC, 2014; Connors & Patel, 2010; Derbarl Yerrigan Health Service, 2013; Esler et al., 2007; Hart, 2012; Haswell-Elkin et al., 2005; Higgins et al., 2013; NSW Department of Health and Centre for Aboriginal Health, 2010; J. Reilly et al., 2011; Warren & Coulthard, 2005).

Objectives

The primary clinical program objective – to prevent or delay the onset of CVD – was outlined in two studies (Katzenellenbogen et al., 2014; R. E. Reilly et al., 2008). Combinations of clinical (e.g. screening for CD risk factors) and process objectives (e.g. to evaluate the role of adult health checks for Aboriginal and Torres Strait Islander people aged 15 to 54 years of age in an urban ACCHS) were outlined in 16 programs (DoHA, 2005a, 2005b; Bailie et al., 2011; Bulman & Hayes, 2011; CAAC, 2014; Curtis, 2004; Derbarl Yerrigan Health Service, 2013; Entwistle et al., 2011; Harvey et al., 2013; Haswell-Elkin et al., 2005; Higgins et al., 2013; KVC, 2012; Katzenellenbogen et al., 2014; Maari Ma Health Aboriginal Corporation, 2011; J. Reilly et al., 2011; Spurling et al., 2009), along with psychological clinical targets explicitly articulated in six of these (DoHA, 2005a; Bailie et al., 2011; Bulman & Hayes, 2011; Curtis, 2004; Harvey et al., 2013; KVC, 2012). Process-orientated goals to provide culturally appropriate care, education, engagement and/or to encourage collaboration were reported in three programs (Hart, 2012; Warren, 2005; WDNWPT, 2009). While the included programs were all designed to address CD and mental health and SEWB outcomes, only three provided sufficient information to determine whether these

objectives were met (Abbott et al., 2012; Garvy & Izquierdo, 2011; NSW Department of Health and Centre for Aboriginal Health, 2010).

3.3.4 Program delivery

Most programs were designed to be delivered by existing clinical health service staff within existing health services (Abbott et al., 2012; Bailie et al., 2011; CAAC, 2014; Derbarl Yerrigan Health Service, 2013; Entwistle et al., 2011; Esler et al., 2008; Harvey et al., 2013; KVC, 2012; Katzenellenbogen et al., 2014; Maari Ma Health Aboriginal Corporation, 2011; J. Reilly et al., 2011; Spurling et al., 2009; Warren, 2005). Four programs were designed for delivery by existing clinical health service staff in conjunction with external organisations (Bailie et al., 2011; Curtis, 2004; Harvey et al., 2013; Spurling et al., 2009). Six programs were designed to be delivered only by staff from external organisations (Abbott et al., 2012; Entwistle et al., 2011; Harvey et al., 2013; KVC, 2012; Maari Ma Health Aboriginal Corporation, 2011; J. Reilly et al., 2011). One program was an online resource supposedly not requiring staff involvement (DoHA, 2005b).

3.3.5 Participants

The number of participants was unspecified in nine program reports (DoHA, 2005b; Bailie et al., 2011; Bulman & Hayes, 2011; CAAC, 2014; Connors & Patel, 2010; Haswell-Elkin et al., 2005; NSW Department of Health and Centre for Aboriginal Health, 2010; Warren & Coulthard, 2005; WDNWPT, 2009). Where reported, only a small proportion of attending participants contributed to the overall results. Fifteen programs catered for between 15 and 413 people (Abbott et al., 2012; DoHA, 2005a; Curtis, 2004; Derbarl Yerrigan Health Service, 2013; Entwistle et al., 2011; Esler et al., 2007; Hart, 2012; Harvey et al., 2013; Higgins et al., 2013; KVC, 2012; Katzenellenbogen et al., 2014; Lowitja Institute, 2005; Maari Ma Health Aboriginal Corporation, 2011; J. Reilly et al., 2011; Spurling et al., 2009). Further demographic information (the proportion of females and males) was only provided in two studies. Only one program compared program outcomes with people who did not participate in the program (that is, those people receiving usual medical care) (Entwistle et al., 2011).

3.3.6 Outcomes

Clinical evaluation was planned in half of the programs (DoHA, 2005a; Bailie et al., 2011; Curtis, 2004; Entwistle et al., 2011; Esler et al., 2007; Harvey et al., 2013; Katzenellenbogen et al., 2014; Lowitja Institute, 2005; NSW Department of Health and Centre for Aboriginal Health, 2010; J. Reilly et al., 2011; Spurling et al., 2009; WDNWPT, 2009). However, only one program provided data to indicate that a clinical evaluation had been completed (Bailie et al., 2011). A process evaluation was planned and completed for 12 programs (Abbott et al., 2012; DoHA, 2005a; Bailie et al., 2011; Curtis, 2004; Entwistle et al., 2011; Esler et al., 2007; Harvey et al., 2013; Higgins et al., 2013; Lowitja Institute, 2005; NSW Department of Health and Centre for Aboriginal Health, 2010; Spurling et al., 2009; WDNWPT, 2009). One additional program presented process-evaluation data (Hart, 2012). No program reported data on adverse events. In one program, clinical outcome assessment and the process evaluation was performed by an independent person not involved in program delivery (DoHA, 2005a). Another program used an un-blinded assessor who had been involved in the program to measure clinical outcomes (Curtis, 2004). We were unable to determine if blinded outcome assessors were used in five programs (CAAC, 2014; Connors & Patel, 2010; Haswell-Elkin et al., 2005; Maari Ma Health Aboriginal Corporation, 2011; NSW Department of Health and Centre for Aboriginal Health, 2010).

3.3.7 Participants contributing to results

The number of participants completing outcome assessments was stated in 10 programs (Abbott et al., 2012; DoHA, 2005a; Bailie et al., 2011; Curtis, 2004; Entwistle & Entwistle, 2012; Esler et al., 2007; KVC, 2012; NSW Department of Health and Centre for Aboriginal Health, 2010; Spurling et al., 2009; S. Thompson et al., 2009). Only eight of these also provided information on the number of participants receiving the program (Abbott et al., 2012; DoHA, 2005a; Bailie et al., 2011; Curtis, 2004; Entwistle et al., 2011; Esler et al., 2007; Spurling et al., 2009; S. Thompson et al., 2009). Outcomes for all participants were reported in one study (Esler et al., 2007). Outcome data were presented for between 23 per cent and 61 per cent of participants in six of the studies. One report stated that 504 participants had withdrawn from the program; however, the reasons for these withdrawals were not reported (DoHA, 2005a).

3.3.8 Efficacy

The primary aim was met in 12 of the programs (DoHA, 2005a, 2005b; Bailie et al., 2011; Bulman & Hayes, 2011; Connors & Patel, 2010; Curtis, 2004; Entwistle et al., 2011; Harvey et al., 2013; KVC, 2012; J. Reilly et al., 2011; Spurling et al., 2009; WDNWPT, 2009). It was difficult to establish whether the primary aim was met in 11 of the programs (Abbott et al., 2012; CAAC, 2014; Derbarl Yerrigan Health Service, 2013; Hart, 2012; Haswell-Elkin et al., 2005; Higgins et al., 2013; Katzenellenbogen et al., 2014; Lowitja Institute, 2005; Maari Ma Health Aboriginal Corporation, 2011; NSW Department of Health and Centre for Aboriginal Health, 2010; Warren & Coulthard, 2005). The aim was not met in one program (Esler et al., 2007).

Clinical outcome data were reported in only two programs (both education interventions). Significant improvements in blood pressure (pre-intervention systolic blood pressure (SBP) 135 ± 20 mmHg; post-intervention SBP 120 ± 16 mmHg; $p < 0.01$; pre-diastolic blood pressure (DBP) 77 ± 11 mmHg; post-DBP 72 ± 6 mmHg; $p < 0.05$), waist girth (pre- 112.9 ± 13.6 cm; post- 108.6 ± 13.2 cm; $p < 0.01$) and exercise capacity (pre-6 min walk test 294 ± 115 m; post- 344 ± 135 m; $p < 0.01$) were reported in one program. However, these results were only based on the 23 per cent of participants who had attended at least eight sessions (Curtis, 2004). In a second program, data were presented on 28 per cent of participants who had completed an eight-week course. An improvement in HbA1c was present for 10 per cent of the participants, and 6 per cent reached their target blood pressure. Fourteen per cent reduced their cholesterol to less than 4 mg/dl. Mental health and SEWB outcome data were not reported in any study. Three programs stated significant self-reported improvement in clinical outcomes, but actual clinical data were not provided (Abbott et al., 2012; Curtis, 2004; KVC, 2012).

In one program, a screening tool (PHQ-9) for depression was modified and validated for use with Indigenous people (Esler et al., 2007); therefore, the program had no intervention component. The methods for this study were sound, but the study was stopped before the planned sample of 95 people was reached. While data were presented on 39 participants from one health service, only 34 completed the screening tool and the diagnostic interview (both are required for validation studies). The number of

participants with depression determined via interview was reported as five out of 39, but no indication was provided concerning whether the aforementioned five had also completed the screening tool.

3.3.9 Cost

Only one program including support intervention provided information regarding costs (WDNWPT, 2009). While the WDNWPT program enabled dialysis patients moved to Alice Springs to return to their communities for short periods, this intervention was only transferrable to other conditions or settings requiring removal from community to access care. Two other programs reported the source of funding for their research; however, no effective benefits to government or health services were reported. No cost data were available for the remaining programs.

3.4 Enablers and barriers

Information on enablers and barriers was drawn from the reports on 18 programs (Abbott et al., 2012; DoHA, 2005a, 2005b; Bailie et al., 2011; Bulman & Hayes, 2011; Connors & Patel, 2010; Curtis, 2004; Entwistle et al., 2011; Esler et al., 2007; Harvey et al., 2013; Higgins et al., 2013; KVC, 2012; Katzenellenbogen et al., 2014; NSW Department of Health and Centre for Aboriginal Health, 2010; J. Reilly et al., 2011; Spurling et al., 2009; Warren & Coulthard, 2005; WDNWPT, 2009). One program provided information on cultural sensitivity as an enabler but did not provide data for any other enablers or barriers in this review (Derbarl Yerrigan Health Service, 2013). We gave more weight to the results from process evaluations conducted by blinded outcome assessors (DoHA, 2005a) over those where the assessor was un-blinded (or if this was unclear) or the evaluation was informal.

3.4.1 Pre-program

Community engagement before program implementation involved diverse processes. These included preliminary stakeholder review workshops for strategic planning, the establishment of individual and shared goals between program leaders and community, and the identification of areas requiring extra resourcing (e.g. transport or health promotion material (DoHA, 2005a; Bulman & Hayes, 2011; Curtis, 2004; Entwistle et

al., 2011; Higgins et al., 2013; Spurling et al., 2009). In programs where community engagement was well conducted (Curtis, 2004; Higgins et al., 2013; Spurling et al., 2009), a strong sense of community ownership of the program was apparent. This facilitated a shared vision that led to effective program preparation, and the identification of important outcomes for the program. When community engagement was poor (e.g. with a lack of involvement of Aboriginal health workers in the planning phase and a high staff turnover [Bailie et al., 2011; Bulman & Hayes, 2011; Harvey et al., 2013; J. Reilly et al., 2011]), this was not conducive to developing individual and shared goals. It is possible that this had a negative effect on program implementation. A pre-implementation disconnect between management and staff implementing the program (primary healthcare workers [Hart, 2012] and GPs [Bailie et al., 2011]) working in community organisations resulted in a lack of engagement of primary healthcare workers (NSW Department of Health and Centre for Aboriginal Health, 2010).

3.4.2 During the program

‘Program inclusiveness’ (Abbott et al., 2012) can be defined as practice that enables maximum social and personal benefit from the experience of participation (Lowitja Institute, 2012). ‘Ongoing community ownership’ (Curtis, 2004) was an essential enabler for maintaining participation by all parties. It resulted in the preservation of joint ownership of the program, collaborative problem solving when required and joint ownership of the program results (DoHA, 2005a; Bulman & Hayes, 2011; Higgins et al., 2013).

3.4.3 Program training

A key enabler for program uptake and the ease of starting a program was training for staff and participants. This included participants having access to technical staff at the start of an intervention. Training was facilitated by having well-established administrative and information systems, along with clear guidelines for program implementation (Bailie et al., 2011). Participation in training was facilitated by practical tasks where participants could see the evidence of their new knowledge and skills. An example of this was participants presenting a healthy meal they had prepared in a

diabetes-cooking course (Abbott et al., 2012). Additionally, training Aboriginal health workers to deliver self-management and leadership programs enabled culturally secure knowledge transfer to community members (DoHA, 2005a; Curtis, 2004). This ensured the programs were not limited by language, culture or other similar barriers.

3.4.4 Cultural sensitivity

Cultural sensitivity was highlighted as important in most programs (Abbott et al., 2012; Curtis, 2004; Derbarl Yerrigan Health Service, 2013; Entwistle et al., 2011; Esler et al., 2007; Haswell-Elkin et al., 2005; Higgins et al., 2013; KVC, 2012; Katzenellenbogen et al., 2014; Maari Ma Health Aboriginal Corporation, 2011; J. Reilly et al., 2011; Spurling et al., 2009). Engagement with community during consultation and including elders was essential in the planning and implementation phase (Abbott et al., 2012; DoHA, 2005a; Bulman & Hayes, 2011; Curtis, 2004; Entwistle et al., 2011; Esler et al., 2007; Higgins et al., 2013; KVC, 2012; Katzenellenbogen et al., 2014; Lowitja Institute, 2005; Maari Ma Health Aboriginal Corporation, 2011; J. Reilly et al., 2011; Spurling et al., 2009). When done well, this resulted in a strong sense of ownership and program uptake. It also ensured the project team could identify community needs and build these into the project plan. This resulted in a cohesive working relationship between community members, project teams and external bodies, with all working collaboratively to achieve similar goals (Abbott et al., 2012; Curtis, 2004; Entwistle et al., 2011; Higgins et al., 2013; Katzenellenbogen et al., 2014; Spurling et al., 2009).

Adapting training to enable community involvement (Abbott et al., 2012; Bulman & Hayes, 2011; Connors & Patel, 2010; Curtis, 2004; Entwistle et al., 2011; Haswell-Elkin et al., 2005; Higgins et al., 2013; KVC, 2012; Spurling et al., 2009; Warren & Coulthard, 2005) and modifying screening tools (Abbott et al., 2012; DoHA, 2005b; Bailie et al., 2011; Curtis, 2004; Esler et al., 2007; KVC, 2012; Spurling et al., 2009), as well as the modification of program content and outcome tools (DoHA, 2005a; Bailie et al., 2011; Entwistle et al., 2011; Esler et al., 2007; Harvey et al., 2013; Higgins et al., 2013; NSW Department of Health and Centre for Aboriginal Health, 2010) ensured the projects' cultural security. This included acknowledgement of language barriers and highlighting sensitive topics for discussion, as well as ensuring these were approached in a way that did not affect the cultural security of involved participants.

The demonstration of cultural sensitivity throughout the programs can be largely attributed to the inclusion of Indigenous people in the planning and development stages. Where poor program uptake or a lack of community participation in program implementation was evident, two barriers were identified: the community having limited prior experience with similar processes, and the program increasing workloads for under-resourced and overworked staff (NSW Department of Health and Centre for Aboriginal Health, 2010; WDNWPT, 2009).

3.4.5 Funding and resourcing

Insufficient funding resulted in insufficient resources (people, facilities, time) to conduct or complete programs and their evaluation. For example, the lack of available funding to employ a dedicated educator for a diabetes program affected the program outcomes negatively (Abbott et al., 2012). In a self-management program implementation, although GPs were keen to see positive outcomes, time constraints due to their workloads formed a significant barrier to active involvement. Other barriers included implementing diabetes cooking programs when considering the cost associated with purchasing healthier food (Abbott et al., 2012; DoHA, 2005a; Entwistle et al., 2011; NSW Department of Health and Centre for Aboriginal Health, 2010).

3.5 Discussion

A small number of programs that addressed CD and mental health or SEWB for Indigenous people were identified (Abbott et al., 2012; DoHA, 2005a, 2005b; Bailie et al., 2011; Bulman & Hayes, 2011; CAAC, 2014; Connors & Patel, 2010; Curtis, 2004; Derbarl Yerrigan Health Service, 2013; Entwistle et al., 2011; Esler et al., 2007; Hart, 2012; Harvey et al., 2013; Haswell-Elkin et al., 2005; Higgins et al., 2013; KVC, 2012; Katzenellenbogen et al., 2014; Maari Ma Health Aboriginal Corporation, 2011; NSW Department of Health and Centre for Aboriginal Health, 2010; J. Reilly et al., 2011; Spurling et al., 2009; Lowitja Institute, 2012; Warren & Coulthard, 2005; WDNWPT, 2009). A significant proportion of these programs targeted CD more broadly (Bailie et al., 2011; Bulman & Hayes, 2011; Curtis, 2004; Derbarl Yerrigan Health Service, 2013; DoHA, 2005a; Hart, 2012; Haswell-Elkin et al., 2005; Higgins et al., 2013; KVC, 2012; Maari Ma Health Aboriginal Corporation, 2011; NSW Department of Health and Centre

for Aboriginal Health, 2010; Warren & Coulthard, 2005), followed by CVD and mental health and SEWB (Bailie et al., 2010; DoHA, 2005b; Esler et al., 2007; Katzenellenbogen et al., 2014; J. Reilly et al., 2011; Spurling et al., 2009). The interventions were dispersed evenly across education, self-management, models of care, screening for disorders and capacity building. Most interventions were chosen following stakeholder engagement and a review of the literature. Despite well-articulated objectives in most programs, the researcher's ability to demonstrate improvements attributable to the programs was limited by the selection of subjective 'soft' outcome measures, such as participants' self-reported improvements (Abbott et al., 2012; Curtis, 2004; Derbarl Yerrigan Health Service, 2013; Higgins et al., 2013; J. Reilly et al., 2011). The limited demographic information provided for program participants meant that we were unable to determine whether the study populations were representative of the populations these interventions had been designed to reach (CAAC, 2014; DoHA, 2005a; Hart, 2012; Warren & Coulthard, 2005). This raises some questions about the generalisability of the results from the programs in this review. It is apparent that interventional studies focusing on CD and mental health are needed to build on the current evidence base informing what works for Indigenous peoples. Limited data were also available on the cost of developing and implementing these programs, leaving questions cost-effectiveness unanswered.

Programs were easier to introduce when inclusiveness and community engagement were present, including among Indigenous community leaders. Greater ease was also apparent in the following contexts: where the interventions and programs were culturally sensitive and where shared goals enabled a sense of community ownership to be maintained during program implementation (this was essential for ongoing participation); where program delivery was informal; and where resources, including funding, were provided and appropriate. In contrast, when engagement with health services was limited to management-level staff, this created a barrier for GPs and other health service staff delivering the programs. Insufficient training, limited experience with similar programs and poor resourcing (not enough staff, high staff turnover, variable funding and increased workloads) made program uptake and participation more difficult. However, in most instances these enablers and barriers were gleaned from comments in the discussion sections of published reports and not from formal

evaluations of the research or its processes. There is substantial scope to develop the research capacity of participating staff, which would extend beyond the life of the funded project. This could ultimately lead to a sustainable workforce of research-knowledgeable Indigenous staff with adequate training and experience with research practices.

A key strength of the programs in this review is that they were designed within the settings and environments in which they were delivered. They also appeared to have a high level of cultural appropriateness and acceptance within the respective communities. The deficiencies identified in this review do not necessarily lie in the interventions or in the program design, but in the lack of clearly articulated and measurable program aims and reporting, and the less-than-optimal reporting methods. To ensure the rigour of program outcomes, program evaluations should be conducted by an external party, use validated and well-delineated outcome measures. Such evaluations need to be embedded into program and budgetary planning.

3.6 Conclusion

Overall, the program results are inconsistent and we have been unable to determine the efficacy, cost-effectiveness, or the potential for using programs beyond the original research reliably. This mainly flows from a lack of high-quality intervention trials, poor methods, the reporting of some trials with a strong potential for bias in their results, and the poor delineation of key outcome measures and indicators of success. We are left to conclude that a weak evidence base exists from which to inform policy making regarding programs addressing CD and SEWB for Indigenous Australians.

The excessive burden of CD and the inter-related mental illness experienced by Indigenous Australians – along with the clear recognition by governments that these health issues must be addressed if we are to achieve equity in health and maximise wellbeing – is notable. We suggest that the timeline from evidence generation about interventions that work and the implementation of such evidence into practice must be truncated. The newly established Australian Medical Research Future Fund should prioritise initiatives bringing together communities, researchers, service providers and policy makers that aim to implement programs based on this and other evidence

reviews. It should also pilot, evaluate rigorously, increase and demonstrate the efficacy and cost-effectiveness of intervention programs, as well as embedding and sustaining these interventions as part of routine care delivery. In this way, and with an explicit focus on building a research-capable health workforce, we will achieve real improvements in health and wellbeing.

The weak evidence base and lack of RCT evidence relating to effective strategies for CD management in Indigenous communities suggests that significant challenges remain for overall improvement in the management of CD. Intervention trials, such as Kanyini-GAP trial discussed in Chapter 4, provide strong support for the need for collaborative research, undertaken in the context of Aboriginal primary care, aiming to improve management of CD.

3.7 Acknowledgements and funding

An earlier version of this systematic review on a similar but broader topic was commissioned by the Aboriginal Health and Medical Research Council (AHMRC) of NSW and was funded via the Sax Institute as a ‘rapid review’ in 2012. The review topic was then modified, the searches updated and the review was undertaken systematically. During the completion of this work, the author was in receipt of an NHMRC Indigenous Health research scholarship and Maree Hackett was in receipt of a National Heart Foundation Future Leader Fellowship 100034. Neither funding body had a role in the conduct or reporting of this review.

CHAPTER 4: EXPLORING THE VIEWS OF INDIGENOUS PATIENTS AND THEIR HEALTHCARE PROVIDERS

4.1 Introduction

CVD is the leading cause of death for all Australians and is one of the major contributors to lower LE for Indigenous peoples (AIHW, 2016b). Improved prevention and management strategies are required to decrease mortality rates. A multifaceted approach to addressing patient–provider, health service and health system issues is required to improve health outcomes (AHMAC, 2011).

People with CVD and other comorbid chronic conditions are frequently prescribed multiple medications for prevention and treatment of CVD, which result in difficulties in taking all their medication as prescribed (Brown & Bussell, 2011). Research on strategies to simplify complex dosage regimes, such as the use of fixed combination medication packs, are not new initiatives in Indigenous populations. Initiatives such as the Quality Use of Medicines Maximised for Aboriginal and Torres Strait Islanders program (Couzos, Sheedy, & Thiele, 2011), the Pharmaceutical Benefits Scheme Section 100 (Department of Health, 2014), and the Close the Gap (CTG) co-payment relief (Department of Health, 2016) are all policy strategies undertaken to improve medication adherence in this population. However, the views and attitudes of participants regarding these strategies have not been evaluated.

The *Kanyini Guidelines Adherence with the Polypill Study* (Kanyini GAP) RCT was designed to improve the implementation of guideline-recommended CVD therapy at the patient and provider level (Liu et al., 2010; Patel et al., 2014). The primary aim of the trial was to assess whether the provision of a polypill containing low-dose aspirin, a statin and two anti-hypertensive agents, compared with usual individual cardiovascular medications would improve adherence to the indicated therapies and clinical outcomes among high-risk patients compared to those in usual care. The trial results showed that the polypill strategy was effective in improving adherence in Indigenous participants requiring cardiovascular preventative or early intervention treatment (Patel et al., 2014). On completion of the RCT, a qualitative process evaluation was conducted to assess the

impact of the trial on health service providers and participants accessing their services. In this thesis, we present the key themes from the Indigenous participants and their health providers relating to the acceptability of the polypill and its reported advantages and disadvantages. Adherence and non-adherence to medications are discussed as sub-themes.

4.2 Methods

The Kanyini GAP RCT was part of a wider collaborative program of research conducted by the KVC. The KVC was established by Indigenous and non-Indigenous researchers, health professionals, policy makers and communities. The KVC aims to improve health outcomes for Indigenous people at high risk of vascular disease, including people with heart disease, kidney disease and diabetes. The polypill RCT was conducted across multiple sites throughout Australia over two years and four months (Patel et al., 2014).

During the Kanyini GAP process evaluation, in-depth interviews were conducted to explore the views of providers and participants on the impact of the polypill in relation to cardiovascular risk management, medication adherence and acceptability of the Kanyini GAP strategy (Jan et al., 2011; Laba et al., 2013). The process-evaluation research team consisted of Indigenous and non-Indigenous researchers based at the coordinating research institute and at ACCHSs in rural and remote locations in NSW and Queensland, Australia. Interviews were conducted with mainstream health service staff, ACCHS staff and participants in the usual care and intervention arms. Interviews were digitally recorded, professionally transcribed and analysed using NVivo 9 software. Thematic analysis of interview transcripts was conducted. An inductive approach was used to identify similarities or differences in the perceptions about the polypill strategy's effectiveness for managing CVD patients. Three researchers independently analysed the data and generation of emerging themes. The results in this thesis focus specifically on Indigenous participants and their healthcare providers.

Ethics approval for this study was obtained from Sydney South West Area Health Service Human Ethics Research Ethics Committee (Royal Prince Alfred Hospital zone), HREC Reference 08/RPAH/126.

4.3 Results

Ninety-four semi-structured interviews were conducted, 47 with health service staff and 47 with patients; 21 were Indigenous patient participants from ACCHS, and four of these were from regional and remote areas. We included 11 women (three in the polypill arm) and 10 men (five in the polypill arm). Thirty-two participants provided healthcare services to Indigenous patients, including GPs, nurses, pharmacists and Aboriginal health workers (Liu et al., 2015).

Table 4.1 contains demographic data related to 21 Indigenous patient participants from four ACCHS in New South Wales and Queensland, recruited as part of a Kanyini GAP process evaluation.

Table 4.1 Demographic data

Kanyini-Gap Process Evaluation Demographic Data	
Demographic Characteristics	N (%)
Female	11 (52)
Male	10 (48)
Urban	11 (52)
Remote	4 (19)
Rural	6 (29)
Polypill arm	8 (38)
Control Arm	13(62)

4.3.1 Patients' perceptions about factors influencing adherence and non-adherence

Sense of achievement

Some participants in the polypill trial reported feeling a sense of achievement and a greater ability to manage their own blood pressure and cholesterol levels due to the ease associated with the simple medication strategy:

Well I didn't think it'd be that easy ... I thought it'd be harder ... I thought I'd have to take so many tablets ... and I wouldn't be able to do this and can't do that ... but once you actually get to know that

[medication regime] well, you can still do certain things in moderation and things like that, that'll help you when you're taking medication. So my biggest thing was that if I take... tablet after tablet after tablet it all will work. Like ...but not thinking that if I work with the medication I won't have to take that one and this one or that one. (Male Participant 2, Intervention group, Urban ACCHS)

4.3.2 Big tablets and lots of them

Patients reported other reasons for not wanting to take their medications. Such reasons included the tablets being large and difficult to swallow and that there were simply too many tablets to take. One participant said:

Sometimes I get sick of taking them, you know, and when I put the pills in my hand, I go 'oh my god ... I have to swallow all of these ... they're really big' I mean they're horse tablets. (Female Participant 1, Control group, Urban ACCHS)

The views expressed by participants in their interviews suggested that at times, they tired of taking such a large number of tablets every day, and this is why they sometimes skipped a day.

One participant said:

Because I keep forgetting to take them half the time, I will admit. But yeah, but because I was taking so many of them it was making, like I said it was making me sick taking so many tablets. (Female Participant 9, Intervention group, Urban ACCHS)

However, the motivation for recommencing medications the following day was because this participant felt dizzy or unwell. Another participant in the control group reported that having to admit to someone else (i.e. the interviewer) that he did not take his daily medication caused him to reflect on the number of times he had not taken his medication. In doing so, he realised that that he needed to be more aware and to better plan his day to ensure he did take it regularly. An outcome of this reflection (not captured during normal trial processes) resulted in this patient organising his work-bag to include his medication, giving him the best chance of adhering to his schedule.

Such reflection on the part of participants in the study reinforces the importance of conducting this research. The Kanin-GAP study and process evaluation did more than describe the problem. This research promoted self-reflection necessary for better self-management.

Another provider reported one of his client's medication adherence was successful because he wanted to live and see his children grow up. He reported his client as saying:

I just want to stay alive. And if it means me takin' one or four or five tablets then so be it, but I don't want my veins, I don't want blood clots and stuff like that, I just want my heart to work and function and see my kids grow up. (Provider, Urban ACCHS)

Adherence to medication regimes was very important for patients. When patients saw positive results, such as blood pressure and cholesterol rates returning to within normal limits, as reported by health providers and perceived by the patients themselves, this gave them a sense of being in control of their lives.

4.3.3 Burden of pill-taking

Managing my health and my family

Taking medication to manage multiple chronic illnesses for long periods can be difficult, particularly when there are competing priorities such as getting children to school or having to be at work early with no time to eat breakfast. This difficulty affects patients' motivation not only to take their medications, but also to remain well. For example, with diabetic patients, the need to eat breakfast can have major implications for adherence to medications and management of their chronic illness:

So now I bring [my breakfast to work], because I've got [to], I don't eat breakfast of a morning, I don't eat because I just don't feel like eating, so before I could take my tablets I've got to eat something. (Female Participant 1, Control group, Urban ACCHS)

For the following participant who handled multiple tasks simultaneously and relied on set routines, any disturbance to the normal routines sometimes led to the mismanagement of medications:

Oh, now and then, you know, you might be doing something and you just happen to forget ... [to take your medication] ... might get up early in the morning and go ... and do something [else]. (Male Participant 22, Control group, Urban ACCHS)

4.3.4 Providers' perceptions about factors influencing adherence and non-adherence

Awareness of the significance of non-adherence to medications

One provider reported the importance of adherence not only to the patients on the polypill regime, but also to their families. This provider believed that many patients using the health service would have a very short LE were it not for strategies such as the polypill. This provider indicated that some patients were unaware of having had a heart attack until they were screened for their suitability to participate in the polypill study. In this instance, the polypill was a contributing factor in influencing medication adherence:

A lot of them are even unaware that they've had heart attacks before. Even though they've been diagnosed with it. They just need more education from their doctors. I know with the trial they had a full-on review with their GPs so they actually found out during that process that what they have is serious and the polypill will help. (Provider 41, Remote ACCHS)

Fatalism

Despite positive impacts of the polypill in relation to fostering control over one's health and expected increased LE as a result, some providers suggested that a sense of fatalism existed among some clients regarding the presence of CD. This might lead to a decision not to seek healthcare, ultimately leading to a poorer health status. This was reinforced by one provider who reported that he had had conversations with his patients who said they would cease all medications for management of their disease beyond a certain age:

Say, if you consider the patients always believe that at 57 they will die ... now that basically impacts on how they are going to take their medications, how these patients say, 'doctor, after 50 I'm not going to take anything'. (Provider 6, Urban ACCHS)

This has special significance for Indigenous people, who have a LE of 10 to 12 years less than non-Indigenous Australians and a much heavier burden of chronic conditions,

as reported in results from the *National Aboriginal and Torres Strait Islander Health Measures Survey*. While some doctors perceived that patients did not adhere due to this sense of fatalism, no patients made comments that indicated a sense of fatalism.

Value of family and community

Healthcare providers highlighted the role of family and community in relation to supporting each other regarding medication adherence. Reports suggested that when a family member ran out of their diabetic medications, they would borrow them from a family member:

So people might [go] over there and borrow somebody else's insulin just because they don't have the current dosage for that day ... It's easy for them to go over to aunty and uncle and ask them for the same medication rather than going to the doctors. (Provider 26, Urban ACCHS)

The implications for family sharing their medications could include non-adherence, poor follow up by their GP and even hospitalisation, which was reported as a concern by the provider in this instance.

4.3.5 Strategies for adherence

Health literacy

GPs reported using several adherence-related strategies to promote CD management that involved the individual and their family, along with the fear of recurring major health events. The GPs used pictorial health literacy strategies:

The visual works ... they leave here with a picture in their mind that the cholesterol is clogging up their arteries ... they can have a stroke ... or heart attack; for me personally, what works for me with this community is to explain in detail how this tablet works why it is important to be on the cholesterol, why it's important to be on the blood pressure tablet, because I think for those two tablets and insulin as well, they [the patients] don't feel the symptoms. (Provider, Remote ACCHS)

This GP was referring to adherence to all medications that his patients were taking, rather than focusing specifically on the CVD polypill strategy.

Preventing recurrence of a cardiac event

Providers also indicated greater challenges in promoting adherence among people needing to prevent a first cardiac event:

Patients who've had a heart attack also [tend] to be more compliant than those patients who are ... given primary preventative medications just because they are scared. (Provider 5, Urban ACCHS)

4.3.6 Complexities associated with taking a large number of pills

Primary preventative medications not enough

Reports exist of an initial enthusiasm among patients regarding their involvement in the polypill trial from a particular ACCHS where the GP was keen to participate. This enthusiasm was related, in one case, to the GP's view that there was a need to reduce the heavy burden of CD in his service. The GP believed that the polypill strategy might simplify and improve CD management. However, he soon realised that to obtain the best results when using the polypill, it was necessary to target early-onset CVD. Here, the polypill might be best suited for patients requiring primary preventative medication.

Most clients of this particular ACCHS were patients with established CVD. One GP reported:

Yeah, I guess when we started we were very enthusiastic about the study, and [believed] that many on our books would be eligible ... when we looked at the polypill and whether that fits our clientele, that's our major issue there, because ... we have more sick patients. (Provider, Rural ACCHS)

This initial enthusiasm of GPs for their clients to participate may have caused confusion with some patients and uncertainty about the value of the polypill:

The difficulty came from the clinicians not wanting to refer [patients] in the first place ... and then tending to take people off the polypill at the drop of a hat ... they [the patients] stop feeling that they are on the correct medications ... making the patients be unsettled ... if we'd been ... tailoring it [polypill] for primary prevention ... that would have been the easy group to target. (Provider, Urban ACCHS)

4.3.7 Locus of control

There were times when patients made the conscious decision to have a break from taking their medications, simply because they were tired of taking such big tablets, and lots of them, every day. This was reported by a patient in the control group, who did not take the polypill. When asked anything had stopped her from taking her medication, she said that sometimes she just needed a rest from them. However, she also reported that when this happened, she was forced to take her medication the following day because she started to feel unwell. When the interviewer asked if being involved in the control group arm of the polypill strategy improved how she managed her health, the patient said:

Yes, it has because I know what I'm taking, I know what I'm doing, I know. (Female Patient 1, Control group, Urban ACCHS)

4.3.8 Acceptability of the polypill strategy

Some participants viewed the polypill as being one of the most important contributors to their health improvements. However, healthcare providers reported that given that many of their clients needed a range of interventions to manage their CD, the clinical benefits of the polypill were minimal. The psychosocial benefits of the polypill were reported as substantial for participants and potentially for their families and communities. One provider thought the polypill strategy provided clear benefits for the community.

4.3.9 Advantages of the polypill strategy

Reduction in the burden of pills

The potential to take a reduced number of pills was reported as a positive factor. This was due to the perception that a reduction in the number of pills represented a reduction in the burden of pill-taking:

Well, I find it's easier to take the tablets now because ... it's cut down heaps of my tablets, and I'm at the stage where, because before when I was taking all the other tablets it was making my stomach feel unsettled, but I feel okay with this polypill. (Female Participant 9, Intervention group, Urban ACCHS)

Yeah, and my blood pressure has gone down and he was going to reduce the Monoplus that I'm on to a lower dosage. I've already stopped the Somac and no side effects from that and that was under doctor's guidance. He said, 'give it a trial, see how you go'. Well it's two weeks now since I've stopped and it's been perfect but I'm just thinking, and if it's just one pill [talking about taking the polypill], but I suppose we'll get that assessed later with doc. (Female Participant 12, Intervention group, Urban ACCHS)

Another participant spoke of family members dying in his community because they did not take their medication due to the high number of pills required. He said:

When you get a nephew that's probably younger than me dying ... it's all to do with not taking his medication, maybe if they were given the one pill instead of half a dozen, they might still be here today. (Male Participant 4, Control group, Urban ACCHS)

Affordable medications

Patients' access to affordable medications also improved medication adherence. In addition, patients reported that having fewer medications to take (as well as being able to take this medication at more flexible times) made it easier for them to comply with their medication regimes. Patients who adhered to their medication also reported feeling better:

Yeah, it's doing my blood pressure, it's doing my cholesterol, and it's doing the blood thinner ... there are four different tablets ... they replaced them, which means less money and... it takes away a series of tablets, right, that I would have to take if I wasn't on the polypill. The polypill just takes it away. (Male Participant 10, Intervention group, Urban ACCHS)

If I was on a polypill it would be a lot easier because it's one pill and you just take it that same time and if it's only once a day you take it and that's it ... it's over and done with ... also it would be cost effective. (Female Participant 12, Control group, Urban ACCHS)

I think just the general health benefits that I'm feeling, like that I don't feel as sluggish as before and I ... think I sort of, well the biggest thing for me is to get me brain fixed first because then if that's sort of working then everything else will fall into place ... if my mind doesn't [feel like taking the medication], if I don't feel like taking it me body can't make me take it. (Male Participant 2, Intervention group, Urban ACCHS)

It was also important to people that the polypill cost less than multiple individual tablets. Taking multiple medications to manage CD is costly, and one participant reported having to decide between buying food or buying the medication:

Keep the medication affordable; [the] cost of living is high enough now, and people who need to take medication, who've got smaller families, or got close family that's living with them, every dollar is being competed for, and the one that most individuals will give away first is the one that belongs to them, that's meant for them ... they'll put their family before themselves ... so have to keep it down, the dollars and cents down low because the electricity's going up, the food costs going up. (Male Participant 10, Intervention group, Urban ACCHS)

However, the provider reported that the potential cost benefit of a polypill strategy was blunted due to the coincident introduction of the CTG Pharmaceutical Benefit Scheme (CTG-PBS) by COAG (AHMAC, 2011). This scheme ensured access to medicines for all Indigenous people:

It's a ... major issue. I mean if it wasn't for the Close the Gap, the polypill would have, in this population ... taken off. Everybody would want to be on it because of the cost effect. But because the Close the Gap came in around the time it started, it probably masked the benefit in terms of cost. (Provider 5, Urban ACCHS)

Treatment regimes suited to patient lifestyle

Timing of family responsibilities also affected medication-taking behaviour. For example, one participant reported that her failure to take her prescribed medications at the required time was related directly to her family responsibilities. This participant's afternoon and evenings were the busiest times of the day for her regarding these responsibilities and she also failed to take her prescribed medication more frequently at these times. Having to take medication at this time of the day was so difficult that she usually ended up taking her medication undesirably late at night when she remembered (Participant 13, Urban AMS). Being able to take the polypill once in the morning made managing her CD much simpler as she could take it during a quieter time in her day.

Another participant said:

It's like a never-ending chore for them ... [the community members reported this to Participant 31], they said to him, 'if I could take one tablet it'd be a better world ... it would be much easier, it's more convenient, even when travelling'. (Female Participant 31, Rural ACCHS)

4.3.10 Disadvantages of the polypill strategy

Strategy not integrated properly into a system

A healthcare provider reported that following recruitment into the study, there was a sense of confusion in terms of participants in the trial versus patients not in the trial and management issues to do with documentation:

Once they're in it tends to cause confusion in their management. Lots of things seem to have sort of impacted potentially negatively on the care of patients, particularly confusion around their medications and people entering the medications correctly in to [the] medical director. Making it clear the way it was entered, what exactly the patient was on, confusion about what they were on when they then went to hospital. The patients not really understanding usually what they were on. And then concern by community specialists about medication changes that they weren't in charge of. (Provider, Urban ACCHS)

Staff at one health service thought the polypill's acceptability might have been reduced due to a lack of awareness of the study among staff outside the participating health service also involved in care of the polypill study participants. This caused issues for one patient in the polypill study when they needed to attend hospital for surgery. The anaesthetist was hesitant about a patient having a surgical procedure at the local hospital and continuing to take the polypill. The anaesthetist noted that the participant's referral letter provided no information about the patient being on the polypill, nor was there information regarding the individual medications contained in the polypill:

Yeah, it was a bit frightening because when I had to go and have a kidney stone removed from my left side ... they asked me what medications I had, I said, the polypill, and they [then] had to get in contact with [the GP] and then to find out exactly what the polypill was, or what did it contain, for putting me under. And then they found that they'd better not do their injection, they [would] probably do the mask, and that's how they knocked me out to do that operation. (Male Participant 10, Intervention group, Urban ACCHS)

The potential implications for patients where this occurred were twofold. First, their surgery could be cancelled. Second, they could be without their anti-hypertensive medications for some time due to inadequate communication between the primary and tertiary services they used.

4.3.11 Overarching nodes from the Kanyini GAP Process-Evaluation Study

Two overarching themes from the Kanyini GAP Process-Evaluation Study are: (i) adherence and non-adherence to medications; and (ii) acceptability of the polypill strategy (Table 4.2).

Table 4.2 Overarching nodes with findings, themes and sub-themes from the Kanyini GAP Process-Evaluation Study for ACCHS providers and patients

Adherence and non-adherence to medications
<p>Patients' perception about factors that influence adherence/non-adherence</p> <ul style="list-style-type: none"> • Sense of achievement • Big tablets and lots of them <p>The burden of pill-taking</p> <ul style="list-style-type: none"> • Managing my health and my family <p>Providers' perception about factors that influence adherence/non-adherence</p> <ul style="list-style-type: none"> • Awareness of significance of non-adherence to medications • Fatalism • The value of family and community <p>Strategies for adherence</p> <ul style="list-style-type: none"> • Health literacy • Preventing recurrence of a cardiac event <p>Complexities associated with taking a large number of pills</p> <ul style="list-style-type: none"> • Primary preventative medications not enough • Locus of control
Acceptability of the polypill strategy
<p>Advantages of the polypill strategy</p> <ul style="list-style-type: none"> • Reduction in the burden of pills • Affordable medication • Treatment regimes suited to patient lifestyle <p>Disadvantages of the polypill strategy</p> <ul style="list-style-type: none"> • Strategy that is not properly integrated into a system

Adherence and non-adherence to medications

The views reported on adherence and non-adherence to medications were from patients and their providers. Patients on the polypill arm of the study described factors that influenced their decision to adhere to medication regimes, which included feeling a sense of achievement about positive changes in their blood pressure monitoring. However, some patients, particularly those in the control arm of the study, reported not taking their medication because the tablets were too big or there were too many of them. They stated that taking their medication was a burden, and felt that the burden took them away from being able to spend time with their family.

Healthcare provider perceptions about factors that influence adherence or non-adherence to patients taking their medication were because their patients were not knowledgeable about the health implications of not taking their medication. Providers reported that some of their patients viewed their health and wellbeing through a fatalistic lens; particularly when patients believed their life expectancy to be significantly limited. Healthcare providers also reported that family and community are strengths that support patients in adhering to their medication. They conveyed the importance of health literacy and preventative measures used to curtail the reoccurrence of cardiac events as strategies for patients adhering to their medication.

Providers agreed that there were complexities associated with taking a large quantity of medication. They were aware that the greater the burden of pills, the more likely there would be contra-indication concerns for patients. Providers also agreed that where the patient's locus of control was low, his/her views were more fatalistic. However, if patients believed that they could manage their own health with the support of a healthcare provider, their locus of control was considered high.

Acceptability of the polypill strategy

The acceptability of the polypill strategy reported on the advantages and disadvantages of taking the polypill. In some situations, participants in the polypill arm of the study had a reduction in the number of pills to be taken each day. Where patients had to pay for their medication, they found that reducing the number of prescriptions being filled

resulted in a reduced cost for them. However, patients highlighted the polypill not being integrated into the PBS as a disadvantage of their acceptability of the polypill strategy.

4.4 Discussion

Indigenous participants accepted the polypill strategy due to its convenience and potential for reduced cost within the context of the various challenges faced in their daily lives. These challenges included the nexus between personal and community responsibilities and the loss of family where medication adherence was perceived as a factor in that loss. Medication adherence is crucial for achieving good health outcomes, particularly where people with CD are on multiple medications for long periods, as is the case for many Indigenous Australians (Davidson, Abbott, Davison, & Digiacomio, 2010).

The well-known barriers to medication adherence, such as cost, complex medication regimens and low health literacy, are well documented (Brown & Bussell, 2011; Davidson et al., 2010; Liu et al., 2010) and affect Indigenous and non-Indigenous Australians. In this study, we found differences between the reasons reported by providers and their Indigenous patients for non-adherence. For instance, providers attributed much of the non-adherence to low health literacy and a perception of fatalism, while participants suggested more structural problems. Our findings indicate that improvements in medication adherence are most likely to occur when an appreciation exists about the complexities of community living and how this impacts health behaviours, and when individual lifestyle and dietary changes are incorporated into behaviour change.

The polypill study explored Indigenous participants' experiences of the polypill's impact on adherence to medication. In addition to the benefits that participants identified as a result of taking one pill, structural impediments still remained for participants, such as cost and low health literacy and complexities associated with community living. However, a study conducted to understand the beliefs and perspectives of Indigenous people in WA with cancer found a different set of challenges. This study found that health practices and care-seeking behaviour were culturally bound, rather than structural. In this WA study, differences were apparent

between Indigenous and non-Indigenous Australians' perceptions and definitions of health, wellbeing, illness, sickness and disease (Shahid, Finn, Bessarab, & Thompson, 2009). Some examples of these differences reported by the Indigenous participants to Shahid et al. (2009) included preferring seeking care from a traditional healer rather than the conventional healthcare available in primary health services, fatalism, shame and a fear of death. These differences had an impact on patients' understanding and decisions to seek care and access services (Liu et al., 2010). This may be similar to the differences we found between providers' and participants' assumptions and reasoning behind medication non-adherence. Providers who assume a sense of fatalism in their patients may be resigned to non-adherence and come to expect it, while their patients may be hoping to determine how they can improve engagement with their healthcare, increase adherence and improve their health. Understanding a patient's experience, their cultural identity and belief structures is essential if a polypill strategy is to be implemented into primary healthcare for CVD management.

The different perspectives of providers and participants regarding the burden of disease, and the barriers to provider and patient interaction, are consistent with other literature on service delivery to Indigenous patients (Peiris, Brown, & Cass, 2008). One barrier faced by healthcare providers in improving health service delivery to their Indigenous patients and community is the tension between the demand for quality and significant resource constraints. The allocated resources are often insufficient to address the needs and challenges encountered when trying to provide quality primary and follow-up care (Durey & Thompson, 2012).

This study has many strong elements. The in-depth interviews have provided important insights into why medication regimes for CD management may or may not work for Indigenous people. The KVC team included Indigenous and non-Indigenous researchers working together to conduct all aspects of the research, having built close and respectful partnerships with health services and communities over a number of years. The level of care displayed ensured participants felt safe discussing their views about the effectiveness of the polypill strategy and other issues that mattered to them. The KVC researchers were available and willing to interview participants in the community, health services or in participants' homes.

Identified weaknesses in this study include the focus on urban and regional Indigenous health services, with the involvement of few remote services or participants with English as a second language. With more research funding and time, other sites might have been added and more interviews conducted for this study. However, we were able to capture a breadth of issues from participants and providers across the two states with the largest Indigenous populations.

4.5 Conclusion

A polypill-based treatment regimen seems to be an acceptable strategy for improving medication adherence among Indigenous people. Additionally, the imperative for consistency with broader initiatives to improve access to necessary medications has been noted. Translation into practice will require consideration of other possible combinations of the polypill that will cater specifically to the health needs of this particular population, the healthcare providers' understanding of factors affecting their patients' ability to manage their health and continuation of the CTG scheme. This is especially important in the current environment in terms of the federal government's proposed changes to the Medicare system. The potential implications of any reduction in access to healthcare are important for the many Indigenous Australians taking multiple medications to manage their CDs who are already reporting financial burdens associated with maintaining their health.

However, a polypill-based strategy is only one element necessary for improving medication adherence among Indigenous Australians. Educating individuals and broader family networks on the importance of medication adherence and follow up with healthcare providers must also be addressed. Improved communication is vital between primary, tertiary and hospital-based health providers, along with an improved understanding among health providers regarding the attitudes and factors shaping patients' health seeking and treatment adherence behaviours. This is necessary if we are to improve medication adherence among Indigenous Australians with or at a high risk of CD.

CHAPTER 5: ROLES AND RESPONSIBILITIES OF INDIGENOUS WOMEN AND THEIR IMPACT ON HEALTH – FINDINGS FROM A QUALITATIVE STUDY

5.1 Introduction

This chapter explores the impact of the multiple and conflicting roles and responsibilities that Australian Indigenous women have in their families, cultural groups and communities on their capacity to look after their own health needs.

The health of Indigenous women is poor compared with non-Indigenous women from Australia and other developed countries (Fredericks et al., 2010). Late presentation for healthcare, leading to diagnosis at advanced stages of disease, is one factor influencing the poor health status of Indigenous Australian women (Burns et al., 2013). Much speculation exists regarding why Indigenous women might present late for medical care (Haebich, 1992). One perspective is that the requirement to fulfil multiple roles within their family, cultural groups and community affects their capacity to seek out health services (Carers Australia, 2006). The roles these women have extend beyond the nuclear family structure, as do the expectations placed upon these women (Burns et al., 2013). Further, there is an expectation that women in Indigenous families take care of the sick members of their household, possibly at the expense of their own health (Burns et al., 2013; Thackrah & Scott, 2011). Conflicting demands might contribute to the reported high levels of stress (Gee et al., 2014). In this study, the author conducted in-depth interviews with Indigenous women to explore how roles and responsibilities that they have within their families and communities affect the way they manage their CD. The interviews explored whether a relationship exists between stress, psychosocial health and the management of CD for Indigenous women.

This chapter presents the findings based on 72 interviews with Indigenous women conducted in four AMSs concerning their roles and responsibilities within their families and communities. The interviews identified three major areas of focus for the women: (i) the many stressors that Indigenous women have in their family and community; (ii) the formal and informal support identified to help combat some of these stressors; and

(iii) the accessible service levels these women experience in their community. The interviews identified themes related to the women's experiences when taking care of their families and their communities. In many cases, this was a significant stressor for them in relation to taking care of their *own* health needs. Women described multiple significant stressors that they dealt with in their daily lives, the reality of minimal formal or informal support systems to help deal with the stressors, and concerns regarding access to healthcare services for them to manage their own health better.

5.2 Reflections on talking with Indigenous women about their health and wellbeing

A brief reflection on experiences conducting this qualitative research with women attending these four AMSs will provide an important context to aid interpretation and understanding of the information they provided. The impact that conducting this research has had on the author is explored more fully in Chapter 7.

During the consultation phase of this study, the author conducted information sessions with clinical staff. She remembers Indigenous health workers and nurses at these consultations nodding their heads as she explained how the roles and responsibilities that Indigenous women had within their families and communities affected the way they managed their health. She further explained that researchers thought the need for women to fulfil multiple roles and responsibilities might affect how they managed their health. It was added that this study could provide a deeper understanding and clarity around these issues.

When talking to the women about their health and wellbeing during the data collection phase, the author listened intently to their stories of strength, resilience and cohesiveness. These stories were underpinned by pride and a strong identity about the women's identities, communities and where they had come from. This was particularly apparent when the women narrated how well they juggled hectic workplace and family responsibilities. For example, many spoke of having to ensure (during their full working day) that children were cared for and elderly parents had been fed or taken for appointments, which often meant they had little time for themselves.

In contrast, the author heard distressing stories of rejection, family violence, homelessness, grief, loss, despair and drug abuse and of how these experiences affected the women's families. Throughout the conversations, stories of incarceration and its impact on families, stories of intergenerational domestic violence, and stories of helplessness, death and loss were told.

Repeatedly listening to these experiences of trauma – such as domestic violence, incarceration, homelessness and death and dying – also initiated questions in the author about the extent to which similar traumas in her own family may have affected her, along with several challenges her family had confronted. The author also wondered if she had difficulty separating the women's feelings from her own, and therefore created the potential for further entrenchment of traumatic experiences she previously experienced. However, as an Indigenous woman, the author acknowledges the complexities associated with Indigenous culture and that not all lived experiences are the same. Some examples of the recounted trauma that she was exposed to frequently throughout this study can be demonstrated by the two stories given below:

He found the biggest steak knife [a] threaded steak knife, and walked behind me and stabbed me from behind. My daughter witnessed it.
(Participant 10, Site 1)

Another woman conveyed, with some disturbingly blunt language, that:

[My husband], he broke my jaw ... and booted three kids out of me.
(Participant 12, Site 3)

The stories and experiences shared with the author throughout this qualitative study were coupled with a methodological approach seeking to ensure that Indigenous women felt comfortable enough to tell their stories to the author as a researcher with whom they could identify and feel at ease. This situation made the author a high-risk candidate for experiencing VT.

The methodological approach that was employed for this study, IPA, aims to explore the lived experiences of study participants. Consistent with IPA, throughout these interviews, the author was trying to understand the lived experiences of the women in

relation to their roles and responsibilities within their families and communities better and if, or how, these roles affected the management of their own health.

The first part of this chapter provides an overview of the methods, data collection, participant selection, case study settings, and ethical issues raised through the study. The later part of the chapter analyses the interview data and discusses the key findings.

5.3 Methods, sampling and ethical issues

Our methods are outlined as per the consolidated criteria for reporting of qualitative research (Streubert & Carpenter, 1999).

5.3.1 Research setting

The research was conducted in four AMSs in two states and one territory of Australia. The services were located in urban, rural and remote settings. The first health service provided 22 participants; nine of these women were aged between 26 and 49 years, 13 were aged 50 years and over. Of the 13 women interviewed at the second health service, one woman was aged between 26 and 49 years and 12 women were aged 50 years and over. Twenty-one women were interviewed at the third health service; four of these were aged between 26 and 49 years, and 17 were aged 50 years and over. Sixteen women were interviewed at the fourth health service, where six were aged between 26 and 49 and 10 were aged 50 years and above. All these women were managing at least one chronic condition, including diabetes, CKD or CVD (see Appendix 8). A small proportion of these women also reported having disorders of thought and thinking specifically reported as depression.

5.3.2 Research team and reflexivity

Study team reflexivity

The research team consisted of the author (as the chief investigator who led the study and conducted the qualitative interviews with participants, led the data analysis and writing), a research fellow (who assisted in the analysis and writing) and three non-Indigenous investigators with medical and psychology backgrounds who have also had significant health service research experience working in collaboration with AMSs or

ACCHS. Although the author situates herself as a researcher with a nursing background and significant health service research experience working in collaboration with ACCHS, she also positions herself as an Indigenous woman.

5.3.3 Study design

An IPA methodology underpins this study. IPA is a qualitative research approach concerned with exploring and understanding the lived experiences of a specified phenomenon. It involves a detailed examination of the participants' world in which they live, their experiences and the meaning they attach to these experiences (Smith, 2004). This approach provided a framework through which the author could understand what it was like to live the experiences of Indigenous women within their families and communities. From those experiences reported here, the aim was to highlight the factors that might enhance or impede these women in their efforts to manage their health and wellbeing (Streubert & Carpenter, 1999).

Phenomenology is both a philosophy and a research method concerned with exploring and understanding human experience. Researchers use this method to uncover the meaning of an individual's experience of a specified phenomenon through focusing on a concrete experiential account grounded in everyday life (Langridge, 2007). Consistent with IPA, throughout these interviews, an attempt to understand the lived experiences of the women in relation to their roles and responsibilities within their family and community better and to identify if or how these roles affected the management of their own health was made.

The author is an Indigenous woman with similar lived experiences as the participants in this study. She identified interpretive phenomenological analysis (IPA) as a study design that would enable her to conceptualise what the participants were experiencing, as well as provide a rich account of their lived experiences, including their roles and responsibilities to their family and community. However, this study design did not directly address how the author might play a 'dual role' because she is an Indigenous woman with similar experiences to the participants in this study.

An alternative study design for this chapter would have been Indigenous Women's Standpoint Theory – a study design which would see the researcher as having a '*dual role*' within this study, as *both like the participants and unlike the participants at the same time*' (Alase, 2017, p:11). The researcher, an Indigenous woman with strong family commitments and responsibilities, interviewed other Indigenous woman about how their family roles and responsibilities influenced their health management. What this approach would allow, is for the researcher to move freely in and out of the world of the participants in order to obtain the richest data from the interviews. However, in order to do so, the researcher would need to explicitly view the participants from an Indigenous woman's standpoint.

The Indigenous women's standpoint theory captures the notion that Indigenous women share common ground, such as experiences perpetuated by colonialism, which saw Indigenous women dispossessed of their homes, their children and their families. Despite this upheaval, they maintained their roles and responsibilities within family and community. According to Moreton-Robinson (2003), 'this tool must not take away from the significance and uniqueness of Indigenous women's experiences, nor should we ignore the need to maintain respectful behaviour towards Indigenous cultural protocols' (Moreton-Robinson, 2003, p. 74).

Nevertheless, as an Indigenous woman, the researcher was able to engage with study participants in such a way to allow them to feel comfortable sharing their stories for the purposes of this study. She was also well placed to understand, interpret and report their experiences.

5.3.4 Data collection

Interviews were conducted in the clinic of the first health service where the author was provided with a private office to ensure privacy and confidentiality was maintained for participants. In the second health service, she was also provided with an office to conduct the interviews. However, on four occasions, meetings with participants were conducted at the hostel where they lived while they awaited dialysis treatment. An office was also provided at the third health service. Yet, in three instances, interviews took place at participants' workplace; and in one instance, an interview was conducted

at the participant's home. Confidentiality and safety of the author and participants were maintained at all times. The fourth health service, due to office space constraints, could only provide the author with desk space. For this health service, all but four of the interviews were conducted in the participant's home. Two of the remaining interviews were conducted in another healthcare facility and two interviews were conducted at the health service. Nonetheless, confidentiality and physical safety of the author and participants were maintained at all times.

5.3.5 Presence of non-participants

Interviews at the first health service only involved active participants. At the second health service, two participants wanted to be interviewed consecutively. At their request, each remained in the room while the other was being interviewed. In health service four, two participants consented to having an Aboriginal liaison officer present in the room when they were being interviewed.

The participants with a CD were interviewed to explore the relationship between family and community and how the participants managed their own health. One-on-one interviews were conducted at local AMS site or a nominated venue as arranged by the author and participants. The interview guide was a set of questions based on where participants were originally from, their family and household structures, and the roles of these women both in the home and in their community. The next set of questions focused on health, in particular who cared for family members when they became unwell, and who took care of the participants when, and if they were sick. The final set of questions focused on SEWB and the impact of stress and worry on the participants (Appendix 6).

Due to the potentially stressful nature of the questions asked of the research participants, they were also asked to complete a questionnaire related to depression as a precautionary measure. This form, the *Patient Health Questionnaire* (PHQ-9; see Table 5.1), is a way of measuring the severity of depression. This depression tool may assist in the diagnosis and management of people with undetected depression. Where there was concern about the PHQ-9 results, those who gave their permission were referred to a GP at the AMS for further review. As seen below in Table 5.1, 16 participants recorded

PHQ-9 results indicating some level of depression. Of these 16, four referrals were made to medical practitioners for patients with no reported history of depression. Five of these patients recorded PHQ-9 scores for moderate depression and one recorded levels consistent with severe depression.

Table 5.1 Patient Health Questionnaire (PHQ-9) results

PHQ-9 depression scale for participants interviewed for the qualitative study	Site 1	Site 2	Site 3	Site 4
5–9 Mild depression	3	3	3	1
10–14 Moderate depression	3	0	2	0
15–19 Moderate to severe depression	0	0	0	0
20–27 Severe depression	1	0	0	0
Total from 72 interviews	7/22	3/13	5/21	1/16

Although the participants’ questions and the PHQ-9 questions were not formally piloted with participants at each site, the questions were provided as part of an information package to health service executive staff and clinical teams prior to meeting with their health service. Guidance was also provided from the contact person at each site during the study’s community engagement and collaborative phase. The feedback from each site indicated satisfaction with the documents provided and no refinement of the interview guide was requested.

The first interview was conducted in May 2014 and the final interview was conducted in October 2014. As the author was initially less familiar with the NVivo 9 program chosen to support the study’s analysis, she sought an amendment to the ethics application to include a second analysis person (HL) to assist with analysis rigour.

5.3.6 Interview recording and transcription

Interviews were audio-recorded and conducted in English, using a voice memo program installed on an iPhone 6 electronic device, with permission from the participants. In the first health service, access to two local Indigenous women employed by the health service for interpretation was required, and no additional interpreting service was required for that site. The fourth health service provided access to an Aboriginal liaison

worker as an interpreter for two women. Field notes were taken during all stages of data collection. However, these field notes were a mechanism for the author to reflect on uncertainties or to explore her own thoughts. The interview duration ranged from 15 to 60 minutes. Prior to leaving each study site, any uncertainties were clarified with the participants. Audio-files were uploaded to a password-protected web folder at the George Institute and subsequently, via a password-protected website to a commercial transcribing service. Uploading and downloading of files and draft transcripts was secure and password protected, and the transcribing service signed a confidentiality agreement. Transcripts were not returned to participants for clarification, as any uncertainties were discussed with participants prior to leaving each site. However, the draft transcripts were reviewed against the audio-recordings prior to data coding.

5.3.7 Participant selection

Sampling strategy

A purposive sampling approach was used to select participants for this study. Potential participants were invited to participate in the study if they met the following criteria: being an Indigenous woman with a CD (diabetes, CKD, or CVD). The criteria also included women who – in addition to one of these CDs – might also have a disorder of thought or thinking, including depression, anxiety, stress or worry; being a current AMS client; and being selected by their service as a potential participant fitting the study criteria.

Description of sample

Current AMS clients who were Indigenous women with at least one CD (diabetes, CKD or CVD, and who also may have had disorders of thought and thinking such as depression, anxiety, stress or worry) met the criteria for inclusion in the study. Females aged up to 17 years and people diagnosed with dementia or at risk of invalid informed consent were excluded from this study. However, all the women interviewed for this study fell into the age range of 26 to 49 years and 50 and above. This reduced the number of categories when establishing the de-identified data characteristics in the NVivo 9 analysis program.

Potential participants read the *Notification to Inform Potential Participant Form* (see Appendix 9) and expressed an interest in participating. Initial negotiation, consultation, agreement and ethics approval was sought and given at each site prior to engagement with AMS participants.

Recruitment of participants was purposive. The views, understanding and stories of Indigenous women presenting with chronic disease from four AMS in Queensland, Western Australia and Central Australia were sought. A list of suitable participants was generated on the basis of current clients of the ACCHOs, selected by clinicians as potential participants fitting the criteria of the study (older than 18 with a diagnosis of a chronic disease such as cardiovascular disease or diabetes) who may be interested in participating. An ethics approved information sheet and invitation letter were sent to each participant.

Face-to-face semi-structured interviews were conducted with these participants which lasted 30-45 minutes. These were conducted either at the participant's homes or in a private room at the AMS. All participants gave written informed consent via a study consent form. An interview guide was developed in discussion with the team to explore the interplay between the participant's family and the community and how they managed their own health. Fundamentally, the questions explored their origins, family structure, roles and responsibilities, health and how this was managed, and their socio-emotional wellbeing.

The interviews were digitally recorded, professionally transcribed and managed using NVivo software. Data was coded line by line in an inductive and iterative manner using thematic analysis and a methodological approach of Interpretive Phenomenological Analysis was used to gain a deeper understanding and meaning that participants attached to their lived experiences. A coding framework was developed, discussed and reviewed by the author and HL, and the findings were discussed with the rest of the team. Although some themes were obvious and highlighted during the early stages of the coding process, all themes were derived from the data, following the inductive and iterative process described above.

Information sessions were held for members of the executive committee and clinical teams in each of the four health services. The purpose of the information sessions was to reiterate the approach for data collection and to request support and guidance on recruitment. After these information sessions, clinicians asked clients attending the clinic if they would be interested in talking to the author about this research. Each of the health services allocated a clinical support staff member to help with recruitment and provided a private room to ensure that privacy and confidentiality was maintained for the potential participants. For those clients who agreed to meet with the author, the study was explained to them, including what would be required of them if they agreed to participate. They were provided with a *Participant Information Statement* (see Appendix 4), reiterating what had just been discussed with them. After the participants had read the *Participant Information Statement* and understood what the author was planning to ask of them, participants were then provided with a *Consent Form* (see Appendix 5), which was explained further. If they agreed to participate, the consent form was signed and a suitable time and place was established to conduct the interview. The author used a face-to-face approach to conduct interviews with the 72 participants. These interviews were audio-recorded with participant permission.

Figure 5.1 contains demographic data related to 72 Indigenous women participants from four community controlled health services recruited as part of a qualitative study to understand how individual, family and societal influences impact on Indigenous women's health and wellbeing.

Qld - Urban	NT - Rural	WA - Urban 1	WA - Rural
<ul style="list-style-type: none"> • Indigenous women • Age: 26 - 49 = 14 • Age: 50 Plus = 08 • Chronic Disease: • Diabetes = 19 • CKD = 03 • CVD = 06 • MH = 03 	<ul style="list-style-type: none"> • Indigenous women • Age: 26 - 49 = 01 • Age: 50 Plus = 12 • Chronic Disease: • Diabetes = 13 • CKD = 04 • CVD = 06 • MH = 07 	<ul style="list-style-type: none"> • Indigenous women • Age: 26 - 49 = 04 • Age: 50 Plus = 17 • Chronic Disease: • Diabetes = 21 • CKD = 01 • CVD = 05 • MH = 05 	<ul style="list-style-type: none"> • Indigenous women • Age: 26 - 49 = 06 • Age: 50 Plus = 10 • Chronic Disease: • Diabetes = 15 • CKD = 02 • CVD = 03 • MH = 01

Figure 5.1 Demographic data of influences impacting on Indigenous women's health and wellbeing

5.4 Managing and analysing data

Interview transcripts were entered into NVivo 9, which enable multilevel text coding. Participants' comments were coded against a set of identified analytic categories, or 'nodes'. Themes and sub-themes were identified in relation to groupings of these nodes. The following steps were taken in developing and refining the coding framework:

- A set of five interview transcripts were read by the analysis team individually; the team met a week later and major themes and issues were discussed, along with the coding framework.
- Using NVivo 9, HL and the author independently coded the remaining transcripts using the coding framework, identifying additional themes and sub-themes.
- These coding frameworks were compared and a consolidated framework was produced.
- The revised framework was discussed by all members of the research team.

5.5 Ethical issues

This project excluded children and young people as this study focused on the experience of Indigenous Australian adult women. Women with CD, some of whom are highly dependent on medical care, were recruited for this study. It was not the primary intent of this research to recruit people whose primary language was other than English, pregnant women, people in existing dependant or unequal relationships, or people who may have been involved in illegal activity. Nevertheless, we recognised that some people may have been recruited who fell within these categories. Despite the author not having specifically set out to recruit people in these categories, they were likely to be recruited due to the aim of the research.

Ethics approval to conduct research in four AMSs in Australia was obtained in March 2014 (see Appendices 1–3). Amendments to the ethics applications were submitted and approved because it was necessary to add an additional researcher for assistance with the analysis process, and to extend the research in one AMS [see Appendices 1–3]). Between April and July 2014, the author conducted information sessions for executive committee members and clinical teams at each site. Qualitative interviews with participants from each were conducted between May and October 2014.

5.6 Analysis and findings: Stressors, support factors, access and effects

The participants talked openly about the issues affecting them and their ability to manage their own health. The findings were presented in terms of stressors and support factors as discussed, and the effects they had on their access to care and management of their own health conditions.

5.6.1 Stressors

The women identified a number of significant stressors (Table 5.2). These stressors were identified in response to a group of questions focusing on SEWB and the impact of stress and worry on participants (Appendix 8).

Table 5.2 Stressors: Themes from the interviews

Roles and responsibilities	Family and family history	Intergenerational circumstances
<ul style="list-style-type: none"> • Caring for children • Care for ill parents or siblings • Caring for extended family which included aunts, grandmothers or children of their siblings. • Caring for Country • Working full-time • Managing the household • Living in two worlds • Older women or grandmother roles • Financial burden 	<ul style="list-style-type: none"> • Grief and loss • Alcohol abuse • Death and dying • The Stolen Generation • Separation • Unsafe environment • Death in custody • Transient lifestyle • Homelessness 	<ul style="list-style-type: none"> • Incarceration • Domestic violence • Childhood negative events • Unsafe environment • Cycle of abuse

Roles and responsibilities

The women in this study maintained throughout the interviews how important their caring roles and responsibilities to their family and community were to them. At times

maintaining these roles and responsibilities resulted in them having to deal with a great deal of burden of stress. However, they saw these roles and responsibilities as pertinent to their way of life; particularly in relation to their caring roles that extended far beyond their nuclear families. One participant shared how important her caring responsibilities were:

So I know that I need a better surrounding. But, there you go again, the Aboriginality in me tells me that it's our culture to share and care. Hard to let go of. Hard to act white and say, I have to do this. I can't – I've got to not feel bad about (it) ... But you're not taught to look after yourself; you're taught to look after others. (Participant 11, Site 3)

This woman also shared how caring for many people in her household impacted directly on her forgetting to take her medication because of the chaos in the household:

You wake up every morning, and there (it) is in your face, something. So you wake up and you're traumatised, before the day has ended, and by the time you're – in the afternoon you sometimes – because of the trauma, because of the carryings on in the house, sometimes you forget your insulin, you forget your medication. Um, so – or you're taking it late, because you go, well, oh, geez, I'd better have something to eat and take this tablet. (Participant 11, Site 3)

Another example of the impact of caring roles and responsibilities for the women was seen when a healthcare worker shared how her clients were unable to adhere to their medication regimes due to their caring roles:

And they're not eating and doing the right thing, not taking medication and all that kind of stuff. And they were all too busy because they'd be looking after grandchildren or something like that. Travelling around chasing meetings and stuff like that. (Participant 14, Site 2)

The caring roles that Indigenous woman commit to their families and communities caused stress that affected their health. For instance, one grandmother shared with the author how she could manage her hypertension under normal circumstances, but looking after her grandchildren caused her blood pressure to go up at times:

Well ... when I have kids with me, grandchildren, they make humbug yeah. They make me scream, you know? And I ... run around after them.

I chase them around [and say] 'sit down there and listen'. That's how ... my blood pressure gets high. Too much stress. (Participant 3, Site 3)

Caring for children

The participants reported caring roles that extended far beyond their nuclear family. Women not only cared for their own children but also for the children of others. In relation to caring for children, one woman said:

I'll grab kids off the street and just help look after them while their parents are gambling or ... drinking alcohol. That's my way. (Participant 10, Site 1)

Caring for ill parents or siblings

Another woman shared that although her elderly parents were still relatively independent, she was considered to be their unofficial carer. She explained that when she was at work, she would go home during her lunch break to check on whether her elderly parents had eaten lunch or been picked up for their appointments:

All the medical stuff, all the appointments, I'm the person that they ring for Mum and Dad's appointments, medicals, um, any of that – anything to do with them. I'm like their carer, but unofficial carers. (Participant 6, Site 1)

Caring for extended family members

In addition to caring for children, ill parents or siblings, the women participants reported caring for extended family members, which included aunts, grandparents, nephews and nieces while in many instances working full-time and managing their own household. One woman explained:

Well, I do a lot for my family. And it could be any of my aunts or my uncles, my brothers and sisters. When they need me – they always come to me when they need something. Just a bit of advice or something like that. I don't know why, probably because I don't say no, I'm always there to help. But my children say – I do help them as well but they say, 'Oh you do too much for people, you need to stop and think about yourself'. Because there's days I'm really worn out. (Participant 14, Site 2)

Caring for country

For women, competing tensions existed regarding making compromises for employment versus compromises for cultural obligations and responsibilities in terms of caring for country. For instance, if they neglected their employment, they risked losing their job. However, if they neglected cultural obligations and responsibilities, they risked being reprimanded for not meeting their cultural responsibilities to attend funerals or participate in the Sorry Business associated with the death and dying of family and community members:

You don't get the times or the pleasure to do a lot of cultural stuff with your family, you know, and so all the sorry just gets condensed down to one or two days, wherein, in reality it goes on for weeks. And I'm on ... I'm very lucky that my family understand me because I was taken away otherwise there ... are a lot of repercussions for things like that, if you don't go to these funerals, you know. (Participant 13, Site 3)

Caring and working full-time

The same participant gave a snapshot of what her day was like in terms of her caring roles and working full time:

My mother had a fall ... she couldn't get up, (this happened) about two months ago and, because she had a knee reconstruction ... it felt like it was grinding and it must have just went out of place, well, she couldn't get up. So she went into hospital but when she came home, ... I ended up staying up there at night, so I'll stay up there with her at night, ... go to work in the morning, come back into work, come back to my place, ... probably have a quick breakfast then come to work and then I would go back home in the afternoon after five, have tea with Dad and then go back up and then stay overnight. (Participant 6, Site 1)

Older women or grandmother roles

Older Indigenous women reported immense responsibilities that they took on at the expense of their own health. At times, they appeared to worry about the impacts of intergenerational caring, particularly with an ageing cohort of women. Participants reported a diversity of roles as grandmothers within Indigenous communities. These roles included being the primary caregiver for their grandchildren, or playing a significant caring role while their parents were at work, in hospital or in prison.

Some participants discussed being a cultural knowledge-broker who transferred that knowledge to their grandchildren. One grandmother shared how she worried for her granddaughter, and wondered how she would cope with being so young and trying to bring up three children on her own while her partner was in jail:

My granddaughter, I worry [about her] ... she's got ... three little children, [and] she's only in her twenties and her boyfriend, he's in jail.
(Participant 20, Site 1)

Another woman spoke of many grandchildren and extended family's children in her care because of situational circumstances where the parents were unable to care for their children:

I've had the kids while I was looking after David's son's kids, while they were in care; the five of them. Plus my son's five, plus my other son's three, 13 all at once. (Participant 11, Site 3)

Another woman expressed that at times she was unable to go to work after spending the night at the hospital with her grandchildren, or making sure they had taken medication for their fever because their mother was unable to get up and take them to the hospital or to manage her children's fever:

... with the grandchildren ... I'll say to their mother, can you take them? (to the doctor), I don't know how many times I come to the doctors with these kids. I'll take time off to bring the kids into hospital because (their) mother is so lost ... I'm making sure that they take their medication. I'm making sure that I get up in the middle of the night and giving them Panadol. (Participant 2, Site 4)

One woman shared how she worried for the older grandmothers in the town where she lived:

I think it's getting very bad. Especially for a lot of the grandmothers, they're just not getting the rest. They're going from bringing their own children up to taking on their grandchildren. They're sick and ... they can't do anything – they know that they have to take that child because otherwise the mother's doing something else or drinking ... they feel that that's their responsibility. And, I don't know very many grandmothers that would have – would not have looked after their children.
(Participant 13, Site 2)

Another woman said:

Many of ... the elderly ladies have taken on the role as, carer for their third and fourth generations at times, and they're getting that old, they need to have this time out for themselves. (Participant 1, Site 3)

For the grandmother to support her granddaughter and her husband to attend Sorry Business away from their home enabled these young couple to establish themselves in the community by attending important community business (such as death). Providing support to young families to allow parents time to themselves away from their children was seen as important by the women elders in the community:

So the kids can go out and, sort of, still enjoy their ... young time and nightclubs and that, I'll babysit all weekend for them. (Participant 4, Site 1)

Grandmothers understood the importance of strengthening families by supporting them so they did not feel overwhelmed with parenthood and the responsibilities this entailed.

Financial burden

Many working women in this study reported a heavy financial burden on their caring needs for expenses, such as paying for medications for children and grandchildren, school uniforms, lunch money and sporting activity fees, which resulted in little funds left for themselves. For example, one woman said:

It is a financial burden, very much so. Just even for myself to be able to get out there (to community for funeral), I mean, that's, you know, all my gear, my car, fuel, food and that's just for a weekend or when I can get – well, that's the only time I can really get to them if this is on a weekend when I can leave Friday and come back Sunday. (Participant 13, Site 2)

Family and family history

The burden of stress for families caused anxiety to be experienced by women in this study as they coped with layer upon layer of stressors. In some instances, the stressors are seen across two or more generations.

Grief and loss

It became apparent throughout the interviews that many women were sharing stories of extremely traumatic experiences, many of which had been relayed to the participants from their parents, and now they were sharing these stories with the author.

In some cases, stories from their parents were similar to their own stories of domestic and family violence, or grief and loss. In particular, one participant shared the difficulties encountered by her 'Nana', as well as her two parents during their childhood. She shared her own journey and the hardship she had experienced, as well as shared the experiences of her children:

Nana [name], there was eight kids by [first name and surname] [he] kicked her and kicked her and kicked her until the baby was dead and she was a mess. (Participant 12, Site 3)

The participant then shared her father and mother's experiences as children:

My parents had horrific, absolutely horrific childhoods of starvation, of abuse, sexually, abuse by the nuns, the priest, you know, my mum's Methodist church minister raped her. You know, the whole of my parents' childhoods was ugly. (Participant 12, Site 3)

This participant was able to reflect on the mistreatment of her grandmother and parents, and was provide details of her own positive childhood experiences, as well as experiences with her ex-husband and children. She said of herself:

Beautiful childhood. Dad taught us how to track and told us stories, and we had camp fires and he built cubbies and everything ... we were poor, but we didn't go without too much. (Participant 12, Site 3)

She described what happened following her marriage breakdown:

I'm living in a house with an ex-husband. I've signed the papers, he just hasn't sent them back in. He ... kicked me and then pushed me. I'm still getting over that now. You can't kick a 57-year-old woman across the room and not cause damage. (Participant 12, Site 3)

This research uncovered many stories of families devastated by CD, cancer and accidents. One woman's story demonstrates the extent to which death and dying can penetrate the immediate family:

My father died ... he had a heart attack ... and my mother passed away ... she had cancer in her lungs. My sister passed away, young sister ... she had problem[s] with her back. Yeah, and my brother passed away in a car accident. I got no family left. I'm just myself and my daughter. My cousin and my aunt ... we live in [name of town] all our lives. Because we are sick with our kidneys. (Participant 11, Site 4)

The above participant's words and experiences reflect the hardship encountered by women in her family over generations. They also convey the strength and resilience evident not only in her, but also in the women who came before her in this family. The women spoke of hardship but never of giving up.

Alcohol abuse

The abuse experienced by many Indigenous women as a result of alcohol in out-of-control situations was viewed as changing the behaviour of family members from gentle role models into people whom the women no longer felt safe with, as one participant said:

They were perfect good grandparents and good parents, unless they drank, you know. And then that drink ... it's evil. I don't care what anyone says, it's evil. You've got evil attached to it and you drink it down and it turns you ugly. It takes a perfectly good hero, and I'm talking about bad drugs and everything like that, and makes them into an evil pig. It takes our heroes and makes them into evil pigs, and the men have got to know that, you know, they're the warriors, they have to stand up and start protecting us, not abusing us, not being our enemy. (Participant 12, Site 3)

Throughout the interviews, many women spoke of the impact that drug and alcohol misuse had on their families. One woman shared how drugs and alcohol caused a great deal of distress for her family. While under the influence of marijuana, her son engaged in illegal activities that led to him being incarcerated, and ultimately being institutionalised for the management of his mental illness:

My oldest boy, he's in ... [a] mental health [hospital] ... he's been there for the last five years I think but I'm really annoyed with the mental health and ... the courts because of the fact that he's still under His Majesty's ... I think he was off his face ... with a lot of young ... boys being daring and whatever they were doing, and they held up a shop for \$55. So he was put in jail and because of his smoking dope. (Participant 2, Site 2)

Death and dying

Experiences around death and dying have an enormous effect on the lives of Indigenous people, their families and communities. This point was demonstrated powerfully during data collection for this study where, in every AMS in which interviews were being conducted, between one to seven funerals were either being held or planned in the week in which the research was conducted. Not only were staff members in these AMSs dealing with the loss of a client, they were also dealing with the death of a community member, and in many instances, the death of a family member. In some cases, a death in the community could also mean ceremonial business around death. On a practical level, this often led to reduced service delivery as staff were absent to attend Sorry Business.

Deaths, although a cause of prolonged stress, could bring the community together to support a family, enabling them to grieve for the loss of a family member. The cohesive nature of family and community was discussed by the participant below, along with how these elements interact in times of grief and sadness:

There was 18 months there ... we had all this grief, you know, there was a time when I couldn't even (cope) ... I got really depressed with all the deaths. But we just – the community – it's not only the families, it's the community that's constantly grieving. (Participant 19, Site 3)

Death and dying bring the underlying importance of respect in Indigenous families to the fore. Respect plays a significant role in the everyday life and culture of Indigenous people. This is particularly the case with the death of a loved one within the family or community. Here, respect for the deceased person can disrupt routines and break familiarity for Indigenous women, who leave their home and community out of respect for the deceased. Interruption and dislocation affected the management of participants'

health and other aspects of their lives. It was often felt for indefinite or uncertain periods, as demonstrated below:

I come from [name of community] community and I came here to [name of town] and [am] staying at a Hostel at the moment because ... I lost my nephew – my favourite nephew not long ago and he was only a young fellow, a football player. When he was playing football he just collapsed and died ... that's why I don't want to stay at the community ... he used to live not far, so that's why ... with respect ... I'm staying here for what might be a year or two. (Participant 12, Site 2)

Where the burden of death and dying for Indigenous people (and the frequency with which death and dying occurs) is unrecognised, further stressors can be created. Participants reported restrictions on the leave they could take, or even on the number of funerals they were permitted to attend in any given period, which did little to assist the grieving process for these women with their families and communities. Women reported how their obligations to the workplace conflicted with their obligations to family and community:

Well, in the last year I've lost five family members from bush. And, you know ... working in town and having time to be able to go back just for the funerals is impossible. We get 10 days' bereavement for here. To go back for a bush funeral is a couple of weeks. So, hence, I only can go out on the day they're getting buried and come back the same day, you know, more or less. So, that's hard because when my two older sisters, ah, passed away, my family out bush [didn't] understand all the – the – paperwork. (Participant 13, Site 2)

The Stolen Generation

The impact of the Stolen Generation on Indigenous people, their family and culture resulted in enormous detriment to Indigenous Australians, particularly in relation to their social and emotional wellbeing, and connection to country. The government-sanctioned child removal policies of the 19th and 20th centuries destroyed the family structure, dislocated people from support networks and interrupted the continuity of language and cultural practices that had previously provided healthy and nutritious diet and exercise. The impacts of the child removal policies and disconnectedness resulting from them were referred to by many participants in this study:

Cause like my mum she was the Stolen Generation and my brothers didn't really get to know mum and I reconnected over ten years ago and I get my young ones to come with their mums and their nanas to come and sit with uncle and listen to stories. (Participant 5, Site 2)

I'm originally from the top end, Roper River in the gulf country Nunkurra ah but I'm one of them Stolen Generation people taken away from there. When the war started, 1942 was it? Sent down this way um, went through to um, Mulgoa outside of Penrith. (Participant 7, Site 2)

But my daughter and my son they're in the care of the welfare, yeah. (Participant 8, Site 2)

That's all right. And ... I just wanted to say something about the first – where you've said where we come from and do I speak the language – well, I was one of the (Stolen Generation) taken away when I was three, so, hence, I didn't have my language. My mother was a full blood Aboriginal woman who spoke her own language and many more, but, we didn't get to have any of that, because she was married to a Caucasian man and in those days, it wasn't accepted. (Participant 13, 2)

I come from Northam, but in my childhood I was in a mission outside of Perth. But really come from Northam, and born in Northam. And got taken away and lived somewhere else and came back. And then worked for a while, for about four years. And then I stopped because I got pregnant. Then, ever since, just been looking after my children. (Participant 5, Site 3)

Connection to country is integral to the very essence of Indigenous culture. When connection is broken, optimum emotional and social wellbeing cannot be achieved.

Unsafe environment

Living in an unsafe environment was a common experience for some of the women in this study. Family and domestic violence, drug and alcohol issues, and grief were frequently identified as factors that further placed them at risk of harm.

Domestic violence: While acknowledging that incidents of domestic violence often go unreported (ABS, 2014e), it features in the lives of the study participants. Eleven women identified domestic and family violence as a concern when asked what worried them about their family. The question was designed to elicit responses that would help the author to categorise broad themes related to family stressors. Family violence affected how these women managed their health. Participants often had to take on

caring responsibilities while sons, fathers, brothers or husbands were in prison for domestic or family violence-related offences. Women who were direct victims of domestic or family violence often needed to focus on attending to physical injuries and the emotional trauma related to the violence, rather than managing their CDs. Furthermore, other women reported on being immersed in legal issues related to the violence.

Many participants reported the integral role of alcohol in family violence. Family members who were caring and protective when sober were described as changing into perpetrators of violence when intoxicated. A woman recounts:

They were perfect good grandparents and good parents, unless they drank, you know. And then that drink ... it's evil. I don't care what anyone says, it's evil. You've got evil attached to it and you drink it down and it turns you ugly. It takes a perfectly good hero, and I'm talking about bad drugs and everything like that, and makes them into an evil pig. It takes our heroes and makes them into evil pigs, and the men have got to know that, you know, they're the warriors, they have to stand up and start protecting us, not abusing us, not being our enemy.
(Participant 12, Site 3)

Alcohol abuse: Some women, having been exposed to a lifetime of alcohol-fuelled violence, used the knowledge to protect themselves and act decisively:

I met my first partner, my first relationship and I thought it was good but when you're young you think that the first love of your life – but I mean he was a good person but he just did drugs and I couldn't handle drugs and alcohol because – I guess because I [had] seen my mother drinking all the time and I didn't want to be – to get in that predicament of being an alcoholic like them. So I left him and he was quite violent to me.
(Participant 2, Site 4)

Grief: Some participants described members of the community as being overwhelmed by grief due to the loss of a close community member and turning to alcohol and drug use for support:

Reckon we grieve too heavy, we grieve too hard in ... that's how our culture is, grieving, and some people haven't been taught how to pull themselves out of that or how to even it out. I'll give you an example. When my mum died, um, my younger brothers, well they, you know,

[began] abusing alcohol and drugs and that sort of stuff, they still haven't been able to pull themselves out of it and still get drunk and cry around and I'm saying, 'Hey, snap out of it, mum and dad have been gone for a while now, dad's been gone for 19 years, let them rest, you need to start thinking about yourself and the future, don't use them as an example.' So sometimes there's that little, um, extra thing where people use grief in a way for other things, um, but, yeah, we grieve far too heavily where people just become totally depressed. (Participant 19, Site 3)

The same participant described the importance of recognising that grieving loss is important; without this process, further alcohol abuse could occur:

And they say that's so we can move on, but the problem to me is that people don't deal with a lot of issues that they have to deal with by moving on, whereas our mob, we do deal with our issues and, um, we do – we do deal with our issues and ... how to deal on with stuff, but sometimes people don't, they don't know how to pull themselves out of it and that's when depression kicks in and it might be ... psychosis or something that's induced by drugs and alcohol. (Participant 19, Site 3)

Intergenerational circumstances

Incarceration

Women affected by incarceration reported suddenly being faced with extra caring responsibilities. These involved supporting family or assuming additional caring responsibilities for the children of those incarcerated more directly. One woman indicated the multifaceted issues that arise under these circumstances:

So, I'm always there for her trying to help out whichever way ... to the courthouse and lawyers and all that kind of stuff in between my jobs. (Participant 14, Site 2)

Women identified how the stress of having family members in prison affected how they managed their own health and SEWB. For example, one woman shared how her son in prison led to a range of disturbances, such as unable to sleep, heightened anxiety and poor control of her blood sugar level due to stress:

Every time I travel I come and I see the doctor, make sure my asthma is under control, my sugar, it's not too good at the moment because ... my son is in jail and my brother is in jail ... I have been going to see my son

all the time ... I wake up at night and ... I can hear him, or I think about him and ... (when I see him again) ... and then I woke up the other night a couple of weeks ago, screaming out to him. (Participant 1, Site 2)

Intergenerational incarceration

Having a husband who is a repeat offender in and out of prison for most of his children's lives can significantly affect the health and wellbeing of women. It is even more distressing for mothers whose children are also imprisoned while their husband or partner is incarcerated. This cycle can perpetuate distress and despair for these women with the effect of further entrenching ill health. It also creates the potential for mismanagement and/or neglect of their health needs. One woman stated:

My second eldest son is pretty ... stressed out. Um, yeah, I don't get to see him or ... hear his voice or anything which is pretty upsetting. [He] ... was doing 10 years in jail. Because Harry [the father] has always been in and out of jail since the day he was born. (Participant 10, Site 1)

Unfortunately, this story was common among the Indigenous women interviewed. The reality of intergenerational incarceration, demonstrated by the above quotation, is distressing for all involved. This breakdown in family structure is further exacerbating already over-burdened and over-stressed lives of many Indigenous women. Despite this, these women displayed resilience in continuing to take care of their families:

Our men have been incarcerated. Our men have given to drugs. Our men have mental health problems. Our men are ... working more away from home than being home ... and sometimes the women have to go and look for work as well as try to look after the family. (Participant 2, Site 3)

Intergenerational domestic violence

One participant was able to reflect on the mistreatment of her grandmother and both her parents, and was even able to provide details of her own positive childhood experiences, as well as experiences with her ex-husband and children:

Beautiful childhood. Dad taught us how to track and told us stories, and we had camp fires and he built cubbies and everything ... we were poor, but we didn't go without too much. (Participant 12, Site 3)

She described what happened following her marriage breakdown:

I'm living in a house with an ex-husband. I've signed the papers, he just hasn't sent them back in. He ... kicked me and then pushed me. I'm still getting over that now. You can't kick a 57-year-old woman across the room and not cause damage. (Participant 12, Site 3)

It is apparent from the number of stressors identified in this study that Indigenous women carry a heavy burden. In many cases, they had little ability to choose the roles and responsibilities they had in their families and communities; they just do what is necessary. It also clear that fulfilling their roles and responsibilities was often done at the detriment of their own health.

Women described their roles in caring for their extended family, the wide-reaching impact of death and dying, and living with a heavy burden of incarceration and family violence. Nevertheless, they spoke repeatedly of resilience, including how effectively they had moved on from crises of family violence to endure yet more challenges. Despite this, they still managed to raise their children in safe environments and educate them.

5.6.2 Support factors

Concept of family

Research participants described challenges that deeply affected their strength and resilience. Strong family support and community connectedness were described by women as protective factors. Women discussed family in terms of networks extending well beyond the traditional nuclear family of parents and children.

Women in this study identified their ability to obtain help from others in their family when navigating their own challenges, rather than accessing formal support services. Family support manifested in many ways, including provision of both financial and social support and for support in accessing social and health services.

Table 5.3 Support factors: Themes from the interviews

Concept of family	Informal family support networks	Education	Identity and Country
<ul style="list-style-type: none"> • Nuclear family • Extended family • Live with siblings 	<ul style="list-style-type: none"> • Provide social support for family visiting from community for hospital appointments • A cross-over of togetherness and innate cultural practices • Unspoken identification of fulfilling familial practices • Social community caring • Active caregiving drawing on empathy • Financial benefits for family festivities or funeral expenses 	<ul style="list-style-type: none"> • Access to education • Education as an enabler 	<ul style="list-style-type: none"> • Childhood teachings • Strength drawn from returning to country • Healing • Religion • Awareness

Although respondents mentioned their relationships with their spouses and children, it was more common for participants to refer to family as including their siblings, parents, grandchildren, aunts and uncles. Some participants spoke first of their siblings and their parents as being family. Their own children and husbands came up in later conversations. A strong sense that family extended far beyond the nuclear family was apparent. This was evident during the interviews with Indigenous women when asked about their family structure:

Um, I have 15 in my family ... six living [alive] ... I have two children, two girls, one grandson, we all live [together]. (Participant 2, Site 3)

Another participant when asked about her family said:

Well, my grandmother had nine children, and grand-dad had nine children, all my uncles and aunties, they got lots of kids and they are all grown up, and they got kids of their own. We've got our grandchildren. They got their own children. So we're a big mob in our family from my dad's side. Now from my mother's side, there is a lot ... she's got a lot of grandchildren and I've got a lot of nieces and nephews and my cousins ... we got a lot of great grandchildren. (Participant 3, Site 3)

The living arrangements for participants interviewed for this study varied. For some women, the household consisted of a husband, a wife and their children. Other arrangements included a nuclear family with additional parents or siblings also living in the household; a single parent of grown children living alone; a husband and wife, their adult children, the children's partners and children; and in some instances, children of siblings as well. All of these arrangements were considered normal when discussing family living arrangements.

Descriptions of families and households included:

Only me and my dad, and my three grandchildren and my daughter and a niece and grandson and a son. (Participant 4, Site 2)

I've been living by myself but I have my nephew with me, eh, he came when he was 16 and he's 21 this year, yeah. (Participant 5, Site 2)

Informal family support networks

In describing their own roles, and giving examples in which they had received support through family networks, participants highlighted the importance of these informal support systems:

My oldest brother died when he was 50 ... I got to be ... the family member on his side [of the family] that did all of the running around for them and helping and anything to do with funerals, so your helping with funerals and if people run out of food because for whatever reason, so you're doing food stuff and ... people don't know how to fill out forms. (Participant 19, Site 3)

Well when I do get a phone call from either one of my sisters mainly and they tell me the concern about their children and ... we all tend to worry together and because I live out bush there's not much I can do. But just listening to them and giving advice where I can, me being the eldest. (Participant 5, Site 3)

I believe that ... for me as a diabetic I want to be a ... role model, to share that to the women, they don't have to be on the couch and yes, in the community, I look at other people and I say, 'there goes I by the grace of God' it could be me and that's said, yeah. But to – I talk to everybody, I talk to anybody in the street if they want to talk to me about diabetes or weight or, 'hey sis, you're getting skinny' and stuff like that because I'm – I got diabetes I need to look after myself. I do not want to go into dialysis. (Participant 11, Site 3)

Ah, for funeral cost and for functions ... for, um, Christmas and ... for Easter or something like that if anybody comes down. See ... we've got money in the bank and there was 11 of us all putting money in the bank and out of that we had three sudden deaths of my brothers and we were able to pay for our own brother's funerals and buy – buy ... headstones out of our own personal account. (Participant 1, Site 3)

So ... yeah, but I do worry about them too much, I think. Financially, it's just, you know, they don't have anything, what can they – you know, do they want, not that they want any, do they need anything? Well, they know how to draw on my purse strings, they say. It's, like, 'oh, we – you got [a] show on and we've got no money, it's coming to school' or, 'oh, they need a uniform' or the medications, because they need medications. I have an account at the chemist. (Participant 1, Site 1)

Some described the particular support offered to meet the complex health needs of relatives:

She's a chronic mental ... health patient and we brought her back from New Zealand last year after their dad died, so there was no-one to look after her in New Zealand so they made the decision that she come back to [name of town] ... that was a promise to her parents. (Participant 19, Site 3)

She's used to situation in Australia being here before her son was born in Port Hedland and I have cousins, my niece works in the mental health unit here, so coming across, bringing her across, I did all the paperwork so that she'd get transferred and that took three months, did all the paperwork so that her pension would be transferred over, sorted out all the, um, psych reports, the doctor's reports, um, it was pretty stressful, I got really stressed out, um, and linked her up, and it's just so lucky I've got family and established networks that work and Katie, um, my cousin, came across to New Zealand and helped and, um, came to the funeral and then we all sat around and talked with the Maori Mental Health, um, Unit. (Participant 19, Site 3)

In this situation, family members with expertise in mental health supported the integration of the participant's relative into Australian mental health services in a timely manner.

Education

Education was described as a key driver of life change for those able to access it. Whether it involved learning to read and write, complete primary school or being able to attend university and gain a degree, all the women reported accessing education as a positive aspect in their lives. However, where access to education was either not available or denied, participants reported the limitations and barriers they faced. As one participant said:

I got to find a job, and because I didn't know anybody up here ... didn't know what to do ... I haven't got any education, like good education, because I only went to grade [primary] school, you know, we didn't have high school in those days ... we were sent out to work at an early age, I was only 'bout 14, 15 [years of age] ... when I remember I used to cry every night, I was sent out on a community, I mean on a station to work and look after, you know white people's kids – I used to cry every night because I wasn't used to that. (Participant 20, Site 1)

One participant said she believed that she was very fortunate to have access to a good Catholic education:

You know, they had to pay for the schooling in those days. You know, pay for a Catholic school [education and] pay all them, yeah. But it was good. Well, way back then, you know. But it was good at the school, because we had good teachers and all that, you know, the nuns and all that, priests. So it was good to us. (Participant 5, Site 3)

Identity and country

Women identified themselves based on where their parents and grandparents had come from. This identity was formed based on the stories and practices shared with them. The women knew where they came from and where they fitted within society. A participant shared how her father taught the children the significance of family and country:

Beautiful childhood. Dad taught us how to track and told us stories, and we had campfires and he built cubbies and everything. We were poor, but we didn't go without too much. You know, I do remember crying as a child being hungry, but I think that was only a few times in desperate need. I remember Mum and Dad got hungry more than us kids, you know, as a parent, that's what you do, you go hungry, the kids get the feed. (Participant 12, Site 3)

Another participant described how this wealth of knowledge and experience gained while growing up could be challenged, leading to rejection from family and community:

My mother who passed away, um, I was actually told that I wasn't her biological daughter on her funeral day and was told to get out and had no right being there. So, yeah, I just got out of [name of community], jumped on the bus and just came to [name of city] and this is where I stayed. (Participant 10, Site 1)

Women discussed the unique and complex connection with their land. Returning to country for many women was very significant, as the land where they grew up was sacred to their culture. Not only was the land sacred, but the women drew inner strength from returning to their lands when feeling vulnerable, weakened or unwell. Many examples of this significance were revealed during the interviews. As one participant stated:

I'll just go home, it's like going home back to country, where you're doing that healing and, you know, because we – we live in a town situation here in [name of town], so where my sister lives, she lives in [name of town]. (Participant 1, Site 4)

Yet another participant wondered when she would return to country:

No, I'm okay. I'm just thinking about things, you know. Thinking about other families back in [name of town], when are we going to go visit and things like that, you know. Maybe one day we'll get a chance to.
(Participant 13, Site 4)

Women described the importance of being in a supportive environment and having support mechanisms, especially where exposed to the stressors reported in this study. Such support mechanisms came in various forms, one of these being religion. Some women viewed religion as a particular support mechanism to help people stay away from alcohol and drugs and remain healthy. One participant, referring to her affiliation with a Christian community, said:

Yeah. It's good for my health, no drinking – just when they were bringing me clothes from second hand. They come and look – come to – to look after us, and bring some food from shop. (Participant 2, Site 2)

Another participant reported how not having that support made her feel:

Before I come to (name of town), I was Christian woman and first I used to go to church with others, you know? I used to be really happy. Never used to worry about anything. Just go to meet people. But, when I come to [name of town], it's pretty hard to – no-one ... come talk to you.
(Participant 6, Site 4)

5.6.3 Access to necessary and culturally appropriate services

Where services were community controlled, or at least had a strong engagement with community, women felt they had better access to necessary services. An example of this is the views of the women discussing the deaths of a baby and mother at a hospital (a mainstream service):

I remember my auntie ... she died ... during childbirth in [name of town]. She went to the hospital twice, she was in labour, and the matron kept on telling her, 'go away, you're not ready yet. You're not ready yet'. She sat on the steps of the [name of town] hospital, gave birth to the baby, and died there and then. Six months later the baby went to hospital with ... the flu or something, and she died. (Participant 6, Site 3)

Participants expressed mixed feelings about access to government, health and education services. One participant reported how the school she was employed by had a before and after school care service, for which she was the bus driver:

I go out and do the early morning bus run, drive the bus, go and pick up the kids – children – from their doorsteps to enable them to get to school. (Participant 3, Site 3)

This same participant also discussed how the local Aboriginal health service was available and accessible, with appropriate services to meet the needs of the local community:

I think there's a lot of, um, facilities here at [name of health service], you know, they do a fair bit with women's health and – but women have to put themselves first and they have to make that step to – to be able for people to help them I guess, you know. (Participant 3, Site 3)

Another participant's views differed to the point where she felt that women in her community did not access services as they felt the services were not open to them. This participant said:

Um, see – a lot of – from where I'm sitting, I think Indigenous women, it's a shame job, you know, they don't like to – black fellas – they don't like to go to white fellas and tell them, you know, this and that's wrong with them. Plus a lot of white fellas don't believe you anyway. (Participant 6, Site 3)

Another participant reported how she was able to engage with others in the community and gain their support. That support through organisations in her community enabled participation in various activities. She said:

We got a group and we go on ... outings. We go to ... shopping centres and have morning tea. We go to the beach and have barbeques and, um, sing song and whatever. Yeah and – and [they] take me shopping and they come and do housework for two hours a week. (Participant 2, Site 1)

The Indigenous women in this study shared powerful stories of the burden of care they carry in filling the gap that health and social services should ordinarily provide.

Therefore, it would seem that they are not just taking care of family, they are taking care of the structural barriers that Indigenous men, women and children face.

5.6.4 Effects on the management of women's health

Many factors can explain why the women in this study did not manage their health as well as they would have liked to at times. These include being engrossed in caring for their grandchildren, others being ashamed of their CD diagnosis, or just feeling too burdened by their responsibilities taking care of others. Sometimes, the women were too busy to take their medications due to the medication schedule clashing with their busy work schedule:

Because I've been babysitting my granddaughter all this time, and I asked my daughter ... can you give me a break, give me a break so I can concentrate on me taking my medication for my diabetes? Because when I'm with her, I'm always ... responsible for her and can't be responsible for myself. I find it hard. (Participant 11, Site 1)

I was 40 when ... I was given tablets to take – because ... some of our mob down her make fun of the people with diabetes and call them the sugar people and ... it was embarrassing ... I never told anyone for ages that I had diabetes. (Participant 19, Site 3)

I was trying to look after her, you know. That's why I asked the nurse, can somebody come over just for a day, stay with her till I finish dialysis? But I have no-one at the moment in home, they stay there for the time being, but it was pretty hard for me then. (Participant 5, Site 2)

I know it's silly because when it comes to looking [after myself] ... you know, just taking my insulin and making sure I have that, and my Webster pack of my medications to take. I'll be honest, I think I might miss at least two days a week when I don't take my insulin and at least two days where I don't take my medications. (Participant 1, Site 1)

5.8 Discussion

An urgent need exists to explore strategies that address the factors leading to poor health and to improve SEWB for Indigenous women. The *Close the Gap Progress and Priorities Report 2015* highlighted that to improve health and LE, a greater focus is required on access to appropriate primary healthcare services to detect, treat and manage CD (Holland, 2015).

Few programs have been developed to address the intersection of CD and mental health for Indigenous women. The women interviewed described a number of critical stressors that must be understood in terms of the very real affect they have on their ability to manage their own health. The women also described protective factors such as social cohesion, informal family support, connection to land, culture and spirituality, which need to be understood and leveraged to provide appropriate and effective health services.

From the existing research, we know that CD and mental health disorders affect Indigenous women, their families and communities significantly. This disproportionate burden of disease, when compared with the wider community, poses great challenges for people managing their own chronic conditions, such as CVD, CKD and diabetes. Managing one or more of these conditions, coupled with depression, stress, anxiety or worry, contributes significantly to the burden of disease for Indigenous people in Australia (AIHW, 2016).

This study highlights some of the stresses that Indigenous women must deal with. Women spoke of the impact that incarceration, domestic violence, alcohol and drug abuse has had on their husbands, brothers and sisters; how these are being replicated in their sons, daughters, nieces and nephews; and, ultimately, how they have affected their own ability to manage their health.

Incarceration rates for Indigenous women have increased dramatically in the past five years (ABS, 2013c). In 2014, for example, Indigenous women made up less than 3 per cent of the total population in Australia, yet they made up 34 per cent of the total adult prisoner population (MacGillivray & Baldry, 2015). The high incarceration rate has had an enormous effect on the roles and responsibilities of Indigenous women. In addition, exposure to repeated incidences of trauma is directly linked to psychosocial distress that can lead to CD (Gee et al., 2014).

5.9 Recommendations

Research participants spoke clearly to the devastating impact of domestic violence and incarceration. A strategy that could alleviate some of the worry for these women would

be the introduction of diversionary programs seeking to reduce incarceration rates within Indigenous communities and an increased focus on efforts to reintegrate and retrain people caught up in the justice system. This approach could also alleviate concerns about the partners or wives being left to care for the children at home when a partner has been imprisoned. Ultimately, this may deter re-offending and enable family re-grouping with positive outcomes for the family concerned.

The women also spoke clearly about the grieving associated with death and dying and its impact on families and communities. Grief counselling should be embedded into SEWB programs in the health services attended by these families. This is especially the case where an entire community is grieving and grieving frequently, particularly given that death and dying is one of the most significant causes of psychosocial distress (as reported in Chapter 2).

The Indigenous women discussed the pressure placed upon them through their cultural and family obligations conflicting with their work obligations and impacting their own health. This highlights the need for workplace environments to embed cultural security into their policies and procedures. This could ensure that Indigenous women in employment are not forced to choose between their family, culture and their workplace.

5.10 Strengths

This study has several evident strengths. As an Indigenous woman undertaking this research with other Indigenous women, the author was able to develop a rapport with the participants. This meant they could discuss and share their life experiences with her. When she felt that a participant was at risk at any time during the interview, using a validated tool (PH-Q9) and having access to the health provider was vital. Being able to discuss the coding and derive the thematic framework with another researcher (HL), and to review emerging themes with the research team, increased the finding's reliability and validity.

The author built on the collaborative relationship developed during her work as a researcher within the KVC. This was further supported by supervisor AC, who was the lead investigator for KVC. The relationship that KVC had established with the

Aboriginal health services enabled the author to engage with these services and their staff in the first instance. This also helped with future planning in terms of knowledge translation back to the services and communities. The author was able to engage with four health services, in urban, rural and remote settings, and recruit more than 70 participants to complete in-depth interviews. This has provided a rich dataset to explore and understand the issues that are important to Indigenous women. These issues are also relevant when planning health services to meet their needs.

The incorporation of a gendered approach to managing chronic disease represents a strength of this study, rather than the usual reporting which does not take into account differences in needs, behaviours and experiences for Indigenous men and women. This study privileged and witnessed the accounts of Indigenous women. Given the women reported that their needs were often met *after* those of other family members, this research is necessary in order to develop strategies that will improve their health and wellbeing.

5.11 Limitations

This study does not explore the perspectives of Indigenous men. However, seeking the views of men would not necessarily add value to this study other than to reinforce what the research had already found and reported. In this study, we sought to include women when they had received a diagnosis of a heart disease, CKD or diabetes. We therefore recruited fewer young women who might have had different views regarding some of the key issues.

5.12 Summary

The stories shared with the author by Indigenous women indicate clearly that the roles and responsibilities the women have in their families and communities affect their ability to manage their own health. However, it is also apparent that the women's families and communities shape who these women are and where they fit in society. Culture and identity were vital to all the women interviewed. The significant roles and responsibilities required to maintain cultural obligations in the family and community

revealed these women's strengths. This strength was also apparent in women experiencing the effects of CD.

The support factors described by participants and their contribution to resilience are referred to by Gee et al. (2014), who state that 'Cultural concepts such as connection to land, spirituality, ancestry and family and community are commonly identified by Indigenous Australian people as protective factors, which can serve as a source of resilience and can moderate the impact of stressful circumstances on SEWB at an individual, family and community level' (p. 81). Health service programs, as well as the broader range of services seeking to meet the needs of Indigenous women and their families, need to be fully cognisant of these factors if they are to prove effective in improving physical and psychological health and wellbeing.

CHAPTER 6: EXPLORING THE DETERMINANTS OF DOMESTIC VIOLENCE IN INDIGENOUS COMMUNITIES

6.1 Introduction

As illustrated in Chapter 5, participants in this study conveyed to the author their experiences of domestic and family violence, and in many cases, the far-reaching consequences this had for them in managing their own health.

Domestic violence is not a geographical or socio-economically limited problem; it is a global public health issue. This is evidenced by the priority given to eliminating domestic or family violence by the United Nations Entity for Gender Equality and the Empowerment of Women (United Nations Women, 2016). The United Nations Entity for Gender Equality and the Empowerment of Women reported that globally, 35 per cent of women have been exposed to either physical, and/or sexual violence by either an intimate partner or persons not intimately involved with them. As recently as 2014, the United Nations Women's *Progress Report* drew attention to 143 countries who gave assurances that equality between men and women would be explicitly stated within their constitution. Despite this, only 119 of these countries have passed legislation on the prevention of domestic violence against women (United Nations Entity for Gender Equality and the Empowerment of Women, 2015).

Australia was one of the countries to pass legislation on domestic violence against women. The issue of domestic and family violence and its impact on Indigenous women is now seen as a problem of significant complexity and not just the purview of the criminal justice system. One Supreme Court judge commented when sentencing a woman who fatally stabbed her abusive partner while defending herself from an alcohol-fuelled attack: 'Domestic violence deaths in the Indigenous community are an 'intractable social problem' which is well beyond the scope of criminal law' (Banks, cited in *The West Australian*, 13 April 2015).

6.1.1 Overview of domestic violence in Australia

Domestic violence in Australia is common and widespread. Women exposed to family or domestic violence are more likely to be killed in the home by a male partner than anywhere else or by anyone else (Phillips & Vandenbraek, 2014). Most women do not report family violent incidents to police and are even less likely to report violent incidents to police when the perpetrator is a current partner (ABS, 2014e). Significant gaps exist in the available statistics and research on the extent and nature of family violence in Indigenous communities. The existing data suggest that Indigenous women suffer violence, including family violence, at significantly higher rates than other Australians (Fredericks et al., 2010).

The National Council to Reduce Violence against Women and Children reported that ‘family violence’ is the preferred term in many Indigenous communities when referring to domestic violence or violence against women (Mitchell, 2011). The comparison between the stereotypical image of a passive victim being battered behind closed doors and those of Indigenous family violence may differ (Morgan & Chadwick, 2009). However, neither form of violence against women is acceptable. The National Council to Reduce Violence against Women and Children reported that in some instances family violence within Indigenous families can take place in public places and may involve a number of people rather than occurring behind closed doors (Phillips & Vandenbraek, 2014).

Australia is at the global forefront in terms of addressing violence against women. A joint initiative by Australian states and territories enabled the allocation of \$30 million to fund a national awareness-raising campaign to address domestic violence in Australia (Baird et al., 2016). However, frontline services such as the Community Housing Federation of Australia and National Shelters for the homeless, women’s and Aboriginal legal services have either not had their funding renewed or have received significant cuts to their funding in the current budget (United Nations Women, 2016). Although it is promising to see substantial funding to raise awareness about domestic violence in Australia, many Indigenous women remain unable to access culturally safe environments for themselves and their children when attempting to escape family violence. This is because of the reduction in funding allocation to Indigenous-specific

safe places. This is of particular concern given the high rates of family violence in Indigenous communities. The recent *Victorian Royal Commission into Family Violence Report* found a link between children affected directly by family violence and becoming victims or becoming perpetrators as adults themselves (Victorian Government, 2016). This is consistent with what has been referred to as intergenerational family violence.

Approximately 87 Indigenous-specific programs or projects addressing issues related to family violence in ACCHSs exist in Australia (Australian Indigenous HealthInfoNet, 2016b). The majority of these programs were implemented in NSW and the NT, followed by WA. The Australian Capital Territory has implemented no programs. No identified data are available to report on whether these programs received further funding in the 2015–2016 federal budget.

All of the authors in this chapter are part of the KVC. This collaboration of researchers, clinicians, health services, government and stakeholders has worked together for almost a decade. KVC's focus has been on conducting health service research with the ACCHSs to improve CD management within Indigenous communities and ultimately to improve the health outcomes for communities involved in the collaboration.

Initially, the author worked on KVC as the research coordinator overseeing the east coast program sites. She then commenced a PhD seeking to explore Indigenous women's experience of living with a CD within the context of their families, and the communities in which they live. As part of this PhD, qualitative interviews were conducted with Indigenous women from four ACCHSs in Australia. These interviews explored the roles and responsibilities that these Indigenous women had in their families and communities. They also explored if these roles affected the women when managing their CD.

In the overall analysis of the qualitative study, domestic violence emerged as a significant code that required unpacking. The findings from our qualitative interviews exploring the roles and responsibilities that Indigenous women have within their family and community shed light on the determinants and repercussions of this 'epidemic' of family violence. From the 72 interviews with Indigenous women from the four AMSs,

11 interviews had references coded as 'Domestic Violence'. These 11 women described experiences of domestic violence affecting themselves, other family members, and other people the community in which they lived. This chapter will explore the determinants of domestic violence in Indigenous communities to help inform the development of programs to address this issue.

6.2 Methods

6.2.1 Study design: Qualitative approach and research paradigm

The methodological approach that underpins this study is IPA. IPA is a qualitative research approach concerned with exploring and understanding the lived experiences of a specified phenomenon and involves the detailed examination of the world in which the participants live their experiences, and the meaning they attach to these experiences (Smith, 2004).

6.2.2 Author characteristics and reflexivity

The research team consisted of the author (AE) who is the chief investigator of this study, a research fellow (HL) who assisted in the analysis and writing, and the author's PhD supervisors (AC, MH and JC). HL, MH and AC are non-Indigenous investigators with medical and psychology backgrounds and have had significant experience working in collaboration with ACCHs on other health service research. JC is an Indigenous man also with a medical background and significant experience working in collaboration with ACCHs on other health service research.

The author had a previous professional or personal relationship with all four AMSs prior to the commencement of any negotiations, consultations or agreement to conduct research in those health services. However, no relationship was established with any of the participants prior to them reading the *Notification to Inform Potential Participant Form* (Form 1). The selection of potential participants was established based on current AMS clients selected by clinicians as a potential participant fitting the study criteria and who may have been interested in becoming involved. Information was provided to potential participants via the *Notification to Inform Potential Participant Form*. This information included a brief introduction of the author, the research aims, why the study

was important, and what the author hoped to gain from the study. An overview of the research was also included in this form, as was information relating to ethics approval for the study, assurances about the confidentiality of information collected, and contact information for the author, her supervisors and the ethics committee for any concerns or issues arising from the conduct of the research.

6.2.3 Setting or context

The research was conducted in four AMSs in two states and one territory of Australia. The services were located in urban, regional and remote settings. Further details regarding setting and context were provided in Chapter 5, Sections 5.3.1 and 5.3.4.

6.2.4 Sampling strategy

A purposive sampling approach was used to select participants for this study. Potential participants were invited to participate in the study if they fitted certain criteria. These were being an Indigenous woman with a CD, including diabetes, CKD or CVD. The woman also had to be a current client of the AMS, and had to have been selected by their service as a potential participant fitting the criteria of the study. The potential participant must have read the *Notification to Inform Potential Participant Form* and expressed an interest in participating. Initial negotiation, consultation, agreement and ethics approval was sought at each site prior to engagement with participants of the health service.

6.2.5 Ethical issues pertaining to human subjects

Ethics approval to conduct research in four ACCHS sites in Australia was received in March 2014. Information sessions for executive committees and clinical teams were completed in July regarding the qualitative components. Semi-structured interviews with participants at the four participating sites were completed between May and October 2014, and professional transcription was completed shortly after. The author and HL then undertook the analysis and interpretation of the qualitative data.

6.2.6 Method of approach

Interviews were conducted in person and audio-recorded with participants' permission.

6.2.7 Participant selection

Sample size

The study sample size consisted of 72 Indigenous women.

6.2.8 Description of the sample

Current AMS clients who were Indigenous female patients presenting with at least one CD, including diabetes, CKD or CVD and disorders of thought and thinking which may have included depression, anxiety, stress or worry. Females aged 0 to 17 years were excluded, along with any person diagnosed with dementia or as being at risk of not giving valid informed consent.

6.2.9 Data collection: Interview guide

Indigenous women with a CD were interviewed to explore the interplay between their family and community and how they managed their own health. One-on-one interviews were conducted at local AMS sites or a nominated venue as arranged by the author and participant. The interview guide was a set of questions based on where participants were originally from, their family structure, household structure and roles of the women both in the home and in community. The next set of questions focused on health, in particular who cared for ill family members, and who took care of the participants when and if they were sick. The final set of questions focused on SEWB and the impact of stress and worry on the participants.

Further details of data collection are provided in Chapter 5.

6.3 Results

6.3.1 Determinants of 'domestic violence' and 'grief, alcohol and family history' codes

Alcohol was described as a fuelling factor for intimate violence by all participants. A woman described her parents as such:

They were perfect good grandparents and good parents, unless they drank, you know. And then that drink ... it's evil. You've got evil attached to it and you drink it down and it turns you ugly. It takes a

perfectly good hero, and I'm talking about bad drugs and everything like that, and makes them into an evil pig. It takes our heroes and makes them into evil pigs, and the men have got to know that, you know, they're the warriors, they have to stand up and start protecting us; not abusing us, not being our enemy. (Participant 12, Site 3)

What the author found compelling in this woman's description of her parents and the men in her family was that she seemed to overlook their actions when drunk, and focused on how good they were when either sober or no longer under the influence of other drugs. In effect, this woman was recognising the impact that alcohol and drugs had had on her family.

Similarly, in the following quotation, although the participant is referring to an intimate partner, she still focuses on him being a good person. It is only towards the end of the conversation that she states he was violent to her. More importantly, she was able to recognise she was living a similar fate to that of her mother. She chose not to pursue that journey:

I met my first partner, my first relationship and I thought it was good but when you're young you think that the first love of your life – but I mean he was a good person but he just did drugs and I couldn't handle drugs and alcohol because – I guess because I [saw] my mother drinking all the time and I didn't want to be – to get in that predicament of being an alcoholic like them. So I left him and he was quite violent to me. (Participant 2, Site 4)

Grief was a major code reported by the participants. Many participants thought of alcohol abuse as resulting from the inadequate management of their grief. For instance, one participant described some members of the community as being so overwhelmed by grief due to the loss of close family and community members that the only way they could cope was through using alcohol and drugs:

Reckon we grieve too heavy, we grieve too hard in – we go right into it, that's how our culture is, um, grieving and some people haven't been taught how to pull themselves out of that or how to even it out. I'll give you an example. When my mum died, um, my younger brothers, well they, you know, abusing alcohol and drugs and that sort of stuff, they still haven't been able to pull themselves out of it and still get drunk and cry around and I'm saying, 'hey, snap out of it, mum and dad have been gone for a while now, dad's been gone for 19 years, let them rest, you

need to start thinking about yourself and the future, don't use them as an example' ... but, yeah, we grieve far too heavily where people just become totally depressed. (Participant 19, Site 3)

Another participant shared her story of losing a child. She attributed the car accident to her partner striking the back of her head while she was driving. This caused her to lose control of the car, which led to the horrible tragedy of her child's death. Her partner had hit her when she refused to stop the car to get him another beer out of the car's boot. She said:

She lived for 19 months. We had a car accident. He hit me in the – in the back of the head with an empty beer bottle because I wouldn't stop to get him another one out of the boot, and the roadhouse was only a mile away. (Participant 18, Site 3)

Recognising the importance of acknowledging when someone is grieving for the loss of a loved one was vital for another participant. This participant felt that without the acknowledgement and support to manage grief, a downward spiral of out-of-control behaviour could result, potentially leading to volatile behaviour such as alcohol or drug abuse. She noted:

And they say that's so we can move on, but the problem to me is that people don't deal with a lot of issues that they have to deal with by moving on, whereas [us] mob, we do deal with our issues and ... um, how to deal with stuff, but sometimes people don't, they don't know how to pull themselves out of it and that's when depression kicks in and it might be, um, psychosis or something that's induced by drugs and alcohol. (Participant 19, Site 3)

Such stories are important for service providers when dealing with clients suffering grief and loss. If service providers are aware of their patients' suffering related to grief and loss they can initiate appropriate strategies. These could include preventative measures being introduced earlier following the loss of a loved one, preventing a downward spiral into heavy drug abuse that could lead to depression or other forms of mental ill health.

6.3.2 Repercussions: Cycle of abuse, resilience and shame

Another participant spoke of the impact that ‘shame’ can have when a woman has had enough of abuse and is contemplating leaving her home and husband or partner following ongoing family violence. She said:

It is not alright for a man to bash his woman and then tell her that he loves her ... and the shame that the women experience after [they have] been bashed should be on the man. (Participant 18, Site 3)

For some of these women, the shame of everyone knowing about their family seemed to be a contributing factor behind them remaining in the relationship longer than they would have liked to. One participant stayed with her husband in an abusive relationship for 12 years before finally leaving him. Unfortunately, this cycle of abuse can continue. In another example, a woman who was stabbed multiple times by her partner described the impact that the trauma had had on her children:

My youngest daughter, she [now] lives a violent life ... as well ... it was in her eyes as she grew up, she thought it would be right to live with a violent boyfriend too. (Participant 10, Site 1)

This participant also expressed her concern about the generational abuse in her own family when she described how her son was also abusing women and being incarcerated due to his violent behaviour. She noted how her daughter was a victim of family violence in her current relationship.

As highlighted earlier in this study, where children are directly exposed to family violence during their childhood, this can result in them becoming the victims or perpetrators of family violence when they are adults. However, the cycle of abuse can also be broken. Most participants described moving on and raising their children in safety and good health:

And I met my first partner, my first relationship and I thought it was good but when you're young you think that the first love of your life – I mean, we went to Darwin to live with my oldest son and, um, he tried to kill me a number of times but I – I managed to live it through. (Participant 2, Site 4)

Another participant discussed the level of violence she had encountered during her relationship with her children's father. She also described how trying to rescue her relationship led her down a path of escalated violence and potential further compromise to her own safety. However, this participant did leave her partner of that time. She related:

I got myself a pretty bad name here. But the beauty of it all is my kids didn't get hurt. I got hurt. He broke my jaw in three places, booted three children out of me and I put all of my kids up the top in the top bracket. (Participant 18, Site 3)

Another woman described how she decided not to have any more children with her abusive partner:

It's a good thing that she did go [her daughter passed away] when she did, when she went. It, sort of, woke me up, after he beat me up. I said, 'no, I couldn't have any more kids from you'. So I went and I had my tubes tied. I met my second husband that just idolised the ground that I walked on, and he put all my kids through. (Participant 7, Site 3)

Due to her husband's infidelity, this same woman shared how she had to manage repeated sexually transmitted infections, and how contracting syphilis had made her very sick, to the extent where she thought she would die.

Participants also described how not only women were victims of violence; men were as well. The domestic violence experienced by men was not only physical, but could be verbal. A participant cited an example of her brother (who she described as defending himself from his drunken wife and being jailed for assaulting her):

Like my brother, I'd tell him you need to speak up because you seem to be copping all the blame and ending up in gaol. Speak up and, you know, let someone know what's happening in your life to maybe help you. And to stop that all the time, you know. But I don't know, he just – he's a father and a mother to his children. And that's where I find he gets himself into trouble because he – he's one of those people who is really – he's a clean person, takes good care of his children. And his wife is on the other side. Not so much caring. But I think it's always fuelled by the grog anyway, what happens. (Participant 14, Site 2)

6.3.3 Accessibility to 'safe havens'

Finding a solution to this problem is not easy. For instance, one woman craved peace and quiet, but instead she was abused by the relatives of an extended family member who was generous enough to allow her to stay for a short period so she could gather her thoughts. When they were under the influence of alcohol, the relatives would abuse the woman until she was forced to leave the house. She would then lie in a park until the relatives had fallen asleep, when she would return to the house to sleep, as she had nowhere else to go. The need for safe places is very important during a crisis, as described by this woman:

I did – I just packed my kids up and just got off there then went to the creek in the back and just sit there all day with my children. (Participant 12, Site 3)

A participant suggested that services were also needed for men to address this issue. Several participants described having to move interstate due to domestic violence and the associated difficulties such as social isolation and the lack of welfare solutions. Another grandmother discussed the reasons for her grandchildren being placed with her:

My daughter is in [a] DV [domestic violence situation] and now with their kids being taken from them [by DCP (Department for Child Protection WA)]. (Participant 12, Site 4)

Unlike her mother, this woman chose not to drink as an adult, and when her partner attempted to kill her on a number of occasions, she finally got the courage to leave him. Help is needed to break the cycle of alcohol abuse, as described by the following woman:

Where do they get the help? I was saying to one of them in my family, you know, 'you drink too much, go and get help otherwise, you know, because you've got – you've got – you've got kids, and you should be doing things for yourself and for your kids'. And I tell these young fellas same thing: 'you will need help, you know, you don't want to go too far to the deep end, and you won't be able to get out of it'. (Participant 5, Site 4)

Another participant noted how obtaining an education could break the cycle of violence. She also stated how, despite being victims of domestic abuse, her children had grown up in a positive environment:

It changes a person going to uni[versity], because while they were studying, I went to TAFE. I did a short course. I do [a] confidence course and all that kind of stuff, and probably need to do another one, it might help. (Participant 12 Site 3)

Education can help break the cycle of family abuse for Indigenous people:

And, because I was doing a, um, trauma thing with a group of psychologists and stuff like that and teachers and stuff and – and they – teachers asked, they say, like, ‘If, you know, so-and-so comes into my class and then he gets up and he starts throwing chairs and stuff around, you know, what am I supposed to do?’ and I – because I thought – I was sitting there thinking. I said, ‘don’t you people talk about stuff, you know. You must know if something happens over the weekend, you must know about it. Surely you must be able to sit down as a group and community – those leaders of the school to sit down and talk about it. Look, so-and-so’s parents have done this, regardless, you know, black or white. You know, you talk about those things. So, you know, who is this going to have the impact on?’ What – what – but it’s obvious that they don’t do it. (Participant 12, Site 3)

The intrinsic strength, resilience and protective nature of a mother in surviving the trauma (of domestic violence) were described by a participant when she said:

But the beauty of it all is my kids didn’t get hurt. I got hurt. He broke my jaw in three places, booted three children out of me and I put all of my kids up the top in the top bracket. (Participant 18, Site 3)

Another grandmother felt that approaching police might not be an option for victims, due to possible institutionalised racism:

Um, see – a lot of – from where I’m sitting, I think Indigenous women, it’s a shame job, you know, they don’t like to – black fellas, they don’t like to go to white fellas and tell them, you know, this and that’s wrong with them. Plus a lot of white fellas don’t believe you anyway. (Participant 6, Site 3)

6.4 Discussion

6.4.1 Summary

Domestic and family violence is a major social problem that is entrenched within our society. It is no longer shocking to hear in the media that another woman has been murdered by her husband or partner. Although society does not generally accept what is happening to women in this country, the laws that govern this country still operate in a way that is not optimal for women and children exposed to family violence.

This study highlights factors that fuel the family violence experienced by Indigenous women. Beyond the alcohol and drugs lie very deep scars, such as the loss of identity, the repercussions of being part of the Stolen Generation, displacement, family breakdown, grief, financial difficulties and ongoing crises in communities. It is of course vital to remove women and children from unsafe environments, but it is also important to address the issues that lead to violence in the first place. Solutions will need to be multi-sectoral to ensure that the women, children and men are given the appropriate care and support needed to prevent reoccurrence. This is necessary to ensure the protection of victims, especially children, enabling them to break the cycle while embracing the community's resilience.

6.4.2 Findings from the literature

When defining domestic violence, we must consider the broader definition of domestic violence and what this means for Indigenous Australians. In the broader context, domestic violence refers to 'an act of violence that occurs between two people who have had an intimate relationship in a domestic setting'. These acts include physical, sexual, emotional and psychological abuse (Morgan & Chadwick, 2009). However, the broader term 'family violence' has been highlighted as a more favourable term when referring to Indigenous Australians' experience of domestic violence (Mitchell, 2011). This is to ensure that all associated relationships that relate to Indigenous families are captured; these can include intimate, family and other non-intimate relationship connections.

In Australia, 2 per cent of the overall female population and 1 per cent of the male population experience domestic violence from a current partner. As many as 15 per cent

of woman and 5 per cent of men have experienced domestic violence from a former partner (Garcia-Moreno, Jansen, Ellsberg, & Watts, 2011). Although no one trigger for domestic or family violence exists, the associated risk factors reportedly relate to alcohol and drug abuse, financial and personal stress. Along with these, a lack of social support is also a strong indicator of violence against women. However, the literature needs further exploration to determine if these factors are associated primarily as a cause or consequence of violence against women (Weatherburn, 2011).

An even greater issue in contemporary Australia is intimate partner homicides. According to the NSW Bureau of Crime Statistics and Research, between 2000 and 2006, 44 per cent of intimate partner homicides were related to alcohol. The involvement of alcohol was reported as being almost twice as high for Indigenous intimate partner homicides (Deardon & Payne, 2009; Gretch & Burgess, 2011). Indigenous women have also been reported as being more vulnerable to domestic violence and less likely to leave a volatile relationship (ABS, 2005). This could be due to a fear of the implications of exposing domestic violence in interconnected and isolated communities, where anonymity may not be possible. Other reasons for not wanting to leave their community could include fear and mistrust of the judicial system, cultural considerations and the coercion that may result from the interconnectedness of Indigenous society and its underlying rules and obligations to protect family and community (Mitchell, 2011). Due to the shortage of statistics and research related to the severity or the types of family violence in Indigenous communities, it is difficult to gain an effective analysis of the impact of family violence on Indigenous communities. However, based on what we do know, Indigenous women experience violence at twice the rate of non-Indigenous people and this number is even greater in remote communities of Australia.

6.4.3 Strengths and limitations

This study has many strong elements: uppermost among these are the insights the author gained from the study. This was probably due to the rapport developed with participants, given that she is an Indigenous woman herself. A further strength was due to the collaboration developed during the author's work with KVC, which was further supported by her supervisor AC, who was the lead chief investigators for KVC. The

relationship that KVC had with the ACCHs enabled the author to engage with the health services in the first instance, given that she was already working collaboratively through KVC. This helped with future planning regarding feeding back to the ACCHs. Additionally, if the author felt that a participant was at risk at any time during the interview, then using the validated tool PH-Q9 and referral to a health provider was vital. Using two researchers to discuss the coding and derive the themes increased the finding's reliability and validity.

One of this study's limitations is that it only explores women's perspectives and not those of men. Additionally, as the inclusion criteria only selected women with a diagnosis of a CD (including CVD, CKD and diabetes), it excluded a younger demographic and the current issues that cohort may have raised.

6.4.4 Implications of the views of domestic violence

The peer review literature did not reveal a particular nor exhaustive focus on Australian Indigenous women's experiences of domestic and family violence. This may be attributable to the fact that Indigenous women living in smaller communities are less likely to report episodes of family violence and are scared to leave their communities due to the risk of disrupting and breaking down the family structure. Again, this underscores the importance of the research conducted for this thesis, and the care taken to allow the Indigenous women to tell their personal stories, thus privileging their voice.

This research highlights that Indigenous Australian women's experiences of family and domestic violence are intergenerational, interconnected and at times foreseeable.

Of the cohort of women in this study who reported family and domestic violence, some reported husbands and sons as having been incarcerated on account of such behaviour. In some instances, there was an identifiable link between grief and domestic violence, usually facilitated by alcohol consumption presenting what would appear to be an interconnectedness of issues.

One alarming finding was that some women seemed to expect and almost accept that violence followed drunkenness. This may not be a new revelation. However, these women seemed prepared to overlook episodes of violent behaviour, by choosing instead to focus on the non-drunken behaviour of these men and the importance of keeping their family together.

In recent years, frontline culturally-safe services such as community women's shelters, homeless shelters, women's and Aboriginal legal services have had their funding significantly reduced. When reports of family and domestic violence remain highly prevalent, and the impact on women, children and families of such behaviour is so profound, reducing service availability would appear to represent poor decision-making. There is a pressing need to generate evidence regarding models of delivery of domestic violence services for Indigenous women that are accessible, acceptable, culturally safe, sustainable and cost-effective. Service providers, community members and policy makers should partner in generating this evidence, to facilitate research translation into policy and practice.

6.5 Future possibilities

A range of family violence prevention programs have been implemented in Indigenous communities. Their particular focus is to provide different levels of services to Indigenous women in the community (Loxton et al., 2008), including advice and support on topics such as 'Addressing alcohol abuse' in Fitzroy Valley (Western Australia), and 'Working with Government in Alice Springs' (Northern Territory) to understand the services available to people experiencing domestic violence. Innovative models to address violence against Indigenous women, that are targeted to specific communities and reliant on the expertise and skills of local women and elders, have been implemented in Queensland (Blagg, Bluet, & Williams, 2015).

Other programs lend themselves to a primary prevention framework, such as a community development approach for men and women. An example of a community development approach is the Balgo women's law camps and the *Cross Borders Indigenous Family Violence Program* (Australian Indigenous HealthInfoNet, 2016b). There are also programs such as the *Working with Aboriginal Families: A Family*

Centred Approach, that target Indigenous families specifically, providing support to the family as a whole by not referring to a ‘victim’ and a ‘perpetrator’ but rather a ‘disengaged family unit’ (AIHW, 2016c). This program gets to the core of what triggered the violence initially, and provides support to the husband, wife and their children throughout their ordeal with the aim of strengthening the family where possible.

Another example of Indigenous-specific programs addressing family violence is an outreach service implemented in Alice Springs. The aim of this project was to target outreach support to women living in Alice Springs and surrounding town camps who were experiencing family violence. Support and education groups were conducted for women in the camps. An evaluation of the project identified that women reported feeling safer after using this service (Australian Indigenous HealthInfoNet, 2016b).

At this time, little evidence is available regarding which programs addressing family violence in Indigenous communities are acceptable, culturally appropriate, sustainable and cost-effective. As very few programs addressing family violence in Indigenous communities have been evaluated (Phillips & Vandenbraek, 2014), we would suggest a critically important opportunity exists to rigorously evaluate these programs. We need to appropriately target such programs to be effective in addressing family violence within Indigenous communities.

CHAPTER 7: VICARIOUS TRAUMA – REFLECTIONS OF AN INDIGENOUS RESEARCHER

7.1 Introduction

The lived experience of Indigenous people in this country is framed by colonisation, discrimination, racism and poverty. Indigenous people share a socio-historical landscape in which external non-Indigenous control is the predominant theme. The colonisation of Australia represented the beginning of the destruction of Indigenous Australians' lifestyles and cultures (Fredericks et al., 2010). Australia today is considered a developed nation with a high standard of living. However, many Indigenous Australians live in poverty, with inequitable access to basic needs, including adequate housing, employment and educational opportunities, which are essential requirements for health. (Walters & Sagers, 2007). Racism has also been widely acknowledged as a determinant of poor health for Indigenous populations and other minority groups globally (Priest, Paradies, Gunthorpe, Cairney, & Sayers, 2011).

Building capacity in Indigenous health research and among Indigenous researchers is a national health research priority (Laycock, Walker, Harrison, & Brands, 2009; NHMRC, 2014a). However, many challenges face early career Indigenous health researchers. Best-practice principles to underpin the conduct of Indigenous health research have been suggested, including a focus on capacity building and the need for sufficient resources to support this (Jamieson et al., 2012). The 2011 NHMRC Indigenous Scientific forum (NHMRC, 2014a), the 2013 Tripartite Agreement Mentorship workshop, and the National Aboriginal and Torres Strait Islander health plan (DoHA, 2013), have all highlighted issues or barriers that need to be overcome. An example of a barrier to building capacity in Indigenous researchers occurs when researchers and research institutes marginalise or discredit the values of Indigenous people and communities (NHMRC, 2014b).

Improving research capacity can occur if researchers and research institutes stop exploiting communities and conduct research in an ethical and trustworthy manner in collaboration with community: 'Nothing about Us without Us'. The presence of

culturally safe spaces in research institutes and universities has been identified as an urgent need to ensure that researchers' potential and learning capacity is both encouraged and supported (NHMRC, 2014a). The cultural safety and SEWB of Indigenous health researchers when conducting research must be a priority.

The conduct of Indigenous health research should be informed by Indigenous frameworks of theory and practice (NHMRC, 2014b). Respectful relationships between researchers and Indigenous community groups are built over time – a commodity not usually available to research teams that operate on the tight timetables imposed by research funding bodies. Therefore, an additional challenge is faced by many Indigenous communities participating in research. This concerns being able to negotiate with external organisations to enter genuine partnerships on a level playing field, often within the inappropriately tight timetables imposed by researchers (NHMRC, 2010). Commonly, an Indigenous research team member is relied upon to develop and sustain respectful relationships with individuals and the community, regardless of whether they identify with that particular community. This derives from the mistaken assumption that one Indigenous research team member can speak for, or on behalf of, all Indigenous people.

Engaging Indigenous people in discussions about their health and SEWB must include a significant focus on family and community and less focus on the individual (Monahan & Twining, 2007). This is due to the complex, extended kin network that operates in Indigenous communities. Such a network may include aunts and cousins, for example, which would be unusual in a traditional nuclear family. These familial and community relationships and connections are integral to maintaining the health and wellbeing of Indigenous peoples. We should seek to understand how these relationships affect both health and health-related behaviours, while being sensitive to the ongoing negative impact of colonisation (Monahan & Twining, 2007).

Qualitative research can be used to gain an understanding of underlying reasons, opinions and motivations that drive the health behaviours of individuals, families and communities. During PhD research in the four Australian AMSs included in this study, the author used a qualitative approach to elicit Indigenous women's stories about their

many and varying roles and determine how these roles affected their health. Qualitative research fits well with communities' customs relating to the sharing of knowledge.

Many guidelines relate to caring for Indigenous and non-Indigenous researchers during their research. In addition, much of the scholarly literature is related to the processes around conducting research in the Indigenous health space. These resources focus on the importance of good supervision and effective strategies for relationship building between supervisor and candidate (Laycock et al., 2009; NHMRC, 2014a, 2014b; World Medical Association, 2013). These guidelines and strategies also, as appropriate, outline how to maintain community and participant safety during the research process (NHMRC, 2006, 2014b; World Medical Association, 2013). Little information is available on how to safeguard the SEWB of Indigenous researchers conducting research within Indigenous communities.

When developing a safety protocol for research with Indigenous people, one that aligns with university guidelines for postgraduate supervision, the supervisor and (student) researcher should consider the psychosocial and cultural implications for an Indigenous researcher. This is in addition to ensuring the safety of participants and communities. The similarities of the author's own lived experiences might aid in community and participant engagement and ownership, encourage participants to share their stories and inform the interpretation and understanding of data. However, Indigenous researchers may attach their own meanings to the lived experiences shared by the community research participants, or perhaps even re-live their or their family's experiences after hearing the stories shared by participants.

In this chapter, having conducted interviews and completed the thematic coding of the transcripts, the author reflects on the impact it had on her as an Indigenous female researcher, of gathering, listening to and analysing the stories shared by Indigenous women in the communities she visited. She found herself asking if more needs to be done in preparing Indigenous researchers for, and providing ways of, discussing and addressing the potential risk of experiencing VT when conducting qualitative research with Indigenous people.

7.2 Vicarious trauma

Vicarious trauma (VT) is the technical name given to a psychological state that can result from being repeatedly exposed to the traumatic experiences of others. It is described as ‘the inner transformation that occurs in the inner experience of the therapist (or other professional) that comes about as a result of empathic engagement with clients’ trauma material’ (Pearlman & Saakvitne, 1996). The concept is similar to emotional exhaustion, ‘burnout’, disrupted spirituality and feeling heavy, states that are all well understood in counselling, trauma care and other similar professions. During any collaborative research, the sharing of personal opinions and feelings exposes researchers to a certain amount of vulnerability (Streubert & Carpenter, 2011). For Indigenous researchers, this vulnerability may run deep and be profoundly personal, involving experiences of intergenerational trauma. With qualitative work, in an effort to understand and give meaning to participants’ responses and stories, researchers are required to immerse themselves in the lived experiences of others emotionally during storytelling, transcription and the thematic analysis of interviews.

During the planning stages of the research, the author was very aware of the ethical requirement to prepare and follow a safety protocol to maintain the study participants’ physical and psychological safety, in addition to her own safety and wellbeing. The potential exists for power imbalances between researcher and participant.

Acknowledging that sharing some stories might be distressing for participants, the author worked with her supervisors to develop a safety protocol aligned with Sydney University regulations (see Appendix 10). At this early stage in the research the author had not heard the term ‘vicarious trauma’, nor was she aware of the possibility of its existence.

When the author travelled to each of the participating health services to conduct interviews, bringing her ethical approval and safety protocol, a health service provider from each site engaged with and supported her during the recruitment of potential participants. Generally, by the time she spoke with potential participants, they had already been approached by their local health service provider and had a general idea of

what the study would focus on. They had also expressed an interest to meet with the author to learn more about the study.

At each health service, the author invited clinical staff to an information session where she presented her proposed study. She remembers them listening to her explain the purpose of her visit and research intently. She also noticed the Indigenous women health workers in the audience nodding their heads as she began to explain that her research on whether the roles and responsibilities Indigenous women held within their families and communities affected the management of their health and CD.

Furthermore, the author explained why she, as a researcher, thought that women's roles and responsibilities *might* affect how women managed their health, and that she anticipated this study would provide some understanding and clarity around this issue.

7.3 In the women's own words

When interviewing participants for the qualitative study component of this thesis, the following terms were used constantly: 'us', 'we' and 'our', rather than 'I' or 'me'. The author listened closely to the participating women's stories of strength, resilience and cohesiveness, stories underpinned by pride and a strong identity about who they were, their community and where they came from. This was particularly apparent when the women narrated how well they juggled hectic workplace responsibilities with ensuring their children were cared for and elderly parents had had lunch or been taken to their appointments. The author also heard compelling stories of rejection, family violence, homelessness, grief, loss, despair and drug abuse and how these experiences had affected them and their families. Throughout these conversations, repeated stories of incarceration and the negative impact of this on families, stories of intergenerational domestic and family violence, along with stories of helplessness, death and loss were told.

The women's stories affected the author deeply. In fact, at one service, she became overwhelmed with sadness. After finishing her interviews for the day, she went home and cried, reflecting on what had made her cry. Despite there being so much sadness in the stories the author had heard from the women, they had also displayed a great deal of strength. The author was not entirely sure why she had cried that day, or why she was

affected so deeply. Perhaps her response was related to the stories she had heard from the women she had interviewed at the previous health service. Or perhaps she was recognising some of the circumstances as being similar to aspects of her own life and familial networks, immersing herself in the narrative to the point where her objectivity was being compromised. Would the author's reaction been different if she was not an Indigenous woman with similar lived experiences, but rather a non-Indigenous researcher or someone with a very different lived experience? Not only did these stories elicit a strong emotional response, but she also noticed that she had begun to withdraw in her personal life, experiencing ongoing sadness with a heightened sense of isolation and helplessness.

Repeatedly listening to these experiences of trauma, such as domestic violence, incarceration, homelessness, and death and dying made the author question the extent to which similar traumas may have played a role in her own family and some of the challenges that were confronted. For instance, one participant said bluntly:

He found a steak knife, [a] threaded steak knife, and walked behind me and stabbed me from behind. My daughter witnessed it. (Participant 10, Site 1)

Another woman disclosed:

[My husband], he broke my jaw ... and booted three kids out of me. (Participant 12, Site 3)

The stories of incarceration and intergenerational incarceration had the same effect. One woman said:

Because Reg [the father] had always been in and out of jail ... [now] my second eldest son is doing 10 years in jail. (Participant 10, Site 1)

Another woman worried about the impact of incarceration on caring for the younger generation. She said:

My granddaughter, I worry about her, she's got them little children, and she's only in her twenties and her boyfriend he's in jail at the moment. (Participant 20, Site 1)

Hearing women seemingly accept the cycle of family violence also weighed heavily on the author. For example, one woman was resigned to the cycle:

Because my brother is always one of those forever lasting in gaol for domestic violence – stuff like that ... but when he's – goes to gaol it's only because everyone has feelings and he has feelings when he's hurt and he has to defend himself and each time he does [defend himself against his partner], he goes to gaol. (Participant 14, Site 2)

Experiences of homelessness were also disclosed on several occasions:

I come to Cairns, live in a park, having a baby ... and when the social worker ... went past, see me and my son was hiding ... we're getting shelter from the rain. I don't know where all my family was. They don't want me. I tried to knock on the door, they say, 'oh go stay in the park'. So I went to live in the park so (I) have my baby in hospital. (Participant 12, Site 1)

Women also discussed the trauma of experiencing the death of family and community members. At one health service, the author saw notices for seven pending funerals on the wall. One woman said:

Yeah, I worry about my mother because I miss her a lot and my father, my sister, my granddaughter, my grandmother. They all passed away. (Participant 11, Site 2)

Another woman had a particularly tragic story:

What brought me to Cairns was I had my mother who passed away and, um, I was actually told that I wasn't her biological daughter on her funeral day and was told to get out and had no right being there. So, yeah, I just got out of [the community], jumped on the bus and just came to Cairns and this is where I stayed. (Participant 10, Site 1)

Wondering whether the challenges encountered while conducting the research had become insurmountable, the author began to feel the same sense of hopelessness that she had witnessed in others during their interviews. She experienced ongoing sadness, a heightened sense of isolation and helplessness.

7.4 A high-risk candidate for vicarious trauma

The stories and experiences the author was exposed to throughout this qualitative research, coupled with an approach that sought to empower Indigenous women to share their stories with her (a researcher with whom they could identify and feel at ease), made the author a high-risk candidate for VT. Her methodological approach (IPA) aims to explore the lived experiences of study participants (Smith, 2004), but also exposes researchers to the risk of VT. No university, ethics documents or conversation encountered during the establishment of the research suggested strategies to protect researchers from VT.

Until the author understood that she was likely to be experiencing VT, she spent much time trying to determine whether attaching the participants' meanings to their lived experiences – as required by the IPA approach – or instead attaching *their* meaning to *my own* lived experience. Alternatively, was the author re-living her own experiences or her family's? Perhaps she was simply finding it increasingly difficult to separate their feelings from her own.

It had become apparent early in the interview process that these women were very resilient, despite the trauma they had experienced. Many had very complex roles within their families and communities, caring for an array of people within their family, their extended family and their wider circle of friends. The women discussed the importance of their relationships within family networks, and how these relationships enabled them to manage their roles and responsibilities within their family and community more effectively. They explained carefully how these relationships helped them navigate through their own lives and care for their children and others. Interestingly, the author did not dwell on these examples of strength and kinship in the same way that she dwelt on the stories of loss, trauma and separation. This resulted in a profound sadness in her, a feeling unexpected and unprepared for.

As an Indigenous woman researching other Indigenous women, the author and participants shared a 'common ground', that is, the effects of racism, poverty, colonisation, discrimination and oppression. These commonalities likely enabled the women's willingness to share their stories, which enabled the author to relate her own

experiences to theirs. The author can only conclude that this ‘common ground’ also allowed her to relate to their stories on a much more personal, knowing and deeply felt level than would have been the case had the author been a non-Indigenous woman or an Indigenous woman interviewing non-Indigenous women.

The author was not alone in feeling that her experiences and responsibilities to the community, and those of other Indigenous researchers, differ to those experienced by non-Indigenous researchers. Another Indigenous researcher highlighted the enormous responsibility and expectation she felt during her studies as an Indigenous woman conducting research in Indigenous communities with other Indigenous women. Due to her being considered an ‘insider’ within the community in which she was working, the expectation placed on her to conduct research in a culturally safe manner appeared greater than the expectations placed on non-Indigenous researchers working in the same communities (Laycock et al., 2009). The expectations of community and the implications for Indigenous researchers conducting research within Indigenous communities could be detrimental to their social, emotional and cultural wellbeing, especially if the conduct of their research was not carefully planned to meet such community expectations.

When conducting research with Indigenous communities, all researchers should be made aware of the possibility of VT. In the same way, protocols should be developed to safeguard study participants and student researchers. Safety protocols and training should also be available to highlight the possibility of VT for researchers and the ways in which they can safeguard against it. Supervisors should be made aware of the potential for VT, along with strategies to assist students in preventing or mitigating its impact. An additional concern is the usual stress and anxiety that students may encounter during the conduct of their research. When developing a safety protocol for research conducted with Indigenous people, the supervisor and student researcher should consider the psychosocial and cultural implications for all Indigenous researchers, while also ensuring the safety of participants. Supervisors should also be aware of which research methods, such as IPA, explicitly explore the lived experiences of research participants, and are likely to put researchers at the most risk.

7.5 Recognition and management of vicarious trauma

One of the main risks for researchers or clinicians working with repeated exposure to traumatic experiences (as is the case for victims of VT) are the cognitive changes that can potentially cause an altered worldview (Berg Raunick, Sane, Lindell, Morris, & Backman, 2015). This change in cognition causes a shift in how a person perceives the world (Pearlman & Saakvitne, 1996). In most cases, the shift in cognition is a negative change, and the world is viewed through a deleterious lens (Morrison, 2007). This shift in cognition often manifests in symptoms such as anxiety, depression, unreasonable feelings regarding a lack of safety, mood swings and the increased use of alcohol, caffeine or other drugs (Queensland Government, Department of Communities, Child Safety and Disability Services, 2017). The shift in worldview experienced by people dealing with VT can also affect psychosocial relationships, particularly with family and friends (Morrison, 2007). One main strategy that could manage the accumulation of stress leading to VT would involve acknowledging that having a strong reaction to others' traumatic experiences is normal; the abnormality would occur if this strong reaction did not diminish over time. These strong reactions should not last for more than a few weeks; if they do continue and clinicians or researchers are concerned, the person experiencing VT should seek professional help or counselling. Other strategies for managing VT include debriefing and taking responsibility for personal self-care, in particular, ensuring that one has a work–life balance.

7.6 Conclusion

Research that contributes to a deeper understanding of the issues that shape Indigenous women's roles, behaviours and approaches to maintaining their own health and wellbeing is a priority. We are seeking to build the capacity of Indigenous researchers to take a leading role in the conduct of such health research. Although institutional policies and procedures address the safety of study participants, less focus is given to the safety considerations of Indigenous researchers. Universities, research institutions and supervisors should work to ensure the best possible outcome for Indigenous researchers in terms of equipping them with the necessary research skills and providing support systems and strategies to reduce the risk of any detrimental effect on their own mental and physical health.

CHAPTER 8: DISCUSSION AND CONCLUSION

8.1 Synopsis

In this chapter, the author provides an overview of the findings of the program of research conducted as part of this thesis. She identified many challenges influencing Indigenous women's ability to manage their health while continuing to fulfil their many roles and responsibilities within their family and community. This chapter also ties together what this might mean in terms of identifying the implications for the community, clinicians, researchers and policy-makers. Indigenous women have learned to navigate our healthcare system on behalf of their family and their community; however, much of this new knowledge about accessing healthcare tends to be utilised for their family rather than for themselves. The research presented here reinforces that for clinicians, when an Indigenous woman presents to them for care, the deeper causal pathways, family and societal context need to be taken into account, in addition to the clinical presentation, if a care plan is to be developed that will improve a woman's health and wellbeing.

8.2 Strengths of the study

The key learning emerging from this body of work are consistent with previously reported literature. However, the author was compelled to reflect on the adversity and resilience displayed through the depth with which participants shared their experiences of survival. Reflecting on this adversity and resilience aided in identifying key health priorities for Indigenous women, as well as for their families. Chapter 2 provides a review of the literature in relation to Indigenous women with CD. This chapter also reports on the effects of colonisation and racism and discusses how these effects continue to operate in contemporary Indigenous Australia. The chapter highlights some of the effects that CD has on Indigenous women, as well as highlights the significant roles and responsibilities that Indigenous women have in their family and community. The chapter concludes by reporting on the physical and social impact that CD have had on Indigenous women and their families. Chapter 3 systematically reviews programs addressing CD and SEWB implemented in AMS in Australia. A strength of the systematic review was the inclusion of programs designed within the setting or

environment in which they were delivered, which meant that the review focused on programs that were developed with a focus on cultural appropriateness and security, and designed to address the particular socioeconomic, cultural and service needs and contexts of the community.

Chapter 4 explores the views of Indigenous patients and their health providers regarding the factors that influence treatment adherence and the acceptability of a polypill-based strategy for Indigenous people at high cardiovascular risk. For Indigenous patients, a sense of wellbeing was associated with treatment adherence. This sense of wellbeing was experienced against a background of witnessing family members dying at an early age, something that participants attributed to those people not taking their CVD medication. Providers tended to focus on patient factors as shaping adherence and highlighted low levels of health literacy, a sense of fatalism regarding shortened LE, and an excessive disease burden. Patients, on the other hand, focused on broader societal factors and health system factors. Patients and providers alike indicated that if new approaches, such as a polypill-based strategy, are to be implemented sustainably, they will need to be embedded in the health system.

Ultimately, while a polypill-based strategy has great promise, it needs to be developed as part of a holistic strategy that addresses medical and non-medical factors influencing adherence, such as continuity of care by healthcare providers. The introduction of new approaches, such as a polypill-based strategy for the management of cardiovascular risk, will require collaboration and agreement between primary care, specialist and hospital services involved in the provision of care for Indigenous patients.

Chapter 5 reports on a qualitative study conducted to explore if the roles and responsibilities of Indigenous women within their family and community affect how they manage their CD. It was found that Indigenous women often prioritise their caring responsibilities for family and community members above their own health needs. Along with other stressors they experienced, including intergenerational violence, the devastating impact of incarceration and grief associated with death of family and community members, the women's health is negatively impacted. However, the level of support women indicated they received through informal family networks showed these

networks to be positive enablers of good health and wellbeing. Although the women reported multiple stresses and adverse events that affected their lives and health, they drew great strength from their extended family, community and culture.

Chapter 6 reports on a particular issue reported by some women in this study, but which had a fundamental impact on their health and wellbeing. Amongst women who discussed family violence, the descriptions were graphic. This led the author to consider this topic as one that needed to be separately and carefully reported.

In Chapter 7, the author wanted to share the effect that this program of research had on her as an Indigenous woman with a similar background and experiences to some of the study participants. It is apparent from the outcomes reported in each of the chapters that using a holistic framework that included the patient, their family and community, is important when conducting research on, or working with, Indigenous women. It is also important that social determinants of health and illness are embedded across any model of care aimed at improving health outcomes for Indigenous women and their family.

8.3 Analytical framework

In the research program, the author applied a holistic framework aimed at improving the health and wellbeing of Indigenous women. In order to understand how these women managed their CD, the author sought to capture a complete picture of the cultural, historical, political and socio-economic landscape in which these women lived. Additionally, the research was aimed to reinforce the significance of the roles and responsibilities these women have in their families and community, and how this influenced their health and wellbeing. Ultimately, this understanding should inform the design, uptake and utilisation of targeted and culturally appropriate health interventions for Indigenous women with CD.

The framework applied in this research increases our understanding of the drivers behind the burden of CD among Indigenous women, the impact of psychological distress on their health and wellbeing, and their lived experiences both in terms of fulfilling multiple family and community roles, and in managing their own health. Of particular interest was how women relied on and utilised informal support networks in

times of family or community need. These informal support networks, comprised of family and extended family, seemed to become stronger or better defined at times when families were dealing with profound stress. The strengthening of this connectedness was reported to stem from an inherent commitment to family, and willingness to support them in time of need, rather than from any onerous sense of obligation. Finally, applying this framework enabled the author to highlight how the roles and responsibilities that Indigenous women have in their families affect their management of CD, as well as their health and wellbeing remaining below acceptable standards.

8.4 Implications for policy and practice

To improve health outcomes for Indigenous Australians, the central caring roles of Indigenous women within their extended families must be recognised. Research has often focused on health disparities for Indigenous men, including that they are less likely to present for their own necessary healthcare. However, this program of research has documented that very significant health disparities exist also for Indigenous women, and that the care they provide for others might impact their own health and wellbeing.

We identified in this study the need to understand the complexity of positive and negative factors – both stressors and supports – that impact Indigenous women and families. On one hand, we see the strong support structures that cocooned those women in need of support, and nurtured them with psychosocial and spiritual strength as a source of resilience. On the other hand, we heard of the immense strain on the women in this study, and how stress and competing priorities impaired the women's ability to self-manage and care for their own health.

In addition, it is not enough to say that connection to country is important, but we must recognise real challenges for women in the workforce unable to fulfil those responsibilities required to retain their connection to community and country. Many of them worked in institutions that recognised some aspects of the importance of attendance at funerals and sorry business. For instance, additional cultural leave had been added to their annual leave and bereavement leave entitlements. This worked well with families experiencing two or three deaths per year, but regrettably, many Indigenous families in this study were required to attend funerals almost monthly.

It was identified in this study that Indigenous women care for their extended families, as well as face the structural barriers that confront Indigenous men, women and children. Supporting these women to maintain their own health and wellbeing will benefit their broader social and family networks. Service delivery policies to improve health outcomes for Indigenous communities should place Indigenous women at the front and centre to ensure they are well supported to enable their broader networks to access necessary care and social support. If, for example, we are to succeed in encouraging Indigenous men to seek care, it will be necessary to address stressors and remove barriers to enable Indigenous women to act effectively in their caring roles for family and community. Therefore, if health outcomes are to be improved for the whole community, service delivery policies must address the health needs of Indigenous women to ensure that they are well supported in their essential caring roles.

8.5 Direction for future research

This body of research has identified issues, based on deeper understanding of causative and contextual factors affecting the health and wellbeing of Indigenous women, which programs might be designed, implemented and evaluated to address. These areas include culturally competent and secure service delivery; resource allocation according to the burden of complex and comorbid CD and targeted towards programs developed in partnership with community; and developing strategy and policy based on best evidence about what works in different contexts. More flexible models of care that take into account the psychosocial factors impacting women and their families, as well as the management of their CD, are needed. For women having to deal with domestic violence, we must ensure that there are safe places for them to go with their family when having to leave their homes due to domestic violence. We also need to understand the ongoing impact on health and wellbeing for these women, resulting from their roles and responsibilities in family and community such as caring for multiple family members due to incarceration and repeated exposure to death and dying

An example of a flexible model of care for women experiencing domestic violence or otherwise involved in the criminal justice system could include a pilot project that focuses on information sharing between the local AMS and the criminal justice system

(be it courts, prisons or the police). This would ensure that healthcare for these women is customised to accommodate the interruptions, dislocation and psychosocial trauma they experience when family members are caught up in the criminal justice system, to ensure a consistency in management of their health.

Research is needed to capture what it is that constitutes this commitment and connectedness within family and community that builds and strengthens the resilience of these women. Research that can inform strategies to build coping skills and understanding might help more vulnerable families, whose health and wellbeing is at risk due to their inability to draw on this connectedness, such as those removed from country or who are members of the Stolen Generation.

8.6 Conclusion

The greater incidence and prevalence of CD and premature death for Indigenous women has been clearly highlighted in this body of research. It has also become apparent that the management of the women's CD is affected by their roles and responsibilities within their family and community. Many of the roles and responsibilities relate to psychosocial factors beyond the control of the women themselves. Incarceration of family members forced some women to take on the caring roles of an entire family in addition to their own. When the women talked about the many issues causing stress in their lives, they described informal family support networks as being fundamental to their resilience. The women described poor access to more formal support structures, which might reinforce the importance of these informal support networks that the family and community had put in place to meet their complex needs.

If we are to close the gap in LE for Indigenous women, and successfully implement programs and supports that enable these women to maintain their wellbeing, we will need to build on and learn from the culturally-based strengths and support networks that already exist. In order to do this, we need to target service delivery and resources to meet the particular needs of Indigenous women. If service delivery models are to improve Indigenous women's health and wellbeing, they must take into account the consequences of the range of caring responsibilities they assume within their close and extended families and communities.

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APPENDIX 1: COMBINED CAIRNS & HINTERLAND ETHICS APPROVAL

Submission Code Date: 25/09/2013
13:52:44

Reference:

Online Form

Online Forms National Ethics Application Form

Within which Jurisdictions will your research application be submitted to: *(tick all that apply)*

- New South Wales
 Queensland
 South Australia
 Victoria

HREC Application Reference Number:

1. TITLE AND SUMMARY OF PROJECT

1. Title

What is the formal title of this research proposal?
Exploring the impact of Chronic disease on Aboriginal women: Is there a relationship between stress, psychosocial health and management of chronic disease for Aboriginal women?
What is the short title / acronym of this research proposal (if applicable)?
Exploring the impact on Aboriginal and Torres Strait Islander women of living with Chronic Disease

2. Description of the project in plain language

Give a concise and simple description (not more than 400 words), in plain language, of the aims of this project, the proposal research design and the methods to be used to achieve those aims.

The health of Aboriginal and Torres Strait Islander women is poor when compared with non Aboriginal and Torres Strait Islander women in Australia and other first world countries. A heavy burden of chronic diseases contributes to this poor health status. The literature infers that one of the major factors for the poor health status of Aboriginal and Torres Strait Islander women in Australia is due to late presentation leading to diagnosis at advanced stages of disease, resulting in poor health outcomes. How does living with a chronic disease impact on Aboriginal and Torres Strait Islander women and how do the roles they play within their families and communities impact on caring for their own health?

In this project, the researcher, an Aboriginal woman and health professional, will interview Aboriginal and Torres Strait Islander women living with a chronic disease. She will discuss how living with a chronic disease influences the roles women play within the family. She will also explore how Aboriginal and Torres Strait Islander women's roles within their families influence management of their own health.

The researcher will engage with Aboriginal Community Controlled Health Services in urban and regional areas to seek their support. Local reference groups will oversee the conduct of the study. She will obtain consent to conduct in-depth, one-on-one interviews, digitally record, transcribe and analyse the results. Feedback will be given to participants and health services, providing the opportunity to critically evaluate research results and research conduct and to participate in discussion regarding research outcomes.

2. RESEARCHER / INVESTIGATOR

2. Principal researcher(s) / investigator(s)

Principal researcher / investigator 1

Title: Forename/Initials: Surname:
Ms Anne-Marie Eades

Mailing Address:

Level 10, King George V Building, 83-117 Missenden Road

Suburb/Town: Camperdown
State: NSW
Postcode: 2050
Country: Australia
Organisation: The George Institute for Global Health
Department*: Renal and Metabolic
Position: PhD Candidate/Research Fellow
E-mail: aeades@georgeinstitute.org.au
Phone (BH): 0889514734
Phone (AH)*: 0407983720
Mobile*: 0407983720
Pager*: n/a
Fax:

Is this person the contact person for this application?

Yes No

Summary of qualifications and relevant expertise

I am an early career researcher and commenced a PhD studies in July 2012 on chronic disease in Aboriginal communities with a particular focus on Aboriginal and Torres Strait Islander women's roles and responsibilities. I completed my nursing degree in 1999, in Western Australia and specialised in peri-operative nursing. I worked in urban, rural and remote settings. Despite being passionate about nursing,

over my years in clinical practice I became concerned at the high rates of chronic disease complications in Aboriginal patients, and the apparent inadequacy of current management strategies. In particular, observation of high rates of amputation among Aboriginal patients in their thirties and forties, even among those who had received care for debridement in the past, led me to focus increasingly on improving care and on prevention. I went on to complete a Masters degree in nursing, focussing on decreasing amputation rates in Western Australia.

Please declare any general competing interests

Possible competing interests are that I am the researcher and the PhD student.

Name the site(s) for which this principal researcher / investigator is responsible.

Wuchopperen Aboriginal Health Service, Geraldton Regional Aboriginal Medical Service, Wirraka Maya Health Service.

Describe the role of the principal researcher / investigator in this project.

I will be responsible for community engagement, preparation and initiation of protocol and consent forms, recruitment of participants for the study and establishment of reference groups to help guide the study in each of the sites. I will conduct interviews during the data collection process of the study. Following completion of the interviews with the women, and de-identification of the data, I will analyse the data, prepare manuscripts and presentations, feedback the results and publish the data.

Is the principal researcher a student?

Yes No

What is the educational organisation, faculty and degree course of the student?

Organisation: University of Sydney

Faculty: Division of Public Health, School of Medicine

Degree course: Doctor of Philosophy

Is this research project part of the assessment of the student?

Yes No

Is the student's involvement in this project elective or compulsory?

Elective Compulsory

What training or experience does the student have in the relevant research methodology?

I have a background in nursing in metropolitan, rural and remote settings. I have worked in the University sector, in Government, in Aboriginal health, research and education and in training and support of Aboriginal Health Workers. I am currently a Research Fellow with the Kanyini Vascular Collaboration (KVC) at the George Institute in Sydney. In my current role I am responsible for assisting in the educational, research and community collaboration activities of the Kanyini Vascular Collaboration. I have experience in conducting in-depth interviews with Aboriginal and Torres Strait Islander women through my clinical roles, Masters of Nursing and

research conducted through KVC. I am undertaking further training in qualitative research methodology through the School of Public Health at Sydney University.

- Introduction to Qualitative Research Techniques - Workshop Australian Consortium (2013)
- Qualitative Research Methods - when conducting research with Aboriginal & Torres Strait Islander participants The George Institute (2012)
- Completed Ethics in Nursing postgraduate unit of study as required by NHMRC when completing my Masters in 2008
- The many years of working in the Aboriginal health sector has given me a deep insight into the needs to conduct appropriate and respectful research addressing the health priorities of Aboriginal and Torres Strait Islander people and their communities.

What training has the student received in the ethics of research?

Describe the supervision to be provided to the student.

The student will be provided appropriate supervision by Professor Cass, Hackett and Brown, who have many years of experience in conducting chronic disease research with Aboriginal and Torres Strait Islander communities. Regular meetings are held with Professor Cass and Hackett, discussing all aspects of the research, and frequent advice and guidance will be obtained from Professor Brown.

How many supervisors does the student have? 3

Supervisor 1

Provide the name, qualifications, and expertise, relevant to this research, of the students' supervisor.

Title: Professor
First Name: Alan
Surname: Cass

Summary of qualifications and relevant expertise

Professor Alan Cass is Director of the Menzies School of Health Research and a Professorial Fellow: Renal and Metabolic Division The George Institute and The University of Sydney. Alan is a Chief Investigator on the Kanyini Vascular Collaboration and works actively with health services, community organisations and government to develop strategies to improve access to health services for Aboriginal people. Professor Cass has an extensive track record in quantitative and qualitative research.

Supervisor 2

Provide the name, qualifications, and expertise, relevant to this research, of the students' supervisor.

Title: Associate
Professor
First Name: Maree
Surname: Hackett

Summary of qualifications and relevant expertise

Maree Hackett – Head Mental Health and Chronic Disease Program, Neurological & Mental Health Division, The George Institute and Associate Professor, The University of Sydney. A/Prof Maree Hackett's long standing area of expertise is in health outcomes research, in particular, psychological problems in people with chronic disease. Maree is a Chief Investigator on an Australian Primary Health Care Research Institute Centre of Research Excellence for Indigenous primary care intervention research

Supervisor 3

Provide the name, qualifications, and expertise, relevant to this research, of the students' supervisor.

Title: Professor
First Name: Alex
Surname: Brown

Summary of qualifications and relevant expertise

Professor Alex Brown is an Aboriginal medical doctor and researcher. In 2007, Alex was appointed to set up a research program in Central Australia with Baker IDI Heart and Diabetes Institute, with a focus on heart disease and diabetes in Aboriginal people. During this time, Alex commenced and completed his PhD on depression and heart disease in Aboriginal men. In July 2012, Alex joined the South Australian health and Medical Research institute to lead

Aboriginal health research.

3. Associate Researcher(s) / investigator(s)

How many known associate researchers are there? (You will be asked to give contact details for these associate researchers / investigators)

Do you intend to employ other associate researchers / investigators? Yes No

5. Other personnel relevant to the research project

5a. How many known other people will play a specified role in the conduct of this research project?

0

5b. Describe the role, and expertise where relevant (e.g. counsellor), of these other personnel.

5c. Is it intended that other people, not yet known, will play a specified role in the conduct of this research project?

Yes No

6. Certification of researchers / investigators

6a. Are there any relevant certification, accreditation or credentialing requirements relevant to the conduct of this research?

Yes No

7. Training of researchers

7a. Do the researchers / investigators or others involved in any aspect of this research project require any additional training in order to undertake this research?

Yes No

RESOURCES

Project Funding / Support

1. Indicate how the project will be funded?

Type of funding.

[Please note that all fields in any selected funding detail column (with the exception of the code) will need to be completed.]

Funding	Confirmed or Sought?			
External Competitive Grant	<input checked="" type="radio"/> Confirmed	<input type="radio"/> Sought	<input type="radio"/> Not Sought	Amount of funding \$78,437

Internal Competitive Grant	<input type="radio"/> Confirmed <input type="radio"/> Sought <input type="radio"/> Not Sought	Amount of funding
Sponsor	<input type="radio"/> Confirmed <input type="radio"/> Sought <input type="radio"/> Not Sought	Amount of funding
By Researchers Department or Organisation	<input checked="" type="radio"/> Confirmed <input type="radio"/> Sought <input type="radio"/> Not Sought	Amount of funding \$2,500.000

1a. External Competitive Grant

Name of Grant / Sponsor	National Health & Medical Research Committee
Code (optional)	APP1056434
Detail in kind support	Student specific scholarship
Indicate the extent to which the scope of the grant and the scope of this HREC application are aligned:	This a Training Scholarship for people conducting research in Indigenous Australian health and funds my income while I am focusing specifically on this HREC application.

1b. Internal Competitive Grant

Name of Grant / Sponsor
Code (optional)
Detail in kind support
Indicate the extent to which the scope of the grant and the scope of this HREC application are aligned:

1c. Sponsor

Name of Grant / Sponsor
Code (optional)
Detail in kind support
Indicate the extent to which the scope of the grant and the scope of this HREC application are aligned:

1d. By Researchers Department or Organisation

Name of Grant / Sponsor	Australian Primary Health Care Research Institute - Centre for Excellence in Research - Collaboration between The Baker IDI and The George Institute for Global Health.
Code (optional)	
Detail in kind support	Currently providing on-going support via access to partner sites to enable the PhD candidate to access research participants to conduct the qualitative study. Also ensures the applicant has access to Senior Clinicians and Researchers to provide in-kind support where requested at the Research Institute.
Indicate the extent to which the scope of the grant and the scope of this HREC application are aligned:	Currently providing on-going support via access to partner sites to enable the PhD candidate to access research participants to conduct the qualitative study.

2. How will you manage a funding shortfall. (if any)

The KVC retains an ongoing commitment to building capacity as one of four key aims. A core component is strengthening workforce capacity which includes my employment as a research fellow as well as a PhD candidate. The KVC provides ongoing support through use of existing data, regular face to face and teleconference meetings, and a sound and workable governance structure.

3. Will the project be supported in other ways eg. in-kind support/equipment by an external party eg. sponsor?

Yes No

4. Is this a study where capitation payments are to be made, and will participants be made aware of these payments to clinicians or researchers / investigators?

Duality of Interest

5. Describe any commercialisation or intellectual property implications of the funding/support arrangement.

Not Applicable

6. Does the funding/support provider(s) have a financial interest in the outcome of the research?

Yes No

7. Does any member of the research team have any affiliation with the provider(s) of funding/support, or a financial interest in the outcome of the research?

Yes No

8. Does any other individual or organisation have an interest in the outcome of this research?

Yes No

9. Are there any restrictions on the publication of results from this research?

Yes No

4. PRIOR REVIEW

Ethical Review

Some HRECs may require researchers to provide information additional to that contained in a NEAF proposal. For this reason, it is prudent to check whether the HRECs to whom you propose to submit this proposal require additional information.

Duration and location

1. In how many Australian sites, or site types, will the research be conducted?

3

2. In how many overseas sites, or site types, will the research be conducted?

0

3. Provide the following information for each site or site type (Australian and overseas, if applicable) at which the research is to be conducted

1

Site / Site Type Name:	Wuchopperen Health Service Limited
Site / Site Type Location:	Wuchopperen Health Service Limited - Aboriginal Medical Service MANOORA QLD 4870 Ph: (07) 3812 3843
2	
Site / Site Type Name:	Geraldton Regional Aboriginal Medical Service
Site / Site Type Location:	Geraldton Regional Aboriginal Medical Service PO Box 4109 60 Riferange Road Rangeway WA 6530
3	
Site / Site Type Name:	Wirraka Maya Health Service - Port Hedland
Site / Site Type Location:	Wirraka Maya Health Services Corporation 1-5 Hamilton Rd South Hedland, WA, 6722 (08) 9140 2922

4. Provide the start and finish dates for the whole of the study including data analysis

Anticipated start date: 13/01/2014 (dd/mm/yyyy)
Anticipated finish date: 18/12/2015 (dd/mm/yyyy)

5. Are there any time-critical aspects of the research project of which an HREC should be aware?

Yes No

Describe the time-critical aspects:

As a NHMRC Scholarship recipient APP1056434, one of my milestones is that I must have ethics clearance for conduct of my qualitative study through a HREC by December 2013. I also plan to submit my thesis by 23 December 2015.

6. To how many Australian HRECs (representing site organisations or the researcher's / investigator's organisation) is it intended that this research proposal be submitted?

2

A list of NHMRC registered Human Research Ethics Committees (HRECs), along with their institutional affiliations and contact details is available on the NHMRC website at the following web address:
http://www.nhmrc.gov.au/health_ethics/hrecs/overview.htm#d

7. HRECs

HREC 1

Name of HREC:

Cairns & Hinterland Health Service District Ethics Committee (EC00157)

Provide the start and finish dates for the research for which this HREC is providing ethical review:

Anticipated start date or date range: 14/01/2014 (dd/mm/yyyy)
Anticipated finish date or date range: 23/12/2014 (dd/mm/yyyy)

For how many sites at which the research is to be conducted will this HREC provide ethical review?

1

Site 1

Name of Site: Wuchopperen Health Service Limited

Principal Researcher 1

Principal Researcher Name:
Ms Anne-Marie Eades

Associate Researcher 1

Associate Researcher Name:

HREC 2

Name of HREC:

Western Australian Aboriginal Health Ethics Committee (EC00292)

Provide the start and finish dates for the research for which this HREC is providing ethical review:

Anticipated start date or date range: 14/01/2014 (dd/mm/yyyy)

Anticipated finish date or date range: 23/12/2014 (dd/mm/yyyy)

For how many sites at which the research is to be conducted will this HREC provide ethical review?

2

Site 1

Name of Site: Geraldton Regional Aboriginal Medical Service

Principal Researcher 1

Principal Researcher Name:
Ms Anne-Marie Eades

Principal Researcher 2

Principal Researcher Name:

Associate Researcher 1

Associate Researcher Name:

<p>Site 2</p> <p>Name of Site: Wirraka Maya Health Service - Port Hedland</p> <p>Principal Researcher 1</p> <p>Principal Researcher Name: Ms Anne-Marie Eades</p> <p>Associate Researcher 1</p> <p>Associate Researcher Name:</p>

8. Have you previously submitted an application, whether in NEAF or otherwise, for ethical review of this research project to any other HRECs?

Yes No

9. HRECs

Research conducted overseas

Peer review

11. Has the research proposal, including design, methodology and evaluation undergone, or will it undergo, a peer review process?

Yes No

Provide details of the review and the outcome. A copy of the letter / notification, where available, should be attached to this application.

Yes, the research proposal was submitted as part of successful application APP1056434 for a National Health & Medical Research Committee Indigenous Health Scholarship award for 2013, and underwent stringent peer review as part of the process for applicants of this scholarship.

THE PROJECT

1. Type of Research

Tick as many of the following 'types of research' as apply to this project. Your answers will assist HRECs in considering your proposal. A tick in some of these boxes will generate additional questions relevant to your proposal (mainly because the National Statement requires additional ethical matters to be considered), which will appear in Section 4 of NEAF.

The project involves:

Research using qualitative methods

Research using quantitative methods, population level data or databanks, e.g survey research, epidemiological research

Clinical research

Research involving the collection and / or use of human samples

Genetic testing/research

A cellular therapy

Research on workplace practices or possibly impacting on workplace relationships

Research conducted overseas involving participants

Research involving ionising radiation

Research involving gametes or use or creation of embryos

None of the above

Does the research involve limited disclosure to participants?
 Yes No

Are the applicants asking the HREC / review body to waive the requirement of consent?
 Yes No

Research plan

2. Describe the theoretical, empirical and/or conceptual basis, and background evidence, for the research proposal, eg. previous studies, anecdotal evidence, review of literature, prior observation, laboratory or animal studies.

Aboriginal and Torres Strait Islander people develop risk factors for chronic disease at an early age, are often diagnosed late when risk factors have progressed in severity and once identified those risk factors are sub-optimally managed. Dixon-Woods et al derived the concept of candidacy in understanding access to health care. This is defined as: the ways in which people's eligibility for medical attention and intervention are jointly negotiated between individuals and health services. It recognises that health service users in vulnerable groups must work hard to access health care and that the depth and complexity of this effort can evolve into insurmountable obstacles. Some key factors affecting candidacy include:

(1) Social Determinants: The recognition that health outcomes are strongly influenced by social determinants is now well recognised particularly through the landmark Whitehall studies. These determinants can be divided into institutional and psychosocial components. Thus racism can be understood at both the systemic level where its ideology is embedded in institutional structures and the individual level where racism is experienced between individuals and within their community. The practical impact of these issues on accessing health care has not been well acknowledged.

(2) Competing needs: People tend to place issues of immediate concern (acute

stressful events, family needs, financial needs, housing, employment, etc.....) over planning for future concerns (eg. prevention of complications from chronic disease). When this is combined with factors such as more rigid working patterns, obstacles in mobilising practical resources (eg. transport), and fear of being blamed by health professionals there are large disincentives to seeking health care. The range and importance of competing needs for Aboriginal and Torres Strait Islander people has been poorly described.

- (3) The role of family, kinship and relationship to healthcare providers: The Devitt and McMasters study revealed family support as the single most influential factor in affecting Aboriginal renal dialysis patients' acceptance and adherence to treatment. Other studies have highlighted the importance of the relationship between Aboriginal patients and their health care providers. Further work is needed to better understand the nature and importance of relationships in health care provision particularly across different settings (urban, rural and remote sites). This is particularly significant for Aboriginal women.
- (4) Shared decision making: This can be defined as a process by which patients and providers consider outcome probabilities and patient preferences and reach a health care decision based on mutual agreement. Given that the Western biomedical paradigm largely functions outside of the broader family and community context, care is frequently negotiated from different vantage points for patients when compared with their health providers. The Humphrey et al study revealed entrenched power imbalances in how decisions about health care are made. Aboriginal and Torres Strait Islander perspectives on how treatment is negotiated is again under explored.
- (5) Cultural competency: This can be seen as: a set of congruent behaviours, attitudes, and policies that come together in a system, agency or amongst professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations. Barriers to culturally competent care can occur at the organisational, systemic and clinical levels. The Aboriginal Medical Services movement emerged to respond to a massive unmet health need. It is a direct expression of community development and self-determination in primary health care. Culturally sensitive care can be seen as a key component of this movement. In contrast, hospital based services tend to be strongly aligned with the biomedical paradigm. This study will seek to explore the strengths and weaknesses of the primary care and hospital sectors in relation to this issue.

3. State the aims of the research and the research question and/or hypotheses, where appropriate.

Overview of Research

I am about to commence the qualitative component of my research project which will be to conduct interviews with Aboriginal and Torres Strait Islander women living with a chronic disease. My research topic is on chronic disease in Aboriginal communities with a particular focus on Aboriginal and Torres Strait Islander women's roles and responsibilities, and how these roles can impact on how these women manage their chronic disease. Highlighting to women the important role they play within their family and community and being able to document the interplay between these roles and managing their own health is important for improving health outcomes for Aboriginal women. I hope these improvements may lead to programs that nurture Aboriginal women in order for them to take care of business in their homes and community and to take better care of them self.

Research Aims

The main aim of my research will be to examine the level of knowledge and comprehension that Aboriginal and Torres Strait Islander women with chronic disease have about managing their chronic disease to achieve good health outcomes. This research aims to explore the experiences of these women having a chronic disease within the context of their family and community in which they live. I would like to talk with adult women who are or have utilized the services of the Aboriginal Medical Service (AMS) of the nominated site/s.

Research Questions

1. What is the impact on Aboriginal women of living with chronic disease?
2. How does living with chronic disease influence Aboriginal women's roles within their families?

3. How do the role women play within their families' impact on the management of their chronic disease?
4. Explore the meaning of psychosocial health and well being from the perspective of Aboriginal and Torres Strait Islander women
5. How does stress and poor psychosocial health in Aboriginal and Torres Strait Islander women impact on their ability to manage their chronic disease?

4. Has this project been undertaken previously?

Yes No

Benefits/Risks

In answering the following questions (Q 5 – 11) please ensure that you address all issues relevant to the type of participants that will be involved in your research project. Refer for guidance to relevant chapters of the National Statement.

5. Does the research involve a practice or intervention which is an alternative to a standard practice or intervention?

Yes No

6. Describe how the research demonstrates an understanding of and respect for and engages with the knowledge systems, cultural practices, heritage, beliefs, experiences and values of Aboriginal or Torres Strait Islander individuals and communities. Include, as appropriate:

-how the proposal responds to the diversity between communities eg. Different languages, cultures, histories, decision-making and perspectives (refer to Chapter 4.7 of the National Statement, Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, and the AIATSIS Guidelines for Ethical Research in Indigenous Studies)

-how the proposal contributes to and does not erode social and cultural bonds among Aboriginal and Torres Strait Islander participants and communities,

-how the research respects the values based expectations and identity and protects and promotes cultural distinctiveness of Aboriginal and Torres Strait Islander people participants.

Initial negotiation, consultation, agreement and mutual understanding will be established with the AMS at each of the sites prior to engagement with participants. A mutual understanding of all consultation and negotiations to achieve best outcomes for all concerned without compromise or harm to any of the participants, health services or researcher. The researcher will take responsibility for ensuring ongoing consultation and negotiation is planned and ensured throughout the conduct of the research.

The researcher will be guided by the health worker in each of the AMS sites to ensure language barriers and cultural values and practices are not compromised during the conduct of the research. The researcher will seek to have access to interpreting services in the appropriate languages where required. Interviews will be conducted at a venue suitable for both the researcher and the participant. Consent to participate in the study will be informed with assurance by the researcher that the participant is free to withdraw without risk of penalty to the participant at any time throughout the interview. As per principle 2, the researcher will be guided by the participant at all times to ensure there is no power imbalance that may compromise the participant's level of control and autonomy when disclosing personal information about themselves to the researcher.

As per principle 3, the researcher will at all times adhere to the participant's right to maintain control in the protection and development of their cultural heritage, traditional knowledge, cultural expressions and other tangible heritage issues. Principle 4 will be adhered to, whereby rights in the traditional knowledge and cultural expressions will be respected, protected and maintained throughout the conduct of this research. As highlighted in the research proposal, although the information collected belongs to the participant, this information will be stored with the researcher at a specified site. Acknowledgement of ownership will be expressed at all times via reports, presentations and publications. As per principle 5, all data collected during the interviews with women will be transcribed and then clarity will be sought by the researcher from each of the participants to ensure that the information reported on by the researcher is in fact what the participants had said.

7. What expected benefits (if any) will this research have for the wider community?

Potential benefits to community will include the identification and management of psychosocial health issues among Aboriginal and Torres Strait Islander women with chronic disease. If there are barriers to management of psychosocial health among Aboriginal and Torres Strait Islander women, the enhancing factor will be the development and or improvement in availability and accessibility of resources. There will also be an increased awareness of the issues related to Aboriginal and Torres Strait Islander women living with a chronic disease. The research will inform the development, implementation and evaluation of strategies to reduce the burden of chronic disease in Aboriginal and Torres Strait Islander women.

8. What expected benefits (if any) will this research have for participants?

Potential benefits to the individual like the community will include the identification and management of psychosocial health issues among Aboriginal and Torres Strait Islander women with chronic disease. If there are barriers to management of psychosocial health among Aboriginal and Torres Strait Islander women, the enhancing factor will be the development and or improvement in availability and accessibility of resources. There will also be an increased awareness of the issues related to Aboriginal and Torres Strait Islander women living with a chronic disease.

9. Are there any risks to participants as a result of participation in this research project?

Yes No

10. Explain how the likely benefit of the research justifies the risks of harm or discomfort to participants.

There is a risk to participants that when disclosing personal and sometimes sensitive information about themselves to the researcher, this may cause the participant to experience a sense of re-living sensitive issues or events that may have occurred in the past. However the aim of conducting this research is to identify issues related to these experiences and develop strategies to enhance effective ways of dealing with such issues in order to improve the well-being of these women.

11. Are there any other risks involved in this research? eg. to the research team, the organisation, others

Yes No

12. Is it anticipated that the research will lead to commercial benefit for the investigator(s) and or the research sponsor (s)?

Yes No

16. Is there a risk that the dissemination of results could cause harm of any kind to individual participants - whether their physical, psychological, spiritual, emotional, social or financial well-being, or to their employability or professional relationships - or to their communities?

Yes No

Monitoring

17. What mechanisms do the researchers / investigators intend to implement to monitor the conduct and progress of the research project?

The Researcher meets fortnightly with Supervisors and will provide a report on progress of study. The Researcher provides both the site and participants with contact details of her Primary Supervisor and the Research Higher Degree Ethics committee of the University of Sydney and Cairns & Hinterland Health Service District Ethics Committee that participants or sites can contact if they have any concerns.

Reporting

1. Research participants

The National Statement identifies the need to pay additional attention to ethical issues associated with research involving certain specific populations.

This question aims to assist you and the HREC to identify and address ethical issues that are likely to arise in your research, if its design will include one or more of these populations. Further, the National Statement recognizes the cultural diversity of Australia's population and the importance of respect for that diversity in the recruitment and involvement of participants. Your answer to this question will guide you to additional questions (if any) relevant to the participants in your study.

Tick as many of the following 'types of research participants' who will be included because of the project design, or their inclusion is possible, given the diversity of Australia's population. If none apply, please indicate this below.

If you select column (a) or (b), column (c) will not apply.

The participants who may be involved in this research are:	a) Primary intent of research	b) Probable coincidental recruitment	c) Design specifically excludes
<i>If you select column (a) or (b), column (c) will not apply.</i>			
People whose primary language is other than English (LOTE)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Women who are pregnant and the human foetus	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Children and/or young people (ie. <18 years)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
People in existing dependent or unequal relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
People highly dependent on medical care	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
People with a cognitive impairment, an intellectual disability or a mental illness	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Aboriginal and/or Torres Strait Islander peoples	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
People who may be involved in illegal activity	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
None apply	<input type="checkbox"/>		

You have indicated that it is probable that

- People whose primary language is other than English (LOTE)
- Women who are pregnant and the human foetus
- People highly dependent on medical care
- People with a cognitive impairment, an intellectual disability or a mental illness
- People who may be involved in illegal activity

may be coincidentally recruited into this project. The National Statement identifies specific ethical considerations for these groups(s).

Please explain how you will address these considerations in your proposed research.

This project will exclude children and/or young people. All participants will be Aboriginal and/or Torres Strait Islander women and we have described issues around appropriate conduct of research within this population. Women with chronic diseases, some of whom might be highly dependent on medical care will be recruited. We will explore their experiences and understanding of living with their medical conditions.

It is not the primary intent of this research to recruit people whose primary language is other than English, women who

are pregnant, people in existing dependent or unequal relationships, people with a cognitive impairment, an intellectual disability or a mental illness, or people who may be involved in illegal activity. Nevertheless, we recognise that some people will be recruited who are within such categories. We will work with their community-based providers and health services to ensure that we engage appropriate interpreters and support services to minimise potential burden on such participants. We will ensure that people understand they have the right not to participate and to withdraw from the research at any stage, without prejudicing their access to healthcare and support.

Participant description

2. How many participant groups are involved in this research project?

1

3. What is the expected total number of participants in this project at all sites?

50-80 participants

4. Groups

Group 1

Group name for participants in this group:	Aboriginal and Torres Strait Islander Women
Expected number of participants in this group:	50-80
Age range:	18-99

Other relevant characteristics of this participant group:

Participants will be Aboriginal and Torres Strait Islander women over the age of 18 years with a diagnosed chronic condition of at least one of the following disorders: diabetes, chronic kidney disease and cardiovascular conditions that include myocardial infarction and stroke and disorders of thought and thinking which may include depression, anxiety, stress and worry. Any Aboriginal women aged over 18 years utilising the Aboriginal Medical Service in the prospective site with a chronic disease that gives permission for Anne to interview her about her chronic disease.

Why are these characteristics relevant to the aims of the project?

The embedding of psychosocial and cultural factors into health care programs for Aboriginal and Torres Strait Islander people is linked to health and well-being. This link is particularly evident when programs focus on family and community needs being met as well as those of the individual. When discussing the social and emotional well-being of Aboriginal and Torres Strait Islander people, it is important to understand what is meant by well-being. Terms such as social and emotional well-being reflect information about a person's social, emotional, spiritual and cultural well-being. Such reference reflects people's feelings, how they cope with events, and how they function in their everyday lives. However, social and emotional well-being is also related to connection to land, family, community and tradition. Major influences on social and emotional well-being are reflected in historical events, discrimination, ill health, death of a family member, drug abuse and legal issues. The 2008 National Aboriginal Torres Strait Islander Social Survey reported that 80 percent of Aboriginal people who participated in the survey had experienced at least one significant stressor in the 12 months leading up to when the survey was conducted. The impact of these stressors on Aboriginal women's health is poorly understood.

Your response to question 1 at Section 6 - "Research Participants" indicates that the following participant groups are excluded from your research. If this is not correct please return to question 1 at Section 6 to amend your answer.

- Children and/or young people (ie. <18 years)
- People in existing dependent or unequal relationships with any member of the research team, the researcher(s), and/or the person undertaking the recruitment/consent process (eg. student/teacher; employee/employer; warden/prisoner; officer, enlisted soldier; patient/doctor)

5. Have any particular potential participants or groups of participants been excluded from this research? In answering this question you need to consider if it would be unjust to exclude these potential participants.

All males.

Females aged 0 – 17 year

Any person diagnosed with dementia or where there is risk of informed consent not being valid.

This study focuses on the experience of Aboriginal and Torres Strait Islander women living with chronic disease. It builds on work undertaken by my supervisor, Professor Alex Brown, who explored similar issues with Aboriginal men.

Participant experience

6. Provide a concise detailed description, in not more than 200 words, in terms which are easily understood by the lay reader of what the participation will involve.

Qualitative Interviews

The participant will be asked to sign a Participant Consent Form. The interview will be audio-taped and discussion will focus on chronic disease in Aboriginal communities with a particular focus on Aboriginal and Torres Strait Islander women's roles and responsibilities, and how these roles may impact on women managing their chronic disease.

At commencement of the interview, participants will be asked their age, gender, occupation, medical history and family structure which will be used to capture base-line data. The participant will also be asked about their role in the family and community, and also about her opinion about what she considers to be of most importance in this role. The participant will have the opportunity to provide additional information that she would like to include, but was not covered in the interview questions.

Participants may also be invited to participate in a group to elaborate on themes developed during the interviews. The researcher will discuss with the participant at the end of the interview with the participant's permission, date and time to meet with them again to clarify the accuracy of interpretation of content of the interview and amend where necessary.

All of the information collected from the study would be treated with the strictest confidence, and only the researcher will have access to your personal information. Her supervisor's Professor Alan Cass, Associate Professor Maree Hackett or Professor Alex Brown would have access to the data collected once it has been de-identified. The study results may be presented at a conference or via publication; but individual participants would not be identifiable in any such presentation. This research will greatly benefit the researcher and your generosity of time and sharing your knowledge is greatly appreciated.

Relationship of researchers / investigators to participants

7. Specify the nature of any existing relationship or one likely to arise during the research, between the potential participants and any member of the research team or an organisation involved in the research.

No additional relationship anticipated other than that of researcher and research participant.

No member of the research team has a role in provision of healthcare to potential participants and no member of the research team has a role within any of the community controlled health services.

9. Describe what steps, if any, will be taken to ensure that the relationship does not impair participants' free and voluntary consent and participation in the project.

Not relevant.

10. Describe what steps, if any, will be taken to ensure that decisions about participation in the research do not impair any existing or foreseeable future relationship between participants and researcher / investigator or organisations.

We will ensure that women understand they have the right not to participate and to withdraw from the research at any stage, without prejudicing their access to healthcare and support.

11. Will the research impact upon, or change, an existing relationship between participants and researcher / investigator or organisations?

Yes No

12. Is it intended that the interview transcript will be shown or made available to participants?

Yes No

Why is it considered important that participants have access to this information?
In order to clarify that the researcher has interpreted correctly what the research participant is articulating.

Recruitment

13. What processes will be used to identify potential participants?

The Aboriginal Medical Service will be the first point of contact for engagement within the community. One of the Aboriginal Health Workers will approach the participants to see if they would be interested in talking to her about your experiences, about their roles and responsibilities as a women in their family and community; and how these roles and responsibilities impact on how well participants manage thier chronic disease. Following agreement to participate and take part in the interviews, arrangements will be made with the prospective participants for the interview to take place at a time and place convenient to the participant.

14. Is it proposed to 'screen' or assess the suitability of the potential participants for the study?

Yes No

How will this be done?

The Researcher will be guided by the Aboriginal Health Worker or person allocated by the Aboriginal Community Controlled health service site and potential suitability will be determined prior to the researcher approaching the participants.

15. Describe how initial contact will be made with potential participants.

One of the Aboriginal Health Workers will approach the potential participants to see if they would be interested in talking to the researcher about their experiences, about their roles and responsibilities as a woman in their family and community; and how their roles and responsibilities impact on how well they manage their chronic disease. Following agreement to participate and take part in the interviews, arrangements will be made with the prospective participants for the interview to take place at a time and place convenient to the participant.

16. Do you intend to include both males and females in this study?

Yes No

Please explain why only one sex is involved in the study. In doing this you will need to demonstrate why this approach is valid.
This study relates directly to Aboriginal and Torres Strait Islander women only.

17. Is an advertisement, e-mail, website, letter or telephone call proposed as the form of intial contact with potential participants?

Yes No

18. If it became known that a person was recruited to, participated in, or was excluded from the research, would that knowledge expose the person to any disadvantage or risk?

Yes No

Consent process

19. Will consent for participation in this research be sought from all participants?

Yes No

Will there be participants who have capacity to give consent for themselves?

Yes No

What mechanisms/assessments/tools are to be used, if any, to determine each of these participant's capacity to decide whether or not to participate?

The Researcher will be guided by the Aboriginal Health Worker or person allocated by the Aboriginal Community Controlled health service site and where translation is required this will be accessed for the participant through local interpreting services.

Are any of the participants children or young people?

Yes No

Will there be participants who do not have capacity to give consent for themselves?

Yes No

The following questions relate to participants who are able to provide consent and also to participants for whom consent may be provided by a person with legal authority to do so. When answering these questions you need to describe any differences in the processes followed, or the documentation used, for different groups of participants in your proposal, e.g. processes and documentation for users of facilities/services will differ from those for providers of those facilities/services. Where your proposal involves participants with an intellectual or mental impairment, or people in dependent relationships, additional questions about their consent appear at section 7 questions 19-20 and questions 15-18 respectively.

Describe the consent process, ie how participants or those deciding for them will be informed about, and choose whether or not to participate in, the project. Not Applicable - As participants will only be included in the study if they themselves have the legal authority to consent to participation in the study. No person will be included for whom consent needs to be provided by a person with legal authority to do so other than the person them self.

If a participant or person on behalf of a participant chooses not to participate, are there specific consequences of which they should be made aware, prior to making this decision? Not Applicable - As participants will only be included in the study if they themselves have the legal authority to consent to participation in the study. No person will be included for whom consent needs to be provided by a person with legal authority to do so other than the person them self.

Might individual participants be identifiable by other members of their group, and if so could this identification could expose them to risks? Yes individual participants may be identifiable by other members of their group when either entering or leaving the interview room on the day of the qualitative interviews. Where there is concern about being exposed to risk - the researcher will arrange to meet the participants at a place where the potential risk is reduced.

If a participant or person on behalf of a participant chooses to withdraw from the research, are there specific consequences of which they should be made aware, prior to giving consent? No. Potential participants will be advised that participation in this study is entirely voluntary and that they do not have to take part. If they do take part, they can withdraw at any time without having to give a reason. Only the researcher named above will be aware of their participation or non-participation. They may stop the interview at any time if they do not wish to continue or they may elect not to answer certain questions. The researcher will ask that any data collected prior to withdrawal, where applicable, will be allowed to be used. This data will only be used where consent has been given.

Specify the nature and value of any proposed incentive/payment (eg. movie tickets, food vouchers) or reimbursement (eg travel expenses) to participants. Reimbursement will be provided when applicable to cover travel expenses. Explain why this offer will not impair the voluntary nature of the consent, whether by participants' or persons deciding for their behalf. No incentive is provided. Only reimbursement of travel expenses incurred solely as a result of participation in the study.

Do you propose to obtain consent from individual participants for your use of their stored data/samples for this research project?

Yes No

7. Participants Specific

8. CONFIDENTIALITY/PRIVACY

Answers to the questions in section 8.1 will establish whether an HREC will need to apply guidelines under federal or State/territory privacy legislation in reviewing your application. Answers to questions in the remaining parts of section 8 will show how confidentiality of participants is to be protected in your research.

1. Do privacy guidelines need to be applied in the ethical review of this proposal?

Indicate whether the source of the information about participants which will be used in this research project will involve:

- collection directly from the participant
- collection from another person about the participant
- use or disclosure of information by an agency, authority or organisation other than your organisation
- use of information which you or your organisation collected previously for a purpose other than this research project

Information which will be collected for this research project directly from the participant

Describe the information that will be collected directly from participants. Be specific where appropriate. Information will be collected from participants regarding their experiences of living with chronic disease, how they manage their own health, and how this impacts on their roles within their family and community. The participants will have the opportunity to provide additional information that they would like to include, but was not covered in the interview questions.

At commencement of the interview, participants will also be asked demographic questions such as age, gender, occupation, medical history and family structure which will be used to capture base-line data about the participants.

The participants may also be invited to participate in a group to elaborate on themes developed during the interviews. The researcher will discuss with the participant at the end of the interview. With the participants permission, a date and time to meet with them again to clarify the accuracy of the interpretation of the data collected of the interview and amend where necessary.

The information collected by the research team about participants will be in the following form(s). Tick more than one box if applicable.

- individually identifiable
- re-identifiable
- non-identifiable

Give reasons why it is necessary to collect information in individually identifiable or re-identifiable form
Identifiable information is necessary for the researcher to follow up with participants to provide them with copy of transcript and to clarify the accuracy of the interviews reported in the transcript. It is also important when reporting back to each of the sites to be able to identify site specific information.
Any stored data will de-identified. Each participant transcript will be stored under a study and participant-specific number with initials, site number and study participant number.

Using information from participants

2. Describe how information collected about participants will be used in this project.

- Information will be transcribed
- Transcripts will be read and coded for recurring themes related to the impact of the roles and responsibilities of participants, and how these roles and responsibilities impact on management of their chronic disease.
- Themes/topics recurring frequently and spontaneously will become main themes that indicate significant topic areas
- Each main theme may have many 'sub themes'
- These themes and sub-themes will identify areas of concern and be 'hypothesis generating' for future research.
- De-identified demographic information will be used to describe the participants in the study

3. Will any of the information be used by the research team be in identified or re-identifiable (coded) form?

Yes No

Indicate whichever of the following applies to this project:

- Information collected for, used in, or generated by, this project will not be used for any other purpose.
- Information collected for, used in, or generated by, this project will/may be used for another purpose by the researcher for which ethical approval will be sought.
- Information collected for, used in, or generated by, this project is intended to be used for establishing a database/data collection/register for future use by the researcher for which ethical approval will be sought.
- Information collected for, used in, or generated by, this project will/may be made available to a third party for a subsequent use for which ethical approval will be sought.

4. List ALL research personnel and others who, for the purposes of this research, will have authority to use or have access to the information and describe the nature of the use or access. Examples of others are: student supervisors, research monitors, pharmaceutical company monitors.

All of the information collected from the study would be treated with the strictest confidence. Only the researcher would have the participants contact information and her supervisors Professor Alan Cass, Associate Professor Maree Hackett or Professor Alex Brown would have access to the data collected once it has been coded and de-identified. The supervisors will not have access to any information that can identify individual participants. The study results may be presented at a conference or via publication; but individual participants would not be identifiable in any such presentation.

Storage of information about participants during and after completion of the project

5. In what formats will the information be stored during and after the research project? (eg. paper copy, computer file on floppy disk or CD, audio tape, videotape, film)

Some basic demographic information will be collected and stored as paper copies. Interviews will be conducted with portable digital recording devices. Records of interviews will be stored electronically as computer files in secure, password-protected storage.

6. Specify the measures to be taken to ensure the security of information from misuse, loss, or unauthorised access while stored during and after the research project? (eg. will identifiers be removed and at what stage? Will the information be physically stored in a locked cabinet?)

Information will be stored in a locked filing cabinet and in password-protected computer files, to which the student will have access. Well-established processes for secure data storage at the George Institute will ensure security of information throughout conduct of the research and after the research project is completed.

9. The information which will be stored at the completion of this project is of the following type(s). Tick more than one box if applicable.

- individually identifiable
- re-identifiable
- non-identifiable

Give reasons why it is necessary to store information in individually identifiable or re-identifiable form.

If the data can be re-identified using a code, specify the security arrangements and access for the code.
Interview transcripts will be stored as non-identifiable information. Separately, a master-file will be stored which would allow the research team to re-identify participants. One reason will be that we will offer research participants the right to destroy their interview record and transcript, if they request this, after their death.

10. For how long will the information be stored after the completion of the project and why has this period been chosen?

The information related to the project must be stored for a minimum of 7 years following completion of the project.

11. What arrangements are in place with regard to the storage of the information collected for, used in, or generated by this project in the event that the principal researcher / investigator ceases to be engaged at the current organisation?

In the event that the student ceases to be engaged at the George Institute, information collected during this study would remain securely stored and be used for the intended purposes.

Ownership of the information collected during the research project and resulting from the research project

12. Describe how the research will respect and acknowledge the contribution of Aboriginal or Torres Strait Islander peoples to the research. Include, as appropriate:

- acknowledgement of cultural property rights in relation to knowledge, ideas, cultural expressions and cultural materials,
- acknowledgement of the sources of information and those who have contributed to the research
- a description of any agreement (preferably written) between the researchers / investigators and the community regarding research intentions, methods and potential results.

The information collected during this study will be stored by the researcher but owned by the participant. It is for this reason that the researcher will clarify with each of the participants where ever possible, that the researchers interpretation is in fact what was provided by each participant. Where knowledge, ideas, cultural expressions and or cultural materials may be used during the project, acknowledgement will be given at feedback to community, public presentations and in all publications to the property rights owner where these have been shared with the researcher.

The researcher has agreed to keep the Aboriginal Health Service informed of the progress of the research via a local reference group once established following ethics approval to conduct research with their health service. The researcher has also agreed to provide both a summary of the findings via a power point presentation at the completion of the study and to acknowledge the health service through my report of findings where appropriate.

13. Who is understood to own the information resulting from the research, eg. the final report or published form of the results?

Although the information will be reported by the PhD Candidate, ownership of the information will always belong to the participant providing the information.

14. Does the owner of the information or any other party have any right to impose limitations or conditions on the publication of the results of this project?

Yes No

Specify any limitations on publication:

That as assured by the researcher no participant will be identified in any way or form when the researcher is reporting via publication or presentations. If a participants does not want their data to be reported on then the researcher will respect their request.

Disposal of the information

15. Will the information collected for, used in, or generated by this project be disposed of at some stage?

Yes No

At what stage will the information be disposed?

Following the 7 year storage time-frame, all information will be destroyed.

How will information, in all forms, be disposed?

Recordings will be erased from the recording device.

Data held in paper form will be shredded.

All computer files will be deleted.

Reporting individual results to participants and others

16. Is it intended that results of the research that relate to a specific participant be reported to that participant?

Yes No

Explain/justify why results will not be reported to participants:

All participants will be invited to attend a presentation at the health service site or women's health centre to report results. The researcher will also prepare a report for each site which will be disseminated to participants utilising that site.

17. Is the research likely to produce information of personal significance to individual participants?

Yes No

18. Will individual participant's results be recorded with their personal records?

Yes No

19. Is it intended that results that relate to a specific participant be reported to anyone other than that participant?

Yes No

20. Is the research likely to reveal a significant risk to the health or well being of persons other than the participant, eg family members, colleagues

Yes No

21. Is there a risk that the dissemination of results could cause harm of any kind to individual participants - whether their physical, psychological, spiritual, emotional, social or financial well-being, or to their employability or professional relationships - or to their communities?

Yes No

22. How is it intended to disseminate the results of the research? eg report, publication, thesis

The results of the research will be disseminated back to each of the sites via a report and presentation. Dissemination of results will also be via publications and a thesis.

23. Will the confidentiality of participants and their data be protected in the dissemination of research results?

Yes No

Explain how confidentiality of participants and their data will be protected in the dissemination of research results:

The data will be reported for all participants and each site. Confidentiality of individual participants will be protected in the dissemination of results.

Research involving Aboriginal and/or Torres Strait Islander peoples

You have indicated that the research involves Aboriginal and/or Torres Strait Islander peoples. You should refer to relevant guidelines as appropriate eg. Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres

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Strait Islander Health Research <http://www.nhmrc.gov.au/publications/synopses/e52syn.htm>
National Statement Chapter 4.7 and AIATSIS Guidelines for Ethical Research in Indigenous Studies.

1. What is the estimated proportion of Aboriginal and Torres Strait Islanders peoples in the population from which participants will be recruited?

100 percent

2. Will the Aboriginal or Torres Strait Islander status of participants be recorded?

Yes No

Explain why the Aboriginal or Torres Strait Islander status of participants will be recorded:

The crux of this study is about understanding the roles and responsibilities of Aboriginal and Torres Strait Islander women, and how these roles and responsibilities impact on how the women manage their chronic disease. Therefore it is essential that the study contains Aboriginal and Torres Strait Islander women.

3. Will there be or has there been a process of consultation and negotiation between Aboriginal or Torres Strait Islander peoples and the researchers regarding the proposed research?

Yes No

Describe this process of consultation and negotiation.

Include, as appropriate:

- how the consultation process and the research proposal demonstrates the integrity of the researcher,
- negotiation of the aims, anticipated outcomes and priorities of the research,
- consultation regarding community and individual consent to participation in the research,
- the process for negotiating ongoing advice as the research progresses, to monitor ethical standards and minimise unintended consequences,
- how the processes show engagement with the values and processes of participating communities, and
- the process of negotiating access to, and /or control of the results of the research.

The process of consultation at each of the sites will commence following HREC approval. At this point, a letter has been sent to each of the CEO's of the health services outlining my research proposal. I have requested a letter of support from the health services to allow further engagement regarding the proposed research with their community. Such a letter of support has been obtained from Wuchopperen Aboriginal Health Service.

I have been engaged in similar research with Wuchopperen since 2011. As the Program Coordinator for the Kanyini Vascular Collaboration, I have been engaging with Wuchopperen Aboriginal Health Service to progress research conducted by Kanyini via a Centre of Excellence research grant, which includes a focus on stress, depression and chronic disease. I was also part of a team that established the Kanyini Vascular Collaboration Indigenous Caucus. This engagement should aid discussions with Wuchopperen Health Service regarding this proposed research.

4. Has there been a role for Aboriginal or Torres Strait Islander peoples in the development of the research and or will there be a role for Aboriginal or Torres Strait Islander peoples in the implementation of the research proposal?

Yes No

Describe the role of Aboriginal or Torres Strait Islander peoples in the development and or implementation of the research.

Include, as appropriate:

- whether any or all of the researchers are Aboriginal or Torres Strait Islander people,
- how Aboriginal or Torres Strait Islander peoples from the community involved in, or affected by, the research have collaborated in the development of the research,
- whether the participating communities have expressed satisfaction with the research agreement, potential benefits and their distribution,
- the extent to which reciprocal obligations, responsibilities and benefits is demonstrated between the researchers and the community.

This research will be part of my PhD candidacy, Although I will be supervised appropriately, I will be responsible for the development, implementation and conduct of the research. I am a member of the Noongar community from the South West of Western Australia and have combined experience and expertise in nursing practice and Aboriginal Health, with a commitment to identifying preventative strategies

for chronic disease improvements. I have a particular interest in the role of psychosocial factors in chronic disease and in building resilience in Aboriginal Health. I have a good understanding of the practical and policy issues underlying care for chronic disease in Aboriginal communities, as well as the need for prevention. Should this application be successful, I will explore the role of psychosocial factors related to the roles and responsibilities of Aboriginal and Torres Strait Islander women and how these impact on management of chronic disease and to identify practical preventive strategies, for improved outcomes where necessary.

5. Describe how the research will provide benefits to the Aboriginal and Torres Strait Islander peoples.

Include, as appropriate

- a description of how the research relates to the health priorities and needs of participant communities,
- a description of benefits for participants and the communities, including establishment and/or enhancement of capacities, opportunities and outcomes beyond the project,
- a description of how the research shows an intent to contribute to the advancement of the health and well being of participants and their communities.

The health of Aboriginal and Torres Strait Islander women is poor when compared with non Aboriginal and Torres Strait Islander women in Australia and other first world countries. The literature infers that one of the major factors for the poor health status of Aboriginal and Torres Strait Islander women in Australia is due to late presentation leading to diagnosis at advanced stages of disease, resulting in poor health outcomes. This project will explore the impact on Aboriginal and Torres Strait Islander women of living with a chronic disease. The roles Aboriginal and Torres Strait Islander women maintain in the family will have to be explored in order to collect this information. This study will also explore how Aboriginal and Torres Strait Islander women's roles within their families influence management of their own health. Local reference groups will oversee the conduct of the study.

10. Declarations And Signatures

Applicant / Principal Researchers (including students where permitted)

Project Title (in full):	Exploring the impact of Chronic disease on Aboriginal women: Is there a relationship between stress, psychosocial health and management of chronic disease for Aboriginal women?
HREC to which this application is made:	
HREC Reference number:	

I/we certify that:

- All information is truthful and as complete as possible.
- I/we have had access to and read the National Statement on Ethical Conduct in Research Involving Humans.
- The research will be conducted in accordance with the National Statement.
- The research will be conducted in accordance with the ethical and research arrangements of the organisations involved.
- The research will be conducted in accordance with the ethical and research arrangements of the organisations involved.
- I/we have consulted any relevant legislation and regulations, and the research will be conducted in accordance with these.
- I/we will immediately report to the HREC anything which might warrant review of the ethical approval of the proposal (NS 2.37), including:
 - serious or unexpected adverse effects on participants;
 - proposed changes in the protocol; and
 - unforeseen events that might affect continued ethical acceptability of the project.
- I/we will inform the HREC, giving reasons, if the research project is discontinued before the expected date of completion (NS 2.38);
- I/we will not continue the research if ethical approval is withdrawn and will comply with any special conditions required by the HREC (NS. 2.45);
- I/we will adhere to the conditions of approval stipulated by the HREC and will cooperate with HREC monitoring

requirements. At a minimum annual progress reports and a final report will be provided to the HREC.

Applicant / Chief Researcher(s) / Principal Researcher(s)

Principal Researcher section was signed electronically by Professor Alex Brown on 24/09/2013 21:51

Job Title/Post: Deputy Director, Program Lead Aboriginal Health
Organisation: SAHMRI
Email: alex.brown@sahmri.com
Decision/Comments: Authorised

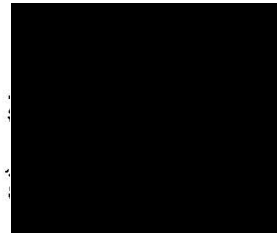
Principal Researcher section was signed electronically by Professor Alan Cass on 25/09/2013 13:04

Job Title/Post: Director
Organisation: Menzies School of Health Research
Email: alan.cass@menzies.edu.au
Decision/Comments:

Principal Researcher section was signed electronically by Associate Professor Maree Hackett on 25/09/2013 10:54

Job Title/Post: Head, Mental Health and Chronic Disease Program
Organisation: The George Institute for Global Health
Email: mhackett@george.org.au
Decision/Comments:

Ms Anne-Marie Eades
The George Institute for Global Health



25.9.2013
Date

25.09.2013
Date

Associate Researchers

Supervisor(s) of student(s)

Project Title (in full): Exploring the impact of Chronic disease on Aboriginal women: Is there a relationship between stress, psychosocial health and management of chronic disease for Aboriginal women?
HREC to which this application is made:
HREC Reference number:

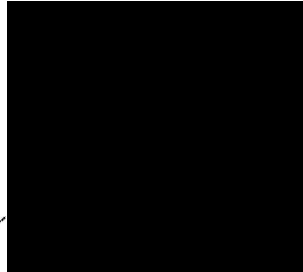
I/we certify that

- I/we will provide appropriate supervision to the student to ensure that the project is undertaken in accordance with the undertakings above;
- I/we will ensure that training is provided necessary to enable the project to be undertaken skillfully and ethically.

Professor Alan Cass

Associate Professor Maree Hackett

Professor Alex Brown



26.9.2013
Date

25.9.2013
Date

25.9.2013
Date

Heads of departments/schools/research organisation

Project Title (in full): Exploring the Impact of Chronic disease on Aboriginal women: Is there a relationship between stress, psychosocial health and management of chronic disease for Aboriginal women?

HREC to which this application is made:

HREC Reference number:

I/we certify that:

- I/we are familiar with this project and endorse its undertaking;
- the resources required to undertake this project are available;
- the researchers have the skill and expertise to undertake this project appropriately or will undergo appropriate training as specified in this application.

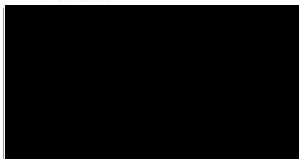
A-PROP
Title

TEAM
First Name

Maree
Surname

Acctyng H.O.S.
Position

SYDNEY SCHOOL OF PUBLIC HEALTH
Organisation Name



27.9.13
Date

List of Attachments

Core Attachments	Attachments which may be required/appropriate
Recruitment/invitation	Copy of advertisement, letter of invitation etc
Participant Information	Copy or script for participant Copy or script for parent, legal guardian or person responsible as appropriate
Consent Form	Copy for participant For parent, legal guardian or person responsible as appropriate For, optional components of the project eg. genetic sub study
Peer review	Copy of peer review report or grant submission outcome
HREC approvals	Copy of outcome of other HREC reviews

Attachments specific to project or participant group	Attachments which may be required/appropriate
People whose primary language is other than English (LOTE)	English translation of participant information/consent forms
People with an intellectual or mental impairment	Information/consent form for legal guardian or person responsible
People highly dependent on medical care	Information/consent form for legal guardian or person responsible
Aboriginal and/or Torres Strait Islander peoples	Evidence of support / permission of elders and/or other appropriate bodies

Participant information elements

Core Elements

Provision of information to participants about the following topics should be considered for all research projects.

Core Elements	Issues to consider in participant information
About the project	Full title and / or short title of the project Plain language description of the project Purpose / aim of the project and research methods as appropriate Demands, risks, inconveniences, discomforts of participation in the project Outcomes and benefits of the project Project start, finish, duration
About the investigators / organisation	Researchers conducting the project (including whether student researchers are involved) Organisations which are involved / responsible Organisations which have given approvals Relationship between researchers and participants and organisations
Participant description	How and why participants are chosen How participants are recruited How many participants are to be recruited
Participant experience	What will happen to the participant, what will they have to do, what will they experience? Benefits to individual, community, and contribution to knowledge Risks to individual, community

APPENDIX 2: CENTRAL AUSTRALIAN HUMAN RESEARCH ETHICS COMMITTEE

CENTRAL AUSTRALIAN HUMAN RESEARCH ETHICS COMMITTEE

Centre for Remote Health

PO Box 4066 Alice Springs NT 0871
Ph: (08) 8951 4700 Fax: (08) 8951 4777
Email: cahrec@flinders.edu.au

Ms Anne-Marie Eades
PO Box M201
Missendon Rd
The University of Sydney
NSW 2050

25th March 2014

Our Ref: HREC-14-212

Dear Ms Eades

RE: Ethics Application – Approval

The Central Australian Human Research Ethics Committee (CAHREC) Chair has considered your response to the Committee's request for further information about your research project 'Exploring the impact of Chronic Disease on Aboriginal women: Is there a relationship between stress, psychosocial health and management of chronic disease for Aboriginal women?'

The Chair agreed that this project now meets the requirements of the National Statement on Ethical Conduct in Human Research.

The Chair decided to **grant approval** for your project to proceed.

The period for which approval has been given is from the date of this letter until the **30th June 2014**. If you do not complete the research within the projected time please request an extension from CAHREC.

Ethics approval is contingent upon the submission of an annual Progress Report and a Final Report upon completion of the project. Please make a note of the following dates as failure to submit reports in a timely manner will result in your ethics approval lapsing.

Your Final report is due on:

30th June 2014

Copies of the report form can be downloaded from the CAHREC website.

Yours sincerely

Chris Schwarz
Secretariat Support
Central Australian Human Research Ethics Committee

APPENDIX 3: WESTERN AUSTRALIAN INDIGENOUS HEALTH ETHICS COMMITTEE ETHICS APPROVAL

Western Australian Aboriginal Health Ethics Committee



31st March 2014

Dear Anne-Marie,

RE: HREC Reference number: 535

Title: Exploring the impact of Chronic disease on Aboriginal women: Is there a relationship between stress, psychosocial health and management of chronic disease for Aboriginal women.

Thank you for your response to the committees request for further information/clarity for the above research project. Your response was considered by the WAAHEC out of session.

I am pleased to advise that the WAAHEC has granted approval of this research project. WAAHEC approval is granted from 31st March 2014 pending your agreement of the following conditions:

1. Conditions

- The WAAHEC will be notified, giving reasons, if the project is discontinued before the expected date of completion.
- The Coordinating Investigator will provide an annual report to the WAAHEC and at completion of the study in the specified format. This form can be found on the AHCWA website (www.ahcwa.org).
- The approval for studies is for three years and the research should be commenced and completed within that period of time. Projects must be resubmitted if an extension of time is required.
- Publications that arise from this research are to be provided to the WAAHEC for review prior to submission for dissemination.
- That the Aboriginal and Torres Strait Islander community are formally acknowledged for their contribution to this research project.

2. Amendments

If there is an event requiring amendments to be submitted you should immediately contact ethics@ahcwa.org for advice.

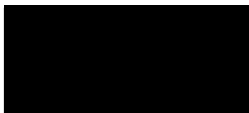
Western Australian Aboriginal Health Ethics Committee



Should you have any queries about the WAAHEC's consideration of your project please contact ethics@ahcwa.org.

The WAAHEC wishes you every success in your research.

Kind regards



Chelsea Bell
For
Tammy Prouse
Chair, WAAHEC

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, *NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. The process this HREC uses to review multi-centre research proposals has been certified by the NHMRC.

APPENDIX 4: PARTICIPANT INFORMATION STATEMENT



PARTICIPANT INFORMATION STATEMENT:

Exploring the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

(1) What is the study about?

You have been invited to participate in a study that seeks to explore the impact of the roles and responsibilities of Aboriginal and Torres Strait Islander women, their families and their communities. The goal of the study is to highlight to women the important role they play within their family and community; and then being able to document the interplay between these roles and managing their own health.

This research may highlight a need for the development of programs that nurture Aboriginal and Torres Strait Islander women in order for them to take care of business at home, in the community and most importantly to themselves.

You are receiving this **Participant Information Statement** because you are a current client of Wuchopperen Aboriginal Health Service, and you were selected by your service as a potential participant fitting the criteria of the study, you are a woman, aged 18 years or more and you have at least one of the following diagnosed chronic conditions: diabetes, chronic kidney disease, cardiovascular disease or disorders of thought and thinking which may include depression, anxiety, stress or worry. You have read the **Notification to Inform Potential Participant Form** and have expressed an interest in being part of the study.

(2) Who is carrying out the Study?

The Study is being conducted by Anne Eades and will form the basis of her PhD studies and will be part of the basis of her Doctor of Philosophy dissertation from the University of Sydney and the George Institute for Global Health and supported by a NHMRC Aboriginal Health Scholarship. Anne

Anne-Marie Eades: Exploring the impact of the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

Participant Information Statement

10/03/2014

Version 2.0

1

will have the supervision of Professor Alan Cass, Director of Menzies School of Health Research, Associate Professor Maree Hackett, Head Chronic Disease at The George Institute and Professor Alex Brown, Theme Leader of Aboriginal Health of the South Australian Health and Medical Research Institute (SAHMRI).

(3) **What does the study involve?**

If you agree to participate in this study, you will be asked to take part in an interview with Anne Eades. This interview will take place at a location and time convenient to you. She will first go through this form with you, once you are very clear on what the study involves and all of your questions have been answered, Anne will ask you to sign a Participant Consent Form.

The interviews will be audio-taped and discussion will focus on Chronic Disease in Aboriginal communities with a particular focus on Aboriginal and Torres Islander women's roles and responsibilities, and how these roles impact on women managing their chronic disease.

You will also be asked about your role in your family and community, and your opinion about what you consider to be of most importance in this role. Additionally, you will be asked to complete a questionnaire related to depression. This form is called a Patient Health Questionnaire (PHQ-9) and is a way of measuring the severity of depression.

This depression tool could potentially assist in the diagnosis and management of some people with undetected depression. With your permission, the results of this questionnaire will be placed on your health file at the Aboriginal Medical Service.

A standard letter for the General Practice will be attached to the PHQ-9 results advising the Doctor of the results of your depression test and ask that these results be placed on your file and to follow up with you as they see necessary.

You will have the opportunity to provide additional information that you would like to include, but was not covered in the interview questions. Prior to commencement of the interview, she will ask

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Anne-Marie Eades: Exploring the impact of the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

you about your age, gender, occupation, medical history related to your chronic disease and family structure which will be used to capture base-line data about you.

You may also be invited to participate in a group to elaborate on themes developed during the interviews. Anne will discuss with you at the end of the interview with your permission, date and time to meet with you again to clarify the accuracy of interpretation of content of the interview and amend where necessary.

(4) **How much time will the study take?**

The interview will take between 30 – 90 Minutes.

(5) **Can I withdraw from the study?**

Yes, if you wish, at any time. Participation in this study is **entirely voluntary**. You do not have to take part. If you do take part, **you can withdraw at any time without having to give a reason**. If you choose to withdraw from the study, **your medical treatment will not be impacted**. Only the researcher named above will be aware of your participation or non-participation. You may stop the interview at any time if you do not wish to continue or you may elect not to answer certain questions.

(6) **Will anyone else know the results?**

All the information collected from you for the study will be treated confidentially, and only the researcher named above will have access to your personal information. My Supervisors will have access to your data once it has been de-identified. The study results may be presented at a conference or in a scientific publication, but individual participants will not be identifiable.

(7) **Will the study benefit me?**

While we intend that the research study will further increase the knowledge and awareness about the issues related to Aboriginal and Torres Strait Islander women living with a chronic disease, it may not be of direct benefit to you.

Anne-Marie Eades: Exploring the impact of the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

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(8) Can I tell other people about the study?

Yes. You are free to discuss your participation in this study with anyone.

(9) What if I require further information about the study or my involvement in it?

When you have read this information, the researcher will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Anne Eades at the George Institute on (02) 8507 2503/040 798 3720

(10) What if I have a complaint or any concerns?

Any person with concerns or complaints about the conduct of this research study can contact the HREC Co-ordinator of Cairns & Hinterland Hospital & Health Service Human Research Ethics Committee on telephone: 07 4226 5312 or via email Cairns.Ethics@health.qld.gov.au. Alternatively you can contact Wuchopperen Aboriginal Health Service on 07 4080 1000

This information sheet is for you to keep.

Anne-Marie Eades: Exploring the impact of the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

Participant Information Statement

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APPENDIX 5: CONSENT FORM



Participant Consent Form

I, [PRINT NAME], give consent to my participation in the research project:

Exploring the impact of Chronic Disease on the roles and responsibilities of Aboriginal and Torres Strait Islander women: Is there a relationship between stress, psychosocial health and management of chronic disease for Aboriginal women?

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement with the researcher.
3. I understand that being in this study is completely voluntary – I am not under any obligation to consent.
4. I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of my study may be published however no information about me will be used in any way that is identifiable.
5. I understand that I can withdraw from the study at any time without my withdrawal from the study impacting on my medical treatment
6. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher or the University of Sydney now or in the future.
7. I understand that I can stop the interview at any time if I do not wish to continue. Should you request it, the audio recording will be erased and the information provided will not be included in the study.

Anne-Marie Eades: Exploring the impact of the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

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Participant Consent Form

10/03/2014

Version 2.0

8. I consent to my general practice clinic being contacted by research staff if necessary.

General Practice Clinic: _____

Telephone Number: _____

9. I consent to:

- | | | |
|----------------------|-----|----|
| • Audio-recording | YES | NO |
| • Receiving Feedback | YES | NO |

If you answered YES to the "Receiving Feedback" question, please provide your details i.e. Mailing address or email address.

Feedback Option

Address: _____

Email: _____

.....

Signature

.....

Please PRINT name

.....

Date

Anne-Marie Eades: Exploring the impact of the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

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APPENDIX 6: PARTICIPANT QUESTIONS



Questions to Participant

Demographics

1. Can you tell me a bit about where you come from?

Roles in Household/Community

2. What about your family – can you tell me how many people are in your family and how they are related to you?

Do you all live together? How many people live with you in your house?
3. We would like to better understand all of the things that you do for this family.
 - Can you give me an idea of some of the things that you do?
 - What are your roles in looking after the family?
4. Can you tell me who takes care of the house for things like cleaning, shopping, paying the bills, cooking and getting the kids off to school?
5. What about in your community – can you tell me what roles or jobs you have in your community?

Health

6. When someone in your family gets sick and can't look after themselves, who takes care of them at home?
7. What happens when you get sick? Does anyone look after you? Can you tell me?
8. Think about your health problems, can you tell me what happens when you get sick?
9. Since being diagnosed with the chronic disease, has there been any impact or changes on how you take care of your family or get your work done?

Anne-Marie Eades: Exploring the impact of the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

Appendix 11_Participant Questions

Version 1.0,

18/09/2013

Page 1 of 1

10. What happens to your jobs in the community if you get sick?
11. Can you tell me how you feel or what you think - when people ask you about Aboriginal women's health and wellbeing?-

Social and Emotional Wellbeing

12. Do you worry about your family
13. Can you tell me about that
14. Does it affect how you look after your own health?
15. Always having to worry that your family are alright – how does this make you feel?
16. Do you ever feel as though it's all too much?
17. Where do you get this help from?

Anne-Marie Eade: Exploring the impact of the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

Appendix 11_Participant Questions

Version 1.0,

18/09/2013

Page 1 of 1

APPENDIX 7: PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

NAME: _____ DATE: _____

Over the *last 2 weeks*, how often have you been bothered by any of the following problems?
(use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way	0	1	2	3

add columns: + +

(Healthcare professional: For interpretation of TOTAL, please refer to accompanying scoring card.)

TOTAL:

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

	Not difficult at all	_____
	Somewhat difficult	_____
	Very difficult	_____
	Extremely difficult	_____

PHQ-9 is adapted from PRIME MD TODAY, developed by Drs Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke, and colleagues, with an educational grant from Pfizer Inc. For research information, contact Dr Spitzer at rls8@columbia.edu. Use of the PHQ-9 may only be made in accordance with the Terms of Use available at <http://www.pfizer.com>. Copyright ©1999 Pfizer Inc. All rights reserved. PRIME MD TODAY is a trademark of Pfizer Inc.

ZT274388

Fold back this page before administering this questionnaire

INSTRUCTIONS FOR USE

for doctor or healthcare professional use only

PHQ-9 QUICK DEPRESSION ASSESSMENT

For initial diagnosis:

1. Patient completes PHQ-9 Quick Depression Assessment on accompanying tear-off pad.
2. If there are at least 4 ✓s in the blue highlighted section (including Questions #1 and #2), consider a depressive disorder. Add score to determine severity.
3. **Consider Major Depressive Disorder**
—if there are at least 5 ✓s in the blue highlighted section (one of which corresponds to Question #1 or #2)
Consider Other Depressive Disorder
—if there are 2 to 4 ✓s in the blue highlighted section (one of which corresponds to Question #1 or #2)

Note: Since the questionnaire relies on patient self-report, all responses should be verified by the clinician and a definitive diagnosis made on clinical grounds, taking into account how well the patient understood the questionnaire, as well as other relevant information from the patient. Diagnoses of Major Depressive Disorder or Other Depressive Disorder also require impairment of social, occupational, or other important areas of functioning (Question #10) and ruling out normal bereavement, a history of a Manic Episode (Bipolar Disorder), and a physical disorder, medication, or other drug as the biological cause of the depressive symptoms.

To monitor severity over time for newly diagnosed patients or patients in current treatment for depression:

1. Patients may complete questionnaires at baseline and at regular intervals (eg, every 2 weeks) at home and bring them in at their next appointment for scoring or they may complete the questionnaire during each scheduled appointment.
2. Add up ✓s by column. For every ✓: Several days = 1 More than half the days = 2 Nearly every day = 3
3. Add together column scores to get a TOTAL score.
4. Refer to the accompanying PHQ-9 Scoring Card to interpret the TOTAL score.
5. Results may be included in patients' files to assist you in setting up a treatment goal, determining degree of response, as well as guiding treatment intervention.

PHQ-9 SCORING CARD FOR SEVERITY DETERMINATION

for healthcare professional use only

Scoring—add up all checked boxes on PHQ-9

For every ✓: Not at all = 0; Several days = 1;
More than half the days = 2; Nearly every day = 3

Interpretation of Total Score

Total Score	Depression Severity
0-4	None
5-9	Mild depression
10-14	Moderate depression
15-19	Moderately severe depression
20-27	Severe depression

APPENDIX 8: PARTICIPANT INFORMATION

TABLE 1 – PARTICIPANT INFORMATION

	A : Age Group	B : Chronic Disease	C : Marital Status	D : Employment	E : Local or Relocated	F : Geographic
31 : Site 2_11254	50 and above	Diabetes only	Not Married	Employed	Local	Remote
32 : Site 2_122511	50 and above	Diabetes only	Not Married	Employed	Local	Remote
33 : Site 2_132152	50 and above	Diabetes only	Not Married	Employed	Local	Remote
34 : Site 2_14189	50 and above	Diabetes only	Not Married	Employed	Local	Remote
35 : Site 3_01183_1	50 and above	Diabetes only	Not Married	Employed	Local	Urban
36 : Site 3_02291_1	50 and above	Diabetes only	Not Married	Employed	Local	Urban
37 : Site 3_03108	50 and above	Diabetes only	Not Married	Employed	Local	Urban
38 : Site 3_042510	26 to 49	Diabetes only	Not Married	Employed	Local	Urban
39 : Site 3_0547	50 and above	Diabetes only	Not Married	Employed	Local	Urban
40 : Site 3_06315	50 and above	Diabetes only	Not Married	Employed	Local	Urban
41 : Site 3_071610	26 to 49	Diabetes only	Not Married	Employed	Local	Urban
42 : Site 3_0811	50 and above	Diabetes only	Not Married	Employed	Local	Urban
43 : Site 3_09248	50 and above	Diabetes only	Not Married	Employed	Local	Urban
44 : Site 3_10269	50 and above	Diabetes only	Not Married	Employed	Local	Urban
45 : Site 3_11611	50 and above	Diabetes only	Not Married	Employed	Local	Urban
46 : Site 3_1183_2	50 and above	Diabetes only	Not Married	Employed	Local	Urban
47 : Site 3_12224_01	50 and above	Diabetes only	Not Married	Employed	Local	Urban
48 : Site 3_1315_2	50 and above	Diabetes only	Not Married	Employed	Local	Urban
49 : Site 3_14510_01	50 and above	Diabetes only	Not Married	Employed	Local	Urban
50 : Site 3_151810	26 to 49	Diabetes only	Not Married	Employed	Local	Urban
51 : Site 3_16811	50 and above	Diabetes only	Not Married	Employed	Local	Urban
52 : Site 3_1763	26 to 49	Diabetes only	Not Married	Employed	Local	Urban
53 : Site 3_1838	50 and above	Diabetes only	Not Married	Employed	Local	Urban
54 : Site 3_19291	50 and above	Diabetes only	Not Married	Employed	Local	Urban
55 : Site 3_20251	50 and above	Diabetes only	Not Married	Employed	Local	Urban
56 : Site 4_01305	50 and above	Diabetes only	Not Married	Employed	Local	Remote
57 : Site 4_02272	50 and above	Diabetes only	Not Married	Employed	Local	Remote
58 : Site 4_03185	26 to 49	Diabetes only	Not Married	Employed	Local	Remote
59 : Site 4_04282	50 and above	Diabetes only	Not Married	Employed	Local	Remote
60 : Site 4_05309	50 and above	Diabetes only	Not Married	Employed	Local	Remote

	A : Age Group	B : Chronic Disease	C : Marital Status	D : Employment	E : Local or Relocated	F : Geographic
1 : Site 1_0156	50 and above	Diabetes only	Married	Employed	Relocated	Rural
2 : Site 1_02268	50 and above	Diabetes only	Not Married	Employed	Local	Rural
3 : Site 1_03204	50 and above	CVD only	Not Married	Employed	Local	Rural
4 : Site 1_04146	50 and above	CVD only	Not Married	Employed	Local	Rural
5 : Site 1_05303	50 and above	Diabetes only	Not Married	Employed	Local	Rural
6 : Site 1_06179	50 and above	Diabetes only	Not Married	Employed	Local	Rural
7 : Site 1_07215	26 to 49	Diabetes only	Not Married	Employed	Local	Rural
8 : Site 1_08102	26 to 49	Diabetes only	Not Married	Employed	Local	Rural
9 : Site 1_09267	50 and above	Diabetes only	Not Married	Employed	Local	Rural
10 : Site 1_x1066	26 to 49	Diabetes only	Not Married	Employed	Local	Rural
11 : Site 1_x11218	26 to 49	Diabetes only	Not Married	Employed	Local	Rural
12 : Site 1_x12261	26 to 49	Diabetes only	Not Married	Employed	Local	Rural
13 : Site 1_x13168	50 and above	Diabetes, CKD, CVD	Not Married	Employed	Local	Rural
14 : Site 1_x14245	26 to 49	Diabetes only	Not Married	Employed	Local	Rural
15 : Site 1_x152310	50 and above	Diabetes only	Not Married	Employed	Local	Rural
16 : Site 1_x16306	26 to 49	Diabetes only	Not Married	Employed	Local	Rural
17 : Site 1_x17105	50 and above	Diabetes and CKD	Not Married	Employed	Local	Rural
18 : Site 1_x18266	50 and above	Diabetes only	Not Married	Employed	Local	Rural
19 : Site 1_x19162	26 to 49	Diabetes, CKD, CVD	Not Married	Employed	Local	Rural
20 : Site 1_x20285	50 and above	Diabetes and CVD	Not Married	Employed	Local	Rural
21 : Site 1_x22307	50 and above	Diabetes and CVD	Not Married	Employed	Local	Rural
22 : Site 2_02212	50 and above	Diabetes only	Not Married	Employed	Local	Remote
23 : Site 2_03278	50 and above	Diabetes only	Not Married	Employed	Local	Remote
24 : Site 2_04295	50 and above	Diabetes only	Not Married	Employed	Local	Remote
25 : Site 2_0558	50 and above	Diabetes only	Not Married	Employed	Local	Remote
26 : Site 2_06211	50 and above	Diabetes only	Not Married	Employed	Local	Remote
27 : Site 2_07212	50 and above	Diabetes only	Not Married	Employed	Local	Remote
28 : Site 2_0835	26 to 49	Diabetes only	Not Married	Employed	Local	Remote
29 : Site 2_09198	50 and above	Diabetes only	Not Married	Employed	Local	Remote
30 : Site 2_100101	50 and above	Diabetes only	Not Married	Employed	Local	Remote

	A : Age Group	B : Chronic Disease	C : Marital Status	D : Employment	E : Local or Relocated	F : Geographic
61 : Site 4_06266	26 to 49	Diabetes only	Not Married	Employed	Local	Remote
62 : Site 4_07251	26 to 49	Diabetes only	Not Married	Employed	Local	Remote
63 : Site 4_09204	50 and above	Diabetes only	Not Married	Employed	Local	Remote
64 : Site 4_1069	26 to 49	Diabetes only	Not Married	Employed	Local	Remote
65 : Site 4_11247	50 and above	Diabetes only	Not Married	Employed	Local	Remote
66 : Site 4_122710	50 and above	Diabetes only	Not Married	Employed	Local	Remote
67 : Site 4_13214	26 to 49	Diabetes only	Not Married	Employed	Local	Remote
68 : Site 4_14411	50 and above	Diabetes only	Not Married	Employed	Local	Remote
69 : Site 4_15103	50 and above	Diabetes only	Not Married	Employed	Local	Remote
70 : Site 4_1618	50 and above	Diabetes only	Not Married	Employed	Local	Remote

APPENDIX 9: NOTIFICATION TO INFORM POTENTIAL PARTICIPANT FORM



NOTIFICATION TO INFORM POTENTIAL PARTICIPANT:

Exploring the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

The following information will be given to potential participants by the health service workers from the _____ Aboriginal Medical Service about the study.

Dear [insert name of potential participant],

I am writing to ask if it might be possible for Anne Eades, a PhD Candidate, at the University of Sydney meet with you and to speak about her research exploring the roles and responsibilities of Aboriginal women and how these roles impact on the management of chronic disease

Overview of Research

The qualitative component of her studies will involve the conduct of interviews with Aboriginal and Torres Strait Islander women living with a chronic disease. Her research is on chronic disease in Aboriginal and Torres Strait Islander communities with a particular focus on women's roles and responsibilities, and how these roles can impact on how they manage their chronic disease. Anne hopes her work may result in the development of programs that nurture Aboriginal women in order for them to take care of business in their homes and community and to take care of themselves.

Interviews

Anne is engaging with the local Aboriginal Medical Services (AMS) Human Research Ethics Committee HREC/13/QCH/118-870 to talk to you about your experiences, about your roles and responsibilities as a woman in your family and community; and how these roles and responsibilities impact on how well you manage your chronic disease. The interview will be based on a set of questions related to the structure of your family, the roles women play both in their family and community, if living with a chronic disease (diabetes, kidney disease or cardiovascular disease) influences these roles and responsibilities and finally if stress and poor psychosocial health impacts on management of the chronic disease.

Secondly, you will be asked to complete a questionnaire related to depression. This form is called a Patient Health Questionnaire (PHQ-9) and is a way of measuring the severity of depression. This depression tool could potentially assist in the diagnosis and management of people with undetected depression. With your permission, the results of this questionnaire will be placed on your health file at the Aboriginal Medical Service.

1

Anne-Marie Eades: Exploring the impact of the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

Notification to inform potential participants

10/03/2014

Version 3.0

All of the information collected from the study would be treated with the strictest confidence. Only Anne would have your contact information and her supervisor's Professor Alan Cass, Associate Professor Maree Hackett or Professor Alex Brown would have access to the data collected, but my supervisors will not access information that can identify you. The study results may be presented at a conference or via publication; but individual participants would not be identifiable in any such presentation.

I would like to provide Anne with your contact details so she can let you know more about the study. If you do not wish me to pass on your contact information, please contact me by return email or in person. Alternatively, you can contact Anne on 040 798 3720 email aeades@georgeinstitute.org.au to participate, or decline participation.

Any person with concerns or complaints about the conduct of this research study can contact the HREC Co-ordinator of Cairns & Hinterland Hospital & Health Service Human Research Ethics Committee on telephone: 07 4226 5312 or via email Cairns.Ethics@health.qld.gov.au. Alternatively you can contact Wuchopperen Aboriginal Health Service on 07 4080 1000.

This study is important as more information is needed on the impact of chronic disease on women, their families and their communities. Highlighting to women the important role they play within their family and community and being able to document the interplay between these roles and managing their own health, may lead to programs that nurture Aboriginal women in order for them to take care of business in their homes, community and to take better care of them self.

Anne's research would greatly benefit from your generosity of time and sharing your knowledge.

I would like to thank you in advance for your time in considering your participation.

Anne Eades

APPENDIX 10: SAFETY PROTOCOL



Exploring the impact of the roles and responsibilities of Aboriginal and Torres Strait Islander women and how these roles impact on management of their chronic disease.

SAFETY PROTOCOL

The researcher and supervisors agree to the following:

- All interviews will be conducted in a safe, public place which is convenient to both people (e.g. a library or cafe or the local Aboriginal Medical Service) .
- There will be no interviewing after sunset or before sunrise.
- The interviewer will wear photo identification with a University of Sydney logo.
- The interviewer will be dressed appropriately.
- The interviewer will practice the interview, the introduction and conclusion, before doing it in the field.
- Another member of the research team will be available for contact while interviews are being conducted.
- The interviewer will carry a mobile phone and always let a third party know the time and location of each interview and the expected finish time.
- If at any time the interviewer feels unsafe before or during an interview, the interview will be immediately cancelled or terminated and they will exit the interview area.

Researcher Name _____

Researcher Signature _____

Date _____

Primary Supervisor Name _____

Primary Supervisor Signature _____

Date _____

Anne-Marie Eades: Exploring the impact of the roles and responsibilities of Aboriginal women and how these roles impact on management of their chronic disease.

Safety Protocol

Version 1.0,

18/09/2013

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