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Influences on food and lifestyle choices for Aboriginal and Torres Strait Islander Australians: An Aboriginal perspective

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This thesis is submitted in fulfilment of the requirements for the degree of Doctor of Philosophy, School of Public Health, Faculty of Medicine, University of Sydney The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

Chiften

Christopher Grant Lawrence 12 January 2015

DEDICATION

To my incredible and loving parents, Mary (nee Blurton) Lawrence, Dawson, my biological Aboriginal (Noongar) grandmother and Jack Henry James Dawson (both deceased) who adopted and raised and taught me to be responsible, respectful, honest, strong and independent. To my younger brother Kelvin John Lawrence (deceased) my childhood friend who passed away at the young age of 38 years old. I miss you every day mate. To my wonderful biological Aboriginal (Noongar) mother Gloria (nee Lawrence) Bennell who gave birth to me, thank you for your unconditional love and support. My biological Aboriginal (Noongar) father Dean David (George) Nelson (deceased) who died at the age of 46 years of age from Type 2 diabetes and heart disease. Sorry we did not get to know each other as adults. To my sister-girl/cousin Lesley Nelson for all your strength, support, love and friendship; thank you for all the laughs, tears and funny stories every day that keep me going. To my many other Aboriginal brothers and sisters, cousins, uncles and aunties and all my extended families for all the love, support, encouragement and laughter that you provide in our life journey together I say thank you. To my many friends in Perth, Sydney and Queensland, and all over Australia for all the love and support through uncertain periods of this PhD journey I say thank you for being there and standing by me.

At the time of writing this thesis a close Noongar Elder and family member Mrs Dorothy (Nana Dot) (nee Garlett) Winmar passed away. Nana Dot was the last surviving child of fourteen children born to my great-grandparents Dolly (nee Humes) and Richard Garlett (both deceased). Nana Dot was the youngest sister of my paternal grandmother Rene (nee Garlett) Nelson (whom I never met). Nana Dot passed away peacefully in her sleep at home. She was 76 years old. Nana Dot lived with Type 2 diabetes and was on kidney dialysis for a number of years. I want to pay homage and tribute to her for all her Noongar knowledge, wisdom, culture and life experiences that she happily shared with us. Thank you Nana Dot for all your love and support for me all through my life. I know you were very proud of me and of this PhD research. May you rest peacefully with all our families and loved ancestors. A special dedication to Dr Naomi Mayers (Aboriginal Medical Service, Redfern, thank you for being a friend and a 'mother' to me all these years in Sydney and for supporting me through the good and bad times. To Shireen Malamoo, Dulcie Flowers, Geraldine O'Brien, Michael Von Reth, Leone Malamoo, Cheryl Hayward, Wendy Hermasten, Will Harris, John Byrne and Chris Rauchle, Mary Poynton, Wendy Ribbands and mate Marko Paoli, you guys see me at my best and worst. Thank you for putting up with me and encouraging me to not give up. Your friendship means a lot to me.

In dedication to Uncle Charlie Perkins, one of my hero's who I had the privilege to meet and work with in fighting for human rights for Aboriginal people I offer the following quote that summarises much of this thesis;

All my youth, my best years, were taken from me and I regret it bitterly. The hunger and the poverty of it all. Always hungry. Sometimes when I have a meal now I eat too much ... It's that stolen youth. Stolen youth. And that's the saddest thing of all which I'm so bitterly resentful about. (Charles Perkins, interview with Peter Read, 1989)

The work presented in this thesis was carried out by the author under the supervision of Professor Alan Cass and Professor Sandra Eades. Both Alan and Sandra conceived the broad area for investigation, the study to reduce onset of diabetes through early intervention (STRIDE) and the 45 & Up data analyses, and under their supervision, I refined the methods and the analytical framework applied to the empirical research included in this thesis. In addition, I had a substantial involvement in all of the research that comprises this thesis. I was the lead author and wrote the first draft of the manuscripts included in Chapters 1, 2, 3, 4 and 6. In Chapter 6, I worked closely with Federica Barzi (biostatistician) and Julie Brimblecombe (nutritionist) on formulating the analysis plan. Together we refined the variables to analyse to ensure maximum statistical power to determine conclusive results. I wrote the draft abstract and the journal article for submission. I circulated the draft article to all the coauthors for their input. All authors provided their expert comments. I also provided substantial contributions to the conception, development; conduct and analysis of the research reported in Chapter 5 and co-authored the manuscript in Chapter 7. This thesis benefited from multidisciplinary collaboration and the relative contributions of each author and contributor are provided before each manuscript is presented.

As an Aboriginal (Noongar) from Perth, Western Australia, I have firsthand experience of the burden of disease among Indigenous Australians. In my own large Aboriginal family and extended families, preventable chronic diseases, such as Type 2 diabetes and cardiovascular disease, impact upon many members. Social determinants that can often escalate these diseases include poor and often overcrowded housing, lack of education, poor literacy and numeracy, high unemployment and low uptake of training opportunities.

The political history of the South-West Noongar people should also be considered when contextualising these issues, for example, the Western Australian Aborigines Protection Act 1905,¹ 'established the position of Chief Protector who was the legal guardian of 'every aboriginal and half-caste child' to the age of 16 years. Regional protectors were to be appointed with power to grant permits for employment of Aboriginal males less than 14 years and Aboriginal females. No person was to remove any 'aboriginal', any male 'half-caste' under 16, or any female 'half-caste' without the written authority of a protector. The Minister for Aboriginal Affairs may remove 'aboriginals' from one reserve or district to another reserve or district. The marriage of an 'aboriginal' woman and a non-Aboriginal man was to require the permission of the Chief Protector. The Minister may exempt 'aboriginals' from the Act but an exemption could be cancelled at any time. Regulations may be made for 'the care, custody and education of the children of aborigines and half-castes' and 'enabling any aboriginal or half-caste child to be sent to and detained in an aboriginal institution, industrial school or orphanage'. The Fauna Protection Act 1950² was also used to govern Aboriginal people in the state; other states and territories had similar laws.

Both my parents are Aboriginal (Noongar and Yamitji) people from Western Australia. Both were taken to institutions. My Mother, Gloria, was taken to New Norcia Mission, 132 kilometres north of Perth when she was eight years old (around 1957). My Father, Dean (dec) was taken to Norseman Mission, 724 kilometres north of Perth, at the age of eight or nine years old (around 1955). Both parents experienced extreme psychological distress, cruelty, abuse and neglect in these missions that would haunt them all their lives. In 1966, just before the 1967 Referendum, I was born. I was a non-citizen in the small wheat belt town of Northam; 100 kilometres east of Perth. I was immediately made a 'Ward of the State' under The Child Welfare Department of Western Australia (1927-1972)³ which was 'responsible for the welfare of children in out of home care for much of the twentieth century. Known as the 'CWD' or 'the welfare', the department had an impact on the lives of many West Australian families. The CWD ran its own Children's Homes, 'placed' children in other children's homes or foster homes and organised adoptions. It licensed and inspected the places and people who were registered to provide care and kept statistics on the number of children who were in care. The CWD also had the power to bring children before the Children's Court'.

After I was born I was taken home to the local Aboriginal Reserve⁴ where we lived in tin shacks with dirt floors with no running water or sewage system. This was the beginning of my life.

Growing up, my mother would often talk about her days in the mission. She and three of her siblings plus one nephew would spend their childhood and adolescence in New Norcia Mission. Gloria was released when she turned 16 years old. Besides the inhumane cruel, physical and psychological treatment of the Aboriginal children, Gloria would often talk about food in the missions; especially when she saw food being wasted; or when certain types of food reminded her of her mission days. Gloria would tell us how she had to collect eggs from the chook-pen first thing in the morning, even in winter, with no shoes. She said the eggs were never to be eaten by the Aboriginal children; they were to be collected and prepared for the pastoralists non-Aboriginal boarding school students who resided there. Instead the Aboriginal children were fed 'weevil' infested porridge or 'bread-slops' (a mix of stale bread and milk) for breakfast; 'stale bread and biscuits' during the day; and 'sheep head soup' for dinner. The 'sheep head soup' was often 'cleaned of maggots' before being cooked in boiling water; there were no vegetables. As a way of 'enjoying' and 'filling up' on the stale bread and sheep head soup at dinner, the Aboriginal children would scrape the sides of the pot to capture fat residue and use as a substitute for butter. Gloria often said 'salt made it taste better'. Although Gloria recalls 'fresh fruit and vegetables coming in trucks' Aboriginal children were forbidden to eat any. When fruit (if any) was given to Aboriginal children the fruit was often rotten and inedible. Gloria also fondly remembers one of the 'good' Nuns who would take the Aboriginal girls to the side and give them 'Holy Bread' to fill up on.

My mother started smoking at the age of 15 years and smoked for 30 years. She smoked while pregnant for both my younger brother and me. In 1999 she gave up smoking after being diagnosed with Type 2 diabetes. In 2005 she needed a coronary artery bypass surgery operation. This operation has extended Gloria's life; she now enjoys living a healthy lifestyle and she has stopped smoking.

My father (George) died at the age of 46 years from Type 2 diabetes and cardiovascular disease. He too was a cigarette smoker. George refused to talk about his days in the mission as they were probably too disturbing for him to recall. My father was one of seventeen children; only two are alive at the time of writing this PhD thesis. My father and five of his siblings were placed into the Norseman Mission after their mother died at a young age. Some of my father's siblings died from tragic circumstances (most related to alcohol and violence) while others died from cardiovascular disease (CVD) caused by Type 2 diabetes. I witnessed some of my aunts and uncles endure psychological distress and pain from having their limbs amputated and losing their eyesight due to Type 2 diabetes. They were all heavy consumers of alcohol and cigarette smokers and led unhealthy lifestyles. The two remaining siblings, an aunt and an uncle, also have Type 2 diabetes; only one has smoked cigarettes in her life.

Many children of my aunts and uncles (my first cousins) were also placed into missions or were fostered into white families. Some of these cousins later committed suicide or died tragically from violent alcohol related events. In 1990 three of my first cousins died in Alice Springs in the Northern Territory. One shot himself, one drowned in a local water hole after consuming too much alcohol and the other from a car accident where alcohol was involved. The three of them were under the age of twenty five years. All three had been exposed to violence, institutions, foster care and abuse.

The 'Bringing them Home Report'⁵ examined the experiences of many Aboriginal children who were taken from their parents and placed into missions, institutions, or placed into foster care and or adopted illegally. The report details traumatic personal testimonies of people who discuss their personal psychological distress of the inhumane physical, emotional and sexual abuse that they received while in these settings. While the Royal Commission focused on the fundamental treatment of Aboriginal children in these settings, the Commission did not explore food security, access to or nutritional neglect of Aboriginal children as part of their enquiry. From the anecdotal evidence of my mother, aunts and uncles, it would appear that food security; access or nutritional value was limited, poorly provided and not a priority. Either way, we now know that Aboriginal and Torres Strait Islander people suffer epidemic proportions of preventable chronic disease, such as Type 2 diabetes and CVD, which mostly stems from living a poor and unhealthy lifestyle. We also know Aboriginal and Torres Strait Islander people are increasingly becoming obese and that the gap in life expectancy is between 12 and 15 years compared to other Australians⁶. This gap is still too wide and we need to conduct further robust health research to address these alarming concerns.

This PhD thesis focuses on 'Influences on food and lifestyle choices among Aboriginal and Torres Strait Islander Australians'. It also discusses aspects of past Australian government history, policies and treatment of Aboriginal and Torres Strait Islander people and how these past practices have and still do impact on their health and wellbeing. In addition to other social determinants of poor health, such as poor housing, low socio-economic status, high unemployment and poor retention rates in education, this PhD also explores psychological distress associated with poor health and diet outcomes. This research presents new evidence on associations with diet and psychological distress and what factors might be influencing food choices and risky lifestyle behaviours that can lead to early onset of Type 2 diabetes and cardiovascular disease, as well as acquisition of blood borne viruses, causing early mortality among Aboriginal and Torres Strait Islander Australians. I chose these topics for my PhD as there is limited researched evidence in the literature about the impact of psychological distress on food choices, dietary patterns and lifestyle risk factors, particularly among urban Aboriginal and Torres Strait Islander Australians. What has been reported focuses largely on remote Aboriginal and Torres Strait Islander communities with food purchased from local community stores through food receipts. What we must be mindful of when exploring the literature, is that food products brought into remote communities is often not fresh fruit or vegetables but rather processed foods, high in saturated fats, sugar, salt and carbohydrates. We must also be mindful that there is not a large variety of fresh food products to choose from or indeed compare with in remote areas of Australia. As with urban-based supermarkets, the cost of fresh food often outweighs that of fast and processed foods; so it appears cheaper for the consumer to buy the poor nutrient food items rather than the fresh food products. Environmental settings as well as psychological distress should all be considered when investigating these concerns. Exploring how popular television shows and food advertisements influence eating behaviours in these communities should also be taken into account.

The qualitative and quantitative work presented in this PhD thesis is based upon my own original research work in urban metropolitan and regional parts of New South Wales (NSW). The literature review (Chapter 1: Introduction) provides background information and sets the scene for this PhD thesis. The Study to Reduce Incidence of Diabetes through Early Intervention (STRIDE), as well as self-reported survey baseline data used from the longitudinal 45 & Up Study in New South Wales (NSW) are presented as the major components of my PhD research. These chapters report and discuss how social determinants shape patterns of health and illness for Aboriginal and Torres Strait Islander participants in these two different studies, with similar issues being raised in the different settings around relationships with food, identity, disadvantage, socio-economic status, diet and risk behaviour associated with psychological distress.

My article, 'Aboriginal health and the Australian Constitution: How do we fix them both?' published in the *Australian and New Zealand Journal of Public Health*, provides a 'snap-shot' perspective of how the Australian political system affects many Aboriginal and Torres Strait Islander peoples, and how these past policies continue to impact on the health and social wellbeing of Aboriginal and Torres Strait Islander peoples. This article also discusses how these political and historical factors need to be incorporated when conducting research in these areas.

The article, 'The urgency of monitoring salt consumption and its effects in Aboriginal and Torres Strait Islander Australians' published in the *Medical Journal of Australia* (Chapter 5, p. 77), provides crucial information for future research and highlights the need to better understand the food choices and salt levels consumed in the diets of many Aboriginal and Torres Strait Islander Australians. Understanding these issues will enable new research to be performed among Aboriginal and Torres Strait Islander Australians which will explore how high salt consumption can cause hypertension (high blood pressure) and be a powerful driver of vascular risk. New research methods can be developed in partnership with Aboriginal and Torres Strait Islander communities and lead to the generation of new knowledge.

I have gained a range of high-level research skills and experiences while conducting my PhD research and writing. These skills and experience include health research study design, questionnaire design, surveys and focus group methods, data collection and entry processes, participant recruitment, as well using statistical software to perform more complex statistical analyses including multiple logistic regression. All these critical research methods have elevated my knowledge, experience and skills and equipped me with strong foundations to undertake further independent research and post-doctoral studies in my academic future.

I am proud of my PhD research and this thesis and I look forward to continuing to contribute to the scientific literature and to making a fundamental difference to improving the health and wellbeing of Aboriginal and Torres Strait Islander Australians.

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Journal articles

The care and management of chronic diseases and comorbidity impose a substantial burden on the Australian government, Aboriginal Medical Services (non-government primary health care organisations) and mainstream health services and systems. Nowhere is this burden more felt than upon Aboriginal and Torres Strait Islander Australian individuals, their families and communities. Most health research studies that have measured the burden of chronic disease tend to take only a partial view of the socio-economic consequences, focusing on measuring the burden on the health system of responding to an illness rather than apply a holistic perspective of the overall historical, political, social, cultural and emotional wellbeing (psychological distress) that impact upon Aboriginal and Torres Strait Islander peoples, their families and communities.

I aimed to provide a holistic analysis of the social and cultural determinants of the health and wellbeing of Aboriginal and Torres Strait Islander Australians and the association with historical, political, psychological distress, socio-economic burden of chronic disease and comorbidity from the perspectives of individuals, their partners and or their informal carers; as well as the data available to me for analyses. The analytical framework that was developed and applied in this thesis takes into account that historical, political, cultural, social and psychological distress factors manifest in many different ways and individuals will cope differently, based on a wide variety of potential short and long-term strategies.

The research objectives were to:

 Develop and apply an analytical framework that provides a holistic assessment of the burden of disease impacting on Aboriginal and Torres Strait Islander Australians, recognising the complex and multidimensional nature of the issues as found in Chapter 2 and 3;

- 2. Describe individuals' and carers' experience of the burden of disease as found in Chapter 3 (p. 15) and Chapter 7 (p. 97);
- 3. Measure the association of psychological distress and diet and food choices impacting on the burden of disease among older Aboriginal and Torres Strait Islander people (>45 years) as described in Chapter 6 (p. 80);
- 4. Describe the impact of forced removal and institutionalism, and the political and historical factors upon health and wellbeing and how these issues can impact upon healthcare participation among Aboriginal and Torres Strait Islander Australians as illustrated in Chapter 2 (p. 11), Chapter 3 (p. 14) and Chapter 6 (p. 80); and
- 5. Contribute to the policy and health strategies debate about the burden of chronic disease, risk behaviour in relation to blood borne viruses and vascular and metabolic diseases among Aboriginal and Torres Strait Islander peoples and other Australians as presented in Chapter 2 (p. 11), Chapter 3 (p. 15), Chapter 6 (p. 80) and Chapter 7 (p. 97).

In addressing these research objectives, the following five hypotheses were tested:

- Poor diet and lifestyle choices among Aboriginal and Torres Strait Islander Australians is associated with psychological distress stemming from historical, political, social and cultural factors as described in Chapter 3 (p. 15) and Chapter 6 (p. 80);
- Social determinants of health such as poverty, low education and high unemployment can restrict many Aboriginal and Torres Strait Islander people seeking and accessing appropriate health care, treatment and support services as outlined in Chapter 3 (p. 15), Chapter 6 (p. 80), Chapter 7 (p. 97);
- 3. Strategies and health promotion material aimed at preventing and managing chronic diseases as well as blood borne viruses and sexually transmissible

infections (STI's) among Aboriginal and Torres Strait Islander Australians need to incorporate social and cultural factors as well as the emotional wellbeing and psychological distress associated with poor lifestyle choices and high risk behaviours among Aboriginal and Torres Strait Islander people as found in Chapter 3, Chapter 6 and Chapter 7;

- Chronic disease and illness leads to turning points and changes in individuals and family carers, including lifestyle changes, food and diet choices as described in Chapter 3 (p. 40) and Chapter 5 (p. 77); and
- 5. Evidence of the negative lived experiences, associations with psychological distress and consequences of chronic disease can be used to inform and stimulate debate about policy options to improve health care, treatment and support for Aboriginal and Torres Strait Islander individuals, families and their communities as described in Chapter 2 (pp. 11-14), Chapter 3 (pp. 27-57), Chapter 6 (pp. 80-92) and Chapter 7 (pp. 97-117).

Methods

The analytical framework applied in this thesis used mixed methods of research, study design, data collection and analysis in order to provide a holistic assessment of the population, socio-economic and cultural burden of disease. Research was undertaken in a number of different settings; including Aboriginal Medical Services and the Eora (TAFE) College. Responses provided by Aboriginal and Torres Strait Islander participants in the 45 and Up longitudinal cohort study were analysed. The framework incorporated features to assess the key dimensions of Aboriginal and Torres Strait Islander Health and incorporated a holistic definition of Aboriginal health:

Aboriginal health is not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole community in which each individual is able to achieve their full potential as a human being, and thereby contributing to the total well-being of their Community. It is a whole-of-life view that includes the cyclical concept of life-death-life. (NACCHO 2013) The framework was applied in every setting. The experiences of diet, food choices, chronic disease, lifestyle, risk behaviour, social, cultural and emotional wellbeing as well as psychological distress were explored using previously collected data, and also elicited from individuals, their partners and their informal carers, as well as from focus groups held at Aboriginal Medical Services and the Eora (TAFE) College. The prevalence, risk factors and social determinants of chronic disease were measured in two lifestyle-specific case studies – the STRIDE study (Chapter 3: STRIDE, p. 15) and 45 & Up study (Chapter 6: 45 & Up study, p. 80).

Large survey datasets were used to identify diet patterns and food choices, social determinants of disease, and their association with psychological distress in the older Aboriginal and Torres Strait Islander populations. The impact of psychological distress and its association with diet was measured in a population-based cross-sectional longitudinal study of older (>45 years) Aboriginal and Torres Strait Islander adults (Chapter 6, p. 80). All being aged over 45, Aboriginal and Torres Strait Islander members of the cohort are likely to have a range of similar cultural, socio-economic and lived experienced backgrounds. Healthy and unhealthy lifestyle choices, decisions and participation were explored using mixed qualitative methods among other study participants (Chapter 3: STRIDE, p. 15).

The holistic framework was applied in all settings of research contained in this thesis. This framework was used to assess dimensions of the social determinants of poor health, as well as psychological distress and social and emotional wellbeing, as they relate to food, diet and lifestyle choices and the burden of chronic disease.

Finally, the framework was applied to stimulate policy dialogue in the Australian Aboriginal and Torres Strait Islander health context. Seminars and opinion papers were used as tools to raise awareness about the negative consequences associated with Australian political status, historical practices, psychological distress and chronic disease; and to provoke discussion about strategies to mitigate the burden of historical, political, social and cultural factors experienced by Aboriginal and Torres Strait Islander individuals, their families and communities and how these can impact on the prevention and burden of chronic disease among this population.

Main findings

Within the studies presented in this thesis, burden of disease, care, support and treatment, poor lifestyle choices, risky behaviour, emotional wellbeing and psychological distress were influenced by culture, social determinants of health (e.g. institutionalism, poor housing, etc.) negative childhood experiences, history, political status, identity, community attachments, alcohol and other drugs, and sexual relationships. Other factors that influenced these experiences included the loss of loved ones and when a loved one was diagnosed with a chronic disease; which were often referred to as 'turning points' for individuals and their partners. These factors were also conceived as barriers or enablers to accessing health care education promotion material, health care check-ups and healthcare, thus directly affecting patterns of health and illness.

The main strength of the STRIDE study (Chapter 3, p. 15) was that this is one of the few studies that combine a review of patterns of health service utilisation and qualitative investigations of diet and food related choices among urban Aboriginal and Torres Strait Islander people. The generalizability of the research may be limited by the fact that only two focus groups were conducted. However, our results found that similar themes and issues were raised in the two focus groups. The groups represented diverse urban/outer metropolitan Aboriginal and Torres Strait Islander populations, one college-based, located in the inner-city of Sydney and the other, at an Aboriginal Medical Service, located in the outer regions of Sydney.

In the 45 & Up study in Chapter 6 (p. 88), a study which recruited 1,949 older Aboriginal and Torres Strait Islander people across New South Wales, the main results showed there was a significant association between psychological distress, measured using the Kessler 10 score, and reports of food consumption. People who reported a higher consumption of fruit, vegetables and fish were less likely to be psychologically distressed.

The study of sexual behaviour, drug use and health service utilisation by young Noongar people in Western Australia study (Chapter 7, p. 97) showed that the sample was more disadvantaged than the wider Noongar population. Sexual activity was initiated at a young age. Approximately 40% had at least one casual sex partner in the previous 12 months, with men more likely to have had two or more casual partners (23% vs. 14%). Condoms were always or often carried by 57% of men and 37% of women and 36% of men and 23% of women reported using a condom the last time they had sex with a casual partner. Self-reported lifetime STI diagnosis was 14%. Forty per cent currently smoked tobacco and 25% reported risky alcohol consumption on a weekly and 7% on an almost daily basis. Cannabis alone was used by 37%, 12% used other illicit drugs as well as cannabis, and 11% reported recently injecting drugs. In the previous 12 months 66% had a health check and 31% had been tested for HIV or an STI. Additionally 25% had sought advice or assistance for mental health issues.

While most were not engaged in unsafe sexual practices or harmful levels of alcohol and other drug use, a relatively high proportion were – of particular concern being the high level of injecting drug use. Encouragingly, a higher percentage of those engaged in risky behaviours were more likely to have been tested for HIV or an STI or to have had a recent health check.

This project has provided a snapshot of a group of young Aboriginal people in urban and rural settings. The picture that emerges is one of a particularly disadvantaged group within a disadvantaged population. Although it is not possible to extrapolate from this study to the wider Noongar population, it is clear from the study that there is at least a segment of the population that is under stress and engaged in behaviours which pose considerable risks to health and wellbeing. Equally clear, however, is that fact that most Noongars in the sample are not behaving in such a way.

The findings of all these studies highlight that there is a need to investigate further the resilience factors, relationships and psychological distress which influence Aboriginal and Torres Strait Islander people's food choices, diet patterns, risky behaviour and lifestyle choices. While knowledge of what constitutes healthy eating was good among the participants, research should also explore how daily food preferences among these groups reflect the Australian Dietary Guidelines, if at all. Clearly, diverse cultural considerations and the complex issues of psychological distress, social and emotional wellbeing need to be considered when designing and implementing diet and food education and lifestyle intervention programs for Aboriginal and Torres Strait Islander people. Much more investigation needs to be undertaken into the associations between wellbeing, psychological distress, fast food, diet, food advertising, barriers and enablers and in particular the relationship between identity, cultural influences, depression, stress and how these factors can shape food choices and overeating as well as facilitate poor lifestyle choices and engaging in risky behaviour.

Key government strategies for the prevention and management of Type 2 diabetes in Australia include the National Diabetes Strategy and in NSW Chronic Disease Prevention Strategies. These strategies focus on the prevention of Type 2 diabetes mellitus through the modification of risk factors, particularly through lifestyle changes and effective clinical management. These strategies have identified principles for developing strategies aimed at preventing and managing diabetes among Aboriginal and Torres Strait Islander people. They emphasise a holistic approach to health care, delivery of services in the communities where people live, training of GPs and local Aboriginal and Torres Strait Islander health care workers and staff of community-controlled health care services. The strategies also promote that programs be based on needs determined by the community, developed, supported and run by the community, and that they be coordinated with other Aboriginal and Torres Strait Islander health care promotion programs.

The Second National Sexual Health Strategy 2010-2013 states that priority population groups identified in the strategy are young people, Aboriginal and Torres Strait Islander peoples, gay men and other men who have sex with men as well as sex workers. There are three main variables that influence the spread of sexually transmissible infections (STIs) which are; the risk of transmission; the number of atrisk partners an individual has; and the period of infectiousness. Comprehensive responses to STIs must address these aspects. The main elements of a comprehensive response to STI control are: health promotion and prevention; patient and provider initiated testing; early intervention and partner notification; access to and delivery of clinical care and support; surveillance and research.

Type 2 diabetes, obesity, food and diet choices

In keeping with current National and New South Wales policies for the prevention and management of Type 2 diabetes, community consultation and pilot work should be carried out among Aboriginal communities in NSW aiming to develop, implement and evaluate a culturally-appropriate program to prevent and reduce the burden of diabetes and related chronic diseases. Pilot work would aim to establish ways in which to improve prevention and service delivery efforts in relation to prevention and onset of Type 2 diabetes by exploring some of the following research gaps:

- 1. AMS clinic population pilot studies of the prevalence of impaired glucose tolerance (IGT) and diabetes.
- 2. Implement and evaluate continuous quality improvement approaches aiming to improve the screening and management of chronic disease, building on the relevant body of evidence from the ABCD Partnership.
- 3. Pilot intervention studies to explore and better understand psychological distress associated with self-management and lifestyle intervention programs (including food and diet) among clinic patients at risk of obesity, developing and with existing diabetes.*
- 4. Pilot intervention studies among people who attend the clinic who have impaired glucose tolerance in order to delay the onset of type 2 diabetes with a focus on lifestyle components such as food education and physical activity uptake of the program as well as exploring any associations with psychological distress.*
- 5. Conduct research with the aim of exploring the development of family and community-based intervention strategies addressing norms regarding identity, food and discrimination.*
- * Evidence supporting these pilot studies and further research is presented in Chapter 4.

The research program could be used to pilot and develop aspects of a detailed research and service delivery framework for prevention and management of diabetes in NSW and nationally among Aboriginal and Torres Strait Islander people.

Sexual behaviour, drug use and health service utilisation

There are a number of approaches that can improve the knowledge and reduce the risk behaviour to address sexually transmissible infections and blood borne viruses among Aboriginal and Torres Strait Islander Australians and increase health service access. The Kirby Institute¹ makes the following research recommendations:

- Research: To conduct research in partnership with Aboriginal and Torres Strait Islander communities in the areas of Sexually Transmissible Infections (STIs), HIV/AIDS and other Blood Borne Viruses (BBVs).
- 2. **Surveillance:** To support existing surveillance activities and to identify innovative new areas and methods of surveillance that will benefit Aboriginal and Torres Strait Islander communities.
- 3. **Capacity building:** To work with existing health services to enhance the capacity of existing systems and workforces in the areas of sexual health and BBV service delivery; research; and surveillance.
- 4. **Information:** Dissemination through the development of a comprehensive clearinghouse of Aboriginal and Torres Strait Islander Sexual Health initiatives including surveillance and research.

In addition to the recommendations above, this PhD thesis recommends community research projects be undertaken that explore resilience and psychological distress factors among Aboriginal and Torres Strait Islander individuals who engage in sexual and injecting drug use risky behaviour.

Exploring the issues that workforces confront when providing care, treatment or support to individuals and family members affected by STIs, Injecting Drug Use (IDU), BBV and HIV/AIDS would also allow an insight into concerns that psychological distress plays an important role in health outcomes relating to highrisk behaviours; that in the long term may contribute to better understanding and addressing high risky behaviour and prevention, better health care services, access and provision.

The framework applied in this thesis has been effective in raising wider awareness of the socio-economic, emotional wellbeing, psychological distress of the burden of chronic disease and lifestyle choices and risk behaviour Among Aboriginal and Torres Strait Islander Australians in stimulating discussion about options to reduce the burden of diseases and improve the support provided by health care practitioners, services and systems, for individuals, their families and their communities.

Discussion and conclusion

This research has helped to establish that there is a heavy burden of disease and an underlining unexplored association between psychological distress, lifestyle choices, risky behaviour and chronic disease among Aboriginal and Torres Strait Islander peoples in Australia. Individuals who are at risk or who have chronic disease and comorbidity are experiencing a considerable socio-economic and emotional burden. There are three main dimensions to this burden including: psychological distress, childhood and adult lived experiences, resilience and lifestyle choices. Some of these dimensions are offset by existing factors such as the early historical and political systems of Australia. Socio-economically disadvantaged individuals whose lives are influenced by poor social determinants, such as poor housing, low education, high incarceration rates and low income in particular, would benefit from better targeted health and social welfare initiatives to reduce the psychological distress and ameliorate its consequences. This thesis provides an analytical framework that can be effectively applied among Aboriginal and Torres Strait Islander individuals and communities to comprehensively and holistically assess the socio-economic burden of chronic disease and comorbidity and its impact on social and emotional wellbeing.

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A Human Research Ethics Committee (HREC) in each of the studies' jurisdictions has approved all of the empirical research included in this thesis.

- 1. The University of Sydney HREC approved the study in Chapter 3 (p. 15), Chapter 4 (p. 62) and Chapter 6 (p. 80).
- 2. The Aboriginal Health and Medical Research Council (AHMRC) approved the study in Chapter 3 (p. 15), Chapter 4 (p. 62) and Chapter 6 (p. 80).
- 3. Western Australian Aboriginal Health Ethics Committee approved the study in Chapter 7 (p. 97) (DYHS).

Ethical approval was not required for the manuscripts in Chapter 2 (p. 11) and Chapter 5 (p. 77) (MJA & ANZJPH).

I have thoroughly enjoyed the last five and a half years. My doctoral studies have allowed me the opportunity to study, travel abroad, learn and grow academically and as an early career researcher, make mistakes, new friends and make a difference in Aboriginal and Torres Strait Islander health. I have had many positives experiences and met some amazing people along the way who work tirelessly to improve Aboriginal and Torres Strait Islander Australian people's health and wellbeing. I would not have been able to do my doctorate without a strong and supportive network of family, friends and work colleagues.

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LIST OF ABBREVIATIONS

45&UP	45 & Up study
ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Services
AH & MRC	Aboriginal Health and Medical Research Council of New South Wales
AIHW	Australian Institute of Health and Welfare
AMS	Aboriginal Medical Service
ATSI	Aboriginal and Torres Strait Islander
BMI	Body Mass Index
CI	Confidence interval
CKD	Chronic kidney disease
CVD	Cardiovascular disease
DM	Diabetes Mellitus
HREC	Human Research Ethics Committee
KOORI	Generic term for the Aboriginal people of NSW
NCDs	Non Communicable Diseases
NGOs	Non-government organisations
NHMRC	National Health and Medical Research Council (of Australia)
NOONGAR	Generic term for the Aboriginal people of the south west of Western Australia
NSW	New South Wales
OR	Odds ratio
PD	Psychological distress
SES	Socioeconomic status
SNAP	Smoking, Nutrition, and moderate Alcohol, more Physical activity
STIs	Sexually transmissible infections
STRIDE	Study to reduce onset of Type 2 diabetes through early intervention

Many of the terms used in this thesis do not have a single, universally agreed upon definition. The following list of selected terms indicates the definition used in this thesis.

Chronic diseases are conditions with a long duration and generally a slow progression.

Chronic kidney disease is defined as kidney damage that exists for three months or longer due to structural or functional abnormalities of the kidney, with or without a decreased glomerular filtration (GFR) that can lead to decreased GFR.¹ Individuals with chronic kidney disease include those who have not commenced dialysis or received a kidney transplant, those already on renal replacement therapy (i.e. dialysis or transplant) and those who will not commence dialysis (i.e. are managed conservatively without dialysis).

Comorbidity refers to the existence of accompanying chronic conditions reported by an individual with an index chronic condition.²

Concessional status refers to coverage that is provided by a number of governmentissued cards which entitle the card holder, and in some cases their dependents, to a variety of health benefits or concessions on medical care, hospital treatment, supply of pharmaceuticals and reduced rates on several living expenses (e.g. utility bills, rent assistance).³

Consumption smoothing are strategies used to deal with an economic shock to the household's resources (e.g. the onset of illness) to help insulate consumption patterns from changes in income and available resources.⁴

Deprivation is defined as an enforced lack of socially perceived essentials.⁵

Direct costs refer to the range of costs that individuals and their households will incur when accessing treatment and care and costs to the health system of providing that treatment and care.⁶ These include costs related to medical and health-related goods and services.

Dissaving behaviour is any action where spending is greater than income thereby reducing already accumulated savings or leading to borrowing to finance the expenditure.⁷

Financial stress is an indication of cash flow problems and is measured using a set of questions that assess a household's ability to maintain consumption patterns over a specified period of time.

First Peoples is a term used to describe Indigenous inhabitants. There are many different definitions for each country. In Australia First Peoples refers to Aboriginal and Torres Strait Islander peoples. For example, The National Congress of Australia's First Peoples is the national representative voice for Aboriginal and Torres Strait Islander peoples.⁸

Household includes one or more people who usually reside in the same private dwelling, who generally pool income, share resources and employ joint strategies to maintain economic wellbeing.⁹

Household economic hardship refers to the inability of household members to maintain usual consumption patterns (e.g. paying for necessary living and medical expenses) and whether assistance from others is required.^{10, 11}

Holistic refers to the definition of Aboriginal health as described by the National Aboriginal Community Controlled Health Sector.¹²

Hunter-Gather is a term that describes nomadic peoples whose food sources are obtained directly from wild plants and animals in contrast to societies that use agricultural methods.¹³

Income support, concessions and subsidies are programs provided by the Australian government as part of a national social welfare system that aim to support Australians to achieve social and economic outcomes and to participate in society. Individual programs provide income support for the retired, people with disabilities, informal carers and unemployed people. In addition, various programs provide concessions and subsidies to help people meet specific needs for example, assistance is also provided for a range of goods and services (e.g. living and medical) through pensioner concession and health care cards.¹⁴

Indirect costs refer to productive time losses of the person who is ill and other household members who may or may not be directly involved in caring for the sick individual.¹⁰

Informal care refers to support that is provided by a family member (e.g. spouses, siblings, relatives, children or parents) or close friend to someone who requires assistance due to an illness or disability. Informal care is generally unpaid. However, some informal carers may be eligible to receive income support from the government in the form of a carer payment. Informal carers are also referred to as family carers.

Multimorbidity refers to the co-existence of more than one chronic condition, with no reference to an index condition.^{15, 16}

Pharmaceutical Benefits Scheme (PBS) safety net is designed to keep medicines affordable by reducing the out-of-pocket costs of prescription medications for individuals and families who require a large number of medications. Individuals and families are eligible for the PBS safety net once the PBS safety net threshold is reached. Eligibility for the threshold is calculated on a calendar year basis. There is a lower PBS safety net threshold for individuals and families with concessional status. When the concessional PBS safety net threshold is reached, individuals and families may qualify to receive eligible PBS listed pharmaceuticals at no cost for the rest of the calendar year. When the general (non-concessional) PBS safety net threshold is reached, individuals and families may qualify to pay a lower concessional copayment amount for eligible PBS listed pharmaceuticals for the rest of the calendar year. The PBS safety net thresholds are adjusted on January 1st of each year in line with inflation. In 2012, the concessional PBS safety net threshold was AUD\$354.00 and the general PBS safety net threshold was AUD\$1390.60.

Poverty describes a situation where individuals or households lack minimum resources to obtain the types of diet, participate in the activities and have the living conditions and amenities which are customary, widely encouraged or approved, in the societies to which they belong. Their levels of resources are below those commanded by the average individual or family. A consequence is that these individuals can be excluded from ordinary living patterns and activities.¹⁷

Socioeconomically disadvantaged is a term that is used to describe individuals who, compared with those who have social and economic advantages, are more likely to have shorter lives, higher levels of disease risk factors and have lower use of preventive health services.¹⁸

Social determinants of health refers to other risk factors, such as poor housing, low education and high unemployment issues, that need to be considered when conducting health research among Aboriginal and Torres Strait Islander Australians that seeks to understand patterns of health and illness.¹⁹

Social and emotional wellbeing is a term defined as Aboriginal and Torres Strait Islander holistic and whole-of-life view of health. It includes mental health, but also considers the impact of other factors on emotional wellbeing, such as life stressors, removal from family, discrimination and cultural identification.²⁰

SNAP refers to quite smoking, better nutrition, moderate alcohol intake, and more physical activity. It is a population health guide to behavioural risk factors in general practice. The guide helps GPs to systematically target patients and offer treatment appropriate to their needs.²¹

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This thesis contains three publications for submission with one under review for re-submission (Chapter 6). Chapter 7 has been accepted for publication with the Sexual Health Journal. The University of Sydney's Academic Board approved submission of published work as a thesis on 14 August 2002. Specific author contributions are specified at the beginning of each chapter.

Chapter	Status	Details
Chapter 2, p. 13	Published	Lawrence C. Aboriginal Health and the Australian Constitution; how do we fix them both? <i>Australian New Zealand Journal of Public Health</i> , 2013, Vol. 37, No. 2.
Chapter 4, p. 70	To be submitted	Lawrence C, O'Dea K, Cass A & Eades S. What influences food choices, and diet among urban Aboriginal and Torres Strait Islander adults: Findings from a qualitative study in Sydney, New South Wales.
Chapter 5, p. 85	Published	Lawrence C. The urgency of monitoring salt consumption and its health impacts in Indigenous Australians' <i>MJA</i> , 2013, 198(7).
Chapter 6, p. 88	To be submitted	Lawrence C, Barzi F, Brimblecombe J, Banks E, Eades S & Cass A. Associations between psychological distress and diet among older Aboriginal and Torres Strait Islander adults in the New South Wales 45 and Up study.
Chapter 7, p. 107	Published	Williams R, Lawrence C, Wilkes E, Shipp M, Henry B, Eades S, Mathers B, Kaldor J, Maher L & Gray D. The role of resilience in responding to blood borne viral and sexually transmitted infections in indigenous communities, CSIRO Publishing, Sexual Health http://dx.doi.org/10.1071/SH14038.

Conference presentation

Lawrence C, Williams G, Cass A. *Recognising Aboriginal people in the Australian Constitution: why is it so important and why does it matter to Aboriginal health?* The George Institute for Global Health; Seminar 9 September 2013. Oral presentation

Lawrence C, Cass A, O'Dea K. *Social determinants of Aboriginal and Torres Strait Islander health*. The Australian Indigenous Leadership Centre Conference 2013. Oral presentation

International conference presentations

Lawrence C. Ethical considerations when conducting research with minority groups in the United States; an Aboriginal Australian perspective using the National Health and Medical Research Councils 'Road Map' Guidelines, African-American Psychologists Annual Conference, Columbia University NY, 2009

Chris Lawrence, Federica Barzi, Julie Brimblecombe, Emily Banks, Sandra Eades and Alan Cass. *Associations between psychological distress and diet among older Aboriginal and Torres Strait Islander adults in the New South Wales 45 and Up study*. International Health Economics Association Annual Conference, Dublin Ireland, July 2014.

Submissions

Lawrence C, Cass A, O'Dea K, Eades S, Webster J, Land M, O'Neal B, *Salt consumption among Aboriginal and Torres Strait Islander Australians*, Submission, Australian Research Council, April 2012 and 2013

Scholarship awards

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Sydney Medical School, University of Sydney – Australian-American Fulbright Scholarship, National Indigenous Award, 2008-09. *Funds awarded for travel and living expenses towards capacity development of doctoral research*

1.1 Chapter overview

A number of literature searches were performed to support the research undertaken and the studies presented and discussed in this thesis. The following search engines were used including MedLine/PubMed, Australian Institute of Health and Welfare, BioMed Central, CINAHL, Scopus, Google scholar and the Australian Indigenous HealthInfoNet. National and international medical and public health journal websites were also used for the latest evidenced-based publications.

A range of terms was applied in order to identify the most appropriate literature. These included the following: indigenous people and chronic disease, Aboriginal and or Torres Strait Islander Australians and chronic disease, nutrition, food, bush tucker, diet, exercise, physical exercise, physical activity, psychological distress and Aboriginal and Torres Strait Islanders, psychological distress and food, psychological distress and diet, colonization and psychological distress, psychological distress, colonization and chronic disease, obesity and Indigenous people, obesity and Aboriginal and Torres Strait Islander Australians, obesity and psychological distress.

Other sources of information included grey literature/ government reports, direct feedback from Aboriginal health researchers and discussions with health professionals and community participants.

The health and wellbeing of Aboriginal and Torres Strait Islander Australians has been well documented over many years. There have been numerous targeted health programs and research over decades to assist in 'Closing the Gap' in life expectancy between Aboriginal and Torres Strait Islander people and other Australians. In 2014 the Abbott government launched their 'Close the Gap' Report.¹ These yearly reports examine government attempts at 'Closing the Gap' since its inception in 2008. The 2014 report clearly states that 'While there has been a small improvement in Indigenous life expectancy, progress will need to accelerate considerably if the gap is to be closed by 2031'. The report further adds that 'Life expectancy is affected by a range of factors such as education, employment, housing, exposure to violence and poverty which in turn impact on health risk behaviours and the physiological impact of stress' or as health researchers like to define as *social determinants of health*. Previous research has also shown that there are other exacerbating risk factors attributing to this life expectancy and poor health outcomes. These include tobacco smoking, physical inactivity, poor nutrition, obesity and high blood pressure, which are key modifiable risk factors for chronic diseases.^{2, 3} Addressing these lifestyle issues is pivotal to long term health improvements.

The Abbott government's 'Close the Gap' Report 2014 highlighted:

... between 2010-12, Indigenous life expectancy was estimated to be 69.1 years for males and 73.7 years for females. The gap in life expectancy between Indigenous and non-Indigenous people was 10.6 years for males and 9.5 years for females. Over the last five years, there has been a small reduction in the gap of 0.8 years for males and 0.1 years for females. The current rate of progress will have to gather considerable pace from now on if the target is to be met by 2031.

These figures are still too wide and much more has to be done to address these alarming health concerns.

Addressing modifiable risk factors such as smoking, excessive alcohol consumption, poor nutrition and diet patterns, obesity and physical inactivity should be key health priorities if we are to reduce preventable chronic diseases such as Type 2 diabetes and cardio vascular disease (CVD) among Aboriginal and Torres Strait Islander Australians. If we were to focus on overweight and obesity the Australian Aboriginal and Torres Strait Islander Health Survey; First Results 2012-2013⁴ conducted by the Australian Bureau of Statistics showed that 'almost one-third (30.4%) of Aboriginal and Torres Strait Islander children aged two to 14 years were overweight or obese according to their body mass index (BMI). For those people aged 15 years and over 'two-thirds (65.6%) were overweight or obese (28.6% and 37.0% respectively)' and that 'Obesity rates for Aboriginal and Torres Strait Islander females and males were

significantly higher than the comparable rates for non-Indigenous people in almost every age group.'

The 2013 Australian Dietary Guidelines developed by the National Health and Medical Research Council (NHMRC)⁵ promote the daily consumption of the five major food groups, which include fruit, vegetables, cereals/breads, lean meat, fish, dairy products and drinking water. In addition the guidelines recommend limited intake of foods and drinks that are high in salt, sugar, saturated and trans fats as well as limiting alcohol intake. The guidelines also recommend individuals prepare and store food safely, and encourage people to maintain a healthy weight by including daily physical activity. Whilst the Australian dietary guidelines are relevant for all Australians, Aboriginal and Torres Strait Islander people are considered 'at greater risk of diet-mediated poor health' and further knowledge about what influences food choices is required to improve the provision of dietary advice to Aboriginal and Torres Strait Islander people.

One area about which there is little understanding, is attitudes to and the consumption of salt by Aboriginal and Torres Strait Islander Australians. The World Health Organization's (WHO) 2010 Global status report on non-communicable diseases (NCDs)⁶ recommends that reducing salt intake and salt content of food are cost effective actions that should be undertaken immediately, with expected accelerated results in terms of lives saved, cases of disease prevented and costs avoided. This position has since been endorsed by the 2011 Political Declaration of the United Nations High Level Meeting on NCDs⁷ which lead to the development and adoption of the Global Monitoring Framework and Voluntary Global Targets for the Prevention and Control of NCDs in which salt reduction is a core target.⁸

1.2 The burden of chronic illness

Early mortality due to chronic diseases among Aboriginal and Torres Strait Islander peoples is the major contributing factor to the life expectancy gap between Indigenous and non-Indigenous Australians. The Australian Institute for Health and Welfare (AIHW) estimates that the life expectancy gap for Aboriginal and Torres Strait Islander people is 12 years for males and 10 years for females.⁹ Estimates of the gap in life expectancy need to be understood in the context of broader social determinants that contribute to patterns of health and illness among Indigenous Australians. These determinants include poor housing conditions, lower incomes, lower educational attainment, low literacy and numeracy skills, higher unemployment and higher levels of harmful behaviours including excessive alcohol and tobacco consumption and poor diets.

The high rates of stroke and cardiovascular disease (CVD) among Aboriginal and Torres Strait Islander people cannot simply be attributed to genetics or tobacco smoking and poor access to preventive health checks. The food Indigenous Australians purchase at fast food outlets, or at supermarkets, prepare and cook at home and what their portion meal sizes are, are fundamental to the better understanding of the high rates of obesity, high blood pressure, stroke and CVD among these groups. A recently completed George Institute project to measure salt intakes in Lithgow, New South Wales (NSW) has demonstrated a clinically proven method of collecting and analysing salt consumption in a sample of around 500 participants and showed salt intakes in this community were around 8.9 (3.6) grams per day, which is in line with previous studies in Australia.¹⁰ Using the same approach, further research will be able to determine the levels of salt consumed by Aboriginal and Torres Strait Islander Australians. This information is crucial to better understand how to develop intervention programs that can reduce chronic diseases through the provision of new evidence and essential information about the types of processed food bought and how they are prepared, cooked, and eaten at home. Such programs will help us increase Aboriginal and Torres Strait Islander peoples' food literacy to allow them to make more informed decisions about food choices, cooking methods and consumption.

The 'hunter gatherer' diet is either totally out of reach or very restricted for many Aboriginal and Torres Strait Islander groups, particularly those living in urban areas.¹¹ The diet of many Aboriginal and Torres Strait Islander peoples now includes a combination of high fat, sugar and salt containing processed food products; even for those groups living in rural and remote areas.¹² For example in many regional areas across Australia, the types of food available in the large supermarkets and fast food chains for Aboriginal and Torres Strait Islander populations, who are already deemed at risk of obesity and chronic diseases, facilitate access to these unhealthy food products.

There is compelling scientific evidence about the poor quality food supply in many Aboriginal and Torres Strait Islander communities – both urban and remote^{11, 12}. Research conducted in remote Aboriginal and Torres Strait Islander communities shows that fresh fruit and vegetables and other healthy perishable foods are high cost and the socio-economic circumstances of many Aboriginal and Torres Strait Islander peoples limit their access and consumption. Highly processed, nutrient-poor foods high in salt, refined carbohydrates and fats cost significantly less, in terms of calories that can be consumed per dollar spent, than nutrient-rich whole foods.¹³

1.3 Gaps in the literature

Premature chronic diseases are the major contributors to the mortality gap between Aboriginal and Torres Strait Islander peoples and the rest of the Australian population: with diabetes (12%) and ischaemic heart diseases (22%) being major contributors.⁹ Kidney disease is also an important contributing factor for females (35-54 years) and both males and females aged 55-74 years. The major concern for Aboriginal and Torres Strait Islander people's health is that life expectancy is shorter due to high and premature mortality due to chronic diseases.⁹

Management of chronic diseases varies depending on the disease and the individual's ability to self-manage. Depending on the person's lifestyle, most people can have a good quality of life that allows them to manage and live longer with chronic diseases. However for many Aboriginal and Torres Strait Islander people living with multiple health risk factors and complex lifestyles, being diagnosed with diabetes or CVD can have a profound impact on their ability to self-manage and make informed decisions. This, in turn, impacts on their own health care and the ability of family members and health providers to provide adequate care and support on an ongoing basis.^{4, 9}

Recent research has confirmed there is a lack of reliable, population-representative data for Aboriginal and Torres Strait Islander Australians regarding the burden of

chronic conditions, risk factors for the development and progression of chronic disease, and utilization of relevant preventative and treatment services. As concluded in an AIHW report on prevention of cardiovascular disease, diabetes and (chronic kidney disease) CKD,² there is clearly a need for monitoring in the area of prevention. However, better quality data are needed, in particular those based on measurement rather than self-reported data, as well as systematic data on population-level initiatives.

Health research has shown that physical activity and exercise combined with a nutritious diet, rich in minimally processed foods can prevent weight gain, improve overall health and prevent Type 2 diabetes and cardiovascular disease. There is good evidence of an association between obesity and overweight with high blood pressure, high LDL and low HDL, and Type 2 diabetes, particularly amongst socioeconomically disadvantaged population with a heavy burden of chronic disease such as Aboriginal and Torres Strait Islander populations.¹⁴

There is much information in the health literature about the poor health and wellbeing of Aboriginal and Torres Strait Islander people with a focus on commonly addressed risk factors such as smoking. In 2008 almost half (47%) of Indigenous people aged 15 years and over were current smokers with Indigenous people who lived in remote areas [being] more likely to be current smokers than those living in major cities (53% and 42% respectively).¹⁵ Despite this health data, we know little about the daily levels of physical activity and dietary practices in this population. Why is it that many Aboriginal and Torres Strait Islander people find it difficult to participate in some form of physical activity and/or consume a healthy diet?

Shame and low personal self-esteem are factors that can explain the patterns of poor uptake of physical activity among some Aboriginal and Torres Strait Islander peoples. A study promoting fit bodies and exploring healthy eating among Aboriginal and Torres Strait Islander men in Australia concluded that 'sociocultural factors' play a crucial role in the deciding factor of participating in physical activity programs.¹⁶ A 2004 literature review regarding physical activity and Aboriginal and Torres Strait Islander people¹⁷ found only one intervention program published which focused on promotion of physical activity, but not reduction of obesity. The review highlighted additional disparities such as psychosocial stresses, smoking, isolation, separation from family and culture, unemployment and economic hardship.

From a personal experience, I grew up in a large extended Aboriginal family and community. I grew up in an urban area where many Aboriginal families lived in public housing. Many of my friends were Aboriginal and we attended public school together. Shame was a common issue, which stemmed from racist stereotypes being thrown at us: 'black', 'Abo' or a 'boong' – derogatory terms used to alienate Aboriginal people. For many, these terms impacted on their identity and self-image. This sense of shame and other social stressors are likely to impact on individuals making healthy informed lifestyle decisions relating to both diet and exercise.

Current efforts to prevent disease caused by high blood pressure in Australia are focused on the pharmacological management of hypertension. The problem with this hypertension-based approach is that it fails to address the primary behavioural causes of the problem – such as poor diet, physical inactivity and smoking. In addition, hypertension programs can only prevent blood pressure-related diseases amongst individuals identified and treated. In practice this represents only a minority of affected individuals and only a small proportion of the total blood pressure related disease burden is adequately addressed by this approach.¹⁸ Salt reduction programs and dietary intervention, on the other hand, can be implemented population-wide and have the potential to address much more of the disease burden caused by high blood pressure.¹⁹

1.4 Research to close the gap in life expectancy

The four national research priorities under the Promoting and Maintaining Good Health objectives of the Australian Research Council $(2012)^{20}$ are the following:

- 1. **A healthy start to life**;
- 2. Ageing well, ageing productively;
- 3. **Preventive healthcare**; and
- 4. Strengthening Australia's social and economic fabric.

Research to improve the health of Aboriginal and Torres Strait Islander Australians, needs to address these overarching priorities, to be conducted in partnership with communities and Aboriginal health services, and to focus on addressing the premature burden of chronic disease. In this thesis, seeking to contribute to closing the gap, I have undertaken and reported research findings and advocated for further research and policies that aim to do the following:

- To conduct rigorous health research to identify and better understand the barriers and enablers to behaviour change as it relates to diet and exercise;
- To identify emerging health research areas and opportunities for early intervention to reduce chronic disease and improve food security and healthy lifestyle changes for long term prevention healthcare;
- To propose rigorous implementation research be undertaken to demonstrate whether strategies developed from these research findings are effective, costeffective, acceptable and sustainable and can contribute towards strengthening Australia's social and economic fabric; and
- To advocate, based on research evidence confirmation of effective strategies, for greater allocation of resources and orientation of prevention systems towards chronic disease prevention.

One example, based on emerging research findings, is to advocate for rigorous research exploring dietary composition and especially salt consumption as a major risk factor for hypertension and CVD. We currently have a poor understanding about the dangerous high levels of poor nutrient foods being consumed among Aboriginal and Torres Strait Islander peoples. This thesis promotes that more rigorous investigation into food security, access, purchases and consumption needs to be conducted.

What we do know is that the impact of eating too much salt is cumulative throughout life so reducing salt intakes in infants and children will have substantial benefits in

later life. Salt reduction and following a healthy diet have been identified as an effective intervention for improving population health and further research in this area will help Aboriginal and Torres Strait Islander people to live longer and lead more productive lives as a result of reduced incidence of heart disease and stroke. Effective salt reduction interventions require the co-operation of government, local agencies, the food industry and health and consumer organisations to improve access to healthier foods and services for families and individuals.²¹

There are no data that can provide a robust estimate of population levels of salt consumption in Australian Indigenous adults, although daily intake is certainly several times greater than the 1-2g per day required.²¹ The gold standard method for measuring dietary salt consumption is the collection of 24 hour urine samples.²² The few recent studies that have collected 24 hour urine samples are mostly comprised of highly selected individuals enrolled in small-scale clinical studies and neither individually or in combination do they provide a reliable direct estimate of levels of dietary salt consumption by Indigenous peoples.^{23, 24} An alternate indirect approach to measuring dietary salt consumption is to estimate it through a modelling process that combines questionnaire data defining dietary intakes with information about food composition. The most recent effort to achieve this was done by Food Standards Australia New Zealand (FSANZ) as part of an effort to estimate iodine intake in Australian adults. The levels of daily salt intake estimated for Australian adults arising from this work (between 7.3g per day for young adults and 5.8g per day for older adults) are low when compared against known and estimated levels of salt consumption for other developed countries eating broadly similar diets. On balance, it is likely that the average salt consumption of Australian adults, including Indigenous adults, is between 8g and 10g per day although this needs to be definitively established such that an appropriate response can be formulated and monitored.

In Australia, it has been estimated that a one off reduction in population salt consumption of 3g per day would produce a fall in mean population blood pressure and would reduce strokes by about 15% and coronary heart disease by about 9%. If sustained there would be an additional continued progressive decline in population

mean blood pressure each year as the rise in blood pressure with age is attenuated, resulting in progressive small annual increments in risk reduction for decades. The feasibility of national salt reduction programs is clearly demonstrated by the achievements of the United Kingdom where mean levels of salt consumption have fallen by 1g per day in the last few years. The magnitude of the potential health gains from plausible population salt reduction programs is considered to be enormous. A more recent report in the Lancet suggested greater reductions in global mortality could be achieved with salt reduction than could be achieved through tobacco controls programs.^{25, 26}

As clearly illustrated above, non-communicable diseases including cardiovascular disease and diabetes are major causes of the gap in Aboriginal and Torres Strait Islander health including life expectancy.^{2, 3} Programs that target prevention of these chronic diseases and premature deaths in middle life from these conditions are urgently required to reduce the gap in Aboriginal and Torres Strait Islander health. There is poor understanding about dietary patterns among Aboriginal and Torres Strait Islander people, particularly in urban areas. Poor nutrition patterns developed with the introduction of tea, sugar, salt and flour rations to Aboriginal people in the early 1900s. In addition limited nutritional education and the availability of fast food outlets and sales of highly processed foods in areas with high Aboriginal and Torres Strait Islander populations have entrenched and encouraged the consumption of diets high in saturated fats, refined carbohydrates and salt through processed foods. Salt is a tangible and important dietary issue that contributes to hypertension and cardiovascular disease that can be used as a trigger to explore broader improvements in nutrition and physical inactivity²⁷ for Aboriginal and Torres Strait Islander people.

As outlined above, such research would potentially contribute substantially to our understanding of factors influencing dietary choice and to advocacy for evidencebased strategies to improve health outcomes. Such examples will be further developed in the following chapters of this thesis.

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CHAPTER 2:

ABORIGINAL HEALTH AND THE AUSTRALIAN CONSTITUTION: HOW DO WE FIX THEM BOTH?

The following article was published in the *Australian and New Zealand Journal of Public Health*, 2013, Vol. 37, No. 2, pp. 108-110.

I developed the original concept based on the political public debate about recognising Aboriginal and Torres Strait Islander people in the Australian Constitution. I researched and wrote the article. Professor Alan Cass did however provide guidance and direction and had input into the content.

2.1 Abstract

As an Aboriginal *Noongar* person from *Whadjuk* country (Perth) Western Australia, I know and have seen first-hand the experiences and devastating impact of poor health and the effects of premature death on loved ones. In my own large family and communities, there have been many preventable deaths in young and mature age people, but poor health decisions still occur. Acquiring diabetes or heart disease is almost like a 'rite of passage', some sort of 'cultural initiation'. 'We all die from something eventually' is the general notion. This saddens me to no end hearing many Aboriginal and Torres Strait Islander people talk about early death as if it's inevitable and life is not worth living.

Since the first Aboriginal Medical Service was set up in 1972 in Redfern, NSW, health care services have improved for Aboriginal and Torres Strait Islander people across the country. So there's really no excuse for people to not have regular health checks; or is there? The life expectancy gap between an Aboriginal and Torres Strait Islander and other Australians is still too wide. The Australian Bureau of Statistics (ABS)¹ in 2011 estimated that this life gap is 12 years for males and 10 years for females. These health statistics clearly illustrate that Aboriginal and Torres Strait Islander people are still not taking full advantage of these health services or programs. Why is that?

I believe there are two fundamental issues to help us understand this disparity; one is about the individual and their health status and the second is about their status as an Australian citizen.

This essay will discuss the association between the health and wellbeing of Australia's First Peoples; Aboriginal and Torres Strait Islanders and the fundamental legal right to be officially recognized in the Australian Constitution. I acknowledge there are other important determinants of health and wellbeing however, for the purposes of this paper I will focus on health and citizenship status.

2.2 Health status

In 1946 the World Health Organization (WHO) Constitution² stated that 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. In Australia in 1989 the first and only National Aboriginal and Islander Health Strategy³ clearly advocated for a 'holistic approach' to addressing Aboriginal and Torres Strait Islander health; meaning we need to recognize the whole person, their environment and not just treat sick body parts.

It has been widely documented that poor people are more often unhealthy people. The more money you earn the more likely you are to look after yourself (in theory; not always in practice). In research terms this is known as 'social determinants' of health where socio-economic factors are often taken into consideration to help explain poor health outcomes. For many Aboriginal and Torres Strait Islander people these social determinants of health are largely related to the legacy of British colonial history⁴ and the generations of poor government policies, that have continued to have a profound impact on Aboriginal and Torres Strait Islander health and wellbeing. The 'stolen generations' 1997 report 'Bringing them Home'⁵ provided detailed information about the forced removal of Aboriginal and Torres Strait Islander children. For the first time, the report highlighted the depth of this legacy and in particular the traumatic experiences of childhood issues (often physical and sexual abuse) and the relationship of the social and emotional wellbeing to the health of the person. This report only scratched the surface and there is a need for a follow up report that more deeply explores the consequences for long term health.

As an early career researcher in Aboriginal and Torres Strait Islander health, exploring ways of reducing obesity, diabetes and heart disease through early intervention methods by way of nutritious diets and exercise, I research attitudes and behaviours that influence health decisions. I regularly see data showing conflicting patterns of attitudes and behaviour, a complex array of 'mixed messages' shaping how people make decisions regarding their own health. On the one hand, people know that good food and exercise means good health. However, at the same time people will acknowledge that they smoke, are diabetic and are overweight. In some of our focus groups research participants will talk about their childhood experiences and relate these to their own poor health status; demonstrating a direct connection.

2.3 Citizenship status

As an Aboriginal person, I often find myself feeling like a second-class citizen and perhaps this has something to do with my own birth date and where I lived at that time. I was born in 1966 the year before the Australian 1967 Referendum,⁶ which was not explicitly about citizenship for Aboriginal and Torres Strait Islander people. The Commonwealth Electoral Act was amended in 1962⁷ to give franchise to all Aboriginal people, extending the right to vote to Aboriginal people in Western Australia, Queensland and the Northern Territory. The Referendum changed sections of the constitution from 1901 which stated 'in reckoning the numbers of people ... Aboriginal natives shall not be counted'. It also changed sections that said the Commonwealth would legislate for any race *except* Aboriginal people.⁶ This left the power over Aboriginal people were counted in the Census and 2) the Commonwealth was given the power to legislate for Aboriginal people; ironic that the Commonwealth government now uses this power to mount the intervention in the Northern Territory.⁶

While the Referendum did provide voting rights for Aboriginal and Torres Strait Islander people many were still living in conditions shaped by the White Australia Policy⁸ which was enacted at Federation in 1901. The Western Australia Aborigines Act⁹ was passed in 1905, making the Chief Protector the legal guardian of every Aboriginal and 'half-caste' child under 16. Reserves¹⁰ were established, a local protector appointed and rules governing Aboriginal employment were laid down.

My own Aboriginal mother and father were fresh from the Missions and were aged 16 and 17 when I was born. While my mother was allowed to give birth to me in a hospital, I was later taken home to the local Reserve where I am told we lived in tin shacks with dirt floors, over-crowding and no sanitation. I often recall going back to the Reserve during my childhood holidays and it has always haunted me to think that governments segregated Aboriginal people to live this way.

In great contrast, also in 1966, the same year I was born, the United Nations launched the International Covenant on Economic, Social and Cultural Rights¹¹ which states that 'recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world'.

I also become perplexed about my own 'citizenship status' particularly when I listen to discussions about Native Title and Land Rights as well as Human Rights in Australia. We have a long way to go to address the First Peoples' issues, but it is very disturbing and disheartening when watching mainstream TV or listening to radio talk-back shows discussing these topics. Most panellists are either ill informed, ignorant or are deliberately misleading the audience to gain political points for their own respective political parties. Listening to these programs does not encourage Aboriginal and Torres Strait Islander people to be 'proud' Australians but rather the discussion can further isolate people from the wider Australian population. I believe not feeling like a proud citizen of your own country can impact on your own sense of self-worth and directly shape decisions and choices about one's own health and wellbeing.

2.4 The Australian Constitution

For more than 100 years the Australian Constitution has been providing the basic rules by which Australia is governed. It is of continuing importance to Australia because it is the legal and political foundation on which our nation is built and continues to function.¹²

What does the Constitution represent for Aboriginal and Torres Strait Islander people? From my perspective, the Australian Constitution discriminates and does not provide adequate (if any) protection for Aboriginal and Torres Strait Islander people as the First Peoples of this country. We would need to go to a referendum to make any changes to the Constitution, but in great contrast the Racial Discrimination Act 1975¹³ has been amended at least three times. All three times were related to Aboriginal and Torres Strait Islander issues – most recently to accommodate the expansion of the Commonwealth Government's Northern Territory intervention/ response and 'therefore, it was ineffective in protecting our peoples from the most fundamental of all freedoms, the freedom from discrimination'.¹⁴

Recognizing Aboriginal and Torres Strait Islander people in the Australian Constitution is inherently the right thing to do as we are the First Peoples of Australia. In 1992, Prime Minister Paul Keating addressed the nation from Redfern Park, he said 'complex as our contemporary identity is, it cannot be separated from Aboriginal Australia' and 'the starting point might be to recognize that the problem starts with non-Aboriginal Australians'. Keating went on to discuss the need for constitutional recognition: 'It begins with the act of recognition ... We have to give meaning to 'justice' and 'equality'... We need these practical building blocks of change'.¹⁵

If we change the Constitution to recognize Aboriginal and Torres Strait Islander people and include a preamble that describes our important place in Australia, it will start to deliver and address a wide range of human and Indigenous rights issues. It will also be a unique catalyst to improving the health and wellbeing of ALL Aboriginal and Torres Strait Islander people and our future generations. In 2008, when Prime Minister Kevin Rudd delivered a national 'apology' to Aboriginal and Torres Strait Islander people, he said:

We apologise for the laws and policies of successive parliaments and governments that have inflicted profound grief, suffering and loss on these our fellow Australians ... We today take this first step by acknowledging the past and laying claim to a future that embraces all Australians. A future where this parliament resolves that the injustices of the past must never, never happen again ... A future where we harness the determination of all Australians, indigenous and non-indigenous, to close the gap that lies between us in life expectancy, educational achievement and economic opportunity. A future where we embrace the possibility of new solutions to enduring problems where old approaches have failed.¹⁶

The monumental legal act of recognizing Aboriginal and Torres Strait Islander people in the Australian Constitution will instil a real sense of pride and dignity for our First Peoples and be one of the solutions to closing the life expectancy gap. It will strongly encourage a more robust participation in the health, as well as the education and employment systems to build strong and proud future generations of Australians. In regards to health, it will particularly benefit Aboriginal and Torres Strait Islander people at the primary health stages, where people will utilize community health programs and embrace health promotion to reduce chronic and preventable diseases, rather than people presenting with advanced or end-stage disease. This would have the potential to save millions of dollars in health care, and social support and most importantly, save lives.

The timing of the Recognition of Aboriginal and Torres Strait Islander people in the Australian Constitution couldn't have come at a more crucial time. It is time that we recognize the true First Peoples of this country in our Constitution, but more importantly from a health perspective, we need to address these issues as a nation in unity. Health education and funding resources are essential, but recognizing one's own value and worth in the framework of this country as a first class citizen is vital to taking personal responsibility and addressing one's own health needs. It has to start with the individual if we as a nation and as health care professionals can truly make any difference.

A healthy Australian is a proud Australian.

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CHAPTER 3: STUDY TO REDUCE THE INCIDENCE OF DIABETES THROUGH EARLY INTERVENTION (STRIDE)

3.1 Chapter overview

An exploratory, mixed methods study to determine the key components needed in lifestyle-based interventions for the prevention and management of diabetes in Aboriginal and Torres Strait Islander communities in New South Wales.

3.1.1 Publication details

A journal article which arose from this work titled, '*What influences food choices, diet and exercise among Aboriginal and Torres Strait Islander adults: findings from a qualitative pilot study in Sydney, New South Wales* (Chapter 4, p. 70) was submitted to the *Medical Journal of Australia* in late 2013. I am currently revising the manuscript to address reviewers' comments for publication in 2014.



3.1.2 Author contributions

My contribution to this study included the study design, questionnaire design, ethics applications, focus groups facilitation, data collection and analysis, and write up of results.

3.1.3 Specific aims

To determine the feasibility of a culturally specific nutritional, diet, and physical activity intervention among Aboriginal and Torres Strait Islander Australian adults aged 15 years and older.

Potential endpoints include:

- 1. Reduction in progression to Type 2 diabetes over a five year period
- Improved food choices, diet, physical activity and weight loss outcomes at 12, 24 and 48 months

3.1.4 Objectives

- 1. To develop an intervention program that will be tested in a subsequent randomized controlled trial.
- To contribute to a better understanding of the number of Aboriginal and Torres Strait Islander people who could benefit from a lifestyle and food/nutritional intervention program to reduce the common risk factors for obesity, diabetes and cardio-vascular disease (CVD).

3.1.5 Methods used

Clinical audit

- Undertaken in NSW (n=294 records)
- Done in partnership with the Kanyini Vascular Collaboration
- Client records randomly selected from AMS patient databases
- Results entered into a web-based data form

Survey

Sixty-one responses (43 females, 18 males in total), of whom 50 (35 females, 15 males) identified as Aboriginal and or Torres Strait Islander. While all participants' demographics are presented, all other lifestyle results are those of participants who identified as Aboriginal and or Torres Strait Islander

- Self-administered questionnaires
- Data entered into Access and Excel
- Data analysed using STATA and SPSS

Focus groups

- 40 Aboriginal and Torres Strait Islander participants (20 female, 10 males) two focus groups
- Diversity sampling technique used
- Audio recorded interviews using trigger questions
- Professionally transcribed
- Full results for the focus groups are presented in Chapter 4

3.1.6 Ethics

Ethical clearance was sought for STRIDE from The University of Sydney and the Aboriginal Health and Medical Research Council of New South Wales (AH & MRC) number: (606/07) and full approval was granted in late December 2007. Data collection commenced in March 2008. Separate prior ethics approval was obtained for the Kanyini Vascular Collaboration Audit study. In New South Wales this approval was granted by the AH & MRC in September 2007. Approval was also granted by three other human research ethics committees in Queensland and Central Australia.

3.1.7 Summary of key results

The early results from this exploratory study of diabetes risk among Aboriginal and Torres Strait Islander people in New South Wales show:

- 1. A high prevalence of lifestyle risk factors for diabetes and cardio vascular disease was demonstrated.
- 2. Screening for kidney disease (CKD) needs to be improved.
- 3. Noting the high ongoing prevalence of smoking, Quit smoking campaigns and health promotion should be accompanied with follow up care and support.
- 4. BMI recordings needs to be more encouraged in clinics as well as waist circumference.
- 5. Lifestyle (SNAP) advice was consistently given to patients who attended the AMS over a two-year period.

3.1.8 Summary of recommendations

- Interventions should be targeted across the life course;
- A family-based model, in collaboration with AMS, might be more effective than interventions targeted at high risk individuals;
- Tobacco cessation should be considered;
- AMS systems should be strengthened for screening/recording risks factors;
- Multidisciplinary models of care would be required using international evidence about effective strategies working with disadvantaged populations; and
- Further research is required to better understand barriers and enablers to behaviour change to support health diets and increased physical activity.

3.1.9 Acknowledgments

- 1. All Aboriginal and Torres Strait Islander participants and organisations who gave up their time to participate in this research project
- 2. Professor Alan Cass (PhD primary supervisor who provided academic leadership and support throughout this research)

- 3. Dr. David Peiris (a colleague who provided me with invaluable research inputs, directions, advice)
- 4. Professor Sandra Eades (Co-PhD supervisor and source of original funding for this research project)

3.2 Background

3.2.1 Diabetes in New South Wales

Type 2 diabetes is Australia's fastest-growing chronic disease and the seventh highest cause of death in Australia. In 2002, there were 520,000 Australians diagnosed with diabetes with an average of 55,000 people diagnosed every year¹. Results of the recent diabetes national prevalence survey confirmed that for every person with diagnosed Type 2 diabetes there is one person with undiagnosed diabetes². In NSW the number of people with diabetes or high blood glucose has increased from 5.2% of males and 4.3% of females in 1997 to 6.7% of males and 5.6% of females in 2002 and 2003³.

Australia's Aboriginal and Torres Strait Islander population suffers the fourth highest rate of Type 2 diabetes in the world, with people aged over 35 years making up one of the major high-risk categories for developing the disease.¹ The rates of self-reported diabetes mellitus from the 1997 and 1998 Health Surveys were 7.1% for Indigenous people compared to 3.5% for non-Indigenous people. Of those surveyed, 47% of Indigenous people were overweight or obese compared to 42% of non-Indigenous people, with slightly higher rates in rural and remote than urban areas.³

Age-adjusted hospital separation rates for a primary diagnosis of diabetes mellitus among Aboriginal and Torres Strait Islander people were over five times higher than the rates for non-Indigenous people over the period 1993-1994 to 1999-2000. Aboriginal and Torres Strait Islander people also have a much higher rate of diabetic nephropathy requiring dialysis than non-Indigenous.⁴

Key government strategies for the prevention and management of Type 2 diabetes in Australia include the National Diabetes Strategy 2000-2004⁵ and NSW Chronic

Disease Prevention Strategy 2003-2007⁶. Both are focused on the prevention of Type 2 diabetes mellitus through the modification of risk factors, particularly through lifestyle changes and effective clinical management. The National Evidence Based Guidelines for the care of people with Type 2 diabetes recommend regular screening and intensive management for diabetes for those at high risk, including Aboriginal and Torres Strait Islander people aged 35 years and over; people aged 45 years and over who have hypertension or obesity; and people with cardiovascular disease. The guidelines recognise that 'integral to the success of the clinical management of diabetes is the self-care knowledge ability and the capacity of the person with diabetes to adapt their lifestyle to optimise their physical and psychological wellbeing'.⁷

Current government policies have identified principles for developing strategies for the prevention and management of diabetes among Indigenous people. They emphasise that strategies should be part of an holistic approach to health care and where possible, deliver services in the communities where people live, should involve training of local Aboriginal health workers and staff of Aboriginal community-controlled services, be based on needs determined by the community, with programs developed, supported and run by the community itself, and be coordinated with other Aboriginal health promotion programs. In keeping with these principles, the NSW Department of Health developed the *New South Wales Aboriginal Vascular Health Program* in 2000 (subsequently reviewed in 2003).⁸

3.2.2 Australian intervention studies

To date, little published evidence exists about successful intervention strategies to prevent chronic diseases such as diabetes and cardiovascular disease in urban Aboriginal and Torres Strait Islander people in Australia through early lifestyle intervention. What research has been conducted has been performed mostly in rural and remote areas but nonetheless clearly provides evidence that Aboriginal and Torres Strait Islander people are among the world's highest group at risk of obesity, diabetes and cardiovascular disease from an early age onset.⁹

Compelling evidence clearly demonstrates that Aboriginal and Torres Strait Islander Australians have a significantly shorter life expectancy than other Australians and between the ages of 25 and 55 years have a 10 fold higher risk of developing Type 2 diabetes. There have been few studies which have tested the extent to which progression from Impaired Glucose Tolerance (IGT) to diabetes can be prevented or delayed among Australian Aboriginal and Torres Strait Islanders.⁹

Here we present some brief descriptions of research which has been performed in an Aboriginal and Torres Strait Islander setting, and while these are based in or represent analyses of existing data collected from remote and rural communities they are still nonetheless helpful in understanding risk factors, research methods and designs which could inform an intervention program in an urban setting.

A stratified analysis of data from an eight-year community-based longitudinal study in 1999 was performed to determine the association between age and Body Mass Index (BMI), and subsequent incidence of Type 2 diabetes among Aboriginal and Torres Strait Islander people in Australia. This study followed 882 men and women aged between 15 and 77 and included 2808 person years of follow up. In total there were 46 incidence cases of diabetes after follow up. BMI modified strongly among females and males, and community adjusted association between age and diabetes incidence (P<0.001). 'The population's attributable risk (95% CI) associated with BMI beyond the reference category was 70.1% (58.1-82.4)' concluded that Aboriginal and Torres Strait Islander people were among the highest in the world for BMI specific diabetes and that an urgent need is required for intervention to prevent weight gain associated with diabetes. Furthermore, research is recommended to develop an 'optimal range of BMI' lower than that for non-Aboriginal and Torres Strait Islander people.⁹

In 2002, a cross sectional survey of Aboriginal and Torres Strait Islanders (2,862 individuals – aged >13 years) was conducted. Information was based on people who self-reported diabetes and health behaviour to researchers in remote and rural communities in Far North Queensland. The study examined associations between self-reported diabetes and smoking, alcohol and food consumption, using data from

the Well Persons Health Check. Results showed that smoking rates among selfreported diabetics (40%) were lower than among non-diabetics (63%). Alcohol consumption was high among self-reported diabetics (43%), yet lower than among non-diabetics (72%). Physical activity rates were similar among both groups – (58%) and (51%) respectively. Final conclusions suggest that Aboriginal and Torres Strait Islander people living in remote and rural areas in Australia are not adopting or utilising lifestyle interventions to reduce risk of obesity, heart disease and diabetes leading to continued high rates of mortality and morbidity among this population.¹⁰

Furthermore there are few studies reporting the up-take of physical activity among Aboriginal and Torres Strait Islander people.^{11, 12} What research has been done is still very 'grey' in terms of rigorous scientific methods. The National Heart Foundation of Australia in Western Australia in collaboration with the University of Queensland (2004) provides an epidemiological rationale for physical activity among Aboriginal and Torres Strait Islander people. Their research paper acknowledges that there are few publications on interventions or the 'powerful rationale' and 'effectiveness of community strategies to promote increased physical activity in Aboriginal and Torres Strait Islander' communities. They argue that if physical activity programs were strategically implemented in Aboriginal and Torres Strait Islander communities not only would this strengthen Aboriginal and Torres Strait Islander peoples own ability to reduce the incidence of future chronic illness, but improve their own social and emotional wellbeing also.^{11, 12}

3.2.3 International evidence

In international studies, there is compelling evidence that Type 2 diabetes can be prevented or delayed in onset by the implementation of supported nutritional and physical exercise lifestyle changes.¹³ Three independent randomised controlled trials have shown that maintenance of modest weight loss (3-5 kg) through sustained lifestyle interventions that include diet and physical activity reduce the incidence of Type 2 diabetes in high risk persons by 40% to 60% over three to four years. These studies also showed a strong correlation between success in modification of diet and physical activity and the reduction in risk of developing diabetes.

Prevention of Type 2 diabetes among younger populations is difficult to define given that the best method of screening is still not known.¹⁴ This is mostly due to 'diagnostic separation of Type 2 from other types of diabetes in young people can be difficult, and sophisticated testing may be necessary'. Mass screening in Taiwan and Japan among younger people has been conducted but results suggest that individuals in high risk groups are probably more appropriate, especially among Indigenous peoples.¹³ These studies further recommend that targeted lifestyle interventions (particularly in schools) are also required.

In the United Kingdom, clinical trials have established that tight glycaemic control is critical to preventing the disabling and costly complications of diabetes.¹⁵ Moreover, good blood pressure control and lipid control as well as medications such as aspirin and angiotensin blockers are important to reducing the micro-vascular and macro-vascular complications of diabetes.¹⁶ In addition to attending regular primary health care visits, completing preventive health screening, and adhering to appropriately prescribed medications, clients with diabetes must also achieve sufficiency in self-management and adopt significant lifestyle changes, including smoking cessation, good dietary habits and exercise, in order to achieve good health outcomes during life. Regular practice of these protective behaviours by the diabetic client often requires relevant health literacy, significant organizational skills, motivation, and the relative absence of competing social and medical conditions such as depression, substance use, poverty, and social marginalisation.¹⁷

National statistics in the United States (US) show that there are estimated to be at least 21 million people affected with diabetes. In addition to this there are a further 57 million American adults who have diagnosed impaired fasting glucose. This huge health burden costs the American government approximately \$132 billion dollars each year. Direct medical payments cost \$92 billion dollars and a further \$40 billion dollars indirectly (for example sick days off work and productivity loss). Diabetes in the US is the sixth leading cause of death. As in Australia, diabetes disproportionately affects minority and marginalised groups. In America, those most affected and who are more likely to die from diabetes and attributed disease complications are African-Americans and Latino adults who are '1.8 times more likely to develop diabetes than white non-Hispanics adults'.¹⁸

3.2.4 The study to reduce the incidence of diabetes through early intervention (STRIDE)

STRIDE sought to gather relevant data from a variety of sources about the care and prevention of Type 2 diabetes for Aboriginal and Torres Strait Islander people and to determine what might be key components to a large scale lifestyle-based intervention in this area. It was conducted by The George Institute for Global Health in collaboration with the Ministry of Health NSW, the Aboriginal Health and Medical Research Council (AHMRC) and The Sax Institute. STRIDE was linked with the Coalition for Research to Improve Aboriginal Health (CRIAH) in collaboration with the AHMRC and the Sax Institute in New South Wales in 2003. In 2008 STRIDE became integrated with the existing Indigenous health research program at the George Institute. The major component of this program is a five-year national research collaboration, the Kanyini Vascular Collaboration, which seeks to identify and overcoming barriers to best practice chronic disease care for Aboriginal and Torres Strait Islander people.

3.3 Methods

We took a mixed methods approach to gathering data. We collected (1) quantitative information from health services in NSW primary health care settings and (2) a mix of quantitative survey and qualitative focus group information to gain Aboriginal and Torres Strait Islander peoples' perspectives on diabetes preventions and care. The results of the qualitative focus group studies are presented in full in Chapter 4.

3.3.1 Audit

A retrospective, cross-sectional audit of a random sample of health care records was conducted in collaboration with two rural and one urban health services in NSW as a part of the Kanyini Vascular Collaboration Audit study. The broader study worked with an additional five services in Queensland and the Northern Territory. All three of these NSW services identify as Aboriginal Community Controlled Health Services (ACCHS). They predominantly use electronic health records to capture client information with some sites using supplementary paper records for additional information such as specialist correspondence. Electronic client database queries were generated at each site and records were randomly selected from these lists. A case record was eligible for review if (1) the record identified the client as Aboriginal and/or Torres Strait Islander; (2) the client was aged 18 years or over and (3) the client had been seen at least twice at that service in the preceding two years. In the larger urban service 200 records were sampled and in the two smaller services approximately one third of the eligible records were sampled.

Data were collected in the following areas: (1) past medical conditions and vascular risk factor measurements; (2) care provided by particular health professional groups (General Practitioners (GPs), Registered Nurses (RNs) and Aboriginal Health Workers (AHWs) including lifestyle and pharmacological management advice; (3) provision of government funded well-person's checks and chronic disease care plans. A centralised, web-based data collection form was used. Built into this form was an accompanying electronic data guide that provided definitions for each variable and access to a pharmaceuticals database. Auditors were trained in the use of this form and pilot testing of ten records was conducted at each site prior to commencing full data collection. Analyses were conducted in conjunction with the broader Kanyini project and mainly focussed on reporting frequency distributions (as proportions or means/medians) for variables of interest. Statistical analyses were carried out using SAS v9.1.

3.3.2 Survey

Self-complete questionnaires were designed using a range of international research designs and methods including the United Kingdom Prospective Diabetes Study (UKPDS), and the Australian Diabetes, Obesity and Lifestyle² (AusDiab) (please refer to Appendix A) and were administered at waiting areas through the two NSW ACCHS (one urban and one rural) and an Aboriginal Vocational Education Training college. These were self-reporting and self-explanatory (Appendices A-C). The questionnaire was a tick box response with simple language and visuals to assist the respondent. The purpose of the questionnaire survey was to gather invaluable

information about participants who may not have disclosed personal information in an interview or focus group discussion. The aim for the surveys was to collect this information to complement the focus group methodology. The administration and sampling process for the survey was discussed in consultation with our AMS partners and the Eora College. One potential option was that the surveys would be made available within the reception areas of the AMS's and Eora College; thus allowing individuals the choice of completing the survey privately and anonymously. Trained staff was on call to assist those people with literacy problems or difficulty in understanding the questions and where appropriate offer assistance to complete the survey. The surveys provide useful information that may not necessarily have been disclosed in the focus groups as the questions centre on individual knowledge and behaviour as well as questions about personal demographics and finance.

Standard criteria for participant eligibility were used to recruit survey participants which included the following:

- 1. Must be 16 years or older;
- 2. Identifying as Aboriginal and/or Torres Strait Islander; and
- 3. Able to provide informed voluntary consent.

3.3.3 Focus groups

In the qualitative phase of STRIDE, we recruited participants to be involved in focus group discussions in one community college and one health service setting. Facilitators sought to ensure a maximal representation of opinions from participants and were guided by the ACCHS and community college partners on the appropriate people to invite to participate in the study. Interviews were digitally recorded, and professionally transcribed. Analyses were primarily thematic in nature and sought to gain an insight into Aboriginal and Torres Strait Islander peoples' own personal experiences (including experiences of their own families and communities) as to what their views were about good food and nutrition, physical activity and health associated with diabetes, and their experiences of successful initiatives to promote

healthy lifestyles. Results of the focus group studies are presented and discussed in full in Chapter 4.

3.3.4 Ethics

Ethical clearance was sought for STRIDE from The University of Sydney and the AH & MRC and full approval was granted in late December 2007. Data collection commenced in February 2008. Separate prior ethics approval was obtained for the Kanyini Vascular Collaboration Audit study. In New South Wales this approval was granted by the AH & MRC in September 2007. Approval was also granted by three other human research ethics committees in Queensland and Central Australia.

3.4 Results

3.4.1 Clinical audit

Sample characteristics: In total 314 adult records were reviewed at three NSW ACCHS and 851 records at the Central Australian and Queensland sites. The mean age of the NSW sample was 40.5 years (95% CI 38.9-42.1, 61% female, 39% male). Figure 1 below shows the age distribution of the sample in NSW compared with NT/Qld. Females were over-represented in all age groups except the 50-59 year age bracket where the female to male ratio was approximately equal.

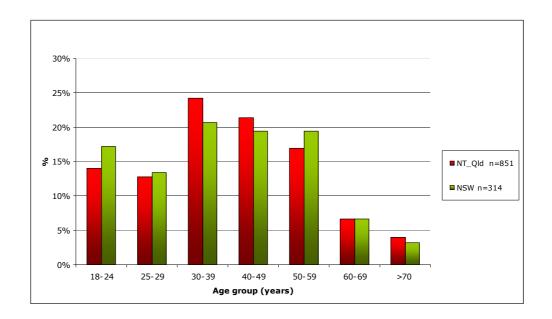


Figure 3.1: Age distribution of the sample

3.4.2 Recorded medical conditions

Table 3.1 shows the profile of selected recorded medical conditions in the NSW sites when compared to NT/Qld sites. Although limited by the accuracy of consistency in recording these conditions, these figures demonstrate high prevalence rates of vascular related diseases.

Recorded condition -	NSW	(n=314)	NT/Qld (n=851)	
Recorded condition	Ν	%	Ν	%
Elevated Blood Pressure	75	23.9%	205	24.1%
Diabetes/Impaired Glucose tolerance	52	16.6%	207	24.3%
Elevated Lipids	79	25.2%	164	19.3%
Depression	58	18.5%	64	7.5%
Established cardiovascular disease (CVD)	43	13.7%	58	6.8%
Obesity	32	10.2%	71	8.3%
Chronic Kidney Disease (CKD)	12	3.8%	77	9.0%
Chronic Obstructive Pulmonary Disease	15	4.8%	23	2.7%

Table 3.1:Recorded medical conditions at NSW sites compared with NT/Qld sites
(% of column totals)

3.4.3 Vascular and diabetes risk factors and their recording rates

Smoking: Figure 3.2 shows the smoking prevalence rates in those for whom information was available. 16% of the case records sample in NSW did not have sufficient information with which to assess smoking status. This was considerably better than in NT/Qld where over one third of cases sampled did not have smoking status recorded. In those for whom information was available, extremely high smoking prevalence rates were noted for both males and females.

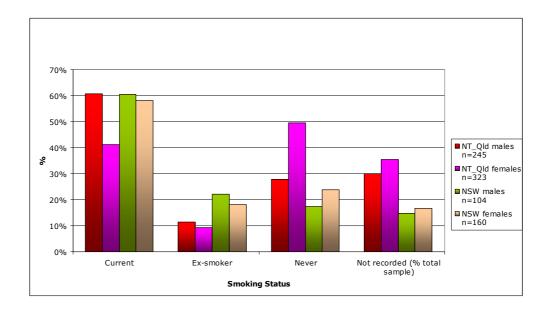


Figure 3.2: Smoking status at NSW sites compared with NT/Qld sites

Body Mass Index: Figure 3.3 shows the body mass index profile of the sample. More than 40% of clinical records had no BMI recorded. This was similar in both NSW and NT/Qld sites. For those people for whom BMI information was available, 54% of females and 25% of males had a BMI >30kg/m2.

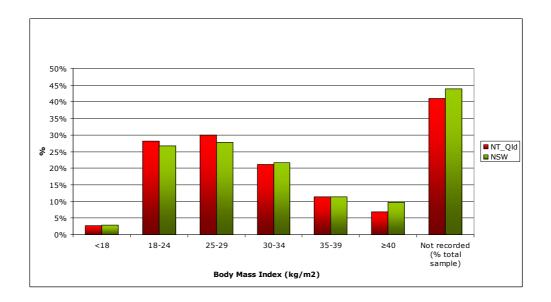


Figure 3.3: Body mass index

Other vascular risk factors: Table 3.2 summarises the key findings for blood pressure, cholesterol and kidney disease screening.

	NSW		NT/Qld	
Variable		Missing information*		Missing information*
Mean Systolic BP (mean mmHg (SD))	123 (18.4)	51 (16%)	124 (16.8)	63 (7%)
Total Cholesterol: HDL ratio (mean (SD))	4.1 (1.3)	177 (56%)	4.7 (1.5)	432 (51%)
Albuminuria ** (n (%))	18 (38%)	267 (85%)	164 (56%)	560 (66%)
eGFR<60 ml/min/1.73m ² (n (%))	11 (6%)	140 (45%)	56 (11%)	345 (40%)

Table 3.2: Blood pressure, cholesterol and chronic kidney disease screening

* % of total sample n=314 in NSW and n=851 in NT/Qld

3.4.4 Management practices

Diabetes: Table 3.3 summarises the key management considerations for people recorded as having diabetes.

Table 3.3:	Diabetes management practices at NSW and NT/Qld sites (% of column
	totals unless otherwise stated)

Variable	NSW (n=49)		NT/Qld (n=200)	
v at fable	Ν	%		Ν
Diabetes duration >10 years	13	27%	50	25%
Albuminuria*	14	41%	100	73%
HbA1C>8%	15	31%	111	56%
BP Systolic>130mmHg	20	41%	67	34%
Eye review recorded in last 2 years	20	41%	62	31%
Physician review recorded in last 2 years	25	51%	52	26%

* % calculated for those with data available (n=34 in NSW, n=137 in NT/Qld)

Lifestyle management: Figure 3.4 shows the proportion of the sample in which there was some mention of the patient receiving a lifestyle assessment or management advice in the four areas of smoking, nutrition, alcohol consumption and physical activity.

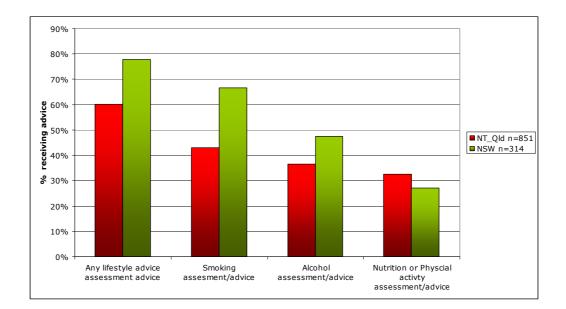


Figure 3.4: Proportion of patients receiving any form of lifestyle assessment or advice at least once in the previous two years in NSW and NT/Qld sites

Medical notes on lifestyle issues are often cursory and are usually found in the daily progress notes rather than in pre-formatted templates. It was intended to capture any reference whatsoever to lifestyle management in this variable. Due to the often brief nature of the notes referring to lifestyle related issues it was not possible to separate assessment from advice. Similarly it was often difficult to distinguish between physical activity and nutritional issues and so these two components were grouped together. There was also a substantial variation in interpretation of what constituted lifestyle advice between auditors (particularly between NSW and NT/Qld auditors) and so the results presented below ought to be interpreted with caution. Despite these caveats the most common lifestyle assessment or advice at all sites was related to smoking.

Medicare enhanced primary care items: Figure 3.5 summarises the uptake of a of the following Medicare enhanced primary care items: Item 710 – An adult health check provided every 18 months to an Aboriginal and/or Torres Strait Islander person aged 15-54 years; Items 704 – Older person's check provided annually to an Aboriginal and/or Torres Strait Islander person aged 55+ years; Items 721, 723, 725

- General Practitioner Management plans and Team Care arrangements provided to people identified as having a chronic disease.

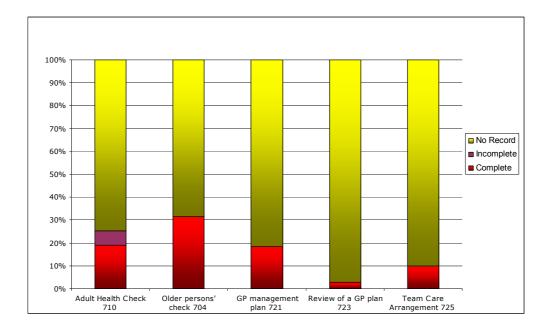


Figure 3.5: EPC Medicare items NSW (for items 710 n=254, 704 n=60, 721-725 n=70)

For these latter item numbers we calculated the denominator as being anybody recorded as having diabetes, CVD, or CKD. A complete check was defined as evidence in the record of the check having been conducted and claimed for through the practice billing system. An incomplete check was recorded if there was evidence of the item being initiated but not completed or claimed for. Generally rates of completed checks were better in NT/Qld sites (32% for item 710, 34% for item 704, 23% for Item 721, and 12% each for Items 723 and 725)

Medication prescribing: Figure 3.6 describes the prescribing rates of the major cardiovascular medication groups (Blood pressure lowering, statin, anti-platelet therapies) for the total sample and clients identified as having diabetes or cardiovascular disease. Whilst prescribing rates for individual therapies was relatively high, a smaller percentage of clients with diabetes and CVD were prescribed all three therapies in combination (61% and 70% respectively). Although this gap is significant it was substantially better than in NT/Qld sites where

prescribing rates of all three therapies combined were 38% and 52% for diabetes and CVD respectively.

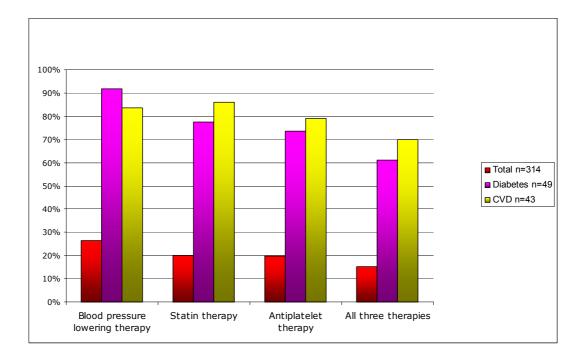


Figure 3.6: Patients receiving chronic disease medicines at three NSW ACCHS

3.5 Survey

Table 3.4: Survey respondent characteristics

	Aboriginal N=50 (82%)	Non-Aboriginal N=11 (18%)	Total n=61
Male	15 (30%)	3 (27%)	18 (30%)
Female	35 (70%)	8 (73%)	43 (70%)
Age			
15-19 years	8 (16%)	-	8 (13%)
20-29 years	5 (10%)	3 (27%)	8 (13%)
30-39 years	13 (26%)	2 (18%)	15 (25%)
40-49 years	15 (31%)	2 (18%)	17 (28%)
50+ years	8 (16%)	4 (36%)	12 (20%)
Missing/not known	1 (2%)	-	1 (2%)

	Aboriginal N=50 (82%)	Non-Aboriginal N=11 (18%)	Total n=61
Marital Status			
Married/de-facto/living with a partner	15 (30%)	4 (36%)	19 (31%)
Single/separated/widowed	35 (70%)	7 (64%)	42 (69%)
Proportion with dependents	31 (62%)	5 (45%)	36 (59%)
Job Status			
Full time/part time employment	19 (38%)	3 (27%)	22 (36%)
Full time student	12 (24%)	4 (36%)	16 (26%)
Other	19 (38%)	4 (36%)	23 (38%)
Annual Income			
Less than \$40,000	24 (48%)	6 (55%)	30 (49%)
More than \$40,000	14 (28%)	2 (18%)	16 (26%)
Preferred not answered	7 (14%)	2 (18%)	9 (15%)
Missing	5 (10%)	1 (9%)	6 (10%)
% experiencing difficulty paying th	ne following bills		
Rent/mortgage	11 (22%)	3 (27%)	14 (23%)
Gas/electricity, etc.	17 (34%)	3 (27%)	20 (41%)
Medical consultation	5 (10%)	1 (9%)	6 (13%)
Medications	13 (26%)	3 (27%)	16 (32%)
Dental appointment	9 (18%)	2 (18%)	11 (23%)
Childcare	3 (6%)	2 (18%)	5 (12%)
Schooling costs	12 (24%)	2 (18%)	14 (29%)

Responses in Table 3.4 show that participants were aged between 15 years and 50+ years with most identifying their age between 30 years and 50+ years. Most were single/separated or widowed. The majority of participants indicated they worked or studied full time. Over 60% of the Indigenous participants had dependants. The average income was around \$40,000 per annum or less. Many reported trouble paying their bills and experienced difficulty affording medical care and medications.

	Male (n=15)	Female (n=35)	Total (n=50)
General health status			
Excellent	2 (13%)	1 (3%)	3 (6%)
Very good	4 (27%)	14(40%)	18 (36%)
Good	6 (40%)	11 (31%)	17 (34%)
Fair	3 (20%)	8 (23%)	11 (22%)
Poor	0 (0%)	1 (3%)	1 (2%)
Smoking			
Current smoker	8 (53%)	22 (63%)	30 (60%)
Non-smoker	7 (47%)	10 (29%)	17 (34%)
Ex-smoker	0 (0%)	2 (6%)	2 (4%)
Diagnosed with diabetes			
Yes	2 (13%)	7 (20%)	9 (18%)
No	11 (73%)	26 (74%)	37 (74%)
Not sure/unknown	2 (13%)	2 (6%)	4 (8%)
Perception of body weight			
Healthy weight	6 (40%)	15 (43%)	21 (43%)
Overweight	6 (40%	14 (40%)	20 (41%)
Underweight	3 (20%)	3 (9%)	6 (12%)
Other	0 (0%)	2 (6%)	2 (4%)
Last time seen a health care provider			
<1 month ago	7 (47%)	16 (46%)	23 (47%)
1-6 months ago	3(20%)	15 (43%)	18 (36%)
>6 months ago	4 (27%)	2 (6%)	6 (12%)
Can't remember	1 (7%)	1 (3%)	2 (4%)
Place of most recent health care consultat	tion		
AMS	7 (47%)	17 (49%)	24 (48%)
Local private doctor	5 (33%)	14 (40%)	19 (38%)
Other (after hours clinic)	0 (0%)	2 (6%)	2 (4%)
Hospital Emergency Department	1 (7%)	1 (3%)	2 (4%)
Can't remember	2 (13%)	1 (3%)	3 (6%)

Table 3.5:Self-reported health characteristics and access to health care for
participants identifying as Aboriginal and/or Torres Strait Islander only

Participants were asked to rate their own health status. Most rated their health as being either good or very good, with very few rating their health as poor. Nevertheless, most indicated they were smokers, almost 20% stated they were diabetics and 40% considered themselves to be overweight. More than 80% of respondents reported having seen a heath provider in the previous six months and almost 50% reported their most recent consultation was at an Aboriginal Medical Service.

	Male (n=15)	Female (n=35)	Total (n=50)
Number of respondents who are the prima following	ary people respor	nsible in their hous	sehold for the
Choice of food eaten	11 (73%)	26 (74%)	37 (74%)
Purchasing food	7 (47%)	26 (74%)	33 (66%)
Preparation of food	10 (66%)	27 (77%)	37 (74%)
Serving food	7 (47%)	23 (65%)	30 (60%)
When eating at home, the number of peop	le in the househo	ld who usually eat	together
The respondent usually eats on their own	5 (33%)	5 (14%)	10 (20%)
2-3 people	5 (33%)	14 (40%)	19 (38%)
4-5 people	5 (33%)	12 (34%)	17 (34%)
>5 people	0 (0%)	4 (11%)	4 (8%)
In the last week where you have eaten at t	he following loca	tions	
Home	13 (86%)	29 (82%)	42 (84%)
Family or friend's place	4 (26%)	14 (40%)	18 (36%)
School/college/university	4 (26%)	10 (28%)	14 (28%)
Work	6 (40%)	5 (14%)	11 22%)
Café/food courts	3 (20%)	9 (25%)	12 (24%)
Pub/clubs	3 (20%)	3 (8%)	6 (12%)
Restaurant	2 (13%)	3 (8%)	5 (10%)
Community centre	0 (0%)	3 (8%)	3 (6%)

Table 3.6:Food consumption and preparation practices by gender for participants
identifying as Aboriginal and Torres Strait Islander only

	Male (n=15)	Female (n=35)	Total (n=50)
Frequency of eating breakfast			
Never	2 (13%)	2 (5%)	4 (8%)
Not very often	2 (13%)	2 (5%)	4 (8%)
Sometimes	11 (73%)	4 (11%)	15 (30%)
Most of the time	0 (0%)	6 (17%)	6 (12%)
Everyday	7 (47%)	13 (37%)	20 (40%)
Consumption of fast food meals			
Very rarely or never	4 (26%)	11 (31%)	15 (30%)
1-2 times per week	7 (47%)	21 (60%)	28 (56%)
>3 times per week	4 (26%)	3 (8%)	7 (14%)
Consumption of vitamin supplements			
Never	11 (73%)	17 (48%)	28 (56%)
Not very often	0 (0%)	7 (20%)	7 (14%)
Sometimes	3 (20%)	7 (20%)	10 (20%)
Everyday	1 (6%)	4 (11%)	5 (10%)
Mean rating on the weekly frequency of consuming the following food types:	Mean	Mean	
(1= never, 5=always)			
Cereal	3.1	3.2	
Fresh fruit	3.4	3.4	
Fresh vegetable	3.6	4.0	
Meat	3.6	4.0	
Fish	2.4	2.6	
Dried nuts/fruit	2.3	2.3	
Breads	3.9	4.0	
Yoghurt (yogurt, cheese or milk)	2.0	2.8	
Cheese	3.2	3.7	
Milk	4.1	4.1	

Women were more likely to choose, purchase, prepare and serve food at home. They were also more likely to eat with other members of the household regularly. Only 40% of participants consumed breakfast on a daily basis. Amongst both males and females, approximately 70% consumed fast food meals at least once per week. The majority never or rarely take vitamin supplements. Participants indicated they regularly consumed food from the five major food groups.

Female participants were more likely to drink between three and six glasses of water a day. Approximately 80% of males and females consume between one and four soft drinks per day and the majority at least one glass of juice daily. Approximately 50% of males and 30% of females reported consuming alcohol more than once or twice per week.

	Male (N=15)	Female (N=35)	Total (N=50)
Number of glasses of water consu	med on an average day		
None	0 (0%)	0 (0%)	0 (0%)
1-2	5 (33%)	9 (25%)	14 (28%)
3-4	7 (46%)	13 (37%)	20 (40%)
5-6	2 (13%)	9 (25%)	11 (22%)
>6	1 (6%)	4 (11%)	5 (10%)
Number of cans/small bottles of se	oft drink on an average da	ny	
None	3 (20%)	7 (20%)	10 (20%)
1-2	6 (40%)	21 (60%)	27 (54%)
3-4	6 (40%)	6 (17%)	12 (24%)
5-6	0 (0%)	0 (0%)	0 (0%)
>6	0 (0%)	1 (2%)	1 (2%)
Number of glasses of juice on an a	average day		
None	5 (33%)	11 (31%)	16 (32%)
1-2	8 (53%)	19 (54%)	27 (54%)
3-4	2 (13%)	3 (8%)	5 (10%)
5->6	0 (0%)	2 (5%)	2 (4%)

Table 3.7:Beverage drinking patterns for participants identifying as Aboriginal and
Torres Strait Islander only

	Male (N=15)	Female (N=35)	Total (N=50)
Frequency of drinking any kind of al	coholic beverage		
Never	2 (13%)	11 (31%)	13 (26%)
Less than once a month	2 (13%)	2 (5%)	4 (8%)
Once or twice a month	3 (20%)	9 (25%)	12 24%)
Three or four times per week	3 (20%)	1 (2%)	4 (8%)
Once or twice per week	4 (26%)	10 (28%)	14 (28%)
Daily or almost every day	1 (6%)	0 (0%)	1 (2%)

Table 3.8:Physical activity for participants identifying as Aboriginal and Torres
Strait Islander only

	Male (N=15)	Female (N=35)	Total (N=50)
Frequency of any sort of physical	l activity		
None	2 (13%)	5 (14%)	7 (14%)
1-2 times per week	4 (26%)	7 (20%)	11 (22%)
3-4 times per week	3 (20%)	10 (28%)	13 (27%)
>5 times per week	6 (40%)	12 (34%)	18 (36%)
Frequency of heavy physical acti	vity		
None	1 (6%)	9 (25%)	10 (20%)
1-2 times per week	9 (60%)	14 (40%)	23 (47%)
3-4 times per week	1 (6%)	8 (22%)	9 (18%)
>5 times per week	4 (26%)	3 (8%)	7 (14%)
Average amount of television/DV	D viewing per day		
<1 hour	3 (20%)	5 (14%)	8 (16%)
1-2 hours	2 (13%)	13 (37%)	15 (30%)
3-4 hours	8 (53%)	12 (34%)	20 (40%)
>5 hours	2 (13%)	5 (14%)	7 (14%)
Average amount of computer usa	age per day		
<1 hour	6 (40%)	14 (40%)	20 (40%)
1-2 hours	5 (33%)	9 (25%)	14 (28%)
3-4 hours	1 (6%)	6 (17%)	7 (14%)
>4 hours	3 (20%)	5 (14%)	8 (16%)

	Male (N=15)	Female (N=35)	Total (N=50)
Barriers to performing physical activity			
Physical disability	2 (13%)	0 (0%)	2 (4%)
Lack of motivation	3 (20%)	10 (28%)	13 (26%)
Not enough time	2 (13%)	10 (28%)	12 (24%)
Shame - worried what others will think	1 (6%)	4 (11%)	5 (10%)
Can't afford cost of memberships	3 (20%)	9 (25%)	12 (24%)
No local facilities	2 (13%)	2 (5%)	4 (8%)

Both males and females were likely to participate in some form of physical activity and both are likely to engage in heavy activity at least one to two times a week. However, more females indicated that lack of motivation and or time was deemed as 'barriers'. Approximately 50% of participants reported watching TV/DVDs at least three hours per day and 30% used the computer more than three hours per day.

3.6 Focus groups

Two focus groups were conducted; one at the Tharawal Aborginal Corporation Campbelltown and one at the Eora TAFE College in Redfern respectively. In total there were 40 participants. The duration of each focus group was approximately one hour 30 minutes. Results of the focus group interviews are presented in Chapter 4 and the key themes emerging from the focus groups discussed in Chapter 4 in full.

3.7 Discussion

This exploratory study was performed to determine the feasibility of conducting a culturally specific nutritional and physical activity intervention among Aboriginal and Torres Strait Islander adults. The participants in this study were aged 15 years and older. The intention of this study was to collect preliminary data towards the development of an intervention program, which would be tested in a subsequent controlled trial. This would contribute to a better understanding of the number of Aboriginal and Torres Strait Islander people who could benefit from a lifestyle and

nutritional intervention program to reduce the common risk factors for diabetes and CVD and improve overall health and wellbeing.

The early results from this study must be read with caution given the limitations in timeframes and resources impacting on the number of sites and communities in which the research could be conducted. Nevertheless, the information collected, including data from an audit of health service provision, survey and qualitative research with community members, provides a snap-shot perspective into the lifestyle of urbanised and rural-based Indigenous groups living within New South Wales.

The audit study confirmed both a heavy burden of chronic disease and underlying risk factors including high rates of obesity and smoking. Some gaps in the primary care-based screening and management of chronic disease were identified. These included a lack of documentation of measurement of obesity and low rates of screening for albuminuria and eGFR as risk factors for chronic kidney disease, The audit also revealed most patients received some form of lifestyle advice, however few received alcohol, nutrition or physical activity assessment or advice. Uptake of EPC items related to chronic disease was also low.

The survey results were consistent with the heavy burden of smoking and obesity as revealed in the audit study. The majority of respondents viewed their own health as good or very good and reported consuming a wide range of healthy foods and undertaking at least some regular exercise. Nevertheless, the focus group results, which are not presented in this chapter of the thesis, provide the most useful insight into the attitudes and issues that might underpin dietary and exercise patterns of Aboriginal and Torres Strait Islander people living in NSW.

Daily or almost daily consumption of alcohol was reported by few survey respondents. However, these results are consistent with Australian Bureau of Statistics 2007-2010 surveys which have shown that even while Indigenous Australians are less likely to consume alcohol, those that do consume alcohol drink excessively at harmful levels. In the 2002 survey, one in six people (15%) and aged 15 years or over reported drinking at high risk levels in the last 12 months. The rate of drinking for Indigenous people was higher among males than females. In this context, it would appear there are unrealised opportunities to discuss alcohol intake and offer advice in primary care. The review of AMS activities in regard to lifestyle assessment and advice indicates there is potential to broaden the scope of activities beyond smoking cessation to more comprehensively address key issues around alcohol, diet and exercise.

Both the audit and survey conducted for the STRIDE study confirmed a very high prevalence of current smokers. In 2004-05, the rate of regular smoking among Aboriginal and Torres Strait Islander men was 'around twice that of non-Aboriginal and Torres Strait Islander men (51% compared with 24%) and the rate for Aboriginal and Torres Strait Islander women was around two-and-a-half times that of non-Aboriginal and Torres Strait Islander women (49% compared with 18%)'. Further, in 'the Aboriginal and Torres Strait Islander population, rates of regular smoking were high in younger age groups (reaching 57% for men aged 35-44 years and 54% for women aged 25-34 years and 35-44 years) and lower among those aged 55 years and over'. Rates of smoking in the non-Aboriginal and Torres Strait Islander population followed a 'similar pattern by age, although at considerably lower levels'. ABS 2006¹⁹ data also report that 'one in five Indigenous adults (20%) were ex-smokers and 28% of Indigenous adults reported that they had never smoked'.

Uptake and adherence to a nutritious diet combined with daily physical activity, nonsmoking, moderate alcohol consumption and regular health check-ups can be difficult to maintain. In addition, people with a diagnosed chronic disease may also find it even more challenging to lead a healthy lifestyle and adhere to treatments such as glycaemic control, lipid-lowering and other cardiovascular medications which are critical to reduction in cardiovascular risk.²⁰ Healthy lifestyle changes can be very difficult to begin and maintain for most people, especially for those individuals already struggling with being overweight, living with a disability or illness, and or living in poverty. In addition, many Aboriginal and Torres Strait Islander people are often confronted and overwhelmed with the burden of diseases at home with family members and within the wider community. All these factors can impact on leading a healthy lifestyle, making informed diet and routine exercise decisions, as well as regular health care access that can lead to quality health care outcomes.

Key government strategies for the prevention and management of Type 2 diabetes in Australia, including the National Diabetes Strategy 2000-2004²¹ and NSW Chronic Disease Prevention Strategy 2003-2007²² and the recent Chronic Care for Aboriginal People Model of Care 2010²³, are all focused on the prevention of Type 2 diabetes mellitus and CVD through the modification of risk factors, particularly through lifestyle changes and effective clinical management.

These strategies have identified principles for developing strategies aimed at preventing and managing diabetes among Indigenous people. They emphasise a holistic approach to health care, delivery of services in the communities where people live, training of local Aboriginal and Torres Strait Islander care health workers and staff of community-controlled health care services, and that programs be based on needs determined by the community, developed, supported and run by the community, and that they be coordinated with other Aboriginal and Torres Strait Islander health care promotion programs.

3.8 Recommendations for an Intervention program

In keeping with current National and New South Wales policies for the prevention and management of Type 2 diabetes, community consultation and pilot work should be carried out among Aboriginal communities in NSW aiming to develop, implement and evaluate a culturally-appropriate program to prevent and reduce the burden of diabetes and related chronic diseases.

Pilot work would aim to establish ways in which to improve prevention and service delivery efforts in relation to diabetes by exploring some of the following research gaps:

 AMS clinic population pilot studies of the prevalence of impaired glucose tolerance (IGT) and diabetes.

- 2. Implement and evaluate continuous quality improvement approaches aiming to improve the screening and management of chronic disease, building on the relevant body of evidence from the ABCD Partnership.
- 3. Pilot intervention studies to explore and better understand psychological distress associated with self-management and lifestyle intervention programs (including food and diet) among clinic patients at risk of obesity, developing and with existing diabetes.*
- 4. Pilot intervention studies among people who attend the clinic who have impaired glucose tolerance in order to delay the onset of Type 2 diabetes with a focus on lifestyle components such as food education and physical activity uptake of the program as well as exploring any associations with psychological distress.*
- 5. Conduct research with the aim of exploring the development of family and community-based intervention strategies addressing norms regarding identity, food and discrimination.*

* Evidence supporting these pilot studies and further research is presented in Chapter 4.

The research program could be used to pilot and develop aspects of a detailed research and service delivery framework for prevention and management of diabetes in NSW and nationally among Aboriginal and Torres Strait Islander people.

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CHAPTER 4:

WHAT INFLUENCES FOOD CHOICES AND DIET AMONG URBAN ABORIGINAL AND TORRES STRAIT ISLANDER ADULTS: FINDINGS FROM A QUALITATIVE STUDY IN SYDNEY, NEW SOUTH WALES

This chapter presents the findings of the focus group study, which was previously mentioned in Chapter 3. This chapter represents the version of the qualitative research conducted for STRIDE that has been submitted for publication.

4.1 Abstract

Objective: To explore themes related to the knowledge, attitudes and cultural influences on urban Aboriginal and Torres Strait Islander people's dietary choices.

Design, setting and participants: Between February 2008 and June 2008, two qualitative focus groups were held in a local Aboriginal Medical Service and a Technical and Further Education (TAFE) college in Sydney. Forty Aboriginal and Torres Strait Islander people participated (30 women and 10 men).

Results: A number of major themes were identified as being associated with food choices and eating behaviours. These included people's understandings of what is healthy food; understandings of the standard and quality of fresh and processed foods; understanding of salt in the diet; bush tucker associated with food, identity and culture; a personal or family history of diabetes or heart disease; family perceptions of appropriate body weight associated with Aboriginal identity; the role of stress and depression in overeating for comfort and social and emotional wellbeing.

Conclusions: Health and nutrition professionals working with Aboriginal and Torres Strait Islander people should be mindful of the critical importance of identity, family, cultural and mental health factors when assessing possible lifestyle interventions to improve dietary intake to reduce obesity and prevent chronic disease among this group.

4.2 Introduction

In Australia, there is compelling evidence that Aboriginal and Torres Strait Islander peoples have a significantly shorter life expectancy than other Australians.¹ To date, little published evidence exists about the key influences on food choices and dietary patterns among Aboriginal and Torres Strait Islander people, particularly in urban areas, or the impact of diet on morbidity and mortality among these peoples. Previous research that has been conducted mostly in rural and remote areas provides clear evidence that Aboriginal and Torres Strait Islander people's food choices consist mainly of nutrient-poor foods that are often high in refined carbohydrates and low in fresh fruit and vegetables.² Minimal research has been conducted among Aboriginal and Torres Strait Islander people living in urban areas. However, one study conducted in an urban Indigenous population showed that lower socioeconomic status (SES) was associated with low levels of biomarkers for fruit and vegetable intake.³ In a 2007 study of the burden of disease and injury in Aboriginal and Torres Strait Islander peoples.⁴ the results showed that urban Aboriginal and Torres Strait Islander populations make up 74% of the total Indigenous population, they contribute 65% to the burden and injury disease and experience 60% of the Indigenous life gap. Similar research among urban Indigenous Australians also identifies this gap in life expectancy.⁵ This underscores the need to better understand dietary influences and patterns in the urban Indigenous population.

The Australian Dietary Guidelines, developed by the NHMRC,⁶ promote the daily consumption of the five major food groups, which include fruit, vegetables, cereals/breads, lean meat, fish, dairy products and drinking water. In addition the guidelines recommend limited intake of foods and drinks that are high in salt, sugar, saturated and trans fats as well as limiting alcohol intake. The guidelines also recommend individuals prepare and store food safely, and encourage people to maintain a healthy weight by including daily physical activity. For newborns the guidelines promote and support breastfeeding. Whilst the Australian dietary

guidelines are available for all Australians, Aboriginal and Torres Strait Islander people are considered 'at greater risk of diet-mediated poor health' and further knowledge about what influences food choices is required to improve the provision of dietary advice to Aboriginal and Torres Strait Islander people.

In this paper we report the findings from qualitative research conducted to better understand the influences on food choices and diet of Aboriginal and Torres Strait Islander people living in urban settings in Sydney NSW. We aimed to explore knowledge and attitudes to dietary risk factors to inform the development of a lifestyle intervention program in an Aboriginal and Torres Strait Islander urban setting.

4.3 Methods

Focus groups were conducted at the Tharawal Aboriginal Corporation (AMS), Campbelltown, and at the Eora Technical and Further Education (TAFE) College in Redfern between February and June 2008. Participants were recruited through advertising at the reception desks of each site. Eora College further assisted by publicizing the focus group among their students and staff. Two moderators, one Aboriginal and one non-Aboriginal researcher, facilitated the focus groups. This promoted a safe environment to ensure all participants were able to participate in the discussion and freely express their opinions. The group interviews were not structured, but lifestyle questions including the following were used to prompt discussion:

- What does good health mean to you?
- What does bad or poor health mean to you?
- Tell me about the food you eat?
- What do you think is healthy/ unhealthy food?
- Can you tell me about the things that affect you and your family's eating?
- Can you tell me about a family member being sick? How did that affect you?

A grounded theory practice was used to allow themes to evolve naturally. Interviews were digitally recorded and transcribed. Analyses were primarily thematic in nature and sought to gain an insight into Aboriginal and Torres Strait Islander peoples' personal experiences (including experiences of their identity, families and communities) as to what their concepts were about food, good nutrition, and diet associated with diabetes, poor and healthy lifestyles. Ethical clearance was obtained from The University of Sydney and the Aboriginal Health and Medical Research Council of New South Wales. Data collection commenced in late February 2008. While the AMS and Eora College supported and approved the study, the researchers initiated the study. However, through prior meetings with management, both organisations had input into the study design. There was a real sense that improving the health and wellbeing of staff, clients and students was an important priority.

4.4 Results

Two separate focus groups were conducted. In total, 40 people participated, including 30 women and 10 men. The duration of each focus group was approximately one and a half hours. One group had an equal number of men and women (a recruitment strategy led by the participating organisation), while the other groups were all women. Participants were aged between 16 and 66 years. Most of the participants, apart from staff members who volunteered to participate, were either receiving study benefits or were welfare dependent. Several participants were homemakers, with partners working fulltime.

Key themes arising from the focus groups were understandings of what are healthy foods as well as quality and standards; concerns about the quality of fresh and processed foods in major supermarkets; understanding and attitudes regarding salt in the diet; the association of bush tucker with good food, identity and culture; the onset of diabetes or heart disease as a turning point for change in dietary-related behaviour;

Themes that were associated with poor food choices included the attitudes of family regarding health, body weight, portion size and reasons for weight loss; the role of depression in reducing motivation to make healthy food choices; and the tendency to overeat for comfort when stressed.

4.4.1 Understandings of what are healthy foods as well as quality and standards

Most participants showed a good awareness of the importance of consuming the five major foods groups. They also conveyed knowledge of what are considered to be healthy foods and the importance of cooking at home.

I always have some rice and pasta in there and I add me own spices for flavouring and then I just go and add some mince. And I grab me veggies, but I found out that the best vegetables is your ground vegies... Not your packet, not your tins, it is your ground. But ground veggies are very expensive you know.

Well healthy, nice vegetables and it hasn't been sprayed with chemical. Good kangaroo that's been hopping around the bush free, not kept up in a cage or something.

One female participant talked about her own understanding of good food but also discussed the difficulties she had to maintain this at home:

I like me wholemeal bread, but my family don't and they want their white bread and they can have their white bread. My husband eats big tubs of margarine and sometimes I think he is using margarine as a dip, just to dip his biscuits in the margarine and that is what he does.

Both groups also discussed an appreciation of foods from other cultures and had access to a wide selection of cuisines; reflecting access to the many different types of foods and drinks available in Australia.⁶ The participants also expressed how they often enjoyed a diverse variety of foods in their diet, including organic produce, to incorporate a wide selection of healthy food types in their daily nutrition intake.

It's usually multicultural. Lebanese because it's really healthy.

4.4.2 Concerns about the quality of foods available in supermarkets

An important topic that participants also identified and discussed in both focus groups was the quality and choice of fresh and processed foods and the food quality and standards in popular supermarkets where they did their weekly food shopping. I think most of the food that's in [xxx] and the shops is probably...most of it is rubbish. So more of these food standards, you have a look at half of it's not even proper food, it's something else to make it cheaper so it will last longer on the bloody shelf or whatever like that. If you're munching down on that all the time, what else is that putting into your kidneys and your liver and all that ... You don't feel real good when you haven't got food feed in you. And I mean a good feed.

And there's so much salt and sugar in a lot of the processed foods ... I am really aware of it now.

One participant described how she calculated and justified food choices:

But a lot of those foods that are healthier are more expensive than the junk food out there now. Get take-away, if you're on the run it's cheaper to get like a meat pie than a vegemite sandwich or a peanut butter sandwich. \$2 it will cost you for a peanut butter sandwich or you can get a meat pie just for about that price too. And it gives you that sort of heat, especially in the weather.

4.4.3 Attitudes regarding salt in the diet

Much discussion was generated on the topic of people's attitudes regarding salt in the diet. Most of the participants said they enjoyed the taste of salt and included salt in their daily diet. Many felt that salt was a part of their normal diet and could not see themselves using less salt or choosing foods that are low in salt.

We all love salt' ... 'I love salt. I carry it in my purse.

Some participants however knew that too much salt in the diet was not good.

It's just as bad like sugar to your body. So cut down a little bit but not too much. You've still got to have tomato with salt. Can't have tomato.

Participants showed an understanding that salt was contained in different processed foods as in addition to adding salt to food during cooking or before eating.

But a lot of foods have salts anyway.

4.4.4 Bush tucker associated with good food, Identity and culture

There was much discussion among participants who associated identity and culture with foods and discussed bush tucker as alternative methods of eating good foods. Participants also talked about incorporating traditional practices of collecting bush tucker into their diets. They talked about how eating bush tucker was as a central part of their Aboriginal and Torres Strait Islander identity.

We're designed to eat that bush tucker we been growing up with for thousands and thousands of years'.

'Go fishing, eat your bush tucker'.

They grow a lot of native plants for ornamental thing but you can eat them, they're good medicine'.

Many talked about how food is related to relationships, religion and cultural beliefs. They also described how these complex factors could influence identity and eating behaviours among young people.

In the street, there's every other nationality and I watched them mob and they don't take their kids, either Chinese or Arabs or whatever, they don't take their kids to [fast food outlet] and that. The ones who have live their religion, their culture or whatever, they live their way. The fellas who stand away from their culture, well you see all the young fellas looking like xxx in [fast food outlet] and whatever. But the mob who stick with their culture, their kids are shown, emphasised the things about their culture. And probably even run down and point out the western place. But they're showing them by not taking them there. No, we don't do that. And then the young fellas got to appreciate, oh no we don't do that, so we've got our wholesome tucker here from our country or whatever.

4.4.5 Personal or family history of diabetes or heart disease as 'turning points'

Many of the participants talked about their own personal experiences of loved ones who became sick and had died from diabetes and heart disease and how these experiences became a 'turning point' in their own lives. A mother states:

I mean I have got two little obese children and I call them the terrible twins which cracks me up. But since I found out about my heart, there is no way my two little babies are going to die through obesity. They will eat what I am eating now – I have changed my whole lifestyle.

Participants described how being diagnosed with diabetes made them much more aware of nutritional value in foods.

And there's so much sugar in a lot of the processed food [I'm] really aware of. I was never aware of that until I actually realised I had diabetes and [I'm] vigilant these days and I wasn't, I just threw caution to the wind.

A young person talked about eating less due to her mother being sick:

I don't eat a lot because me Mum was diagnosed with kidney disease and me and Mum's on a no salt diet, so we were brought up with no salt.

One participant talked about her experiences with her husband when he became unwell and complained of chest pains at home. She took him to the local AMS doctor and described how difficult and emotionally stressed it was to have him checked and treated.

So I got him in and we were there till 5:30 pm with him, just to put him on that ECG. As soon as he walked out, he lit up a cigarette. And he said to me, 'I don't want to go in there.' And I said to him, 'If we let you walk out of here now and something happens to you out there, how do you think we are going to feel? When you have just come from a medical centre and the doctor is prepared to stay behind and wait for the ECG and all this and see how you are.' And he said, 'Well I don't want to wait here.' And I said, 'Well let me take you to the hospital.' So I ended up conning him in to stay and get the ECG done and I actually wanted to bring him back into the Vascular Clinic, just so that they could assess all his risk factors and that.

The participant later described how this incident with her husband influenced smoking, food and dietary changes at home.

4.4.6 Family perceptions of appropriate body weight associated with Aboriginal identity

Participants discussed the role that their family's perceptions about what constitutes a healthy body weight played in making decisions about what they ate and maintaining what they thought was a healthy body weight. Family members associated weight loss with sickness, drug use or a desire to be not identified with other Aboriginal people.

You lose weight and you get healthier and that's the stigma of the family. Oh are you sick? Something's wrong with you. You're fading away to nothing. That sort of thing. And it's not real, 'cause you can see I'm still overweight. Like I'm not perfect weight but I've lost like over 10 kilos, but still that sort of - it's conditioning and it's the people around you too, it's not only you got to change your ideas and your habits, it's people around you have got to change in some ways too. Because they pressure you, it's like peer pressure, family pressure. Yeah.

My family thinks I'm the skinniest. They're even spreading around that I was on heroin. I never shot up anything. Things like that. Little things like that get around, yeah.

Family and community peer pressure was highlighted as issues that influenced people's food choices and portion sizes. Cultural events and ceremonies that brought people together often involved a feast and a sharing of foods. The way some participants interacted within these settings often influenced their attitudes and eating behaviours. One particular young female who moved to Sydney to study and pursue a career as a dancer, described how she ate small portions when she attended community events when she went home. *'They think I'm a coconut ... brown on the outside and white on the inside ... they think I want to be a skinny white girl.'* This misperception affected the participant in that she felt *'they don't really know me'* or understood the discipline required to become a professional dancer.

4.4.7 Stress and depression

Participants discussed the role stress and depression played in influencing their attitudes to food and diet choices. When stressed or depressed they lacked motivation to eat healthy foods or maintain other health promoting behaviours.

Like when you're suffering from depression you're not motivated. You don't care what you look like and what you eat, that sort of things. Yeah. So you eat garbage, you don't do any exercise, you mope around the house. When you're really depressed you don't clean up, you live in like.

Participants also discussed the role that major stressful life events associated with depression had in their food and diet choices.

I don't use a lot of meat, I try and eat a lot of beans and vegetables because my only daughter is with me now and so we eat a lot healthier. But one of those things, like with depression, when I split up with my wife about seven years ago I didn't care what I ate. Didn't care about what I ate. Or what I was eating. Now I've got diabetes I've got to try and control it. You know, I'm a lot more healthier, the food wise. But the food can be addictive with me too 'cause certain foods like chocolate or something, when I start with chocolate I'm gone, like a sort of a binge. It's really, like sugar like that. Just a little sugar attack or if I start on the chips I'm gone. So I've got to really watch like certain foods that can trigger off.

Some participants highlighted the impact that mental illness had on their attitudes and dietary patterns.

Cause often with me, I binge but I have a mental illness and my mental illness affects the way I eat. So I'm a really – like I have bipolar disorder so I might be in a really depressive phase and all I eat is junk food...or whatever. And like when I'm in a manic phase I'll sort of eat healthy for a while.

Many of the participants in the focus groups described their own personal experiences of social and emotional wellbeing in terms of a sense of frustration, anger and lack of control and self-esteem. People talked about community and individual isolation, family pressures and the burden of dealing with relatives who were sick with chronic diseases such as diabetes. Some alluded to childhood memories of neglect and abuse.

Try not to have too much stress in your life. Stress is a really you know, destroying thing.

4.4.8 Overeating for comfort and social and emotional wellbeing

Emotional and social well-being issues were common themes raised by participants. Many saw their childhood and upbringing as being associated with their adulthood health and lifestyle decisions. Poverty was discussed as having a direct link to poor food choices and cooking methods. When childhood experiences were raised, most participants talked about being poor and about how their parents struggled to 'make ends meet'. Participants discussed how fatty, salty, sugary foods were given to compensate for a lack of income or when money was spent on smoking, gambling and alcohol. These childhood experiences seemed to continue to influence most of the participants' attitudes towards food choices, diet and eating behaviours into adulthood where they would eat nutrient-poor foods for 'comfort'.

Could come from your diet. Drugs. Could come from your background, what's happened to you in the past when you were growing up, things like that. These sort of issues. Well food for me was a security, so that's why we overate and Mum showed her love – like we felt we were more loved and other people because we got fed a lot and we were overweight. So that food was another compensation for maybe physical love and that insecurity within the home.

Participants showed awareness of the role of overeating in order to feel comfortable with themselves and the need to learn about appropriate portion size for meals as adults. The discussion highlighted an awareness of food addictions among the group and the practice of binge eating with certain foods.

I was sort of like yeah, compensated a bit and I overate to feel comfortable with myself because I was like that as well ... and now when I cook I have to learn my portion size and stuff like that.

4.5 Discussion

We undertook this research seeking to better understand and explore the knowledge, attitudes, and cultural influences that shape the food choices of Aboriginal and Torres Strait Islander people living in urban areas. Key findings included that people demonstrated a clear understanding regarding the constituents of a healthy diet, yet described a complex interplay of psychosocial factors – in particular stress and depression, family and cultural influences that acted as barriers to following a healthy diet. The commonly described experience of living with chronic disease, either the study participant themselves or a family member was indicated as a turning point for many people in changing their attitudes and behaviour with regard to dietary intake. Although further research evidence is required, it seems clear that

public health campaigns to support Aboriginal and Torres Strait Islander people in urban areas to follow a healthy diet should focus on these barriers and enablers to healthy food choices, to complement the current focus on providing information regarding what constitutes a healthy diet.

For many Aboriginal and Torres Strait Islander people, being told by family members someone is sick or has been recently diagnosed with diabetes, heart disease or died as a result of these is a daily experience.⁷ The participants in this study highlighted these experiences as 'turning points' in their own lives and in particular their own decision-making around food choices and eating behaviours. Experiencing the sadness and uncertainty of those close relatives (particularly if a partner) diagnosed with an illness can and does impact on our own life situations and it often encourages people to rethink and re-evaluate 'family life in the shadow of suffering and hope'.⁸ However, for many Aboriginal and Torres Strait Islander people, trauma, loss and grief are regularly experienced and these overwhelming experiences often impact on their own decision-making, which can have a direct impact on their health and wellbeing.

While there seemed to be a good understanding of healthy foods and sense of how important good nutrients are in foods, most participants agreed that fatty, salty, sugary foods were their preferred foods. Our research findings are consistent with research undertaken in remote Aboriginal and Torres Strait Islander settings; in particular relating to knowledge of healthy diet, accessibility and affordability of healthy foods, and general family and cultural influences on food choices^{2, 3}. Our findings also complement the 'Acting on food insecurity in urban Aboriginal and Torres Strait Islander communities'⁹ report that acknowledges social, political, and cultural determinants, such as history, financial constraints, education, alcohol, smoking and other drug use, accessibility and transient lifestyles as crucial influences on people's attitudes and eating behaviours.

All participants expected to be able to purchase high quality fresh and frozen food products at the supermarkets where they did their weekly shopping. However, participants stated that they felt major supermarkets overwhelmingly stocked 'rubbish foods' high in fat, salt and sugar. Given that there is much debate regarding how the alcohol, food and soft drink industries use similar strategies to the tobacco industry to undermine effective public health policies and programs,¹⁰ we aimed to explore how Aboriginal and Torres Strait Islander food consumers perceive these messages and how they are interpreted into their daily food choices.

Salt use was an important topic of discussion among the participants. One participant talked about carrying salt in her purse to ensure she had it when she needed it. Fast food, with high salt content, was also a means of a quick substitute meal; especially when people were living with depression or where mental health issues affected their wellbeing. This indication that a high salt diet might be common highlights the need to monitor salt consumption and dietary composition among Aboriginal and Torres Strait Islander peoples.¹¹

As with most people there is often a complex interplay of emotional wellbeing, personal identity and how it is shaped within a family, community and country as major influences on food choices. These 'inherited' values can have a profound impact in early childhood and lead to negative attitudes towards eating and leading a healthy lifestyle in adulthood.¹²

Most participants who talked about food experiences in their childhood highlighted the deep relationship between identity and food and how food was often used as an, 'expression' of love and affection from parents and relatives. Previous research has questioned whether stress-induced eating causes obesity.¹³ This would seem an important issue to further explore in relation to Indigenous health.

Food was also discussed in the context of Aboriginal identity and how certain foods such as kangaroo and native plants reinforced peoples' Aboriginality. Personal identity encompasses a complex array of factors that include ethnicity and environmental upbringing. Given the political and social history of Aboriginal and Torres Strait Islander peoples it is no surprise that eating 'bush tucker' such as native animals and plants is considered to be a positive reinforcement of identity. While 'bush tucker' may have positive reinforcements benefits for most Aboriginal and Torres Strait Islander people, eating more bush tucker is of little relevance to urban populations given limited and restricted access to traditional foods.

The main strength of this research is that this is one of the few qualitative investigations of diet and food related choices among urban Aboriginal and Torres Strait Islander people. The research was conducted several years ago, however findings are consistent with those of the more recent Kanyini Qualitative Study, which involved in-depth interviews with more than 100 Aboriginal and Torres Strait Islanders Australians attending Aboriginal Health Services across Australia.¹⁴ The generalizability of the research may be limited by the fact that only two focus groups were conducted. However, similar themes and issues were raised across the two focus groups which represented diverse urban Aboriginal populations. The first group was recruited amongst staff and students attending an inner city Indigenous educational facility. The second group was recruited amongst community members presenting to an Aboriginal Medical Service in an outer urban and particularly socioeconomically disadvantaged area of Sydney

4.6 Conclusion

The findings of this study highlight that there is a need to investigate further the key factors shaping Aboriginal and Torres Strait Islander people's food choices and diet. While knowledge of what constitutes healthy eating was good among the participants, research should also explore how the Australian Dietary Guidelines, if at all, are incorporated into daily food preferences and practices among these groups. Clearly, issues of social and emotional well-being and cultural identity need to be considered when designing and implementing diet and food education and engagement programs for Aboriginal and Torres Strait Islander people.¹⁵⁻¹⁷ We need to better understand the key barriers and enablers^{18, 19} to making healthy dietary choices and in particular the relationship between identity, cultural influences, depression, stress and how these factors can shape food choices and overeating.

Australia can learn much from other international Indigenous health research in addressing these issues. For example in New Zealand, diabetes and cardiovascular diseases are a significant health burden, particularly in Māori communities, and this

burden is likely to worsen dramatically unless effective prevention programs are implemented. To address this burden, the University of Otago developed the Ngati and Healthy project.¹⁹ The project aims to reduce the incidence of insulin resistance in the short term, and Type 2 diabetes in the long term. Implementation of the diabetes prevention community intervention began in 2004.

Issues relating to racism in health care settings must also be considered when addressing Indigenous health. Research addressing health inequities for Indigenous populations in New Zealand²⁰ has highlighted the need to better understand the relationship between racism and health and for ongoing monitoring of racism as a determinant of access and utilisation of health services. Such an understanding will be required to develop, implement and evaluate programs aiming to improve healthy lifestyles with life-long positive health outcomes among Indigenous Australians.

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CHAPTER 5:

THE URGENCY OF MONITORING SALT CONSUMPTION AND ITS EFFECTS IN ABORIGINAL AND TORRES STRAIT ISLANDER AUSTRALIAN

5.1 Introduction

There is compelling evidence that too much salt in the diet is deleterious to our health. In the context of the health of Indigenous Australians, where evidence indicates both poor dietary patterns and an overwhelming burden on chronic diseases, I wrote this letter to the Medical Journal of Australia based on results from research conducted as part of this PhD. In the STRIDE survey and focus group research, reported in Chapters 3 and 4, participants reported high salt consumption as an important feature of their diets.

This research letter represented an opportunity to highlight the increasing concern health researchers have regarding the dangers of too much salt in the diet. Interventions aiming to reduce dietary consumption of salt have been developed overseas and proven to be effective, including amongst disadvantaged populations. The letter was an opportunity to encourage health research focusing on salt in the diet among Indigenous Australians that has not been performed before among this population.

The outcome of this letter has promoted and encouraged health research about salt consumption among Indigenous Australians. Unfortunately at the time of writing this thesis my research team were not successful in our NHMRC or Australian Research Council (ARC) applications during 2013/14, nevertheless this issue is recognised as a priority in Indigenous health research in Australia.

The following research letter was published in the *Medical Journal of Australia* (MJA) 198 (7), pp 365-366 on 15 April 2013.

5.2 Research letter

TO THE EDITOR: There is convincing evidence that high salt diets are linked to elevated blood pressure – a major risk factor for chronic diseases.¹ Premature mortality due to chronic diseases is a major contributor to the life expectancy gap between Indigenous and non-Indigenous Australians.² Although much has been written about the health benefits of a traditional hunter-gatherer diet and the detrimental effects of colonisation on diet and exercise patterns,³ we know little about how colonisation has affected salt intake among Indigenous Australians.

Currently in Australia, most efforts to prevent disease caused by high blood pressure focus on the clinical management of hypertension. Such programs can only affect individuals identified and treated for high blood pressure. In population terms, a small proportion of the total blood pressure-related disease burden is adequately addressed by this approach.⁴ Salt reduction programs, on the other hand, have the potential to address much more of the disease burden. A modest reduction in salt intake has been found to have a significant blood pressure-lowering effect.⁵ Furthermore, salt reduction programs that are implemented by modifications to the food supply have the potential to prevent disease at a very low cost.⁶

Salt consumption data in Australia are limited. A recent study in regional New South Wales, Drop the Salt Lithgow, confirmed that Australians are eating too much salt. The average salt intake in this Australian population was 9g per day (Mary-Anne Land, Research Assistant, The George Institute for Global Health, unpublished data), which is 50% higher than the upper limit of 6g per day recommended by the National Health and Medical Research Council⁷). Unfortunately, this study only captured a small number of Indigenous Australians.

We suggest expanding the scope of this research to Indigenous communities in New South Wales (by adapting the methods used in Drop the Salt Lithgow) to determine the types of food bought, prepared and eaten that have high levels of salt. This would involve: collecting baseline data on salt intake (by measuring 24-hour urinary sodium excretion) and dietary sources of salt (via 24-hour dietary recall questionnaires); implementing a salt-reduction program; and collecting follow-up data on dietary sources of salt (by repeat questionnaires). Surveying 500 people at baseline and follow-up would provide power to detect a difference in salt consumption that would translate to real differences in individual and population health.

5.3 Conclusion

We believe that research aimed at recruiting a community-based sample of Indigenous adults to precisely and reliably measure salt intake and to better understand behaviours that underpin dietary patterns is a public health priority. Such research should aim to determine: i) how much salt Indigenous Australians consume in their diet; ii) if an intervention focused on reducing salt consumption would be acceptable and effective in reducing risks associated with chronic diseases among Indigenous Australians; and iii) if an intervention proved to be effective, to consider how such an intervention could be up-scaled to provide more widespread benefit.

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CHAPTER 6:

ASSOCIATIONS BETWEEN PSYCHOLOGICAL DISTRESS AND DIET AMONG OLDER ABORIGINAL AND TORRES STRAIT ISLANDER ADULTS IN THE NEW SOUTH WALES 45 AND UP STUDY

6.1 Chapter overview

This chapter explores the association between stress and diet among older Aboriginal and Torres Strait Islander individuals. Understanding and addressing causes of psychological distress may improve emotional and social wellbeing and impact on diet. This would reduce the burden of obesity and chronic disease such as Type 2 diabetes and cardiovascular disease (CVD) among this population.

Statistical analyses presented in this chapter were performed by me, with the support of Dr Federica Barzi, senior statistician at The George Institute for Global Health and The Menzies School of Health Research. I developed the analysis plan with Dr Federica Barzi and Dr Julie Brimblecombe. Dr Barzi provided statistical direction and support throughout the analyses.

6.2 Background

This paper describes the association between psychological distress and dietary patterns among Aboriginal and Torres Strait Islander participants in the New South Wales 45 and Up Study. National population health surveys about psychological distress and diet among Aboriginal and Torres Strait Islander Australians report that these groups are twice more likely than other Australians to experience very high levels of psychological distress, poorer diets and a heavy burden of chronic disease.

Methods: Using self-reported lifestyle questions from the 45 and Up study, we analysed responses from 1949 adult Aboriginal and Torres Strait Islander participants who were asked to provide information about how much food they

consume weekly, daily and how many serves per day. Food questions are based on the five major food groups as recommended by the Australian Dietary Guidelines. Psychological distress was calculated using the Kessler 10 (K10) psychological distress score with cut off points \leq 22 and \geq 22 to dichotomise levels of psychological distress among participants. Please refer to 6.4.3, p. 92, 'Classification of data' for more detailed breakdown.

Results: There was a significant association (p<0.001) between psychological distress and vegetable, fruit and fish consumption. People eating more than 2 serves of fruit a day were 48% (95% CI: 26-63%) less likely to be psychological distressed. Fish consumption was also associated with a decreased likelihood of psychological distress with participants eating between one to six serves per week showing over a 45% reduction as compared to those who ate fish less than once per week

Discussion: This study suggests that there is an association between stress and diet among older Aboriginal and Torres Strait Islander individuals. Understanding and addressing causes of psychological distress may improve emotional and social wellbeing and impact on diet. This would reduce the burden of obesity and chronic disease such as Type 2 diabetes and cardiovascular disease (CVD) among this population.

Keywords: Aboriginal and Torres Strait Islander Australians, psychological distress, diet, food, body weight, chronic disease, regression analyses

6.3 Introduction

Prior to English colonisation in Australia in 1788, traditional hunter-gatherer diets of (Indigenous) Aboriginal and Torres Strait Islander peoples largely consisted of lean meats and vegetables, such as kangaroo, goanna, lizards, fish and seafood, and grubs high in protein, wild root vegetables, bush fruits, as well as seeds. Coastal regions contained an abundance of fresh food varieties due to cooler climates whereas desert regions were more limited to seasonal food products. Traditionally, Aboriginal and Torres Strait Islander peoples would cover vast areas of land or sea to provide foods for their communities; this would have required emotional as well as physical

strength and stamina^{1, 2,} The combination of a low fat diet high in protein and nutrients, mixed with daily physical activity meant traditional lifestyles of Aboriginal and Torres Strait Islander people were ideal for prevention of obesity and chronic diseases such as Type 2 diabetes and cardiovascular diseases.³⁻⁵

In 2014, the 'hunter-gatherer' diet is no longer sustainable due to direct factors associated with colonization, migration and globalization.⁶⁻⁸ The forced removal of Aboriginal and Torres Strait Islander children during colonization periods, as late as the 1970s, also contributed to the 'breakdown' of traditional communities and hunter-gatherer diet and lifestyles; particularly for southern coastal Aboriginal and Torres Strait Islander peoples.^{6, 8}

This 'breakdown' has had traumatic generational effects on many Aboriginal and Torres Strait Islander Australians. Many have experienced childhood psychological distress (PD) and suffering as a direct result of forced removal from their parents. Many children also experienced emotional, physical and sexual abuse either in Christian missions, institutions, or foster care.^{5, 8} These experiences have impacted on the social and emotional wellbeing of many Aboriginal or Torres Strait Islander people and among some, affected their identity, language and community attachment. The legacy of past forced removal of children has fundamentally contributed to the poor health, social and emotional wellbeing of many Aboriginal and Torres Strait Islander peoples in contemporary Australia.^{4, 5, 8, 9} In turn these experiences have to a large degree, shaped and influenced poor lifestyles, poor food choices and poor eating behaviours that have led to an increase of obesity and epidemic proportions of chronic diseases such as Type 2 diabetes and cardiovascular diseases among these populations.⁴

As of 31 March 2013, Australia's population is almost 23 and a quarter million people. Approximately 13.8% of Australians are aged 65 years and over. By contrast, of those who stated they were Indigenous in the 2006 Census, only 4% of the total Aboriginal and Torres Strait Islander population are aged 65 years and over.¹⁰ The Australian Bureau of Statistics (ABS) calculate that the proportion of Indigenous people aged 55 years and over increased from 6% in 1991 to 8% in 2006, and is

projected to increase to between 11% (713,300) and 12% (721,100) in 2021 at an average growth rate of 2.2% per year.¹¹ The ABS are continuing to project calculations for Aboriginal and Torres Strait Islander peoples growth, however, burden of diseases such as Type 2 diabetes and cardiovascular diseases as well as the 'life expectancy gap' make it difficult to project 'healthy ageing' calculations for this population and these figures should be read with caution.

Early mortality due to chronic diseases among Aboriginal and Torres Strait Islander peoples is the major contributing factor to the life expectancy gap between Indigenous and non-Indigenous Australians. The Australian Institute for Health and Welfare (AIHW) estimates that the life expectancy gap is 12 years for males and 10 years for females.^{4, 11, 12} Estimates of the gap in life expectancy need to be understood in the context of broader social determinants that contribute to patterns of poor health and illness. These determinants include poor housing conditions, lower incomes, lower educational attainment, low literacy and numeracy skills, higher unemployment and higher levels of harmful behaviours including excessive alcohol and tobacco consumption, suicide, and poorer diets.

In 2008, the National Aboriginal and Torres Strait Islander Social Survey (NATSISS)¹³ collected information from 13,300 people who provided responses to a range of questions about psychological distress including social and emotional wellbeing. Using selected questions from the Kessler 10 (K10)¹⁴ psychology score to estimate the burden of psychological distress, the AIHW¹³ reported:

Nearly one-third (32%) of Aboriginal and Torres Strait Islander people aged 18 years and over had experienced high to very high levels of psychological distress, which was more than twice the rate for non-Indigenous people.

This gap was evident in all broad age groups, which ranged from 18 years to 55 years and over.¹³

The purpose of this paper is to describe the food and diet intake as well as the psychological distress of Aboriginal and Torres Strait Islander adults in the 45 and Up Study in NSW. 45 and Up seeks to answer important 'health and quality-of-life

questions' with the aim of exploring ways to 'help manage and prevent illness through improved knowledge of conditions such as cancer, heart disease, depression, obesity and diabetes.¹⁰ Exploring the association between psychological distress and diet will enable understanding and addressing causes of psychological distress that may improve emotional and social wellbeing and impact on diet. This would reduce the burden of chronic disease such as Type 2 diabetes and cardiovascular disease (CVD) among this population.

6.4 Methods

This descriptive cross-sectional longitudinal study began collecting data in 2006. By 2009 the study had enrolled more than 250,000 participants across NSW, using completed baseline self-report questionnaires.¹⁰

6.4.1 Participants

A total of 1949 (1108 women) and (841 men) participants identified as either Aboriginal, or Torres Strait Islander or both. Details of participant recruitment, data collection and socio-demographics have been reported previously.^{15, 16}

6.4.2 Survey questionnaire

Questionnaires were posted to all participants in the study. There are two questionnaires, one for males and one for females that ask a range of questions about socio-demographics, lifestyle, general health and diet. The surveys also ask questions about emotional wellbeing, such as experiences of depression, anxiety, use of anti-depressants and self-worth.^{15, 16}

Participants were asked to provide information about how much food they consume weekly, daily and how many serves per day. Food questions were based on the five major food groups as recommended by the Australian Dietary Guidelines.¹⁷ These include lean meats, fresh fruits and vegetables, brown, whole or multigrain breads, milks, cheese and fruit juice.

6.4.3 Classifications of data

Psychological distress was calculated using the Kessler 10 $(K10)^{14}$ psychology score. A K10 score greater than 22 was used to define psychological distress.

Each food item was recorded as a discrete variable. To simplify the analyses we grouped participants into three or four intake groups. Cereals and cheese intakes were grouped as Never, 1-3 times per week, 4-6 times per week and seven or more times per week. Fish and seafood, meat and processed meat intakes were grouped as less than once per week, 1-3 times per week, 4-6 times per week and seven or more times per week. Fruit juice and fresh fruit were grouped as less than once, once and over once per day. Vegetables intake grouping was: less than one per day, 1-2 times per day, 3-4 times per week, 8-14 slices per week and 15 or more slices per week. Alcohol intake groping was: None, 1-7 drinks per week, 8-14 drinks per week and 15 or more drinks per week.

Types of milk intakes were dichotomous variables codified as 'Yes' or 'No'.

Smoking habit was codified as not regular current smoker and regular current smoker. Daily smoking, even if only small amounts of tobacco were involved, was defined as regular smoking.

6.4.4 Statistical analysis

Age and BMI were compared between men and women using Student's t-tests, smoking and drinking habits and each food item intakes were compared between sexes using Chi-Squared tests.

Odds Ratios and 95% confidence intervals of suffering from psychological distress in relation to diet were derived using logistic multivariate models with people in the lowest consumption group for each food item, not regular current smokers, and the category 'No' for each milk type as reference.

Log linear trend across each food item was explored fitting a summary relationship (straight line) between the levels of the ordered categorical variable. All models were adjusted for age and gender.

Logistic regression was performed using SAS statistical software version 9.2 to estimate adjusted odds ratios (OR).

6.5 Results

This analysis includes 1108 females and 841 males who identified as Aboriginal and Torres Strait Islander. Mean age was similar in both sexes (58.5 years male and 57.5 years female) as was body mass index (BMI) approximately 29 kg/m² (Table 6.1).

Female participants had a better dietary pattern than males. They were more likely to have more than three serves of vegetables a day (29.1% vs. 20.9%) and more than two serves of fruit a day (56.2% vs. 46.1%). They were less likely to consume processed meats more than three times a week (7.0% vs. 17.3%) less likely to drink whole milk (40.6% vs. 51.1%) and more likely to drink skim milk (23.9% vs. 15.8%). Women were also less likely to consume alcohol (35.8% vs. 57.7%) and less likely to be a regular cigarette smoker (54.2% vs. 63.9%).

Men were more likely to have more than two slices of bread per day (29.2% vs. 14.0%). There were no difference in cereal, cheese, fruit juice and fish or seafood consumption between women and men (Table 6.2).

Whole milk consumption was associated with a 41% (95% CIs: 11-79%) increase odds of PD, conversely reduced and skim milk consumption were associated respectively with a 29% (95% CI: 5-47%) and 33% (95% CI: 8-51%) reduction of likelihood of PD. There was a significant association (p<0.001) between odds of psychological distress and vegetable consumption. There was a 36% (95% CI: 13-53%) reduction in the likelihood of PD for those consuming 1-2 serves a day as compared to those consuming <1 serve a day, the reductions were equal to 42% (95% CI: 18-59%) and 45% (95% CI: 4-69%) for those in the 3-4 and 5+ serves a week groups respectively. Similarly there was a significant association (p<0.001)

with fruit consumption, those eating over 2 serves a day were associated with a 48% (95% CI: 26-63%) reduction in the likelihood of PD. Fish consumption was also associated with a decreased likelihood of PD with participants eating between one to six serves per week showing over a 45% reduction as compared to those who ate fish less than once per week. Fruit juice over twice a day increased the odds of PD by 48% (95% CI: 3-112%) similarly high intakes of processed meat were associated with an increased likelihood, over seven servings a week, increased the odds by over two folds compared to less than once a week. Current smokers were 77% (95% CI: 33-120%) more likely to suffer for psychological distress. There was not a clear association with cereals, bread and current drinking. There was no association with meats (Table 6.3).

In total, 351 participants were categorised as having psychological distress with a K10 score greater than 22.

6.6 Discussion

This study is one of very few both nationally and internationally that have explored associations between psychological distress and diet among older Indigenous peoples. Contextualizing the lived experiences of older people living with chronic diseases, such as Type 2 diabetes and CVD, which have a direct link to lifestyle factors such as poor diet and inactivity, is crucial in better understanding and providing high quality health care and management support for an ageing population.

There is limited research that has primarily focused on healthy ageing among Aboriginal and Torres Strait Islander people and their eating behaviours. Even though Aboriginal and Torres Strait Islander women were just as likely to be overweight as men in this study, they were much more likely to make better food choices and have a better diet pattern than men. They are also more likely to consume more fruit and vegetables daily; less likely to consume processed meats more than three times a week; less likely to drink whole milk and more likely to drink skim or reduced fat milk. They were also less likely to consume alcohol and less likely to be a regular cigarette smoker. After adjusting for age and sex, and using the Kessler 10 psychological distress score <22 and more >22 to dichotomize levels of stress among the Aboriginal and Torres Strait Islander study participants, results show that significant psychological distress was associated with eating lower amounts of fresh fruit and vegetables as well as not including fish and seafood in the diet. Those participants who suffered from psychological distress were more likely to report being a regular smoker.

The valuable information provided by participants in this study provides an important 'snap-shot' into older Aboriginal and Torres Strait Islander health and wellbeing. In some respects, the responses could also be viewed as being a 'self-assessment of health' (SAH)¹⁸ report and perhaps reflect participants 'lived experiences'. The information given could be used as an 'independent predictor' for health and wellbeing outcomes among this population.

Participants in the 45 and Up Study have given consent for ongoing follow-up; including data linkage to explore access to and utilization of health care, medical treatments and services, the incidence and outcomes relating to major health morbidities and mortality. Understanding how psychological stress and dietary patterns predict such outcomes will be of major importance. Psychological distress information could also be used to measure and explore resilience factors associated with social and emotional wellbeing that influence the occurrence and recovery from major health events.

Similar international research among Indigenous groups in the USA, Canada and New Zealand show that mental health disorders are very common among Indigenous populations.¹⁹ A national health survey in New Zealand showed that Maori people were 51% more likely to develop a mental disorder at some point in their life with anxiety being commonly reported. Canadian First Nations Regional Health Survey*¹⁹ identified high rates of depression (18%) and alcohol disorders (27%) among those surveyed. Other factors that have been identified and associated with mental health disorders among other Indigenous peoples also include effects from colonisation, loss of land and language, cultural disconnectedness, marginalization and discrimination. These studies also explored 'lived experiences' among older Indigenous peoples and acknowledge that forced removal as a child and or being institutionalized have a direct effect on the burden of chronic disease and life expectancy among these populations.

While the 45 and Up study does not ask questions about 'lived experiences' per se, such as whether participants were adopted, fostered or children of forced removal periods, some participants will have experienced childhood trauma from these experiences. Such trauma and consequent ongoing psychological distress might underlie behaviours that shape food choices and dietary patterns demonstrated in this study. Many older Aboriginal and Torres Strait Islander people who were placed in missions, foster care and or institutions during their childhoods experienced physical cruelty and traumatic psychological distress.^{5, 8, 20} Given these well-documented experiences, whether these children may have also experienced nutritional neglect needs to be better explored. Any differences in patterns of both reported psychological distress and dietary intake amongst this older cohort in comparison to younger cohorts of Aboriginal and Torres Strait Islander Australians will also be important to explore.

6.7 Conclusion

Further research should seek to understand the causes of psychological distress and how it influences food choices amongst Aboriginal and Torres Strait Islander Australians in this cohort of people aged 45 years and older. The ability to follow the group in relation to exploring healthy patterns of ageing is also critical. Perhaps one issue relates to the need to explore the lived experience and impact of institutionalization on the behaviours and health decisions among this group.

Understanding the lived experiences of Aboriginal and Torres Strait Islander Australians who have experienced institutionalization is very important in addressing psychological distress and social and emotional wellbeing. Psychological distress can impact on diet patterns and lifestyle choices; particularly smoking and high saturated fatty foods high in salt, sugar and carbohydrates that can lead to onset of Type 2 diabetes and CVD. The *Australian Dietary Guidelines and the Australian Guide to Healthy Eating*²¹ provide evidence-based recommendations that promote food products high in nutrients that are essential for good health and also help reduce the risks of chronic health problems such as obesity, heart disease, Type 2 diabetes and some cancers. This important information can contribute to future health policies and strategies that are aimed at reducing chronic diseases through early lifestyle intervention programs.

For older Aboriginal and Torres Strait Islander people who grew up in the eras of the 'Stolen Generations' and civil rights in Australia, particularly during the years leading up to the 1967 Referendum, contextualizing their 'lived experiences' of racism, fear, discrimination, marginalization and segregation is essential when analysing Aboriginal and Torres Strait Islander health research data. Such experiences, occurring throughout life, are likely to critically influence behaviours and shape patterns of health and illness. To improve health outcomes, we need not only to address the biomedical and socioeconomic determinants of health, but to also understand and address the broader cultural and historical factors that are associated with high levels of psychological distress amongst older Aboriginal and Torres Strait Islanders.

The Canadian First Nations Regional Survey provides a comprehensive and representative sample of Indigenous health and wellbeing that can be compared to Indigenous Australians health and wellbeing. For example, Indigenous Australians health and wellbeing (as defined throughout this thesis) is seen through the lens of 'holistic' health care. Meaning the physical, mental, emotional and spiritual health issues of the individual and the community. The Canadian First Nations Regional Survey incorporates a 'cultural framework' from a 'holistic' perspective such as that defined in the 1989 National Aboriginal Health Strategy.²² While Indigenous Australians and Canadian First Nations are two different populations they share similar experiences of English colonisation and historical government policies and strategies. They also have high burden of chronic diseases and mortality than non-Indigenous populations respectively.

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6.9 Appendices

Table 6.1: Mean (95% CI) BMI by gender

	Male (841)	Female (1108)	<i>P</i> -value for sex difference
Age (years)	58.5 (9.3)	57.5 (9.2)	0.014
BMI (kg/m ²)	28.8 (5.3)	29.0 (6.3)	0.47

Food groups by category	Male (<i>n=</i> 841) %	Female (<i>n</i> =1108) %	P value	Total (<i>n</i> 1949) %
Cereals			0.5259	
Never	160 (21.7)	240 (24.5)		400 (23.3)
1-3 per week	155 (21.0)	200 (20.4)		355 (20.7)
4-6 per week	147 (20.0)	198 (20.2)		345 (20.1)
7+ per week	275 (37.3)	341 (34.8)		616 (35.9)
Bread			<.001	
Never	140 (18.8)	172 (16.8)		312 (17.6)
1-7 slices per wk	193 (25.9)	414 (40.4)		607 (34.3)
8-14 slices per wk	194 (26.0)	296 (28.9)		490 (27.7)
15+ per wk	218 (29.3)	144 (14.0)		362 (20.4)
Milks				
Whole	430 (51.1)	450 (40.6)	<.001	880 (47.8)
Reduced	187 (22.2)	270 (24.4)	0.2710	457 (24.8)
Skim	133 (15.8)	265 (23.9)	<.001	398 (21.6)
Soy	38 (4.5)	68 (6.1)	0.1186	106 (5.8)
Cheese			0.1273	
Never	86 (11.5)	90 (8.9)		176 (10.0)
1-3 per week	368 (49.3)	491 (48.8)		859 (49.0)
4-6 per week	203 (27.2)	315 (31.3)		518 (29.5)
7+ per week	90 (12.1)	111 (11.0)		201 (11.5)
Vegetables (cooked and raw*)			<.001	
<1	206 (24.5)	169 (15.3)		375 (19.2)
1-2	432 (51.4)	519 (46.8)		951 (48.8)
3-4	176 (20.9)	323 (29.2)		499 (25.6)
<u>≥</u> 5	27 (3.2)	97 (8.8)		124 (6.4)
Fruit			<.001	
Less <1	129 (17.0)	123 (12.1)		252 (14.2)
One per day	281 (36.9)	322 (31.7)		603 (33.9)
≥2 per day	351 (46.1)	572 (56.2)		923 (51.9)

Table 6.2: Food, smoking, alcohol categories by gender

Food groups by category	Male (<i>n</i> =841) %	Female (<i>n</i> =1108) %	P value	Total (<i>n</i> 1949) %
Fruit Juice			0.0705	
<1 per day	259 (41.7)	407 (47.6)		666 (45.1)
One per day	250 (40.3)	302 (35.3)		552 (37.4)
≥2 per day	112 (18.0)	146 (17.1)		258 (17.5)
Fish/seafood			0.0523	
<1 per week	82 (10.8)	142 (14.1)		224 (12.7)
1-3 per week	611 (80.4)	755 (74.8)		1366 (77.2)
4-6 per week	53 (7.0)	87 (8.6)		140 (7.9)
≥7 per week	14 (1.8)	25 (2.5)		39 (2.2)
Meats**			0.0205	
<1 per week	189 (22.5)	248 (22.4)		437 (22.4)
1-3 per week	438 (52.1)	623 (56.2)		1061 (54.4)
4-6 per week	175 (20.8)	211 (19.0)		386 (19.8)
≥7 per week	39 (4.6)	26 (2.4)		65 (3.3)
Processed meats			<.001	
<1 per week	223 (26.5)	479 (43.2)		702 (36.0)
1-3 per week	472 (56.1)	552 (49.8)		1024 (52.5)
4-6 per week	112 (13.3)	57 (5.1)		169 (8.7)
≥7 per week	34 (4.0)	20 (1.8)		54 92.8)
Alcohol Drinks			<.001	
None	268 (35.8)	588 (56.7)		856 (47.9)
1-7 per week	209 (27.9)	284 (27.4)		493 (27.6)
8.14 per week	233 (31.2)	159 (15.3)		392 (22.0)
15+ per week	38 (5.1)	7 (0.7)		45 (2.5)
Smoking	535 (63.9)	600 (54.2)	<.001	1135 (58.4)

*Indicates a(Data available: NSW n=264; NT/Qld n=568)

(Data available: NT/Qld n=502; NSW n=176)

** A recorded urinary albumin creatinine ratio > 3mg/mmol

**Indicates all meat categories were collapsed (beef lamb, plus beef, lamb and pork, plus chicken and pork, plus chicken turkey and duck)

Il vegetables categories were collapsed (cooked veg plus raw veg)

Food groups by category	K10≤22 n (%)	K10>22 n (%)	OR (CI)*	P value for log- linear trend
Cereals				
Never	301 (22.02)	84 (27.81)	1.00	0.077
1-3 per week	274 (20.04)	73 (24.17)	0.95 (0.67-1.36)	
4-6 per week	286 (20.92)	51 (16.89)	0.65 (0.44-0.96)	
7+ per week	506 (37.02)	94 (31.13)	0.79 (0.57-1.11)	
Bread				
Never	233 (16.57)	72 (22.86)	1.00	0.083
1-7 slices per wk	480 (34.14)	110 (59.0)	0.74 (0.52-1.04)	
8-14 slices per wk	409 (29.09)	63 (20.00)	0.53 (0.37-0.78)	
15+ per wk	284 (20.20)	70 (22.22)	0.95 (0.65-1.39)	
Milks				
Whole	670 (43.8)	184 (52.4)	1.41 (1.11-1.79)	
Reduced	376 (24.6)	66 (18.8)	0.71 (0.53-0.95)	
Skim	329 (21.5)	54 (15.4)	0.67 (0.49-0.92)	
Soy	88 (5.8)	16 (4.6)	0.77 (0.44-133)	
Cheese				
Never	134 (9.63)	37 (11.90)	1.00	0.38
1-3 per week	692 (49.71)	141 (45.34)	0.72 (0.48-1.09)	
4-6 per week	415 (29.81)	88 (28.30)	0.78 (0.50-1.20)	
7+ per week	151 (10.85)	45 (14.47)	1.10 (0.67-1.82)	
Vegetables (cooked and raw)				
<1	267 (17.44)	84 (23.93)	1.00	0.0039
1-2	757 (49.44)	168 (47.86)	0.64 (0.47-0.87)	
3-4	404 (26.39)	80 (22.79)	0.58 (0.41-0.82)	
<u>></u> 5	103 (6.73)	19 (5.41)	0.55 (0.31-0.96)	
Fruit				
Less <1	177 (12.60)	64 (20.25)	1.00	0.0002
One per day	468 (33.31)	115 (36.39)	0.69 (0.49-0.99)	
<u>≥</u> 2 per day	760 (54.09)	137 (43.35)	0.52 (0.37-0.74)	
Fruit Juice				
<1 per day	523 (45.48)	125 (44.80)	1.00	0.057
One per day	442 (38.43)	90 (32.26)	0.88 (0.65-1.19)	
≥ 2 per day	185 (16.09)	64 (22.94)	1.48 (1.03-2.12)	

 Table 6.3:
 Food categories by presence or absence of psychological distress.

Food groups by category	K10≤22 n (%)	K10>22 n (%)	OR (CI)*	P value for log- linear trend
Fish/seafood				
<1 per week	155 (11.07)	64 (20.19)	1.00	0.092
1-3 per week	1103 (78.79)	220 (69.40)	0.53 (0.38-0.74)	
4-6 per week	115 (8.21)	22 (6.94)	0.52 (0.30-0.90)	
\geq 7 per week	27 (1.93)	11 (3.47)	1.12 (0.52-2.41)	
Meats				
<1 per week	328 (21.42)	76 (21.65)	1.00	0.66
1-3 per week	836 (54.60)	202 (57.55)	1.05 (0.78-1.41)	
4-6 per week	315 (20.57)	60 (17.09)	0.86 (0.59-1.25)	
≥7 per week	52 (3.40)	13 (3.70)	1.15 (0.59-2.23)	
Processed meats				
<1 per week	556 (36.32)	116 (33.05)	1.00	0.033
1-3 per week	811 (52.97)	185 (52.71)	1.05 (0.81-1.36)	
4-6 per week	129 (8.43)	35 (9.97)	1.35 (0.87-2.09)	
≥7 per week	35 (2.29)	15 (4.27)	2.23 (1.16-4.29)	
Alcohol drinks				
None	650 (46.23)	178 (54.77)	1.00	0.22
1-7 per week	410 (29.16)	68 (20.92)	0.61 (0.45-0.84)	
8.14 per week	315 (22.40)	65 (20.00)	0.76 (0.55-1.06)	
15+ per week	31 (2.20)	14 (4.31)	1.58 (0.80-3.11)	
Smoking	858 (56.2)	244 (69.7)	1.77 (1.33-2.20)	

* Odds ratios are reported for the presence of psychological distress, determined by a K10 score >22, in association with each level of consumption for each category of food. The reference level of consumption for each food category is indicated with the OR of 1.00.

CHAPTER 7: THE ROLE OF RESILIENCE IN RESPONDING TO BLOOD BORNE VIRAL AND SEXUALLY TRANSMITTED

INFECTIONS IN INDIGENOUS COMMUNITIES

7.1 Chapter overview

In the context of addressing Aboriginal and Torres Strait Islander health in a 'holistic' manner, this PhD thesis discusses aspects of lifestyle behaviour that includes sexuality, sexual relationships and their association with high-risk behaviour that can lead to blood borne viruses and chronic disease.

This is a journal article that has been accepted and published in *Sexual Health* on the 15 December 2014*. I am named as second author. This article discusses the overall aims, methods and results of the Derbarl Yerrigan Health Service (DYHS) and Perth Young Noongar Peoples study. This study is a project of the International Collaborative Indigenous Health Research Partnership (ICIHRP). I believe this chapter complements all the chapters in this PhD thesis in a number of ways. Firstly, I had first-hand involvement in the overall international research study concept and inception as these originated from my Master in Applied epidemiology in 2003-2005. Secondly, I had direct involvement in all the research partnerships, research protocols, study instruments and development. Thirdly, this chapter is about research describing the resilience factors, psychological distress, and social determinants of health, risky behaviours, knowledge and attitudes that can often influence and underpin lifestyle choices in the context of sexual health, smoking, alcohol and other drug use among Aboriginal and Torres Strait Islander people.

The International Collaborative Indigenous Health Research Partnership (ICIHRP) is a study between Australia, New Zealand and Canada. I am a named Chief Investigator (CI) on the ICIHRP. The National Health and Medical Research Council (NHMRC) approved funding through the University New South Wales (UNSW) in 2006 with international countries beginning research in 2007. For a number of administrative and professional reasons data collection did not begin in Australia until 2008. The major aim of the study was to explore *'The role of Resilience in responding to Blood Borne Viral and Sexually Transmitted Infections in Indigenous Communities'*.

In Australia, the ICIHRP had a focus primarily among younger Aboriginal and Torres Strait Islander people (adolescents and young adults) in urban settings with the following objectives:

- 1. Identify factors among Aboriginal and Torres Strait Islander people that indicate protection against acquisition of blood borne viral and sexually transmitted infections (BBV/STI).
- 2. Identify factors that enhance and influence access to services for prevention and management of BBV/STI.
- Develop and assess interventions to enhance these protective factors that can be delivered through Aboriginal Community-Controlled Health Services (ACCHS).

I had a fundamental role throughout the life of this study in all the research sites; both international (Canada and New Zealand) and national, including Redfern, Townsville and Perth. However, for the purpose of this PhD thesis and chapter I will only discuss my direct involvement in the Derbarl Yerrigan Health Service (DYHS) site study where I directly contributed and was responsible for the ethics application and approval, research protocol, research training, survey questionnaire, focus groups, interviews, data collection, follow-ups, analyses, and write-up of results.

In the Perth survey I wrote the original and amended ethics applications to the Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC), which approved the ethics application for the Perth-based survey in March 2010. In 2010 the project focused on the completion of the survey tool in two ACCHS who were the research partners in Australia. Consultations were held in Perth and Townsville – the other research site using the survey, to discuss the aims of the project and to consult on the protocols of the survey. In both sites the consultations involved members of the Australian ICIHRP researchers, AMS staff, staff of other local health care services and local community members with the aim of utilising researcher-administered surveys to collect data on characteristics related to young people's sexual histories, condom use, health service usage, alcohol and other drug use and BBV/STI knowledge.

Local demographic information was also collected as part of the survey in both Townsville and Perth to enhance the data collection and entry ultimately with the goal of reducing errors and costs.

In Perth, along with Robyn Williams, the local Noongar project coordinator of the (DYHS), we set up a Critical Reference Group with defined roles and responsibilities of the Perth study. The reference group comprised representation from the DYHS Board; the Aboriginal Alcohol and Drug Service; Yorgum Aboriginal Counselling Service; Family Planning Western Australia and the National Drug Research Institute. The CRG met three times leading the development and implementation of the Survey within local Aboriginal communities within the reach of the DYHS.

I was a facilitator in the pilot survey and training that commenced in May 2010 in Perth. I facilitated a workshop where training was offered to locally-based researchers and peer recruiters. Training included modules on research, ethics, survey methods (including fieldwork, mapping and outreach), interviewing techniques, research skills and capacity building, to enable the survey to be carried out with marginalised individuals and communities. Participation included site coordinators, Aboriginal Health Workers and peer/community members involved in the field research. Young people were also recruited for the pilot consultation.

The formal Survey commenced at the opening of NAIDOC Celebrations on the 2 July 2010. I was one of the recruiters who participated in many NAIDOC activities to conduct the surveys and focus groups. Visits were also conducted at a number of key organisations during Perth NAIDOC Week including Midland PCYC; Next Step, Youth Detox, Fairbridge Farm and PEEDAC (a local Indigenous organization that facilitates employment and professional development for their clients).

A follow up debriefing session was also provided in late July 2010 to bring all recruiters together to discuss the strengths and weaknesses of the NAIDOC events survey. The aim of this was to inform the remainder of the data collection in regional towns of the South West of Perth.

The survey was also conducted in the South West Region of Perth with visits to Narrogin, Albany, Bunbury and Northam through collaborative approaches with key Aboriginal organisations. The survey timeframe was extended due to the increased communication in these regions to August 2010 with 209 Surveys completed. Results were then presented to the Critical Reference Group for their information and feedback. This article is the product of this study.

I thoroughly enjoyed my involvement in the ICIHRP and Perth 'Young Noongar Peoples' study. I gained an enormous amount of research knowledge, skills, and experience that have complimented my other PhD research projects presented in this thesis. There were a number of cultural and at times, personal administrative challenges that all CIs and the funding bodies had to confront. I see these issues as 'lessons from the field'; a term I inherited from my Master in Applied Epidemiology (MAE). I will take these 'lessons from the field' and use them positively to guide, strengthen and improve how I and other researchers conduct health research with Aboriginal and Torres Strait Islander Australians in future projects and studies.

7.1.1 Publication details

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7.1.2 Contribution of authors

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7.1.3 Title

Sexual behaviour, drug use and health service utilisation by young Noongar people in Western Australia: A snapshot

7.2 Abstract

Objective. To describe sexual health behaviour, alcohol and other drug use, and health service utilisation among young Noongar people in the southwest of Western Australia.

Method. A cross-sectional survey among a convenience sample of 244 Noongar people aged 16–30 years. Data were described using simple frequencies and cross-tabulations and Chi-square tests of significance.

Results. The sample was more disadvantaged than the wider Noongar population. Sexual activity was initiated an a young age, about 40% had at least one casual sex partner in the previous 12 months with men more likely to have had two or more casual partners (23% vs. 14%). Condoms were always or often carried by 57% of men and 37% of women and 36% of men and 23% of women reported using a condom the last time they had sex with a casual partner. Self-reported lifetime STI diagnosis was 14%. Forty per cent currently smoked tobacco and 25% reported risky alcohol consumption on a weekly and 7% on an almost daily basis. Cannabis alone was used by 37%, 12% used other illicit drugs as well as cannabis, and 11% reported recently injecting drugs. In the previous 12 months 66% had a health check and 31% had been tested for HIV or an STI. Additionally 25% had sought advice or assistance for mental health issues.

Discussion and conclusion. While most were not engaged in unsafe sexual practices or harmful levels of alcohol and other drug use, a relatively high proportion were – of particular concern being the high level of injecting drug use. Encouragingly, a higher percentage of those engaged in risky behaviours were more likely to have been tested for HIV or an STI or to have had a recent health check.

Key words. Aboriginal, youth, sexual health, drug use, health service utilisation

Word count. 3166 (excluding abstract, references and tables)

7.3 Introduction

The broad health and social disparities between Aboriginal and Torres Strait Islanders and non-Indigenous Australians at the national level have been summarised.¹⁻³ However, given that the Aboriginal and Torres Strait Islander population is considerably younger than the non-Indigenous population, there has been increasing interest in documenting patterns of health-related harms and risk factors among young Aboriginal people in order to inform the development of culturally sensitive/appropriate prevention strategies. Evidence also indicates significant regional differences in some health outcomes, suggesting the need to develop interventions that take account of and are sensitive to local and regional variation.⁴

As is the case nationally, the Western Australian Aboriginal and Torres Strait Islander population is young, with 35% aged less than 15 years and a median age of 22 years, compared to 19.7% and a median of 36 years among non-Indigenous Western Australians.^{5, 6} The Western Australian Child Health Survey found that Aboriginal youth first engage in sexual activity at a younger age than their nonAboriginal counterparts and that 27% of 16 year olds had had sexual intercourse, compared to 16% of non-Aboriginal 16 year olds.⁷ The survey also found that Aboriginal adolescents who stayed engaged in education commenced their first sexual activity at a later age than those who had left school. Early school leaving was also an indicator of earlier up-take of tobacco and alcohol use.⁸ Unfortunately, there is little data on illicit drug use in general and injecting drug use in particular among young Aboriginal people in WA. However, given indications of higher levels of both behaviours reported in the national population, this is a cause for concern.⁹

In WA, in 2010, age standardised rates of newly acquired sexually transmitted infections (STIs) among Aboriginal people were significantly higher than in the non-Aboriginal population; the rate ratios were chlamydia 4.8:1, gonorrhoea 36.0:1 and syphilis 8.1:1.¹⁰ Although the number of newly acquired HIV infections among Aboriginal people was low, the rate ratios for other blood-borne viruses were high: hepatitis B 1.7:1 and hepatitis C 9.7:1.¹⁰ These rates are cause for great concern, and highlight the need for more detailed information to enable health services to address the transmission and treatment of these infections and to improve the social wellbeing of young Aboriginal people.

Derbarl Yerrigan Health Service (DHYS) – located in Perth – provides a range of holistic health services, including services to local youth. In 2010– in response to its own concerns and those raised in the studies cited above – DYHS conducted a study as a component of an International Collaborative Indigenous Health Research Project (ICIHRP). With a primary focus on adolescents and young adults, and moving beyond a past emphasis on risk and disadvantage, this study aimed to:

- 1. Identify factors among Aboriginal and Torres Strait Islander people that protect against acquisition of BBV/STIs;
- 2. Identify factors that enhance access to services for prevention and management of BBV/STI; and

 Develop interventions to enhance protective factors that can be delivered through Aboriginal community-controlled health services.

The objective of the local component – the subject of this paper – was to describe sexual health behaviour, alcohol and other drug use, and health service utilisation among Noongar people aged 16 to 30 years in the south-west of Western Australia to inform development of health services by DYHS.

7.4 Methods

A cross-sectional survey, using a paper-based questionnaire was conducted in Perth, Albany, Northam and Bunbury – cities and towns located in the ABS' Indigenous Regions of Perth and South-Western Australia. The questionnaire – similar to one used in a parallel study in Townsville – included sections on: demographic characteristics; family and community; sexual behaviour and health; alcohol and other drug use; and items on general health and wellbeing.

To be eligible for inclusion, participants had to be of Aboriginal or Torres Strait Islander descent, and aged between 16 and 30 years of age. Potential participants were approached in the Perth metropolitan area by male and female Aboriginal recruiters – at various NAIDOC events (a week-long cultural festival) or when attending DYHS, the Aboriginal Alcohol and Drug Service, or Next Step Drug Service. In the South-West towns, participants were recruited at similar events. However, as potential participants had a clear preference for being approached by older Aboriginal people, recruiters were engaged who were 'elders', respected members of their communities and who had backgrounds in Aboriginal and sexual health.

A total of 244 interviews were completed between July and September 2010. Questionnaire data were cleaned and entered into an SPSS database (version 21.0, IBM Corp, 2012). Analyses included descriptive frequency counts, simple cross-tabulations and Chi-square tests of association. As the participants were not randomly selected, to assess how representative they were of the broader Noongar population from which they were drawn, we compared the demographic data with that from the 2011 Census of Population and Housing for the ABS' Perth and South-Western Australia Indigenous Regions. These data were generated using ABS' Table Builder Function,¹¹ and they were downloaded into Microsoft Excel spread-sheets and the relationships tested using the Excel Chi-square Test function.

Ethical approval was obtained from the Western Australian Aboriginal Health Ethics Committee (WAAHEC approval 27302/10). A reference group consisting of representatives from the DYHS board and key Aboriginal agencies from the Perth metropolitan area was established to guide the project and to ensure cultural sensitivity and security.

7.5 Results

7.5.1 Socio-demographic characteristics of survey participants

Participant demographic characteristics are summarised in Table 1. A larger proportion of participants in our study were recruited from outside Perth compared to Census data (41% vs. 29% p=0.000). Among the participants, 230 identified as Aboriginal, four as Torres Strait Islander and ten as both Aboriginal and Torres Strait Islander. The majority of participants were female (56%) and the median age was 21 years. Women were significantly more likely than men to be aged \geq 20 years (66% vs. 46% p=0.003). Despite this gender difference, percentages in the five-year age categories were not significantly different to those in the Census (p=0.096).

Twelve per cent of participants were currently enrolled in secondary school/education and 15 per cent in post-secondary educational courses. The difference between the percentage in the sample and that in broader Noongar population was small and not statistically significant (25% vs. 27% p=0.435). Male participants were more likely than female participants to be enrolled in secondary school (18% vs. 7%, p=0.014) and female participants were more likely than male

participants to be enrolled in vocational courses (21% vs. 8% p=0.011). Of those not enrolled in education at the time of the survey, 39% had completed years 11 and 12.

Four per cent held a vocational or post-secondary qualification – a significantly smaller proportion than the 20% in the broader Aboriginal population (p=0.000). One in four participants (28%) were in either full or part-time employment at the time of data collection and this was the same as the larger population (p=0.627). Almost two thirds of participants (61%) indicated they were either receiving unemployment or pension/welfare benefits. One in five participants (22% reported being married or living with a partner, compared to 16% in the broader Noongar community (p=0.022). More women than men reported this (27% vs. 16%) but this was a consequence of the greater mean age of the women in the sample. Of those aged \leq 19 years 7% were in such a relationship compared to 32% of those aged \geq 20 years or more (p=0.000).

More than one in three participants (37% - 26% of men and 46% of women) reported having children. As with marital status, this was age-related, with 56% of those aged ≥ 20 years having children compared to 9% of those aged ≤ 19 years (p=0.000). Again there were no statistically significant differences between men and women in these age categories. Census data were not available on men and parenthood; however, the percentage in our sample of women with one or more children was significantly higher than in the broader Noongar population (46% vs. 34% p=0.001).

Overall, 41% reported that they had ever been arrested with a significantly higher proportion of men than women arrested (52% vs. 32% p=0.004). However, there was no statistically significant difference in the proportion of men and women who had been imprisoned or in juvenile detention in the previous 12 months (14% vs. 12%).

Characteristic	Male	Female	Total
Gender	(n = 108)	(n = 136)	(n = 244)
	44%	56%	100%
Age	(n = 108)	(n = 136)	(n = 244)
16 – 19 years	50%	29%	38%
20 – 24 years	20%	30%	26%
25 – 30 years	26%	36%	31%
No response	4%	5%	5%
	(n = 104)	(n = 129)	(n = 233)
Mean	24 years	26 years	25 years
Median	20 years	23 years	21 years
Range	16 – 30 years	16 – 30 years	16 – 30 years
Indigenous status	(n = 108)	(n = 136)	(n = 244)
Aboriginal	94%	95%	94%
Torres Strait Islander	2%	2%	2%
Aboriginal and Torres Strait Islander	5%	4%	4%
Current living location	(n = 108)	(n = 136)	(n = 244)
Perth	62%	57%	59%
South-West	19%	27%	23%
Other	6%	6%	6%
No response	14%	10%	12%
Educational status	(n = 108)	(n = 136)	(n = 244)
Currently enrolled			
High school	18%	7%	12%
Vocational and other post-secondary	8%	21%	15%
Completed			
Year 10 or less	27%	26%	26%
Years 11 & 12	40%	38%	39%
Post-secondary	4%	4%	4%
No response	4%	4%	4%
Current employment status	(n = 108)	(n = 136)	(n = 244)
Full-time employment	21%	15%	18%
Part-time or causal employment	9%	8%	9%
Not in paid employment	63%	71%	68%
No response	7%	6%	6%

Table 7.1: Socio-demographic characteristics of survey participants

Characteristic	Male	Female	Total
Relationship status	(n = 108)	(n = 136)	(n = 244)
Single/separated	82%	74%	78%
Married or living with a partner	16%	27%	22%
No response	2%	0%	1%
Parenthood	(n = 108)	(n = 136)	(n = 244)
Participants without children	71%	52%	60%
Participants with children	26%	46%	37%
No response	4%	2%	3%
Ever arrested			
No	44	56	50
Yes	52	32	41
No response	5	12	9
Prison/detention in previous 12 months	(n = 108)	(n = 136)	(n = 244)
No	80%	80%	80%
Yes	14%	12%	13%
No response	7%	9%	8%

Errors due to rounding

7.5.2 Sex-related behaviour and risk

The majority of participants (77%) identified as heterosexual. Two men and two women identified as gay or lesbian (3%) and two men and two women identified as bisexual (2%). Fifteen men (14%) and 23 women (23%) did not respond to this question.

Among the 189 participants who had ever had sex, the median age at first sex was 15.0 years among men and 16.5 years among women, and 30% reported having had sex by the age of 14 years. Among those aged \leq 19 years, 65% of men and 64% of women reported ever having had sex – compared to 86% of men and 85% of women aged \geq 20 years.

Females were significantly more likely than men to report having had only one sex partner in the previous 12 months (41% vs. 27% p=0.007) and women only one

current regular partner (46% vs. 28% p=0.003). Women were also significantly more likely than men to report having no casual sex partners in the previous 12 months than men (23% vs. 11%) and men to having two or more casual sex partners (23% vs. 14% p=0.019).

Twice the proportion of women than men (29% vs. 15%) declined to answer a question about frequency of carrying a condom. Nevertheless, more than half (57%) of men reported that they always, or often carried a condom, compared to 37% of women.

Twenty-six per cent of men and 30% of women reported having no casual sexual partners or not being sexually active. Among 78 men and 88 women who reported being sexually active, 36% of men and 23% of women reported using a condom the last time they had sex with a casual partner. Among those not using a condom the most common reasons were: trusting their partner (23%), their partner did not like condoms (19%), and that they knew their partner's sexual history (16%).

Behaviour/risk	Male	Female	Total
Sexual identity	(n = 108)	(n = 136)	(n = 244)
Straight/heterosexual	81%	74%	77%
Gay/lesbian/homosexual/sister-girl	4%	2%	3%
Bisexual	2%	2%	2%
No response	14%	23%	19%
Ever had sex	(n = 108)	(n = 136)	(n = 244)
Yes	75%	80%	78%
No	15%	7%	10%
No response	10%	14%	12%
Participants aged ≤19 years	(n = 54)	(n =39)	(n = 93)
Reported ever had sex	65%	64%	65%
Participants aged ≥20 years	(n = 50)	(n = 90)	(n = 140)
Reported ever had sex	86%	85%	85%
Median age at first sex	(n = 68)	(n = 80)	(n = 148)
	15.0	16.5	16.0

Table 7.2: Sex-related behaviours and risk

Behaviour/risk	Male	Female	Total
Number of sex partners in the previous 12 months	(n = 108)	(n = 136)	(n = 244)
No sex partners	1%	2%	2%
1 sex partner	27%	41%	35%
2-4 sex partners	19%	18%	18%
\geq 5 sex partners	15%	4%	9%
Not sexually active	15%	7%	10%
No response	23%	29%	26%
Number of current <i>regular</i> sex partners	(n = 108)	(n = 136)	(n = 244)
No regular sex partner	28%	15%	21%
1 regular sex partner	28%	46%	38%
\geq 2 regular sex partners	8%	6%	7%
Not sexually active	15%	7%	10%
No response	21%	27%	24%
Number of <i>casual</i> sex partners in the previous 12 months	(n = 108)	(n = 136)	(n = 244)
No casual partners	11%	23%	18%
1 casual partner	17%	23%	20%
2 casual partners	9%	10%	9%
3 or more casual partners	14%	4%	9%
Not sexually active	15%	7%	10%
No response	34%	33%	34%
Frequency condom carried	(n = 108)	(n = 136)	(n = 244)
Never	14%	28%	22%
Sometimes/often	27%	25%	26%
Always	30%	12%	20%
Not sexually active	15%	7%	10%
No response	15%	29%	23%
Used condom last time had sex with a casual partner	(n = 108)	(n = 136)	(n = 244)
No	19%	17%	18%
Yes	36%	23%	29%
No casual partner	11%	23%	18%
Not sexually active	15%	7%	10%
No response	19%	31%	26%

Behaviour/risk	Male	Female	Total
Ever diagnosed with an STI	(n = 108)	(n = 136)	(n = 244)
Yes	8%	19%	14%
No	50%	48%	49%
No response	42%	33%	37%
Ever diagnosed with a BBV	(n = 108)	(n = 136)	(n = 244)
Yes	6%	4%	5%
No	87%	84%	85%
No response	7%	12%	10%

Errors due to rounding

Self-reported prevalence of a lifetime STI diagnosis was (14%). Among both men and women, the most commonly reported infections were chlamydia (8%), gonorrhoea (5%), and herpes and lice (4% each). One per cent of the sample also reported being diagnosed with HPV, syphilis or trichomoniasis. Five per cent of the sample reported having been diagnosed with a blood borne viral infection including hepatitis C (n=7), hepatitis B (n=5), and HIV (n=1).

7.5.3 Tobacco alcohol and other drug use

Overall, 40% of participants reported currently smoking tobacco with no gender differences. For the purpose of the study 'risky drinking' was defined as the consumption of \geq 6 standard drinks on any one occasion. Almost half the sample (47%) reported never consuming alcohol at this level (19%) or that they did so infrequently (28%). However, 25% reported such consumption weekly and 7% 'almost daily'. Men were significantly more likely than women to report risky alcohol consumption on a daily or almost daily basis (3% vs. 13% p=0.019).

About half the respondents reported not using any illicit drugs in the previous 12 months. Cannabis was the most frequently used illicit drug, with 36% reporting using it alone (23%) or as well as other illicit drugs (13%) in the previous 12 months.

The most commonly used illicit drugs other than cannabis were 'speed' (10%), opioids such as oxycontin (8%) and 'ecstasy' (6%). There were no gender differences in the prevalence of illicit drug use in the last 12 months.

Characteristic	Male	Female	Total
Current tobacco use	(n = 108)	(n = 136)	(n = 244)
Non-smoker	46%	37%	41%
Smoker	36%	42%	40%
No response	18%	21%	20%
Risky alcohol use (≥6 drinks on one occasion)	(n = 108)	(n = 136)	(n = 244)
Never	19%	20%	19%
Monthly or less	23%	32%	28%
Weekly	29%	23%	25%
Almost daily	13%	3%	7%
No response	17%	22%	20%
Illicit drug use in the previous 12 months	(n = 108)	(n = 136)	(n = 244)
None	50%	48%	49%
Cannabis only	20%	26%	23%
Cannabis and other illicit drugs	17%	10%	13%
Illicit drugs excluding cannabis	7%	8%	7%
No response	3%	5%	7%
Injected drugs in previous 12 months	(n = 108)	(n = 136)	(n = 244)
No	82%	77%	79%
Yes	10%	11%	11%
No response	8%	12%	10%
Used someone else's needle and syringe in previous month	(n=11)	(n=15)	(n=26)
No	55%	47%	50%
Yes	9%	40%	27%
No response	36%	13%	23%

Table 7.3: Tobacco, alcohol and other drug use

Errors due to rounding

Eleven per cent of participants (n=27) reported injecting drugs in the previous 12 months – most commonly amphetamine type substances. Of this group, one man and six women reported using a needle and syringe *after* another person had used it. As discussed below, the prevalence of self-reported injecting drug use is extremely high and a cause for great concern.

7.5.4 Health service utilisation

Two thirds of participants (66%) reported having a preventive health check in the previous 12 months (Table 6.4). About 44% reported ever having received information on safe sex, 22% that they had ever received free condoms from a health professional, and only 12% that they had received instruction on their use. Sixty-six per cent of women reported ever having received advice or services dealing with sexual or reproductive health.

Thirty-one per cent of participants had been tested for HIV or another STI in the previous 12 months and 13% had been tested more than 12 months previously. Most of those had been tested at a general practice (51%), an Aboriginal health service (13%), or sexual health clinic (13%). The others were tested at a variety of locations including prison/detention centre and hospitals. The most common reasons for being tested were 'to be sure' they were not infected (59%) or having had sex without a condom (12%). Other reasons included 'condom broke', partner had an STI or sex with another person, or symptoms.

Twenty-five per cent of participants reported having sought advice or assistance for mental health issues. Such advice was most commonly sought from Aboriginal community-based agencies such as DYHS. In addition, 22% also sought advice about their own alcohol or other drug (AOD) use. The most frequently used service was the Aboriginal Alcohol and Drug Service in Perth.

Table 7.4: Health service utilisation

Characteristic	Male	Female	Total
Received a health check	(n = 108)	(n = 136)	(n = 244)
Within the previous 12 months	63%	68%	66%
More than 12 months previously	4%	4%	4%
No response	33%	28%	30%
Ever received information on safe sex	(n = 108)	(n = 136)	(n = 244)
Yes	46%	43%	44%
No	31%	31%	31%
No response	23%	27%	25%
Ever received free condoms from health professional	(n = 108)	(n = 136)	(n = 244)
Yes	28%	17%	22%
No	49%	57%	53%
No response	23%	27%	25%
Ever received information or instruction on condom use	(n = 108)	(n = 136)	(n = 244)
Yes	15%	10%	12%
No	62%	63%	63%
No response	23%	27%	25%
Ever received contraceptive advice or sexual health care		(n = 136)	
Yes		66%	
No		18%	
No response		15%	
Last tested for HIV or STIs	(n = 108)	(n = 136)	(n = 244)
Not tested	26%	18%	22%
≤ 12 months	26%	35%	31%
>12 months	11%	15%	13%
No response	36%	33%	34%
Where last tested for HIV or STIs	(n = 40)	(n = 67)	(n = 107)
General practice	43%	55%	51%
Aboriginal Health service	23%	6%	12%
Sexual health clinic	13%	12%	12%
Other	21%	27%	25%
Reason for HIV or STI testing	(n = 40)	(n = 67)	(n = 107)
To be sure	65%	55%	59%
Had sex without a condom	18%	9%	12%
Other	17%	36%	29%

Characteristic	Male	Female	Total
Ever sought advice/assistance for own mental health	(n = 108)	(n = 136)	(n = 244)
Yes	31%	21%	25%
No	65%	60%	62%
No response	5%	20%	13%
Ever sought for advice/assistance for own AOD use	(n = 108)	(n = 136)	(n = 244)
Yes	24%	20%	22%
No	61%	57%	59%
No response	15%	23%	19%

Errors due to rounding

The 18 participants drinking alcohol at risky levels on a daily on nearly daily basis were more likely to have had a health check in the previous 12 months than those drinking less frequently (94% vs. 63% p=0.007) and were more likely to have been tested for HIV or and STI in the previous 12 months (72% vs. 27% p=0.000).

The 44 participants who had two or more casual partners in the previous 12 months were more likely than the 200 who had not to have been tested for HIV or an STI in the previous 12 months (50% vs. 27% p=0.002) as were the 26 participants who had injected drugs compared to the 218 who had not (54% vs. 28% p=0.007).

7.6 Discussion

Considerable evidence attests to the social, economic and health disparities between Aboriginal and non-Aboriginal Australians. Comparisons of our survey participants with the broader Noongar population in the same age group shows that they share some characteristics, such as low levels of employment and high proportions in receipt of social security benefits. In other areas, they face even greater levels of disadvantage including lower levels of educational attainment and single parenthood. They also have relatively high levels of contact with the justice system. These factors are known to interact in complex ways and both directly and indirectly increase the risk of adverse health and social outcomes.^{12–14} Among these are high levels of stress,¹⁵ (reflected in the high percentage seeking advice for mental health issues) and high rates of contact with the justice system.¹⁶

Most participants were willing to answer questions about whether or not they had had sex and, if so, at what age this had been initiated. However, there were high nonresponse rates to most other questions about sex-related behaviour – reflecting the fact that discussion of these topics is often a source of embarrassment or 'shame' among Noongar people. This makes it difficult to know to what extent the responses of those who did respond can be extrapolated to non-responders. Nevertheless, almost one in four men and women reported sex with casual partner in the previous 12 months and men were significantly more likely than women to report having more than one casual partner and more likely to report not using a condom with casual partners.

Levels of tobacco, alcohol and other drug use – especially the reported level of injecting – among some participants are of particular concern. Published data are not available on age-specific smoking rates among Aboriginal and Torres Strait Islanders. However, when the high non-response rate is taken into account, the percentage of smokers among participants is likely to be little less than the 50% nationally – a percentage twice that in the non-Indigenous population.¹⁷ Outcomes of this, and associated passive smoking, are likely to include high levels of chronic disease and adverse effects on foetal and infant development.

Comparisons of surveys of self-reported alcohol consumption are difficult because of differences in the methods used.¹⁷ The 2001 Australian Alcohol Guidelines, defined risky and high risk drinking in the short term as >6 standard drinks on any one day for men and >4 for women.¹⁸ The 2008 National Aboriginal and Torres Strait Islander Social Survey (NATSISS) found that 46% of men and 28% of women aged \geq 15 years drank at that level in the two weeks before they were interviewed.¹⁷ In our study, 42% of men and 26% of women reported consuming \geq 6 drinks at least weekly. While our data and the NATSISS data are not directly comparable, they nevertheless suggest levels of consumption that are considerably higher than in the non-Indigenous population.

Of particular concern in this study are the high reported levels of illicit and injecting drug use. In the 2008 NATSISS, 23% of Aboriginal and Torres Strait Islander people aged \geq 15 years reported use of any illicit drug in the previous 12 months,¹⁷ but in our study 43% did so. While in the NATSISS, women were less likely to than men to report illicit drug use (36% vs. 51%), there were no gender differences in our sample. There have been no recent estimates of the prevalence of injecting drug use among Aboriginal and Torres Strait Islander people,⁹ however, the prevalence of injecting drug use in the last 12 months in our sample (10% of men and 11% of women) is alarming when compared to the percentages among non-Aboriginal people aged \geq 14 years (0.6% and 0.3%).¹⁹ Also alarming is the high frequency of sharing injecting equipment, especially among women.

Encouragingly about two-thirds of participants reported having a health check in the previous 12 months. The percentages seeking specific sexual health, BBV or AOD services were less than this and highlight the need for more active screening. However, while there is still some way to go, it is encouraging that those engaged in high risk behaviours such as injecting drug use, sex with multiple casual partners, and drinking at risky levels on a daily or almost daily basis were more likely to have been tested for HIV or and STI, and in the latter case to have had a recent health check that those who were not.

Finally the notion of 'resiliency' for Noongar youth in these data is reflected in the high rates of uptake of preventative health checks among sexually active youth. Results indicate that these youth valued their health and wellbeing and sought support from their peers. Other studies about Indigenous resilience have shown similar results.^{20,21} Whiteside et al, in an interview study of 30 community members in North Queensland, identified the need to address community barriers to recognising that STIs and HIV/AIDS are a threat to young people and to destigmatise the issue, if young people are to be deeply engaged in strategies to maintain their own health.²⁰ Mooney-Somers et al undertook an in-depth qualitative study in which young people reported strategies for overcoming challenges to prevention and accessing treatment services, including being proactive by carrying condoms and persisting with behavioural intentions despite feeling shame.²¹

7.7 Conclusion

This project has provided a snapshot of a group of young Aboriginal people in urban and rural settings. The picture that emerges is one of a particularly disadvantaged group within a disadvantaged population. Although it is not possible to extrapolate from this study to the wider Noongar population, it is clear from the study that there is at least a segment of the population, which is under stress and engaged in behaviours which pose considerable risks to health and wellbeing. Equally clear, however, is that fact that most Noongars in the sample are not behaving in such a way.

7.8 Acknowledgements

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CHAPTER 8: CONCLUSION AND FUTURE DIRECTIONS

8.1 Chapter overview

This chapter describes the main findings from the program of research conducted and reported in this thesis. It also makes recommendations regarding the conduct of further research and strategies to address the health and wellbeing issues identified throughout the thesis.

8.2 Main strengths

The main strengths of the body of research presented in this thesis are that we addressed key Aboriginal and Torres Strait Islander health priorities; the research was conducted in partnership with Aboriginal Medical Services and communities; and we combined analyses of large research and administrative datasets, with surveys and qualitative research, to achieve a deeper understanding of issues around psychological distress, dietary patterns and risks for chronic disease. There is a clear need to explore further the association between psychological distress and food choices, exercise, risk taking behaviour and their relationship with the social, political and cultural determinants that fundamentally impact upon the health and wellbeing of Aboriginal and Torres Strait Islander Australians.

This research work highlights an important message to researchers, Aboriginal Medical Services, health service providers and government agencies: when conducting health research or working with Aboriginal and Torres Strait Islander Australians, a holistic framework should be adopted that incorporates all the social determinants of health and illness in this population.

8.2.1 Analytical framework

In this thesis, I applied a holistic framework that incorporated a mixed methods approach in order to paint a more complete picture of the cultural, political, socioeconomic and social determinants of health for Aboriginal and Torres Strait Islander Australians affected by chronic diseases and blood borne viruses. The framework takes account of accepted holistic definitions of Aboriginal health, but also three dimensions of burden of disease among Aboriginal and Torres Strait Islander people including: psychological distress, childhood and adulthood lived experiences and lifestyle choices. A focus on these three dimensions, and a methodological approach that triangulated the findings from qualitative and quantitative research, has provided a more in-depth understanding of the nature of this problem.

My research demonstrates the feasibility and value of adopting an alternative approach and methods to investigating the socio-economic burden of chronic disease among Aboriginal and Torres Strait Islander Australians. The tendency has been to use 'cost of illness' studies to estimate the societal burden that is associated with illness, which is potentially avoidable through targeted culturally appropriate prevention, education and health promotion. While these studies can be useful from an advocacy perspective, they offer little guidance for governments and service providers on strategies to improve support and service delivery for individuals, their families, carers and communities.

My research incorporated historical, political, social and cultural factors and developed and applied an analytical framework that evolved from previous work in this field.^{1, 2} I applied this analytical framework within an Indigenous setting to investigate the circumstances of lived experiences of individual Aboriginal and Torres Strait Islander people and their families affected by chronic disease and to explore the associations of psychological distress, food choices, lifestyle and risk behaviour and their impact of illness. This research establishes that this analytical framework can be applied to different health related areas.

This thesis fills an important gap in the evidence and has helped to establish the existence of a deeper social and emotional wellbeing problem that requires attention by health researchers, the Aboriginal and Torres Strait Islander sector and the Australian government. The coverage that this research attracted has also helped to raise the profile of this problem in Australia (Chapter 2, p. 14 and Chapter 5, p. 72.

8.2.2 Potential for future research

This research has identified the need to include a focus on psychological distress in chronic disease research and the importance that Aboriginal and Torres Strait Islander people place on stress and depression as factors shaping their behaviour and general health. Observational studies that investigate the psychosocial and socioeconomic impact of illness among Aboriginal and Torres Strait Islanders should also explore associations with stress, distress and depression. Intervention trials might focus on addressing depression and stress in an effort to improve chronic disease health outcomes. This research demonstrates that relevant information regarding psychological stress can be collected, and that a simple yet comprehensive suite of questions could be incorporated into existing studies as well as there being a need to establish stand-alone studies as described in Chapter 3 (p. 22) and Chapter 6 (p. 76) to investigate the associations between psychological distress and illness.

This research will extend beyond the term of this thesis and current research funding. Future funding and research will enable further investigation of these important findings. Such research will have the potential to build collaborations within the Aboriginal and Torres Strait Islander health sector, including Aboriginal Medical Services and state and federal peak bodies, but also within the wider health sector in seeking to improve health outcomes for Aboriginal and Torres Strait Islander Australians.

8.3 Limitations

There are several limitations to the research undertaken in this thesis, many of which have already been identified in the 'Discussion' section of each of the chapters. This section highlights the key limitations of the overall thesis and notes ways in which these could be addressed in future research.

8.3.1 Measurement of psychological distress

I approached the measurement of psychological distress in the thesis from a range of perspectives. In the quantitative analysis of the 45 & Up study, psychological distress was defined using the Kessler Psychological Distress (K10) score with cut off points

 \leq 22 and >22 to dichotomise levels of psychological distress among participants. As discussed in Chapter 6 (p. 80), analyses suggest that there is an association between psychological distress and diet among older Aboriginal and Torres Strait Islander individuals. Understanding and addressing causes of psychological distress may improve emotional and social wellbeing and impact on diet. This would reduce the burden of obesity and chronic diseases such as Type 2 diabetes and cardiovascular disease (CVD) among this population. As illustrated in the sexual health article (Chapter 7, p. 94, it is also possible that addressing stress and depression will impact on high-risk behaviours that might reduce the acquisition of BBVs and STIs.

It is possible that the threshold measurement using the K10 score is either too sensitive or insensitive and thus overestimates or underestimates the burden of psychological distress. However, in the absence of a validated approach to measuring psychological distress among Aboriginal and Torres Strait Islander people, the multidimensional framework and mixed methods approach that were applied in this thesis provide one alternative that offers a more holistic assessment of the burden of psychological distress and its association with chronic disease and illness. I investigated the issue from multiple perspectives, using both quantitative and qualitative methods in different illness populations in order to generate an in-depth understanding of the burden of psychological distress that Aboriginal and Torres Strait Islander peoples face when managing chronic disease and navigating both the Aboriginal Medical Services and mainstream health systems.

In addition, over time, it is likely that Aboriginal and Torres Strait Islander Australians will adopt strategies to deal with psychological distress, make healthy lifestyle changes and manage their health. The timing and funding restrictions of my thesis and the associated studies meant that cross-sectional, rather than longitudinal studies were used. In this thesis, I have suggested that psychological distress affects people's food choices and dietary intake and this then influences their chronic disease risk. Although this explanatory framework is plausible, longitudinal followup of the 45 & Up study cohort would allow exploration of the direct influence of psychological distress at baseline on health outcomes and whether dietary patterns might protect against the development of psychological distress over time. Seeking the opportunity to follow this cohort of older Aboriginal and Torres Strait Islander Australians and collect additional information regarding social and emotional wellbeing represents a high research priority.

Future research can address these limitations by developing a standardised and validated approach for measuring psychological distress in Aboriginal and Torres Strait Islander populations that integrates a mixed methods approach. The framework that was developed and applied in this thesis provides a valuable starting point. A standardised approach will help to ensure the comparability of findings across studies. Qualitative methods will help to develop a better understanding of the social determinants of health and associations with psychological distress among Aboriginal and Torres Strait Islander people, and also the impact of loved ones dying prematurely on wellbeing and health.

Development of a standardised approach, as suggested above, would be further strengthened through the conduct of multiple assessments of psychological distress, social, behavioural and biological determinants and health outcomes over time. This would ensure better understanding of key intervention points to improve health outcomes. Two recent national reviews of social and emotional wellbeing among Aboriginal and Torres Strait Islander peoples identified key principles for investigating these issues and their impact on overall health.^{3, 4} Any initiatives to develop a standardised approach to measuring psychological distress and its association with the burden of chronic disease should be guided by these principles.

8.3.2 Populations studied

The studies in this thesis investigated psychological distress, influences on diet and food choices, sexual health and risk behaviour, social determinants of health and their impact on the burden of chronic disease in a number of at-risk Aboriginal and Torres Strait Islander individuals and populations. All of the studies included individuals who identified as being Aboriginal and or Torres Strait Islander Australian. The studies reported in this thesis predominantly recruited Aboriginal and Torres Strait Islander Australians from urban and rural settings in New South Wales, Queensland and Western Australia. The questions explored would also be highly relevant to people living in remote areas and there is a need to validate measures of psychological distress in remote-living populations. This research was also not designed to investigate differences in patterns of psychological distress and burden of chronic disease between Aboriginal and Torres Strait Islanders and other Australians. Additional research should explore the generalisability of findings across Indigenous Australia and key aspects of comparison with non-Indigenous Australians.

8.4 Directions for future research

This research has advanced the tools, methods and concepts used to measure psychological distress and its association with food and lifestyle choices. A number of key directions for future research are discussed below.

First, there is a need for a standardised approach for measuring psychological distress in at-risk Aboriginal and Torres Strait Islander populations. The development of this approach can build on the framework that was applied in this research and should integrate a mixed methods approach, multiple assessments and where possible, a longer follow-up period. Such a standardised approach will also assist in understanding how the social determinants of chronic diseases are experienced by Aboriginal and Torres Strait Islander people and the impact of historical and political factors that continue to shape and influence lifestyle decisions and choices.

Second, this research identified psychological distress and lifestyle factors that are important to individuals and could be incorporated into intervention studies in to assess the effect of lifestyle interventions on chronic disease outcomes. This research demonstrated that it is feasible to integrate measurement of psychological distress into existing studies and that these outcomes are of interest to health researchers, health care providers and Aboriginal and Torres Strait Islander health and community organisations.

Third, a necessary extension of this research is to explore the associations between psychological distress and the burden of chronic disease with other important health outcomes such as quality of life and adherence to treatment, care and support. In addition, the long term effectiveness and consequences of any healthy lifestyle changes requires additional investigation.

Finally, this research has helped to establish that there is a fundamental underlying psychological distress associated with lifestyle choices and affecting the burden of chronic disease among Aboriginal and Torres Strait Islander Australians. This empirical research, along with well-established research by the Australian Bureau of Statistics (ABS)⁵, the Australian Institute for Health and Welfare (AIHW)⁶ and those studies referenced throughout this thesis, provides crucial evidenced to demonstrate that interventions to address psychological distress and to improve socioeconomic disadvantage are likely to have direct benefits in improving key health outcomes.

Noting that there are a number of health programs in Australia that address stress and resilience, with an aim to improve health outcomes among Indigenous Australians, it is important that we evaluate the acceptability and effectiveness of these programs. The East Gippsland Aboriginal sport and physical activity program⁷ aims to promote and support increased participation of Aboriginal people in sport and recreation. The program has activities for all age groups and supports physical activity for those clients with a chronic disease. The 'Close the gap' Aboriginal sexual health program⁸ was developed in South Australia, after receiving funding from the National Indigenous Partnerships (Indigenous early childhood development and 'close the gap' on Indigenous sexual and reproductive health). The overall purpose of the program is to enhance the sexual and reproductive health, wellbeing and safety of young Aboriginal South Australians. It aims to improve the sexual health literacy of Aboriginal young people and encourages positive and respectful relationships.

In NSW a partnership model was established among key education providers, policy makers, non-government organisations, the local area health service and Aboriginal community controlled organisations aimed at increasing collaboration, skill development, cultural competence and increasing access to mentorship and expertise for Aboriginal Health Workers (AHWs).⁹ Research that aims to evaluate the acceptability, effectiveness and sustainability of these programs should be prioritized. In addition, racism and social exclusion factors amongst Aboriginal and

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Torres Strait Islander Australians need to be considered when seeking to understand what type of programs will be needed to reduce psychological distress and to have a real impact on the burden of chronic disease.¹⁰

8.5 Conclusion

In this thesis I developed and applied an analytical framework that provided a holistic and comprehensive assessment of the association between psychological distress and high-risk lifestyle behaviours and their impact on the burden of chronic disease. Many Aboriginal and Torres Strait Islander people experience significant psychological distress, arising from experiences accumulated throughout life, which underpins or influences their risk taking behaviour and lifestyle choices. This research has raised awareness regarding the many complex social problems affecting Aboriginal and Torres Strait Islander Australians and has been a catalyst for discussion among academics, healthcare providers and policy makers about options to improve research methods, clinical care, treatment and social support for Aboriginal and Torres Strait Islander peoples affected or at risk of developing a chronic disease. We need to develop, implement and evaluate appropriate and targeted approaches to address psychological distress amongst Aboriginal and Torres Strait Islander between the swere burden of chronic diseases among Indigenous populations.

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- Appendix A: Study to reduce the incidence of diabetes through early intervention (STRIDE) questionnaire (15 pages)
- Appendix B: 45 and Up study questionnaire for men (6 pages)
- Appendix C: 45 and Up study questionnaire for women (6 pages)



The University of Sydney School of Public Health Faculty of Medicine



THE GEORGE INSTITUTE for International Health

Study to reduce the incidence of diabetes through early intervention (STRIDE)

ABORIGINAL AND TORRES STRAIT ISLANDER ADULT HEALTH SURVEY QUESTIONNAIRE

This questionnaire is designed to gather information on issues related to nutrition, physical activity and diabetes.

To complete this questionnaire, please tick the appropriate box (in some questions you can tick more than one box for the one question) or provide written comments in the space provided. All information provided by you will be subject to privacy legislation and may not be provided to any other organisation without your prior consent. We have attached information sheets about the study and consent forms for you to sign.

Gender:	□ Male □ Female	
Indigenous status	□ Aboriginal □ Torres Strait Islander □ Both □ Non-Indigenous	
What is your age group:	.□ 15 – 19 yrs □ 20 – 29 yrs □ 30 – 39 yrs	□ 40 – 49 yrs □ 50 – 59 yrs □ 60 + yrs
Postcode		

Chris Lawrence Study Manager STRIDE	Tel: 02 9993 4500 Fax: 02 9993 4501 Mob: 0438 964 929 Email: <u>chris.lawrence@george.org</u>

Section 1 GENERAL STUFF ABOUT YOU AND YOUR HEALTH

1. What best describes your current situation?

Sinale
Olingic

Married

De Facto/living with partner

U Widowed

Divorced

Separated

2. Do you have children?

No

🗌 Yes

If yes how many children live with you at home?

3. Please describe your current job status?

- Employed full time
- Employed part-time
- Full time student
- Part time student
- Home duties
- Unemployed
- Pensioner
- Disabled/sick
- Retired
- Other (please specify)
- 4. In general, would you say your health is: (please tick only one)
- Excellent
- Very good
- Good
- 🗌 Fair
- Poor

- 5. When was the last time you saw a health care provider (eg. Doctor, Nurse. Health worker)?
- Less than 1 month ago
- 1 to 3 months ago
- 4 to 6 months ago
- 7 to 12 months ago
- More than 12 months ago
- I can't remember the last time I saw a health care provider
- 6. Where did you go for your most recent health check-up?
- Local Aboriginal Medical Service
- Local private doctor/GP
- After hours clinic
- Hospital Emergency Department
- Can't remember
- Other (please specify)
- 7. Do you have private health insurance?

Yes
No

- 8. Do you currently smoke cigarettes?
- 🗌 Yes
- 🗌 No
- Ex smoker (e.g. more than 3 months ago)
- 9. Do you have diabetes?

Yes – what	year were	you diagnosed?
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- 🗌 No
- Not sure/don't know

- 10. What is your usual yearly HOUSEHOLD income before tax, from all sources (please include benefits, pensions, superannuation, etc.) for all members of your household
- Less than \$5,000 per year
- 5,000-9,000 per year
- \$10,000-19,999 per year
- \$20,000 \$29,999 per year
- \$30,000 \$39,999 per year
- \$40,000 \$49,999 per year
- 550,000 \$59,999 per year
- 560,000 \$69,999 per year
- \$70,000 or more per year
- I would rather not answer this question
- 11. In the past 12 months, has there been a time when your household has been unable to pay the full amount of the following?

Rent or mortgage	Yes No
Gas, electricity or telephone bills	Yes No
Medical consultations and tests	Yes No
Medications	Yes No
Dental appointments	Yes No
Schooling costs including (school uniforms, textbooks, necessary equipment for school, excursions)	Yes No
Child care costs	Yes No
Other (please indicate)	☐ Yes ☐ No

12. Did any person or organisation help with meeting these costs?

🗌 Yes 🔄 No
If yes, who:
 Centrelink Other government agency Non-government welfare agency (e.g. St Vincent de Paul, Salvation Army) Aboriginal organisation Extended family Friends Other
Please indicate

Section 2

WHAT YOU EAT AND DRINK

13. How often do you eat breakfast?

Never
Not very often
Sometimes
Most of the time

Always – everyday



14. On an average day please indicate how often you eat the following foods. Please choose a number between 1 and 5, where 1 is never and 5 is always.

	1 (Never)	2	3 (Sometimes)	4	5 (Always)
Cereal					
Fresh fruit					
Fresh vegetables					
Meat					
Fish					
Dried nuts or dried fruit					
Bread					
Yoghurt					
Cheese					
Milk					

15. On an average day how often do you eat snack foods between meals?

- 1 2 snacks per day
- 3 4 snacks day
- 5 6 snacks per day
- More than 6 snacks per day
- 16. In the last week how often did you eat fast food meals (e.g. MacDonald's, KFC, Pizza Hut, Hungry Jacks, local hamburger/ pizza/ fish and chips shops)
- Very rarely or never
- 1- 2 times per week
- 3 4 times per week
- 5 6 times per week
- More than 6 times per week
- 17. In the last week tick the places where you have eaten your meals? (tick as many boxes as apply to you)
- Home
- Family or friend's place
- School/ College/ University
- Work
- Community centre
- Café/food courts
- Pub/clubs
- Restaurant
- Other (please specify)
- 18. On an average day how much water do you drink daily?
- None
- 1- 2 glasses per day
- 3 4 glasses per day
- 5 6 glasses per day
- More than 6 glasses per day

19. On an average day how many cans/ small bottles of soft drink do you drink a day? (Coke, Pepsi, Sprite etc)

None

1- 2 per day

3 - 4 per day

5 - 6 per day

More than 6 per day

20. On an average day how many glasses of fruit juice do you drink a day?

None

1 or 2 per day

3 or 4 per day

5 or 6 per day

More than 6 per day

21. Do you take vitamin supplements?

Never

Not very often

Sometimes

Often

Every day

22. How would you describe your current weight?

Underweight
Overweight

Healthy weight

Other – please specify

23. If you know your current weight, please tell us.

.....

I don't know my current weight

24. If you know, please tell us how tall are you?

.....

I don't know my height

Please answer the following questions about food preparation at your place.

25. Who usually decides on what type of food you eat?

.....

26. Who usually buys the food?

.....

27. Who is responsible for preparing the food?

.....

28. Who is responsible for serving the food?



.....

29. How often is your food cooked at home in the following ways? Please choose a number between 1 and 5, where 1 is never and 5 is always.

	1 (Never)	2	3 (Sometimes)	4	5 (Always)
Fried					
Baked					
Grilled					
Boiled					
Steamed					
BBQ					
Microwave					

30. How often do you (*Please tick one box for every question*)

	Often	Sometimes	Never	Not Applicable
Add salt during cooking?	0	0	0	0
Add salt at the table to your food?	0	0	0	0
Try to buy 'low salt' foods?	0	0	0	0
Try to buy 'no added salt' foods?	0	0	0	0
Check the label on foods for the salt content?	0	0	0	0

31. When you eat at home, how many people (including children) usually eat together?

I usually eat on my own

2 to 3 people

4 to 5 people

6 or more people

32. When you eat at home, where do you usually eat your meals (e.g. Lounge room, in front of TV, dining table, kitchen, outside veranda or patio etc)?

.....

Section 3

PHYSICAL ACTIVITY

- 33. In a typical week how often would you do physical activity of any sort (eg. walking, running, swimming, footy, other sport, going to the gym, aerobics, etc)
- Never
- 1- 2 times per week
- 3-4 times per week
- 5-6 times per week
- More than 6 times per week
- 34. In a typical week how often would you do some heavy physical activity that makes you sweaty or breathless for at least 30 minutes each time?

Never

- 1- 2 times per week
- 3-4 times per week
- 5-6 times per week
- More than 6 times per week

35. If you do regular physical activity please describe the kinds of physical activity you do?

 •	 	

36. Please tick any of the following places where you do physical activity?

Gym/ Sports centre		
Home		
Parks		
Footy oval		
River		
Swimming pool		
Other (please specify)		

37. How much time do you spend watching television or DVD's?

- Less than an hour day
- 1-2 hours a day
- 3-4 hours a day
- 5+ hours a day

38. How much time do you spend using a computer (either for work or leisure)?

Less than an hour day

1-2 hours a day

3-4 hours a day

- 5+ hours a day
- 39. Which of the following make it hard for you to be physically active? (tick as many as apply to you)
- I have a physical disability
- No motivation / can't be bothered
- Shame worried what other people will think
- Can't afford cost of memberships
- Not enough time to do it
- There aren't any good facilities in the area
- None of the above
- Other (please specify)

App A – page 10

40. For each of the following please score from 1 to 5 what you think are important health problems for Aboriginal people in your community (with 1 being not very important and 5 being very important)

	1 (Not very important)	2	3	4	5 (Very important)
Heart disease					
Alcohol or other drug problems					
Diabetes					
Being overweight		\square		\square	
Smoking		\square		\Box	\square
Kidney disease		\square		\Box	\square
Depression or other mental illnesses		\square		\Box	\square
Asthma or other chest sickness					

Section 4

ALCOHOL CONSUMPTION

41. Do you drink alcohol? If no please go to question 40

Never
Not very often
Sometimes
Often
Every day

42. If you do you drink alcohol at what age did you start drinking alcohol?

- 10 12
- 12 14
- 14 16
- 16 -18
- 18 21
- 21 25
- 25 and over

43. About how often do you drink some kind of alcoholic beverage?

O Daily or almost every day	O 3 or 4 times a week	O Once or twice a week
O Once or twice a month	O less than once a month	O Never

Please look at the pictures of drinks following before answering

44. On average, on the days that you do drink beer how many standard drinks do you have in one day? Please circle which beer you drink.

-	-		-	
O One	Ο Τωο	O Three	O Four	O More than four
		O Thies		
Middy of FULL STR				
📁 O One	O Two	O Three	O Four	O More than four
Schooner of FULL STRE	NGTH beer			
O One	О Тwo	O Three	O Four	O More than four
Middy of LIGHT beer				
O One	O Two	O Three	O Four	O More than four
Schooner of LIGHT beer				
	e O Two	O Three	O Four	O More than four
Can or stubby of full stre	ength beer			
O One	Ο Τωο	O Three	O Four	O More than four
Can or stubby of light be		0 11100	0.001	
can of stubby of light be				

45. On average, on the days that you do drink wine or spirits how many standard drinks do you have in one day? Please circle which beverage you drink.

	OneO Two	O Thre	e O Fou	- O More	e than four
Can of Pre-r	nix spirits				
	One	O Two	O Three	O Four	O More than four
Bottle of Pre					
Q	One	O Two	O Three	O Four	O More than four
	arkling wine/o				
	One	O Two	O Three	O Four	O More than four
Glass of whi		0 110			
	O One	O Two	O Three	O Four	O More than four
Glass of red					
Oine					
	One	O Two	O Three	O Four	\ensuremath{O} More than four
Bottle of wir	ne – white or	Red			
		O Two	O Three	O Four	O More than four
Shot of spiri	its				

	O One	O Two	O Three	O Four	○ More than four
Nip of wh	iskey				
S. Refe	O One	O Two	O Three	O Four	O More than four
Bottle of s	spirits – any kir	nd			

Section 5	Gambling		
46. Do you gamble?			
 Never Not very often Sometimes Often Every day 			
47. Where do you go to gamble? (1	Fick as many apply)		
O Local pub	O Casino	O local RSL	
O Friends/family's place	O Dog races	O Horse races	
 48. How much would you place on \$10 - \$20 \$20 - \$50 \$50 - \$100 \$100 - \$200 More than \$200 	a bet in one go?		

49. Have you ever lost your whole pay in one gambling session?

Never

Not very often

Sometimes

Often

Always

Section 6

Recreational Drug Use

50. Do you use recreational drugs?

Never

Not very often

Sometimes

- Often
- Every day

51. If you do you use recreational drugs, have you used any of the following drugs at anytime in the last 6 months?

Yarndi/dope/pot
Speed Speed
Cocaine
Ice/Crystal Meth
Heroine
Other

THANK YOU FOR YOUR TIME IN COMPLETING THIS IMPORTANT HEALTH SURVEY TO FIND CULTURALLY APPROPRIATE WAYS OF STRENGTHING AND IMPROVING ABORIGINAL HEALTH IN NSW.

A REPORT WILL BE MADE AVAILABLE SOON AT THE PLACE WHERE YOU FILLED IN THIS SURVEY.

Appendix B: 45 and Up study questionnaire for men

THE 45 45 and Up Stud AND UP STUDY for Men	dy Questionnaire
Research to improve health and wellbeing	
The 45 and Up Study relies on the willingness of people their lives and experiences, to provide knowledge that w as long as possible. Participation is completely voluntary, any time. To take part, please read the participant inform consent form and return them in the envelope provided.	rill help people live healthy and fulfilling lives for and you are free to withdraw from the Study at ation leaflet, then complete the questionnaire and
Any questions or comments? Please call the Study help	pline: 1300 45 11 45 or go to www.45andUp.org.au
Auspiced by In collaboration with	4
TT the state to the The	
Sature And	ON NSWOHEALTH
Your answers and experiences are important to us.	Please put a cross in the appropriate box(es) Yes No
To help us read your answers, please write as clearly as possible using a BLACK or BLUE pen, and be sure to complete the questionnaire as shown:	OR put numbers in the appropriate box, e.g. 21st June 1945 2 1 0 6 1 9 4 5 age 6 2
General questions about you	
1. What is your day month year	8. What year did you first come to live in Australia for one year or more? (e.g. 1970)
2. What is today's date? day month year 3. How tall are you without shoes? crm OR feet inches (blease dive to the nearest cm or inch)	9. What is your ancestry? (please cross up to 2 boxes) Australian English Irish Chinese Italian Greek Scottish German Lebanese Dutch Maltese Polish Filipino Indian Croatian Vietnamese other (please specify)
4. About how much kg OR stone bbs	10. Do you speak a language other than English at home?
5. What is the highest qualification you have completed?	11. Have you ever been a regular smoker?
(please put a cross in the most appropriate box)	Yes ▼ No ► If No − please go to question 12 How old were you when you started
school or intermediate certificate (or equivalent)	smoking regularly?
higher school or leaving certificate (or equivalent) trade/apprenticeship (e.g. hairdresser, chef)	Are you a regular smoker now? Yes No
certificate/diploma (e.g. child care, technician)	stopped smoking regularly?
university degree or higher	About how much do you/did you smoke on average each day? (If you are an ex-smoker, how much did you smoke on average when you smoked?)
6. Are you of Aboriginal or Torres Strait Islander origin? (you can cross more than one box)	cigarettes per day pipes and cigars per day
 No Yes, Aboriginal Yes, Torres Strait Islander 7. In which country were you born? 	12. About how many alcoholic drinks do you have each week? one drink = a glass of wine, middy of beer or nip of spirits (out "0" if you do not drink, or have less than one drink each week)
Australia	number of alcoholic drinks each week
Philippines Netherlands Vietnam Malta	13. On how many days each week do you usually drink alcohol?

14. What best describes your current situation? (please cross one box) single married de facto/living with a partner widowed divorced separated	20. Have you ever tried for more than 1 year but have been unable to father children? Yes No
15. What best describes your current housing? (please cross one box) house flat, unit, apartment hostel for the aged mobile home other nursing home retirement village, self care unit	Questions about your health 21. About how many hours a week are you exposed to someone else's tobacco smoke?
16. How many TIMES did you do each of these activities LAST WEEK? times in the last week (but "0" if you did not do this activity) last week	hours per week hours per week in other places (e.g. work, going out, cars)
Walking continuously, for at least 10 minutes (for recreation or exercise or to get to or from places) Vigorous physical activity (that made you breathe harder or puff and pant, like jogging, cycling, aerobics, competitive tennis, but not household chores	22. Over the last month, not some almost how often have you: at all times often always found it difficult to postpone urination? had to push or strain to start urination?
or gardening) Moderate physical activity (like gentle swimming, social tennis, vigorous gardening or work around the house)	had a weak urinary stream?
17. If you add up all the time you spent doing each activity LAST WEEK, how much time did you spend ALTOGETHER doing each type of activity? (put "0" if you did not do this activity) hours minutes	after you finished urinating?
Walking continuously, for at least 10 minutes (for recreation or exercise or to get to or from places) Vigorous physical activity (that made you breathe harder or put f and pant,	Over the past month, how many times did you usually get up from bed to urinate during the night?
like jogging, cycling, aerobics, competitive tennis, but not household chores or gardening) Moderate physical activity (like gentle swimming, social tennis, vigorous	23. Have you taken any medications, vitamins or supplements for most of the last 4 weeks? Yes ▼ No
gardening or work around the house) Questions about your family	If Yes, was it: multivitamins + minerals multivitamins alone fish oil glucosamine omega 3 paracetamol aspirin for the heart aspirin for other reasons Lipitor Avapro, Karvea warfarin, Coumadin
18. Have your mother, father, brother(s) or sister(s) ever had: (blood relatives only: please put a cross in the appropriate box(es))	Pravachol Coversyl, Coversyl Plus Lasix, frusemide Zocor, Lipex Cardizem, Vasocordol Micardis Nexium Norvasc Fosamax Somac Tritace Caltrate
heart disease breast cancer	Losec, Acimax. Noten, Tenormin Oroxine omeprazole atenolol thyroxine Ventolin Zyloprim, Progout 300 Diabex, Diaformin salloutamol allopurinol metformin
diabetes melanoma dementia/Alzheimer's prostate cancer Parkinson's disease ovarian cancer	Zoloft Cipramil Efexor sertraline citaloprim ventafaxine please list any other regular medications or supplements here
severe depression osteoporosis depression severe arthritis depression do not know	
19. How many children have you fathered? (please include stillbirths but do not include miscarriages, please write '0' if you have not had any children) How old were you when you fathered your	
FIRST child? years old when you fathered your years old years old LAST child?	

f YES, please cross the box and give your age he condition was first found)	Aç	ge when cond		Yes	▼ No	NE AND A		_
	Yes	was first four	hd	Please des	scribe this illness and its treatment			
kin cancer (not melanoma)			age					
nelanoma			age					
prostate cancer			age					
ther cancer			age					
type of cancer (please describe)								
			10.00	27. Do you r	egularly need help with dai	v tasks be	cause	
				of long-t	erm illness or disability? nal care, getting around, preparing n			
neart disease			age	Yes	No	loaioj		
type of heart disease (please describe)								
					ur health now LIMIT YOU	yes,	yes,	по
high blood pressure			age	in any of	the following activities?	limited a lot	limited a little	lim at
stroke			age		S activities			[
diabetes			age	MODERA	TE activities			ſ
blood clot (thrombosis)			age	A COLORADOR STOLEN	ng a vacuum cleaner, playing goll) carrying shopping			
				Contraction of the local day of the	several flights of stairs			[
enlarged prostate			age	College and a second second	one flight of stairs			Ĩ
asthma			age	walking o	ne kilometre			[
hayfever			age		half a kilometre			[
			and the second second		()() metres	1.2		
depression			age	walking 1	An international second s			
depression anxiety			age age	bending,	kneeling or stooping or dressing yourself]
			100-010	bending,	kneeling or stooping]
anxiety		0	age	bending, bathing o	kneeling or stooping or dressing yourself	ving opera	tions?	[
anxiety Parkinson's disease		2	age	bending, bathing o 29. Have you (If YES, plea	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your	ving opera]]
anxiety Parkinson's disease none of these		Q	age	bending, bathing o (f YES, ple age when y age at the	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your you had the operation; give your most recent operation if you		Age wh	
anxiety Parkinson's disease none of these In the last month have you been tre (If YES, please cross the box and give your age	L L L L L L L L L L L L L L L L L L L	Age started	age age	bending, bathing o (If YES, ple age when y age at the have had n	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your you had the operation; give your most recent operation if you nore than one)	ving opera Yes		ation
anxiety Parkinson's disease none of these In the last month have you been the	eated for: Yes	Age started treatment	age age	bending, bathing o 29. Have you (If YES, ple age when) age at the have had n removal o	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your you had the operation; give your most recent operation if you nore than one) of skin cancer		Age wh	ation
anxiety Parkinson's disease none of these In the last month have you been tre (If YES, please cross the box and give your age		and the second	age age	bending, bathing o 29. Have you (If YES, ple age when y age at the have had n removal o vasector	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your you had the operation; give your most recent operation if you nore than one) of skin cancer		Age wh	ation a a
anxiety Parkinson's disease none of these In the last month have you been tre (f YES, please cross the box and give your age when the treatment started)		and the second	age age	bending, bathing o 29. Have you (If YES, Bie age when age at the have had n removal o vasector part of p	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your most recent operation; give your most recent operation if you nore than one) of skin cancer ny rostate removed		Age wh	ation a a a
anxiety Parkinson's disease none of these In the last month have you been tre (If YES, please cross the box and give your age when the treatment started) cancer		and the second	age age i age	bending, bathing o 29. Have you (If YES ple age when age at the have had n removal o vasector part of p whole pr	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your most recent operation; give your most recent operation if you nore than one) of skin cancer ny rostate removed ostate removed		Age wh	ation a a a a
anxiety Parkinson's disease none of these In the last month have you been tre (If YES, please cross the box and give your age when the treatment started) cancer heart attack or angina		and the second	age age i age age	bending, bathing o 29. Have you (#YES, ple age when ; age at the have had in removal o vasectom part of pi whole pir knee rep	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your most recent operation; give your more than one) of skin cancer hy rostate removed lacement		Age wh	ation a a a
anxiety Parkinson's disease none of these In the last month have you been tre (If YES, please cross the box and give your age when the treatment started) cancer heart attack or angina other heart disease		and the second	age age age age age	bending, bathing of 29. Have you (If YES, Bie age when age at the have had n removal u vasector part of p whole pr knee rep hip repla	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your most recent operation; give your most recent operation if you nore than one) of skin cancer hy rostate removed lacement cement		Age wh	ation a a a a
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anxiety Parkinson's disease none of these In the last month have you been tre (If YES, please cross the box and give your age when the treatment started) cancer heart attack or angina other heart disease high blood pressure high blood cholesterol		and the second	age age age age age age age	bending, bathing of 29. Have you (If YES, Bie age when age at the have had in removal of vasectori part of pi whole pri knee rep hip repla gallbladd heart or	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your most recent operation; give your most than one) of skin cancer ny rostate removed lacement cement ter removed coronary bypass surgery		Age wh	
anxiety Parkinson's disease none of these In the last month have you been tre (If YES, please cross the box and give your age when the treatment started) cancer heart attack or angina other heart disease high blood pressure high blood pressure high blood cholesterol blood clotting problems asthma		and the second	age age age age age age age age age	bending, bathing of 29. Have you (If YES, Jile age when age at the have had in removal vasectori part of pi whole pri knee rep hip repla gallbladd heart or <i>(include st)</i>	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your most recent operation; give your most recent operation if you nore than one) of skin cancer ny rostate removed lacement cement ler removed coronary bypass surgery tents and balloons)	Yes	Age when the had oper	ation a a a a a a a a a a a a a a a a a a a
anxiety Parkinson's disease none of these In the last month have you been tre (If YES, please cross the box and give your age when the treatment started) cancer heart attack or angina other heart disease high blood pressure high blood cholesterol blood clotting problems asthma osteoarthritis		and the second	age age age age age age age age age age	bending, bathing of 29. Have you (If YES, Bie age when age at the have had in removal of vasectori part of pi whole pir knee rep hip repla galibladd heart or <i>include st</i> other (pit	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your most recent operation; give your most than one) of skin cancer ny rostate removed lacement cement ter removed coronary bypass surgery	Yes	Age when the had oper	ation a a a a a a a a a a a a a a a a a a a
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anxiety Parkinson's disease none of these In the last month have you been tre (If YES, please cross the box and give your age when the treatment started) cancer heart attack or angina other heart disease high blood pressure high blood pressure high blood cholesterol blood clotting problems asthma osteoarthritis thyroid problems osteoprosis or low bone density		and the second	age age age age age age age age age age	bending, bathing of 29. Have you (If YES, Bie age when age at the have had in removal of vasectori part of pi whole pir knee rep hip repla galibladd heart or <i>include st</i> other (pit	kneeling or stooping or dressing yourself u ever had any of the follow ase cross the box and give your most recent operation; give your most recent operation if you nore than one) of skin cancer ny rostate removed lacement cement ler removed coronary bypass surgery tents and balloons) ease describe any other operations	Yes	Age when the had oper	ation a a a a a a a a a a a a a a a a a a a
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30. Do you regularly care for a sick or disabled family member or friend?	Questions about your diet
Yes ▼ No If Yes, about how much time each week do you usually spend caring for this person?	40. About how many times each week do you eat: (please count all meals and snacks. put '0' if never eaten or eaten less than once a week) number of times eaten each week
full time OR hours/wk	beef, lamb or pork
31. In general, how would & &	chicken, turkey or duck
you rate your:	processed meat
overall health?	(include bacon, sausages, salami, devon, burgers, etc)
quality of life?	fish or seafood
eyesight? (with glasses or contact lenses, if you wear them)	cheese
memory?	
teeth and gums?	41. About how many of the following do you usually eat:
32. Do you feel you have a hearing loss? Yes No	slices or pieces of brown/wholemeakbread each week (also include multigrain, rye bread, etc.)
33. How many of your own teeth do you have left?	bowls of breakfast cereal each week
None – all of my teeth are missing 1-9 teeth left	If you eat breakfast cereal is it usually: (please cross)
10-19 teeth left 20 or more teeth left	bran cereal (allbran, branflakes, etc.) unuesli biscuit cereal (weetbix, other (comflakes,
34. During the past 12 months, how many times have you fallen to the floor or ground? (put "0" if you haven't fallen in this time)	
times	oat cereal (porridge, etc.)
	42. Which type of milk do you mostly have?
35. Have you had a broken/fractured bone in the last 5 years?	whole milk reduced fat milk skim milk
Yes ▼ No	soy milk other milk I don't drink milk
If Yes, which bones were broken?	43. About how many serves of vegetables do you usually eat
ib finger/toe other	each day? A serve is half a cup of cooked vegetables or one cup of salad
How old were you when it happened? (give age at most recent fracture if more than one)	Efease include potatoes and put "0" if less than one a day)
	number of serves of cooked vegetables each day
36. About how many times a week are you usually troubled by leaking urine?	number of serves of raw vegetables each day (e.g. salad)
2-3 times 4-6 times every day	
	44. About how many serves of fruit or glasses of fruit juice do you usually have each day? A serve is 1 medium piece or 2 small pieces or
37. How often are you able to get and keep an erection that is firm enough for satisfactory sexual activity?	1 cup of diced or canned fruit pieces (put "0" if you eat less than one serve a day)
always usually sometimes	number of serves of fruit each day
never Dwould rather not answer this question	number of glasses of fruit juice each day
38. Have you ever had a blood test ordered by your doctor to check for prostate disease? (PSA test)	I don't eat fruit
Yes V No	45. Please put a cross in the box if you NEVER eat:
If Yes, what year did you have your last PSA test? (e.g. 2005)	red meat chicken/poultry pork/ham dairy products
How many times have you had a PSA	any meat eggs sugar wheat products fish seafood cream cheese
test altogether?	
39. Have you ever been screened for colorectal (bowel) cancer?	
Ves 🔻 🗌 No	Questions about time and work
If Yes, please indicate which test(s) you had:	46. What is your usual yearly HOUSEHOLD income before tax,
faecal occult blood test (test for blood in the stool/faeces) sigmoidoscopy (a tube is used to examine the lower bowel:	from all sources? (please include benefits, pensions, superannuation, etc)
this is usually done in a doctor's office without pain relief)	less than \$5,000 per year \$30,000-\$39,999 per year
COLONOSCODY (a long tube is used to examine the whole large bowel; you would usually have to have an enema or drink large amounts	\$5,000-\$9,999 per year \$40,000-\$49,999 per year
of special liquid to prepare the bowel for this)	\$10,000-\$19,999 per year \$20,000-\$29,999 per year \$20,000-\$29,999 per year \$20,000 or more per year
What year did you have the most recent one of these tests? (e.g. 2005)	\$20,000-\$29,999 per year \$70,000 or more per year I would rather not answer this question

47. What is your current work status? (you can cross more than one box) in full time paid work self-employed	54. About how many HOURS in each 24 hour DAY do you usually spend doing the following?
in part time paid work doing unpaid work	(please put "0" if you do not spend any time doing it)
completely retired/pensioner studying	hours per day hours per day
partially retired looking after home/family	at night & naps) sitting
disabled/sick unemployed	watching television standing
other	or using a computer
48. If you are partially or completely retired, how old were you when you retired?	55. How many TIMES in the LAST WEEK did you: (please put "0" if you did not spend any time doing it) times in the last week
Why did you retire? (you can cross more than one box)	spend time with friends or family who do not live with you?
reached usual retirement age	talk to someone (friends, relatives or others)
to care for family member/friend ill health	on the telephone?
made redundant could not find a job	go to meetings of social clubs, religious groups
other	or other groups you belong to?
49. About how many HOURS each WEEK do you usually spend doing the following? (please put "0" if you do not spend any time doing it) hours per week hours per week	56. How many people outside your home, but within one hour of travel, do you feel you can depend on or feel very close to?
paid work voluntary/unpaid work	57. During the past 4 weeks, none a little some most all about how often did you teel: time time time time time
50. Which of the following do you have? (excluding Medicare)	tired out for no good reason?
Private health insurance – with extras	nervous?
Department of Veterans' Affairs white or gold card	so nervous that nothing could
Health care concession card	calm you down?
none of these	restless or fidgety?
	so restless that you could
51. What best describes the colour of the skin on the inside of your upper arm, that is your skin colour without any tanning?	pot sit still?
very fair light olive brown	depressed?
🗌 fair 🔄 dark olive 🗌 black	that everything was an effort?
FO What would have a literate ship was an and all and a	so sad that nothing could
52. What would happen if your skin was repeatedly exposed to bright sunlight during summer without any protection?	worthless?
Would it:	
Get very tanned? Get mildly or occasionally tanned? Get moderately tanned? Never tan, or only get freckled?	58. During the past 4 weeks, have you had any of the following problems with your work or daily activities because of any emotional problems (such as being depressed or anxious)?
53. About how many hours a DAY would you usually spend outdoors on a weekday and on the weekend?	cut down on the amount of time you spent ves No
hours per day	achieved less than you would have liked to Yes No
weekday weekend	did work or other activities less carefully Yes No
	than usual
	filling in the questionnaire
DON'T FORGET TO SIGN THE C	
Are your name and address correct on the front of this questionn	aire? Yes No
If INCORRECT, give details below.	
Surname:	
Given name(s):	
Postal address:	
and the second s	
Town or Suburb:	
State or Territory: Postcode:	

Consent form



The 45 and Up Study relies on the willingness of people in New South Wales to share information about their lives and experiences and to have their health followed over time. By signing this form you are agreeing to take part in the 45 and Up Study and for the Study team to follow your health over time. Participation is completely voluntary, and you are free to ask questions or to withdraw from the Study at any time, by calling the Study helpline on 1300 45 11 45. More information on the Study can be found at www.45andup.org.au

I agree to have my health followed over time through:

the 45 and Up Study team following health and other records relating to me, including NSW hospital records, cancer records, death records and other health-related records, as outlined in the Study leaflet: *The 45 and Up Study: Information for participants;*

Medicare Australia releasing to the 45 and Up Study my enrolment details, including Medicare number, and information concerning services provided to me under Medicare, the Department of Veterans' Affairs, the Pharmaceutical Benefits Scheme and the Repatriation Pharmaceutical Benefits Scheme, including past information, until the end of the Study or for the duration of my involvement in the Study;

being contacted in the future to provide information on changes to my health and lifestyle. I may also be asked to provide further information including questionnaire responses or biological samples; my participation in any of these would be completely voluntary. I give my consent on the understanding that:

my information will only be used for the purposes outlined in the Study leaflet entitled *The 45 and Up Study: Information for participants*, of which I have a copy;

my information will be kept strictly confidential and will be used for health research only;

reports and publications from the Study will be based on de-identified information and will not identify any individual taking part;

my participation in this Study is entirely voluntary and my consent will continue to be valid following death or disablement unless withdrawn by my next of kin or other person responsible. I am free to withdraw from the Study at any time by calling the Study helpline on 1300 45 11 45;

my decision on whether or not to take part in the Study or in any additional research will not disadvantage me or affect my uture health care in any way.

I have been provided with information about the 45 and Up Study including how it will gather, store, use and disclose information about me, in the Study leaflet. I have been given an opportunity to ask questions and have been fully informed about the Study.

Name (Print):
Signature:
Extra contact details
It would be very helpful and reduce Study costs if we could contact you in future by email. If you are happy for us to do this, please write your email address here:
Email address:
Sometimes we find that people have moved when we try to contact them again. It would be very helpful if you could give us your mobile phone number and/or the contact details of someone close to you (such as a relative or friend) who would be happy for us to contact them if we are unable to reach you. We would only get in touch with that person if we were unable to contact you directly and we would need to tell them our reason for contacting you. Please leave this section blank if you do not wish to provide these extra contact details.
Your home home home home home home home home
Full name of contact person:
Phone number of contact person: (
If you have any questions about the Study, please ring the Study helpline on 1300 45 11 45 . You can also write to or send your questionnaire (no stamp required) directly to: Associate Professor Emily Banks, Scientific Director, The 45 and Up Study, Reply paid 5289, Sydney NSW 2001.
Thank you very much for taking part

Appendix C: 45 and Up study questionnaire for women

THE 45 AND UP Study Research to improve health and wellbeing The 45 and Up Study relies on the willingness of people in their lives and experiences, to provide knowledge that we as long as possible. Participation is completely voluntary,	in New South Wales to share information about
any time. To take part, please read the participant information	ation leaflet, then complete the questionnaire and
consent form and return them in the envelope provided.	
Any questions or comments? Please call the Study help	bline: 1300 45 11 45 or go to www.45andup.org.au
	1
Auspiced by In collaboration with	равне
RELAVICIT MAINTERBURST FOR LETTER HEALTH	NSW@HEALTH
Your answers and experiences are important to us.	Please put a cross in the appropriate box(es) X Yes No
To help us read your answers, please write as clearly as possible using a BLACK or BLUE pen, and be sure to complete the questionnaire as shown:	OR put numbers in the appropriate box, e.g. 21st June 1945 2 1 / 0 6 / 1 9 4 5 age 6 2
General questions about you	
1. What is your date of birth?	8. What year did you first come to live in Australia for one year or more? (e.g. 1970)
2. What is today's date?	9. What is your ancestry? (please cross up to 2 boxes) Australian English Irish Chinese Italian Greek Scottish German Lebanese Dutch Maltese Polish
without shoes? cm OR ieeu inches (please give to the nearest cm or inch)	Filipino Indian Croatian Vietnamese other (please specify)
4. About how much do you weigh? kg OR stone lbs	10. Do you speak a language other than English at home?
5. What is the highest qualification you have completed?	11. Have you ever been a regular smoker?
(please put a cross in the most appropriate box)	Yes ▼ No ► If No − please go to question 12 How old were you when you started
school or intermediate certificate (or equivalent)	smoking regularly?
higher school or leaving certificate (or equivalent)	Are you a regular smoker now? Yes No
trade/apprenticeship (e.g. hairdresser, chef)	If No – how old were you when you stopped smoking regularly?
university degree or higher	About how much do you/did you smoke on average each day? (If you are an ex-smoker, how much did you smoke on average when you smoked?)
6. Are you of Aboriginal or Torres Strait Islander origin? (you can cross more than one box)	cigarettes per day pipes and cigars per day
No Yes, Aboriginal Yes, Torres Strait Islander	12. About how many alcoholic drinks do you have each week?
7. In which country were you born?	one drink = a glass of wine, middy of beer or nip of spirits (put "0" if you do not drink, or have less than one drink each week)
Australia ► please go to question 9 UK Ireland Italy China	number of alcoholic drinks each week
Greece New Zealand Germany Lebanon	12 On how many days and wash
Philippines Netherlands Vietnam Malta Poland other (please specify)	13. On how many days each week do you usually drink alcohol?

14. What best describes your current situation? (please cross one box) single married de facto/living with a partner	Questions about your health
widowed divorced separated	20. About how many hours a week are you exposed to someone else's tobacco smoke?
15. What best describes your current housing? (please cross one box)	hours per week hours per week
house flat, unit, apartment house on farm hostel for the aged mobile home other	at home in other places (e.g. work, going out, cars)
nursing home retirement village, self care unit	21. Have you ever used the pill or other hormonal contraceptives?
16. How many TIMES did you do each of these	(e.g. the combined pill, mini pill, contraceptive implant or injections)
activities LAST WEEK? times in the	If Yes, for how long altogether have you
(put "0" if you did not do this activity) Iast week Walking continuously, for at least 10 minutes	used hormonal contraceptives? years (please write '0' if you used them for less than a year in total)
(for recreation or exercise or to get to or from places) Vigorous physical activity (that made you breathe harder or puff and pant, like jogging, cycling, aerobics, competitive tennis, but not household chores	If Yes, how old were you when you LAST used hormonal contraceptives? (please write your current age if you are still using them)
or gardening) Moderate physical activity	Which type of pill or other hormonal contraceptive did you use MOST RECENTLY?
(like gentle swimming, social tennis, vigorous gardening or work around the house)	 "the pill", combined pill (e.g. Microgynon, Levlen) progesterone-only pill ("mini pill") (e.g. Micronar, Noriday, Microval)
17. If you add up all the time you spent doing each activity	Depo Provera
LAST WEEK, how much time did you spend ALTOGETHER doing each type of activity? (out "0" if you did not do this activity)	contraceptive implant (e.g. Implanon, Norplant) do not know
hours minutes	22. Have you ever used hormone replacement therapy (HRT)?
Walking continuously, for at least 10 minutes (for recreation or exercise or to get to or from places)	If yes, for how long altogether have you
Vigorous physical activity (that made you breathe harder or puff and pant, like jogging, cycling, aerobics, competitive tennis,	used HRT? (please write '0' if you used HRT for less than a year in total)
but not household chores or gardening)	Are you currently taking HRT?
Moderate physical activity (like gentle swimming, social tennis, vigorous gardening or work around the house)	No, at what age did you stop?
	23. Have you taken any medications, vitamins or supplements for most of the last 4 weeks, including HRT and the pill?
Questions about your family	Yes V No
	If Yes, was it: multivitamins + minerals multivitamins alone
18. Have your mother, father, brother(s) or sister(s) ever had:	fish oil glucosamine omega 3
(blood relatives only: please put a cross in the appropriate box(es))	paracetamol aspirin for the heart aspirin for other reasons
A to B to B to B to B to	Lipitor Avapro, Karvea warfarin, Coumadin
	Pravachol Coversyl, Coversyl Plus Lasix, frusemide
heart disease	Zocor, Lipex Cardizem, Vasocordol Micardis
high blood pressure	Nexium Norvasc Fosamax
stroke	Somac Tritace Caltrate
diabetes diabetes	Losec, Acimax Noten, Tenormin Oroxine
dementia/Alzheimer's	omeprazole atenolol thyroxine
Parkinson's disease	Ventolin Zyloprim, Progout 300 Diabex, Diaformin
severe depression	salbutamol allopurinol metformin
severe arthritis	Zoloft Cipramil Efexor sertraline citaloprim venlafaxine
do not know	
	please list any other regular medications or supplements here
19. How many children have you given birth to? (please include stillbirths but do not include miscarriages,	
please write "0" if you have not had any children)	
How old were you when you gave birth to your FIRST child?	
How old were you when you gave birth to your LAST child?	
For how many months, in total, have months months	
(please add together all the time you spent breastfeeding all of your children; put "O" if you never breastfed)	

the condition was first found)	Yes	Age when co was first fo		Please describe this illness and its treatment			
skin cancer (not melanoma)			age				
melanoma			age				
breast cancer	Π		age				
other cancer			-				
type of cancer (please describe)	<u> </u>		age				
type of cancer (please describe)						and the	12
				27. Do you regularly need help with daily ta of long-term illness or disability?	isks be	ecause	
heart disease			age	(e.g. personal care, getting around, preparing meals))		
type of heart disease (please describe)	1.1.1			Yes No			
			1	28. Does your health now LIMIT YOU	yes,	yes,	n
					mited	limited	li
high blood pressure - when pregnant			age	VIGOROUS activities	a lot	a little	-
high blood pressure - when not pregnant			age	(e.g. running, strenuous sports) MODERATE activities			
stroke			age	(e.g. pushing a vacuum cleaner, playing golf)			
diabetes			age	lifting or carrying shopping			
blood clot (thrombosis)			age	climbing several flights of stairs			
the second s			www.cold	climbing one flight of stairs walking one kilometre	H	H	
asthma			age	walking half a kilometre	H		
hayfever			age	walking 100 metres	П	H	
depression			age	bending, kneeling or stooping	ŏ		
anxiety			age	bathing or dressing yourself			
Parkinson's disease		-	age	•			
none of these		$\langle \mathbf{T}$		29. Have you ever had any of the following (If YES, please cross the box and give your	operat	tions?	
	R	X		age when you had the operation; give your age at the most recent operation if you		Age wh	nen
		1.		have had more than one)	Yes	had open	
In the last month have you been treate	d for:	5		removal of skin cancer			
(If YES, please cross the box and give your age when the treatment started)		Age start		hysterectomy			
cancer	Yes	treatmen	age	both ovaries removed			
			=	sterilisation (tubes tied)			
heart attack or angina			age	repair of prolapsed womb, bladder or bowel			-
other heart disease			age	and a manufacture and the result of the result of the			-
high blood pressure			age	knee replacement		H	-
high blood cholesterol			age	hip replacement	Ц		_
blood clotting problems			age	gallbladder removed			_
asthma			age	heart or coronary bypass surgery (include stents and balloons)			
osteoarthritis			age	other (please describe any other operations you	have ha	d in the last	
thyroid problems			age	10 years, with your age when you had them)			
and the second			age				
osteoporosis or low pone density			The second				
osteoporosis or low bone density			206				
depression anxiety			age				

30. Do you regularly care for a sick or disabled family member or friend?	Questions about your diet
Yes ▼ No If Yes, about how much time each week do you usually spend caring for this person?	40. About how many times each week do you eat: number of (please count all meals and snacks. put '0' if never eaten or eaten less than once a week)
full time OR hours/wk	beef, lamb or pork
	chicken, turkey or duck
31. In general, how would you rate your:	processed meat (include bacon, sausages, salami, devon, burgers, etc)
quality of life?	fish or seafood
contact lenses, if you wear them)	cheese
memory?	41. About how many of the following do you usually eat:
teeth and gums?	slices or pieces of brown/wholemearbread each week
32. Do you feel you have a hearing loss? Yes No	(also include multigrain, rye bread, etc.)
33. How many of your own teeth do you have left?	bowls of breakfast cereal each week
None – all of my teeth are missing 1-9 teeth left 10-19 teeth left 20 or more teeth left	If you eat breakfast cereal is it usually: (please cross)
34. During the past 12 months, how many times have you fallen to the floor or ground? (put "0" if you haven't fallen in this time)	biscuit cereal (weetbix, other (comflakes, shredded wheat, etc.)
times	at cereal (porridge, etc.)
35. Have you had a broken/fractured bone in the last 5 years?	42. Which type of milk do you mostly have?
Yes V No	vhole milk reduced fat milk skim milk sov milk other milk I don't drink milk
If Yes, which bones were broken?	
wrist arm hip ankle	43. About how many serves of vegetables do you usually eat each day? A serve is half a cup of cooked vegetables or one cup of salad
How old were you when it happened? (give age at most recent fracture if more than one)	please include potatoes and put "0" if less than one a day)
36. About how many times a week are you usually troubled	number of serves of cooked vegetables each day
by leaking urine?	number of serves of raw vegetables each day (e.g. salad)
2-3 times 4-6 times every day	I don't eat vegetables
37. Have you been through menopause?	44. About how many serves of fruit or glasses of fruit juice do you
No	usually have each day? A serve is 1 medium piece or 2 small pieces or 1 cup of diced or canned fruit pieces (put "0" if you eat less than one serve a day)
Not sure (because hysterectory), taking HRT, etc.)	number of serves of fruit each day
Yes - How old were you when you	number of glasses of fruit juice each day
went through menopause?	I don't eat fruit
38. Have you ever been for a breast screening mammogram?	45 Diseas sub a sease in the hey if you NEVED act
If Yes, what year did you have your last	45. Please put a cross in the box if you NEVER eat:
mammogram? (e.g. 2005)	any meat eggs sugar wheat products
How many times have you been for breast screening altogether?	fish seafood cream cheese
39. Have you ever been screened for colorectal (bowel) cancer?	
Yes Ves No	Questions about time and work
If Yes, please indicate which test(s) you had: faecal occult blood test (test for blood in the stool/faeces)	46. What is your usual yearly HOUSEHOLD income before tax,
 Interval occurr block test itest for mixed in the suborateses sigmoidoscopy (a tube is used to examine the lower bowel: this is usually done in a doctor's office without pain relief) 	from all sources? (please include benefits, pensions, superannuation, etc)
colonoscopy (a long tube is used to examine the whole large bowel; you would usually have to have an enema or drink large amounts of special liquid to prepare the bowel for this)	\$5,000-\$9,999 per year \$40,000-\$49,999 per year \$10,000-\$19,999 per year \$50,000-\$69,999 per year
What year did you have the most recent	\$20,000-\$29,999 per year \$70,000 or more per year
one of these tests? (e.g. 2005)	I would rather not answer this question

47. What is your current work status? (you can cross more than one box) in full time paid work self-employed in part time paid work doing unpaid work completely retired/pensioner studying partially retired looking after home/family disabled/sick unemployed other other	54. About how many HOURS in each 24 hour DAY do you usually spend doing the following? (please put '0' if you do not spend any time doing it) hours per day sleeping (including at night & naps) watching television or using a computer standing
48. If you are partially or completely retired, how old were you when you retired? years old Why did you retire? (you can cross more than one box) reached usual retirement age lifestyle reasons to care for family member/friend ill health made redundant could not find a job other other intervention intervention intervention	55. How many TIMES in the LAST WEEK did you: (please put "0" if you did not spend any time doing it) times in the last week spend time with friends or family image: spend time with friends or family who do not live with you? image: spend time with friends, relatives or others) on the telephone? image: spend time spend times in the telephone? go to meetings of social clubs, religious groups or other groups you belong to? image: spend times in the last week 56. How many people outside your home, but image: spend times in the last week
49. About how many HOURS each WEEK do you usually spend doing the following? (please put "0" if you do not spend any time doing it) hours per week hours per week paid work voluntary/unpaid work	within one hour of travel, do you feel you can depend on or feel very close to? people 57. During the past 4 weeks. gone a little some most all
50. Which of the following do you have? (excluding Medicare)	about how often did you feel: of the of the of the of the of the time time time time time time time tim
Private health insurance - with extras	nervous?
Private health insurance – without extras	so nervous that nothing could
Department of Veterans' Affairs white or gold card Health care concession card	calm you down?
none of these	hopeless?
	restless or fidgety?
51. What best describes the colour of the skin on the inside of your upper arm, that is your skin colour without any tanning?	so restless that you could
very fair light olive brown	depressed?
air dark olive black	that everything was an effort?
52. What would happen if your skin was repeatedly exposed	so sad that nothing could cheer you up?
to bright sunlight during summer without any protection?	worthless?
Would it: Get very tanned? Get very tanned? Get middly or oncasionally tanned? Get moderately tanned? Never tan, or only get freckled?	58. During the past 4 weeks, have you had any of the following problems with your work or daily activities because of any emotional problems (such as being depressed or anxious)?
53. About how many hours a DAY would you usually spend outdoors on a weekday and on the weekend?	cut down on the amount of time you spent Yes No
hours per day	achieved less than you would have liked to Yes No
weekday weekend	did work or other activities less carefully Yes No
	filling in the questionnaire
Are your name and address correct on the front of this questionn	naire? Yes No
If INCORRECT, give details below.	-
Surname:	
Given name(s):	
Postal address:	
Town or Suburb:	
State or Territory: Postcode:	

Consent form



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Signature:		
Extra contact details		
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Email address:		
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Your home phone number: Your mobile phone number: Full name of contact person:		
Phone number of contact person: (
If you have any questions about the Study, please ring the Study helpline on 1300 45 11 45. You can also write to or send your questionnaire (no stamp required) directly to: Associate Professor Emily Banks, Scientific Director, The 45 and Up Study, Reply paid 5289, Sydney NSW 2001.		
Thank you very much for taking part		