

# CHAPTER 1: A MATTER OF URGENCY!

## Remote Aboriginal Women's health: Examining the transfer, adaptation and implementation of an established holistic Aboriginal Well Women's Health program from one remote community to another with similar needs and characteristics

### *1.1 Introduction*

In this research the terms 'Aboriginal' and occasionally 'Indigenous' are used interchangeably to describe the original traditional owners of Australia, depending on preference of the group, community members, health providers or researchers to whom I was responding. Goold (2005) makes a clear distinction between Australian Aboriginal and Indigenous people, describing those who belong to country within mainland Australia as Aboriginal, and those who belong to the islands of Torres Straits just north of Australia, as Torres Strait Islanders. When these peoples are described together they are generally referred to as Australia's Indigenous people, even though both groups have their own separate cultural identities and flags and are very proud of their history and ancestry as Australia's original inhabitants (Goold 2005).



**Aboriginal Flag**



**Torres Strait Islander Flag**

National statistics and reports include Aboriginal and Torres Strait Islanders. However, as my research was with Aboriginal people from the Far North of SA and Central Australia, it did not include Torres Strait Islanders.

### *Introducing the Research topic*

#### **Aim**

The aim of this research was to explore successful strategies in remote Aboriginal women's health that may be transferable to another community with similar health needs.

#### **Objectives**

The objectives of the research were to identify the elements of a successfully established health program that would support transfer and adaptation to another remote community, which had identified their need and willingness to participate in the program. These issues have been examined in the context of worsening Aboriginal health and lack of clarity about successful strategies to address healthcare needs.

#### **Methodology outline**

This descriptive study drew on an interpretive paradigm using qualitative methodology, in Participatory Action Research (Lewin 1951; Stringer and Genat 2005), informed by Critical Social Science (Jay 1973; Held 1980; Horkheimer, Fromm, Lowenthal, Marcuse, Pollock, Adorno, Habermas, Kracauer and Benjamin 1989) and Naturalistic Inquiry (Lincoln and Guba 1989; Guba and Lincoln 2005), and Community Development and Empowerment (Labonte 2004; Laverack 2004). Following initial and continuous consultation, these approaches enabled me to investigate, interpret and

evaluate a model of program transfer that was informed by various concepts and issues affecting Aboriginal women's health in a remote community. Successful strategies in well women's health were investigated that identified an effective Aboriginal Well Women's holistic health program for remote communities in the Northern Territory.

The successful elements of a well established and effective Aboriginal women's health program from Central Australia were identified, transferred and adapted to meet the needs of a willing recipient remote community in South Australia. Working together with healthcare providers, the adapted Well Women's Health program was implemented in an Aboriginal Health Service and evaluated.

### ***1.2 The Setting***

#### *Indigenous history, environmental and social determinants of Aboriginal ill health*

The issues of serious ill health and poor wellbeing of Aboriginal people living in the Far North of South Australia (SA) are as evident and challenging today as they were fifty years ago. The media during 2001-2006 has continued to report the significant decline in health and wellbeing of Aboriginal families in remote communities in SA (Toohey 2001; Williams 2002; Oakley 2003; Craig 2004; Debelle 2004; Rothwell 2006), a situation originating with colonial settlement more than 200 years ago (Rowley 1978; Reynolds 1998; Burns and Irvine 2003).

The environmental, social and political history that has dominated Indigenous Australians has diminished their capacity and created a sense of powerlessness and hopelessness that cannot easily be ameliorated. There continues to be a tendency to replicate and reinforce negative attitudes and behaviours towards Aboriginal people

living in remote communities by many non-Aboriginal people (Lomas 1997; Reynolds 1998; Humphery 2001; Ring and Brown 2002).

Aboriginal people living in remote communities in SA are experiencing a continual decline in their health. They live in a fragile, volatile environment that is often punctuated by episodes of conflict, injury, sickness and premature death and enveloping sadness, grief and a sense of futility. Many of the older people, and women and children are the victims of violence that is often attributed, both directly and indirectly, to alcohol and drug use and behaviours that pervade their daily lives (Jones 2006).

The cry for help to overcome lives seriously affected by drug use, including petrol sniffing, alcohol, cannabis and amphetamines, which are destroying the traditional social and family system, has come repeatedly from groups of respected women in the community, such as the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council (Rothwell 2006). These calls for assistance have, in the past, fallen on deaf ears of government representatives and policy makers alike.

### ***1.3 Higher Mortality of Aboriginal people***

In the period 1988-2000, life expectancy for Aboriginal men was 59.6 years, and women 65 years, that is, seventeen years less than for non-Aboriginal people (Australian Bureau of Statistics 2000; Australian Institute of Health and Welfare 2005, p14-15). The higher morbidity and mortality rates among Aboriginal people living in remote areas are the result of a number of factors. Failure of State and Federal

governments to address the social, economic and environmental determinants of poor health, and to take action on recommendations determined by numerous reports over many years, has compounded the continuing destruction and devastation of Aboriginal people's lives (Couzos and Murray 1999; Australian Bureau of Statistics 2000). This is reaffirmed by Ring and Brown (2002) who report that, although some health gains especially in infant health have been made and some improvement in living conditions are evident, there has been little overall progress in the health of Aboriginal people. There has been a lack of commitment to, and implementation of good policies, as well as inadequate funding to support primary health care and effective community programs to 'break the ill health cycle' (Ring et al. 2002).

This lack of action may also be a consequence of previous research that has been undertaken in isolation from Aboriginal people, rather than in collaboration with them. Those responsible for the provision of treatment interventions and initiatives in prevention of disease, that is decision and policy makers, and healthcare providers, have often failed to collaborate with the community concerned (Lomas 1997) and with their Aboriginal boards of governance.

Research projects that have led to successful health programs have often not been sustained because of short-term funding arrangements of governments, usually of 12 months. This has made it impossible to fully establish and evaluate such programs effectively, and then access sustainable funding within such a short time frame (Gray and Sputore 2002; NATSIHC 2003) The disruption to health programs and initiatives leaves community members dispirited and distrustful adding to their feelings of

hopelessness, and resulting in disinterest in any efforts to implement future research and programs.

Poverty, limited education and isolation combined with escalating disease, injury and violence, have increased antisocial and violent behaviours and added to the overall morbidity and premature death rates of Aboriginal people (Chivell 2002; ABS 2003). Petrol sniffing, alcohol and other drug use have all been implicated in the increased the incidence of youth suicide and family violence in these communities (Saggers and Gray 1998; Toohey 2001). Aboriginal communities in the Pitjantjatjara Lands continue to be disempowered and therefore, less able to instigate effective action that would improve the situation (Debelle 2004; DiGirolamo 2004a).

#### ***1.4 The health crisis that provided the original catalyst for my research***

*The impact of petrol sniffing on the health and wellbeing of Aboriginal families living in the Anangu Pitjantjatjara Lands and Coober Pedy*

The continuing plight of Aboriginal people living in remote communities in and south of the Pitjantjatjara Lands (AP Y Lands), was brought to the attention of the media and general public through the coronial inquest into deaths of three young Aboriginal people from petrol sniffing. An Elder, the father of one of the victims, brought these cases before the SA State Coroner, Wayne Chivell. The inquest exposed the continuing problems and lack of response by government to provide effective strategies and funding, and to address the issues (Chivell 2002).

The coronal inquiry (2002) revealed:

*Clearly, socio-economic factors play a part in the general aetiology of petrol sniffing. Poverty, hunger, illness, low education levels, almost total unemployment, boredom and general feelings of hopelessness form the environment in which such self-destructive behaviour takes place...*

*That such conditions should exist among a group of people defined by race in the 21<sup>st</sup> century in a developed nation like Australia is a disgrace and should shame us all (Chivell 2002).*

The inquest identified the magnitude of the drug problem that included the use of other substances, particularly alcohol and cannabis, and the devastation this evoked through violence and the disruption of family life. This created a double jeopardy for many of the women in these remote communities in relation to their health, safety and wellbeing as victims of assault, and in their role as carers of family members (DiGirolamo 2004b).

Petrol sniffing in remote Aboriginal communities has been an escalating health issue since the early 1980s in remote SA, when I worked as a remote area nurse in the APY Lands. It has contributed to the deaths of many young Aboriginal people, and caused others irreversible harm, leaving victims with severe physical and intellectual handicaps (Goodheart and Dunne 1994). It was petrol sniffing and the media reports that were the catalyst for my interest into research in Aboriginal health.

*My first ideas of research into petrol sniffing in remote communities*

For this PhD research I originally planned to undertake research into petrol sniffing in the APY Lands and to explore successful strategies in other parts of Australia that may be transferable to these communities within South Australia. As I investigated this and consulted with Aboriginal people and healthcare providers, firstly in Adelaide and then the Far North West of SA and Central Australia, I found that petrol

sniffing and inhalant use, although a major issue, was not the highest priority for these communities. Through this extended consultation process, the Aboriginal women informed me that, for them to be able to undertake their cultural roles and responsibilities in their communities, women's ill health was a much greater priority.

Some very significant harm reduction practices have been employed to reduce petrol sniffing. One example is the 'Avgas program', where all available fuel on the community is aviation fuel. Aviation fuel does not have the ethanol component responsible for the euphoric effect in petrol and this strategy was effective for some period of time (Roper 1998). The strategy, however, has lost its significance because newer cars running on lead-free petrol do not run as well with Comgas (Avgas), which contains lead. To obtain other fuel, individuals have brought petrol into the community and sold it for \$50.00 or more per litre, undermining the program to reduce petrol sniffing (DiGirolamo 2004a):

*The can holding a little fluid hangs heavy around his neck  
Without purpose, he walks slowly, in an uncoordinated fashion across the  
sand  
His eyes are glazed, his head droops nonchalantly, his body a wreck  
Where is his culture and his cause? He's just a young man and this is his land!  
(Mitchell 2003)*

A more recent strategy in 2005-2006 was the introduction of another lead-free fuel named "Opal". This fuel has been developed by BP Australia (BP Australia 2005; Hall 2006) and introduced to some remote communities, with a government subsidy to reduce the cost compared to other petrol (McLaughlin 2005). Since the introduction of Opal fuel there has been growing pressure on the Federal government



from Aboriginal leaders and communities to extend this to all remote areas in Central Australia and all petrol stations in Alice Springs (Hall 2006). This would then provide fuel (that is not likely to be sold or stolen), for all motorists, including tourists travelling through Aboriginal reserves such as Uluru, as well as for people working and living in remote Aboriginal communities. However, petrol sniffing, alcohol and other drugs play a significant role in the continued abuse of women and children in these remote communities.

#### *Sexual assault on women and children*

Despite the initiatives that have been implemented, the health and wellbeing of Aboriginal women and children continue to worsen. Their safety is not assured and rape and violence are reported in the news media on a regular basis. The Crown Prosecutor in Central Australia reported her knowledge of rape and sexual assaults on very small children that have gone unpunished and unreported, for fear of reprisal by the offender's family (Jones 2006). This is not, however, a new occurrence. Women have been complaining of these sexual assaults and injuries for many years (Wilson 2006). In 2003 a doctor from the Royal Flying Doctor Service (RFDS) approached Prime Minister John Howard at the Aboriginal community he was visiting and gave him a letter she had written reporting sexual abuse in very young children as young as five or six years old who had been left with sexually transmitted diseases such as syphilis and chlamydia. Still nothing was done to help the women and children (O'Donoghue 2004; Koch 2006). Such occurrences of violence are not unusual and leave women and children very vulnerable to further harm and shame.

The ill health of Aboriginal women is now discussed considering a holistic approach that meets the goals of the National Aboriginal Community Controlled Health Organisation (Gray et al. 2002; National Aboriginal and Torres Strait Islander Health Council 2003). Aboriginal women's health is described in terms of their right to wellbeing, dignity and respect for their culture and lore, recognition of their role and responsibilities together with their contribution to the wellbeing of their communities (NACCHO 2006).

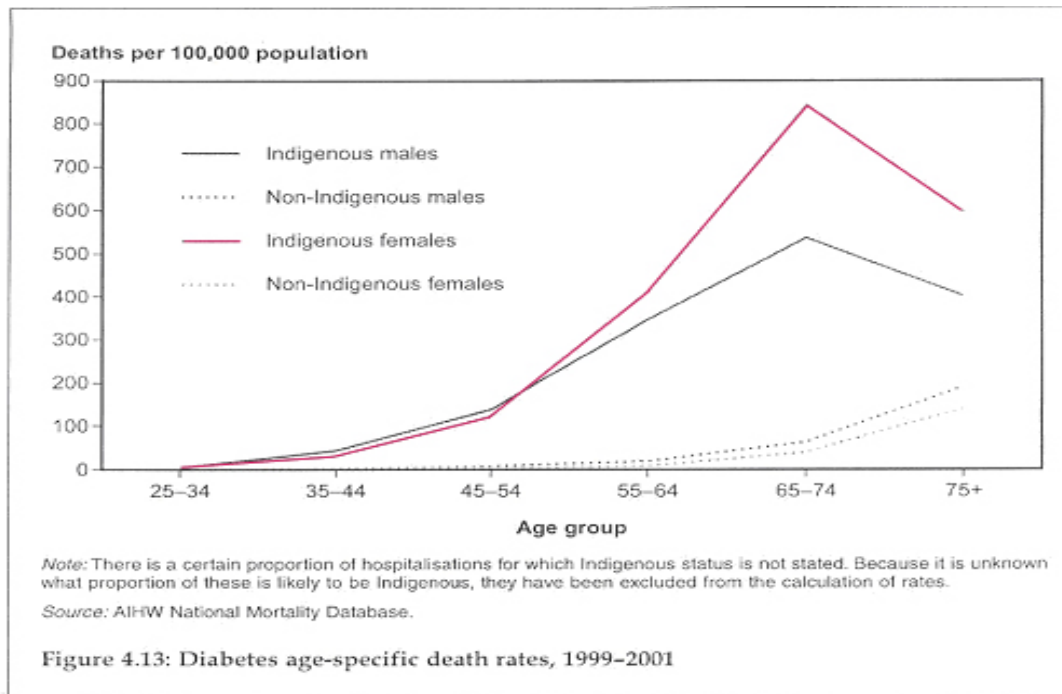
*The health of Aboriginal women*

"Most collected data on health tends to be about ill health as positive health is more difficult to measure" (AIHW 2004a, p 11). The latest report that focuses on aspects of ill health, mortality and morbidity details significant differences that persist in the health status of specific Australian population groups, such as Aboriginal women. The death rate for Aboriginal people was 27-35 times greater than for other Australians from 1999-2001 (AIHW 2004a). While this high incidence of disease, injury and mortality reported is applicable to Aboriginal men and women, my research has focused on Aboriginal women's health in response to community request. Men's health is beyond the scope of this study.

Aboriginal women are resilient, being the mainstay of their families, providing for the health and safety of their children and older family members. However, amongst Aboriginal women, statistics of premature death remain high. During 1999 to 2001, 33% of deaths among Aboriginal women occurred before the age of 45 years, compared with 5% of non-Aboriginal women (AIHW 2004b). Diabetes, cancer,

cardiovascular and renal disease, together with injury from assault and accidents, are all reported to cause a higher mortality in Aboriginal women especially those living in remote communities (AIHW 2004a; Department of Health and Ageing 2006).

Diabetes and associated complications from life style factors of smoking, alcohol and drug use, poor food and activity choices (de Crespigny, Groenjaer and King 2004b, p 13), are reported as more prominent underlying causes of death, and account more frequently as an additional cause of death (ABS 2003). There is a high prevalence of Type 2 diabetes which appears to have an earlier onset in Aboriginal women (Spencer, Silva, Snelling and Hoy 1998; Bourrier-LaCroix 2001) and is responsible for a significant number of premature deaths especially in the 35-44 and 45-54 age groups.



**Figure 1: Diabetes age-specific death rates 1999-2001 (Australian Institute of Health and Welfare 2004a).**

The above figure is incorporated here to demonstrate the extremely high proportion of Aboriginal women's deaths from diabetes and associated comorbidities, such as cardiac disease, over the period 1999-2001. Moreover, available statistics of hospital admissions and GP management, show there has been no decrease in the prevalence of diabetes or its complications over the last decade (Department of Health and Ageing 2006).

Environment, social and historical factors have impacted enormously on the health of all Aboriginal women and especially very young women who are dying from diabetes and diabetes-related conditions far younger than non-Aboriginal women in Australia.

***1.5 'Aboriginal Women's Business'***

Aboriginal women's business encompasses all physical, spiritual, and cultural aspects of their lives, that include traditional women's lore 'and secret women's business' (Bell 1993). In Aboriginal society, 'Women's Business' is fundamental to all Aboriginal women whether they live in urban or remote areas. Their roles and responsibilities are extensive, from nurturers and carers to decision makers and role models, leaders and teachers of the young women and girls (O'Donoghue 2004).

Women's health includes their spiritual, physical and mental and social wellbeing. A major determinant of their own ill health is the role they play in caring for their extended families from the very young to the elderly. In addition to the many physical diseases there are also particular health issues described as 'Special Women's Business'.

### *Special Women's Business for health and wellbeing*

The sexually transmitted infections (STIs) syphilis, gonorrhoea, trichomonas, and chlamydia were endemic in Aboriginal communities prior to the introduction of organised screening programs that have included HIV testing, since 1994 in the APY Lands in SA (Miller and Torzillo 1998). A strategic plan with intensive screening through a primary health care approach in prevention, earlier detection and treatment has been effective in reducing the incidence of these STIs in the AP Lands and Central Australia (Menon, Coppola, Knox, Ebringer and Waddell 2003; Depraetere 2003a). Away from these well screened and monitored communities, however, screening has been spasmodic at best, and limited by the lack of a culturally acceptable service. This lack of access to acceptable women's health screening and poor knowledge about the prevention of STIs among Aboriginal women has had extensive consequences in spread, and is a contributing cause of other conditions such as HIV, pelvic inflammatory disease and infertility (Miller et al 1999; Kildea and Bowden 2000).

### *Incidence of cancer in Aboriginal women*

Queensland (Qld), South Australia (SA), Northern Territory (NT) and Western Australia (WA) since 1999, have collected nationally comparable statistical data for diseases, including breast and cervical cancer, in Aboriginal women. However, only SA, NT and WA have comparative statistics for longer mortality data trends of ten years (ABS 2003).

Cancer, and its impact on Aboriginal people, does not receive the recognition that it should, partly due to the fact there is no national registry body, and only some states have the capacity to compare statistical data. There is no requirement for people to identify their Aboriginality, which skews the identification of cancer data and incidence of diagnoses that are often reported as death statistics. Further to this, it is very difficult to identify specific communities, or groups of women that have a high incidence of cervical or breast cancer, as statistics are only recorded by region (Kirov, Francis and Thomson 2003), Cervix Screening SA 2005, personal communication).

South Australian Aboriginal women living in remote areas from 1988 to 1999 were found to have higher mortality rates from cancer than any other SA women. The rationale for their increased mortality has been explained by the detection and diagnosis of cancer at a more advanced stage, and therefore with less optimal treatment outcomes (O'Brien, Bailie and Jeffs 2000).

The explanation for this higher mortality given by some Aboriginal women Elders relates back to the 1950s and the Maralinga atomic weapons testing. Some older women claim there was more than one atomic weapon test and that the radiation clouds drifted for some considerable distance, being seen from the Far North of SA. They considered the radiation fall-out to have polluted their bush tucker and underground water supplies (Women Elders, personal communication 2006). The combination of limited, or lack of, culturally appropriate access to health screening processes, late diagnosis, their environmental conditions and lack of health education relating to prevention, early detection and treatment options for cancer, all appear to have

contributed to Aboriginal women's high mortality rate (Australian Bureau of Statistics 1998; Reath and Usherwood 1998; O'Brien et al. 2000; Condon, Armstrong, Barnes and Cunningham 2003; Kirov et al. 2003).

### ***Breast cancer***

Breast cancer is the most common cause of cancer death in Australian women, with mortality remaining stable over a 5-year period 96-01 for the age group 50-69. In 1996, 2589 women died and in 2001, the number was similar with 2585 women dying from the disease. Among Indigenous women, the mortality rate for breast cancer was 42.2 deaths per 100,000 women in the age group 50-69 years. Although not all women indicated their Indigenous or non-Indigenous status, remote area statistics show 46.1 deaths per 100,000. As these statistics tend to be reported in mortality rather than incidence of cancer detected, there is limited available information from cancer registries, and there maybe a tendency to underrate the impact and significance of cancer in Aboriginal women (Kirov et al. 2003).

### ***Cervical cancer***

There were 22 deaths from cervical cancer in South Australia in 2001, although Indigenous statistics were not identified (Department of Human Services SA Cancer Registry 2003). However, the incidence of newly detected cervical cancer in SA in 2002 for the area around the recipient community was from 7.6 to 30 times the annual incidence / 100,000 (DHS Data Analysis and Consulting Unit 2002). The reason for this is presently unclear but factors influencing STI and HIV transmission and environmental causes need to be considered.

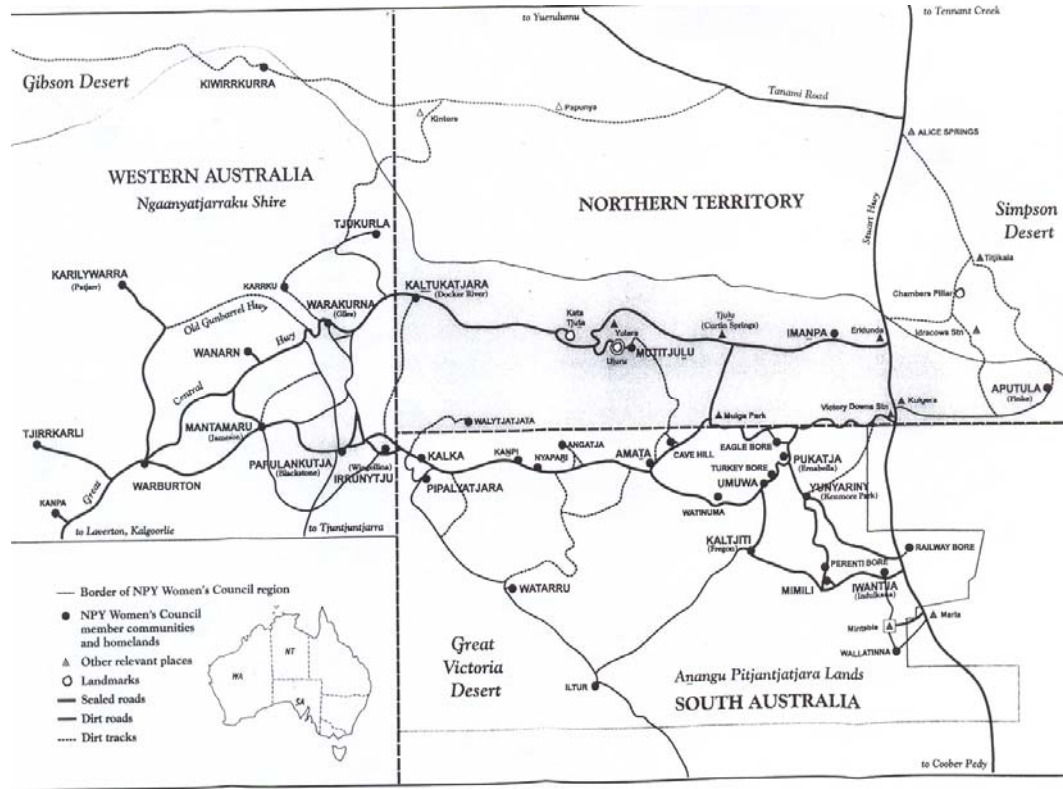
Participating in cervical screening still remains problematic for Aboriginal women in remote areas because of poor access to female General Practitioners (GPs). Other barriers that have been reported are the women's concerns about confidentiality, the past level of cultural appropriateness of service, lack of transport, and poor awareness of health risks and how to access services (Reedman and Radoslovich 1999). Despite the availability of statistics on women's health and wellbeing reported and documented by SA, NT, Qld, and WA (AIHW 2004a) it is difficult to isolate data from particular remote areas, health services, or specific health screening programs, such as cervical screening in a specific community. Therefore, participation rates by Aboriginal women in one area such as the recipient community are not presently identified, as statistics reported are from the larger district of Northern and Far Western region of SA.

This region incorporates all areas from Port Augusta north to the SA-NT border, west to the WA border, and east to the SA/ NSW border, and all statistics for Aboriginal women living in this region of 750,000 square kilometres have been classified together (The South Australian Aboriginal Health Partnership 1998). This specific area covers all of the Pitjantjatjara Lands in SA, where women's health screening is vigilant and well-reported by Nganampa Health Council for all their communities (Depraetere 2003a). However, this health service provision and the computerised data collection facilities do not extend to other communities below the 'The Lands', although statistically they are reported together (refer to map).

*The map below shows the Pitjantjatjara Lands, which extend from South Australia traversing across the Western Australia and Northern Territory borders. It also*



identifies the Stuart Highway leading south towards other remote towns and communities.



Reproduced with permission from Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council 2003.

### *Cervical screening results*

These de-identified results imply that areas such as the 'recipient' community have sufficient and adequate women's screening processes and outcomes. However, prior to November 2004, and the implementation of the Aboriginal Well Women's Health program, the only local women's health cervical screening undertaken by a female doctor, and available for all women living in this remote community, occurred through the Royal Flying Doctor Service (RFDS) during their six weekly visits.

Data for cervical screening for Aboriginal women have been reported directly to Canberra by the RFDS, and these statistics are not available to other organisations, such as Cervix Screening SA (Cervix Screening SA 2004). The lack of available local data again causes delays in reporting of women's health issues and impacts further on Aboriginal women's health outcomes. Further south in Port Augusta, there is a government funded Aboriginal Health Service Pika Wiya, with an Aboriginal Women's Health program and four female GPs to service the Aboriginal community. Aboriginal women from the far north are welcome to use this service. None of these GPs, however, were funded or available to travel to the recipient community for such screenings and therefore women have had to travel out of their community, for four hours by road, to take advantage of these health screening services.

Information from specialist services such as the RFDS could be very useful in providing a more accurate incidence of disease. The increasing demand for evidence-based approaches and outcomes, to assess the effectiveness of programs and evaluate policies implemented to improve women's health, service development and delivery needs to be more available to the communities involved and healthcare providers working with them, to support changes that improve access and deliver more effective primary healthcare.

### ***1.6 Maternal Health***

Antenatal and postnatal healthcare has been a continuing concern for Aboriginal women already compromised by comorbidities, poor nutrition, tobacco smoking and other health risks impacting on their pregnancy and following delivery. This has

resulted in their babies being at risk of low birth weight (below 2,500 grams) at twice the rate of the non-Aboriginal population. Newborn Aboriginal babies are twice as likely to die at birth, or in the early post-natal period, or are predisposed to failure to thrive, and experience premature ill health such as early onset of kidney disease (Australian Institute of Health and Welfare 2004a).

Teenage pregnancy has continued to be of concern in young Aboriginal girls in SA, some of whom are as young as thirteen. Teenage deliveries reported between 1995-1999, had significantly more ill health from sexually transmitted diseases, anaemia and urinary tract infections than non-Aboriginal teenagers and poorer neonatal health. Aboriginal neonates from teenage pregnancies have a greater incidence of low birth weight, both pre-term and small for gestational age, and congenital conditions associated with maternal smoking, alcohol consumption and petrol sniffing together with poor nutrition, STIs and social and environmental factors (Westenberg, van der Klis, Chan, Dekker and Keane 2002)

***Figure 3 Perinatal death rates for SA, NT, WA and Queensland***

While better healthcare of Aboriginal babies with low birth weight in hospitals enables more to survive into adulthood, they are at high risk of renal and other chronic diseases. Health problems during childhood due to malnutrition, infections such as scabies, post streptococcal glomerulonephritis, and in adulthood, increasing weight, high blood pressure, insulin resistance, increased glucose levels and heavy drinking, predispose them to renal failure (Hoy, Baker and Kelly 2000). (Spencer et al. 1998) found a predominance of Aboriginal women in Darwin and ‘The Top End’ presenting between

the ages of 30 and 49 years with end stage renal failure, and this appeared to be consistent with statistics in Central Australia.

### ***1.7 The research question and its genesis***

#### *The influence of Aboriginal women and health providers in the Far North West of South Australia and Central Australia on the research*

My initial consultation with Aboriginal women and healthcare providers working in remote areas was with the Nganampa Health Council. Nganampa Health is a community health organisation controlled by the Anangu people (Western Desert language speaking Aboriginal) and has representation from the (Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation (NPY) 2003). In 1985, the provision of health services in the SA Pitjantjatjara Lands was taken over by the Aboriginal controlled body, Nganampa Health Council, from the SA Government Health Commission & Pipalyatjara Homeland Health Service.

Nganampa Health continues to provide a range of health programs with Aboriginal and non-Aboriginal people working together for all people living on the Anangu Pitjantjatjara Lands. The clinics are attached to communities and are spread over a wide area of 'The Lands', comprising one tenth of the total land area of South Australia (Nganampa Health Council 1998).

The NPY Women's Council is a strong women's advisory group that provides advocacy and services in primary health care (Gillick 2004). The Executive of this group privileged me by inviting me to their Executive Board meeting to discuss issues that involved women's health. They listened and questioned my ideas to

transfer an already established successful program and agreed that women's health was a major priority. However, they had reservations that the transfer of their program could be done successfully, as there were different ways of knowing women's secret business in each kinship group. Their concerns were influenced by the geography of The Pitjantjatjara Lands that are divided by the joint state boundaries of SA and NT and SA and WA.

Central Australian healthcare providers and educators of a remote women's health program were more optimistic and shared their model of a holistic Aboriginal Well Women's Health program with me, providing me with a copy and offering support and advice for its implementation, and an invitation to their next remote program.

### ***1.8 Formulating the research question***

The focus of my inquiry changed from petrol and other inhalants to Well Health for Aboriginal women, to address some of the defined health issues identified by, and for, Aboriginal women in Central Australia. With support from the healthcare providers I had consulted from Nganampa Health and Central Australia, mentoring from the Aboriginal Health Council of SA and Ethics Committee consultations, literature that described Aboriginal women's poor health and taking into consideration the complexities and cultural issues that lay as challenges ahead, I reshaped my question.

### ***1.9 Clarifying the research question***

The question then became:

Could a successfully established Aboriginal Well Women's Health program be transferable from one remote community to another and be effectively adapted to meet the needs of this new community, if the elements that made it successful were identified and implemented with the program?

From this question others then arose:

- Would I be able to find a recipient remote community in SA?
- What would be the facilitators and potential barriers to transferring and implementing a Well Women's Health program?
- How could this transferred program then become sustainable in this new community?
- Is there sufficient capacity within the Aboriginal Health Service to sustain a Well Women's Health program over the longer term?
- What research methodology could answer these questions?

### ***1.10 The research methodology***

In determining the best approach to conducting this research effectively and ethically, there were important factors to consider. This research had extensive ethical requirements and stringent guidelines to follow for it to be acceptable to the SA Aboriginal Health Ethics and University Ethics Committees, as well as the Aboriginal community and healthcare providers with whom I was consulting and collaborating. The key issues and requirements of the research are listed below (Humphery 2001; Laverack 2001; Henry, Dunbar, Arnott, Scrimgeour, Matthews, Murakami-Gold and Chamberlain 2002; Stringer et al. 2005). These represented:

The adoption of an approach that would respect Aboriginal values and knowledge

- Continuous participation, consultation and collaboration in the research and dissemination of findings with the Aboriginal community and healthcare providers
- The provision of practical outcomes and benefits to the community in health improvement and capacity development
- The capacity for sustainable community empowerment and development and social change for Aboriginal women and local healthcare providers
- Strengthening the collaboration between healthcare providers, the community and policy development to address the needs of Aboriginal women.

In assessing these criteria, it became clear from the directions of the Aboriginal community and my own understanding, that a Participatory Action Research methodology informed by Critical Social Science would provide the best approach that would be inclusive, address these factors and consider the injustices and poor determinants of Aboriginal women's health. However, as it was also necessary to identify a second community willing to receive the program that was adapted to meet its needs, a Naturalistic approach was also required to identify the community, its needs, and to build relationships that would enable such a program to be implemented. These identified approaches would enable changes in healthcare in prevention and earlier detection, and improved treatment options in a culturally safe environment. Collectively, this amalgamation of methodologies should empower women and healthcare providers to make informed choices to improve health outcomes. These methodologies are defined in Chapter 4.

The evaluation of the change processes used would be vital for a model of program transfer and adaptation to be developed. Any identification of a positive impact of the program on the community and healthcare providers would be best undertaken by using mixed methods. A qualitative approach would be used to gather data on women's views and experiences and those of healthcare providers. This would be supported by a quantitative approach to gauge evidence of numbers of women accessing the program and to identify the incidence of their health status. This was also listed as a requirement of the research from the Aboriginal Ethics Committee.

Qualitative Methods to be used included observation by the researcher, interviews with healthcare professionals, other workers and women participating in the program who wished to contribute, field notes and minutes of meetings and emails that provided a continuity of interaction when face to face or telephone was not possible. Following the introduction and administration of a series of intensive Well Women's Health programs over twelve to eighteen months, participating health providers and Aboriginal women would be invited, through interviews or small focus groups, to give their views of the program and if and how they thought it met their needs. Through a reflexive action process, each individual program would be critically evaluated by the healthcare providers making up the well women's team and the researcher.

### ***1.11 South of the Anangu Pitjantjatjara Lands (AP Lands)***

Aboriginal families who live in the APY Lands belong to the same family and language groups who live in the north, in Alice Springs, and the south below the APY



Lands to Port Augusta. Family members travel frequently over long distances, depending on their kinship links and cultural business. Sadly, much of this business is ‘Sorry Business’ related to frequent funerals of many family members.

*The recipient community*

This remote community is situated 845 kilometres north west of Adelaide, SA, and currently has an Aboriginal population estimated at over 800. This population appears to have significantly increased in the last twelve months, with many families moving down from The AP Y Lands. The 2001 census accounted for under half this present population with an estimate of 339 Aboriginal persons at that time (AIHW 2004b). The Aboriginal community is neither controlled by the Pitjantjatjara Lands nor by Aboriginal groups living in or near Port Augusta, situated 530 kilometres south. It is referred to as “a stand alone” community and it has fought to retain this independent status.

There is an Aboriginal controlled health service as well as mainstream health services for the Aboriginal and multicultural population. Alongside the Aboriginal community there is a large migrant community, who have come to the area for opal mining and as town service providers, and all require health services. The Aboriginal Health Service is governed by an Aboriginal community board that provides a health clinic for Aboriginal people alongside the independent general practitioners, and government funded Hospital and Community Health Services.

### ***1.12 The community who chose to be the partner in the research***

This remote community chose to become the 'recipient community' in the research through the approach of an Aboriginal woman from the Aboriginal Health Service. This introduction was facilitated through another research project in drug and alcohol and through relevant university personnel aware and supportive of my research goals. Following our introductory meeting, a copy of the Central Australian Well Women's Health program was accepted and taken back to the community for discussion. Some months later, I was contacted and asked if I would like to assist with the introduction and implementation in the transfer and adaptation of the program to meet the needs of Aboriginal women in this community.

A period of time was required to build relationships and establish trust with the Community Board, workers and management from the Aboriginal Health Service so that common goals could be established and appropriate consultation with the Aboriginal women in the community could take place. Consultation with other mainstream health providers in Community Women's health, GP Practice, and hospital services also gave a wider perspective of needs and available health service provision.

#### ***Being invited in***

Throughout this relationship building process, I was offered an invitation to act as a relieving Registered nurse in this Aboriginal Health Service for three weeks. This enabled me to view the setting through a Naturalistic lens and gain a perspective of general ill health of the Aboriginal community and the available services. In

particular, I observed the needs of healthcare providers and health needs of women, as well as forming stronger bonds with the healthcare team. Following this insightful experience, a Project Advisory Group (PAG) was set up to inform the process of the adaptation of the Central Australian program to meet Aboriginal Women's needs in this community. This PAG membership extended previous boundaries and included all the female local Aboriginal health service providers and Community Board representation, together with representatives from mainstream Community Women's health and Hospital management, Diabetes Educator and Women's Sexual health educator and later a Child Health nurse. With the addition of a visiting female GP with expertise in remote Aboriginal women's health, and myself as the researcher, a process of planning and implementing the program was collaboratively organised.

The health needs of Aboriginal women in this community appeared to be similar to those of Aboriginal communities in the APY Lands, with the complexities that related to poor mental health, drug and alcohol problems, injury and violence adding to their physical health problems.

#### *Adaptation of the program and tools*

A participatory action method was required to make significant changes to the existing approach to healthcare, moving from a crisis management approach to planned primary healthcare and early intervention. This met with some initial resistance among some staff in the clinic, but was slowly accepted through the introduction of an Aboriginal Women's Well Health checklist that had been initially adapted from the original Central Australian program. This was organised by the researcher in collaboration with the newly formed women's health team. The checklist had been redesigned to meet the

needs of the community women participating in the health screening program and to conform to the new Medicare rebate for Aboriginal health checks (H710). In addition, a general checklist for clinic use was formulated from this Well Women's checklist by removing the 'Special Women's Business'. This tool could then be used as a guide by all healthcare providers in the daily clinic routine for all clients, male and female, to identify their broader health needs.

The first holistic Aboriginal Well Women's program was conducted some ten months after the initial PAG meeting and a system of continuous evaluation of all the processes required, was implemented to enable constant improvement. The impact of the program was evaluated after five intensive screening programs were conducted over eighteen months. The incidence and comorbidity of disease of Aboriginal women in this community was surprisingly high and identified the need for greater vigilance and monitoring and more effective programs to address their poor primary health. The health of Aboriginal women requires the inclusion of mental health and social health and wellbeing together with health promotion initiatives to provide a holistic approach to the comorbidity of disease.

### ***1.13 The significance of this research***

#### *Changing the focus of health delivery to primary healthcare*

Much research has been undertaken to identify the acute and chronic health problems and social health issues of Aboriginal people (Cunningham, Anderson and Bhatia 1994; Carapedis and Currie 1998; Saggars and Gray 1998b; Miller et al. 1999; Thomson, Winter and Pumphrey 1999; Atkinson 2002; Gibney, Morris, Carapedis,

Skull and Leach 2003; Kirov et al. 2003; Depraetere, Know, Hateley, Mick and Scales 2003b; de Crespigny et al. 2004b). This is especially significant in remote communities, where the isolation and distance from essential services adds additional difficulties and restraints that compound the environmental conditions of poverty, limited sanitation and hygiene, unresolved anguish and violence. These influences have all seriously impacted on the health and wellbeing of people within these communities.

*Filling the gap*

Little has yet been acclaimed of the successful strategies that have been shown to improve the health and wellbeing of Aboriginal men, women and children in remote communities. There are many continuing primary healthcare programs and other community projects that are very successful. Effective elements of such initiatives are often obscured by the national disease statistics that do not allow local data to show health gains, and where recognition is blurred by what still remains to be achieved, and the current political climate and ongoing community crises.

Two examples of such programs are the reduction in incidence of sexually-transmitted diseases and provision of sexual health education and screening to detect the incidence of cervical cancer (Miller et al. 1999; Depraetere et al. 2003b) and the education and training of people handling medication for Aboriginal clients with mental health issues (de Crespigny, Kowanko and Murray 2004c).

### **1.14 Well Health**

Good health and wellbeing for women has been defined as:

*... a state of complete physical, mental and social wellbeing;  
the reduction or elimination of disease and infirmity that women  
experience, and the achievement of change in the social and political  
and economic factors which adversely impact on women's health  
and social wellbeing and women's ability and opportunities  
to fully participate in society. (Reedman et al. 1999).*

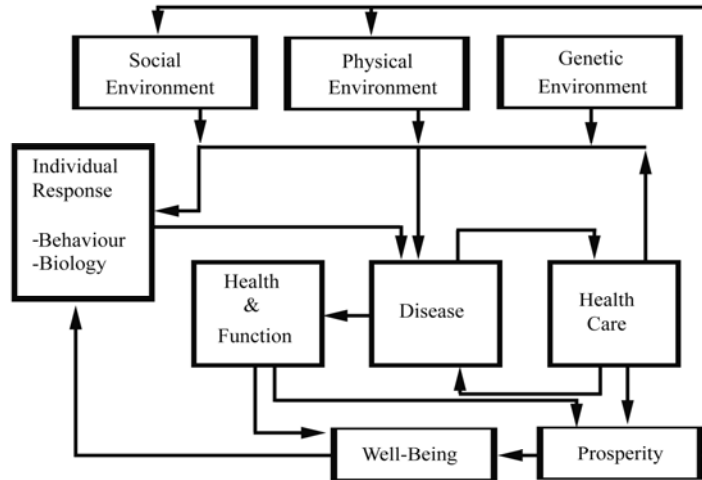
Well health programs should also be described in terms of primary health care delivery that includes health promotion, disease prevention, early intervention and enhancement of social health and wellbeing. Such programs may include health screening and well health checks to maintain wellness, determine states of ill health, and with early intervention of medical /nursing strategies, control elements of the disease to restore good health. Examples of these screening programs are breast screens, cervical screens (Pap smears), urine, swabs and blood sampling for sexually transmitted infections, blood glucose testing for elevated or diminished blood sugar levels, blood pressure monitoring as an indicator of elements of cardiovascular dysfunction. Blood and urine screens will detect renal dysfunction and health histories will assist in determining any other problems affecting health such as alcohol, tobacco and other drug use, injury from violence and mental health issues and social health and wellbeing issues.

In tandem with these health screening programs, education information sessions conducted on aspects of ill health and changes in self-help health practices and life style, can effectively inform people how they can better manage their own health.

These services can be undertaken in the local community by mainstream and Aboriginal health providers.

The World Health Organisation (WHO) defined health as "a state of complete physical, mental and social wellbeing" (WHO 1986). The Ottawa Health Charter of 1986 built on the progress of the Alma Ata convention on primary healthcare to include community participation in prioritising health issues, decision making, planning and implementing strategies, recognising that empowerment through ownership and control would benefit health improvement and promotion (WHO 1986). More strategic directions were required to provide a clearly defined health promotion pathway that could be implemented, internationally through unified collaboration. This was provided by the Jakarta Declaration of 1997, which reviewed the WHO's commitment to 'Health For All by the year 2000' and "re-examined the determinants of health to identify directions and strategies to address the challenges of promoting health in the 21<sup>st</sup> century" (WHO 1981).

Evans and Stoddard (1990) identified the determinants of health as the physical, social environment, individual response, linking behaviour with health and function, disease and healthcare and socio-economic capacity with overall wellbeing. They argued that health was more than an absence of disease, or injury, it implied a much more comprehensive concept (Evans and Stoddart 1990, p 1356).



Evans, R. & Stoddart, G. , 1990, *Producing Health . Consuming Health Care*, Soc. Sci. Med. Vol. 31 No.12. pp 1359 , Pergamon Press, Great Britain.

**Figure 5** **Determinants of Health**

This framework model (*Figure 5*) developed by (Evans et al. 1990) shows the relationship between determinants of health that influence well health(p 1359).

This fits with the holistic concepts of health described by Aboriginal people, which includes relationships to their home country, extended family and kinship, their culture, values and beliefs. This explanation then provides an understanding of how the removal from their home country and families through colonisation, their stolen generations and discriminating policies enforced by white government, have contributed so significantly to their unresolved grief, continued ill health, comorbidities of disease and premature death.

Measuring a state of wellbeing is difficult because it is a complex and dynamic process that considers different attributes for individual people and communities (Baum 2002, p 6). However, the central positive elements include functional ability, quality of life, psychological wellbeing, interactive social networks and support, life satisfaction and morale and economic viability. The Ottawa Charter informs good



health as inclusive of peace, shelter, education, food, income a stable ecosystem, equity and social justice and the importance of advocacy in enabling people to achieve their health potential (Baum 2002, p 35). The Jakarta convention reaffirmed these principles but also identified strategies for achieving this that included an infrastructure for health promotion (WHO 1986, App 2.268). The health and wellbeing of an individual is connected to their physical and social environment in their every day activities and their social and economic control that enables them to make decisions that influence their life.

*Community development as a pathway to improved health outcomes*

Community involvement in healthcare can empower individuals and whole communities to improve their own health by identifying and addressing the factors that impact negatively on their health. This may be through awareness programs (health promotion) and information that explains better ways of managing existing chronic disease and risky health behaviours, for example condoms to prevent sexual transmission. The community development approach enables a more collaborative approach for the community and health providers to work together to meet the specific needs of the community. In this health model, screening services for specific needs, e.g. women's health, can be organised by local health providers in partnership with the community who will participate in the program as they have recognised their need and requested the service.

This method is supported by WHO and recognises that many of the issues affecting health and wellbeing are related to our social economic and political environments. Community ownership is a key component of community development and the

community should decide what they see as their priorities and what services they see best at effecting positive changes in health (McMurray 2003, p 20).

### *Health promotion*

WHO clearly defines health promotion as “the process of enabling people to increase their control over, and to improve their health” (WHO 1986). The focus of health promotion is on achieving equity of health by reducing differences in health status and ensuring equity in opportunity and resources to enable people to fulfil their health potential (WHO 1986; Stringer et al. 2005).

Health promotion is an essential component of primary healthcare. However, it has long moved from the singular concept of prevention of disease by changing behaviour such as giving up smoking, to a far more lateral approach that includes social health attitudes that take into consideration of how the community can be a healthier place to live (Baum 1992, p 83), for instance by improving the water supply. This approach has benefits for the whole community in health improvement.

This approach to primary healthcare provides for the interactive process of community empowerment that can improve people’s health and social wellbeing along a continuum from a single individual to large groups or whole communities. However, community empowerment incorporates other aspects such as community participation, and capacity building and community development that enables the community to take collective action to address their issues (Laverack 2004).

### *1.15 How this program fits the National Aboriginal Health Strategy*

This community empowerment approach in primary health care is in line with the 1989 National Aboriginal Health Strategy, whose goal was to provide all Indigenous people with the same access to health services and facilities as other Australians by the year 2001. Among the goals to accomplish this were improvements in health standards that could raise life expectancy and provide a high level of participation of Aboriginal people in their own health decision-making processes (NATSIHC 2000). Achieving this overall objective within the time frame would have been an extremely difficult task due to the highly complex issues and political environment in which Aboriginal people live in and continue to be disadvantaged.

Therefore, this initial National Aboriginal Health Strategy has only been partially implemented. However, reports to government that have identified the key indicators of Indigenous disadvantage (SCRGPS 2003) and supported the National Aboriginal Health Strategies (NATSIHC 2003; Dwyer, Silburn and Wilson 2004), have provided an additional framework to complement the 1989 National Health Strategy in a collaborative effort in policy and reform implementation, to advance Aboriginal health.

These goals were listed as:

- Developing the infrastructure and resources necessary to achieve comprehensive and effective primary health care for Indigenous peoples
- Addressing some of the specific health issues and risk factors affecting the health status of Indigenous peoples

- Improving the evidence which underpins the health interventions
- Improving communication with primary health care services, Aboriginal and Torres Strait Islander peoples and the general population (Commonwealth Department of Health and Aged Care 1999).

This was built on by the Framework Agreement of 2003 to reflect four key areas

- Increasing the level of resources to reflect the higher level of need of Aboriginal and Torres Strait Islander peoples
- Improving access to both mainstream and Aboriginal and Torres Strait Islander specific health and health-related programs which reflect a higher level of need
- Joint planning processes which allow for full and formal Aboriginal and Torres Strait Islander participation in decision making and determination of priorities
- Improved data collection and evaluation (NATSIHC 2003).

These themes remain fundamental to the improvement of Aboriginal health in 2006. The elements of the Aboriginal Well Women's Health program described in this study are designed to increase access and opportunity for Aboriginal women to health services in their remote community and facilitate health and wellbeing. This can be achieved in the program with prevention and early detection of disease in screening and treatment of identified health problems, running alongside life style sessions that improve morale and self-esteem and build knowledge to enable informed decision-making. The principles of this Well Women's Health program support the strategic directions outlined above.

### *South Australian framework*

In SA, The First Steps document (1998) provided an initial framework that identified the regions and their particular needs in Aboriginal Health through the collaboration of local health providers in each region with policy and decision makers from Aboriginal organisations such as AHC SA, ATSIC, Commonwealth Department of Health and Aged Care (CDHAC) and Aboriginal Services Division Department of Human Services (DHS).

Regional Aboriginal health development has been a dynamic process and has been in a constant state of flux since this initial document was produced as it has tried to address the complex issues in regional and remote communities of SA. There have been tensions between government, mainstream and Aboriginal health services and Aboriginal controlled health services, which are not easily addressed in terms of equity, access and resources. With ATSIC's demise in 2004, regional divisions were devolved to a whole of Government approach, under the auspices of regional Indigenous Coordination Centres (ICCs). The ICC responsible for remote Aboriginal health development in the Far North and Western Region is located at Port Augusta. Health Partnerships across Aboriginal health and mainstream services have been established in SA in an effort to address Aboriginal health needs more effectively (2005). The latest 2006 Health Performance Framework Report identifies that the social determinants and health issues have not changed for Aboriginal people although there is some national improvement in issues, such as infant and perinatal mortality (Department of Health and Ageing 2006).

*Potential barriers to holistic approaches in remote Aboriginal women's health*

In remote communities existing health services often work in isolation from each other, and therefore do not make best use of the limited resources and expertise available or practice case management of clients across services. Aboriginal health services may work in isolation of mainstream services, further alienating Aboriginal health clients from essential community health services. This is particularly apparent in specific health issues where specialist knowledge is required; as in diabetes, renal and cardiovascular disease, and mental illness, which may often present in combination with drug and alcohol problems. This comorbidity of disease in Aboriginal people is difficult to address at best, and is even more arduous without collaboration and information sharing to make the best use of the resources, in local healthcare providers.

Aboriginal women require a culturally sensitive approach and facilities where they feel respected and their holistic needs can be met that is inclusive of their social health and wellbeing. They may feel uncomfortable and unwelcome in mainstream health facilities and, for example, only attend hospital services or local GP services when they are extremely ill. To address this problem, extensive consultation has taken place with health providers across Aboriginal and mainstream services, to conduct this research study from a collaborative approach.

***1.16 Summary***

This research describes the complexity and issues surrounding Aboriginal women's health in remote areas of Australia. It investigates the successful elements of established remote Aboriginal women's health programs that may be transferable to

another remote community with similar characteristics needs. The quest has been to transfer, adapt and implement a successful Aboriginal Well Women's Health program with the elements of its success from one remote community to another similar community that has identified the need for such a program. A response to redress the worsening health of Aboriginal women that is a major priority of many remote Aboriginal communities.

This is presented through the following chapters;

*Chapter One* has introduced this study and outlined the background on remote Aboriginal women's health, thus providing a context for the research.

*Chapter Two* will discuss Aboriginal women's health through the literature in more detail in the context of remote health. It describes the historical aspects from the impact of colonisation and the inequity of health service delivery in remote areas and how this has affected the health and welfare of Aboriginal women, with reference to the reports that have brought this to the attention of government and effected changes in policies.

*Chapter Three* describes various successful women's health programs in remote Aboriginal communities and elements that have led to successful program outcomes. The strategies employed for effective research transfer are discussed in relation to the adaptation and transfer of an established Aboriginal Well Women's Health program from one remote community to another.

*Chapter Four* explores the theoretical approach and rationale used to support this research and builds on existing studies and programs in Aboriginal women's health.

The concepts of transferability are explored through the application of multiple qualitative research methodologies in Naturalistic Inquiry, Participatory Action Research and Community Development. It describes how Critical Social Science has been employed to evaluate the adaptation, transfer, implementation processes and the impact, with the support of quantitative statistics to determine access to the program and incidence of ill health.

*Chapter Five* This chapter discusses the role of the researcher and access to the community, with issues of validity, sampling, methods of data collection, and analysis of the research through this mixed method design. The chapter concludes with an evaluation of the transferred model of the AWWH program and the methods used to conduct and evaluate this study.

*Chapter Six* offers the findings of the research, through interviews, focus groups, document analysis and field notes. It discusses the critical evaluation that determines community empowerment through the structure of organisational domains and the incidence of ill health and complex health problems of Aboriginal women in the remote community.

*Chapter Seven* discusses the issues that have arisen and their impact on the transferability and sustainability of the Aboriginal Well Women's Health Program.

*Chapter Eight* offers the conclusion and recommendations of the research.



## **CHAPTER 2: HISTORICAL OVERVIEW - PAST TO PRESENT**

### ***2.1 Introduction***

This chapter outlines the historical and current context concerning Aboriginal women's health illustrating how Aboriginal people have become disempowered. The literature review has included significant reports and historical perspectives that illustrate why Aboriginal women's health remains fragile in 2006, particularly in remote areas. The impact of geographical and social remoteness on Aboriginal women and their families has been explored to identify the determinants of their poor health and wellbeing, with the view to finding and suggesting strategies to augment existing services. The aim of implementing these strategies has been to create change that facilitated a holistic primary health approach and through the process, empowered Aboriginal women to participate with the goal to improving their health

The history of Aboriginal women and their continuing ill health has been informed by major Commonwealth and State reports that include the following: the Report Of The Royal Commission Into Deaths In Custody (1991); the Social Justice Report (2003; 2005); the Bringing Them Home Report (1997; 2001); and The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples (2001; 2003; 2004a; 2005), and the Aboriginal and Torres Strait Islander Health Framework (2006). These reports have given reliable testimony to the events, political control and consequences that have impacted on the health and wellbeing of Aboriginal people, and also highlight the commitment of these reports' authors and contributors. Even though

innumerable recommendations have been put forward to facilitate change, in many instances, these have not been implemented in 2006.

The question arises as to why significant recommendations from reports dating back as far as 1991 have not been implemented. This may be due to the complexity of issues making it difficult to address singular problems, with the structural, political and social discrimination that continues against Aboriginal people seriously limiting Aboriginal empowerment, as well as lack of understanding of needs and appropriate consultation.

The historical context of this question is explored in order to create an understanding of the determinants of poor Aboriginal health over time, and the impact this has had on the health of Aboriginal women in remote communities today.

## ***2.2 Reaffirming the research question***

Could a successfully established Aboriginal Well Women's health program be transferred from one remote community to another, if the elements that made it successful were identified and implemented in the transferred program? Could this program be effectively adapted to meet the needs of Aboriginal women in the recipient remote community? Would participation in the Well Women's health program empower Aboriginal women in this community to make changes to their lifestyle. This would be facilitated by their improved understanding of their ill health issues and with support from local healthcare providers, could enable them to address these through better self management.

### ***2.3 Empowerment***

Empowerment is defined as “an expansion of choices available to an individual and their enhanced capacity to act on those choices” (Kilby 2004, p 1) . Paulo Freire (1996) stated that achieving success through empowerment started with the people and their knowledge of the problem and how they saw ways forward, rather than as the outsider identifying the problem and providing the solution (Freire 1996, p 22).

Disempowerment may be one reason why report recommendations have not been put into practice, as the people experiencing the problem were not fully involved or did not own these ideas of improvement. Alternatively, the principle of empowerment may have been recognised and Aboriginal people may have been left to implement recommendations without adequate capacity, i.e. resources, education and expertise. While this discussion is speculative, the factors of Aboriginal self-determination in ownership, control and collaboration, are essential components of their empowerment that are necessary to implement research with successful outcomes. Empowerment can be a long and difficult journey for Aboriginal healthcare providers and women participating in the program, which can be influenced by factors such as: the researcher’s approach and values; their own reactions to changes in the way that health is viewed; and how these changes are perceived and accepted.

#### *Facilitating empowerment using Participatory Action Research*

The philosophy underpinning this research exposes the issues of power and powerlessness and the need for redress. The Well Women’s Health Program can empower women by providing knowledge in health information for better self-management of illness. It can also enable them to make informed decisions and

choices about participating in screening strategies for the earlier detection and prevention of disease. The researcher, external healthcare providers and local healthcare providers all have a role to play in assisting local Aboriginal women attending the AWWH program to reach this objective. However, each individual and group will have their ideas on how this can be achieved and each will have a vested interest in the outcomes.

*The Researcher:*

It is difficult for the researcher to come into the local community without preconceived ideas and a method structure that has been detailed through extensive Ethics Committee screening. These ideas together with the knowledge of the health practices, such as other women's health programs, influence both the research design and the collaborating stakeholders.

Research is not value free and the initial acknowledgement of this will enable discussion and an honest approach to address issues, through creating an awareness of different perceptions within the community (Atkinson 2002).

*External Healthcare providers:*

External resources such as the visiting female doctor, sexual health educators, diabetes educators and people conducting lifestyle sessions for the AWWH program will all have their own perceptions on how their contribution to the program will be delivered. How this is received by the local community women will have an impact on their willingness to accept the information and participate in the program.

### *The local health providers*

The local health providers who were consulted on their views about the program working effectively, may perceive any questioning and changes in their role, status, current knowledge and methods of application of their health practice, as threatening. Working in collaboration with new healthcare team members in a partnership model, may create stressors that will affect issues such as self assurance and confidence, and create anxieties about the historical dominance of white nurses and response to culturally sensitive Aboriginal women's health issues. However, a true participatory approach where knowledge is shared, that is women's cultural knowledge and health knowledge, can provide a structure for building community capacity and therefore empowerment.

### *The clientele*

The Aboriginal women participating as clients of the women's health program may find factors of trust, rapport and sharing their own health issues with new healthcare providers relatively daunting and may initially be shy in requesting the services and information that they require. To speak with women, rather than to women, provides an opportunity for the outsider to listen and understand the issues, concerns and difficulties the women experience, and how this impacts on their health, education and social wellbeing. The people's perceptions are their reality of how they see themselves and their situation in relation to the topic under discussion (Freire 1996). Freire emerges as a philosopher who has taught how essential it is to commence with the people's ideas and reality, rather than the expectations of oneself as an educator, healthcare provider or researcher.

The context of how and why people act is based on their previous experiences, the culture and environment in which they live, and the impact of relationships with others both in and outside of this culture. Awareness of cultural differences and sensitivity in accepting people for who they are and why their behaviour occurs, is essential to provide an understanding of issues, that enable the discovery of barriers and options for change. Respect for cultural differences will enable a greater understanding and enhance outcomes.

In Aboriginal culture, the word Dadirri is used when listening to one another. Its purpose is to enable a deep inner listening, quiet still awareness and contemplation (Atkinson 2006). Dadirri - the gift of deep listening - has been shared with us as a special offering, by Aboriginal people:

*From Dadirri a deep spring of silence; flows renewal, peace and a profound connection to the earth and each other... We don't worry. We know that in time and in the spirit of Dadirri (that deep listening and quiet stillness) the way will be made clear (Ungunmerr 2002).*

*If you stay closely united, you are like the tree standing in the middle of a bushfire sweeping through the timber. The leaves are scorched and the tough bark is scarred and burnt, but inside the tree the sap is still flowing and under the ground the roots are still strong. Like that tree we have endured the flames and you still have the power to be re-born (Pope John Paul 1986).*

*Our people are used to the struggle and the long waiting. We still wait for the white people to understand us better. We ourselves have spent many years learning about the white man's ways; we have learnt to speak the white man's language; we have listened to what he had to say. This learning and listening should go both ways. We are hoping people will come closer. We keep on longing for the things that we have always hoped for, respect and understanding (Ungunmerr 2002).*

The context of Aboriginal women's health is now discussed through an overview of Aboriginal history describing how an invading European force called 'colonisation' impacted severely on Aboriginal people affecting their health and wellbeing.

#### ***2.4 How European history has impacted on Aboriginal health***

The early explorers Dampier, Cook and Eyre described Aboriginal men as tall, lean and apparently healthy, with long slender limbs. Captain James Cook reported in 1768:

*...that they live in a tranquillity, which is not disturbed by the inequity of condition: The earth and the sea of their own accord, furnishes them with all things necessary for life: they covet not magnificent houses (Rowley 1978, p 42).*

#### ***Aboriginal Culture***

Aboriginal people have always held a strong connectedness with the lands where their ancestors lived and passed down wisdom in the stories through 'The Dreaming' of mystical creatures that made the rivers, and mountains (Saggers and Gray 1991). The future of the tribe was only assured as long as it remained within the boundaries of tribal territories where their ancestors were present, and recognised in sacred sites (Munn 1970, p 146; Elkin 1979, p 60). They recorded their history and experiences through language, stories, ceremonies, music, song and dance and art. They engraved, decorated and painted their weapons and tools with symbolic designs, together with myths and chants of 'The Dreaming' (Elkin 1979, p 60).

The Dreaming is a sacred spiritual form that enables participants to meditate, and gain strength and new life. It provides the central focus of survival, strength and bonding relationships to the better good. *“It helps the sick to become well, the separated to rejoin, it is the ability to believe”* (Elkin 1979, p 209-213). The Dreaming bound people together with their land, myths and heritage and ensured continuity in ceremony and ritual and everyday life (Mudrooroo 1996, p 34-35).

#### *Traditional food sources*

For thousands of years Aboriginal people have been expert food managers, gatherers and hunters in a land that was often harsh and unforgiving with droughts, bushfires, pests and floods. They adapted to and lived in harmony with nature. Many were semi-nomadic, moving as needed to fresh water and food supplies within their own tribal lands. They knew where, how and when to obtain water and food in the dry arid areas, how to stay cool throughout the long hot summer and warm throughout the cold winter nights. *“Their way of obtaining sufficient food supplies with the minimum of expended energy was business that was learnt very early in life”* (Elkin 1979, p31).

Diets differed greatly depending on the location of the tribal country. Those who lived in coastal areas had a high proportion of fish and crustaceans, while others who lived in more arid areas were more vegetarian with meat, making an important, although lesser contribution (Berndt and Berndt 1999, p 112). The food collection was shared equally, with men as hunters of larger game and women gatherers of berries, plants, roots and other bush foods, such as honey. Hunting methods included



the use of 'traps', nets, and communal drives, whereas spearing represented an individual pursuit for food (Saggers et al. 1991, p33).

### *Tools*

Aboriginal people crafted their unique tools of spears and boomerangs, tomahawks and woomearas to hunt, and fire sticks to start the cooking fire (Saggers et al. 1991, p30). As they were largely nomadic they had little need to build permanent structures and collect multiple possessions and their philosophy was one of sharing or providing gifts for others in kinship and reciprocity. Articles were passed between culturally defined friends and distant relations alike, which strengthened kinship, respect and obligation (Elkin 1979, p238). This philosophy continues today and is often misunderstood by outsiders who see the extended family causing overcrowding and strain on individual families, who may then also have difficulty providing for themselves. Elkin uses the example of an artist who sold his paintings down south and returned to his own country and bought articles for his kin until all his money was gone (Elkin 1979).

### *Families and Kinship*

Aboriginal people have always lived in small family groups, but were members of larger kinship clans, all with their distinct land and social boundaries, meeting for ceremonial occasions such as corroborees 'secret men's business' and 'secret women's business'. Each language group had its particular country to hunt and gather food and other groups respected visiting rites and rules to maintain social relationships and harmony (Elkin 1979p53).

### ***2.5 The Effects of Colonisation- 'The European Invasion'***

Following Cook's claim of the east coast of Australia for England in 1770, the home of the Aboriginal people was disrupted by the arrival of the First Fleet from England, bringing convicts and later free settlers (Reynolds 1989; Neate 2002). There was no recognition of prior land ownership, and Australia was considered 'Terra Nullius' - land belonging to no one, by the British invaders (Reynolds 1989, p 67; Sharp 1996, p 172).

In English custom, the non-existence of houses, fences and land titles meant no ownership – and so this land was taken for the English Crown. There were no treaties offered and signed between Aboriginal peoples and the Crown in contrast with the other British colonies of Canada and New Zealand (Neate 2002, p4). In Victoria, the explorer John Batman was the only Englishman who recognised Aboriginal ownership of land and made a treaty to purchase 600,000 acres in the Port Phillip area in 1836. This was later overturned by the NSW government of the day on the grounds that it was invalid, as individual colonists could not extinguish Native Title. Only the Crown had that power (Reynolds 1989, p 75-87).

#### *The Impact of Dispossession*

The English sailed into Botany Bay in January 1788 and established the first penal colony in Australia. As interest grew, free settlers were encouraged to immigrate and were given 'free land'. Rapidly, Aboriginal people were pushed from their homelands that were integral to their existence as well as to their cultural and spiritual health. Pastoralists claimed ownership of this territory and established fencing and stock that

prevented access and ruined the land for hunting. This transformed the lives of Aboriginal people into one of poverty and cultural disarray, and they were unable to maintain their self respect and self sufficiency (Elkin 1979, p 52). They were dispossessed by:

- the clearing of land and cultivation of crops
- removal of traditional foods in roots, plants, tubers and seeds
- introduction of cattle and sheep competing for the scarce water supplies
- lack of access to their spiritual lands with the introduction of fences
- conflict with the new settlers who had been given their lands (Rowley 1978, p 55-56).

This was the start of the decline in Aboriginal health, wellbeing and autonomy.

#### *Loss of Lands and Cultural Life*

Conflict between the Aboriginal traditional owners and the white settlers continued. However, the supremacy of the settlers was soon established with the enforcement of English law. Driven from their lands the Aboriginal people became dispossessed and dispirited:

*The Nyungar people who once walked tall and proud, now hung their heads in sorrow. They had become dispossessed; these teachers and keepers of the traditional Law were prevented from practicing it. They had to fight to find ways to return to their secret and sacred sites to perform their dances and other ceremonies that were crucial to their culture and whole way of life (Pilkington 2002, p 16).*

Although this description relates to specific historical events involving the Nyungar people, similar events occurred across Australia wherever white settlement eventuated. Only parts of the central Australian and western desert areas were excluded, as these areas were not seen as fertile or useful to early European settlers. Aboriginal control of their homelands and culture was destroyed. Aboriginal people

now came under English law and legislation was passed 'to control' their behaviour, language and their lives.

"European ownership" of Aboriginal land given by the British authorities to military personnel and free settlers, and the constant conflict between Aboriginal and European settlers over land rights, resulted in massacres of many Aboriginal tribes. Others were captured and removed to other parts of Australia, away from their home country. Remaining Aboriginal people either provided free labour for early settlers and pastoralists, working on sheep and cattle stations in exchange for food, tobacco and clothes, or were relocated to "Reserves" and Mission stations where they relied on food handouts and their cultural traditions were forbidden (Trudgen 2000' p 158-169).

#### *Mission stations*

Mission stations were established by religious dominations in the early 1900's and continued until 1953, with the goal of providing Aboriginal people with a safer environment, food, basic commodities and trading areas, together with an introduction to Christian practices and training in European ways. Some missions were more protective and supportive than others, and this depended on the skills and attitudes of missionaries responding to the Aboriginal people under their care. Mission life was confusing for these Aboriginal groups as they tried to assimilate European ideals into their own culture (Trudgen 2000, p 40). The missionaries created an atmosphere of dependence as they aimed to convert Aboriginal people to their own customs and religious beliefs, which were largely in conflict with Aboriginal traditional beliefs and ways of living (Rowley 1978, p 163-173).

*The Devastation of Disease and Depravation*

With this change of lifestyle, whole Aboriginal communities became exposed to diseases of cholera, typhoid, smallpox, tuberculosis, and syphilis that spread rapidly. Many Aboriginal people died from these diseases because they had no immunity, while others died from lack of food, shelter and warmth, and their inability to practice their spiritual cultural beliefs. Whole communities of Aboriginal men, women and children were affected.

A smallpox epidemic broke out in 1789, initially in Sydney Cove, but quickly spread widely among Aboriginal people in NSW due to their poor living conditions and their absence of any immunity. Reynolds (2001) reported that Captain John Hunter, sailing back into the Cove on his return from Cape Town, noted the absence of canoes and Aboriginal people on the shore. He was reported to be shocked beyond belief when he examined the coastal area where many of the families had lived in the surrounding caves. One of the Aboriginal men accompanying him was looking for his kinsfolk:

*He looked anxiously around him in the different caves that we visited: not a vestige on the sand was to be found of human foot; the excavations in the rocks were filled with putrid bodies of those who had fallen victims to the disorder; not a living person was anywhere to be met with. ...he lifted up his hands and eyes in silent agony for some time, at last he exclaimed, "All dead! all dead!" and then he hung his head in mournful silence (Collins 1798, p 496).*

Note: Colonel David Collins arrived with the First Fleet in 1788 and, under the Governor, was responsible for the administration of legal matters in New South Wales until he returned to England in 1797 (National Archives of Australia 2006).

## **2.6 Aboriginal Women**

The importance of Aboriginal women in colonial society appears to have been ignored or very much undervalued (Saggers et al. 1991). They provided many of the services that would usually have been undertaken by English women who did not join their men in this new country until 'civilisation' had been established. Aboriginal women were seen as essential for the settlement or station as they served and enabled white men to succeed in this frontier. Many served as house maids and cooks and others were involved in outdoor work as members of drovers' teams, working in general station maintenance and were even reported as working in mining and repairing the roads (Saggers et al. 1991, p 75-76). The impact of this newly created female unpaid and undervalued 'workforce' forced the disruption of Aboriginal women's culture and maintenance of family life.

Many women were taken for domestic workers and sexual endeavours. Many were raped and physically abused and forced to cohabit with white men against their will. Sexually transmitted diseases, especially syphilis, soon became prevalent as the white settlers infected the Aboriginal women and girls, and disease rapidly spread to the general Aboriginal population (Evans, Saunders and Cronin 1975). No medical treatment was provided for Aboriginal people, as reported by a government medical officer to Commissioner of Police dated 2 May and June 4, 1892:

*The walkabout blacks ... are nearly all suffering from VD and are horrible to look at through being covered with sores; some are almost blind. This class of blacks is dying out very fast as there is no one to cure them or take interest in them* (Evans et al. 1975, p 100).

## **2.7 Slavery and kidnapping of Aboriginal children**

Endeavours to break their ties to kin, country, language and culture of Aboriginal children, were a major objective of government, missionary organisations and

individuals in colonial Australia, that continued till the middle of the twentieth century (Reynolds 2001, p 158-159). In the early days of colonial settlement it was recorded that governors, clerics and magistrates as well as the poorer settlers, took Aboriginal children. These children became unpaid personal servants, or trackers who could find stray animals, navigate through the bush and find food and water. They became a commodity to be bought and sold, especially on the gold fields.

Young Aboriginal children were also seen as useful by members of parliament as well as frontier squatters, and in 1886 the age of children in the workforce was reduced from sixteen to 10 years. Their removal from Aboriginal society and family culture and language, with strict discipline and hard work without pay, imposed by many of those who 'owned' Aboriginal children, was seen as a way to 'assist' them to integrate and find a better life (Reynolds 2001, p 160-162). The removal of generations of Aboriginal children continued under the auspices of different government policies of 'protection of Aborigines'.

### ***2.8 Stolen Generations***

All seven Australian colonies (the future states and territories) had acted independently till the time of Federation when the Commonwealth of Australia was formed in 1901. The Commonwealth passed legislation that discriminated against non-Europeans, and especially against Aboriginal people. Individual state governments also discriminated against Indigenous Australians with the Legislative Act of 1905 in Western Australia, and in Queensland and Northern Territory in 1911. Early governments implemented legislation that gave power to Europeans to control all aspects of Aboriginal people's lives by appointing a 'Chief Protector of Aborigines' as guardian. This Act of

Parliament authorised the removal of Aboriginal children from their parents, families and communities resulting in 'The Stolen Generations'. This legislation was in existence in Queensland (1897-1965), Western Australia (1905-1954), South Australia (1911-1923), Northern Territory (1911-1964), and New South Wales (1915-1940) (Reynolds 2001, p 163).

By forcibly removing Aboriginal children from their families it was intended that they would be assimilated into the wider non-Aboriginal community and their unique cultural values and identities would disappear. It was thought that this action over time would destroy Aboriginal culture. Police and welfare officers were used to enforce restrictions and Aboriginal children were taken to far away missions without any consideration for the outcomes of these actions on their families, or on the children themselves (AHREOC. The Stolen Generation 1995).

These 'stolen' children were often treated very badly by the establishment and many tried to escape. This was well illustrated by Pilkington's true story of 'The Rabbitproof Fence', in which one of the children, Molly, described their capture, the minimal facilities of the dormitory and their duties, and how she escaped with her 'sisters', and walked the 1500 miles back to Jigalong guided by the fence that was constructed in Western Australia north to south, to keep rabbits from destroying the pastures. Molly had been told about the 1831 kilometre long fence by her father who had been involved in its construction (Pilkington 2002). This powerful description was just one family's experience. Many other children's experiences involved grave mistreatment, death and the permanent disconnection from family.



## ***2.9 Discrimination and no recognition of Human Rights***

The Human Rights Equal Opportunity Commission (HREOC) Inquiry (1995), investigated past government practices and policies that affected the removal of Aboriginal children from their families. The inquiry found that many of the children were badly cared for and were often victims of both physical and sexual abuse. Most children received a minimal education that only prepared them for positions of menial labour. Overall the Inquiry reported that:

*The Inquiry found that the forcible removal of Indigenous children was a gross violation of their human rights. It was racially discriminatory and continued after Australia, as a member of the United Nations from 1945, committed itself to abolish racial discrimination.*

*The Inquiry also concluded that even before international human rights laws developed in the 1940's, the treatment of Indigenous people breached Australian legal standards (HREOC The Stolen Generation.1995).*

The 1997 Bringing Them Home Report found that between 1910 and 1970 there were up to 100,000 Aboriginal children forcibly taken from their families by police or welfare workers. Other injustices were reported on how the children were taken many miles from their country, parents were not told where their children were and were unable to trace them. Many children under the age of five were told they were orphans. All Aboriginal children were isolated from any family visits, their letters to home were destroyed, and speaking their native language was forbidden (AHREOC Bringing Them Home.1997).

Notably, Aboriginal children were still being removed from their families and placed in alternative accommodation in 1968 (Mitchell personal experience Darwin 1968);

*People mistakenly believe that the taking of Indigenous babies and children from their mothers only happened in the distant past. But the policies and practices of removal were in effect throughout this century until the early 1970's (AHREOC The Stolen Generation.1995).*

Some of these children are now in their mid thirties, and have still not found their families or been able to reconnect with their country and culture (Social Health and Wellbeing Coordinator Coober Pedy 2005 personal communication). These past actions have resulted in much unresolved grief, anger and bitterness that is still expressed today as lost hope and social distress (O'Donoghue 2004).

As Stolen Generations have grown up in a 'hostile' environment without the influence of family or cultural affiliations, many have had difficulties in finding their place in Australian society. Feelings of worthlessness and insecurity, resulting in suicide and violence, reflect the powerlessness that has resulted in drug and alcohol use and dysfunctional family situations, with a distrust of others, especially government employees in police, welfare and other services (HREOC The Stolen Generation.1995).

### ***2.10 Incarceration of Aboriginal people and deaths in custody***

The overwhelming disadvantage and continuing dispossession of Aboriginal people has created their relentless vulnerability to replicate this removal of children through discriminatory practices of child welfare and juvenile justice systems:

*The Inquiry found that Indigenous children are six times more likely to be removed for welfare reasons and 21 times more likely to be in juvenile detention than non-Indigenous children. There are many reasons for these high rates of removal, including continuing cultural bias against Indigenous modes of parenting, inadequate and inappropriate services for Indigenous families and discriminatory treatment of young Indigenous people before the law (Human Rights Equal Opportunity Commission ( HREOC) 2001).*

The Australian judicial system has been centred on individual responsibility and accountability for people's actions without consideration of the social context of an offender's life situation. The Royal Commission into Aboriginal Deaths in Custody (RCIADIC) provided a historical context, in which the cultural considerations of family and community pivotal to Aboriginal social networks, are considered for offenders from the Stolen Generations. Previously, only social and economic factors had been taken into account, the cultural disadvantage and psychological harm of 'not belonging' and not owning family and community and experiencing Aboriginal culture, had not been considered as mitigating factors in sentencing (Edney 2003).

The deaths of ninety-nine Aboriginal people in police and prison custody were investigated by a Royal Commission, over the previous nine years and five months prior to 1987, with the final report tabled in May 1991 (RCIDIC. 1991). This was the result of Aboriginal communities and others questioning the disproportionate rate of Aboriginal arrests, imprisonment and deaths in custody. One of the significant factors found in this inquiry was that Aboriginal people were more likely to die in police custody within a few hours of arrest, rather than in prison. Fifty-seven percent of Aboriginal arrests were for drunkenness, sixty-four percent of all arrests were alcohol related, and most of the remainder were for unpaid fines. Eighty-eight of these deaths were male and eleven were female, and, of these, forty-three people had been separated from their families through intervention by the state, missions or other organisations, as stolen children (RCIDIC. 1991).

The inquiry also revealed a lack of ‘duty of care’ by police to ensure the safety of their prisoners. The report identified a lack of general observation, medical assessment and attention, to ensure detainees were not suffering from medical conditions such as diabetic coma, alcohol withdrawal, concussion, head injury or other health problems. Of these Aboriginal deaths, almost half of the detainees were under the age of 29 years, yet the cause of death was accepted as ‘by natural causes’ in 37 instances and 30 deaths were suicide by hanging . In retrospect, this was clearly an error in judgement by custodians who did not ensure the safety of their charges.

From reading historical accounts provided by Reynolds (1989, 1998, 2001) and Rowley (1978), many of the atrocities against Aboriginal people were either committed or condoned by those in power and control of the colony. However, there were advocates for Aboriginal people who had witnessed the outcomes of these policies that inflicted such great harm, who then set about to try and create change. One of these was A P Elkin, a leading anthropologist in Australian Aboriginal culture

### ***2.11 Advocacy***

#### *From Anthropologist to Activist*

As an anthropologist, Elkin had spent much time in the field in remote Australia between 1927 and 1930, studying kinship rituals and mythology, living and communicating with Aboriginal people. He discovered the gaps in genealogies from the Forrest River 1926 massacre and, on investigation, found that this murderous exercise had been organised and paid for by the ‘local Protector of Aborigines’. He was deeply disturbed by the things he was told and events he witnessed that included a line of Aboriginal men as prisoners chained together and force marched across the

country. These atrocities influenced Elkin to become an activist and an advisor to various humanitarian organisations (Reynolds 1998, p. 234), and he played a central role in influencing policy makers in the 1930s (RCIDICC 1991).

In 1932, Elkin's student Stanner recalled Elkin's paper 'A policy for Aborigines', which outlined positive policies based on scientific data and analysis of the problems resulting from invasion and subsequent clash of cultures. This was seen as very radical at the time and was the start of moving anthropology into the public discourse and debate, as an authority who knew the Aboriginal people, and an advocate for them (Reynolds 1998, p 232-234). Prior to this time, Aboriginal people had been seen by anthropologists as 'objects of interest' rather than the disempowered remnants of a once healthy and strong first nation. Elkin described the main problems for Aboriginal people as "neglect, poverty, malnutrition and inadequate healthcare. Aborigines died because Europeans were unwilling to make the effort to keep them alive"(Reynolds 1998, p 235-244).

### ***2.12 Advocating for the Rights of Aboriginal Women***

There were female activists prior to Elkin, in the 1920s and 1930s, working for basic human rights for Aboriginal people, and alerting authorities in England of the atrocities that were occurring. Among these were Mary Bennett, Constance Cooke and Edith Jones. Not only did they describe the impact on Aboriginal people of the dispossession of their lands and injustices through neglect, poverty, malnutrition and lack of basic healthcare, they particularly advocated for the rights of Aboriginal women. They lobbied for the rights of Aboriginal women in "the sanctity of her person" and the implementation of reforms for their protection from both white and

Aboriginal men. They agreed that women “who did not have control and discretion over their bodies were as slaves and oppressed” (Reynolds 1998, p 237). They believed that all women should have basic rights of good health and an education and training to assist them to achieve economic independence (Reynolds 1998, p 253-244).

This feminist political lobbying appears to be the first on behalf of Aboriginal women in Australia. However, the political scene changed slowly and assimilation of Aboriginal people into the wider Australian community was only agreed to by the states in 1937. Nevertheless, this was not fully implemented until World War Two ended in 1945. Individual states adopted the Assimilation policy as it suited the dominant society and its goals at the time; for example, Queensland’s policy was not fully applied until minerals were discovered on Aboriginal reserves in 1957. This Assimilation policy implied that all Aboriginal people were expected to enjoy the same rights and privileges, and have the same responsibilities, manner of living and customs as all other Australians (RCIDICC 1991).

### ***2.13 The Impact of the Assimilation policy***

Aboriginal families were encouraged to move off the designated reserves and into the townships. Bureaucratic scrutiny, however, increased as families became more exposed to white society and expected to live like non-Aboriginal Australians but without the same resources, basic facilities and material comforts. Aboriginal women were subjected to impossible circumstances to fit the wider society’s expectations and their rights, as parents, were restricted. Children continued to be removed as women were

seen as unfit mothers, who were 'not caring properly' for their babies and children (RCIDICC 1991).

This Assimilation policy was disastrous as it was another mechanism for controlling Aboriginal people, developed by successive governments to meet expectations of white Australians. Aboriginal people were not consulted about such policies that impacted on their lives. These strategies were doomed to failure and in the process, instilled further distrust and compounded issues of everyday existence for Aboriginal people, through poverty and social disconnection. Aboriginal people were yet again segregated from their kin and cultural way of life and country.

#### *Assimilation to Integration*

The strategy of assimilation was changed to 'integration' introduced through government policies such as the South Australian Aboriginal Affairs Act in 1962. Much of the earlier restrictive legislation was removed as governments responded to criticism that Aboriginal people were denied their basic rights to choose to live in their own way. The Australian referendum of 1967 overwhelmingly supported the rights of Aboriginal people and the Australian constitution was changed to recognise this. In this referendum, ninety-one percent of the Australian population voted to remove discriminatory statements relating to Aboriginal people from the Constitution (National Archives of Australia 2006).

#### *The right to vote*

Aboriginal people had already been given the right to vote, legislated by the Commonwealth in 1962. Western Australia and Queensland (1965) were the last states

to recognise Aboriginal voting rights. However, South Australia, Victoria, New South Wales and Tasmania had framed their constitutions in the 1850s to include Aboriginal men over the age of 21 with the right to vote, as they were British subjects. All women in South Australia were given the right to vote in 1894 and to sit in Parliament.

Although not all Aboriginal people were aware of their rights in these early years, some Aboriginal people voted for the first Commonwealth Parliament in 1901 (Australian Electoral Commission 2005). The recognition of Aboriginal people through the legislative process did not reduce everyday discrimination and they were not represented in parliament until Neville Bonner became the first Aboriginal senator elected to parliament in 1971 (Australian Electoral Commission 2005).

#### ***2.14 The Continuing Inequality of Health***

There has existed a serious imbalance between the allocation of resources, treatment of health problems and strategies for preventing ill health that has severely disadvantaged Aboriginal people, (Saggers and Gray 1996) whose need for prevention programs to better manage their health, is far greater than the non-Aboriginal community (Mooney, Wiseman and Jan 1998; Will's Health and Medical Research Strategic Review 1999; Ring et al. 2002).

#### *The Great Australian Silence*

As an anthropologist, Stanner presented to the Australian public the impact of Aboriginal health and how this was a direct result of colonisation, through the Boyer Lectures on Radio ABC in 1968, in his lecture called 'The Great Australian Silence'. The implications of 'The Great Australian Silence' were claimed to be misunderstood



(Manne 2003). Manne clarified Stanner's assertion, that although anthropology was well developed and recognised in documenting Australia's Aboriginal history, the impact of Aboriginal dispossession and the consequences of this on Aboriginal people and the relationship to their continued survival and future, had not been considered as a consequence of the events of colonisation.

This agreed with the politics of the day, particularly the support for 'a white Australia policy' and the fact that the welfare of Australian Aboriginal people appeared 'invisible' to the Australian public at large. This inspired Henry Reynolds, who was a student of Stanner and with the latter's encouragement, Reynolds researched and wrote the history of Aboriginal people since colonisation, for the Australian public. These books have accurately described the atrocities and policies that were inflicted on Aboriginal people that continue to adversely affect their health and wellbeing today (Reynolds 1983; 1989; 1998; 2000; 2001).

Inequality was identified by Stanner (1968) who stated that the decline in Aboriginal health could be directly attributed to:

- The loss of their ancestral lands for hunting and food gathering requiring the surviving Aboriginal people to change their diet completely.
- Loss of family through sickness, death, and Stolen Generations
- Food rations of tea, sugar flour and water, with very little meat, not providing good nutrition, with many starving and more prone to disease and premature death.

- The loss of their culture through preventing their practices of customs and ceremonies, creating a loss of spirit and the people being disconnected with their lands and spiritual welfare.
- The lack of immunity to introduced diseases.
- Tobacco and alcohol leading to their demise through lung and liver disease and social and behavioural change (Stanner 1968)

*I myself think that these four things,-homelessness, powerlessness, poverty and the continued disparity between plans and styles of life-had much to do with the syndrome we have seen for a long time: the inertia, the non-responsiveness, the withdrawal, the taking with no offer of return and the general anomie that have so widely characterised Aboriginal life during their association with us.(Stanner 1968)*

*In 2006*

In May 2006, ABC Radio News reported that the new Federal Minister for Aboriginal Affairs, Mr Brough, had been touring Aboriginal camps on the fringe of Alice Springs in Central Australia. The report stated that the poverty and squalor and the lack of safe housing and basic amenities, all have contributed greatly to the increased violence and injury reported among Aboriginal people living in this situation (ABC Online 2006).

### ***2.15 Control and Disempowerment***

Aboriginal culture has continued to be oppressed, firstly by early European colonisation and the English laws and traditions instilled, and this was followed by the behaviour of their descendants and other migrants. Today the health of Aboriginal men, women and children is so poor it can be compared to the health of people living in Third World countries ravaged by war or famine (ABS 1998). Their living environments of poor housing and sanitation, isolation and poverty has resulted in

their poor nutrition and high incidence of diabetes, cardiovascular and renal disease with other life threatening yet preventable illnesses and injury. This has been compounded by a sense of hopelessness driven by their disempowerment and inability to change their situation. Decimated through the generations of stolen children, socially acquired harmful behaviours such as; alcohol and drug use along with other social issues (Saggers et al. 1998) now torment their existence and create an environment where interpersonal violence and abuse is evident.

#### *Discrimination and Inequity of Resources*

Catalysts for this continuing health imbalance are not only discrimination through the political history of Aboriginal people, but inequity in accessing essential resources to meet basic needs that include safe, low cost housing, and other essential commodities (Ring et al. 2002; Mooney 2003; 2003). Twenty seven percent of all Aboriginal people live in remote areas where there is far less access to essential education and employment and specialist medical and other health services (AIHW 2004a, p 208), compared with 3% of non-Aboriginal people (AIHW 2004a, p 196). This geographical isolation adds to the difficulties in improving access to essential services such as the provision of adequate healthcare. The continued neglect in the provision of adequate holistic healthcare in the 21<sup>st</sup> century with the Federal government boasting a surplus budget of \$11 million in the context of and daily news reports of Aboriginal violence, drug misuse, and poverty in remote communities (Kemp 2004; Karvalas 2006) reinforces this inequity that is a national shame.

## ***2.16 Remoteness and its impact on the determinants of Aboriginal health***

### *Geographical classification of areas*

The Australian boundaries classification for remote areas changed in 1994, from areas categorised as Statistical Local Areas (SLAs) - where any area which had a mixture of rural and remote was classified as "rural" (Department of Human Services 1994), to the Australian Standard Geographical Classification (ASGC) (ABS2001). The five classified geographical areas for census statistics are now listed to provide a Remoteness Index that can be applied to accessibility for services and social interaction based on road distances. These are:-

1. *Highly Accessible* - relatively unrestricted accessibility and opportunities for social interaction.
2. *Accessible* - some restriction of some goods and opportunities for social interaction.
3. *Moderately - Accessible* – significantly restricted access to goods, services and opportunities for social interaction.
4. *Remote* – very restricted accessibility of goods, services and opportunities for social interaction.
5. *Very Remote* – very little accessibility of goods, services and opportunities for social interaction (CDHAC 2001).

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***Figure 2 Areas of remoteness showing discrete Aboriginal communities.***

Prior to this change, remote statistics were often merged with rural data that did not permit the most accurate reflection of data analysis. Consequently, remote issues were camouflaged and needs of communities obscured. Further to this, it is still not possible to determine if the health of Aboriginal people has improved at all, as tracking the health status in improvement or deterioration in specific communities, has not been attainable (AIHW 2004a).

*The issues of distance*

The vast distances between cities and remote communities of Australia have been a major factor in the limited provision of essential infrastructure and resources that is still problematic today. Isolation from major centres together with inadequate resources and poor recognition by government and decision makers of the range of problems that have existed (CDHAC 2000), and lack of effective strategies to meet these needs, has impacted greatly on remote healthcare delivery (Thompson et al 1999). The health needs of Aboriginal people living in remote communities are greater than non-Aboriginal people due to the environmental and socio economic conditions in which they live.

The high incidence of acute and chronic illness and comorbidity of diseases, and greater exposure to injury from accidents and violence, is compounded by limited access to essential services, and the lack of control over their health needs and wellbeing (Mooney 2003). Further influences of the poor socio-economic conditions; overcrowding and poor

hygiene and sanitation, sub-standard housing, and inadequate nutrition due to a scarcity of bush foods, and accessible cheap foods and good water, limited education, employment and career opportunities, have all contributed to the complexity and continuing decline in the health of Aboriginal people (CDHAC 2000). Aboriginal health is further compromised by restricted transport options and a shortage of health providers that can provide effective, culturally appropriate healthcare delivery. To paint a picture of how healthcare delivery has disadvantaged Aboriginal people in remote communities I reflect back on the historical beginnings of nursing in the Australian bush.

### ***2.17 Nursing History Snapshot:-the establishment of remote healthcare***

#### *White nurses for white settlers in the bush*

Following white settlement in rural and remote Australia in the 1800s, many untrained and poorly skilled men and women provided initial nursing care to communities on a 'need' basis (Pearson and Taylor 1996, p 35). It was not until "Bush Nursing" services were established and the 'Nightingale reforms' were adopted, that a nursing service was established to provide health care to rural and remote communities (Burchill 1992). At this time there was no clear delineation of rural and remote areas.

#### *The Nightingale influence*

The Australian nursing profession was influenced by Florence Nightingale's systems of practice through early immigrants such as Lucy Osburn and her nursing team, who arrived at Sydney in 1866. Nightingale's philosophy of nursing emphasised compassionate care for the sick, training schools for nurses, positions of 'Matron' 'Superintendent' and 'Charge Sister' (Durdin 1991, p 21), together with hygienic and

practical hospital design, and spotlessly clean uniforms for nurses and the reform of public health systems. Miss Osburn had graduated from St. Thomas's, London and was the first Nursing Superintendent appointed at the Sydney hospital where she established the nursing training school. Later in 1915, midwifery training and registration for nurses commenced (Schultz 1991).

*The rural/remote communities' nursing needs*

As free settlers moved from the towns to rural areas to take up farming with their families, 'the Bush,' nursing services were required. The Bush Nursing Association in Victoria was established in 1910 to provide nursing services for the healthcare of rural and remote families, on a fee for service basis. A local committee from the community would guarantee the salaries of nurses from the Bush Nursing Centre. Nurses were expected to carry out their required nursing duties under the direction of local medical practitioners, except in an emergency (Burchill 1992). Trained nurses at the time had concerns relating to the conditions that Bush nurses would be working under with "*...heavy responsibility, low pay, and much reduced access to medical advice and help in lonely areas*" (Burchill 1992, p 77).

John Flynn's decision to initiate health services through the Australian Inland Mission in 1912, and then later the Flying Doctor and pedal wireless to inland Australia, was influenced by his knowledge and support of the Bush Nursing scheme (Burchill 1992). The nursing volunteers for the Australian Inland Mission were carefully chosen for their suitability to the isolated environment and knowledge. Their

extensive skills and abilities included an ability to “... *display a capacity for initiative, responsibility and competence above average and show respect for people of all races*” (Burchill 1992, p.126)

#### *The Bush Nurses’ role*

The isolation and distance from medical help and many occasions where a Medical Officer could not be contacted meant that the nurse was required to manage in the best manner possible. If the patient died, then even a burial service was required. Communications gradually improved and by 1920 many of the Bush Nursing Centres were linked through telephone exchanges that enabled consultation with medical advisers who conveyed instructions for patient management. Nurses were still required to have the expertise to dispense pharmaceutical medication and there were no other professional services available for consultation.

Even in these early times of Bush Nursing, the nursing role required a competency level that far exceeded mainstream nursing. Their advanced practice skills, together with a capacity for survival in the harsh environment to which they were subjected, assisted these nurses to provide essential medical and nursing services. This expectation of the Bush Nurses’ role could be interpreted as a Nurse Practitioner by today’s nursing standards.

#### *Isolation*

For these ‘Bush Nurses’ there were various issues related to their isolation, one of which was the distance from available medical help. The nurse was required to travel



many miles alone, often at night to attend sick or injured clients or to deliver a child. Their transport was usually a horse and in some areas north, a camel. As initially there was only one nurse working in these remote communities, there was no time off allocated. There were expectations from both their employer and the community that these nurses would be on 24 hour call. Primarily these Bush Nursing Services were established in Victoria. However, as colonists moved north, other bush nursing services were established where church organisations or pastoralists could support them.

### *The Border Nurse*

Supported by the Australian Inland Mission (AIM) in 1924 a bush nurse was established in Innamincka, a small town on the edge of Sturt's Stony desert in SA near the south-western Queensland border, to assist people in the neighbouring stations. This nurse became known as the 'Border Nurse' as she serviced and traversed the area of SA, NSW and Queensland borders, some of the most remote country, known as Border Country. It was also the area where Burke and Wills perished seventy years earlier.

This nurse was fully trained with both general and midwifery skills, ready to act, and to put her hand to anything that might be required of her, with the nearest doctor possibly hundreds of miles away. By 1926, the demand on nursing services had increased to twenty nurses who lived in ten Australia Inland Mission hostels to provide clinics and services to various remote places of inland Australia (Burchill 1992). The duties of a border nurse are now outlined to add a context to the vast

terrain and the expectations of the health service that was the predecessor of today's remote clinics.

#### *Duties of a Border Nurse 1924*

These included the ability to:

- Ride a horse over long distances (camel when necessary)
- Eat dried salt beef and damper
- Camp under the stars (listening to the howls of the dingoes)
- Survive extremes of heat and drought
- Drink brackish bore water
- Cope with isolation from professional help and advice
- Conduct burial services
- Make diagnoses, and undertake medical treatment without trained assistance
- Treat influenza epidemics often as the only nurse available (Burchill 1992).

#### *Transition to nursing home clinic services*

The demands for health services increased and the Innamincka nursing home was opened in 1929, staffed by two Bush nurses. This transition required the community to now come to this new facility for nursing treatment, rather than the nurses travelling to them. This reduced the long distances travelled by the nurse in harsh conditions, to deliver nursing care and medicines, and made her more available to the community. As early nursing services were organised primarily for the farming and outback population a larger number of clients could now be attended. Rarely mentioned by Burchill, is how these nurses attended Aboriginal people.

### *Aboriginal healthcare*

Very few Aboriginal people appear to have had the benefits of the early bush nursing services. They were thought to have relied on their own Medicine men at this time. Burchill reported that "...those Aboriginals brave enough to try 'white man's medicine' were seen at the outpatient's clinic at the homestead (Burchill 1992). One other report identified a full blood native woman seen by the Border Nurse at an Aboriginal camp who died of sepsis following childbirth (Burchill 1992).

### *John Flynn's vision and transformation of bush health services*

Once nursing base services such as in Innamincka were organised, it is possible that Aboriginal families were also cared for. However, John Flynn was best known for his active interest in Aboriginal health in the bush. As head of the Australian Inland Mission (AIM), Flynn was able to identify the needs of people living in remote areas, firstly in the Far North of South Australia and then in the Northern Territory. In 1928, after much lobbying, John Flynn's vision of a 'Flying Doctor' was realised, and the need for Border nurses gradually diminished as 10 small hospitals were established across the centre of Australia by the AIM.

### *The Royal Flying Doctor Service*

The first flight of The Royal Flying Doctor in May 1928 was made using a DeHavilland aircraft, model DH 50, called Victory, hired from the company that later became Qantas. Flying was still in its early days and airstrips left much to be desired for landing, navigation and lighting. Originally on trial for one year, the Flying Doctor was based at Cloncurry in Queensland. Twenty-five Flying Doctor bases have

since been established in the seventy years since founding this essential service to remote Australia. Originally organised to evacuate the injured and sick, it has become an established way of providing medical services in isolated remote areas and the provision of specialist clinics and primary healthcare services (Royal Flying Doctor Service 2004):

*The Royal Flying Doctor Service (RFDS) was the first comprehensive aerial medical organisation in the world and remains unique for the range of primary health care and emergency services it provides ... over 24 hours 365 days a year”, over vast distances of sparsely populated country (Royal Flying Doctor Service 2004).*

Through John Flynn’s genius and foresight, the RFDS established radio communications with outback stations and communities. This was achieved firstly through the pedal radio and then by battery operated systems to provide emergency and primary health services, and later ‘School of the Air’ to families living in the ‘Outback’. Among Flynn’s many inspirations was the ‘Remote Control Medicine Chest’ purchased by the owners of each sheep or cattle station, with all medications uniformly labelled by number. This provided an instant pharmacy, used under direction through radio and phone communication systems (Royal Flying Doctor Service 2004). These initiatives have greatly assisted the role of the remote area nurse.

#### *Remote area nurses*

Remote area nurses were required by sheer necessity to perform as advanced nursing practitioners often practicing outside the legislative boundaries of mainstream nursing (Department of Health Western Australia 2000). A Remote Area Nurse (RAN) today

still requires a diversity of skills to address the needs of the local remote communities and the shortage of professional support of medical officers, pharmacist and allied health services.

### ***2.18 Current context of Aboriginal women's health in remote communities***

A major factor in healthcare provision to remote communities has been a lack of speciality services and adequate funding to support the RAN in healthcare delivery. Aboriginal people have a greater incidence of comorbidity of diseases than the non-Aboriginal population and require an integrated and cohesive approach across disease specialty services to improve their health outcomes. In the past, money was provided to specific programs through a grant-in-aid system in a very ad hoc approach, without proper collaboration between health specialties and overarching health bodies. Very few sustainable improvements have resulted from this method of distribution of funding and configuration of health services (Aagaard 2002).

Hanna (2001) investigated the relationship between the persistent poor health of Aboriginal people living in rural and remote communities, and government funding allocation. She identified that remote area nurses received less than one percent of health workforce spending but provided ninety percent of healthcare in remote areas. Doctors directly received over forty-nine percent of the funded support but comprised just seven percent of the workforce. Hanna's findings revealed that millions of dollars invested to reverse the medical shortfall have not appeared to achieve the goal of increased access to health services for communities, and that the needs of remote nurses to service their communities required attention as a matter of priority (Hanna 2001).

*Inability of RAN workforce and resources to meet needs*

The consistently high turn over of nursing staff due to poor working conditions continues to impede efforts to deliver reliable and culturally appropriate, quality healthcare in remote areas. The work of remote area nurses has been “...*largely involved with crisis resolution with insufficient residual time to provide health education, health promotion or adequate counselling*” (Hanna 2001, p 41). Lack of primary healthcare has further disadvantaged remote Aboriginal populations despite their need for such services.

With the exclusion of travelling by horse or camel, many of the issues remain the same for today's nurses as they were for the Bush Nurses in the early 20<sup>th</sup> century.

These factors were identified as the:

- Geographical, social isolation, lack of infrastructure and distance between Australian rural /remote settlements, regional towns and cities with the infrastructure and expertise to provide health services and resources
- Large amount of financial support and human resources necessary to support sufficient and capable medical and nursing and midwifery staff and health facilities in remote communities
- Lack of communication facilities to provide essential links between health consultants, training facilities and emergency services
- The inability to attract nurses, doctors and allied health professionals prepared or able to live in isolated and remote areas for reasonable lengths of time to sustain health initiatives and improved outcomes
- Inadequacy of training and continuing professional development resources and facilities for medical, nursing and allied health, to

provide specific knowledge for this environment, epidemiology of diseases and treatment for the Indigenous population and others in remote and rural communities

- Need for additional training facilities, support and resources for Indigenous health workers to enable them to effectively address health issues
- The opportunity for nurses and doctors to learn and be guided by Aboriginal health professionals and communities
- Lack of cultural awareness that results in communication difficulties and inaccurate identification of health problems (Hanna 2001, p 36-45).

#### *Control and dominance of non-Aboriginal nurses*

Cultural awareness, respect and acknowledgement of Aboriginal ways of knowing and learning are essential principles and practices of remote nursing practice today. Most registered nurses working in remote communities are however, non-Aboriginal and unless they have worked closely with Aboriginal health providers for a significant period, they may not be aware of the customs and cultural issues that influence Aboriginal health.

#### *Limited opportunities for Aboriginal Registered Nurses*

There is a need to address the lack of opportunities for Aboriginal people to become registered nurses and Allied health professionals. It was recognised thirteen years ago that discrimination and marginalisation of Aboriginal nurses has limited their completion of registered nurse training (Goold 1993) and this situation has continued to this present day (Goold 2005).

In the National Review of Nursing Education 2001 (Jones and Cheek 2001), it was reported that nurses in isolated environments require a greater knowledge of pharmacology and microbiology than peers elsewhere, and need to focus on holistic practice. The inclusion of science and technical skills together with good assessment and clinical skills are necessary to maintain accountability for their client care in order to practise in the rural/remote context. Nurses working in rural and remote areas need to take an active role in developing and delivering public health and primary health initiatives, as well as using a one to one clinical approach to improve client health outcomes (Jones et al. 2001).

Registered nurses should also be able to undertake process evaluation of their health programs to establish their usefulness on an access and needs basis, which provides evidence for sustainability of such programs. Too many good programs in the past have been discontinued due to a lack of evidence of their worthiness and others may have continued without the support of the community, limiting access to the specified target group. While government policies relating to the issues that affect the recruitment, retention and education of remote nurses are no longer 'invisible,' the impact that these issues have had on the availability of culturally appropriate health provision in remote communities, is reflected in the continuing incidences of chronic disease, comorbidity and premature deaths of Aboriginal people (ABS 2001).

#### Identifying deficits in health

The lack of recognition of the multiple challenges and problems that have existed, compounded by the poor social and economic conditions and prevalence of chronic



diseases and comorbidities, have all contributed to the difficulty in implementing successful and sustainable health strategies (Thomson et al. 1999). In redressing this situation, environmental factors of improved housing, sewerage, clean water supplies, education, nutrition and employment are as important as the availability and provision of good healthcare. However, Mooney et al. (1998) comment that improving health services would make a valuable contribution, particularly if these services were comparable to those available for all other Australians.

In the last eight years each Australian state has conducted or drawn from considerable research and adopted strategies to address the issues of mortality and morbidity in Indigenous health (CDHAC 2000). However, the Australian Bureau of Statistics shows that incidence of disease and mortality remains much higher in Indigenous Australians in comparison to other Australians (ABS 2001). At the 2001 Sydney conference on Aboriginal health '*From The Ground Up*', the opening speaker in her address stated that resources spent in rural and remote health were still inequitable in comparison to urban health (Bashir 2001). Further and better targeted funding from governments and evidence-based initiatives from nurses, as team members with Aboriginal health workers and other service providers, together with effective and practical collaborative projects were essential. Collaboration between health disciplines and departments of health is necessary to acknowledge the needs and implement evidence-based practice. This multidisciplinary approach is essential to advance primary healthcare initiatives that promote the likelihood of improved health outcomes in remote areas of Australia.

### ***2.19 Context for Remote Health Services in Far North West of SA***

Since 1997 the Department of Human Services in SA has regionalised health services to provide a more effective approach to meeting health service requirements. The Northern and Far Western Regional Health Service that borders the northern, eastern and western SA state boundaries serve the area north of the state where a small number of remote Aboriginal controlled communities and the Pitjantjatjara Lands are situated. This area covers 756,742 square kilometres and is the largest region geographically in SA, but has the lowest population density of 0.1 persons per square kilometre. There are 11 towns of more than 200 people and an Aboriginal population of about 8000 amongst a total population of 54,123 (Reedman et al. 1999).

### **2.20 Women's Health**

The Northern and Far Western Health Service developed a Women's Health and Wellbeing Policy and Plan in 1998. This health strategy encompassing well women's health, was endorsed across the region and includes Aboriginal health services (Reedman et al. 1999). The priorities of this specific program are women's:

- Emotional and mental health
- Reproductive health and sexuality
- Prevention of violence
- Healthy aging
- Health needs as carers
- Poor health from sex role stereotyping
- Occupational health and safety (National Women's Health Policy 1989).

The SA Department of Human Services acknowledged that there was substantial evidence indicating that gender influences an individual's experience of health (S A Department of Human Services 1996). Historically, women's health has been seen as synonymous with reproductive health due to issues of safe maternal health and delivery, or with health issues that relate to family nurturing and social behaviours within the family, such as family violence. Women tend to have greater interaction with the health system as they take on the responsibility as carers for their family's health in ill children, relatives and their own reproductive health (Bohan and Stanton 1992).

#### *Women's Health Reform*

The development of women's health reform began in Australia back in the 1960s as part of wider social and cultural change where the emphasis was to empower women to make their own choices in healthcare, initially in reproductive health and in the provision of alternative services. This developed over the last three decades to encompass independent women's community health centres and shelters as well as advocating for the rights of women. The adoption by Australian governments of women's health policies with the aim of improving the health and wellbeing of all women and encouraging a more responsive approach to women's needs, has provided positive outcomes (Reedman et al. 1999). This Women's Health policy in SA was updated in 2004 to provide improved strategies for all women in both urban and remote areas (Women's Health Statewide 2004). Aboriginal women in some remote

areas are acknowledged as experiencing much poorer health requiring specifically targeted primary health programs (Mitchell 2005b).

The concepts of control and informed choice have empowered women to be active participants in decisions about their health and social wellbeing and challenge other social issues that impact on them and their community. The NPY Women's Council is an excellent example of how women have been advocates in their communities to improve their health and those of other women and their families, living on the Pitjantjatjara Lands (Balmer and Foster 1998; Fejo and Hobson 1998).

Anderson (2002, p. 7) states that Aboriginal people access a variety of primary healthcare services that include Aboriginal community controlled health services, state funded clinics and mainstream health services and general private practice. However, there are difficulties in how best to translate the 'agreed principles of effective primary health care into funding models' to provide these services that will impact on the chronic illness that is so evident. Within the context of regional planning, there are further complications and obstacles to overcome to deliver effectively coordinated funding to Aboriginal primary health care services. (Anderson 2002).

#### *Planning healthcare to benefit Aboriginal women and their families*

A program to build primary care capacity "The Primary Health Access Care Program" (PHCAP) was instigated by the Commonwealth in 1999-2000 to provide

\$78 million over four years where regional planning had been completed, and included South Australia. The three objectives of this program were to:

- increase the availability of appropriate primary healthcare services where they are currently inadequate;
- reform the local health system to better meet the needs of Indigenous people; and
- empower individuals and communities to take greater responsibility for their own health (Anderson 2002).

In 2005 the national political framework for Aboriginal health altered again to a ‘whole of Government approach’ that changed this regionalised structure (Calma 2005). This was in response to the National and State Generational Health Reviews that identified governance as a key issue. This had resulted in some poorly resourced and managed services in some areas, a total absence of others, or in contrast, duplication of other health service provision. All these management responses and plans have severely limited access to marginalised groups, especially Aboriginal people, who have very specific health needs and require targeted programs in primary health in both regional and remote areas of SA (DHS Generational Health Review Committee 2003).

*Attention to the remote environment of Aboriginal women*

In the north of SA, Aboriginal women are living in a fragile, volatile environment, punctuated by continuing episodes of conflict, injury, chronic illness and premature death. As described in Chapter One, their health (ABS 2000; 2003; AIHW 2004.; 2005; DH&A 2006), is in a continual decline. While there may be a multitude of

reasons for this lack of improvement in their health, the elements and factors associated with a specific environment, also require scrutiny.

When describing nursing culture, (Norton 1967) reflected that:

*...solutions to problems were not obscured within the nursing practice experience (as thought), or found in dealing with identified practical difficulties (as expected), but rather lay in the treatment of the environment (p. 109).*

In support of this explanation Stevens and Hall (1992) defined the environment as “...the accumulation of physical, social, cultural, economic and political conditions that influence the lives of communities” (p. 4). While they are describing the community health experience in the United States, many of the examples they use, such as global warming, proliferation of toxic wastes and pollution of food and water supplies through pesticide infiltration, apply universally. The Indigenous people of Maralinga in the Far North of SA, have experienced the environmental impact of exposure to radiation, from nuclear weapons testing by the British Defence Services, in collaboration with Australian Defence Services in the early 1950s. Recently, the Commonwealth government has acknowledged that all servicemen involved with the Maralinga weapons tests will receive free cancer treatments (Sunday Herald Sun 2006). Many of these servicemen have already died from cancer. While this directly acknowledges the radiation release and impact on health from these tests, there is no mention of “free cancer treatment or accelerated screening” for the Aboriginal people who have been exposed as the radiation clouds drifted across their homelands polluting them, their water, food and soil.

At a community level, the environmental conditions, that include inequitable access to healthcare, unsafe physical surroundings from violence and abuse and economic hardship, all impact on the health and wellbeing of women living there. This is supported by Stevens and Hall (1992), who question whether nurses should demand that elementary needs such as food, clothing and shelter, are considered essential components for health and are therefore basic human rights. They emphasise the role of the community health nurse within the community, as a person who should recognise these aspects of the environment and facilitate interventions to ensure change (Stevens et al. 1992). However, if Aboriginal people are to be empowered they need to recognise these needs as basic human rights and work collaboratively with healthcare providers to achieve these goals.

### *Summary*

This chapter has described the impact of colonisation and the inequity of health service delivery in remote areas and how this has affected the health and welfare of Aboriginal women. It has identified the lack of specific healthcare for Aboriginal people and the domination of medical and nursing services by white Australians with limited knowledge of Aboriginal culture and understanding of cultural requirements. The following chapter discusses Aboriginal health programs that have been effectively established to meet needs of women in some remote communities that are making a difference in health outcomes. It discusses the aspects of research transfer and how an established well women's health program was chosen to be transferred to a South Australian community with similar characteristics and problems.

## **CHAPTER 3:**

### **SUCCESSFUL WOMEN'S HEALTH RESEARCH AND RESEARCH TRANSFER**

This chapter explores the issues of Aboriginal women's health and the successful strategies employed through a small selection of effectively delivered programs in remote communities. The dissemination of research findings and the elements of research transfer are defined with the goal of identifying facilitators that enable the transfer, adaptation and implementation of a holistic Aboriginal Well Women's Health program to another similar community.

#### ***3.1 A Feminist approach***

Feminist research investigating the availability and suitability of health services in rural and remote areas of Australia revealed there was a lack of holistic approaches to women's healthcare. In particular, there continues to be a service deficiency in mental health, family violence and injury, and effective models of maternal healthcare. The application of government policies and strategies aimed at assisting healthcare delivery has brought additional difficulties through a heavy reliance on the medical/disease model. One of these strategies, the introduction of overseas trained doctors for rural and remote areas, has created both communication and cultural challenges for Aboriginal women. This almost exclusive reliance on disease pathology has overshadowed quality of life issues in social health and wellbeing caused by geographical isolation, cultural disruption, lack of transport, limited social



interaction and job opportunities (Alston, Allan, Deitsh, Wilkinson, Shankar, Osburn, Bell, Muenstermann, Georgias, Moore, Jennett, Ritter, Gibson, Wallace, Harris and Grantley 2006).

Feminist theory has developed through the critical social science paradigm and provides a theoretical approach to examine the issues of gender, power and powerlessness, with the capacity to influence change (Holmes 2006):

*Less powerful members of society have the potential for a more complete view of social reality than others, precisely because of their disadvantaged position.... in order to survive (socially and sometimes physically)...[they] are attuned to, or attentive to the perspective of the dominant class, as well as their own (Neilson 1990).*

This awareness or “double consciousness” makes this less dominant group, in this instance remote Aboriginal women, more sensitive as they view and experience the world differently, and it is to their advantage to know men’s views and understand their motives, interests, expectations and attitudes (Neilson 1990).

Feminism has provided a focus on ‘gender identity’ that is socially constructed, with gender being recognised as a key determinant of health (Smith JD 2004). The roles of women that include their responsibilities as carers of family and extended relations, their cultural roles, traditions and activities, are often factors that impinge on their own health and wellbeing. While this is applicable to all women, Aboriginal women are particularly affected and are the focus of this research.

### ***3.2 A holistic approach to women's health***

Primary healthcare is an essential component of the health and wellbeing of women (WHO 1986). The screening processes and health information that enable the early detection of illness and provide better options for intervention and treatment of disease, are essential strategies for improving women's physical health. However, these strategies alone do not provide a holistic approach as social health and wellbeing of women are as important, as disease detection and management.

Issues of social and environmental isolation, extreme poverty, lack of transport, and threats to cultural identity and family all impact on the social health and wellbeing of Aboriginal women. Alcohol and other drugs and mental health issues, grief and loss, anxiety and depression, often compound geographical, socio-economic, and cultural issues in an environment of frequent violence. In remote communities, appropriate expertise in mental healthcare, psychology, alcohol and other drug specialist services to address social and mental health problems are severely limited or non-existent due to financial constraints, lack of support for health providers and distance between existing services.

In addition to physical mental health, drug and alcohol support, and safety from violence, holistic Aboriginal women's health programs require additional elements that aim to address their overall social health and wellbeing. These include health and lifestyle sessions, for example; nutrition, hairdressing, massage, art and crafts. Aboriginal women have the ability to portray their stories and history through art and particular crafts such as batik, painting and pottery. This enables some of their thoughts

and feelings towards country and family to be expressed in a manner that provides some solace and healing. Opportunities for these sessions need to be incorporated into well health programs to provide this holistic approach with safe women's space that is welcoming.

In isolated and remote areas there is a paucity of services/programs that extend beyond basic health care relating specifically to improving women's social health and wellbeing (Alston et al. 2006). This chapter explores successful programs in Aboriginal women's health from culturally appropriate primary health and wellbeing perspectives.

### ***3.3 Primary Health Care (PHC)***

Primary health care is defined as both a philosophy and a strategy of community health care (WHO 1986) that is accessible. Moving past crisis management to effective primary healthcare programs is the key to improving Aboriginal health. Historically, service delivery has been based on a sickness and disease model that responds to immediate injury and illness. Well health incorporates prevention and early intervention to restore and maintain health and is inclusive of social health and wellbeing. This impetus to improving social health and wellbeing is a crucial factor in making change to health care to address issues of socio-economic disadvantage and continuing grief, evident in remote Aboriginal communities.

### ***3.4 Determined Principles of Success***

The National Strategic Framework for Aboriginal and Torres Strait Islander Health (introduced in Chapter 1) states that resolving the issues underpinning poor Aboriginal

health, requires a partnership between Aboriginal and government organisations and communities, so as to more effectively address the complex and interrelated factors that contribute to persistent of health problems (NATSIHC 2003). There is evidence of health improvement where collaboration between Aboriginal communities and government agencies have used a comprehensive approach, supported by adequate and sustained funding. An example of this is the reduced child mortality rates, an outcome of the *Strong Women, Strong Babies, Strong Culture Program* (Fejo et al. 1998).

The following nine principles underpin the National Strategic Framework 2003:

- Cultural respect
- A holistic approach
- Health sector responsibility
- Aboriginal community control of primary health care services
- Working together
- Localised decision-making
- Promoting good health
- Building the capacity of health services and the community
- Accountability of services and effective use of funds (NATSIHC 2003, pp. 2-3).

These are discussed in relation to community development and empowerment in Chapters 4 and 6.

*Key elements of an effective and sustainable program*

The availability of effective primary health care that emphasises community ownership and control, with skilled and culturally appropriate health providers and

sufficient funding, are key elements to a sustainable and effective service (NATSIHC 2003). These principles listed below provide the foundation of collaboration between policy makers, health providers and communities to address their key priorities:

- 1. Increased level of resources to reflect the higher level of need of Aboriginal and Torres Strait Islander people*
- 2. Improved access to both mainstream and Aboriginal and Torres Strait Islander specific health-related programs*
- 3. Joint planning processes which allow for full and formal Aboriginal and Torres Strait Islander participation in decision making and determination of priorities*
- 4. Improved data collection and evaluation (NATSHC 2003, p. 2).*

These principles and priorities are not newly discovered as (Morley, Rohde and Williams 1983) and (Moodie 1989) advocated following the Primary Health Care principles endorsed at the 1978 WHO-UNICEF conference in Alma Ata to improve all health. The following selected effective Aboriginal health programs are outlined to demonstrate these principles.

### ***3.5 Exemplars of Successful Aboriginal Women's Health Strategies***

In exploring the successful health programs in remote communities, this research has focused where possible on Aboriginal women's health as a priority of Aboriginal communities and the principles and factors that contributed to the success of each program. Simultaneously, it has also described some of the existing Aboriginal

women's health issues that have required redress to illustrate the need for such programs.

*Poor Nutrition and Low Birth weight*

In remote parts of Australia many Aboriginal communities live in an environment of food insecurity; that is lack of access to affordable and acceptable nourishing food on a daily basis. The existing poverty and difficulty of obtaining good food regularly has seriously impacted on the health of many families and particularly on mothers and babies (Price 2004). In Central Australia, 25% of Aboriginal babies have been diagnosed as 'Failure To Thrive', i.e. they do not reach the standard weight for age on the National Road to Health Charts and may be as much as 50% below this required weight (Balmer et al. 1998). These babies have displayed a slow weight gain, delayed development and abnormal behaviours that predisposed them to acute infections from underdeveloped immune systems. They required frequent hospitalisation as infants and suffered from chronic diseases, especially renal and coronary disease as young adults (WHO 2003).

Mortality rates for respiratory infections and parasitic diseases are currently ten times that of non-Indigenous infants. Statistics for 2000-2002 showed that Indigenous babies were twice as likely to have a low birth weight; that is below 2,500 grams, than other Australian babies. Many of the factors that impact on these low birth weight babies have their origin during pregnancy and are associated with poor maternal health and related behaviours concerning tobacco, cannabis and alcohol consumption and very poor nutrition (AIHW 2005).

### *Improved Nutrition*

In the far North West of South Australia in the Pitjantjatjara Lands, the NPY Women's Council has supported a range of interventional programs to foster improved health outcomes for Aboriginal women and their families in remote communities. Good nutrition has been problematic for many families as most food is expensive as a result of high transportation costs. Food is brought into the communities weekly, by refrigerated trucks, and delivered to the local store. For many years these stores were franchised and the community had little control over what was transported in for sale and items that were popular, such as Coke and potato crisps were sold in large amounts. It has often been quite difficult for healthcare providers to influence the exchange of these products for healthier foods such as frozen orange juice, fresh fruit, vegetables, meat and cereal, as the community had to show a demand for this produce (Mitchell, personal experience 1981).

Over time, healthier eating and cooking sessions have been introduced into the community through women's programs and a healthy food choice policy has been introduced in many stores (Nganampa Health Council, NPY Women's Council and All Community Councils on the AP Lands 2002). Unfortunately, foods high in sugar are still readily available for sale (Balmer et al. 1998) and this influences children and young adults in their food choices. This has implications for these communities already experiencing a high incidence of Type 2 diabetes, especially prevalent in Aboriginal women (Spencer et al. 1998).

***The Nutrition Awareness Program 1998-2005*** was originally initiated by a group of Elder Aboriginal community women in 1996, concerned about the health of their

grandchildren, especially those under the age of two, who were frequently admitted to hospital with gastroenteritis, respiratory and other infections. The babies of young Aboriginal girls and women were often born prematurely, or small for gestational age at delivery, and became ‘failure to thrive’ infants (Balmer and Foster 1997). The young mothers often had difficulties caring for their babies and required support and health education provided within the program.

#### *Program strategies*

The project developed strategies to:

- develop awareness and knowledge about solutions for failure to thrive babies
- promote better health for both mothers and babies through nutrition workshops at the women's centre, cooking sessions, introducing good solid foods early, eating bush tucker, and reducing the availability and intake of high sugar drinks and take away fatty food
- support mothers and their babies and encourage their use of the clinic for weighing and receiving advice from both the senior women and clinic staff and promote hygiene and safe sanitation practices
- encourage family meetings and support in times of crisis.

#### *Program strengths*

The Nutritional Awareness Program, developed through the NPY Women’s Council and driven by the community with support and collaboration of clinic staff, has employed a welfare worker to assist the mothers with frequent hospitalisations and other issues arising. The ‘nutrition team’ has been able to encourage the local community stores to sell healthy foods, enabling mothers to provide nutritional meals for their own health and that of their babies and families, and enhance the growth and



development of their children (Balmer et al. 1998). This has been supported since, by the Mai Wiru (healthy food) Regional Stores Policy (NHC, NPY WC, CC AP Lands 2002).

Health providers and community women have identified the collaboration across agencies such as the Alice Springs Hospital, the NPY Women's Council and community personnel, as strength of the program. Balmer's original report (1998) stated that obtaining funding for continuation of the program was time consuming as allocation of funding had come from different sources as the program expanded, and further funding was required. At the time of publication, only process evaluation had been achieved (Balmer et al. 1998), however outcome evaluation was still in progress (personal communication L Balmer, 2003 Nutrition Program APY Lands).

### ***3.6 Maternal and Infant Health***

The ***Strong Women, Strong Babies, Strong Culture program*** is another program that was developed by Aboriginal women in the Northern Territory to address the issues of poor maternal and infant health and improved management both in ante and postnatal care. This program originated in 1992 in Darwin with planning and submission for funding to improve the health status of pregnant women and the health of their babies at birth, as demonstrated by increased birth weight (Fejo et al. 1998).

#### ***Program strategies***

A respected Elder Aboriginal woman, who was able to coordinate the program in a manner that best suited the other Aboriginal women in the community, commenced

the program in Darwin. It was developed in partnership with healthcare providers sharing a vision, but under Aboriginal control. Aboriginal women were trained to take leading roles as strong women and facilitate health information to young women on all aspects of antenatal, postnatal management and infant care that was inclusive of their cultural traditions and stories. Following its success, the program was then used as a model for other communities and extended to Alice Springs in 1996 and to the APY Lands.

#### *Program strengths*

There were some excellent outcomes identified from the Strong Women, Strong Babies, Strong Culture program. These included women participating in antenatal care earlier in their pregnancy resulting in an increase in mean birth weights of 200gm in two of the original communities that initiated the program. Women were healthier as a result of the program and the pre-term birth rate was reduced by 55% (Mackerras 2001).

Factors that contributed to the success included empowerment and community self esteem, grant funding controlled by the community and collaboration built between the community and health providers. The 'strong women' workers also identified the importance of the right people being selected as workers, and Aboriginal control of the program that addressed an identified community need, together with the formation of partnerships and collaboration with healthcare providers to ensure successful process and outcomes (Fejo et al. 1998). In 1998, this program was

provided with support for three years and extended from three communities to include 14 other communities in the Northern Territory (Mackerras 2001).

### ***3.7 Aboriginal women's screening programs***

Aboriginal women living in remote areas have limited access and opportunity to attend culturally appropriate services for well women's health checks. The issue of cancer is discussed here with the importance of accurate screening mechanisms and reference to programs that have been successfully implemented.

#### *Cancer*

Indigenous Australians have a higher morbidity and lower survival rate of cancer than other Australians (Kirov et al. 2003). Limited accessibility and less effective health programs in screening, relevant health information and fewer treatment options appear to have significantly contributed to this situation. When compared to non-Indigenous Australians, the incidence was greater for cancers of the liver (six times greater), lung and cervix for Aboriginal people. The cancer mortality rates based on the data collected in 2000-2002 for Indigenous Australians have been greater than for other Australians, and for Indigenous women, rates are double that of other Australian women (Condon et al. 2003).

Cancer mortality in the Northern Territory has been found to be an important and increasing health problem. The most prevalent cancer types (lung and cervical) are largely preventable through smoking cessation, Pap smear programs and early treatment intervention, and Hepatitis B vaccination. A decrease in cervical cancer

mortality reported between 1997 and 2000 may have been an initial response to more intensive screening through Pap smear programs, resulting in earlier detection, diagnosis and treatment, thus improving survival (Balmer et al. 1998; Condon, Barnes, Cunningham and Armstrong 2004).

### *Cervical cancer*

*"Cancer of the cervix is a condition where there is a recognisable pre symptomatic stage that can be treated and cured in most cases"* (Angus and Thompson 2000 ). A Pap smear can detect early cell changes in the cervix known as cervical intra-epithelial neoplasia before it develops into cancer. Regular screening of all women is the most effective method of early detection to reduce the incidence and mortality of invasive cervical cancer (Angus et al. 2000 ). Three out of four women who develop cancer of the cervix have not had regular biannual screening, or may never have had a Pap smear (Commonwealth Department of Health & Aged Care 1998). Reasons for Aboriginal women not accessing Women's health checks that include Pap smears and breast checks, can be partially attributed to the lack of health information and knowledge about the importance of this screening, and lack of access to culturally appropriate screening facilities by an experienced female provider (Durdin, Community Women's Health personal communication, 2003).

Human Papillomavirus (HPV) is a risk factor for cervical cancer. Detection of the virus has been shown to be prevalent in Pap tests of Indigenous women in Queensland (Reath, Patel and Moodie 1991). In 2002, cervical cancer was reported as the main cause of cancer death amongst Queensland Indigenous women, being ten

times that of other Australian women. The report endorsed that regular Pap screening can prevent the development of 90% of squamous cell carcinomas of the cervix. Participation rates of cervical screening varied between 19% to 63% in the thirteen communities researched in this study (Coory, Fagan, Muller and Dunn 2002).

### *Breast Cancer*

High fertility levels and childbirth at an early age amongst Indigenous women are thought to be protective factors against breast cancer. Breast cancer mortality rates, although reportedly lower than cervical cancer, are thought most likely to decrease with earlier diagnosis and improved access to effective treatment (Balmer et al. 1998). However obesity remains a risk factor and a cause for higher incidence of breast cancer, diabetes and cardiovascular disease (Condon et al. 2003).

### *Program strengths*

In Coory's research, communities with a higher cervical screening participation rate, of over 50%, considered screening as part of their primary health care and had a commitment to training primary healthcare workers. This approach to health care, together with active maintenance of local information systems, appeared to be the main features of success (Coory et al. 2002). Critical evaluation of Coory et al.'s study reported that consulting with the communities directly, although time-consuming and challenging, could have provided further benefits for all participating communities. Outcomes through consultation could have resulted in increased participation, more knowledge and understanding to provide informed consent and improved participation, and a strengthening of trust that would further develop and assist subsequent programs to be implemented (Hunt and Geia 2002).

As mortality statistics for cervical cancer in Aboriginal women in Queensland remained significantly higher than the remainder of the population, (Kirk, Hoban, Dunne and Manderson 1999) investigated the barriers to cervical screening. Their findings reported that Aboriginal women lacked knowledge about the screening process and its use as a preventative measure for cervical cancer. They feared the procedure and held concerns about the possibility of an abnormal result, and the possible lack of confidentiality of their test results. Aboriginal women also stated they had feelings of shame and embarrassment and had limited opportunity for a female healthcare provider sensitive to their cultural needs, available for screening and follow up (Kirk et al. 1999).

These barriers are likely to be experienced by other women in Indigenous communities where culturally appropriate intensive programs have not been introduced from a primary health care perspective. Screening programs in remote Aboriginal communities in the past have often been associated with research into the prevalence of conditions and have not featured community control or involvement (ANCARD 1997).

### ***3.8 Sexual Health***

Sexually transmitted infections (STIs) are venereal infections spread by sexual contact with an infected person. The infections considered here are HIV/AIDS, hepatitis B, gonorrhoea, syphilis, chlamydia, genital warts and herpes. Many of these infections can result in significant morbidity and mortality (Healthinfonet 2003), especially amongst people living in remote communities if screening and surveillance

is not prioritised and included in well health checks. There may be no early symptoms or awareness of the infection and Aboriginal people in Central Australia have high rates of STIs (Menon et al. 2003) that increase the risk of HIV 3-5 fold (Wright, Giele, Dance and Thompson 2005).

Successful sexual health initiatives have been implemented across the whole Pitjantjatjara community through gender-focussed programs. In the Far North West of SA, Nganampa Health Council has implemented specific strategies to improve sexual health throughout their remote communities by: firstly, intensive screening and treatment for sexually transmitted infections (STIs); and secondly, improved methods of cervical screening and reporting.

#### *Program strategies*

A primary health care approach, targeting age groups from 12 years to 40 years, and providing sexual health education for both genders, has significantly reduced the incidence of syphilis, chlamydia, gonorrhoea and trichomonas. Moreover, earlier detection of cervical smear abnormalities has enabled earlier treatment options and improved prognosis (Nganampa Health Council 2001). A centralised database register and electronically delivered confidential results, has enabled faster reporting and more effective targeting of treatments to transient populations moving from community to community (Miller et al. 1998; Nganampa Health Council 2002).

The Tri-State HIV/STI project based in Central Australia and the National Indigenous Australians' Sexual Health Strategy were both implemented following advice in 1992 from eminent ophthalmologist the late Fred Hollows, who had devoted enormous

energy and commitment to treating trachoma in remote Aboriginal communities. Dr Hollows was concerned with the absence of any HIV screening processes and the possibility of an epidemic in the near future, if specific screening was not conducted as a matter of urgency for Aboriginal people in remote areas. Western Australian statistics revealed that thirty nine percent of female HIV notifications have been amongst Indigenous women since 1994 (Bowden 2005).

In 1994 an HIV program was implemented as a priority alongside STI screening for syphilis, gonorrhoea and chlamydia in the APY Lands in SA. Program organisers addressed the issues of client confidentiality through coding, education and support for all clinic staff and clear protocols for when a test should be offered, to provide a more comprehensive uptake of this screening (Miller and Torzillo 1998).

The community saw cervical cancer and STIs as a priority in women's health in 1996, and the APY community program was developed to empower women to access these screening services. Anangu senior women assisted as key community informants to advise other women through their expertise in Aboriginal women's health. Following training, Aboriginal female health workers together with other healthcare providers, were able to provide culturally sensitive services in the promotion of sexual health education programs for women in their community. The utilisation of community involvement throughout all stages of the program and a commitment to scientifically sound, practical, sustainable interventions, ensured the success of the program (Reath et al. 1998).



### *Program strengths*

This sustainable health program, initiated in 1985, is continuing as an effective strategy in 2004 through the strong support of healthcare providers working for Nganampa Health Council in the seven communities. The incidence of STIs has continued to decrease. This screening and intervention program has resulted in a reduction of active syphilis from 20% in 1985 to 0.4% in 2003, gonorrhoea 14.3 % in 1996 to 4.6% in 2003 and chlamydia 9% in 1996 to 4.2 % in 2003 (Depraetere 2003a; Depraetere, Know, Hateley, Mick and Scales 2003a; Depraetere et al. 2003b).

Key factors identified in the reduction of these infections include:

- Improving access to STI services through separate rooms and access for men and women, staff confidentiality, and the use of more acceptable non-invasive tests.
- Integrating STI screening activities into existing healthcare delivery such as well health and antenatal checks and improved distribution and access of condoms
- Identifying high risk groups and refining strategies to work with these specific groups such as 15-25 year olds, and petrol sniffers, together with the reduction in age of screening girls from 14 to 12 years old
- Monitoring and evaluating the program and directing the program to those at greatest risk
- Keeping the communities and staff well informed and collaborating between clinic staff, community educators and program staff
- Community support and Aboriginal reference groups
- Adequate resources including policies, protocols and language resources (Depraetere 2003a).

This model of sexual health screening intervention and health promotion has been adopted by the Tri-State Program and is administered from Central Australia across the breadth of the Pitjantjatjara Lands which traverses the Northern Territory, Western Australian and South Australian borders. Effective outcomes have been demonstrated through screening, treatment, and promotion of condom use to prevent the spread of STIs. An audit undertaken by Menon et al. (2003) identified that the prevalence of STIs in 23% of women and 19% of men screened, reported that a substantial number of screenings were undertaken as part of well health checks and opportunistic screening as people presented to the clinic for other reasons. For women, the consequences of STIs have additional serious implications which include pelvic inflammatory disease, ectopic pregnancy, infertility, spontaneous abortion, stillbirth, neonate infection and low birth weight (Healthinonet 2003).

More recently, positive health outcomes have been achieved by encouraging further community inclusion in the program planning and development processes (Depraetere 2003a). In addition to this collaboration, culturally appropriate health information is given in a supportive environment to facilitate lifestyle behaviour changes (NATSIHC 2003). Although incidences of STIs and HIV are now low they are still evident, and will quickly escalate if the screening priority was to diminish (Depraetere 2003a).

Aboriginal health workers play an essential role in enhancing communication and knowledge between Aboriginal women and their local healthcare providers. Their role in health promotion and in program delivery can greatly improve the active

participation of community women in better self-management of their own health. The clinic team of health worker, RAN and where possible, a female GP can provide a culturally sensitive environment for Aboriginal women to discuss their health issues (Carey 2003).

### ***3.9 Young teenage women***

Widespread implementation of sexual health interventions for young Aboriginal women has been difficult to achieve in remote settings, especially for those who are no longer attending school. This has been partly due to the heavy workload that healthcare providers carry in remote clinics addressing acute health problems, and who found that primary health programs are often neglected when frequent medical crises occur (Bowden 2005). Constraints include the culturally sensitive issues that surround sexual health for girls and young women and their shyness in discussing these issues with clinic staff. Traditionally, this information sharing has been the role of the Elder women in 'secret women's business' and this information therefore needs to be passed through the most appropriate communication channels in the women's community setting.

Young teenage women require encouragement to attend well health programs as many of the strategies used for prevention, screening and diagnosis to reduce the morbidity and cancer mortality are the same strategies required to reduce the impact of other health and social issues (National Public Health Partnership Achievements 2001-2002). Improved strategies to facilitate Pap screens through holistic women's health programs have other benefits for women, providing health information and

improved access to other diagnosis and treatment options of all infections and chronic conditions, not only cancer (Condon et al. 2003).

*A holistic approach to meet the needs of Aboriginal women*

Beyond the Pitjantjatjara Lands in remote areas of South Australia there has been little evidence of effective, holistic programs implemented to improve Aboriginal well women's health. Sexual health screening alone is not sufficient to address women's health and more effective health assessment has been required. As a result, the Medicare rebate for Aboriginal health checks every 18 months was established in May 2004 to provide for a more complete well health assessment (Commonwealth Department of Health and Aged Care 2004).

This reimbursement encourages and supports regular planned health checks by enabling time for the health worker, RAN and doctor to work together, to undertake a complete physical assessment that includes mental health, drug and alcohol, social health and wellbeing. Other Aboriginal health programs have been effectively established by Aboriginal community women working together with RANs and allied healthcare providers, with Aboriginal women employed in positions as co-ordinators of Aboriginal women's health programs (Gleeson 2003).

Aboriginal women want healthcare that takes a holistic approach to identify and meet their social, emotional and physical needs, with services that are flexible and supportive. The services of female staff that include a doctor, Aboriginal health workers and RAN who are able to communicate well, provide expertise in Aboriginal

health that is inclusive of cultural considerations, respect and dignity, are critical to the acceptance of their healthcare services(Hunt and Geia 2002).

### ***3.10 Aboriginal Well Women's Holistic Health Care in Central Australian Remote Communities***

In Central Australia an Aboriginal Well Women's Health program has been developed which covers ten remote communities. This comprehensive, culturally acceptable program is organised by a NT mainstream community women's health nurse educator for the community women. This program is conducted over three days and covers all aspects of women's health, including nutrition, sexual health, cardiovascular, reproductive, alcohol and other drugs, domestic violence and social health and wellbeing activities such as hairdressing, cosmetics and dancing. This model of women's health program was first established in 1991 that is highly regarded by the participating women has been continuing successfully for 13 years (McElligott 2005).

#### *Program strategies and strengths*

The aim of the program described above was to develop a holistic approach that would incorporate all women's issues and provide a culturally appropriate environment to manage any health problems (Gilles, Crewe, Granites and Coppola 1995; Yeundumu 2001). Through consultation with the remote Women's Health Nurse Educator, the women in each community chose the health information topics and lifestyle sessions they wanted for the program, together with the time of the year that would best suit their community. The team was then built by the co-ordinator to meet the women's needs for the specific program they had requested.

The Well Women's Health team travel to the remote community together, taking all their food and equipment and they stay together in any facility that is available for the program's duration. An evaluation book is available throughout the program for women to record their comments on any aspect, and provide suggestions for further programs. Both during and following this well health program, women's health holistic screening is undertaken at the local clinic by both Aboriginal health workers, female Registered Nurses and recently, a locum female GP.

This program is not only popular amongst women for the social health and wellbeing activities, but also because it achieves a high rate of success from among the health team implementing the health information, lifestyle sessions and women's health checks, using a Women's Well Health check list. This remote program is linked to Congress Alukura, the Aboriginal health service in Alice Springs, where women may also choose to visit for their well health checks that include cervical screening and breast checks (Congress Alukura 2004). This program was selected as the well women's health program that would most likely be suitable to transfer to a remote SA community.

### ***3.11 Mental Health***

To address Aboriginal women's health issues in a holistic manner, physical, mental health and social health and wellbeing must all be included. The first national Australian data on the prevalence and patterns of Indigenous mental health disorders was only reported in 1999 by the Australian Bureau of Statistics (ABS), which

undertook a representative sample of the adult population (Andrews, Hall, Teeson and Henderson 1999).

Measuring mental health in the Aboriginal people has been difficult, as standards and collection tools have not yet been developed to accurately assess the holistic view of health and experience of mental health held by them (Australian Bureau of Statistics 2001). Hospital statistics through separation data especially in SA, have identified that Aboriginal patients have suffered a high incidence of mental and behavioural disorders resulting from psychoactive drug use, that between 1995 to 2000, revealed between two and twenty-five comorbidities per client (de Crespigny et al. 2004c). These issues require further investigation, as poverty, disadvantage, isolation, social and psychological distress, and illness, are precursors of assault and suicide (Australian Bureau of Statistics 2001).

Lowitja O'Donoghue (2004) offered her insight into her own experience as one of 'The Stolen Generation', when as a keynote speaker, she described the environment in which Aboriginal women in remote communities survive. At a forum on Gender Equity she revealed that:

*Many Aboriginal people carry the emotional scars of their earlier experiences. ...Aboriginal traditional culture is not an individualist culture, the bonds of kinship, community and family are absolutely central.*

*The families of these 'stolen' children also suffered greatly from their removal, not knowing where they were, or whether they would ever meet again. Some have not. In describing her first meeting with her mother as an adult, she stated that there was no common language to communicate, and even if they could, they knew nothing of each other's lives and experiences*

*Political decisions of the past, to assimilate these Aboriginal children into the white community by removing them from their*

*families and traditional culture, have had repercussions of enormous proportions on their physical and mental health and wellbeing. This, together with the dispossession of their lands and dissimulation of their culture, has had an enormous impact on the physical and mental health of Aboriginal people. Women in particular suffer unresolved grief from the separation of their children and family bonding and the loss of their traditional kinship and culture.*

*In real terms, a woman in a remote community for example, is inevitably having to cope with a whole range of issues that include grief for family members, both from her past and her present. Fears for the future of her children, surviving physical and sexual violence, struggling with poverty and all the related issues (O'Donoghue 2004).*

Sir William Dean (1996) in his report from the “Bringing Them Home Inquiry” stated:

*The laws, policies and practices which separated Indigenous children from their families have contributed directly to the alienation of Indigenous societies today.... For individuals, their removal as children and the abuse they experienced at the hands of authorities or their delegates have permanently scarred their lives. The harm continues in later generations affecting their children and grandchildren (Dean 1996).*

Unresolved grief continues through today’s generation and is now exacerbated by other social issues of violence, gambling and drug use. These further influence health outcomes and reinforce the vulnerability of Aboriginal people.

Collaborative research identifying the importance of mental health, drug and alcohol problems and issues relating to medication management, has been conducted by deCrespigny et al. (2004d) This project focused on education for Aboriginal people in safe medication management, transport and storage. It revealed amongst many issues related to medication administration and adverse effects; compliance and non-compliance, procurement, cost, sharing of medications together with the serious



general and mental health issues associated with this management for Aboriginal people.

*Program strategies*

By linking Aboriginal controlled services with pharmacists and general practitioners, and using existing resources and services, a problem-solving approach was implemented to address the difficulties experienced by specific Aboriginal communities.

*Program strengths*

Capacity building was orchestrated through local education workshops provided for Aboriginal and non-Aboriginal workers and community leaders on culturally safe medication management, mental health, alcohol and other drugs, clinical interventions and shared care, and referrals. Three day intensive professional education programs were offered, focussing on safe management of intoxicated people, rationale and provision of and clean needles and syringes, safe medication management in community settings, alcohol and other drugs and mental health co-morbidities, and research training for Aboriginal research assistants. Innovative health education resources specifically designed for Aboriginal people were provided throughout the program on a range of topics that included petrol sniffing, cannabis, alcohol, tobacco and medications, diabetes, dementia, asthma and eye care.

The continuing success of this program is reported to be directly related to the consultation, planning, cooperation, collaboration and active participation of

Aboriginal communities, their health workers and community-based service providers working with the research team (de Crespigny et al. 2004c). Sustainable change strategies to support better medication management, education and awareness of mental health issues, are the reported outcomes of this process that has enabled extensive disclosure of previously unreported mental health and medication problems.

Mental health disorders are often complicated by alcohol and other drug use and are more likely to become chronic and debilitating (Teeson, Hall, Lynskey and Degenhardt 2000). Mental health issues are therefore often incorporated under comorbidities of disease.

### *Comorbidities*

Concurrent comorbidity is defined as the occurrence of two or more diseases or disorders at one time. This indicates an extreme vulnerability to illness and ongoing poor health that requires a higher demand on health services (Andrews, Issakidis and Slade 2001). Aboriginal people generally suffer from more than one acute/chronic illness. A high percentage of deaths reported from digestive system diseases including liver failure and pancreatitis, are related to alcohol use and chronic liver disease. Renal disease and the prevalence of renal failure are endemic and diseases such as tuberculosis and STIs of syphilis and gonococcal infections are still markedly evident (Australian Bureau of Statistics 2001). The high incidence of rheumatic fever is associated with Group A Streptococci in throat, and skin infections such as scabies. The propensity for cross-infection through overcrowding and continued poor living conditions in Aboriginal remote communities, is implicated in extensive rheumatic

heart disease that is often undiagnosed until significant cardiac insufficiency is evident (Carapedis et al. 1998). This has serious ramifications on other body systems reducing both the quality of life and life expectancy.

In mental health, comorbidity is used to describe two or more disorders, for example, alcohol dependence and depression. Tobacco is a common concomitant drug often used by people who have mental health issues. Comorbidities are an important issue as one illness may impact on and influence another, worsening symptoms, i.e. depression may increase alcohol consumption and alcohol-related conditions such as liver impairment and this may also affect the effectiveness of treatment regimes (Hall, Lynskey and Teeson 2001). Wilson (2001) stated there was a lack of appropriate and well coordinated services to meet the needs of the significant numbers of Aboriginal people with comorbidities. He recounted previously successful programs that were simple and cost effective. However, they needed better dissemination that involved Indigenous people in the planning and evaluation, as this is known to improve sustainability and acceptability.

### ***3.12 Family Violence and Sexual Assault***

Violence and sexual assault against Aboriginal people were first recorded following the arrival of the First Fleet from England in 1788, described in Chapter 2. This anger and aggression amongst and against Aboriginal people has continued over the last 200 years and is evident as sexual abuse and family violence today (Jones 2006; Skelton and Milovanovic 2006). While violence against women and children is a continuing concern, the healthcare system is failing to provide adequate protection to

assist victims whose wellbeing and safety have been threatened by physical injury, psychological abuse and sexual violence (McMurray 2005).

The violence in communities is attributed to many socio-economic factors, overcrowding, poverty, loss of hope and unresolved grief, as well as the more publicised alcohol and other drug use that aggravates and intensifies the situation. There are few effective programs that have been culturally able to address this issue for Aboriginal women, especially for those living in remote areas where the incidence of family violence is much greater and many instances go unreported (Robertson 2000).

The NPY Women's Council is one group who have been trying unsuccessfully to establish an effective family violence program in the APY Lands and they returned a large amount of Commonwealth funding given to implement such a program (personal communication NPY women 2003). Research into how best to address violence and sexual assault in Aboriginal communities has been limited as these issues and stories are sensitive and are often kept hidden by the victims. In addition, perpetrators are often not prevented from re-offending by the justice system (Dubbo Community Submission 2002).

### ***3.13 Trauma from sexual assault***

The brief outline of one successful program here, may not complement or portray the depth and emotional experience of Aboriginal people who participated in this program. However, the strategies employed significantly influenced participants to enable them to move forward (Atkinson 2002). *Trauma Trails Recreating Song Lines*

(2002) written from Atkinson's PhD research, illustrates the trauma experienced by Aboriginal people following sexual assault, and the healing processes that were employed throughout the program.

#### *Program strategies*

The research was designed to provide insight into the causes of violence, the experience of trauma, and individual healing in a group of Aboriginal people in Central Queensland (Atkinson 2002). The unique structure of the program provided a sensitive approach that was rewarded by increased awareness and responsiveness for both female and male participants. Using the process of Dadirri (deep listening) the research was organised using the principles of confidentiality and cultural safety through a series of workshops where the participants shared their stories and grew their own realisations of their childhood and developing adulthood, and discovered the influences that created their trauma (Atkinson 2002).

#### *Program strengths*

Cultural understanding of the social roles and sensitivity of cultural aspects such as Dadirri, enabled these participants to listen and share their stories, which then provided them with strength to cope with their experience. Cultural values and practices were used to promote healing and recovery for the participants. The principles of reciprocity were shared and understood by the group in a safe environment. The program was able to identify ways that healing of 'spirit' could take place and participants could then contribute to their own communities (Atkinson 2002).

## ***SUMMARY***

Successful programs to improve the health of Aboriginal people described above have identified key elements that have attributed to their success. To enable the successful transfer of an established program, the elements that made the program successful need to be identified and incorporated into the replicated program. These elements are now discussed here.

### ***3.14 Research Transfer***

The main purposes identified for the uptake of research findings as listed by Henry et al. (2004), are to inform health policy inclusive of required resources, to facilitate effective changes in professional healthcare practice and to provide positive changes in health-related behaviours and conditions.

#### *Dissemination and effective implementation of research transfer*

Much of the literature that discusses uptake of research evidence to improve health outcomes, refers to dissemination of the research findings within the community where the research took place (Saywell and Cotton 1999; Duffy 2002).

*Dissemination* is defined as “the process through which target groups become aware of, receive, accept and utilise disseminated information” (Agency for Health Care Policy and Research 1992). Much primary health care research dissemination has been through conference presentations and peer reviewed journals, and transfer to practice has relied more on good fortune than good planning (Kalucy 2002). However, successful health strategies need not be confined to the environment where they were originally initiated if they can be successfully deployed in other

communities with similar problems and characteristics. Dissemination of research findings and research transfer are terms often used in connection with one another, however they are separate and different concepts.

*Research transfer* is described as the linkage between the process of research and decision making in policy and practice and its influences in relation to behaviours and conditions of the community involved (Jenkin, Tjhin and Rubin 2001). O'Donoghue stated in her 2000 - 2001 Report for the Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH), that the process of research transfer should be seen as an essential component of the research in its planning and implementation stages, and be costed into the original project (O'Donoghue 2000). The CRCATH Indigenous Research Reform agenda provides a framework for significant change in research practice and management. Its team has developed a policy and a systematic approach to guide researchers through 'research transfer' into practice, with the collaboration of Aboriginal communities. The Strategic Plan (1999-2004) addresses issues of research transfer and informs practice by documenting the strategies that will assist this process.

A critical issue that is seen to impact on the successful uptake of research is the need for strong and effective collaborative partnerships (CRCATH 1999-2004). Matthews (2002) advocates that this collaboration, incorporating quality communication throughout the research process, will have a significant impact on the successful uptake of Indigenous Health Research (Matthews, Scrimgeour, Dunbar, Arnott, Chamberlain, Murakami-Gold and Henry 2002).

### *Implementation principles*

There are three important principles that need to be addressed as distinct from policy, to ensure the implementation of research. These principles Jenkin et al. (2001) identified as “dialogue, trust and timeliness” Communication, consultation and negotiation are essential elements in building community confidence and trust, together with a common understanding of what the research findings can contribute and how they meet the health priorities of the community concerned (Miller and Rainow 1997).

*Dialogue:* Extensive consultation and planning is necessary with all agencies involved in the research program, from development of the research question that includes the method design, prior to any attempt at implementation. The community’s needs must first be identified and agreement reached between the community and researchers that this a priority for the community at the time, and a full partnership established. All groups who have an interest, or will be affected by the program can then openly discuss the most effective methods of implementation in a forum that is inclusive, representative and continuous.

In the opinion of Lomas (1997), the timely and continuous involvement of community leaders, relevant decision makers and policy makers communicating early in the research project process, will ensure greater success in the application of research, its findings and recommendations. This strategy, when associated with interdisciplinary collaboration, can then provide different views that will further strengthen the research process (Lomas 1997).



*Trust:* Power imbalances have been blamed for many of the past situations in Aboriginal communities where distrust and suspicion have been evident, as researchers retained control of both the research and the researched (O'Donoghue 2000). Resources are valuable and scarce and so agreement needs to be established early, so that the implementation of research findings has the full support of the community together with the healthcare providers working in the community.

The community must be prepared to own and drive the project, taking responsibility to work in partnership with researchers and ensure it is properly established, nurtured, monitored and evaluated. This is best accomplished in a partnership between community controlled organisations and the external organisation that undertakes the research. Realistically, communities are more likely to be enthusiastic about projects where they have actively participated in the planning, conduct and evaluation (Kowanko, de Crespigny and Murray 2003.). Cultural sensitivity is also a significant consideration, as men's and women's business are quite separate and gender issues require full attention and respect. For example, a female researcher and coordinator for women's health programs and a male counterpart for men's health programs, who acknowledge these differences, will obtain the most effective response from their community. Trust relies on the researcher's capability to use appropriate research methods that can be validated by the community, to report back credible findings.

*Timeliness* is a notable component because this in particular has cultural and existence ramifications. Timeliness for the community must consider cultural issues

such as “Sorry Business” when all other affairs are postponed, sometimes indefinitely, as this is a time of mourning for the whole community. Certain ceremonies such as “Men’s Business” and “Women’s Business” need to be attended and kinfolk may need to travel long distances to other areas to visit relatives. Daily life issues also impact on the capacity to fully participate. There are good times to organise meetings, and bad times, such as when the pension or payments are issued or shopping needs to be addressed (Miller et al. 1997). Time has different meaning in Aboriginal communities and it is these time aspects that need to be considered, which may not suit the academic or funding organisation, or political time frames, and can therefore create tensions.

Timeliness for the practitioner is the accessibility of new knowledge or evidence of practice improvements, at a time when it is required by the health consumer (Matthews, Jenkin, Frommer, Tjhin and Rubin 2001). Timeliness for the researcher is a combination of factors that includes the availability of the community to be involved as a partner in the research process, the availability of healthcare providers, the completed process of ethical applications, acceptance and other considerations, within the timelines for the research application, evaluation and feedback to the community. Therefore timeliness is an important component for all involved in the partnership, to implement research programs and to ensure successful outcomes.

#### *Key Elements of program success*

The key elements of success are considered to be the empowerment of Aboriginal people in their communities through their active participation in the planning,

implementation and evaluation of health programs that use their particular knowledge and skills in providing health information and direct services. That is, that the programs are community controlled and driven in collaboration with and supported by those with the expertise in research, program design and healthcare delivery, training, health education and community development. These elements need to be supported through effective processes of dissemination, information transfer, systems and data recording, and financial stability, to ensure sustainability.

### ***3.15 Concepts of transferability***

Research transfer is a dynamic process that includes the socio-political and environmental contexts of the community involved in the transfer experience. Some authors concede that the transfer of research findings into practice can be a slow, difficult and unpredictable process (Lomas 1997; Saywell et al. 1999) and a significant amount of valuable research is often confined to the immediate area of interest (Grimshaw and Thomson 1998). However, research transfer involves more than the reporting data and observations that can become devoid of their social and political context. Research transfer can be applied to reform health systems, structures and processes (Anderson 1996), and Aboriginal health research transfer can employ strategies in knowledge development and skills to build capacity in ethical and collaborative research amongst Aboriginal groups, so they can take the lead in the future.

This research explored the concepts of transferability of a successful Aboriginal women's health program that has been conducted for some years in remote areas of

Central Australia. The participatory action research process has been employed to transfer the successful elements of this program to another remote Aboriginal community with similar health needs and socio-political and environmental context.

The implementation principles and practical strategies of research and research transfer have replicated the principles of participatory action research in their inclusiveness of workers and community members. Through a critical social science approach, the issue of emancipation has been addressed, by moving from a state of powerlessness to one of taking control over their continued poor health. Therefore Aboriginal women can be in a greater position of power, where they can make informed decisions about their situations and how to improve their health. Aboriginal healthcare workers and other workers are also empowered to build their skills and apply their knowledge while delivering the well women's health program.

There are specific strategies to ensure a successful transition of identified health principles from research evidence to health practice that include:

- Open communication and collaboration with other agencies that advocate empowerment and community self esteem (Henry et al 2002)
- Skills and knowledge transfer in policy development, service delivery and people's behaviour (Matthews et al. 2002)
- Building individual and community capacity through the research process through shared responsibility between the researchers and the community. (Henry et al. 2002)

- Financial commitment to ensure the viability and sustainability of the program
- Monitoring and evaluation of the success of the program within a set time frame

These strategies that bring resources such as education, training and practice guidelines, together with improved program systems through community information and new knowledge, into the community setting as part of the research process, enable research transfer to occur continuously throughout the program implementation, as part of the continual improvement and evaluation. This method of research design is described in detail in the following chapter.

### ***3.16 Summary***

This chapter has briefly discussed key issues of Aboriginal women's health, identified various successful health programs in remote Aboriginal communities and elements in program strategies that have led to successful outcomes in Aboriginal health programs. These strategies, together with the process that informs research transfer, can assist the development and implementation of the best method design to transfer, adapt and implement an established holistic Aboriginal well women's health program from Central Australia to a remote South Australian community.

## CHAPTER 4: METHODOLOGY

### *4.1 Introduction*

The previous chapters have identified the research objectives and reasons why women's health is a priority for Aboriginal women living in remote communities in South Australia. This chapter conveys the theoretical approach and rationale used to support this research and builds on existing studies and programs relevant to Aboriginal women's health. The complexity required to address this Aboriginal research in an ethical and culturally sensitive and respectful approach has required a confluence of methodologies. Therefore the study is a Naturalistic Inquiry situated within the Interpretive paradigm. It has been conceptualised within the philosophical approach of feminist /critical social theory against a background of cultural and historical events. It has sought to identify existing strategies and frameworks for women's health within the context of primary health care and community development principles examining Aboriginal women's priorities, practices, perceptions and expectations through Participatory Action Research (PAR). The historical beginnings of these methodologies are discussed and how they are congruent with Aboriginal research and Community Development.

The evaluation methodology is presented using Critical Social Theory to determine whether the AWWH program model and its principles were successfully transferred, adapted and implemented in this community using both the qualitative and quantitative data. The rationale for triangulation is explained that has enabled the collection of diverse data so that phenomena could be examined from different perspectives. The

evaluation model and its reflexive process, has been designed using the domains of Community Development to understand and measure any increase in the empowerment of community women and their healthcare providers working for the local Aboriginal health service.

In formulating this chapter my main concern has been to write it in a way that can easily be understood by a broad audience, and reproduced so that other effective programs can also be transferred to communities that need them, with minimal delay and development costs without 'reinventing the wheel'. The benefits of an already successfully established program being adapted and effectively transferred into another like community that needs it, are significant in time and resource efficiency. Time is something many Aboriginal women (and men) do not have in regards to their worsening health

*Entre`nous.*

As I finish this chapter on methodology and method, the sad news has come through to me from the community involved in this Aboriginal Well Women's Health research that two more women in their early forties, died yesterday. Both women's health crises were separate events and the causes of their death are as yet unknown. The Aboriginal Well Women's Program had been running for the week in the community and one of these deceased women had simply asked a health worker if the female doctor would give her stronger pain relief for her continuing problems. When the health worker responded that this was unlikely, this woman did not stay to see the doctor and team for a Well Women's health check that may have identified an acute health issue. The reader may well ask why this information is included here.

This AWWH program has as its underlying aim, the capacity development of healthcare providers working in a remote Aboriginal community, together with increasing the health knowledge of Aboriginal women through access to the AWWH program and support from the women's health team. This program will assist women to build their confidence in knowledge of health issues, treatments and positive lifestyle changes and enable them to make informed decisions about their own health and that of others. For many women, interaction with the Aboriginal health service and women's health team including well health checks and monitoring of health problems, is a new concept to improving and maintaining better health.

Generally, women and their families would attend the health service only when a health crisis occurred. The small amount of time required for a health check may have made a difference to the outcomes for these women. However, there are many more women in this community who have serious complex health problems. Some will have undiagnosed heart or renal disease, others undiagnosed or uncontrolled diabetes and circulatory problems, as well as poor mental health, drug and alcohol issues. Therefore it is hoped that what is conveyed in this research is readily accessible for readers, who can share with others what the women, healthcare providers and I have experienced together.

#### ***4.2 Overview of the study design***

This research builds on existing knowledge in Aboriginal women's health and uses principles of emancipatory action in developing a reflexive model of program transfer. To describe this emergent model in a way that it can be easily replicated,



some of my description is framed and defined graphically. An overview of the study is given here.

In order to achieve the essential processes of consultation, negotiation and collaboration, the research was designed to comprise three phases.

*The first phase* identified key informants with particular knowledge and skills in remote Aboriginal health, who could identify specific health strategies that were considered successful and possibly transferable. Key informants from peak Aboriginal health bodies, universities and centres of excellence in remote Aboriginal health were asked to define key elements of innovations, initially through phone calls and email communication, then where applicable, by a face-to-face interview. Key informants were asked about their priorities in health research. Both urban and remote informants identified Aboriginal women's health as a major priority for remote SA communities. This was confirmed and supported through contemporary literature and through interaction with an expert Aboriginal mentor from the Aboriginal Health Council of SA.

Successful strategies to improve Aboriginal health outcomes have been reported as those that respond to the particular needs of remote communities or groups and account for influences associated with culture, location, history, poor educational opportunities, poverty, cultural destruction and unresolved grief. Key informants were asked to determine the criteria that they used to establish what they believed was a "successful" strategy.

Examples were identified as those that demonstrate a positive change such as:

- Reduced incidence of a specific infection e.g. scabies; respiratory disease; otitis media
- Slowed progression of a chronic disease such as renal disease
- Fewer crises/emergency evacuations to central health agencies
- Fewer hospital admissions for specific diseases/injury conditions related to harmful alcohol/drug use
- Reduced acute care for interpersonal violence injuries required in community-based clinic facilities
- Increased program attendances and engagement of Aboriginal clients
- Improved health outcomes for a particular client group (less acute diabetic episodes, improved recovery rates, fewer re-presentations).

Innovative strategies were also identified within research reports, document and literature reviews, and key informant interviews and group discussions which were collected, collated, analysed and documented systematically. Professional culturally acceptable interpreters were used where needed, to enable conversation with traditional women whose first or preferred language was not English.

*In the second phase* of the study, the researcher sought permission from Aboriginal leaders to visit a remote community previously identified with a successful health strategy - a remote Aboriginal Well Women's Health program in Central Australia NT. and see the program in action. This gave the researcher the opportunity to consult directly with the community and local healthcare providers and listen to their views as to why they considered it successful. The literature was again consulted to support health providers views of a successful program and concepts of transferability that were discussed in Chapters 2 and 3.

*The third phase* of the study was to clearly determine the key elements of the selected successful program and transfer and adapt these to a SA remote Aboriginal community with similar characteristics, who had identified their need for the program.

As the development and implementation of a program transfer model was the major goal, process (formative) and impact evaluation were imperative. Therefore the study design was formulated with the evaluation methodology and processes clearly outlined for discussion and acceptance by the community who were receiving the program.

A synthesis of Critical Social Theory, Naturalistic Inquiry, and Community

Development were drawn on to inform the model development, data analysis and evaluation of the program processes and outcomes of the model that were developed using Participatory Action Research (PAR). While qualitative evaluation data provided an in-depth and culturally relevant understanding of the participants' and local healthcare providers' views and experiences of the program, some health data was examined quantitatively to provide statistical evidence of the number of women attending and the prevalence of illness and disease. These statistics complemented the qualitative information gained through the direct involvement of the researcher and PAG members in the program delivery, as well as key document analysis and interview processes. (O'Donoghue 2000; Boughton 2001; Rigney 2001).

### ***4.3 Ethical considerations***

#### *Researcher accountability*

Ethical guidelines are the vehicle to ensure that Aboriginal people are equal partners in all research processes involving them and that the researcher, at all times, respects and protects those people who are involved and being researched. It is well documented that Aboriginal people in the 1980s and earlier, were researched continuously without benefit to them or their communities

Ethical guidelines and Aboriginal Ethics Committees now guide the researcher towards the most culturally acceptable and ethical approaches to conducting research in Aboriginal health. For Aboriginal people, establishing, maintaining and growing reciprocal relationships with individuals and community groups reflect strong research ethics. These relationships enable effective communication flow, common understandings and goal setting and outcomes that benefit the community participating with the researcher in the research project (Tuhiwai Smith 2005). For these relationships to grow, mutual respect is essential and this can be a very complex concept that encompasses accepting and reciprocating effectively to different social values and behaviours, meanings and situations.

#### *The community expectations*

To meet the requirements of the SA Aboriginal Community Ethics Committee & NH&MRC Guidelines, the researcher was required, through liaison and advocacy, to strengthen the collaboration between healthcare providers, community and policy makers to address the needs of Aboriginal women in the community. The community expects the researcher to be respectful of Aboriginal culture, values and knowledge,

and to respond to the participants' needs as a higher priority than the research program itself. Undertaking continuous participation, consultation and collaboration in the research process and outcomes, also requires the researcher to disseminate the project information and later the findings through feedback mechanisms as appropriate, with the community, local healthcare providers and policy makers along the way. The community expects the program to provide practical outcomes, benefits and improvements in Aboriginal women's healthcare delivery and strategies that create community empowerment and development.

#### *Cultural considerations*

There is a need to promote cultural sensitivity, advocacy and partnerships and acknowledge the complexities of the people and their environment (McMurray 2004). It is most important to accept Aboriginal values and beliefs and be respectful of customs and traditions. There is a requirement to put aside any judgements and preconceived ideas and listen deeply (known as Dadirri), and not make assumptions about knowing what is best for the individual or group. The communication style should be sincere and open and sensitive.

*Cultural safe practice encompasses holistic consideration of the individual within the context of family and community, including customs, attitudes beliefs and preferred ways of doing things (McMurray 2004).*

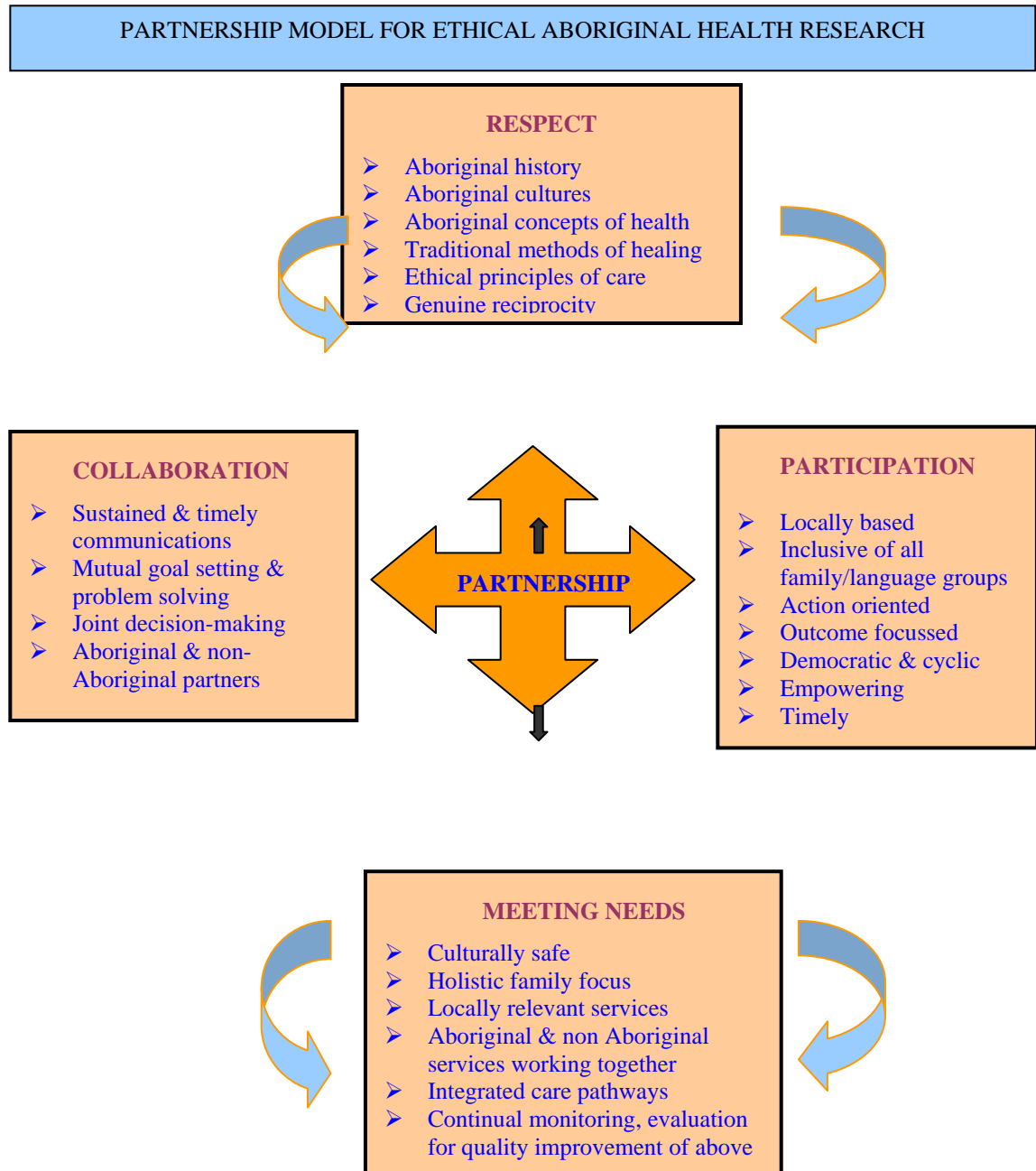
Rigney (2001) stated that there is an urgency in developing a more modern science that is inclusive of Indigenous research ethics and methodologies. He identifies this as "Indigenist research" as First Nation peoples have been excluded in participation

in the scholarship of western science research until recently. Indigenist research offers three specific principles:

- emancipation through resistance to accepting western research that does not consider recognition of cultural knowledge and the capacity of Aboriginal people to accomplish significant research,
- political integrity, and
- privileging Aboriginal and Torres Strait Islander voices (Rigney 2001).

Through his views of Indigenist research, Rigney reinforces the four elements of a partnership model that enables a respectful, collaborative and reciprocal approach to the Aboriginal health research process. A conceptual partnership model for ethical Aboriginal health research and practice was developed by de Crespigny et al. (2004a), evolving from their collaborative engagement, research and intervention processes. This is reproduced below with their permission. This model identifies the relationships between respect, collaboration and participation to meet the identified needs of Aboriginal people. This partnership model for ethical Aboriginal health research clearly displays the relationship between these elements and meeting the Aboriginal community's needs in conducting effective research.

#### 4.4 A Partnership Model for Ethical Indigenous Research



reproduced with kind permission C de Crespigny. (de Crespigny et al. 2004a)

This model influenced the manner in which ethics approval was sought and the research was conducted in this study.

### *Ethics applications*

Ethics applications were made to the Flinders University Social and Behavioural Research Ethics Committee, Yunggoorendi First Nations, Flinders University and the Aboriginal Health Ethics Committee of SA in 2003. Suggestions were made by them to strengthen the research and approval was obtained from these bodies in 2004 for the research to proceed. In addition, local approval was sought and given by the Board and CEO of the community controlled Aboriginal health service that participated.

### **4.5 Participation**

#### *Informed consent*

In this research, informed consent was clearly established and obtained from all participants. The researcher had an obligation to provide a clear explanation that was easily understandable for any of the Aboriginal participants and good culturally safe communication skills that would ensure people could comfortably ask essential questions and seek clarification before deciding to participate. It was essential that once consent was given, that interviews were conducted in ways that reflected consent and data was collected and managed in ways that ensured an honest and accurate account would emerge (Chong 2006).

The guidelines for ethical conduct in Aboriginal research describe these values and ethics as responsibility, survival and protection, equality, respect and reciprocity conducted in the spirit and integrity (NHMRC 2003).

The groups who contributed and participated in this study were:



- Key informants from centres of excellence in remote Aboriginal health and relevant policy advisors
- The Central Australian Well Women's Health team and Aboriginal women living in Central Australian remote communities
- Local and visiting Healthcare providers working in the recipient SA community in the AWWH program
- Aboriginal women who lived in the remote SA community and who actively participated as clients in the AWWH program.

These participant's roles are discussed in more detail in the Methods chapter.

#### ***4.6 Benefits to the community***

Benefits to the community are the objective of the research, and potential benefits need to be expressed explicitly in the study design so that there is a mutual understanding and collaboration between the researcher and the organisation to plan and reach this goal. It has been the experience of the researcher and local health providers, that many people in this Aboriginal community, do not seek early intervention for their health problems. The delay in detection and early treatment of disease for people who have many concurrent health problems significantly contributes to premature deaths from preventable and treatable diseases such as cancer, cardiovascular, diabetes and renal disease (O'Brien et al. 2000; Condon et al. 2003; Thomson and Ali 2003).

The DHS Women's Health and Wellbeing Strategic Plan (1998-2003) Northern and Far Western region, identified the need for further development in Aboriginal women's health services (Radoslovich and Barnett 1998). This AWWH program fits directly into the 2004 Australian government initiative of increased focus in well health screening for Indigenous people, as this primary health initiative aims to reduce the morbidity and

mortality of Aboriginal women in this community. The more frequent availability of a female medical officer may further encourage and increase confidence amongst community women to seek health assistance.

This Aboriginal Well Women's Health program enables Aboriginal women who have not had a holistic well health check, or who require any health consultation, access to the team of a female doctor with expertise in remote Aboriginal women's health, a clinic nurse and Aboriginal health worker, in a culturally sensitive environment. The adaptation of the program to meet the particular needs of women in the community encompassed a well health checklist that met the requirements of the 2004 Medicare holistic check for Aboriginal people. This checklist aims to assist health local care providers to use a more holistic approach when assessing women to determine their mental and social health issues, as well as their physical health.

In this approach, a primary health focus was implemented to address prevention, earlier detection and intervention of disease, issues of concern and to provide women with options in health management and continued monitoring. Health information sessions were incorporated into each intensive program to provide for this informed process. This program aimed to assist local Aboriginal women, who were falling between 'the gap' in mainstream screening in the absence of Aboriginal health screening services. Other women were reported to have travelled large distances to other major cities to access culturally appropriate health services not available in their community. The

program aimed to also identify any other agencies needed to improve the health of women in the community.

The philosophical underpinning that informs the research through the paradigms of Critical Social Science and Naturalistic Inquiry are now discussed and justified.

#### ***4.7 Theoretical Framework***

##### *Using Theory to Develop a Useful Model*

This AWWH research drew on Naturalistic Inquiry and Critical Social Theory using Participatory Action Research to explore the social, political and environmental relationships, and cultural context, of how a successful well health program for Aboriginal women established in one remote Aboriginal community, might be subsequently transferred, adapted and implemented in a second community. The critical theoretical approach was not only used to identify the issues that determined disempowerment and poor health in Aboriginal women, but to also begin to address these determinants through implementing and evaluating a Aboriginal women's well health program that was influenced and accepted by the recipient community.

The participation of Aboriginal women in such a primary health program, implemented by women healthcare providers in their own community, was seen as one way health services could empower community women to make informed decisions, and offer greater capacity for self management of their health. Community ownership could form a more sustainable and empowering model for the program to be transferred, adapted

and developed with the women being fully involved. This would increase opportunities for culturally acceptable ways forward.

Freire (1996) discusses empowerment of people through education that enables individuals to read and write, and therefore make informed choices about their situations. Education and good health are part of the same continuum. Improving understanding and knowledge through health education for both healthcare providers and community women through the AWWH program would then provide a catalyst for change and promote and support new healthier behaviours in the community. Providing health information and education and lifestyle sessions throughout the AWWH program, offered women options to enable them to make better and informed choices about how to manage and improve their health and social wellbeing.

Providing access to, and participation in, a holistic well health program such as this, where immunisation programs are conducted simultaneously with health education, screening and intervention for problems such as hypertension, diabetes, cancer, renal and dental disease and alcohol/drug problems, enables women to enhance their options and access expertise and the limited available resources. Furthermore, throughout the program the women were invited to participate in social health and wellbeing sessions conducted simultaneously, such as hairdressing, massage, art and painting that can enhance their self-esteem, dignity and self-confidence and sense of wellbeing.

Therefore, by drawing on Freire's work and the critical social science paradigm, the Well Women's Program model can extend the personal knowledge and capacity of workers and individual women alike, in this remote SA community. The newly adapted and transferred Aboriginal Well Women's Health model has reflected the elements and principles of the Central Australian Well Women's Health program. In this original program, participating Aboriginal women had already experienced positive health changes with immediate and long-term benefits.

*A synthesis of Naturalistic Inquiry and Critical Social Theory and the use of multiple methods*

Studies incorporating more than one methodology and mixed method approaches are able to generate more comprehensive knowledge about the phenomenon being researched, than studies using a single methodology or method. Mixed approaches may advance different values and positions that contribute to a holistic picture of the research findings and ways of knowing.

It is acknowledged by Guba and Lincoln that much has changed over the last ten years in social scientific inquiry:

*Inquiry methodology can no longer be treated as a set of universally applicable rules or abstractions (p. 191).*

*...There is a much greater synthesis of methods that inform the research process and augmentation of work particularly between Naturalist Inquiry, PAR and Critical Theory (Guba et al. 2005).*

The confluence of elements in Naturalist Inquiry, PAR and Critical theory construct a process whereby greater knowledge will emerge from the data analysis, to address the

research question and provide valid interpretations of the findings. These combined methodologies in research contribute to emancipation by redressing power imbalances of marginalised groups like Aboriginal women in the context of their community. The AWWH program through enabling choices for women in health information and screening, and the opportunity to discuss their health problems and better management, facilitates both individual and community empowerment.

Critical researchers explore “...*the foundations of truth through specific historical, economic racial and social structures of oppression, injustice and marginalisation*” (Guba et al. 2005). Through the process of identifying the issues (raised awareness or consciousness) that created the disempowerment, in a PAR approach, goals and actions can be determined to influence social and political change.

Feminist research within the critical social science perspective focuses on the distinctive experiences of women. It openly acknowledges all aspects of women’s lives including such phenomena as family violence, or sexual harassment, which may have previously been invisible or thought to be non-existent (Neilson 1990, p. 20).

Naturalistic Inquiry provides the rich context of the environment and individual inquiry that enables a comprehensive understanding and knowledge, which also makes social change possible. This is acknowledged by Lincoln and Guba who state that the shift from interpretation to social action in Naturalistic Inquiry is reported to have been:

*...in response to widespread non-utilisation of evaluation findings and the desire to create forms of evaluation that would attract champions who might follow through on*

*recommendations with meaningful action plans* (Guba et al. 2005).

These qualitative methodologies are now discussed in more detail.

#### ***4.8 Naturalistic Inquiry***

Naturalistic Inquiry originated in anthropology and sociology as the observation of people in their own environment undertaking their usual roles in their society. The researcher in Naturalistic Inquiry has a role that is known and acceptable to the community, and makes closer observation of some community behaviours possible. It reports this in ways that is useful to social science (Norris and Walker 2006) Norman Denzin wrote a paper on Naturalistic Inquiry in 1971 and described it as a theory that is grounded in behaviours, languages, definitions attitudes and feelings of those studied. It puts the sociological observer in the centre of the research where their interactions and reflections of themselves and others become essential data in the study (Denzin 1971, p. 167).

Lincoln and Guba first published their Naturalistic Inquiry text in 1985 and described the focus of Naturalistic Inquiry as the ‘natural world’ or real world, as the setting for social research. This is in contrast to a laboratory or artificially constructed environment, therefore the realities of the people researched are multiple, interactive and inseparable. In their later work, Lincoln and Guba (1989) changed the name of Naturalistic Inquiry to Constructivism, stating that Naturalistic theory was made up of constructs. Constructions are defined by Schwant (1994) as “*attempts to make sense of, or to interpret experience and most are self-sustaining and self-renewing*

*states*”. For the purpose of this research, however, I use their original term Naturalistic Inquiry.

In their more recent work Guba and Lincoln (2005) extend their concepts of the context and multiple realities. They postulate that the criteria for judging ‘reality or validity’ are not absolute but are related to the community consensus of basic beliefs in what is real, what is useful, and what has meaning, and these values are inherent in the inquiry process (2005, p. 197). Further to this, principles such as ethical considerations and spirituality are intrinsic in the research methodology, social concepts and realities, which have implications for action (p. 201).

#### ***4.9 The Rationale for Naturalistic Inquiry***

The Naturalistic Paradigm has provided a methodology that enables the researcher to build associations that gain entry to, and then carry out investigation of the people in their environment who are actively involved in the research that is acceptable to them. This overt action enables the researcher ‘as the human instrument’, to feel included and permitted to gain a real sense of the people’s social actions and their complex issues and views of their reality, which can then be interpreted and represented accurately. The researcher explored the environmental context of two Aboriginal women’s remote communities and observed and joined Aboriginal women and healthcare providers interacting throughout a well women’s health program in both of them.



#### *4.10 The context using Naturalistic Inquiry*

- *The Central Australian Community*

The Central Australian Aboriginal community was one of ten remote communities visited by the NT Well Women's Health team. The remote environment was picturesque and typical outback Central Australia with red earth, some native trees and a predominantly Aboriginal population, situated more than four hours drive from Alice Springs, the nearest major town. The local facilities included a general store, school, Aged Care facility, sporting complex of basketball courts, health service with a visiting doctor, registered nurses and health workers and a women's centre. The AWWH program was held at the women's centre over three days, where approximately fifty of the community women came and interacted with the team, and participated in a variety of health information, hairdressing and lifestyle sessions and visited the health clinic for screening purposes. Frequent interaction with, and observation of, the community women and the WH team throughout this program, enabled me as the researcher, to gain a more informed picture of why women thought this program was important and why they attended.

- *The South Australian community*

The South Australian Aboriginal community was located in a remote town about six hours drive from the next major town. The community has a diverse population of Aboriginal people and a large 'originally migrant' community who are involved in mining opal. The Aboriginal people named the town 'white man's hole' due to the opal mining history and evidence of mining shafts and 'slag mounds'. It is traditionally stony desert country with very few trees and hot conditions. The town is

also is a tourist centre and has facilities of a school, swimming pool, shopping centre with a variety of shops, hotels and motels, a hospital and Aged Care facility attached, an Aboriginal Health Service, and three general practitioner practices, and three service stations. The Aboriginal community numbers approximately 800 people but this fluctuates as family groups move up and down from the APY Lands. The AWWH program was held at the Aboriginal Health Service, originally over three days where I, as the researcher, was able to observe and join the healthcare providers and women interacting in activities dispersed with health screening activities.

Using a Naturalistic Inquiry approach, the researcher was able to gain a sense of how the community women interacted with healthcare providers and all aspects of the program. The women's views and their multiple realities could then be represented with those of the healthcare providers, and accurately reported.

#### ***4.11 Critical Theory applied to Aboriginal Women's Health***

Critical social science offers a framework for critique that will augment understanding of the social and environmental context of Aboriginal women's lives and informs how and why their health continues to deteriorate in the remote community in which they live. Critical social theory can reveal the political and social agendas that inform and enable change. Through critical consciousness amongst those affected, oppression can be redressed by empowerment to improve capacity, and control. Feminist theory that informs critical social science, has been utilised to advocate for equal rights and opportunities for Aboriginal women to gain

knowledge about their health and have real choices in health screening, treatment and referral to other services, in an environment that is culturally safe.

The values that critical theory can expose include inequality in economic, social circumstance, gender and ethnicity, and the power relationships experienced by those suffering inequality from the impact of the dominating culture. Critical theory provides a way of understanding power relationships with a clearly defined position allowing the researcher to distinguish values and structures that contribute to inequality in a particular group, and how they are connected:

*Critical theories are not abstractions. Their basis is in a living process created in everyday struggles of a group of people. It is grounded in the historical context of a concrete oppressive condition experienced by a particular group* (Stevens et al. 1992).

Despite the continuing decline in Aboriginal health and wellbeing, governments of the day and Aboriginal groups living in remote communities, have not been able to implement significant changes in the health status of Aboriginal people. This may partially reflect the historical health view that sees medicine as a body of knowledge that remains dominant and largely unchallenged, and which has ignored wider social, cultural and economic implications of health and ill health. The common view has prevailed that the provision of effective healthcare for Aboriginal people could be achieved through society's normal policy and political structures, and concepts of capitalism (Doyal and Pennell 1985, p. 12). Healthcare has been seen as a management of disease and illness, rather than being considered in the more holistic realm incorporating environmental, social and economic effects on health and wellbeing, which must also be addressed if sustainable health improvement is to become evident.

In the past, non-Aboriginal Australians have controlled resource management policy and decision-making for Aboriginal health. Rarely have Aboriginal communities been consulted about their ideas, knowledge and views of what were culturally acceptable. Aboriginal women in particular, have found their cultural beliefs have marginalised them from mainstream services, predominantly serviced by white male doctors and nurses. Many Australian nurses working in remote communities and country hospitals have added to the inequality and powerlessness of Aboriginal women through their dominant approach, lack of cultural understanding and ignorance about Aboriginal women's culture, beliefs and their traditional ways of knowing and managing health.

Although they have had many distinct roles in their own culture, Australian Aboriginal women were excluded from voting rights until 1962 (Maddern 2001). They played a significant role, however, in the 1967 Referendum to have Aboriginal people included in the Commonwealth census. Today, though, Aboriginal women are generally oppressed through the expectations of non-Aboriginal people that they will conform to the dominant society in the way they express themselves, behave, think and speak (Huggins 1997).

Nonetheless, Aboriginal women today remain the strength within their community, by continuing their nurturing roles and family responsibilities, and undertaking governance and leadership roles. Their voices need to be heard and through the feminist approach within the critical social science paradigm, and their differing experiences from men, can be identified. Aboriginal women in remote areas continue to struggle with their

high incidence of disease, unresolved grief through stolen generations, injury and violence and loss of children through suicide. They are strong in courage and leadership, but extremely vulnerable to abuse exacerbated by their socio-economic situations.

*Powerlessness to empowerment*

Since the early 1980s, violence, sexual assault, petrol sniffing and other drug and alcohol problems have been reported in remote communities, along with inadequate and non-existent housing, poor access to water and nutritional food, and lack of employment opportunities. The extent of these problems continue to multiply and raise some political awareness for short periods of time, reported in: 'The Coronial Inquiry Into Petrol Sniffing Deaths 2002' (Chivell 2002), 'The Demise of ATSIC' (Mitchell C 2004); 'Violence Parliamentary Submission' (AIFS 2004); 'Sexual Abuse and Violence' (DiGirolamo 2004a), and again recently in 'Alice Springs Town Camps' in 2006 (Jones 2006). However, for these issues to be addressed effectively, a collaborative process of consultation and strategies needs to be established and maintained between community leaders and policy and decision makers, with recognition of human rights.

An example of ongoing dominance that feeds powerlessness is the action of the Federal Minister of Aboriginal Affairs (Yaxley 2006), who organised a summit to discuss current issues of violence and child sexual assault, inviting only politicians from each state but with little representation by Aboriginal people. Without adequate representation, the views of Aboriginal leaders and community members are difficult

to be heard. Moreover, outcomes of such summits are not assured success when an interventionist approach such as this is taken, i.e. one that determines strategies that will only somewhat manage or contain the problems, rather than address the actual causes (Behrendt 2006).

These deeply entrenched issues of sexual assault, family violence and powerlessness can only be properly addressed through adequate consultation with Aboriginal leaders and community members. Both Federal and State government bodies need to invest in capacity building through real investment in community infrastructure, proper employment and training opportunities with adequate resources that are sustainable. Appropriate and compulsory schooling for all Aboriginal children until adulthood is urgently needed to break the continuous cycle of low economic capacity and develop tomorrow's leaders who are then well placed to address these issues. Currently, leadership and governance education, training and continued support is urgently required to provide specific knowledge to empower today's Aboriginal people who can then, as leaders, comprehensively address these issues in a collaborative manner.

In this research, a critical social science approach supports the collaborative processes of not only identifying the needs of the community, but also establishing an effective partnership in developing and evaluating the strategies that can be implemented to effect significant political and system change that empowers women to take better control over their situation. More relevant and culturally appropriate health screening, education and lifestyle support can achieve this.

#### *4.12 The Rationale for Critical Social Science*

The choice of the philosophical and theoretical paradigm of this research project was determined by the cultural and environmental influences impacting on Aboriginal women's health and their need for empowerment, and meaningful change in their health and social wellbeing. Critical social theory allowed the examination of the elements of domination and control over women's lives, as reflected in the ill health and poor environmental conditions of Aboriginal women in a remote community in the Far North of SA. Historical and recent political and economic decisions and actions have provided the catalyst for their continuing despair, disempowerment and feelings of hopelessness, voiced by leaders of the Aboriginal community (Stanner 1968; Behrendt 2006; Yaxley 2006)

An example of the current situation in Central Australia is the fear of physical harm caused by deliberate assaults from Aboriginal men to disfigure and sexually mutilate Aboriginal women, who refuse to oblige their sexual urges. Women have been burnt by being doused with petrol and set alight or being burnt with fire sticks on the abdomen, genital and upper thigh areas, resulting in burns to 30-40% of their bodies. The actual incidence of this type of assault is unknown as many women are too fearful to report the abuse, but more women are reported to be seeking alternative accommodation in the women's shelter in Alice Springs (Skelton et al. 2006).

Despite these continuing atrocities, Aboriginal women have a resilience learned from their women's culture over generations, which depicts them as survivors rather than victims. Utilising their strengths, hopes, political awareness and cultural knowledge, critical theory can offer the framework to support emancipation and involvement in a well health program that can assist them to better manage their own health. Some parallels have been drawn

between Freire's (1996) philosophies of oppression of the poor, ultimately expressed in sentiments of hopelessness in Chile and Brazil, with the history and circumstances of Australian Aboriginal people since European settlement. This is explored through the illness, disease and poverty that have permeated the lives of Aboriginal women living in a remote community in South Australia, and their opportunity to better manage their health and that of their families, through knowledge gained from access to the AWWH program.

Historical issues such as squalor, poor access to food and clean drinking water, lack of adequate shelter from the environment and minimal education portrayed the plight of many Aboriginal groups in the nineteenth and twentieth centuries (Kidd 2000). Imposed by the dominant white Australian society, these conditions continue in remote communities today. Aboriginal community control of remote communities in SA since the early 1980s, has not addressed the environmental and socio-economic issues that equate living standards of many Aboriginal people, as comparable or worse to Third World countries. Lowitja O'Donoghue described the environment that Aboriginal women were subjected to, following her visit to the APY Lands in South Australia in 2004:

*In many Aboriginal communities in Australia, people are living in third world conditions within a first world country. They do not have the basic requirements of clean water, decent housing or access to health services and on any social indicator, Aboriginal people are always hugely over represented at the wrong end of the scale. These indicators include, their health status, educational achievement, employment, rates of custody, infant mortality, suicide rates, drug and alcohol misuse and family violence. This shocking state of affairs arises from the brutal history of colonisation where traditional Indigenous culture was ravaged and there has been no place for Indigenous people within the new order.*

*Aboriginal people are quite literally struggling to survive and women especially, are working hard to find ways to try to keep their communities going and protect the young. There are inspiring*



*examples of work being done on the ground, but often these are one off initiatives, rather than a coherent and interlocking strategy (O'Donoghue 2004).*

Scientific quantitative research has traditionally taken a very top-down approach, and in Aboriginal research the 'subjects', Aboriginal people, have not been seen as part of the solution or leaders in identifying the problems or achieving solutions that will work for them (O'Donoghue 1998). A decade earlier, Fay had identified power imbalance as a feature in the lack of behavioural change:

*The established structures of power and organisation are able to shape people's lives because they are accepted as the presumptive givens which define how people are to behave and relate to their fellows; in this way people collude in their oppression because they unwittingly obey them in an automatic, uncritical way (Fay 1987).*

Lifestyle changes can only occur if and when people feel hope that change is possible and they have the opportunity, resources, skills and knowledge, to be active managers of their lives and personal change processes. The domains of community empowerment can support women's lifestyle behavioural change and assist them in their health improvement through participating in the AWWH program, utilising the principles of critical social theory advocated by Paulo Freire.

Denzin and Lincoln (1994) state:

*There are two distinct traditions within the ...critical theory model. One school following Paulo Freire, (Freire 1982, p. 30) regards concrete reality, dialectically conceived, as the starting point for analysis that examines how people live their facts of life into existence. The other school reads social texts ...as empirical materials that articulate complex arguments about race, class and gender in contemporary life.*

As this research is examining the lived realities of Aboriginal women in relation to their health, the critical theoretical direction follows the philosophical perspectives of Paulo Freire.

#### *Human consciousness*

*“Human consciousness in Freirean thinking was first defined by its distinctiveness from animal consciousness”* (Blackburn 2000, p. 3-4). Human awareness furnishes us with a consciousness of our own existence in space and time, and the opportunity to decide on a particular course of action as a result of reflection, together with the capacity of creative thinking. This capacity has enabled humans to improve their lives and opportunities “to become more fully human” (Freire 1972, p41). The economic, social, political and cultural environment determines how people live and respond to the restrictions imposed on them by those possessing power.

#### *Oppression*

Oppression is defined in this research *“as the exercise of authority or power in a burdensome, cruel, or unjust manner”* (Macquarie Dictionary 2006). Freire identified oppression through his own experiences in exile from Brazil and interaction with the impoverished and illiterate Chilean peasants. He concluded that “freedom” as a pathway to provide happiness and greater fulfilment was rarely a possibility for the poor: *“man may be free in theory but society appears to exclude some from realising that freedom”* (Blackburn 2000, p. 5).

Freire described the relationship between authority and freedom and the risks of denying people freedom through the consequences of an intensified authority and

supremacy (Freire 1996). While he relates this to his own situation in Brazil, it is evident in Australia's history, where non-Aboriginal authority has controlled the lives of Aboriginal people and discriminated against them in the worst possible manner.

The history of colonisation and treatment of Aboriginal people in Australia over the last two hundred years, and expectations that they will meet "our reality" by assimilating into the dominant culture, has compounded their sense of powerlessness and hopelessness. Chronic disease, premature and violent death, alcohol, tobacco and inhalant use in remote communities are the direct result of such hopelessness and powerlessness, with no indication that this extreme situation may soon change. Family violence that involves men, women and children results in generations of victims in situations that appear irretrievable and escalating. Parents and grandparents lose hope as they see young Aboriginal children some as young as eight, using inhalants (Craig 2004).

Many government reports have documented strategies to provide ways forward in Aboriginal health, such as the (Will's Review 1999) and (Many Ways Forward Report 2004), and National Recommendations for Alcohol Related Problems (2000). These and other reports require urgent implementation through collaborative approaches with Aboriginal communities. Redressing disempowerment in Aboriginal communities can provide hope for both present and future generations of Aboriginal people. Freire's philosophy of hope is quoted here to provide a shared understanding:

*While I certainly cannot ignore hopelessness as a concrete entity, nor turn a blind eye to the historical, economic, and social reasons that explain hopelessness - I do not understand human existence,*

*and the struggle needed to improve it, apart from hope and dream. Hope is an ontological need. Hopelessness is but hope that has lost its bearings, and become a distortion of that ontological need. ... We need critical hope the way that a fish needs unpolluted water (p. 8).*

*The idea that hope alone, will transform the world, and action undertaken in that kind of naiveté, is an excellent route to hopelessness, pessimism and fatalism (p. 8).*

*Without a minimum of hope, we cannot so much as start the struggle. But without the struggle, hope, as an ontological need, dissipates, loses its bearings, and turns into hopelessness. And hopelessness can become tragic despair. ... Hopelessness and despair are both the consequence and the cause of inaction or immobilism (Freire 1996).*

Hope alone will not achieve human goals because it requires a blend of planning, action, truth, optimism and resources to achieve these goals and bring about change. Freire states that hope is essential in existence and to lose hope is to create a situation for hopelessness and despair that are consequences of the inability to act. Ill health and community disruption are core symptoms of such disempowerment.

Freire was aware that when talking with groups of people who were urban and rural workers in their country, he almost always started with the reality of his own world rather than the reality of theirs. During the course of the talk or discussion, he was able to move from his own views "which were based on another type of knowledge" to understand the views of the people he was talking with and listening to and see their reality (Freire 1996, p. 22-23):

*I still nearly always started out with my world, without further explanation, as if it ought to be "the south" to which their compass ought to point in giving them their bearings. It was as if my word, my reading of the world, in themselves, were to be their compass (Freire 1996).*

The reality of how people perceive themselves, with their hopes and aspirations for themselves and their family, is integral to any likely impetus for change. Their behaviours and thoughts will be influenced by the perceived benefits to the individual and the community, together with the degrees of difficulty in anticipating and implementing the change. For example, health information explaining good nutrition by eating fresh fruit and vegetables may be well accepted but people may have difficulty in obtaining this through lack of money, opportunity to shop, or the lack of available produce.

There are many determinants of health; one of these is freedom to make choices. One of these choices is “*freedom to exist in a manner that is conditioned by their own cultural context*” (Freire 1996). Critical social theory, therefore, considers the historical context together with the environmental and political considerations impacting on the group at the time, as fundamental elements to be considered in examining the cultural values and power constructs affecting any required social change.

Aboriginal people have a strong bond with the lands where their ancestors and dreaming are, and they were once self-sufficient. Their human rights encompass their freedom to maintain their customs and traditions, and live in health and harmony.

#### ***4.13 Other philosophers of Critical Social Theory***

Lester (2001, p.120) described the usefulness of critical theory as:

*...overtly political in its intentions whereby it advocates for those most oppressed in society....It allows Indigenous peoples the room to tackle anti-colonialism and its sites of oppression and power.*

The development of critical social theory is important in terms of how it is used today. A historical synopsis is presented here to show how the dominance of one regime, Nazism, influenced the thinking of philosophers when their freedom was at greatest risk. The views of philosophers from the Frankfurt School were influenced by their experiences of disempowerment, as they were exiled from their homeland and were isolated in a new country and different environment. Their personal experiences and their return to Germany after the war and fall of Nazism, at the invitation of the people, affected the way they saw and used social critical science to empower those who had experienced such oppression.

*The Historical Passage of Critical Theory from the 1920s*

Critical Social theory originated in the Frankfurt School in Germany in the 1920-30s. Philosophers, sociologists, economists and historians including Adorno, Pollock, Fromm, Neumann, Marcuse, Lowenthal, and led by Horkheimer from July 1930 (Jay 1973), established the interdisciplinary research paradigm known as critical theory (Held 1980).

*War, oppression and human atrocity*

The 20<sup>th</sup> century involved two World Wars and the destructive philosophy and political actions of fascism and Nazism required explanation to both the European and Western cultures (Held 1980). The social and political views of the central members of the Frankfurt School were threatened in a fascist environment and moves were established to relocate their Institute outside Germany. Pollock re-established the main centre of the Institute in politically neutral Geneva, Switzerland in 1931 and the financial resources were quietly moved to Holland, another neutral country. Other smaller centres were set up in Paris and

London to assist The International Society of Social Research, as the Frankfurt School was now named in 1933 (Jay 1973).

In January 1933, with the rise to power of the Nazi Party in Germany, the lives of the core members of the Frankfurt School who were mainly of Jewish descent were at great risk, and their exile to other sympathetic countries began. Pollock was already in Geneva, Horkheimer left Germany in March, and was followed by other staff members as The Institute in Frankfurt was closed. Members were considered to have "tendencies hostile to the state" and over sixty thousand volumes in the library were confiscated by the German government (Jay 1973).

Fear of persecution continued and Adorno was asked by Pollock to relinquish his family name because of its Jewish significance as Adorno later reflected:

*The idea that Jews should show more pride by sticking to their names is but a thin rationalisation of the desire that they should come into the open so that one might recognise and persecute them more easily (Adorno 1994 cited in Jay 1973, p. 308).*

Geneva was not considered a permanent address for the Research Institute, as infiltration of fascist elements in Switzerland, endangered them and their work, other countries were explored for a safer environment for freedom of speech. Before his exile, Horkheimer had previously abandoned his lectures on logic to speak out on the issues of freedom (Jay 1973), and these implications, together with philosopher colleague, Paul Ludwig Landsburg's murder by the Nazis, made the United States an inviting proposition. The Research Institute was relocated to the United States following Horkheimer's acceptance of Nicholas Murray Butler's (President of Columbia University) invitation to establish the

Research Institute in New York, accommodated within the buildings of Columbia University and affiliated with it (Jay 1973; Held 1980).

*Freedom and expression*

Freedom of speech among the critical social theorists was now restored without political repercussion. However, other difficulties of assimilation into their new community were encountered by them through language and cultural distinctions, isolation from the people to which their theory and research was to support, and the coordination of philosophical grounded research with the empirical techniques of American social science (Jay 1973).

With the passing of time, this dedicated group under the auspices of the Research Institute developed and refined their views of critical theory. This incorporated the critical use of language to examine the elements and attitudes of socio-economic and political environments that impacted on and controlled specific groups, and the historical context from which this had appeared and continued, with an emancipatory view to facilitate social change.

Horkheimer clarified his view by writing:

*The verification and confirmation of ideas, which relate to men and society, does not consist in laboratory experiments or in the search for documents, but in the historical struggles, in which conviction plays an essential role (Horkheimer cited in Held 1980, p91).*

*Despite all its insights into individual steps and the agreement of its elements with those of the most advanced traditional theories, critical theory has no specific instance for itself other than its inherent interest in the supersession of class dominion (Horkheimer, cited in Held 1980, p. 193).*

In 1949, The Research Institute returned to Germany at the request of the people of Frankfurt, and the philosophers found that students and the community were enthusiastic



and revitalised by their teaching and experiences. Bonds with their adopted homes remained and a much smaller group returned from westernised countries. However, under the continuing direction of Horkheimer, the re-establishment of their freedom began, enabling them to express their views on home soil about emancipation and the theoretical concepts of critical social science to achieve this (Jay 1973).

#### ***4.14 Revival through Habermas***

Critical social theory again became prominent in the late 1960s by a revival through second generation German theorists, the most notable of whom was Jurgen Habermas. Habermas' position was that for social critique to be effective it was imperative to address the fundamental structures and ideologies of the social systems of the day. These social systems determined how privilege, exploitation and powerlessness can be confronted by social groups and individuals within specific cultures (Habermas 1985; Stevens 1989).

Distinguishing the basic tenet of Habermas's philosophy of critical theory, it is explained as a combination of both philosophical and scientific principles through systematic analysis exploring the concepts of social action and evaluating the underlying power structures and systems. Therefore communicative action and rationalisation of sociological theory can develop a critical evaluation and explanation of the dynamics of social processes (Bernstein 1985, p. 21-23).

In Habermas's theory of Communicative Action, Bernstein explains:

*We cannot understand the character of the life world unless we understand the social systems that shape it, and we cannot understand social systems unless we see how they arise out of activities of social agents (Bernstein 1985, p22).*

Habermas himself related the philosophy and path of critical theory that emerged in response to the domination by Nazi Germany and Stalin's regime, together with the impact of fascism and totalitarian communism on the people in the countries they oppressed.

Habermas described the Frankfurt School as follows:

*As a school it had been alive only during a few years of American exile. If there ever has been a Frankfurt School, it did not exist in Frankfurt neither before or after the Nazi period, but during the thirties in New York (Habermas 1986, p. 68).*

Herbert Marcuse, Habermas recounts, joined the Frankfurt Institute when it was on its way to the safety of the USA and aligned himself with the school's philosophy in his essay 'Philosophy and Critical Theory' (1937). This was well before the atrocities of Nazi concentration camps, such as at Auschwitz, during the Second World War. However, the philosophies of power and domination were well entrenched in Europe and critical theory was viewed as a methodology that would embellish the concepts of freedom and democracy (Habermas 1986, p. 72-3).

Views expressed by Habermas explained,

*Marcuse stated of his earlier theory of the concept of a free and rational society, that he had only made one mistake and that was, it did not promise too much but rather too little (Habermas 1986, p. 73).*

Under Horkheimer's leadership the Institute developed an interdisciplinary critical social philosophy, social theory and research method that could be used for social change. These two elements of collective autonomy and the power to affect change drive the process and outcomes of the critical paradigm. "*The central aim of a critical theory is action at the socio-political level*" influenced by social relationships and individuals' actions and subsequent outcomes. These occur within a particular

historical and political context providing enlightenment, empowerment and emancipation (Clare and Hamilton 2003).

Marginalisation and oppression can potentially affect an individual's state of health, safety and self esteem (de Laine 1997). The inability to be safe, have sufficient food and be able to feed members of the family, provide shelter, and have self worth and views respected, reflects the oppression of Aboriginal women, both within the culture and externally.

#### ***Linking Critical theory with this Aboriginal Well Women's Health Research***

The critical social science approach using PAR supports the research objective to enable improved health, social and political change for Aboriginal women in a remote community by increased access to, and knowledge of illness and disease, through the implementation of an Aboriginal Well Women's Health program. The transferred and adapted AWWH program will be critically evaluated to determine its usefulness in meeting the health needs of Aboriginal women in this community. The adapted model of well women's health will also be critically evaluated for use or further adaptation by other Aboriginal women in other remote communities with similar needs.

The philosophies of critical social science together with Naturalistic Inquiry are used to introduce a community empowerment model that can be reproduced. This use of mixed methodologies, and mixed methods is now briefly discussed.

#### ***4.15 The Rationale for (Triangulation) mixed methods***

*Triangulation is a term widely used for research designs where different sorts of [collected] data or methods of handling data are brought to bear on the research question (Richards 2005).*

The choice between quantitative and qualitative methodologies has provided much debate for researchers and academics, as to which is considered the most effective approach. More recently, the view has emerged that both quantitative and qualitative methodologies have particular strengths, and when used together they add value, greater integrity and knowledge to the research as each answers different questions relating to the same research (Trochim 2006a).

*Neither methodology exists in a vacuum or can be considered totally devoid of the other ... quantitative research tends to be confirmatory and deductive... but can be classified as exploratory as well. ... while much qualitative research does tend to be exploratory , it can also be used to confirm very specific deductive hypothesis (Trochim 2006a).*

There is an assertion that the use of mixed methods may also mix philosophical assumptions. According to Greene (2005) there are three main positions to consider. The first is that the design and method of the study should be driven by the context or the research purpose, not by philosophical assumptions. Secondly, there are tensions and dissonance between assumptions and this creates more comprehensive and discriminating findings through the use of more than one philosophical framework. Thirdly, the remaining view depicts that because the research should be driven by its aims, differences in philosophical construction are not considered problematic or beneficial.

Mixed methods approaches (discussed in Chapter 5) using two or more different kinds of data collection and analysis techniques, and more rarely divergent inquiry designs within the same study, can extend beyond the numerical/quantitative or narrative/qualitative to include other dimensions such as in-depth understanding of the context and people, such as in Naturalistic Inquiry (Greene et al. 2005, p274). The opportunity then presents itself to collect diverse data and examine the phenomena from different perspectives.

Aboriginal research requires mixed research methods to adequately address the cultural and other considerations in context and ensure dignity, respect and participation of Aboriginal people, within the research processes. This can be accomplished through collaboration, Aboriginal ownership and empowerment and in the exploration of needs and problems and the ways in which they require investigation.

Mixed methods have been employed in this study, ultimately to strengthen the findings and incorporate flexibility and resourceful approaches in order to obtain the true account and multiple realities of women and local healthcare providers. The application of Naturalistic Inquiry with Participatory Action Research techniques provides a greater depth of contextual data and information to guide improvements in health service management and individual women's knowledge.

This work builds on the critical work of others who have researched before, and who have asked difficult questions in how Aboriginal health can move forward, and who

have recognised that empowerment is a key that is difficult to activate, manoeuvre and evaluate. Labonte (2004) challenges researchers to consider how their work has improved the situation and how social inclusion has played a prominent part. Laverack (2004) has revealed his process of measuring empowerment through community development using specified domains and this model of empowerment has been incorporated into the research analysis and program evaluation.

#### ***4.16 Bringing Naturalistic Inquiry, Critical Social Theory, PAR and Community***

##### ***Development together: application to practice***

Naturalistic Inquiry was synthesised with Critical Social Theory PAR and Community Development in this research. The development of community empowerment models that have emerged from anthropological beginnings are discussed here to provide the context. The reason for using Naturalistic Inquiry was firstly to identify the context of a priority issue in Aboriginal women's health through extensive consultation, and then explore the successful elements of an existing women's health program. Exploring the environment of Aboriginal women attending the selected successful health program, and their views on how the program was useful to them, could identify the elements of success that could later be applied in another similar setting. The identified elements of success could then be effectively used to enable transfer of the program to another like community. The environment and social constructs of the accepting community would then be explored using the naturalistic approach to determine the best fit and identify any elements that required further adaptation to meet the needs of the local Aboriginal women living there.

Naturalistic Inquiry was chosen as an approach that would offer a rich description of the local environment in which the Aboriginal women lived and healthcare providers worked. This descriptive account enabled the successful elements identified in the original remote Well Women's Health program to be more easily identified, described, adapted and transferred to another remote community with similar needs and characteristics.

This recipient community could also be more richly understood and described through this approach, so that these successful elements could be constructed and adapted effectively to meet the particular needs of local Aboriginal women living there. This AWWH program followed the implementation guidelines of a community development model, with the critical social scientific goal of empowerment and capacity development, reflecting the acceptability and integrity of the research purpose.

A qualitative approach that supported Participatory Action Research (PAR) and Community Development principles was also selected for this research, following extensive consultations with Aboriginal advisors, health providers, ethics personnel, other researchers and most significantly, the community who chose to participate in the program. Strategies that supported PAR and community ownership were imperative in order for the program to succeed. These were implemented through cultural respect, continuous consultation and choice of approaches that best suited the local Aboriginal women in particular, and the health providers working in the clinic and the wider community.

A quantitative component was added to the qualitative methods following comprehensive discussion and consultation with members of the Aboriginal Health Council Ethics Research Committee of SA. Statistical data identified the number of women who gained access to, and participated in the Well Women's Health program, with the prevalence of disease. These statistics strengthened the validity of the descriptive data collected through qualitative techniques in interviews, personal communication, document review and researcher observation that identified the needs of Aboriginal women, and supported recommended strategies for change. These combined approaches to data collection were seen as an effective strategy that enhanced the quality of the research and identified specific participant issues. A rich description provided an understanding of the context of how and why the Aboriginal Well Women's Health program was adapted, developed and implemented to meet community needs.

#### *Exploring the context*

In this research a focus on primary healthcare was implemented through Naturalistic Inquiry, PAR and a Community Development approach. The Naturalistic Inquiry paradigm as described by Lincoln and Guba (1985) has characteristics that support this research (p.40-44). The *natural setting* enabled the researcher to become accepted, then observe and interact with the participants and explore their multiple realities that existed and therefore more fully understand the context.

Health and illness are always contextual and in remote Aboriginal women's health has been determined by their environment, history, inequality and poverty. Cultural



concepts and life experiences of health and illness are also embedded in people's individual social and cultural understandings of their own situation, and these influences can then affect their health behaviours and outcomes. A rich descriptive context of the social and cultural environment was essential to assist the interpretation of the data, and ensuring that the research provided a trustworthy account. Finally, the process of implementing the AWWH program can be described to illustrate the components of transferability in practice, enabling the development of a model of successful program transfer.

The findings of the research were seen by the researcher and groups involved in this project, as potentially useful for other community groups with the same or similar situations. In fact, an Aboriginal Well Men's Health program has recently emerged in the same recipient community based on their perceived success of the AWWHP model described in this thesis.

The realities and experiences of the women who participated in the AWWH program, and those who provided the services, were influenced by their own personal, experiences, cultural and social values, beliefs and assumptions. Cultural considerations and previous life experiences always impact on people's own knowledge and health behaviours, and these are by their nature, value laden. Outside the person's natural environment, these interactions and findings may alter and result in different explanations. The natural environment is the home country of many of the Aboriginal women participating in this project, and this land is steeped in their traditions and stories, that are a crucial part of their reality. These realities influence their expectations

of life, health and services, and the way in which they interacted with the program, healthcare providers and the researcher.

Other characteristics of Naturalistic Inquiry include the maximising effect of purposive sampling, the rich description of environment and women's values assisting the inductive data analysis. This in turn informs the elements of transferability of the program, and through interactions and observation of the researcher with the participants, the emergent transferable model. As Naturalistic Inquiry was used alongside PAR and community development in this research, the development of community empowerment models that have emerged from anthropological beginnings, are discussed here to provide the context.

#### ***4.17 The background to community empowerment models in Aboriginal research***

This section outlines a historical pathway of Aboriginal research as influenced by anthropology and psychology.

##### *Anthropology*

The pathway to developing research methods that can support Aboriginal community empowerment has been long and arduous. Originally, these research strategies derived from anthropological methods of data collection, where Aboriginal people were regarded as unique 'specimens', being subjects to be observed and described, in an era when anthropologists lived alongside their subjects while documenting their culture and lifestyle. Anthropologists such as Elkin from 1938 onwards, and Tonkinson from 1962 onwards, gained knowledge for historians about how traditional Aboriginal people lived in their communities and survived without the assistance of westernised cultures.

Tonkinson reported on a particular Aboriginal group - "Jigalong" - between 1963 and 1970. These Aboriginal people living in Western Australia were described as;

*...the combination of extremely simple technology and elaborate, integrated social and religious systems which characterises Aboriginal culture, is a rewarding subject for continued research" (Tonkinson 1974 Forward).*

He also stated:

*The tragedy is that, even today, few white Australians are aware of or appreciate the genius of Aboriginal culture. Given white ignorance of Aboriginal culture, and given the immense technological gap that separates Aborigines from western culture, no group could have been expected to have greater difficulty in adapting to the intrusion of the Western world (Tonkinson 1974, p. 4).*

In his works 'The Destruction of Aboriginal Society' (1972) and 'A Matter of Justice'(1978), Rowley documented the dispossession of Aboriginal people from their lands and the changes of this lifestyle to reliance on welfare, living on reservations and the demise of the nomadic strong and healthy, independent Aboriginal as described by Captain James Cook in 1788 (Rowley 1978, p. 42).

Stanner in his history of colonisation, described the political and historical governance of Aboriginal people and the consequences of colonisation on their continued survival in 'The Great Australian Silence' (Stanner 1968). As anthropologists, Stanner and Rowley informed other historians and the general public of the plight of Aboriginal people through avenues such as "The Boyer Lecture" on ABC Radio and their books (Stanner 1968; Rowley 1972; 1978). The main objectives of anthropological Aboriginal research were to observe and document the lives and cultures, of Aboriginal people in

their natural environment for historical purposes, and then describe the dramatic and negative impact of colonisation (invasion) on their lives and culture.

### *Applied Anthropology*

Applied Anthropology has been described as the basic relationship between theoretical and applied science, where the findings of the anthropological research were used to plan and determine future management in communities. The focus of Applied Anthropology moved to the social and cultural problems that accompanied technological change in developing countries after the Second World War with the impact on agriculture, social welfare systems and community development in health and education systems (Foster 1969). Foster suggested, on reflection, that Applied Anthropology may be the forerunner of Participatory Research with the principles relating to research being constant. Foster recognised the relationship between the research and behavioural change:

*Directed culture change goals are dual, almost always involving changes both in the physical environment and in the behaviour of people (Foster 1969, p. 5).*

Foster described the construction of shower houses and wash tubs for a remote community as a change of environment. However, the community women did not like or use these because they faced the wrong way. Unless these were used by the community for washing, no behavioural change had occurred and no advantage had been gained. This behavioural change took some time to occur and only after much consultation with the community concerned resulting in changes that made the washing complex acceptable (Foster 1969).

Applied Anthropology can identify new knowledge that can then be integrated with consultation and support from, and benefit to, the community. Saggers and Gray (1991) demonstrated a good example of Applied Anthropological research in their earlier research where they described and documented Aboriginal peoples' health in the context of their environment and how colonisation and policies of government had negatively impacted on their lives, culture and health. Their later research (1998) identified specific issues of harm from drug and alcohol use, the consequences of this and how the situation could be improved by working with specific communities to determine what they knew and believed would work locally to reduce this serious problem.

Moving towards effective consultation and collaboration with Aboriginal people, Applied Anthropology researchers have engaged with communities in order to determine how improvements in Aboriginal health and environment can be made, revealing existing issues and determinants of poor health, and exploring options for improvement that could meet the needs and approval of communities. Foster described the role of an applied anthropologist as including investigation into the structure and function of a society and the dynamic processes that inhibit or bring about change. He demonstrated the early development of action research by aiming to identify and resolve associated problems in scientific work as described by the example above, in the shower houses and wash tubs (Foster 1969).

#### ***4.18 Participatory Action Research (PAR)***

Building on anthropological research, 'Action Research' was a reflexive research model originally pioneered by Kurt Lewin in the 1940s. Lewin, who was interested in

the socialist movement and improving the position of women, was born in Prussia and injured in the German army in 1916. He attended the University of Berlin where he taught psychology and philosophy. He was invited to the United States as a visiting scholar in 1930 and settled there with his family, becoming an American citizen in 1940. Lewin reflected, that “*Individuals were seen to behave differently according to the way in which tensions between perceptions of the self, and the environment, were worked through*” (Lewin 1951, p. 240).

Lewin developed a reflective spiral of action research directed towards identifying and solving social problems, and providing a strategy for an inclusive, systematic and reflexive approach to collecting and analysing data that could empower those participating in the research to then take ownership and initiate change. Lewin’s goal was to integrate theory and practice. He designed a method that could achieve this through participatory action, reflection on action, and feedback by participants to ensure the researcher’s correct interpretation of data (Lewin 1951, p. 169). This forward cyclic spiral process of reflexivity; that is reflection, response and improvement, would continue until participants and he agreed that the desired research method and strategies were achieved. This was originally used in educational research and practice and refined by (Carr and Kemmis 1986) for this purpose.

#### ***4.19 Participatory Action Research and Community Development***

Since the 1980s, PAR has been used more broadly in community-based research described by Freire (1982, p21 ) and later Stringer (1999). Authors such as Freire

combined community participation in decision-making with methods of social investigation.

Freire, in a seminar he was delivering in Tanzania in 1982, stated:

*If I perceive reality as the dialectical relationship between objectivity and subjectivity, then I have to use methods for investigation, which involve the people of the area being studied, as researchers. They should take part in the investigation themselves and not serve as passive objects of the study (Freire 1982, p. 30).*

The fundamental principles of PAR are to develop needs-based practical research that can be used to develop programs and inform policy that will promote capacity and ensure greater self-reliance and social justice. The basic tenet is the full involvement of those who are the focus of the research, such as Aboriginal women. PAR provides access and opportunity for communities and individuals to act as active agents in participation through all stages of the research process, resulting in outcomes in ownership, decision-making and evaluation in the benefits and value to the community.

PAR principles include:

- methods that are inclusive and provide a better more explanatory approach to a complex reality
- practical methods able to be used as a base for policy and program development that can have immediate and direct benefit (process and results) and which promote social equity and greater self reliance
- a position on human behaviour which supports individuals as active in their own environment and not as passive subjects (Hall 1982).

Community involvement in research is determined as the active involvement and inclusiveness of people who expect to be the beneficiaries of the research, throughout

the entire research process, commencing with the choice of research problem and culminating with interpreting the findings and formulation of recommendations.

The action research process in the community that continues to observe act and reflect, was described by (Freire 1982, p. 30):

*I am researching again as, because to the extent that we put into practice the plans resulting from the investigations, we change the levels of consciousness of the people, and by this change, we do research again. Thus, there is a dynamic movement between researching and acting on the results of the research.*

Community development, through new essential knowledge, changes the state of the people from powerless to empowered. In working in participatory action research it is of fundamental importance to ensure that the interpretation of findings is commonly understood. That is the “*syntax – the people are using the same words in the same context as ourselves and understand our meaning*” (Freire 1982, p35 ).

In Aboriginal research the PAR approach provides the most effective strategies to stimulate sustainable changes that can have positive outcomes for the community’s health. PAR has provided a practical scientific approach to facilitate change in health practices through collaboratively produced programs and projects that involved and drew from the knowledge of the community. Through the community development approach PAR assists community members to work together in building relationships with others, based on shared understandings, develop trust and be involved in the decision-making and evaluation processes that provide for greater awareness and better outcomes (Stringer et al. 2005).



### *Community Empowerment and Development*

Community empowerment is an essential component of community development. This is explained as the potential for people to progress from an individual stance to collective cohesiveness and action along a dynamic continuum, through shared ideals in an organised approach that reflects their contextual elements and values. It also acknowledges their social cultural influences that culminate in social and political change (Laverack. 2001, pp. 134-135).

Community empowerment is not a new concept as it was identified as being a central component in health promotion- ‘a process of enabling people to increase control to improve their health’, back in 1986, acknowledged by the Ottawa Health Charter (WHO 1986). Laverack and Wallerstein (2001) acknowledged that utilising community empowerment in a program context has continued to be elusive. However, Stringer (1999) has described his participatory action research in terms of community empowerment as a central element of community development. Labonte (2004) has clarified that community development, community empowerment and community capacity building, all represent the same principles that describe the goals and practices to empower communities. That is their capabilities to organise actions, and resources and participate in decision-making processes that influence and benefit them and their society around them.

Community empowerment can be considered as both a process to and an outcome of program development (Laverack 2001). Throughout the program individual people can build their own self esteem, confidence and self development through increased skills

and critical awareness of the major issues, which enables them to play a role in promoting change and assisting others in their community, for example improving their healthcare, environment or social change. In this research, as part of the community working together, the healthcare providers would implement an effective program that promotes participants' empowerment through knowledge and choices of improved self-management of chronic disease and illness.

The local Aboriginal health service providers were required to develop their own capacity in new skills and training in screening and assessment to deliver the program with support from the mainstream women's community health nurse and external resources that included the female GP, the women's sexual health educator and facilitation by the researcher. As a cohesive women's health team, they were then able to conduct the program to benefit the local community that enabled women to take up opportunities for healthier choices in food, activities, health screening and factors that influenced their health and wellbeing. The influence of social change has then altered disempowerment to empowerment where community women can choose to attend and apply their new knowledge to make changes in their health and lifestyle.

Community development provides "an explicit purpose to bring about social and political change embodied in its sense of liberation and struggle" (Laverack 2001, p. 136). This is possible through distinctive domains (areas of influence) that are described in organisational change. These are identified by Laverack (2004) and described in context of how organisational change will impact on the AWWH program.

They are listed as: Participation, Leadership, Organisational Structures, Problem Assessment, Resource Mobilisation, Asking Why, Links With Others, The Role of Outside Agents and Program Management.

Inherent in these domains are the attributes of collaboration to plan and prioritise actions and implement strategies that assist health improvement, building capacity through increased knowledge, skills and experience, self-esteem and confidence and taking control. These attributes enable choices to make changes that affect the lives of the individual women and their extended families, and enabling ownership that takes into account responsibility for own health and the health of others. These are also principles of participatory action research.

#### ***4.20 The Emergent AWWH Model***

##### *Building on Policy and Research Findings*

This research has explored the position of Aboriginal health strategies set out by others in the strategic plan of CRCAH 2001-2005, the National Aboriginal Health Strategy (Anderson 1997) and the National Aboriginal Strategic Framework (NATSIHC 2003). These documents were used to determine how these various approaches underpinned other current research undertaken in women's health (Atkinson 2002; de Crespigny et al. 2004a; Kildea 2005), and the implementation of holistic Well Women's health programs (Gleeson 2003; McElligott 2005). For this thesis project, research methods were selected and implemented that could explore opportunities to build on existing knowledge and successful programs, as well as continue to find ways of undertaking

research in Aboriginal women's health that valued their culture, and ensured them respect, dignity and reciprocity.

To address these issues of culture, respect, dignity and reciprocity, this research has integrated the National Aboriginal Health Principles as outlined in Chapter 3. (Column 1), with Laverack's Domains of Community Empowerment (Column 2), and how these influence the way this research has been undertaken (Column 3). For this AWWHP model, consider that the middle wheel of the "nine domains" is revolving (reflexivity), while the outside wheels "Health Principles" and outlined areas of "this research" remain still and are influenced by the dynamics of the central nine domains.

***The dynamic process of interaction and reflection between health principles, Laverack’s domains and the research process.***

Health principles of the National Strategic Framework	Revolving through Laverack’s Nine Domains	Relevance to this Research
<b><i>Cultural respect</i></b>	<b><i>Links with others</i></b>	Ethical considerations <i>Open communication</i> :- Extensive consultation and agreement in research and health needs
<b><i>Holistic approach</i></b>	<b><i>Program management</i></b>	Whole of health approach physical, mental and SH&WB
<b><i>Health sector responsibility</i></b>	<b><i>Resource mobilisation</i></b>	Collaboration between limited resources & identification of specific required resource needs eg diabetes, renal dental
<b><i>Community control</i></b>	<b><i>Organisational structures</i></b>	<i>Financial commitment</i> : Core business community ownership and inter-relationships, partnerships, policy decision-making
<b><i>Working together</i></b>	<b><i>Participation</i></b>	<i>Skills &amp; knowledge transfer</i> :- collaboration from commencement of research design, adaptation to meet unique needs, and implementation of program
<b><i>Localised decision making</i></b>	<b><i>Leadership</i></b>	Governance and active leadership from within community and local health sector, local coordination of programs and transferability
<b><i>Promoting good health</i></b>	<b><i>Problem assessment</i></b>	Identifying the needs of community PHC approach to address
<b><i>Building the capacity</i></b>	<b><i>The role of outside agents</i></b>	<i>Building capacity</i> :- building knowledge of staff and community health information requiring outside resources
<b><i>Accountability</i></b>	<b><i>Asking why</i></b>	Responsibilities of designated roles. <i>Monitoring &amp; Evaluation</i> :- of program that addresses both process and impact ( outcomes long term). Communities’ views of success and HW views. Transferability and financial account for sustainability

The table above shows how the central revolving nine domains are dynamically influenced by, and in themselves place influence on the health principles and

relevance to the research and the interactive processes between them and those that sit either side.

#### ***4.21 Evaluation using Critical Social Science***

The evaluation of the transfer, adaptation and implementation process and the impact of the program were essential components of this emergent model. To be consistent with the emancipatory nature of this research, the evaluation used Critical Social Theory that sought and encompassed the participating Aboriginal women's knowledge, views, experiences, understanding and responses to the AWWH program, and if and how, it met their requirements. It examined how the program impacted on their health while offering equality, ownership and achievement.

The process evaluation examined the elements of program adaptation, development and application, to determine the suitability and effectiveness of its transfer in this community. It investigated the roles and position of healthcare providers involved in delivering the program through the transfer, adaptation and implementation process, and issues of the sustainability of the program. The impact of the program on this community was analysed to determine factors of success. However, some impact evaluation outcomes will need to be investigated over the long term of the program, as some statistical data and women's feedback and health status will need to be examined further over several years to provide evidence of actual health improvement.

Evaluating whether empowerment has improved as a result of particular programs and methods used to determine health outcomes and benefits, have been described by Tsey and Every (2000) as difficult and not well developed in qualitative approaches

(Legge 1999). However, advances in research methods in Aboriginal health continue and Laverack and Wallerstein (2001) have defined a method of achieving this through the use of nine organisational domains. The essence of this approach is in building capacity in the community that can be defined. By identifying empowerment as a process, capacity can be measured in terms of organisational changes that occur throughout the timeframe of the program and changes in community activities and behaviours (Laverack et al. 2001).

The mobile assistance patrol (MAP) initiative is an example of empowerment in the community where previously drug and alcohol problems have caused life-threatening injuries. This community service offers a fully equipped van and qualified MAP workers to patrol the community late afternoon and evening that assist community members who are intoxicated or suffering the effects of recreational drug use to be transported to a safe place. A Sobering Up Unit has been constructed, near the health service, where intoxicated people may be taken and watched safely until they regain sobriety the following day. Previously, these people were often admitted to the hospital emergency suffering injuries they received while intoxicated. The safe environment also permits for drug and alcohol counselling to be included with the initiation of support networks, to assist this endemic problem. The community is responding to this strategy with a greater awareness, support and volunteers to be trained as MAP workers. This community development approach is measurable in its awareness and actions to assist others in the community to cope with these health issues.

#### ***4.22 Process evaluation***

The National Aboriginal Health Principles were employed to guide the initial implementation and adaptation of the AWWH program. This program was then evaluated through the collection of qualitative and statistical data and analysis, to determine the nature of its construction and applicability to meet the needs of Aboriginal women in this SA remote community. Quantifiable data analysis identified attendance numbers, client demographics, and results of screening, interventions that determined the incidence of physical illness and mental health issues of the participating women. The findings were categorised by their areas of influence – domains - to determine the organisational changes that have occurred. The critical evaluation through PAR at the completion of each intensive program has provided the opportunity for continual improvement with community control and response to the effectiveness of the program and transfer process. These domains were used in the analysis as measurable indicators of empowerment through capacity building and organisational change. They will be discussed in more detail in their indicator roles in evaluation and in the findings. As it may have been aspects of the program that required improvement, the process evaluation needed to be considered before impact and outcome evaluation.

#### ***Impact Evaluation***

Impact evaluation sought to determine if the AWWH program objectives were achieved such as increased knowledge awareness, improved health status, changes in health behaviour or lifestyle , skills, policy or system changes with the program transfer and adaptation process. This evaluation analysed and determined the development of a model of successful program transfer and issues of sustainability. The impact



evaluation will be discussed in a systematic manner through the nine domains in more detail in the results chapter.

#### **4.23 Summary**

This chapter has described the synthesis of Naturalistic Inquiry, Critical Social Theory and PAR and its relationship to community development and how these have informed and guided the research design and application in a remote Australian setting. The rationale and theoretical perspectives of Naturalistic Inquiry and Critical Social Science were discussed to provide an understanding of their application to the context of remote Aboriginal women's lives and poor health and the links to oppression and disempowerment. The emergent model using a synthesis of methodologies and mixed research methods, describes a community empowerment model that can be measured through capacity building in specifying particular areas of development, called domains. These have been linked and meshed with the National Aboriginal Health principles so as to provide a framework for the data collection that provides clarity throughout the analysis, that more accurately reflects the complexities of Aboriginal women's health in this community.

The following chapter on methods illustrates the systematic manner used for sampling, data collection, analysis and interpretation in the research and the evaluation processes of the AWWH program.

## CHAPTER 5: METHODS

*“If I can’t dance it’s not my revolution” (Goldman 1931)*

### ***5.1 Introduction***

This chapter discusses the role of the researcher and access to the community, with research integrity. The research design is described with issues of validity, sampling, methods of data collection and analysis of the research. The chapter concludes with an evaluation of the transferred model of the AWWH program.

#### *My Role as the Researcher*

I came to this research as a non-Aboriginal woman and a Registered Nurse Midwife and Nurse Educator. At the time this research project commenced, I was not involved in clinical remote health care, which I found to be a distinct disadvantage in my understanding of Aboriginal cultures and particular health issues, together with gaining access to Aboriginal women in a safe cultural context. Being aware of my Western heritage I consulted extensively with Aboriginal and non-Aboriginal women, who have worked along side the Aboriginal community, and also with an Aboriginal mentor who is a senior research advisor in Aboriginal health issues. In a value-laden context I have brought my own beliefs and values to the research as a woman and a nurse. While these values have influenced the research, they have been tempered by the values and beliefs of local health providers and the community women involved who provide a greater balance for the research.

The researcher has been described in terms of being a 'human instrument' by Lincoln and Guba (1989) who improved the opportunity to gather data in terms of privileged access, responsiveness, adaptability, tacit knowledge and trustworthiness. Gaining access to the community and building rapport and confidence with the community to gain their trust, and ensuring that as a researcher I was credible and represented their specific needs in problem management, have been the most difficult tasks of this project.

## ***5.2 Researcher access to the field***

### *Community approval*

Extensive consultation took place with the Aboriginal Health Council of SA, who then recommended that I speak with several advisors working in Aboriginal health management. Telephone interviews were arranged with the advisors to gather information about the process of contacting healthcare providers and other key informants who could provide information about successful health strategies or programs in Aboriginal health in Central Australia. This consultation was an essential step prior to developing an ethics application that was supported by an Aboriginal community group, and was thought to be a worthwhile research proposal that addressed their current health priority. As it is well acknowledged that Aboriginal people have been over-researched (O'Donoghue 2000), it was extremely important that the health research had a specific purpose and could fill a gap in health knowledge that would produce both immediate and long-term benefits for the community involved.

Following conversations with the advisors in Aboriginal health, I was able to make contact with the NPY Women's Council and other key health providers who were conducting health and screening programs in the APY Lands and Central Australia. Following these face-to-face interviews, and extended conversations, I was then able to write an ethics proposal that was considered acceptable by the Research Ethics Committee, which scrutinises research proposals for their appropriateness in meeting the priorities of specific Aboriginal communities.

The consultations had presented a significant challenge, yet this extensive communication process in obtaining a thorough understanding and building of relationships with key informants was vital to the final outcomes. While time lines are of importance for the researcher in consulting, and developing an ethics application in a collaborative manner, there is not necessarily the same priority for the community, and patience was required to progress at a speed that is comfortable for community representatives, when all protocols have been adequately addressed.

#### *Access to the Pitjantjatjara Lands*

Following ethics approval, this project commenced with a comprehensive consultation with community women and health providers who work for communities in the Pitjantjatjara Lands. Telephone conversations were spasmodic and email proved to be unreliable, so face-to-face conversations were required to build relationships and to provide a clear picture of what specific problems required redress. Gaining access to the community women and health providers was problematic as a permit was required to visit the Pitjantjatjara Lands and although

organised twice, the permit was revoked when other uncontrollable events created crises and anguish for the communities situated there.

Through continual interfamily violence and a series of murders, the APY Lands were closed to outsiders at the time of our intended first visit. The second visit that was organised was also cancelled due to an influenza epidemic, which had local nurses and Aboriginal healthcare providers extending their already long working hours, making it impossible for them to have the time or energy to accept newcomers and enter into a consultation process. Therefore other avenues were sought and supported and the opportunity to discuss the remote holistic Well Women's Health program arose.

#### *Access to effective health programs for Aboriginal women's health*

As the researcher had already arrived in Alice Springs on the dates and times originally organised to visit the APY Lands, the time was then spent consulting with relevant local health professionals working in Alice Springs, who were closely involved in Aboriginal women's health services in the APY Lands. Access to these healthcare providers was welcomed and led to extensive consultation and most valuable information and networking. They readily described their roles and services, including the various strategies used to implement their programs in collaboration with the communities in order to facilitate screening, earlier detection and management of disease. The programs they described were focused on improving health through screening, particularly targeting sexual health and STIs, specifically trichomonas, chlamydia, syphilis and gonorrhoea (Menon et al. 2003; Depraetere 2003a). Such programs also progressed women's physical health through improved nutrition

information and food preparation sessions for women, their families, antenatal and postnatal young women (Balmer et al. 1998) (Gleeson [personal communication] 2003).

#### *Invitations into the community*

An invitation to meet with the Executive Committee of the NPY Women's Council enabled me to interact with Aboriginal women who fulfilled leadership roles in the APY Lands in SA, NT and WA. They provided insight into their expectations of women's health research and how this would be accepted by the women in their communities. They expressed their concerns about the current health status of Aboriginal women and the volatile environment in which they lived through family violence, together with the high incidence of illness and its uppermost priority for address. The Council Executive displayed different sentiments relating to the possible success of a transferred women's program, as 'Women's Business' may be conducted differently in some communities.

Through the support and interest of healthcare providers involved in improving women's health, I was introduced to key informants from the Northern Territory Health Department based in Central Australia, who were involved in providing a holistic Well Women's Health program to remote Aboriginal communities outside Alice Springs. The interest and friendship shown by these health experts provided further access to successful programs and those who were organising them. Subsequently, I was invited as a researcher exploring successful health strategies to visit one of the communities to

experience a Well Women's Health program. During the program's three-day duration I was then able to observe and converse with women participating, and discuss issues with the health team running the program and make my own evaluation. I was also provided with their complete program in a written format, and invited to share this with another remote community in South Australia (McElligott 2005).

*Access into a South Australian remote community*

Access to a particular remote community in South Australia was fortuitous, and an acceptance was made in good faith by the Chief Executive Officer and Social Health and Wellbeing Coordinator of the local community-controlled Aboriginal Health Service. Other trusted research health professionals had been working with them focussing on Aboriginal mental health and better medication management, and alcohol and other drug issues (de Crespigny et al. 2004c). Their success was due to their partnership with the local community and respectful approach, which in turn opened opportunities for me to establish my credibility and relationship with local groups. As Aboriginal women's health was also a priority for this community, the Central Australian WWH health program was discussed with the potential to transfer the successful elements of this program and adapt it for their use.

I was later offered the opportunity to work as a relieving registered nurse for the Aboriginal Health Services for a few weeks, while the permanent RN was on annual leave. This opportunity created an unanticipated passage of entry into the 'world' of the team, and far greater understanding of the day-to-day intricacies, extremely poor health status, and life difficulties experienced by the Aboriginal clients. This gave me

greater exposure to, and interaction with, many of the healthcare providers in the Aboriginal and mainstream health services in the town and provided the context to identify the health and environmental issues experienced by the women and the providers themselves.

I was able to build friendships and good working relationships with the various staff and informally observe the roles they played in providing health services to the Aboriginal community. Observation and consultation also revealed limited interactions between the healthcare providers of the Aboriginal health service with other local health and community services that created a silo effect of services, rather than a combined case management approach. The impact of independent approaches to health service provision had implications for both the community and the use of resources.

In the role of the nurse and researcher, I was able to demonstrate and practice my health knowledge and skills, and work in partnership with the different health teams of this community. As working relationships improved, I was able to assess in more detail the type of health care that was employed throughout the clinic, which appeared to be reactionary to client incidents and crises, rather than an opportunistic and a planned approach to primary healthcare.

Naturalistic inquiry accepts that tacit knowledge is an indispensable, explicit and legitimate part of the research process (Lincoln et al. 1989). Tacit knowledge is defined as personal knowledge gained through experience and or training, and assists the



interpretation and sense of what may be occurring in individual situations. Hodgkin (1991 ) described it as:

*... a range of conceptual and sensory information and images that can be brought to bear in an attempt to make sense of something (p. 15).*

The term ‘tacit knowledge’, originally described as ‘tacit knowing’, was coined by Michael Polanyi in 1966 in his role as an author, educator and a philosopher on the subject of knowledge (Smith M 2003).

As a nurse, my tacit knowledge had been developed through my previous opportunity to work as a registered nurse in a remote Aboriginal community on the Pitjantjatjara Lands, as well as through my nursing experience in Aboriginal community health in Darwin, and later nursing and teaching in Adelaide. This personal knowledge placed me in a better position to raise sensitive issues, and discuss with other healthcare staff alternative ways of working with a focus towards primary healthcare, prevention and early intervention, and systematic client management, rather than crisis management.

### ***5.3 Research integrity***

Research integrity in this thesis refers to a high standard of ethical conduct and the maintenance of accurate, detailed, research procedures with results, and the quality of research in intellectual honesty and accountability, which are hallmarks of good scholarship. The integrity in this research is described through the researcher’s ethical practice and interaction with the community and key informants in the processes of responsiveness, leadership, reciprocity and trustworthiness.

### *Responsiveness*

The demands of time, energy and resources may be very extensive in a naturalistic study, as all factors and influences in the context of the natural setting require investigation (Lincoln et al. 1989). In this instance, a naturalistic approach was used to understand the context, followed by a critical approach using Participatory Action Research (PAR), which enabled the researcher in collaboration with the health team, to influence the focus of healthcare provision. As a ‘human instrument’, the researcher can respond to, and interact with, specific situations that impact on the research participants, that is, remote community Aboriginal women participating in the program, and the Aboriginal and non-Aboriginal health workers providing the service. This role can assist the researcher in identifying issues and making them more explicit with a direct focus on particular aspects of client and research activity management.

The elements of the successful Central Australian program were identified by the researcher with assistance from the Central Australian WWH team and the literature, and discussed and promoted by the researcher with the recipient community WWH team. To transfer, adapt and implement the effective elements of the Central Australian AWWH program, a philosophy of primary healthcare was required in the SA recipient community. Changes were required in health management to include:

- a planned approach to well health screening in improved client documentation and reporting;
- client attendance and screening data collection;
- holistic clinical assessment and monitoring;
- client follow-up and referrals; and

- using the purpose designed Aboriginal Well Health checklist as the screening tool, and associated administration.

This primary care approach also required the collaboration and participation of healthcare providers across mainstream and community services with the healthcare team of the Aboriginal Health Service to implement the program.

### *Leadership*

The researcher acted in leadership roles, as an educator, mentor, clinician, resource provider, and advocate for Aboriginal women and local healthcare providers. These roles were essential to identify the priority of Aboriginal women's health through extensive consultation, to find a holistic women's health program that would suit remote Aboriginal women, and to facilitate its transfer by identifying the elements of the successful program. Furthermore, the researcher was responsible for identifying a SA remote Aboriginal community that would welcome and need such a program, and facilitate this adaptation process in collaboration with the women's health team to meet the needs of local Aboriginal women.

The researcher's role then focused on finding a female GP who would be accepted by the local women, and who had expertise in remote Aboriginal women's health care. The next goal was to integrate the local and visiting healthcare providers through the establishment of the AWWH Project Advisory Group (PAG), which would facilitate the program. The role of the PAG included guiding and continually improving the AWWH program, and unifying the local health providers across mainstream and Aboriginal health services in working towards the same goal, namely Aboriginal

women's health. The researcher remained a member of PAG throughout the project and coordinated its participatory roles as well as supporting the AWWH team. This researcher leadership was achieved through liaison and direct consultation with healthcare providers, community members, and policy- and decision-makers, with the final role being an evaluation of the program with support from the AWWH team and feedback reports to the community and other stakeholders.

### *Reciprocity*

Reciprocity - a philosophy, a practice and a core component of ethics in Aboriginal research - is a term used to describe mutually beneficial relationships. In this study, the researcher created, developed and sustained mutually beneficial relationships with the women's health team, other local healthcare providers and the community where the program has been implemented. Through growing rapport, showing respect, being reliable and flexible, and communicating well, trust and friendship grew. The researcher freely gave her time and expertise, and brought external resources into the community, all of which indicated her willingness to give, and an understanding that the research was not merely conducted in order to undertake a thesis project. This has been a criticism that has been made of research students and researchers by Aboriginal communities who did not experience reciprocity.

Reciprocation, the basis for increasing levels of shared understandings, was possible amongst those involved in this AWWH program. Greater self-awareness and growth in the researcher's own communication and listening skills were obtained, together with a greater level and depth of understanding about the needs and issues faced by Aboriginal people. These aspects of researcher development then influenced and

enhanced the research, and importantly its outcomes, because of the relevance and shared commitment to the WWH program and its adaptation and implementation.

By diligently undertaking regular consultation, giving and receiving feedback about various issues as they arose, and being willing to wait for appropriate time lines based on the capacity and situation of the Aboriginal health service, its staff and clients, a strong partnership developed between the local healthcare providers and the researcher that remains today. These strong ties provide the opportunity for further research and health projects to develop, as trust, friendship and knowledge of working together in this particular community continues. Naturalistic inquiry acknowledges the reciprocal influences that the researcher and the participants of the study experience with each other and how this adds relevance to the true interpretation and representation of the findings. It is the act of reciprocity that invites the researcher to share in the cultural knowledge and understand more fully the realities of the community participating in the research.

These findings would not be generalised to another setting as a whole, as they relate specifically to this community. The specific social phenomena and interrelationships together with the environment in which they are portrayed are unique to a moment in time. However, the elements or principles that were used or determined throughout the research, could be transferred or duplicated through a program model in another setting, that is then adapted to meet the specific community's needs. The rich description of the context of the research provided by Naturalistic Inquiry could help others to determine

whether there were similarities to their own community, and how this research could be of benefit to them.

#### ***5.4 Validity (Trustworthiness)***

The contemporary debate concerning validity in the qualitative paradigm focuses on factors beyond 'objectivity', as this notion is contrary to qualitative philosophy and its various methods. However, validity cannot be dismissed and needs to be considered in the context of authenticity of the research findings and their interpretation in that particular setting (Greenwood and Levin 2005, p54) that is, trustworthiness of the process, account, and interpretation of the findings. Therefore the research requires a credible and strategic approach so that the outcomes can be validated by ensuring their trustworthiness, and that the community can trust and act on the outcomes.

While it can be argued that some methods are better than others when conducting research on the "human construction of social realities", there is no one single method or collection of methods that is absolute, and process and interpretation of the findings require this validity, i.e. trustworthiness. Therefore the question of validity is related to the credibility and strength of the findings and their interpretations, so that the implications can be understood, distributed with community action, and social policy or legislation can honestly be based upon them (Guba et al. 2005).

Validity in the qualitative paradigm relates to the extent of uniformity between the findings and the reality represented. According to Lincoln and Guba (1989) there are

multiple realities that can be represented legitimately in naturalistic findings and all aspects of people's reality are interrelated. Therefore validity is not seen in the same way as in the quantitative paradigm. The Naturalistic (constructivist) perception of the criteria for judging validity or reality is not absolute, rather that validity or reality is reflected by the specific community view relating to what is real, useful, and has meaning for them, particularly in response to action (Guba et al. 2005). The importance of values in the research process originally described by Guba and Lincoln in 1985, remain significant in 2006. This is evident through the way that values influence the theoretical framework, data gathering and analysis and how these are inherently intertwined with culture, spirituality and ethical considerations (Guba et al. 2005, p200).

Trustworthiness in qualitative research that includes naturalistic inquiry and the critical social scientific approach, can be validated by the terms credibility, transferability, dependability and confirmability. These terms equate to the conventional terms in empirical research of internal validity, external validity, reliability and objectivity (Greenwood et al. 2005). These terms are discussed below to provide a clear explanation of how they impact on the validity of the research undertaken.

### *Credibility*

The activity of 'prolonged engagement', which is integral to PAR, has been identified as increasing credibility in Naturalistic Inquiry (Guba et al. 2005, p192). This 'prolonged engagement' necessitates the researcher spending sufficient time in the field

so that essential relationships are built and trust not only develops but can be maintained. Extensive committed time enables the community participating to share their knowledge of their culture and lived experiences in their natural context with the researcher who, as a result, provides a more accurate picture and trustworthy reporting. This includes the community accepting the researcher as a credible and trusted colleague in the group, and this helps to limit distortions of information and inaccurate interpretations and provides for highly credible research outcomes.

### *Transferability*

Transferability may be possible when research reveals shared characteristics of the phenomena and the context of particular groups or situations. This requires the use of appropriate methods that enable the extensive description of the research context, and identifying the existence of congruent characteristics and commonality between the various groups who might benefit from such transfer. For example, in this study, Central Australian Aboriginal community women shared common characteristics with South Australian remote community women. There was congruence between the health needs of the women, the cultural characteristics, and the remoteness of their situation. Therefore it was likely that the effective well health program model would be transferable and able to be adapted to meet the needs of this second group of women.

The in-depth description of the time, the environment and the context of this research can assist others to determine whether the elements of the research can be duplicated or adapted in another similar context, or with a similar group of people with analogous issues (Erlandson, Harris, Skipper and Allen 1993). The findings of the research cannot



be generalised to any population as they occurred in specific circumstances at a specific time. However, the elements of a successful program model may be transferable. This research has been conducted to determine the transferability of a successful program from one community to another community experiencing similar issues.

### *Dependability*

Dependability relies on the process of data collection and analysis that inform the researcher's interpretations and recommendations and in this case, those being researched. Through the approaches of Naturalistic Inquiry and PAR the research data collection and analysis stayed as close as possible to the meanings, thoughts and activities of the participants in their environment, and represented their views in the findings that were reconfirmed by them (Guba et al. 2005, p207).

### *Confirmability*

The inquiry is examined by the degree to which the findings are the response to the inquiry processes and not the subjectivity of the researcher (Erlandson et al. 1993). This can be authenticated by the process of 'Member Checking' through checking data analysis and interpretations with the participants of the program and other key informants, and by the researcher keeping a reflexive journal that is congruent with the analysis.

*Internal validity* can be described in regard to this study as determining whether observed changes can be attributed to the AWWH program and not to alternative causes (Trochim 2006c). This was determined by evaluating the program, noting

whether the program as a whole made a difference to the physical, mental and social health and wellbeing of the Aboriginal women, and to the knowledge and practices of local healthcare providers who participated.

*External validity* is defined as “the degree to which the conclusions in your study would hold for other persons in other places and at other times” (Trochim 2006b). That is by ‘expanding claims’ of transferability to another similar setting and group such as Aboriginal women, using the same criteria (Lewin 2006, p216). External validity is replaced by transferability in this qualitative research, and (Bishop 2005) concurs that external measures for validity are defined within another world view. There have, however, been some quantitative data purposefully collected to determine the incidence of firstly, program attendance and secondly, health issues that support the qualitative data, but not for the purpose of generalising any findings.

### *Reliability*

Reliability relates to the consistency and repeatability of ideas in qualitative research, and accurate measurement in quantitative research (Newell and Burnard 2006). The reliability of the research is increased through systematically and transparently undertaking and reporting all processes. However, reliability is assessed, not only by the processes and quality of the data collection, but also the data analysis, particularly when there is a dependence on the researcher to collect and examine the data.

One way to increase the reliability (and internal validity – trustworthiness) was through ‘member checking’ where participants (healthcare providers) were asked to clarify meaning from the analysis of their interview data, and check any discrepancies or

misinterpretation. The interpretation of PAG minutes was similarly cross-checked with the content and interpretations being fed back to PAG members for comment to ensure the researcher's account and understanding were accurate and the true intent acknowledged. The processes of interpretation and explanation also needed to be transparent and well documented so as to ensure that the research was an honest and trustworthy account. It is anticipated therefore that the participants and others with an interest in this project will have confidence in the reliability and therefore outcomes of this research.

#### *Interrelater reliability*

The ongoing commitment and involvement of, and feedback from, staff of the local community-controlled Aboriginal health service, as well as input by those from mainstream health services, increased the reliability of the research. Many of these groups were involved from the beginning of the project and were able to provide effective feedback on the various issues that emerged from the data 'along the way'. While the confidentiality and identity of all participants was protected, findings were regularly discussed as part of the PAR process. This was one way of improving inter-relater reliability.

In order to maximise the data collection and content of the evaluation by Aboriginal community women, an Aboriginal woman who was a respected female visiting health professional, was able to access and interview some local Aboriginal women and health professionals about their views and experiences of the AWWH program. This ensured

that the researcher did not influence their responses, and that they were culturally comfortable in providing this feedback while being interviewed by an ‘inside outsider’. An Aboriginal woman who was familiar with the nuances of Aboriginal Women’s Business, but unrelated to their family groups, was therefore able to interview them effectively, respect their culture and maintain confidentiality. She also worked with the researcher in interpreting the qualitative evaluation data thus strengthening interrelater reliability. This process enabled cross-checking of participant information.

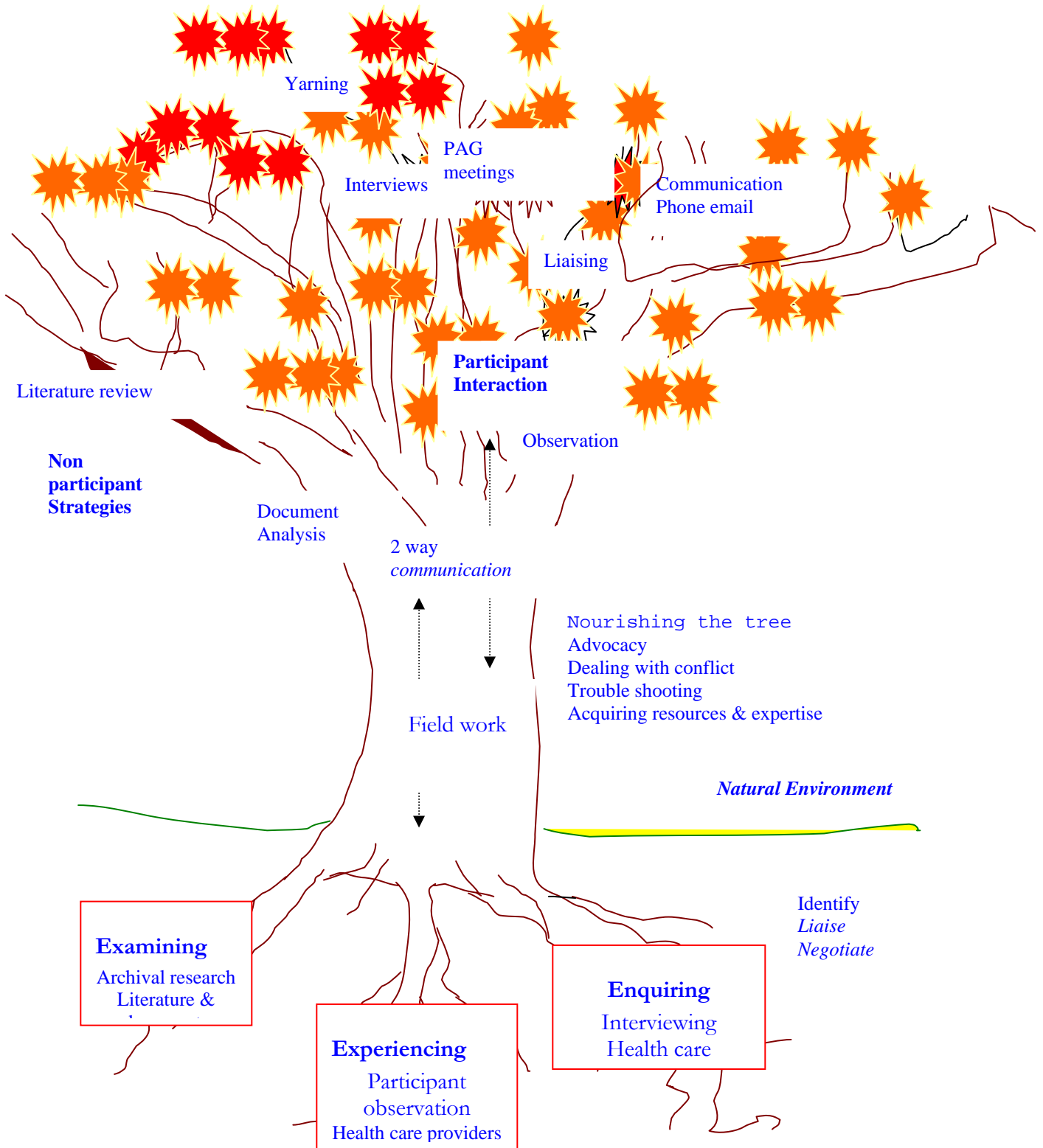
### ***5.5 Research Design***

In order for the methods used in this research to be more easily explained, I have used a pictorial representation (see below) of Wolcott’s tree model ( 2001). Wolcott readily gives licence to other researchers to use his model so that it can be adapted to meet their research design needs. In his model, the analogy is of a tree developing and being sustained by its roots, trunk and branches. Wolcott describes archival research processes such as literature and document review used in this project, as *examining*, participant observation as *experiencing*, and interviewing as *inquiring*. This terminology has been retained in this thesis to provide the clearest explanation for others, who may also wish to follow this line of inquiry in Aboriginal research.

### ***5.6 Adaptation of Wolcott’s Model to this research***

The AWWH model is reflected in the tree root component with methods of examining, experiencing, enquiring, and nourishing as ‘the tree’ grows. The two-way communication running throughout the fieldwork moving as the tree’s sap would flow throughout its branches, and the flowers represent the research participants, and their

interactions, as observed by the researcher in their natural environment. The tree (project) is nourished by the researcher's knowledge, and facilitating roles such as consultation, advocacy, coordination, negotiation, and problem resolution. These roles were undertaken in collaboration with the PAG, that is, all health care providers involved in the WWH team who were committed to implementing the AWWH program.



### ***5.7 Sampling***

Lincoln and Guba (1989, p199) state that “*all sampling is done with some purpose in mind*”. The small samples, or particular populations who need to be included in qualitative research, make it imperative to successfully identify and recruit the people who make up the most appropriate population. Purposive sampling is defined as the selection of a group or category to study that is most relevant to the research question and is meaningful theoretically, by including the criteria required to develop and test the theory and explanations (Mason 1996).

Purposive sampling was used to collect relevant and appropriate qualitative data from the very specific population that were to be the focus of this research. This maximised the researcher’s ability to incorporate the local context and values and the multiple realities of the community women, which may assist future transferability (Lincoln et al. 1989). This sampling technique enabled the researcher to direct her enquiries to those who were best able to assist in providing specific information:

*The purposive sampling is to provide maximal detail of specific information in its unique context* (Lincoln et al. 1989, p201).

#### ***The samples***

The sample overall comprised of two groups, one group were the participants who experienced the program, the other group included the healthcare providers who were implementing and adapting the program. The focus of the research was the transfer, adaptation, application and evaluation of a successful AWWH program from one

remote Aboriginal community to another, in order to improve remote Aboriginal women's health.

*Participants experiencing the program*

The sample needed to comprise local, remote Aboriginal women and girls from 12 years of age, living in, or travelling through the particular area in SA, and who were therefore eligible to attend the community controlled Aboriginal health service in that community. Any Aboriginal women who attended the health service at the time of the AWWH program were considered eligible for the sample as they fitted these criteria.

While the AWWH program was open to all community women, most non-Aboriginal women did not attend as they went to the local GP practices or attended the RFDS clinic that operated on an eight weekly, fly in, fly out same-day service. Interestingly, in the initial program especially, there was a small number of non-Aboriginal women including staff, who attended the intensive screening as there had not been an available female GP in the local community (through the RFDS) for several months.

The criteria for selecting this particular remote Aboriginal community were based on the type of research question, expert advice, community consultation and the target group of the AWWH program. The wider Aboriginal community in SA and Central Australia, and local key informants, advised me that the Aboriginal women and health service in a remote community in the 'Far North' of SA needed such as program and may be interested in becoming involved. Therefore the sample was self-selected and they requested to be involved in the AWWH program.



### *Healthcare providers implementing and adapting the program*

All local healthcare providers who were involved in the implementation and adaptation of the program were asked their views, together with the visiting members of the AWWH team that included the female GP and women's sexual health educator. Data were collected both informally through conversations and also more formally through semi-structured interviews that were taped and transcribed. Their opinions were also reflected through the minutes of the PAG that met both prior to, and at completion of the intensive screening programs.

### *SUMMARY*

In summary, purposive sampling was used to engage particular groups and collect descriptive qualitative data from semi-structured interviews, focus groups, minutes of key informant meetings, document analysis, and evaluation data, and statistical quantification of attendances and identified health conditions. The tools used for data collection are briefly described here (and are included as appendices at the conclusion of the thesis.).

### ***5.8 Data collection tools***

In addition to the researcher's observations and communications by telephone and email with the staff of the local Aboriginal and community mainstream health services, other data collection tools were used. These consisted of the AWWH checklist for screening and diagnosis, semi-structured interviews with Aboriginal women, and semi-structured interviews and questionnaires for healthcare providers.

### *AWWH checklist*

This holistic screening tool included physical, mental and social health and wellbeing questions that enabled the healthcare provider to obtain an accurate picture of each woman's overall health. This checklist identified their family history, nutritional preferences, and social habits such drinking alcohol and drug use, together with factors such as homelessness, lack of basic facilities such as water, electricity and cooking facilities and incidence of family violence.

### *Semi-structured interviews and questionnaire*

The semi-structured interview and questionnaire provided a systematic and consistent process of collecting data from Aboriginal women participants in the AWWH program, healthcare staff providing the program, and other key informants. This enabled data to be collected from a range of individual participants' self reports, which could be contrasted and compared in themes. This process also offered participants the flexibility to raise and discuss their own ideas and issues not anticipated in the structured questions/themes. Therefore all participants had the opportunity to respond to the same themes /questions as well as being able to offer their own unique information as they wished.

### *The participating Aboriginal women's semi-structured interview questionnaire*

The Aboriginal women's semi-structured interview questionnaire was divided into one demographic section and four thematic sections, namely 1) program attendance, 2) program content, 3) helping to improve Aboriginal women's health, and 4) barriers to attendance. Each of these themes had some lead-in questions designed to focus and assist conversation about the women's views and experiences of the AWWH

program, and how they considered this in terms of their health and participatory activities.

*Healthcare provider's semi-structured questionnaire*

To provide systematic data collection that was guided by the literature, the semi-structured interview for healthcare providers was developed into themes, devised from the researcher's knowledge of Aboriginal women's poor health and health needs, also supported by the literature. Questions were also included that related to the healthcare provider's role in the AWWH program, the women who attended, the program content, how the program may or may not have been able to improve Aboriginal women's health, and any barriers that prevented women from attending. Each of these themes had some lead-in questions designed to focus and assist conversation about the health professional's views and experiences of the AWWH program, and how they considered this in terms of local Aboriginal women's health and participatory activities. The tool was trialled at the first interview and refined to provide a comprehensive data compilation of staff views.

The semi-structured healthcare provider interview was initially conducted face-to-face with all participating staff, with a follow-up interview by telephone following the completion of six intensive AWWH programs. The initial interviews took place following either the second or third AWWH program, depending on the WWH team's availability and involvement.

The follow-up telephone interview was eighteen months after the initial AWWH program was implemented. As an open-ended, semi-structured thematic format

particular questions relating to pre-set themes were asked in all interviews. These were designed to explore the participant's role, their perceptions of the roles of others and their views about the AWWH program. They were particularly asked what went well, what did not go well and what changes they would like to see in the next program. They were invited to talk about any other matters they wished to raise regarding the program and the community. Overall, they were asked if they saw that the program was of benefit to the participating women.

### ***5.9 Data Collection***

Mixed methods were used to collect the data as this provided for a broader range of data to emerge with associated clarity of meaning. This reduced the likelihood of misinterpretation of the key issues and resulted in more comprehensive results:

*Triangulation helps to identify different realities [and]... the qualitative researcher is interested in diversity of perception and the multiple realities within which people live (Stake 2005, p454).*

Mixed methods (triangulation), within the paradigm of qualitative research, were firstly used to enhance confidence in the validity of the findings by the convergence of data from different techniques (Denzin & Lincoln 1994), to add rigour, value and trustworthiness to the research process and program evaluation. This approach has added value and richness to the data, and substantiates the trustworthiness of the research outcomes. Qualitative data that includes researcher observation and interaction, field notes and document analysis and semi-structured interviews reveal complex results that are contextual and can not be easily explained by quantitative data (Richards 2005, p34).

Casebeer and Verhoef (1997) report chronic illnesses as prime examples of conditions that necessitate study from a combination of perspectives, and suggest that mixed methods and tools will provide more successful health research outcomes. By using some quantitative methods, the contextual, in depth analysis could be supported by the statistics collected on health diagnoses, number of attendances to the program etc, and provide a more complete picture. For example, the quantitative data calculating the number of women who participated in each program, together with their incidence of disease, enhanced the qualitative data that described the women's views, and the issues discussed at health information sessions, resulted in a far better understanding and estimate of the program's overall value.

Data are collected using different techniques that enable the research question to be explored and analysed from various perspectives. Systematic comparisons of the various data sets can then be explored with the identification of similarities and differences and reasons for these that provide greater confidence in the findings and their interpretation. However, in designing a mixed method study, consideration must be given as to how the methods are constructed as this creates dilemmas in whether the methods are integrated throughout the study or kept separate until after the final analysis (Greene et al. 2005, p276).

In this research all data were collected and merged and analysed using a critical approach with aspects of Naturalistic Inquiry. The critical analysis was focused on emancipation through community capacity development, as it was considered that the

contextual environment would add considerable value to understanding the women's health, their environment and resource management issues that have contributed to their current poor health status. Building trustworthiness relies on data and the analysis being culturally sensitive, and responsive, to the experiences of the women and the healthcare providers in the community adding to the quality of knowledge and the strength of the findings.

Naturalistic findings are created rather than discovered (Egon Guba in Forward Erlandson et al. 1993, pxiv), through the dialectic information exchanged between the researcher and community women, and local healthcare providers where the findings emerge. This form of data collection is dynamic and continuous and through the participatory action research process, can be reflected upon, integrated and then used to inform the next part of the data collection and analysis process, as described in Lewin's reflexive spiral in Chapter 4.

Therefore qualitative and some quantitative data were collected and collated primarily into themes of examining, experiencing and enquiring. The data collection is described here under these primary themes, and analysed in response to specific questions elicited from the research to answer the question whether the elements of a successfully established remote women's health program model can be effectively transferred and adapted to a community with similar characteristics.

### ***5.10 Examining (Archival research)***

#### *Non-participant strategies.*

Document analysis included an extensive literature review that identified the issues in Aboriginal health through refereed research papers, government reports, anthropological and historical accounts of colonisation, newsletters and other journals reporting the decline in Aboriginal health and related issues. In addition, historical and current information on Aboriginal women's culture and health were sought and examined. Research that was deemed culturally appropriate, relevant and effective regarding remote Aboriginal women's health was particularly explored to clarify and support the information given by key informants.

In addition to the above as the researcher, I:

1. attended seminars where Aboriginal women such as Lowitja O'Donoghue, Sally Goold and Judy Atkinson were key speakers, as I sought their professional and cultural knowledge about Aboriginal women's health.
2. examined documented evidence in my field notes taken throughout the periods of planning and conducting the research. In particular, comparisons were made between the content of the field notes, transcripts of interviews and key informants' commentary so as to explore the similarities and differences in accounts.
3. examined the minutes of the Project Advisory Group (PAG), which contained detailed information of the key issues and concerns, progress and reflexive practices that were discussed by the members.

### *5.11 Experiencing (Participant observation)*

The term ‘participant observation’ is a term used in PAR that can describe what the researcher is ‘experiencing’ and therefore more able to understand, the data collecting process (Wolcott 2001, p89). In this instance, as a woman and an experienced nurse, I was accepted and able to discuss “women’s business”, but as an Australian of Anglo-Saxon heritage I could not assume to be an insider with the cultural knowledge of Aboriginal women and their community.

Participant observation enables the researcher to obtain first hand information about social processes of the participants in their natural environment (Silverman 2003, p. 202). In this study, participant observations were recorded in field notes. I aimed to observe and interpret the interactions of the healthcare providers in relation to providing services to Aboriginal people in general, and Aboriginal women in particular, while I was simultaneously working in and exploring their healthcare environment through the naturalistic inquiry process. These data were then continuously examined and reflected on, to increase my understanding of the range and complexity of interactions and relationships between the varying health care providers in the team, the participating community women and wider community as the project progressed.

This observation process occurred through each phase of the study, in the following context:

- in the remote environment of key informants in Central Australia,
- during the three days of the Central Australian remote Well Women’s Health program, and



- throughout the period when the AWWHP was implemented in both in the Aboriginal Health Service and the wider SA remote community.

These observations enabled me to learn who people were, how they interacted with each other, how they accomplished their roles as healthcare providers, and as clients participating in the program, and what facilitators or tensions impacted on them in their familiar environment.

*For example:* The local community controlled Aboriginal Health Service employs both Aboriginal and non Aboriginal healthcare providers. Due to the limited number of Aboriginal registered nurses, these nursing positions are often filled by non-Aboriginal people. This circumstance often perpetuates a hierarchy where non Aboriginal healthcare workers are in positions of authority over Aboriginal workers and may present a barrier to effective team work and equality between Aboriginal health workers and such nurses.

Aboriginal health workers have cultural wisdom and community designated roles that enable them to interact appropriately within their cultural and gender groups, provide health information and clinical care, and ensuring the cultural sensitivity and safety of Aboriginal women attending the clinic and participating in health programs. They have a knowledge of the women's family and community issues and cultural 'business', and are aware of who is accepted or not accepted in receiving certain health and family information, or undertaking certain medical interventions.

Aboriginal healthcare providers are crucial to an effective healthcare team, and their effectiveness depends on the interpersonal relationships between individual staff members, as to how well they work together, respect one another, and collaborate in programs and client care.

### ***5.12 Enquiring (Interviewing)***

All key informants, healthcare providers and Aboriginal women who were interested in providing their views were given a verbal explanation of the research, followed by an information sheet. Informed consent was then gained before any interview was undertaken.

#### *Key Informants*

Unstructured interviews were undertaken with key informants initially in Aboriginal health organisations and as mentors, who provided me with a pathway to others working in remote communities. Key informants then became the healthcare providers working in remote Aboriginal health that identified information about successful health strategies and the research priorities in Aboriginal women's health. This in turn enabled access to the NPY Women's Council (as previously discussed) who then became key informants that generously informed and guided the researcher, and shared their ideas and views on remote Aboriginal women's health.

#### *Healthcare providers in Central Australia and participating women*

Some of the key informants were associated with, or working in, a range of Aboriginal health services in Central Australia and remote SA, and they informed the

researcher about successful health strategies and the research priorities in Aboriginal women's health during these conversations.

Later, following an invitation to participate in the Central Australian remote AWWH program, conversations were also held with healthcare providers who were currently conducting the program. Their views were sought to determine what elements made their AWWH program successful. These perspectives were documented as field notes taken as the program continued on around us. I was able to participate in this program as well as observe, and chat to community women who were actively participating and gain a sense of their purpose for attending, and how successful they thought the program was in meeting their needs.

*Healthcare providers working in the AWWH team in SA*

Conversations were conducted with healthcare providers initially in the local Aboriginal health service as a way of getting to know them and inquire about their views on Aboriginal women's health needs. These conversations built rapport, taught me about many issues and a way of practicing in this setting, and provided a crucial pathway to accessing others who were also working in this and other remote communities.

Interviews with these healthcare providers working in the AWWH program were conducted using a tape recorder in the early introductory phase of the program, and then followed up after the program had been in progress for 18 months. Semi-structured questions allowed me to ask the same questions to different team members to provide an accurate representation of the program and their roles within this. Open-

ended questions enabled them to discuss any issues in a confidential manner and provide a holistic account. These tapes were then transcribed and analysed using the domains outlined in the evaluation process.

*The Community Women participating in the SA AWWH program*

Much consideration was given to determining how best to gain the views of women who had participated in the program. The Aboriginal Health Service Board approved the evaluation process and agreed to an Aboriginal woman interviewing participants. Some of the participating women were particularly shy and this part of the data collection needed to be addressed in the most respectful manner, and at a time when the women were not requiring the services of the program. This approach also created a limitation, in that not all women who participated could be reached, as it was an opportunistic process. The visiting Aboriginal healthcare provider conducted the semi-structured interviews on one of her regular visits to the community, shortly after the completion of the fifth intensive AWWH program. This approach enabled the local Aboriginal women to engage with someone who was an outsider to their community, but who they accepted culturally. The interviews were conducted in the community at a time and in a place of the women's choosing so that they could feel as relaxed as possible, culturally safe and able to speak more freely.

A semi-structured questionnaire was used in 'conversational style' interviews for evaluation purposes. The interviews elicited individual Aboriginal women's opinions, experiences and suggestions, by inviting them to respond to key questions as they wished, as well as encouraging them to expand on any issues, or aspect that concerned

or interested them in regards to the AWWH program. They were encouraged to offer their comments in the hope that they would see that their views would help to improve the program.

### *Ethics in Action*

The ethical considerations have been discussed in the previous chapter on methodology; however, as informed consent and data ownership are fundamental components of research ethics, this is briefly revisited.

### *Informed consent*

Both written and verbal consent were needed for the women to be interviewed, and they all personally received a plain English information sheet and face-to-face verbal explanation from the Aboriginal interviewer. The women were offered their choice of having their conversation (interview data) recorded on audiotape or through written notes taking by the researcher. The Aboriginal interviewer checked that all participants were comfortable with their own interview data before she left the community. One focus group was conducted with small group of teenage girls who were known to be comfortable talking together. Other women preferred to talk by themselves and gave their consent either in writing or verbally on tape. Other women chose to answer the questionnaire and did not wish to be recorded on audiotape. Participants were assured of their confidentiality and that the audiotapes were to be transcribed by the researcher and erased immediately after the research was completed.

### *Data Ownership and Management*

In the early consultation process with the recipient community, it was agreed that the data would be collected and collated by the researcher and held at the university. However, the Aboriginal Health Service would have access to the de-identified data as required, and would actively participate in the collection and evaluation processes. Feedback reports on the progress of the program and the incidence of disease were to be provided back to the Health Service and members of the Project Advisory Group (PAG). The interview data were recorded by audiotape, hand-written notes and email survey results and transcribed to computer. The audiotapes were then erased. All hard copies of the interviews and data under analysis are stored in a locked filing cabinet in an office at Flinders University. The information was analysed using NVIVO computer software as necessary and preliminary reports were formulated and provided to the community and stakeholders concerned. The collated data were stored securely, in accordance with NHMRC guidelines for the School of Nursing and Midwifery and will be held for a period of seven years.

### **5.13 Qualitative data analysis**

#### *Thematic Analysis*

Analysing qualitative data aims to extract the essence of the participants' meanings from their personal accounts (Stynes 1995, p254). The content data analysis in this study was thematic, and undertaken in the three phases that have been described in the methodology overview (Chapter 4). The researcher has a great influence in how the data are reported and what information is shared (Fontana and Frey 2005, p712). It is therefore imperative that the voices of the community women are heard, together

with the local healthcare providers, some of whom are Aboriginal women living in the community. The researcher has made a sincere effort to ensure that the women's voices are accurately represented and heard, and inform this research.

*Phase one* identified the priority of remote Aboriginal women and key informants. Key informants shared their views relating to the essential elements of a successful health program. A document analysis of reports and research literature also identified elements of a successful health program and transferability concepts.

*Phase two* data related to the elements of success in the Central Australian WWH program collected from participating healthcare providers, together with views from Aboriginal women attending, and researcher field notes.

*Phase three* data clearly determined the key elements of the original successful AWWH program and the transfer process that included adaptation and implementation of the AWWH program in the recipient community in SA. In this phase, the evaluation of the transfer and adaptation reflexive process was undertaken using the 'emergent model' of Laverack and Wallerstein's (2001) nine domains and the health principles of the National Aboriginal framework.

#### ***5.14 The data analysis process***

A systematic approach to thematic analysis was used to structure the large amount of data that had been collected through researcher observation, field notes, participant conversations, interviews and document analysis. The process of reflexive action was continuing throughout the data collection period and collaborative decisions were made about continual improvement to the program. This information was initially

collated manually and then transferred to computer under the themes of *examining*, *experiencing* and *enquiring* using NVIVO qualitative software. Taped interviews were transcribed and replayed to ensure their interpretation, and then included in the NVIVO database.

This data were then examined, and re-examined, in the context of the following questions.

*Phase one*

- Q. What were the priorities in Aboriginal health research for key informants?
- Q. What did key informants determine were the key elements of a successful health program?
- Q. What did the literature say about why programs were viewed as successful?
- Q. What did the literature say about the elements of program transfer?

*Phase two*

- Q. What were the key elements of a successful health program?
- Q. What did Aboriginal women in Central Australia like about the program?
- Q. What did the remote healthcare providers determine were the elements that made the program successful?

*Phase three*

- Q. What were the requirements for a remote community in SA to participate in the research?
- Q. What strategies were put in place to transfer and adapt this successful program?
- Q. What adaptations were required to make the program acceptable to the SA community?
- Q. How would this transfer and adaptation process be evaluated?



- Q. What would be identified as a successful transfer and outcome?
- Q. Did the local and visiting healthcare providers view the AWWH program as successful?
- Q. What did the Aboriginal women participating in the AWWH program like about the program?

In this research the investigation was designed to follow a specific, systematic line of enquiry. This was to determine if an established remote Aboriginal women's health program could be transferred from one remote community to another community with similar characteristics and needs.

The data from non-participant inquiry through literature, document analysis and field-notes were collated, analysed and then compared with data from the participant interviews, researcher observations, field notes and informal conversations with various Aboriginal women and healthcare providers who had been participating in the AWWH program. I read and reread all the textual data initially collated under the headings of examining, experiencing and enquiring. The questions in each phase were then organised in NVIVO separately and then later amalgamated to provide a total of fourteen themes. The domains of the emergent model were then included as subsets to categorise the findings, enabling me to write up the results in an organised and systematic manner and identify issues of capacity and empowerment. One of the strategies to quantify the screening results and possible diagnoses was by scrutinising statistical data recorded at the time. This comparison of descriptive qualitative data together with quantitative data, such as the attendance at the program and incidence of disease, added reliability to the analysis and findings.

### *5.15 Quantitative data analysis*

Quantitative data analysis encompasses the process of determining values of specific criteria by examining their numerical and measurable characteristics (Lewin 1951, p215). Quantitative methods of data collection used in this research were constructed through the numerical incidence in computer generated data. Data were quantified through the computer statistical software program 'Medical Director', which was used to collate the women's screening and diagnostic data from the AWWH checklist and physical examination. These data were analysed to answer the specific questions outlined below:

Q. How many Aboriginal women accessed the program?

Q. What were the ages groups of women attending?

Q. Were the women who attended in the 'high risk' or 'target age group', for cancer?

Q. Were the women who attended identified with any chronic disease such as diabetes, renal and cardiovascular disease?

Q. What other diseases or illnesses were the women presenting with?

Q. What were the comorbidities of disease?

Q. What were the mental and social health and well being issues?

Q. What were the incidence of STI's, HIV and

Q. What were the incidence of Hep B & C

Q. What was the incidence of dental disease?

Q. What was the incidence of alcohol and drug issues?

Q. Incidence of undiagnosed pregnancy

Q. What was the incidence of family violence?

Some questions referring to the community women's semi-structured questionnaire could also be quantified. Aboriginal women were able to comment and choose responses that best reflected their views and the well health holistic check undertaken

by the female doctor and clinic team of women's health nurse, and health worker or enrolled nurse.

The following questions were collated and then analysed and compared with qualitative data in a sequential manner:

Q. What health information and lifestyle sessions did the women want?

Q. What influenced the women's attendance/non attendance throughout the intensive programs?

Q. Did the attendance at AWWH program decrease as the intensive screening continued over time?

Q. Did the focus of primary health care and well health checklist help determine women's health problems?

Q. Did the focus towards primary health assist clinic staff to monitor and assist women with their health problems.

Q. Did the women see the Well Women's Health program as successful?

In this research a greater understanding of the data was gained through qualitative interview, participant observation and textual analysis being compared with quantitative statistical data. Therefore both quantitative and qualitative methods of analysis identified the effectiveness of the research and provided a comprehensive account of the context and the process of program transfer and its effectiveness.

### ***5.16 Evaluation of the AWWH program***

The evaluation process of the AWWH program is outlined here to demonstrate the techniques that were used in process and impact evaluation to determine the strengths and weaknesses of the program. Evaluation is defined as:

*... the process by which we judge the worth or value of something.  
...The evaluation process includes observation and measurement,  
and comparison of what was observed against a standard of  
performance (Hawe, Degeling and Hall 1991, p7).*

The qualitative and quantitative evaluation strategies need to be well chosen and planned from the beginning of the project design. The correct questions and type of data collection are crucial to the effectiveness of evaluation in assessing whether or not the aims of the program have been met. In a program that is based on a participatory model, there is a need for transparency of the evaluation intent and processes. Clear communication is required on whose role it is to evaluate, the best evaluation techniques to access the required information that can clearly demonstrate effectiveness of what is being evaluated, and how this is achieved. Strategies on how informed consent, confidentiality of data, and data ownership will be managed, are also important considerations that need agreement (Aylward 2005).

The program evaluation for this research follows Aylward's evaluation model, which is described below. This model has been used to evaluate the AWWH program as it has previously been used for Drug and Alcohol research and has been acknowledged as an appropriate evaluation model for community health programs by the National Centre for Education and Training on Addiction (NCETA) (Aylward 2005).

There are logical linkages between all components of the program and its evaluation. The strategies outlined are the main activities employed to collect the relevant evaluation data in order to assess whether or not each objective was met (Aylward 2005).

#### ***5.17 Aylward's Evaluation Model***

The diagram of Aylward's evaluation model is included here to provide clarity in this evaluation process.

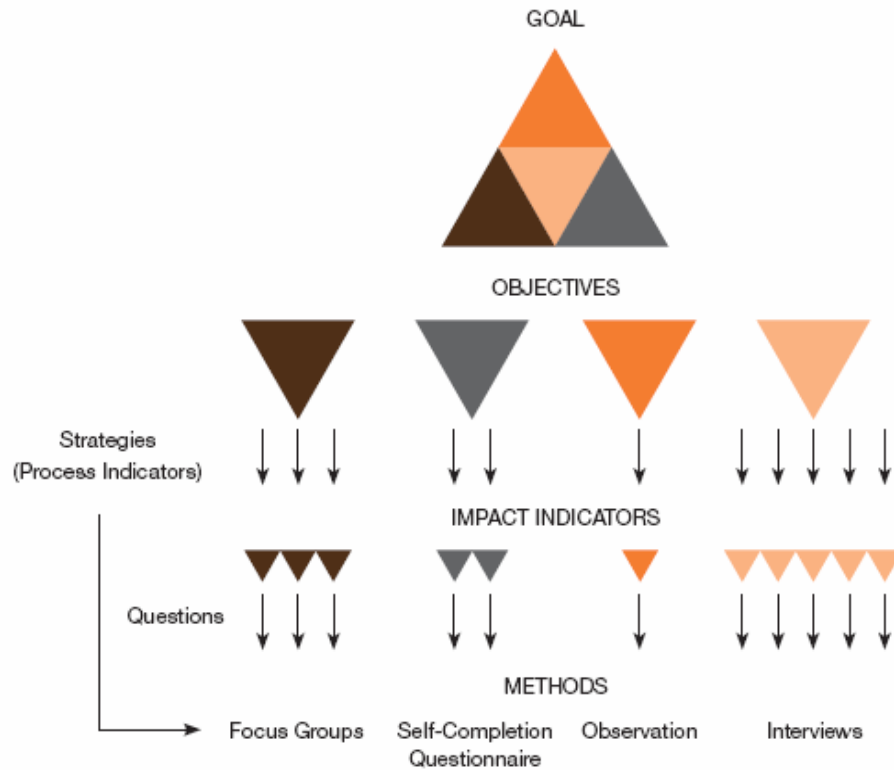


Figure 2. The hierarchical structure of evaluation planning

Reproduced with kind permission of Paul Aylward (Aylward 2005, p11) from *Evaluating AOD Projects and Programs: Chapter 4 in Roche, A. and Skinner, N. An Introduction to Workforce Development. Workforce Development Tips .NCETA.*

The overall goal of the research evaluation was to assess whether the AWWH program was transferable and adaptable in a willing remote community with similar needs, based on the elements of a successfully established AWWH program delivered in Central Australia. The community's goal was to adapt and implement the Aboriginal Well Women's Health program so women could become empowered to make choices about improved self-management of their own health with the support of the program. The objectives in obtaining these goals are listed below.

### ***5.18 The Program Evaluation Objectives***

The objectives were to:

- I. Identify the specific health needs of the Aboriginal women in the community
- II. Identify the capacity building mechanisms and resources required to implement and sustain the program
- III. Evaluate the process of participatory action research that required collaboration between local healthcare providers, visiting members of the women's health team and the researcher.
- IV. Determine what health information the local community women required to assist their health improvement
- V. Access the views of participating local Aboriginal community women and local health care providers, to determine whether their holistic health needs were being met
- VI. Explore opportunities for the program to develop further in order to become sustainable
- VII. Identify any barriers to establishment and the effective management of the implemented program.

### ***5.19 The Evaluation Strategies***

The following strategies define how the objectives can be accomplished.

1. Facilitate the implementation of the AWWH program using key elements as outlined from the original program and identify specific Aboriginal women's health needs using the adapted Well Women's Health Checklist and screening processes.
2. Work with local healthcare providers to identify their needs, and ways to assist them to effectively adapt and implement the AWWH program.
3. Form the Project Advisory Group (PAG) with representatives able to guide, implement and continually improve the program, and through the PAG build relationships for collaboration between internal health

providers of the Aboriginal health service and mainstream services in the community.

4. Through collaboration build capacity within the community in conducting the holistic program in health screening, health information and lifestyle sessions
5. Assess through PAG critique, conversation and interviews how useful the program is to women in the community and how it can continue to improve
6. Examine the strengths and weaknesses of the program with the view to continual improvement and building capacity.
7. Examine and analyse all data from interviews, documents, observation and reflexive journal that can identify any adaptation, implementation, or program issues.

#### *Process evaluation*

Process or formative evaluation enables the researcher to “measure the activities of the program, the program quality and who it is reaching” (Hawe et al. 1991, p60) and also assess the program implementation process and participants’ satisfaction (p84). The way in which the evaluation is conducted will depend on values that include past experiences, expectations and what is seen to be important by those evaluating. In this research, both qualitative and quantitative approaches have been used to determine women’s access to the program and the usefulness of such a program.

Of specific relevance were the following questions: what is the incidence of disease; what are the health priorities that need addressing and influence the activities and health information sessions provided; how many women are attending; who is the

target group; which age groups of women is the program reaching; and how does this program impact on women in any health behaviour changes?

### *Impact Evaluation*

The use of a participatory action and community development methodology has enabled capacity building throughout the reflexive process evaluation and improvement processes. This can be measured through community empowerment as a process in capacity building in skills and resources that can be monitored, including changes in health management, policy and individual outcomes (Laverack 2001, p182). The evaluation will therefore be addressed by Laverack's nine domains to determine the extent of empowerment through capacity building provided by this program:

*Each domain is inter-dependent and can individually influence the effectiveness and utilisation of the process of community empowerment (Laverack 2001, p142).*

### **5.20 Links with others**

Networks and links to other people and organisations, including partnerships, can lead to empowerment through greater access to information and resources, which can assist the community in planning, implementation and evaluation of the program (Laverack 2004, p95). In this research, through extensive consultation, key informants informed the researcher about the priority of Aboriginal women's health and they provided access to their successful Aboriginal women's health programs. The researcher was guided by Aboriginal women and women's healthcare providers in culturally appropriate behaviours when meeting representatives of communities and interacting with the local community women. Links were also established between local mainstream and Aboriginal health providers in the remote SA



community where these did not previously exist, so that all could work together to adapt and implement the AWWH program.

### ***5.21 Program Management***

This required clearly defined roles and responsibilities for all healthcare providers involved in the program and control over decisions of management in planning, implementation, evaluation and administration. (Laverack 2004, p99). One of the initial roles of the researcher in the recipient community was to form a Project Advisory Group of all interested local and invited outside health care providers and representatives of local Aboriginal women, who were interested in adapting and implementing the AWWH program. Implementation of the program was guided by this group and a PAR approach was adopted to continually reflect and evaluate and improve each intensive program to ensure it met the physical and cultural needs and expectations of the community women.

### ***5.22 Resource mobilisation***

The ability to identify the required resources and negotiate inside and outside resources at a local level indicates the level of skill and organisation within the community (Laverack 2004, p93). While such resources are not limited to health, this has been confined here to the requirements of the AWWH program, to improve health knowledge and therefore empower the community women to make healthy lifestyle choices. Accountability for the health sector in Aboriginal Controlled Health Services is the direct responsibility of the Health Service Board, made up of local community members and directed by the Chief Executive Officer (CEO) of the Health Service. The CEO (female) and female representatives of the Health Service

Board were part of the Project Advisory Group (PAG) management, guiding the implementation of the AWWH program.

The PAG identified the available local expertise and the specific roles that were required by visiting health professionals. Outside resources included a female medical officer with expertise in remote Aboriginal women's health, an Aboriginal nurse educator with expertise in women's sexual health, in particular cervical screening and sexual health education. The need for education in other health systems areas, specifically in diabetes, renal and dental disease with health information and treatment, was identified early in the program.

### ***5.23 Organisational structures***

Organisational structures in this research have been identified as the Aboriginal health service and the Project Advisory Group (PAG), which were responsible for adapting and implementing the AWWH program. Within the Aboriginal Health Service, healthcare providers and their management were guided by the governance of the community-controlled Aboriginal Health Service Board, consisting of local Aboriginal community members. This organisation has worked to strategic directions that incorporated the development of clinical services and the consolidation of primary healthcare programs in a culturally appropriate context (Vanajek 2004).

For the AWWH program to be accepted by this community-controlled organisation it needed to be identified as an essential requirement by the Board and core business of the health service. The implementation of the program required interrelationships between the local mainstream health and the Aboriginal health services and

partnership with the researcher's university, which facilitated policy & decision making and ensured the financial and practical commitment, and community ownership. The PAG was formed by the researcher in collaboration with local Aboriginal healthcare providers and mainstream community health, representation from the Aboriginal Health Service Board, and external visiting health care providers. Their role was to implement, guide and develop the AWWH program. Using a community empowerment model through participatory action research, the goals of the program and its evaluation were established. Using this approach the PAG members have been able to meet and identify the issues as they arise both prior to and following the AWWH programs.

The level at which both these organisational structures functioned was crucial to community empowerment. All PAG members were able to act with autonomy using their unique knowledge in their specific area of expertise, but also to combine as a team with a social sense of connectedness and a common goal for the community. Organisational changes and governance issues within the Aboriginal Health Unit to accommodate the program were monitored, together with the focus towards primary health care. The behaviour of healthcare providers and work practice changes with acknowledgement of training needs to accommodate the program, are all identified as important indicators of capacity development.

### ***5.24 Participation***

#### *Individual women*

Participation describes the involvement of individual community members which enables them greater control over factors influencing their lives and health, that is central to community empowerment (Laverack 2004, p87).

#### *Healthcare providers*

Participation relies on the ability of individuals to interact and work together, create trust and rapport that enables them to achieve a consensus in direction, and to identify the issues which influence their lives and health and the health of others. For participation to be empowering it must encompass the development of skills and abilities with the political concern to enable others to take action (Laverack 2004, p87).

Participation through PAR in this AWWH program provided the opportunity for all local healthcare providers to work together and collaborate in the research design, the adaptation, implementation and evaluation to meet the unique needs of Aboriginal women in this community. The individual roles of healthcare providers in planning and implementing strategies, together with .the opportunity of working collaboratively with outside health professionals, enabled skills and knowledge transfer to occur and positive outcomes for the participants of the program.

### *The community*

The Aboriginal community is often a collection of families, or language groups who are often in competition with each other but are grouped together geographically through isolation (Scrimgeour 1997). Often dominant groups or persons within this community may control community needs unless adequate precautions are taken to ensure inclusiveness of the majority of the group, in this case Aboriginal women and their shared interests. This AWWH program provided community women with the health information to enable informed decision making in matters regarding their health and that of their families.

### **5.25 Leadership**

Leadership plays an important role through taking responsibility and accountability for achieving goals, dealing with conflict and providing direction for the workers and the organisation (Laverack 2004, p88). Good leadership provides the influence for empowering practices through sufficient resources and organisation to make effective group decisions that impact positively on the community. The roles of leadership and governance within the Aboriginal Health Service were observed and examined in the context of the transferability and sustainability of the AWWH program.

The researcher, with the support of the CEO and Aboriginal Health Service Board initially undertook leadership in the PAG. The researcher's goal in community development and empowerment was to transfer this leadership to the local health care providers working in the Well Women's Health program team. While outside leaders are often seen by the inside to have the required management skills and expertise,

localised decision-making is an essential component of control and ownership. There is a danger that the community will not own the program and take full responsibility until this active leadership transfer has occurred, and the program is fully controlled by them. This program ownership was transferred fully to the Aboriginal healthcare providers gradually over two years as they became more confident in all aspects of its management.

### ***5.26 Problem assessment***

The identification of problems by the community, and the action taken to provide solutions, builds capacity within the group. Often new skills must be gained to achieve this capacity and this may be learnt through a process of collaboration with outside agencies working together with common goals (Laverack 2004, p91-92). In this research, local community members identified the health problem as a lack of well health services and holistic care for Aboriginal women. The limited resources of the Aboriginal Health Service were overstretched by the reliance of the community on crisis management, which in turn, reduced the capacity to provide any focus towards primary health care initiatives.

In an endeavour to promote a focus towards well health, a primary health care approach was undertaken and a well health checklist was specifically adapted for holistic screening and monitoring for women through the intensive screening days of each program. This checklist was adapted and used in the clinic to assist healthcare providers to monitor conditions such as diabetes and identify potential and actual health problems that could be referred to the local GP or specialist for management.

This tool provided documented evidence of the incidence in disease and health problems identified by community women.

### ***5.27 The role of outside agents***

Outside agents are often an important and essential link between the community and external resources. Health promotion is achieved through enabling people to improve their health through increased knowledge and control that is often provided by such outside resources (Laverack 2004, p98). This enabling process can build capacity through training and development within the community as these resources become known and familiar.

As part of the Aboriginal Health Council SA conditions for Ethics approval, the researcher agreed to undertake the data collection, analysis and evaluation and reporting, in collaboration with the Well Women's Health Team. As well as the process evaluation to determine the transferability of the program, this role enabled the impact of the program to be evaluated, and assessed the usefulness of the AWWH program to the community.

The researcher undertook various roles as an advocate, and one of these responsibilities was to initially locate and persuade a female medical officer, a GP highly skilled in remote Aboriginal women's health, to become a member of the AWWH team and commit to the program. The female doctor's position in this program was an essential component to providing culturally sensitive and appropriate health screening to Aboriginal women. Another important contributor to the AWWH team was the

inclusion of the Senior Project Officer for Aboriginal women's health in cervical screening and sexual health who was already familiar with the community. This holistic program required health promotion in these sensitive topics to be delivered in a manner that was culturally acceptable to the local women.

The assessment process required local healthcare providers working for the Aboriginal Health Service to increase their skills in techniques, such as screening for early renal dysfunction and Type Two diabetes, and asking clients questions about their social health and well being and their home environment. Other outside resources were also required to support the limited resources for dental health, mental health and drug and alcohol.

### ***5.28 Asking why***

This is described as the 'critical awareness' or reflexive process of PAR in discussion, reflection and action of the community in addressing the emancipation process (Laverack 2004, p94). In the research this is not seen as this reflexive process alone, but also one of accountability.

The Aboriginal health service, firstly in assuming the control and ownership of the program, has the responsibilities of designated roles in undertaking specific roles, such as setting up the intensive screening program with material resources and shared communication as to who is doing each particular role. This responsibility extends to the follow-up process after the completion of each program that monitors client progress and improvements, appointments, repeat testing and treatment processes.



This accountability also extends to the overall program, where the documentation of access to the program and any limitations of health resources to attend women's health needs are identified and addressed, in both the short and long term outcome evaluation.

Further reflexive evaluation must continue to ensure that the AWWH program continues to meet Aboriginal women's needs, both culturally and in health improvement, through increased knowledge and empowering them to make informed choices with adequate resources, in their health and lifestyle. Feedback mechanisms by way of verbal and written reports to the Aboriginal Health Service and stakeholders in the wider community have been ongoing throughout this research.

### ***5.29 Summary***

This chapter has described the role of the researcher and the methods undertaken to analyse the data that was collected, collated and analysed through this mixed method design. The program evaluation method has been clearly outlined to illustrate the transparency in this process, and to enable others to understand and replicate the model and determine elements of success and empowerment, which can be identified through capacity building. While the outcomes cannot be generalised for all Aboriginal Well Health programs, the elements of successful transfer of this remote AWWH program can be applied to other settings. The findings of this research are discussed in the following chapters.

## CHAPTER 6: RESULTS

### *6.1 Introduction*

The methodology and method chapters have described the philosophy and approaches used to implement this research. This chapter will firstly discuss the findings from the qualitative data sets in a logical progression through the three phases of the study and then the qualitative and quantitative data findings from the evaluation of the program. The identification of the research priority for remote Aboriginal communities in SA is reported in Phase One. The encounter with a successfully established holistic Aboriginal Well Women's Health program and observation and participation in the program is reported in Phase Two, and the transfer, adaptation and evaluation of this program is discussed in Phase Three. Issues of community empowerment and capacity development are examined through Laverack's nine domains, which were presented in Chapter 4.

#### *Phase 1*

##### *The progress of consultation*

The first phase of the study was conducted over a period of thirteen months from August 2002 to September 2003. Throughout this time, consultation with key informants extended and intensified, and successful strategies in the Far North of South Australia and Central Australia were identified. The direction and guidance provided by key informants in the development of this research is briefly discussed under major themes.

### *The Sample*

The purposive sample of key informants in this phase consisted of both Aboriginal and non-Aboriginal people known to be working in organisations associated with Aboriginal health. They were contacted initially by telephone and then followed up where possible with face-to-face interviews. Six of the sixteen informants who identified specific strategies in health were Aboriginal, and four from a total of eight informants, were working in remote areas. These key informants were approached as they were known to have particular knowledge and skills in remote Aboriginal health and were able to identify specific health strategies that they believed were successful.

### ***6.2 Major Themes from Key Informant data***

#### *Drug and Alcohol and Inhalant substance use*

The effective health strategies “Avgas Fuel” (1998)(BP Australia 2005), and “Makin Trax”(2001-2002), were described as being useful in informing Aboriginal communities about the dangers of inhalants such as petrol and drug and alcohol misuse, and for introducing harm minimisation strategies that could reduce the incidence of such substance use. However, in discussing these health strategies to assist clients using substances, the informants expressed their concerns that the effects of such drug use on other family and community members, especially women.

#### *Interfamily violence*

The incidence of family violence was seen to be increasing, and this was especially affecting the women in the community who were caring for a growing number of grandchildren and other relatives as the continuing drug and alcohol consumption created aggression, violence, injury and death. Women and children were most

vulnerable and their distress increased as their money for food was stolen and their safety was threatened. Informants did not report on any successful programs that addressed these issues related to violence.

#### *Sexual health Screening*

Sexually transmitted infections (STIs) have been a continuing problem in remote communities and informants described the strategies and programs implemented in the APY Lands to overcome their high incidence. Well organised and regular screening strategies with the follow-up of community members through a common database system has enabled healthcare providers to ‘track and treat’ individual clients as they visited different communities (as described in Chapter 2). This approach, together with the provision of culturally appropriate health information, has significantly decreased the STI disease statistics in this region.

#### *Well health screening strategies*

The premature death statistics for both Aboriginal men and women, and the complexity and comorbidity of ill health that are responsible for the mortality and morbidity of disease have been a major catalyst for health screening to be more holistic and not only related to sexual health.

#### *Practical management and research implementation concerns*

One key informant voiced concerns about the relationships between healthcare providers and their value as members of the team, and questioned who makes up the collaborative team. This informant stated:

*The collaborative stuff is starting to happen. One of the biggest problems over the last two years has been trying to get doctors to recognise that*

*other health workers, such as Aboriginal health workers and remote nurses are health professionals, and part of the collaborative team. We are trying to create a pathway from community to hospitals where there is communication between the health worker in the community (who has the most knowledge about the patient) and the doctor at the hospital, for the transfer of patients and their information and vice versa.*

These relationships within and across health organisations have depended on the leadership and governance capabilities of the local organisations. However in this remote region of SA client case management across organisations to benefit Aboriginal people had not previously been established.

There were also concerns of translating research to practice as a significant amount of research undertaken has not translated into practice. A key informant stated:

*That's the problem. We see lots of research completed but not lots of programs developed from it. From a Health Council point of view, that is our biggest issue. The Council now want to know the sustainability of projects.*

Supporting evidence was identified by document analysis and described in field notes.

### **6.3 Document review**

Innovative strategies identified by research reports, document and literature reviews reported in earlier chapters were supported by key informant data. The issues of successful transfer and effective program organisation and management are discussed throughout this chapter.

### **6.4 Field notes**

Field notes taken throughout the Phase 1 period identified the initial difficulties in establishing the direction of the research that was the priority of Aboriginal people in

remote areas of SA. Much time was spent contacting urban and remote key informants to ascertain their views and comparing these with the literature.

Early program strategy information was documented in field notes received from male informants who saw women's health issues as a high priority. In order to balance this with Aboriginal female key informants, the NPY Women's Council Executive was approached to gain their opinion as remote Aboriginal women leaders. Women's health was considered a major priority for them and meetings were organised for their then current chairperson with me, when she next visited Adelaide, to discuss the NPY Women's Council's views further. Interfamily violence was high on the agenda for women but at that time no effective programs had been implemented in the APY Lands.

#### *Summary of findings in Phase 1*

Both urban and remote informants identified Aboriginal women's health as a major priority for remote SA communities. This was confirmed and supported through contemporary literature and through interaction with a senior mentor from the Aboriginal Health Council of SA. Two effective women's health programs were then identified that may be transferable, and these are discussed in Phase Two.

#### *Phase 2 - The consultation process and interaction*

The second phase of the study was conducted over a period of twelve months from August 2003 to August 2004. Key informants in Central Australia were contacted by telephone and email, and face-to-face interviews were then held to enable them to discuss their roles and views in relation to remote Aboriginal women's health

programs. Successful women's health programs were explored with these key informants to determine their elements of success. In particular, one of these Central Australian (CA) holistic well women's health programs was described in detail to the researcher, with the program coordinator prepared to actively support the replication of the program elements.

A recipient South Australian remote Aboriginal community was identified as being interested in introducing an AWWH program and initial consultations took place face-to-face with the Social Health and Wellbeing Coordinator and the CEO of the Aboriginal health service, who were both women. A paper copy of the CA program was provided to these informants for community consideration. Follow-up consultations were held by telephone, email and visits by the researcher to their community.

In June 2003 an invitation was extended by the CA AWWH program coordinator to the researcher and healthcare providers at the remote recipient Aboriginal health service in SA to attend and experience a remote AWWH program in Central Australia during its three days. This enabled the researcher to interact and closely observe the program in action. Disappointingly, other healthcare providers from the remote SA community could not attend.

### *The Sample*

The purposive sample of key informants worked in remote Aboriginal women's health programs in either Central Australia or the Far North of South Australia in the APY Lands. Informants included doctors, remote area nurses (RANs) and midwives

involved in women's programs, and other service providers working in organisations associated with Aboriginal women's health. A total of forty key informants were interviewed, who were predominantly female (36F / 4M).

#### *Aboriginal Women Community Leaders*

Issues of Aboriginal women's health were explored through the opinions of Aboriginal women who were members of the NPY Women's Council Executive that represented remote Aboriginal communities in SA, CA and NT. The researcher was invited to attend part of their meeting that took place in the presence of their interpreter, who was conversant with the dialects of all eleven executive members. The senior women discussed various aspects of women's health, and had strong views about what was needed. They advocated that this research change its focus from inhalant use to women's health and they guided the researcher in this direction.



- *The South Australian (SA) AWWH program*

Four of the key female informants were from the SA remote community which was the potential recipient of the program. These informants discussed the needs of Aboriginal women and introduced the concept of the well health program to their community for consideration. They then further interacted with the community and Board members of the local Aboriginal-controlled health service to ascertain their views and subsequently represented them in planning the transfer and adaptation of the accepted AWWH program that was now the focus of this study.

- *The observed Central Australian AWWH program:*

The fifty Aboriginal community women chatted openly and their specific opinions of the program were represented by a spokeswoman, an Elder. The local healthcare providers were represented by two Aboriginal female health workers, four registered nurses and a female doctor (non-Aboriginal). While other visiting health team members also discussed the successful elements of the AWWH program, only their coordinator was included as a key informant.

### ***6.5 Major themes***

#### *Cultural considerations of traditional women's practices*

The NPY women stated that differences existed in Sacred Women's Lore between Aboriginal groups, and that these aspects were not transferable between communities. They also asked how a grandmother's knowledge of women's health would or could be incorporated into the program. These included topics such as 'smoking the mother

and babe following birth' that would prevent infection and make the babe healthy. It was expressed by one elder that the system of hospital birthing had prevented this practice from continuing and this was partly responsible for the lost ways of their youth, some of whom had turned to petrol sniffing and other drugs.

Successful strategies or health outcomes were identified by the women and health care providers as those that demonstrated a positive change. Examples of these were stated as

- Improved health outcomes for a particular client group
  - Reduced incidence of a specific infection
  - Slowed progression of a chronic disease
  - Reduced acute care for interpersonal violence injuries required in community based clinic facilities
  - Fewer crisis/emergency evacuations to central health agencies
  - Fewer hospital admissions for specific diseases/injury conditions related to harmful alcohol/drug use

*Core elements of successful programs*

Key informants described the elements of successful health strategies or programs. Those that were comprehensive, and were considered the organisation's core business, with a high commitment from both Aboriginal and non-Aboriginal staff and management, were considered most likely to succeed. In Aboriginal health, programs must not only to be culturally appropriate but must also be community-controlled, starting with shared goals and two way learning. As the community is likely to be extremely mobile, it is also necessary to have a central database that can transfer information without difficulty to other remote community health services.

The components of successful *cardiac screening* program were acknowledged as:

- A program of good communication and trusting relationships
- Expertise and skills in a particular area of health
- Consideration of public health and epidemiology issues
- Matching the skills of key players and dovetailing them in to the program
- Getting on with the job as quickly as possible
- Employing good evaluation processes.

This compared favourably with the components of a successful *sexual health screening* program that was described as:

- Careful planning, using the WHO health principles
- Engaging with the communities to inform and collaborate
- Anthropologists employed in the planning and consultation process

The personality of the person setting up the program with expert skills, expertise and good management, and in building relationships:

- Core business of the organisation
- Well resourced with good staffing levels and conditions
- Good marketing and presentation and publishing by organisation
- Comprehensive evaluation using effective database for follow up and statistics.

#### *Difficulties encountered with health programs*

Informants acknowledged that there were many difficulties in implementing health programs. Some difficulties were identified as follows:

- Health promotion programs to benefit and maintain health were seen as a lower priority as attention to illness, accident and injury was overwhelming

and many healthcare providers were not keen, or have limited time, to educate their clients.

- Much of RAN's time in remote communities was spent in administration
- Many health programs have not been appropriately evaluated
- Qualitative data collection is often not considered valuable or able to support statistical data outcomes, and evaluations at present are therefore mainly statistical. This omission qualitative research reporting on people's experiences, beliefs, cultural issues and behavioural aspects diminishes the usefulness or power of current evaluations.

One informant reported:

*There is an epidemic of hopelessness! Aboriginal men and women are dying from heart disease,- and of broken hearts from the Stolen Generation. They need a vaccine for poverty!*

#### *Women's Sexual Health*

Sexual health programs varied considerably depending where they were implemented. The APY Lands in South Australia are considered to have a very effective sexual health program. This program has been developed across the APY Lands into the NT and WA as the Tristate Sexual Health program with its central office in Alice Springs. However, this screening in NT and WA is still opportunistic, with the added difficulties of many language group barriers as each community needs to be consulted and the program negotiated. There still remains a significant incidence of STIs including syphilis (250 new cases annually reported 2003), trichomonas and gonorrhoea. People are not regularly screened for Hepatitis B and C and HIV as there were not the resources to undertake this. However, when STI screens have returned positive results, HIV testing has been implemented where possible. In some NT communities there was still a high risk of congenital syphilis

(10 cases per year). Condoms were available on a twenty-four hour a day basis in heavy duty containers to help reduce the sexual transmission of these infections.

One informant asked:

*What do we do to inform Aboriginal women to make men wear condoms as Aboriginal men would have the lowest use of condoms, though they have the highest rates of STIs and Hepatitis B and C?*

### *Teenage Girls*

Some teenage pregnancies on The APY Lands are associated with petrol sniffing, and these young people also have a high risk of STIs. Foetal Alcohol Syndrome and Failure to Thrive babies have been identified as a consequence of pregnancies associated with petrol sniffing, alcohol use, cannabis, smoking and other drugs, and a lack of good nutrition. There has been no real reduction in the numbers of teenage pregnancies but the availability of termination of pregnancy (TOP) has made a difference. There are other girls who may be infertile due to chlamydia infections that may not be recognised. Young girls from the age of eleven years onward, require a whole of health program in nutrition, exercise and puberty issues. This education was traditionally undertaken by grandmothers as the foundation of women's business. However, this was no longer happening and therefore the health clinics needed to develop a program to address these issues.

- *Sexual abuse in the Top End*

One informant presented a paper and reported the extremely high incidence of sexually transmitted disease in young girls between the ages of ten and fourteen in the Top End of the Territory. Between 1997 and 2002 her data demonstrated there was an acceleration of the incidence of gonorrhoea (ninety cases) and chlamydia (sixty cases)

from rape and sexual abuse in young girls. This was a culturally sensitive issue as most of the children had presented with symptoms from STIs, rather than sexual abuse. In discussion, it was reported that this was unlikely to be the only area experiencing this sort of sexual abuse.

### *Breast Screening*

Breast screening in the APY Lands in SA is a very costly exercise and is therefore restricted to women aged between fifty to sixty-nine years where possible. There are limitations in the access to this service that relies on a portable unit to visit Marla or Alice Springs. Due to the sensitivity of the screening equipment, it is not able to travel the unsealed roads and therefore vehicles are used to transport the women to Indulkina where camps are set up with food for the duration of the screening program.

Breasts have special significance for Aboriginal women and for their ceremonies. Therefore they are very keen to have breast checks. (Several of the local women diagnosed with breast cancer previously had mastectomies and died). Breast screening is undertaken every second year and consideration is being given to include younger women, as breast cancer is being identified in 30 year old women and younger. It was reported that a Breast Screening clinic at Yulara would be helpful as the demand is greater than the services at Alice Springs or Marla can accommodate.

### *A holistic approach to women's health*

A holistic approach for women's health was required that included physical health checks in kidney and cardiac function, blood glucose levels for diabetes, sexual

health and social health and wellbeing. Due to the level of poverty, good nutrition was a problem for many families, but especially for antenatal girls and women. A variety of programs had been established to address this. Family violence was a continuing issue, although the women were talking more about it and becoming more aware of reporting these incidences. However, there were no strategies in place to effect change. Drug and alcohol problems, poverty, lack of education and control over money all contributed to interfamily violence.

#### *Disability programs and rehabilitation*

There was a great demand for disability programs and respite programs within The APY Lands, and for a regional detoxification and treatment centre that could assist petrol sniffers and people with alcohol and drug problems to rehabilitate and enable them to return to their communities. People with a past history of debilitating brain injury caused by inhalants and accidents and who were unable to walk, were required to live away from family and friends in Alice Springs or major centres down south. At the time (2003), there was no plan in process to accommodate this increasing need for Aboriginal people.

#### *Nurse Practitioners*

Remote area nurses and their representative body declared their interest in attaining Nurse Practitioners status and need to overcome the difficulties of extended absences from clinics to attend their study programs, and to receive support to achieve the required criteria. Discussions were held with relevant people as to how this could be more effectively achieved, and the issues of concern were taken back to the university and discussed with the clinical chair and professor for future action.

*CA Well Women's health program (described in Chapter 2)*

This AWWH comprehensive program provides women's health checks and education for women and young girls in remote CA communities. It had a 73% participation rate for pap smears and women's health checks in these communities in 2003. This program did not currently (2003) have a central database system that would further assist in the monitoring of women's health and recall for programmed screening processes. Successful elements of this program included:

- The proper establishment and support by remote health organisations
- Staff training to provide confidence and competence
- Support and back up assistance systems for staff
- A written program and checklist as a package
- A good comprehensive database to record all health check and to access speedy results for pathology and lab screening processes
- Collaboration and good working relationships with other organisations
- Comprehensive women's health checks that are core business
- Equal access to all women including grandmothers and young teenagers
- Specific programs of fun incorporated with educational sessions, for example healthy eating and making meals not normally done
- Building self esteem through programs such as hairdressing, painting, craft days
- Providing opportunity for Elders to incorporate Indigenous knowledge
- Opportunistic screening incorporated with other programs for fun, enjoyment, learning and improved health.

*Central Australian Aboriginal women's views*

The women in the community really looked forward to the women's health program as it had much information that the women could share together over the three days. They could also socialise together with meals that were cooked throughout the



program. The lunch that was cooked for the day was Kangaroo Tail Stew and this was one of their most favourite dishes. Health programs throughout the program included diabetes and foot care, pap smears and contraception, family violence and drug and alcohol and Centrelink issues. Other activities that were very popular included hairdressing, facials and massage, while not so popular was the belly dancing, as the women were shy and reticent. However, it was considered a very successful program. CA Aboriginal women stated:

*It was good that we get together and talk about good things -that we talked about Centrelink and other things. Like violence, sexual abuse and we would like this to happen next time at Yuendumu. It was very good talking with young girls and old women for our future.*

*It was good that women came around for the women's health program*

*We like to have this every year. It is good that women like it Hair cut and drying and talk about the heart and that at the program*

*I liked the games, prizes, hairdresser, health*

*I loved everything*

*Gina liked the basketball and learning health*

*I liked the lot activities, health talks, videos, posters prizes hairdresser*

*I liked sharing our stories together, antenatal, STDs*

*I loved everything Telling stories tucker learning and talking about people's health*

*Ruby liked everything hairdresser, good tucker and everybody telling stories*

*Everything was good prizes, food, health talks, laughing, enjoying company especially seeing Lynette, Margaret and Julie again.*

*I liked sitting down talking sharing stories win prizes and good tucker*

*It was good to share women's stories with everyone*

*The needs of Aboriginal women in the recipient SA remote community*

It was reported that the RFDS had been flying in a female GP at regular six weekly periods for women's health screening for the last two years. However, very few Aboriginal women used this service and even less had used it in the last twelve months (fewer than 8 women). The Aboriginal women were in need of a culturally acceptable service that they could visit, without the strict appointment times that were required to be made well in advance. This then meant that very few Aboriginal women were having pap smears and women's health checks, as there was no other female doctor in the town at the time.

The local Community Women's Health nurse was qualified to undertake women's health checks and breast checks, however she was not credentialed with a Medicare provider number to sign pathology forms and required support from a medical officer for pathology results. Therefore Aboriginal women were forced to travel to the nearest major town for this service, about five hours away by road in a mechanically sound vehicle. The needs of Aboriginal women in this community were identified as complex, with drug and alcohol problems, and mental health issues identified along with issues of physical health in chronic disease, social health and wellbeing.

Staff members at the remote Aboriginal health service were enthusiastic about organising a women's well health program, a feeling that was shared by community women. The women were interested in a culturally acceptable environment and the concepts of well health in a women's program, rather than just attending the clinic when they were ill. Discussions with government healthcare providers working in the community indicated that they were also very supportive of such a program and so

the search for a female GP that was willing to be part of the AWWH program began. This started locally, but it was clear that other resources were needed in the wider community to access available female GPs with Aboriginal health experience. Therefore this became part of the researcher's role.

### ***6.6 Document review***

A paper copy of the CA AWWH program was provided and shared with the recipient remote SA Aboriginal community interested in adapting it. This gave Aboriginal community women and health workers a tangible and visual concept of how the program was conducted and assisted them in their decision to accept the program. The concepts of transferability discussed in the literature (Chapter 2) were compared with key informants' views, for similarities and contrasts. Key informants were able to build on the literature reporting transferability and the nuances and cultural considerations that needed to be taken into account.

### ***6.7 Field Notes***

- *Difficulties of entry to the APY Lands*

There were many difficulties to overcome in accessing relevant information and informants on the APY Lands. A permit is required to visit the Lands and the visit purpose needs to benefit the identified communities. It was suggested that I present my research proposal to the health board representing the APY Lands and that a permit would be forwarded for this. However, modes of travel and accommodation on The APY Lands were still to be organised. Shortly after this invitation was issued The APY Lands were closed due to violence that had resulted in several deaths. The second visit to The APY Lands was postponed at

the very last minute. Because all travel had been organised, the time was spent beneficially in meeting with coordinators of remote Aboriginal health programs and discussing Aboriginal women's health issues in Alice Springs.

There was a genuine interest and support provided by key informants in sharing their knowledge. Through this extended stay in Alice Springs I was able to meet the coordinator of remote CA women's health programs and gain some insight into the program that was to be the most suitable for transfer and adaptation.

- *Meeting the Executive of the NPY Women's Council*

This was a challenging experience as I was not sure what to expect from this well respected group of senior Aboriginal women who represented their communities on so many different committees, and how our proposal would be received. The original proposal submitted for their consideration was to ask one of the NPY women in the community to work alongside me as a co-researcher and interpreter, as I asked Aboriginal women about their experiences of the health programs. While the discussion from these elder women was most informative and useful, the services of the NPY Women's Council were too stretched to accommodate this particular aspect of my research. The outcome of these events determined that the researcher was unable to visit The APY Lands and work with Aboriginal women in these communities and another remote community was sought.

- *Centralised databases*

Centralised databases were seen to be most useful in not only collecting medical statistics but in following clients as they travelled between communities, enabling

other health clinics to respond to people's individual needs. Outside the APY Lands in SA, there was no centralised database to follow STIs and nearby stand alone Aboriginal communities were unable to follow up their clients that also travel into the APY Lands when they had family groups and ceremonial business to attend. The managements of Tristate Sexual Health and APY Lands in SA were asked if these small communities could be included in their screening and database systems. However, there were not adequate resources for this to occur.

- *Coordinated approach to screening programs*

All the programs that were discussed had common features that contributed to their success. These included a planned approach to screening that was well coordinated and enabled quick follow up of results and therefore action, as necessary. Women's business is very separate from men's business and needs to be managed in a way that provides privacy and cultural acceptance, building knowledge and self esteem. It was recommended that where possible Aboriginal grandmothers' knowledge could be incorporated, especially for the young girls.

Correspondence from one informant in response to my statement that the recipient community was also interested in a Men's Well Health program stated:

*Good on them to want a men's health program as well. Very forward and progressive thinking actually. No point in looking after half the population. After all where do the STIs hold up when the women don't have them, we know don't we!*

### *SA Recipient community*

Prior to the introduction of the AWWH program, statistics from Aboriginal women's health checks were difficult to identify for this community. Women's screening results were included in those of the Far North West of SA; therefore, this community was included in the statistics with The APY Lands, which have high rates of participation in women's health checks. This blurred the actual participation results when averaged out per head of population. The concern of local health providers was that very few Aboriginal women in this community were being screened at all! Therefore, diseases were well advanced when symptoms were reported and there were fewer options for management.

The local GPs whom many Aboriginal people attended were so overwhelmed with managing acute and chronic illness in the community that there was not adequate time for them to conduct regular well health checks. This aspect of healthcare was allocated to a (non-Aboriginal) practice nurse who attended to health aspects of diabetes and asthma management.

### *Summary of findings*

Key informants were able to clearly articulate and define the elements that made their Aboriginal health programs successful. This built on the contemporary literature that described successful elements of particular programs. The recipient SA community was able to decide on, justify and promote the need for their own local Aboriginal well women's health program from the information supplied from the CA AWWH program.

*Phase 3 The continuing consultation process, implementation and evaluation of the program*

The third phase of the study was conducted over a period of three years and five months from April 2003 to August 2006. Extensive consultation took place initially with the recipient SA remote community through the Social Health and Well Being Coordinator, the CEO and the Board of the local community controlled Aboriginal Health Service, the local Community Women's Health Nurse, as well as Hospital Management and Aged Care organisations. This was necessary to determine the Aboriginal women's health concerns in this community and ensure the program was adapted appropriately to meet their particular needs, and that the local community women supported this implementation, as a program they wanted that would be useful to them. The first intensive Aboriginal Well Women's Health screening program commenced in November 2004 at the local Aboriginal Health Service.

*The Sample*

- *The Project Advisory Group*

The Project Advisory Group (PAG) was formed in February 2004 to guide the adaptation and implementation process of the AWWH program. This encompassed all Aboriginal Health Service staff and representatives of all local mainstream health services. The total number of healthcare providers making up the PAG, including the researcher was 21; eight of these members were Aboriginal.

- *Participating Aboriginal Community Women*

Many Aboriginal community women who participated in the program did not contribute their views as this was done away from the program, and the health service, at a later date. It was important to be perfectly clear about the information we were seeking from the

women, to clarify that we were not asking them about the general clinic services or health providers themselves. This data collecting process was planned for the week following the fifth program, which also needed the community's approval, and the visiting Aboriginal woman collecting this data, to travel back to the community. Unfortunately, there had been a death and Sorry Business meant that many of the women who had participated in the program were not available to comment. However, 16 women and girls agreed to be interviewed. This information is discussed in the results.

- *Other Informants that supported the transferred AWWH program*

#### *Point of Care program*

An earlier renal screening 'Point of Care' program had lapsed due to a lack of continued funding. However the researcher responsible for the implementation of that program five years earlier was supportive in assisting the researcher to reinstate the screening, on request. He was supportive by supplying cartridges costing \$10 each for the screening processes, and providing relevant information and training for healthcare providers.

#### *The inclusion of the AWWH program as an 'In Kind Project'*

Through key informant collaboration, the researcher was asked to give a presentation that could be critiqued, at the Cooperative Research Centre of Aboriginal Health (CRCAH) seminar series at Menzies School of Health. Researchers from this organisation provided very useful critique and feedback and assistance with the types of evaluation for consideration in this study. CRCAH team members then invited this research to be an 'in kind project' of the CRCAH and this recognised the needs of the community, and entitled



the researcher to further support that included some financial support (\$4000) to enable a more extensive evaluation.

### ***6.7 The Transferred Program Evaluation***

Aylwood's evaluation model has been reported to have effectively evaluated drug and alcohol primary health programs (discussed in Chapter 5) and has now been applied to report the process and impact evaluation of this research. The following objectives previously outlined in Chapter 5, are restated here as these were used as the framework for the evaluation. Each objective was assessed for its effectiveness and/or deficiencies.

The evaluation is reported in three distinctive segments. The first details the establishment of the program, the second the delivery of the program and the essential role of the PAG in the continuing process of improvement driven through PAR. The concluding segment reports the impact of the program and the issues that have arisen along the way through the nine domains of empowerment and how or if, this has empowered Aboriginal women in this recipient community.

### ***6.8 Establishing the Program***

Process evaluation was used to identify the appropriateness and effectiveness of establishing this program

#### ***The objectives***

These overarching objectives were met by implementing specific evaluation strategies that are now identified in boxed text below. While some of these objectives

are directed to evaluate process evaluation, others evaluate both process and impact evaluation. These objectives were to:

- I. Identify the specific health needs of the Aboriginal women in the community
- II. Identify the capacity building mechanisms and resources required to implement and sustain the program
- III. Evaluate the process of participatory action research that required collaboration between local healthcare providers and visiting members of the women's health team and the researcher.
- IV. Determine what health information the local community women required to assist their health improvement
- V. Access the views of participating local Aboriginal community women and local healthcare providers to determine whether their holistic health needs were being met
- VI. Explore opportunities for the program to develop further in order to become sustainable
- VII. Identify any barriers to establishment and the effective management of the implemented program.

## **6.9 Results**

### *Process Evaluation*

The commentary in the process evaluation and in particular the qualitative data that have provided the detail and depth of understanding of various elements of transferability, are explicit and in sufficient detail to replicate this transferred model of well women's health. While the quantitative data have some importance, the PAR

research and the critical nature of the methodology chosen to explain and make decisions about this program, were necessarily qualitative.

The evaluation strategies all interlink to meet the objectives and these are reported after each strategy has been defined with the action that took place. The strategies implemented to determine if and how the objectives were met, are described below.

*Strategy 1*

Facilitate the implementation of the AWWH program using key elements as outlined from the original program and identify specific Aboriginal women's health needs using the adapted Well Women's Health Checklist and screening processes.

In order to facilitate the implementation of the AWWH program, it was essential to identify the components of the original program. Through the process of consultation, these were then assessed in terms of how they translated to, and the need for their inclusion into the adapted program. These were established as the Aboriginal Well Women's Health Checklist, the screening processes, the lifestyle sessions and the health education sessions. These tangible elements could be adapted to meet Aboriginal women's needs, where other elements of the successful program, such as the coordination, leadership and collaboration would need to grow through the local healthcare providers. The program as a whole would also need to be considered as core business of the Aboriginal health service in the recipient community with sufficient resources to be sustainable.

*The original CA program checklist components*

To implement the screening components of the program and provide a physical health check, a well women's health checklist was used as a guide to each health assessment and to provide a documented report. This CA AWWH program had an effective well

health checklist that incorporated small icons for specific body systems requiring assessment. This was accompanied by a check box, to tick or cross, that enabled all health workers (even those with little written English) to undertake the physical assessment and document in a manner that could be read by those not familiar with the local dialect. This checklist prompted CA health workers to gather essential health information for a full health history, and conduct specific screening and physical checks for each client. To implement these effective elements of the program and focus towards primary healthcare, the original well women's health checklist required modification and expansion to meet the specific needs of women in this recipient SA community.

*The Requirements of the reciprocal community*

- ***The adapted Aboriginal Well Women's Health Checklist***

The researcher consulted with the local clinic team and visiting GP on the development and inclusion criteria necessary, in order to provide a holistic checklist for Aboriginal women in this community. Inclusions of mental and social health components were considered essential, together with additional physical health components such as eye and dental checks, blood screens such as Hb1ac for blood glucose levels, and urine screens for Albumin and Creatinine levels (ACR). These additional screening processes would indicate evidence of chronic diseases such as diabetes and kidney dysfunction, and fulfil the requirements of the 2004 Medicare rebate for Aboriginal health screening undertaken collaboratively by a health nurse and female medical officer (Medicare item H 710).

- *Refining the Checklist*

The adapted Checklist consisted of three pages (see Appendix). The first two pages related to the women's general health and living conditions and the third page focused on their sexual health, "women's secret business". Mental health and home environment questions were included to determine how women perceived self-esteem, how well they slept, if they had supportive family and friends and whether they had essential services in the home for cooking and lifestyle needs, such as hygiene, warmth, cooling and light.

These mental health questions had taken some time to formulate, as there was very little local expertise in this area to call upon for assistance. The one person employed in mental health services worked from dawn until after dark. However, together we compiled some short questions that might more specifically identify depression and loneliness.

The adapted Well Health Checklist was redesigned and printed and an education session was held with clinic staff describing how best to use this tool for improved documentation and a methodical approach to primary healthcare. The screening and health assessment tool was then trialled in the clinic by staff with female clients, 6 months prior to the program so that it could be developed fully as a user friendly tool and so staff could be conversant with it prior to the first AWWH intensive program.

Clinic staff found the checklist easy to use since the tool was self explanatory. However, there was some resistance by particular staff to the change in approach to health practice and it took some time for all clinic staff to use it. Some staff stated

that each client visit now took longer to complete and this had led to some clients having to wait for attention, something that they were not keen to do. In other instances, no checklists could be found by staff as they had been ‘filed away’, therefore limiting the systematic application of this tool.

The female clients found the checklist interesting and responded appropriately. Some women revealed issues such as “homelessness” and lack of electricity (often as the bill had not been paid) that could then be assisted by personnel within the health service. The checklist provided documentation that also permitted better monitoring, as all assessments were recorded and could easily be compared to the clients’ subsequent visits.

Following the trial period, after considerable consultation with the healthcare providers using the tool, some refinement took place to the first two pages of the checklist. Two of the picture icons were changed to better represent the type of health screens - these were the urinalysis and Hepatitis B. The third page of the AWWH checklist which related to women’s sexual health, could not be trialled until the first intensive screening program in November, as there was no female doctor available to undertake these screenings and comment on the page layout and user friendliness of this section of the checklist. Subsequently, throughout the first program some small changes were made to the layout and information contained on this page that mainly concerned reporting the doctor’s examination and referrals to other health specialists.

### ***6.10 Evaluating the AWWH Checklist as a useful screening tool***

This tool was an essential part of the screening process that enabled healthcare providers in the clinic to uniformly and systematically conduct health assessments with the opportunity to address elements within their capabilities. For example; a high blood glucose level resulting from Hb1ac screening by finger prick would, during the AWWH program, be followed up with fasting blood glucose level screens, and a history of the woman's diet, any excessive thirst, drinking habits, and another urinalysis checking for sugar and elevated ACR that may indicate renal involvement. Outside of the AWWH program in the clinic, healthcare providers should be able to link any elevation in ACR with recorded elevation in blood pressure readings and potential cardiovascular involvement through assessment for oedema, and any other relevant symptoms using the well health Checklist. As a result of the screening tool assisting in the identification of undiagnosed and poorly managed diabetes amongst women who attended the first program, structured diabetes sessions were then subsequently organised for the following programs.

#### ***Health information***

The mainstream diabetes nurse educator who was the practice nurse for a local GP, agreed to deliver some information sessions on diabetes and individual client education and on discussion with the Aboriginal health service, organised systematic follow-up for these women. Ideally, it was hoped that the diabetes educator could attend the whole program so this could become a 'one stop shop'. This was the preference of the visiting GP and the women, as they found it difficult to return at a

later date after the program had completed, due to other demands on their time, lack of transport and sometimes lack of motivation.

At the time, it was not possible for the diabetic educator to always be present. However, in 2005, an office was organised and set up for their regular attendance at the Aboriginal health service for consultations at other times. This was especially useful as the local GP had started to consult at the Aboriginal health service twice a week from December 2004, after discussions with the visiting female GP and the CEO, due to Aboriginal women and their families having significant needs.

Prior to the introduction of the Checklist, there was no coordinated approach to health screening, or association of health issues that could now be determined by this systematically recorded information. This was an extensive learning exercise for staff who were gradually able to make the connections between the screens and chronic diseases. However, there were lapses. For example, it was reported that some staff stored collected urine samples in the fridge for somebody else to attend, at a later date: (following one program twenty-two early morning urines that had been painstakingly collected for albumin creatinine ratios, were left in the fridge for two weeks without analysis, before being disposed of). The women providing the samples believed that they would be contacted by staff if any early renal disease was identified, and so did not follow up their specimens for the results.

The women who had a full health screening documented on the Checklist could then be monitored by clinic staff outside the AWWH program, for example, regularly coming in for a blood glucose level (BGL) and blood pressure checks. Any elevation



of screens or concerns could then be documented and referred immediately to the local GP for management.

The Checklist identified a variety of health issues that are listed under the results of the AWWH program. Diabetes has been used as an example of one of the health issues that have significant implications for the health and premature death of Aboriginal women living in this community. Other identified health issues have been reported under the results of each AWWH program. The following year, the first two pages of this adapted tool were used in the clinic for all adult clients (male and female) as the change in focus to primary healthcare became accepted practice in the Aboriginal health service.

*Strategy 2*

Work with local healthcare providers to identify their needs, and ways to assist them to effectively adapt and implement the AWWH program.

*The strategies required to transfer and implement the program*

A community empowerment focus was maintained throughout the process of consultation, transfer, implementation and evaluation, of the well women's health program for the recipient community.

- *Building the Team*

The researcher found it necessary to build bridges for communication and collaboration with mainstream health service and Aboriginal health service staff to initiate this program. Historically, these services had operated independently of each other with no combined case management strategies or practices. Most of the mainstream staff had never been inside the Aboriginal Health Service even though

this was built only half a kilometre away from the town's hospital, GP and community services.

This collaboration then provided the opportunity to maximise the limited resources focusing on the primary healthcare of remote Aboriginal women. Between healthcare providers across these organisations, there was a significant amount of expertise in women's health that encompassed social health and wellbeing as well as specific issues of sexual and reproductive health. With common goals established to adapt and implement the AWWH program, relationships developed. This was accelerated through the researcher's time spent working as the relieving RN at the Aboriginal health service for three weeks.

The participatory action approach was used throughout the adaptation and implementation of this program and the skills of mainstream healthcare providers were essential to complement those of the Aboriginal health team to provide the expertise in women's health necessary to implement this program.

- *Change of healthcare management towards primary health*

Over this time, it was necessary to change the healthcare practice in the Aboriginal health clinic from crisis management to opportunistic, systemised primary health care and this progressed initially through the trial and use of the well health checklist. However, not all clinic staff were keen to use this new approach to documenting and delivering healthcare. Some passive and active resistance was encountered from one staff member.

- *Database for client management*

Computer software was installed to enable a patient database file to be organised and for pathology results to be accessed. This database was investigated to ensure compatibility with the local GPs and familiarity for the visiting GPs. 'Medical Director' was the software program that was selected as all GPs were familiar with it as they used it in their other practices, and it was compatible with all information from the well health checklist. This computer program supports medical interventions such as prescriptions and referrals as well as patient files and data collation. This provided an effective system of data retrieval, patient follow-up and statistics as well as the establishment of computerised immunisation data that had previously been recorded in a book on the date that it was given.

- *The reorganisation of health clinic space to accommodate clients*

Throughout the three days of the Well Women's Health program it was necessary to provide male clients with access to the clinic for wound dressings without invading the women's space. This was accomplished by reorganising the whole clinic space so that separate doors could be used at different ends of the building. In the following year, one of the male GPs came to consult at the Aboriginal Health Service twice weekly throughout the year, and this then put further stress on staff throughout the AWWH program to provide this security for women.

- *Client case note files*

Women's health case note files were established in the first instance in separate filing system in the rooms used for the program for practical reasons, namely quick access and confidentiality, and as there was no organised filing system in the service.

- *A suitable female GP*

The researcher investigated many avenues to find a culturally appropriate female GP with skills in remote Aboriginal women's health. The nearest major town had four female GPs servicing the Aboriginal Health Clinic there, but none of these were funded to assist this program and when the recipient community offered funding, there was no interest to do so. The RFDS supported the search for a female GP. This investigation eventually led to a medical organisation supporting rural doctors, who have since assisted and continued to support this program by employing a female GP with great expertise in Aboriginal women's health. This female GP. accepted the invitation from the researcher and the CEO of the local Aboriginal health service to participate in the program as the visiting women's health GP and as a member of the PAG.

*Strategy 3.*

Form the Project Advisory Group (PAG) with representatives able to guide, implement and continually improve the program, and through the PAG build relationships for collaboration between internal health providers of the Aboriginal health service and mainstream services in the community.

*The Project Advisory Group*

The role of the PAG was pivotal to the establishment and continual improvement of the AWWH program. A cohesive approach across local health organisations enabled PAG members to work with the researcher, using PAR, to critically appraise the program through the process of reflective action. The researcher as a member of the PAG and as an outside health professional, assisted this reflexive process through her interaction in the PAG meetings, and by identifying issues and generating discussion

among the group as to what seemed to be working or not working, and encouraging ideas from the PAG to overcome difficulties.

#### *PAG meetings*

The inaugural meeting was held to identify the goals of the program, and strategies to facilitate these, and meet other health providers from the hospital, community and the Aboriginal Health Service. The new female GP was included via telephone link to the group. She later flew to the recipient community and spent time talking with staff and clients over several days.

The second PAG meeting was held immediately prior to the implementation of the first Aboriginal Well Women's Health program to reaffirm the program outline and clarify individual roles. The doctor described another remote Aboriginal community women's program where she had been a member of the visiting health team.

#### *PAG minutes*

The minutes of each meeting were audio taped and transcribed. This was initially done by the researcher and later, in the absence of the researcher, by one of the local health team. The first intensive program was critically evaluated over the three day period, as it was important to gain everyone's ideas and criticisms, so all voices were heard and all details of the program considered. Some members of the newly formed team were quietly spoken and a little shy, therefore the manner in which the meeting was organised was important and encouraged everyone to contribute. The following three intensive screening programs were also scrutinised in the same manner as the primary health concepts and AWWH program continued to develop.

### *The organisation of the first intensive screening program*

There were some limitations as to when the first program could commence. The PAG was formed in July 2004 and had discussed ways how they could best work together to implement the AWWH program. The well health checklist had been adapted and was trialled between April and September and refined. However, the first program could not take place till all necessary women's health team members were available. This depended on the availability of the female doctor who needed to be booked well in advance, the availability of staff at the Aboriginal health service, and also the mainstream women's health nurse.

Another consideration was the availability of an administration staff member who was familiar with the Medicare swipe card system and the different service numbers for Medicare claims, and also familiar with the software program Medical Director for entering the client data. The first program was scheduled for November 2004 when all these people were available together.

### ***6.11 Evaluation of the PAG***

The PAG has been described as a collaborative group that met prior to and post-AWWH programs while the researcher was included as a member, and who worked together to guide and critique the process of implementing the program. These forums were always held at the Aboriginal health service and were considered by the group as well organised, friendly sessions where the organisational program issues could be shared and addressed, with solutions to benefit the program and the community. This group represented all local groups of health providers and visiting

team members including the female GP. All individual members of the PAG contributed with their particular expertise to develop the AWWH program.

*The role of the GP in the PAG*

The female GP's role was pivotal to the whole AWWH program in client consultations in a culturally appropriate approach, completing health assessments and screening processes, giving medical advice and initiating treatment. She was readily accepted by the women as a respected doctor sensitive to their holistic health needs together with environmental and social situation. Her opinions and suggestions in her role as a member of the PAG were also highly regarded and her many years previous experience in other remote communities was most valuable. She saw herself as a member of the AWWH team and was a very genuine, friendly and caring person who was able to assist other members of staff in their education needs and advise the group in aspects of practice that were beneficial to the program. Aware of their extensive health issues, she has committed over the longer term to the program.

*The role of the Social Health and Well Being Coordinator in the PAG*

This Aboriginal woman was partially responsible for identifying the community's need of a well women's health program and for consulting with the researcher, the Aboriginal women in the community and Aboriginal health service staff in advocating for, and procuring the program. This woman, who was initially an outsider to the community because she was born in New South Wales, is a highly respected member of this community who works for the Aboriginal health service. She has recognised the social and mental health needs of women and the unresolved grief from the disconnectedness to family and country through 'the Stolen

Generations', youth suicides and premature deaths of community women through the comorbidity of disease and lack of social health and wellbeing. Her special skills in understanding combined with her skills in Natural Therapy, have assisted her in contributing to the AWWH program and the PAG in representing the views of the community, organisation, and lifestyle sessions.

*Combining skills and expertise with the government employed Women's Health Nurse*

The Social Health and Well Being Coordinator has worked closely with the mainstream Community Women's Health Nurse who is a non-Aboriginal woman with exceptional skills in all aspects of women's health. This nurse has lived in the local community for some considerable years, raised her family and worked with the RFDS in women's health, and with Aboriginal women and other women who visit the mainstream primary healthcare service.

It was this nurse who alerted the researcher to the situation that the Aboriginal women in the community 'were falling through the gap' due to the lack of culturally acceptable services tailored to meet their needs. She has coordinated the AWWH program from outside the Aboriginal health service and worked alongside the Aboriginal health staff to develop the program. Her spirit, expertise and enthusiasm have been important to the successful transition of this AWWH program with the effective cooperation and collaboration across health services and advice and guidance in clinical matters to the PAG. She and her manager committed her time and salary to the AWWH program for the first two years in a collaborative approach across mainstream and Aboriginal health services. This period is now drawing to a close.



*The role of the CEO of the Aboriginal health service in the PAG*

The original CEO of the Aboriginal health service, a non-Aboriginal woman, was a very supportive member of the PAG and instrumental in coordinating the consultation processes required with the Aboriginal Health Service Board members and with community women for the AWWH program. Her skills were in administration with a management approach that was inclusive and considerate. This was the first organised primary health program the Aboriginal health service had considered in some years and was a big undertaking for their small staff who had many demands made on them by the community's health status. Her support was unwavering, as she well understood the many nuances of life for Aboriginal people in this community where she had lived for many years.

Her resignation in July 2005 was a great loss to the PAG who found her to be a very sincere person, well respected by the community, and who struggled to bring governance training and capacity to Board members (with much active resistance from them). She provided great support and a stable environment for her staff and for the PAG and was proud of the team's accomplishment in the transition and implementation of the AWWH program. She was also a major advocate for an Aboriginal Well Men's program to be organised on the same model.

The new incoming CEO of the Aboriginal health service was male and it was not culturally appropriate for him to be a PAG member of an Aboriginal women's program although he was invited to attend the PAG meeting at the close of the September 2005 program, as he had just taken up this position. However, this meant

that the Aboriginal health workers subsequently did not attend and some women's business could not be discussed.

#### *The role of the clinic team in the program and the PAG*

The Aboriginal health service clinic team consisted of three Aboriginal health workers, and one non-Aboriginal health worker, an Aboriginal enrolled nurse, a non-Aboriginal enrolled nurse and a non-Aboriginal RN of Filipino descent. This clinic team played a major role in delivering healthcare to the community on a continuous basis. Each person had particular skills and some found the change to primary healthcare more challenging than others. Clinical assessment skills were minimal, but this could be addressed through staff development. The biggest challenge was how they each perceived their roles in the program, from high to low importance and their enthusiasm to participate. This is discussed in more detail under the nine domains of empowerment.

#### *Visiting team members*

The visiting team members have supported the AWWH program through health education and lifestyle sessions. They showed great diligence in providing culturally appropriate materials in pamphlets, videos and resources in health information for their sessions in sexual health. Specific information was obtained by the researcher for drug and alcohol and renal disease, as there were no local healthcare professionals to deliver these sessions.

Team members blended lifestyle sessions and fun throughout the program, with sexual health, nutrition and good food. These external resources are a continuing and

important part of the program that not only provides variety, but also support the local healthcare team as well as the women to extend their knowledge. With each program there have been volunteers who have accompanied these visiting PAG team members who have added their skills and hands-on approach to anything that required attention. Volunteers were often healthcare providers in the form of PhD students and nursing students or with special skills in massage and natural therapies. All joined in the program wherever needed.

#### *The researcher*

The researcher facilitated the formation of the PAG, chaired the meetings and provided the minutes for the first two programs. She was absent during the third program in June 2005 and this provided a great opportunity to see how the ownership of the program was developing. The June program appeared to work effectively in her absence, while the original CEO involved in developing the program provided leadership to the Aboriginal health service staff.

Other roles for the researcher included finding appropriate resources for the health information and lifestyle sessions and donations for the AWWH program 'goodie bags', and advocating for the women in the wider community to address their health needs, such as negotiating dental and renal follow-up with support from the first CEO.

#### *Participatory role of critique and continual improvement of the program*

The participatory approach and respect for each person's contribution enabled the PAG to function effectively in communicating, collaborating, critiquing and addressing issues as they arose, with the goal of continual improvement. This process

of collaboration started to decline when the management of the local Aboriginal health service changed, and the addition of two registered nurses temporarily acting in the position of clinic RNs. As a result of the different management approach now in place, which was top-down rather than inclusive of staff, there followed an exodus of long-term staff. There was a lack of familiarity of the PAG and the AWWH program by the new RNs, who excluded many of the AWWH team.

This staff changeover affected the two AWWH programs run in 2006 as no critique and follow-up occurred from these programs and data has since been quite difficult to obtain. With further changes to the CEO management and return of some original staff, the researcher has been invited back to support the next program and collaborate with the PAG in supporting ways forward. This has been an extensive learning process for those members of the Aboriginal health service team who remained throughout the fluctuating changes of management structure and strategies. These elements are discussed in more detail under leadership and governance of this remote stand-alone Aboriginal community health service.

### ***6.12 The Delivery of the Program***

#### *Strategy 4*

Through collaboration build capacity within the community in conducting the holistic program in health screening, health information and lifestyle sessions

#### *Program 1 November 2004*

This program ran from Monday to Thursday and the first day was used as ‘participant free’ as the women’s clinic was set up with equipment and staff. The doctor arrived

on the afternoon plane and the team meeting took place with the organisation of roles. The doctor was due to fly out late Friday morning.

*How it was done*

The environment was a welcoming one with cool drinks, tea and coffee and sandwiches available on arrival. Healthcare providers introduced themselves and a small health session on topics such as ‘why have a Pap smear, breast check, blood glucose level’ was organised using videos, with a member of the team. The women came in small groups, as most of the transport was provided by the health service driven by one of the women’s health team. Activities were ongoing throughout the day in the boardroom, which was the largest area in the health service with a kitchen. A hot meal was included in the middle of the day, where both clients and healthcare providers could chat together.

On the first morning the elders from the Aged Care facility were invited. They sat and talked with the staff and ‘checked out the doctor’. Some of these women came back on another day for particular consultations. Activities varied throughout the three days. The first program concentrated on art through painting and drawing and a competition was organised for a well women’s logo. A number of small children accompanied the women and they were entertained by toys, play dough and paints. However, at the end of the day these activities required a major clean-up of the furniture, walls and wooden flooring and so it was decided to restrict these activities to just the toys.

### *The screening*

In privacy, each woman saw a nurse or health worker to collect their history and vital signs, blood glucose level by finger prick, urine sample for analysis, eye test and were asked questions about their lifestyle, issues of concern, drug and alcohol habits, sleeping habits, mental health questions and any difficulties relating to essential services in the home, or other problems. They then saw the doctor for their consultation and further health checks that may have included a pap smear, other examination or tests and health advice.

### *Documentation*

Information was documented by using the well women's health checklist that included all the requirements of the Medicare rebate (H710). The information was then transferred to the database using Medical Director, which became operational during the screening period. Results of laboratory screenings were received through electronic transfer from the examining laboratory, which were accessed, by both the doctor and registered nurse midwife, following the completion of the program. The client was then contacted and any abnormal results requiring intervention were addressed by the registered nurse or the local GP.

### *Participation of community women*

While the Well Women's program was open to all women in the community, the main focus was on reaching Aboriginal women in a culturally sensitive environment. Thirty-seven women participated in the program over the remaining three and a half days; of these thirty were Aboriginal. The first women to attend were the traditional

Elders followed later by younger women. Seventeen women attended on the first day and a further three women arrived late in the day and were booked for the following day at times to suit them. Women were still arriving on the Friday morning (that was supposed to be client-free) as the word had spread. Therefore the doctor consulted until she had to board the plane.

### ***6.13 Reporting the AWWH screening results***

This AWWH program has focused on providing health information about screening processes so that the participating women could make informed decisions regarding their health. For example, a health information session on breast screening was held during the second AWWH program to inform Aboriginal women prior to the arrival of the SA Breast Screening Unit the following week for mammography screening.

Other health information sessions included information about the urinalysis for renal disease and for STIs, so the women made informed choices about having these tests. Therefore the screening has been opportunistic, in that the women attended and the screening processes were explained throughout the initial health assessment. They could discuss these with the doctor and then make choices about the screening tests undertaken, the health information and lifestyle activities in which they participated. In the first program some women chose not to have a pap smear, however they returned during the following program for this screen.

The incidence of disease is reported only from those Aboriginal women who have attended the AWWH program. It is inappropriate to try and make comparisons with any other statistics whether they be National or Regional figures, as there has been

quite some disparity about noting 'Aboriginality' on screening forms and many individuals and organisations have not identified this. In cervical screening these figures are reported directly to the Commonwealth Department of Health and Aged Care and cannot be obtained specifically for local areas. There has been an accepted view that in many instances, disease and population statistics are under reported in Aboriginal people and therefore are not totally reliable.

I have only reported on what has happened in this program and therefore I make no such comparisons against other statistics. However, the program results have been compared between programs in some instances, to identify if the target group of women; that is those women who were not accessing health screening or services were accessing the program, and if their health needs were being identified and then addressed.

While this section of the report focuses on the screening results, of no less importance is the health information and lifestyle sessions that enable the women to make informed choices and to enjoy the activities provided.

*Screening Results Program 1 Nov 30 -Dec 3 2004*

There were thirty consultations for Aboriginal women who had screenings undertaken for; either cervical dysplasia, sexually transmitted infections (STIs), urine screens for detection of early renal impairment (ACR) and several for possible urinary tract infections. Blood glucose levels, blood pressure and pulse, weight and health history were completed on all participants. Twenty-three of these women had a



full health assessment, (not all women required a pap smear, as they may have had total hysterectomy, or a pap smear within the last two years).

**Table 1 Screening results program 1**

<i>Cervical screening</i>	<b>17</b> Pap smears – There was no cervical dysplasia identified in this participant group however six required further review for cervical smears at Dr’s next visit
<i>Sexually Transmitted Infections</i>	<b>13</b> STI swabs taken = 2 Chlamydia and 1 Gonococcal infection. Total =3
<i>Diabetes</i>	<b>17</b> HB1ac = 3 women with undiagnosed Type 2 and one woman who had progressed to Type 1 diabetes
<i>Blood screens</i>	<b>13</b> full blood screens.- <b>9</b> women required other follow-up in haemoglobin checks, & blood glucose monitoring, which could be facilitated through the health clinic.
<i>Renal &amp; urine screens</i>	<b>2</b> MSUs - 2 Urinary tract infections <b>23</b> urinalysis for renal screening: Albumin /Creatinine ratios = <b>9</b> ACR ratio elevation and <b>4</b> other elevated levels. As 20 of the 25 clients had either: positive protein, blood, nitrates or leucocytes, these participants will all be followed for repeat first morning urines on recommendation from the renal consultant (Flinders Medical Centre). Then further blood screens and diagnostic tests will follow for participants requiring them through the local GP service. <b>6</b> women also had elevated blood pressure with their ACRs who were to be followed up and monitored regularly in the clinic by the RN
<i>Elevated Blood pressure requiring Monitoring</i>	
<i>Dental referral</i>	<b>8</b> women required urgent dental treatment. <b>15</b> other women required some dental treatment = <b>23</b>
<i>Eye specialist referral</i>	<b>3</b> women required Eye review
<i>ENT specialist referral</i>	<b>2</b> women needed a ENT review
<i>Breast screens</i>	Although there were no breast lumps detected by physical examination, <b>1</b> person was referred for mammography. Breast screening is undertaken every two years for this community by Breast Screen SA and these reports go straight to the Commonwealth – it is not known how many women attended the SA Breast Screen in 2005.
<i>Family violence</i>	<b>5</b> women volunteered information as victims of violence and injury
<i>Drug and alcohol referral</i>	<b>2</b> women were identified as needing urgent Drug and Alcohol review.
<i>Pregnancy and contraception</i>	<b>1</b> undiagnosed pregnancy <b>1</b> Implanon inserted (subcutaneous, implanted long acting contraceptive )

*Health Education sessions*

Health education sessions were held concerning the relevance of breast self examination for breast lumps. Videos were shown relating to sexual health, pap smears, STIs and the use of condoms. Diabetes videos introduced the different food types and exercise required to help maintain stable blood glucose levels. The women appeared very interested in these and asked for several to be replayed.



Small group session with Chris



Lifestyle session: Hair dressing with Cheryl

A nutrition session on healthy eating was interactive with some of the younger women cutting up the vegetables and making a stew (lunch). This tied in with the diabetes video and the discussion of hidden sugar contained in many foods.



Finishing lunch photo used with kind permission of Community Women

Art - in painting and drawing was another activity enjoyed by all attending with a large poster made up of hands and feet together with a competition for an Aboriginal Well Women's Health logo.



Women's Logo designed by teenage girl Leila Marie, participating in the program.

### ***6.14 Summary***

The results of this first AWWH program of 37 women (30 Aboriginal women), determined the need for further structured health education sessions for women. There may be a significant element of undiagnosed renal impairment. Several women requiring further investigation for undiagnosed diabetes, there is an urgent need for dentistry with anaesthesia, together with a need for further support in domestic violence and drug and alcohol issues.

The initial overall evaluation of the first Well Women's Health program in this recipient community has shown its acceptance by the women and the willing collaboration of health providers. As immediate needs of program participants were identified, a greater focus towards their holistic needs from a primary healthcare perspective can be provided. The Central Australian Well Women's Health model appears to be adaptable to this remote community. However, the issue of sustainability is yet to be addressed.

### ***Screening results Program 2 March 29 -1st April 05***

Of the total of forty-three GP consultations for women in this program, thirty-seven were for Aboriginal women, and nineteen of these had full health checks. Some women returned who had attended the previous program for further consultations and to participate in the lifestyle activities. While this implies that they were comfortable with the way the program was presented for them, it also means that the attendance data are reported in consultations rather than the number of women attending.

**Table 2 Screening results program 2**

<p><i>Cervical Screening</i>          ‘Thin preps’ were used for all women in program 2 and this was organised with IMVS, after consultation with the doctor and women’s health nurse at the beginning of the screening. (This has been done for women in Alice Springs who may not have had a smear for sometime (however the cost is greater = @ \$20)</p>	<p><b>15</b> Pap smears – <b>3</b> women had abnormal cytology requiring further investigation. <b>14</b> of these women either had never had a pap screen or it was more than five years since the last smear = <b>93%</b></p> <p>Some women did not have a Pap smear on their previous visit and were happy to have this carried out.</p>
<p><i>Sexually Transmitted Infections</i>  <i>Chlamydia</i>          Due to the increase in chlamydia Australia wide, all women were checked for chlamydia on consent, either through swab or by urine. (40 x 5 ml collection tubes organised by researcher prior to visit.  <i>Syphilis</i>  <i>Trichomonas</i></p>	<p>13 screens = <b>2</b> positive chlamydia</p> <p>=<b>1</b>          = <b>2</b> Total = <b>5</b></p>
<p><i>Renal screening using ACR ratios</i>          Women with elevated albumin creatinine ratios (ACR’s) were given specimen containers for an early morning urine sample during the program –There was a significant difference between the random samples and the first morning urine and most repeat screens were reported as within an acceptable range.</p>	<p><b>8</b> women had elevated ACR levels requiring further follow up</p> <p><b>8</b> MSU = <b>4</b>UTP’s</p>
<p><i>Medical Reviews</i></p>	<p>Some women came for review from the previous clinic and some of these women were found to have taken better account for their health (however, they were the minority).</p>
<p><i>Diabetes</i></p>	<p><b>6</b> women with uncontrolled diabetes with no care/management plan and still several more women with high BGL undiagnosed at this time.          1 woman newly diagnosed Type Two          1 woman changed to Type 1 requiring regular insulin</p>
<p><i>Dental disease</i></p>	<p><b>18</b> women with continuing dental decay &amp; caries, toothache, and nutritional problems due to the inability to chew or</p>

	eat available foods
<i>Family violence, mental health and social wellbeing</i>	Family violence and mental health, social health and wellbeing have been described by the women, as major issues. There are inadequate resources to address these major issues in this community.
<i>Drug and Alcohol referral</i>	4 women requiring this service, but no local D & A healthcare provider
<i>Contraception</i>	2 Implanon inserted

### **6.15 Health information sessions**

*Sexual health* - A senior female Aboriginal project officer working in Cervix screening was available to join the program and the PAG. Therefore some of the sexual health issues could be addressed on an individual basis. However, the women were still keen to watch the videos on Sexual Health and HIV.

*Diabetes* – the Diabetes Nurse Educator was available for two sessions that related to Type Two diabetes and management care plans.

*Breast examination*- Breast Screening SA was invited to participate in the program as this organisation was due to visit the community for breast screening, however its funding could not support this. It kindly provided some information that was presented by the mainstream women’s health nurse in an interesting participatory health information session.

*No mental health* – there is currently no local mental health worker, and no regional person available to assist in this specialised area at the time, although there is an identified need for this information.

*Dental Health* - There is an urgent need for information on oral and dental health. However, there was no opportunity to provide this. The visiting dentist who was visiting once every six weeks for five days, said they were too busy to provide anyone to assist with oral and dental health promotion. Unless the women were prepared to take 15 minute appointments, booked ahead and were able to turn up on time, they would not be seen. Ten people requiring urgent dental treatment were driven south to Adelaide, however not all were treated on arrival. One was found to have no teeth at all, and four others had required prophylactic antibiotics prior to treatment to prevent any cardiac or renal infection.

#### *Lifestyle sessions*

*Hairdressing* -A hairdresser was employed for one afternoon of this program, much to the delight of the women, who were keen to have hair washes, cuts and colours and every spare person was co-opted to assist.

*Foot care* – Footbaths and foot care and massage were also most welcome and enjoyed by the group. The focus of this session was good foot care for women with diabetes, however all enjoyed the pampering.

*Hand Massage* – Gentle moisturisers were used for these hand massages and the women were shown how to massage each other.

#### *SUMMARY*

The women appeared very interested in the program and continued to attend. There was a growing trust in the female doctor and the AWWH team, and the women appeared to enjoy the interaction with lifestyle and information sessions and the good

food that was provided throughout. Of concern was the lack of mental health, drug and alcohol and dental health services and resources that were urgently required. There were also very few culturally appropriate Aboriginal community resources available following the completion of the program for women to learn about their health issues and particular diseases.

At the PAG meeting the clinic RN stated women would not “go down” to the dentist who worked from the caravan attached to the school. They were unable to keep the tightly scheduled appointments and therefore other ways to provide dental treatment were sought by the researcher who advocated for this with the SA Dental Health Service and visiting dentist. Oral hygiene is considered a major issue that leads to other complications in poor general health and high risk of endocarditis and renal disease. This needs to be addressed in this community.

*Screening results Program 3 June 13-16 2005*

Thirty-four women participated in this program, thirty women were Aboriginal and sixteen of these had a full health check.

**Table 3 Screening results program 3**

<i>Cervical Screening</i>	<b>11</b> Pap smears = <b>2</b> Abnormal cytology <b>4</b> women had their first Pap smear = <b>36%</b>
<i>Sexually Transmitted Infections</i>	<b>5</b> screens = <b>2</b> syphilis, <b>1</b> chlamydia <b>1</b> trichomonas, = <b>4</b>
<i>Blood Screens</i>	<b>3</b>
<i>Renal screens</i> <i>MSU</i>	9 ACR levels = 4 elevated <b>2</b>
<i>Diabetes</i> <i>RN 8 consults</i>	17 Hb1ac = 2 elevated 45 Aboriginal women on the diabetes register
<i>Breast Checks</i>	<b>2</b>
<i>Dental health</i>	<b>16</b> require active treatment
<i>Contraception</i>	<b>2</b> Implanon inserted & 1 removed



The information reported from this program is less detailed as the researcher was not present and needed to rely on feedback from the team undertaking the particular AWWH program.

#### *Health Information*

Sexual health videos were included and the Sexual Health educator was present with an extra volunteer. Cooking sessions with nutritious food were welcomed by the women. The diabetic educator was not available for this clinic and so eight consultations were undertaken by the community women's health registered nurse. There is a desperate need for renal education in the community. One Aboriginal woman with known renal disease went into renal failure shortly after the program and is now on dialysis three times a week. The doctor reported that dental health had not improved as no resources or funding for this appeared to be available.

#### *Lifestyle sessions*

The 'goodie bags' for women who had a full health check continued to be popular. These contained small pots of specially prepared creams from natural therapies using essential oils, hair shampoo and essential items of toothbrushes/ toothpaste, brushes and combs. It was noted that many of the small children attending with their grandmas or family, may also need assessment and the child health nurse, although previously invited, needed a further invitation to join the PAG and AWWH team.

#### *Screening results Program 4 September 5-9 2005*

Twenty-seven women attended this program. Twenty-five were Aboriginal women and fifteen of these had a full health check.

**Table 4 Screening results program 4**

<i>Cervical screening</i>	<b>8</b> Paps. <b>Six</b> women attended who had never had a full health check
<i>Sexually transmitted infections</i>	<b>1</b> trichomonas detected
<i>Renal screens</i>	<b>15</b> ACR = <b>4</b> elevated that require renal follow up
<i>Dental disease</i>	There is still no assistance for dental health and so the issues remain constant = <b>95%</b> of women require dental treatment
<i>Family violence</i>	These issues still require address
<i>Drug and Alcohol</i>	There is still no healthcare provider to implement strategies
<i>Eye Review</i>	Near vision was identified as a significant problem for a number of women. It was suggested that cheap magnified glasses may be useful as most women could not afford the \$40.00 required through the optometrist.
<i>Child Assessment</i>	The child health nurse assessed <b>6</b> children that she had not seen before by attending the program

*Health information*

A new renal video, borrowed from Kidney SA, assisted a session on kidneys and how kidneys become sick with diabetes. There was also information on video about renal dialysis, however most women did not want to view this tape (one woman was present who was undergoing peritoneal dialysis and would shortly need to change to renal dialysis). One Aboriginal health worker who was supposed to help with this session avoided it and was 'not available'. The women were happy to watch the sexual health and diabetes videos and interact with activity sessions.

### *Lifestyle sessions*

The activity was changed to jewellery making for this program. The many coloured beads and equipment were a very popular activity for the women, who made earrings, wrist bangles and necklets while also listening to health sessions.

### *SUMMARY*

There were added issues to address in this program as there had recently been a change in management and style, and the female CEO who had been there for several years had resigned and been replaced by a male CEO. The first two days of the program were much quieter than usual; the showers were 'out of action' as there was a 'Sobering Up Unit' being built adjacent so the external shower block was extended. This affected the women who normally came in and showered before seeing the doctor or clinic staff and asked if they could come back when it was operating.

There had been little prior preparation for this program and no advertising, so towards the end of the program as word spread, the AWWH team became much busier. There were some judgements made by the new CEO that affected the general working atmosphere and the team found out at a later date that he had cancelled the following program scheduled for December 2005. One comment from the new management stated that he expected more participation from community women. To this the Community women's health nurse stated positively;

*We had six new women who had not been before. Some of these had never had women's health checks and this was wonderful and most worthwhile and what the program was all about.*

*Screening Results Program 5 27-31 March 2006*

Forty-two Aboriginal women attended this program. Twenty-eight women and two girls had health assessments. This included two thirteen-year-old girls, six under twenty-two years of age, 10 women under 35 years, 10 under forty-four, and 2 over forty five. .

**Table 5 Screening results program 5**

<i>Cervical screening</i>	<b>15</b> pap smears = 2 abnormalities 1 CIN 2, 1 LGEA. 4 women attended for first Pap smear
<i>Sexually transmitted infections</i>	<b>3</b> =2 chlamydia, 1not known
<i>Blood Screens</i>	<b>3</b> low haemoglobins lowest = 67 Hb <b>1</b> = hypothyroidism
<i>Renal</i>	<b>1</b> Urinary tract infection <b>3</b> elevated ACRs
<i>Diabetes</i>	<b>5</b> = poorly controlled
<i>Family violence</i>	<b>1</b> woman stabbed in the back with a broken bottle with a septic wound
<i>Dental health</i>	<b>10</b> women required urgent treatment
<i>Drug and Alcohol and mental health</i>	<b>1</b> woman requiring urgent referral and support services
<i>Eye checks</i>	<b>1</b> woman requiring urgent referral to Ophthalmologist
<i>Children</i>	<b>3</b> seen by doctor

There had been some concern that the program was not reaching the younger Aboriginal women and girls and that most of the women were between twenty-five and fifty. This program has now started to reach younger groups and perhaps more will visit next time.

### *Health information*

There was limited space to run health sessions as the large Board Room usually used was not made available by the CEO. The Sexual Health nurse educator was not available to attend this program and so very limited opportunistic sessions were run.

### *Lifestyle sessions*

The jewellery making continued and was extremely popular with both the older and younger women. The women continued to enjoy good food and some further nutrition sessions would be of benefit.

### ***Screening Results Program 6 24-28 July 2005***

Forty-seven Aboriginal women were seen at this program, twenty-seven came for well health screening and eleven of these had a full health check. The other twenty women were seen with acute conditions. The doctor also saw a total of thirteen children and men for acute conditions, as the local GP was away.

**Table 6 Screening results program 6**

<i>Cervical screening</i>	<b>6</b> Pap smears- 1 abnormality 4 women attended for first Pap smear
Sexually Transmitted Infections	<b>2</b> Chlamydia There appears to be a small group of untreated men who are reinfecting women.
Renal screens	<b>5</b> Urinary tract infections <b>4</b> elevated ACRs
Dental disease	<b>8</b> women required urgent dental treatment
Drug & alcohol	There is still no local Aboriginal female healthcare provider for these services
Mental health	No health care provider
Diabetes	<b>1</b> newly diagnosed .There is no logical and organised management plan for clients despite two diabetes educators (one being Aboriginal) in the

	community. 5 clients with diabetes s/b Dr
Eye Review	1 referral to Ophthalmologist
Contraception	3 Implanon

The age groups of many of the participants were noted at this sixth AWWH program to see which women and girls were accessing the screening, information and lifestyle sessions. It is interesting to note that both age groups at opposite ends of the spectrum were represented at this program. There was a higher representation in the forty to fifty years age group and no representation in the fifty to fifty-five years group. If this sample were representative of the women in the community it could explain the lower numbers presenting for breast screening in the target group of breast screen (50 – 59 years). Further comparisons across age groups may help to distinguish this.

**Table 7 Age groups of women attending the sixth AWWH program**

14 -19 =2	26 - 30 =4	36 - 40 =1	46 -50 =9	56 -60 =1	66 - 70 =1
20 -25 =5	31 -35 =2	41 - 45 =8	51 - 55 =0	61 - 65 =1	71 -75 =1
					76 - 80 =1

*Health Education sessions*

The nutrition sessions could not take place as no meals could be cooked without the use of the kitchen in the Board Room area. Sexual health information sessions continued again as the Aboriginal Sexual Health educator was available for this program.

*Lifestyle sessions*

Massage and natural therapies were the highlight of these sessions. The women loved to feel a little pampered and delighted in trying some of the home grown products.

'Goodie bags' also enabled them to take small samples away. The women again asked for jewellery making. However, the Boardroom was not available and therefore space to do this was limited. The food for meals was ordered in and disappointingly staff and the women reported that it was high in fat and calorie content and not good for them with so many women with Type Two diabetes. The diabetes nurse educator has since reported that the diabetes register has forty-seven women listed with Type 2 diabetes.

#### *SUMMARY*

There has been another change in CEO management and this time an Aboriginal man has taken over the leadership of the Aboriginal health service. The female doctor described the environment at this program as chaotic and there appeared to be significant diabetes again 'out of control'. Some of the local healthcare team had left, and others seemed discouraged and the clinic times had changed to suit visiting RNs. The researcher had not been invited to these last two programs since the change in management, and has therefore relied on the doctor, the community women's health nurse and social health and coordinator, for the information to complete this evaluation.

***Update October 2006:*** The situation has now improved. The researcher has been invited to the next program to support the local clinic team while they take total control and take on new skills in coordinating the program without the guidance of the mainstream community women's health nurse. The AWWH program has survived the governance changes and differing priorities and is considered by the

Aboriginal health service, as an important and essential part of the health service provision for the Aboriginal women in this community.

### ***6.16 The Impact of the AWWH Program***

#### *Culturally acceptability*

The attendance figures of Aboriginal women throughout the programs have shown that the program is culturally acceptable to them and that they were willing to come to the program and participate in the screening, health information and lifestyle sessions. Women returning for follow-up consultations demonstrate that they trusted the skills and competence of the female doctor and the AWWH team. The attendance of new women and those who returned to each program illustrated a growing confidence within the Aboriginal community that the program was culturally respectful and accessible, and could have tangible benefits for their health and wellbeing as local women.

#### *Reaching the target group of Aboriginal women not accessing mainstream services for well health screening.*

These program statistics show that Aboriginal women living in this remote community were willing to access and participate in the AWWH program. It also demonstrated that despite barriers of language and capacity to formally invite or inform Aboriginal women about the program, ‘word spread’ and with each successive program new women presented indicating other women had informed them and encouraged them to come. This also indicated that Aboriginal women are concerned about their own health and will seek health education and care if it is accessible and safe to do so.



In the very first program there are no figures listed for first time pap smears. The mainstream community health nurse was familiar with those few Aboriginal women (less than eight) who had attended a well health check up through the RFDS female GP. Several women had come south to the next major town or Adelaide, but many of the women could not identify when they last had a pap smear, if ever, and there was no local database to determine this.

*Sexual Health Screening Results*

The Pap smear figures from the second program identified the high proportion of women who were either having their first pap screen, or first screen in five years. The following two programs also showed a significant proportion of first time smears. This indicates that the AWWH program has reached some of the Aboriginal women who had not previously had a well health check that has included a pap smear to identify cervical screening abnormalities. As several women were required to see the doctor more than once during the program, the number of women is written as number of consultations.

**Table 8 Pap smears for AWWH program Nov 2004 –July 2006**

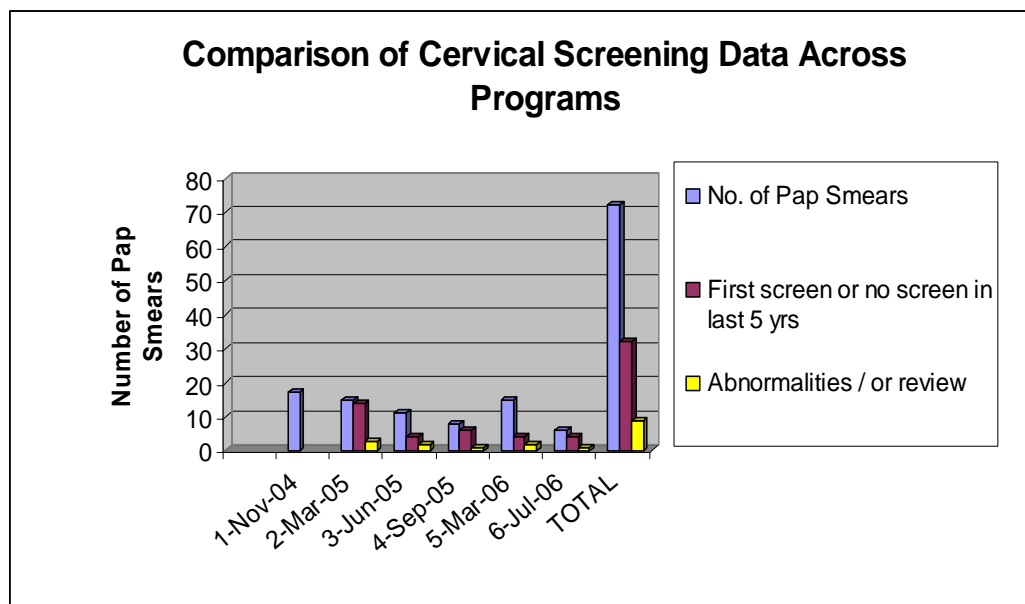
Program	No. Aboriginal Women Consults	Full Well Health checks	No. Pap smears	No. First screen /no screen 5 yrs	%	Abnormalities/or review
1 Nov 04	30	23	17	Not known		6 for review next program
2 Mar 05	37	19	15	14	93%	3
3 June 05	30	16	11	4	36%	2
4 Sept 05	25	15	8	6	75%	1
5 March 06	42	28	15	4	27%	2
6 July 06	47	11	6	4	67%	1
total	<b>211</b>	<b>112</b>	<b>72</b>	<b>32</b>	<b>45%</b>	Total = 9 2 =CIN1 1=CIN2 2= LGEA 4 =Benign Atypia

*CIN 1- mild changes, which indicate a low grade abnormality*  
*CIN2 –moderate changes, which indicate a high grade abnormality*  
*CIN 3-severe changes(dysplasia)indicating a high grade abnormality*  
*LGEA -low grade endocervical abnormality.*  
*Benign atypia -slight changes to the cells although the cause is not obvious. (SA Cervix Screening Program 2001)*

**Note** Although there were no ‘CIN 3’ changes identified in pap smears during the surveillance period for the PhD research, there has been a CIN 3 identified in a young Aboriginal woman with small children, from this Well Women’s Health program in 2007.

This screening detected nine abnormalities, four that required further examination by colposcopy. This revealed one high grade abnormality, two low grade abnormalities and two low grade endocervical abnormality and four benign atypical cells. Without the intervention of this early detection screening, these abnormal smears may not have been detected until advanced cancer in situ was present and diagnosed, with a much poorer prognosis.

**Figure 3 Comparison by graph of the cervical screening data across programs**



The graph compares the total number of pap smears taken at each program against first time smears, or over 5 years since last smear, where these figures were available. It also illustrates the increase in Pap smears in the March 2006 program following the break of six months with no program between the 4<sup>th</sup> September 2005 to 5<sup>th</sup> March 2006. Thirty –two women (45%) had their first Pap smear screening, or first in five years.

The ‘Thin Preps’ used for all smears in the second program and onwards were responsible for revealing three of these abnormalities. Although this laboratory testing is more expensive at \$20, it provides a greater opportunity to identify abnormal cells and greater benefits for clients and less cost in the greater scheme of continuing healthcare.

There is new terminology for reporting cervical abnormalities from July 2006. LSIL- low grade squamous intraepithelial lesion, or HSIL - is high grade squamous intraepithelial lesion. However, abnormalities from these programs have been reported in the old category of CIN 1, CIN 2.

### *Breast screening*

No health promotion person from Breast Screen SA was available to deliver this breast health information at the AWWH program, so this was undertaken by the community women’s health nurse. However, as the Breast Screening program was coming to the community, presentation material was resourced and every effort was made to provide this to the women attending. Thirteen women; five in the 40-49 age

group, seven in the 50-69 age group, 1 in the 70+ age group attended the breast screening following the March 2005 program.

Most recently in October 2006, as the researcher followed up these statistics, an Aboriginal woman has taken up the role of breast screen promotion for Aboriginal women and has been in contact with the researcher. It is hoped that she will be invited to join the PAG and the next AWWH program by the Aboriginal health service staff to fill this particular area of health information and encourage further breast screening in Aboriginal women in this community. Thirteen Aboriginal women is not a high participation rate and more health information delivered by an Aboriginal woman may make a significant difference to attendance at the local mobile Breast Screen Unit.

#### *Statistical evidence*

The software database has provided a mechanism for collecting and collating statistical information that can support the incidence of ill health of Aboriginal women in this community. This evidence can be used to support the application of relevant resources and health needs, such as dental services, drug and alcohol services specifically for women, and family violence healthcare workers, through a collaborative, multidisciplinary case management approach across government and Aboriginal health services.

#### *Comparison of sexually transmitted diseases across programs*

Screening for sexually transmitted infections is opportunistic with informed consent and it appears that a low incidence of chlamydia, and trichomonas remains.

Chlamydia can be responsible for infertility in women, and the use of condoms in safe sex needs to be promoted, as well as universal screening through the Well Men's Health program, to reduce this incidence.

**Table 9 Sexually transmitted infections**

Program	No Aboriginal Women Consults	Full Well Health checks	No STI Screens taken	Positive Results	%	
1 Nov 04	30	23	13	2 chlamydia 1 gonorrhoea	10%	
2 Mar 05	37	19	9 12 Cham	1 syphilis 2 chlamydia 2 trichomonas	14%	
3 June 05	30	16	5	1 chlamydia 1 trichomonas	7%	
4 Sept 05	25	15	?	1 trichomonas	4%	
5 March 06	42	28	?	2 chlamydia 1 not known	7%	
6 July 06	47	11	?	2 chlamydia	4%	
Total	<b>211 consults</b>	<b>112 WHC</b>		<b>16</b>	13%	

Of the 121 women attending the six programs who had full health checks, 16 that is 13%, were reported as having STIs.

The number of STI screens taken in the last three programs is not known, therefore the total number of full health checks is compared against the reported positive findings.

*Comparison of renal screens across programs*

Albumin creatinine ratio (ACR) levels were introduced in the first program and continued throughout each program. A urinalysis was done prior to this to identify any blood, nitrates, leucocytes or glucose that could influence this result. An elevated ACR was then followed with an early morning urine (EMU) sample. Many of these

EMU samples were difficult to obtain as they needed to be well explained, the container given the day before and the woman to remember to collect the first urine of the morning when she awoke. These urine samples then needed to be collected by the health workers on their early morning round. Any ACR that remained elevated was referred to the local GP for blood pressure and possible medication management.

Elevated Albumin levels from an EMU of 30-300mg/L show micro albuminuria, which has been identified as the earliest stage of nephropathy (renal impairment). An albumin/creatinine ratio of 3.5- 25 mg/mmol also indicates early renal damage. Early recognition of renal disease and medical intervention and medication can successfully delay the progression of the disease.

Table 10 below shows the ACR s undertaken throughout the programs, however some data was not reported. Sixty eight women were known to have participated in renal screening for Albumin Creatinine ratios over four programs. Forty-eight women supplied early morning urines in the first four programs and of these twenty-three (48%) were reported with elevated Albumin creatinine ratios requiring further investigation with the local GP.

**Table 10 Renal Screens**

Program	No AB Women consults	ACR	EMU	Elevated ACR	MSU	Diabetes
1 Nov 04	30	23	20	7	2	9 3 newly diagnosed
2 Mar 05	37	21	18	8	6	6 1 new diabetes follow up 1type 1- insulin
3 June 05	30	9	4	4	4	17 Hb1ac 2 diabetes
4 Sept 05	25	15	6	4		1 new diabetes
5 March 06	42	?	?	3		5 diabetes

						1 newly diagnosed
6 July 06	47	5	?	4		5 diabetes Uncontrolled 1 newly diagnosed
total	<b>211</b>			<b>30</b>		<b>9</b> diabetes cases newly diagnosed

Diabetes was reported in eighteen women who participated in the first four programs, five (28%) of these were newly diagnosed by the doctor at the AWWH program and one woman had progressed from diet and medication controlled Type 2 diabetes to requiring regular insulin. These figures are conservative as figures have not been easily available for the 2006 programs. However, the doctor reported numerous consultations for uncontrolled diabetes. Furthermore, mid stream urines (MSU) were collected from women with suspected urinary tract infections and these were treated at the time with antibiotics with the follow up results confirming correct choice of antibiotic for effective treatment.

*Dental disease in the women in this community*

Of the 73 women who had full health assessments in the first four programs, 72 women (98.6%) were reported to require dental treatment for very poor dental health. Of these eight women were transported to Adelaide for dental treatment. The number of women with dental disease for the last two programs was not so clearly identified and documented, however the doctor reported that 85% of women seen at this Aboriginal Well Women's Health program have severe dental caries, loose, wobbly or broken teeth. This causes severe pain, difficulty in chewing and has consequences for nutrition and cardiac and renal disease. Of the total number of women seen for a

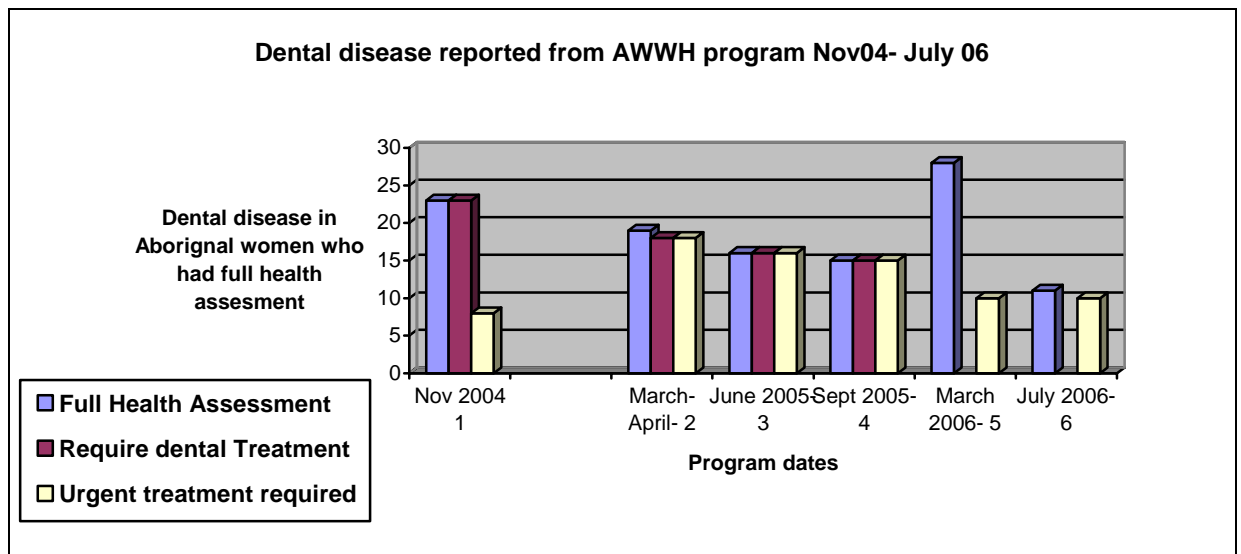
full health assessment (112), 90 women for a required dental treatment. Of these 75 required very urgent treatment.

**Table 11 Dental disease**

Program No & Date	Full Health Assessment	Require dental treatment	Urgent treatment required
Nov 2004- 1	23	23	8 Taken to Adelaide
March-April- 2	19	18	18
June 2005- 3	16	16	16
September- 4	15	15	15 Dr stated 95% of all women attending required dental care
March- 5	28	? +10	10 Severe dental caries
July - 6	11	? + 8	8 Dr has stated that 85% women attending require dental treatment
<b>Total</b>	<b>112</b>	<b>90 (80%)</b>	<b>75 Urgent = 67%</b>

This table has only taken into account those women who have had a full health assessment. As this is only a proportion of the women attending the program this figure is conservative.

**Figure 4 Reported dental disease**





The need for dental treatment has been compared against full health assessments for the Aboriginal women attending the program, as they have one full assessment with provision for a Medicare rebate every eighteen months to two years. No women have had more than one full assessment at this time, which makes these figures reliable so that each full assessment represents one woman. This is in contrast to the number of women attending the program overall, that is represented by episodes of care as women may consult the visiting doctor for continuous monitoring of chronic disease and to gauge any improvement in their health.

#### *Access to dental services*

Women stated that they have found it difficult to attend the dental sessions of the visiting dentist who visits on a six weekly basis with appointments made so far in advance. As there have been no antibiotics taken in preventative management the dentist also has reported that he found it difficult to assist. The dental team reported that the large demand for dental services has forced tight scheduling of clients every fifteen minutes and failure to attend on time has also resulted in clients not being seen. Therefore many of these women have not received dental healthcare due to their limited access to services and their need for prophylactic antibiotics prior to treatment to prevent further infection and in particular streptococcus A.

#### *Family violence and drug and alcohol issues*

While family violence and drug and alcohol issues are not reported in detail in each program, these issues continue to be problematic and without resolution for some women in the community.

## ***SUMMARY***

The AWWH program has identified a high incidence of Type Two diabetes, renal and dental disease and a significant incidence of sexually transmitted infections and cervical screening abnormalities. The reported statistics show the program is reaching Aboriginal women in the community who have not previously had a well health check and who are prepared to visit the program to participate in the screening, health information and lifestyle activities. Some women's views are reported in the following section on the domains of community involvement and empowerment, together with the opinions of the healthcare providers involved in the program. The remaining three strategies are also included in this section that reports the outcomes of the PAG reflexive action in continual improvement. The primary healthcare approach used in this program has assisted staff in providing a holistic approach to health assessment and screening and identify areas where they can continue to gain skills.

### ***6.17 Evaluation of Community empowerment***

The following three strategies outlined below relate to the empowerment of the community and continual development with the view to sustainability of the AWWH program.

Strategy 5 Determine what health information the local community women required to assist their health improvement
---

Strategy 6 Explore opportunities for the program to develop further in order to become sustainable
---

Strategy 7 Identify any barriers to establishment and the effective management of the implemented program
--

These are discussed together through the framework model, which incorporates the health principals of the National Aboriginal Strategic Framework and Laverack's Nine Domains of Empowerment to determine the aspects of empowerment for the Aboriginal community women and local healthcare providers. These themes were discussed in the methodology chapter.

The PAG minutes, together with field notes, report the program issues the AWWH team addressed through a PAR reflexive process. Program management issues were addressed where possible. However, there were some broader community issues, such as community transport, gambling and alcohol that were beyond the scope of the PAG members at the time.

The opinions of healthcare providers and some of the community women are incorporated and evaluated through the principles of health and domains of empowerment model that were previously discussed in chapter 4 and are listed below.

**Table 12 Health Principles Domains Evaluation**

<i>Cultural respect</i>	Links with others
<i>Holistic approach</i>	Program Management
<i>Health sector responsibility</i>	Resource mobilisation
<i>Community control</i>	Organisational structures
<i>Working together</i>	Participation
<i>Localised decision making</i>	Leadership
<i>Promoting good health</i>	Problem assessment
<i>Building the capacity</i>	The role of outside agents
<i>Accountability</i>	Asking why

These domains are discussed in the following section as to how they demonstrate empowerment in this research although not necessarily in the order that they are presented above. Some of these domain topics are revisited in different result sections.

### ***6.18 Program management (domain)***

Community empowerment can be demonstrated by control over decisions of management in planning, implementation, administration and evaluation. Within this structure, good program management requires clearly defined roles and responsibilities for all healthcare providers involved in the program. The third PAG meeting was conducted at the close of the first program where food was provided and the team could relax and openly discuss what went well and what could be improved. Listed below is the critique and recommendations following the first AWWH program in November 2004.

#### *PAR critique Program 1*

##### *Process issues*

Issues that impacted on the staff and performance were identified with possible solutions for the next program. These are listed briefly as there were expected to be some general organisational issues as the program was established.

- *Requirement of non-clinic time* - Identification of specific non-clinic time to enable the doctor and team to attend to other aspects of a successful clinic, (eg referral letters to other specialists, team meeting, education updates for staff and debrief, and lunch breaks).

- *Established clinic times for clients* - Clearly identified times of doctor availability, and availability of other visiting specialty team members and their programs eg diabetes educator were required for the community. This would provide for a more systematic consultation process that would provide time for proper meal breaks for the AWWH team members.
- *Transport availability* - More emphasis on availability of transport for women, as there was no local bus service. A designated driver who is not one of the clinic team could be employed for the week, as health workers in particular, were being taken from the clinic to drive the clients to and from the program.
- *Increased resources* - Further assistance was required for computerised data entry and data analysis that was not completed by the end of the program. Limited team members of the doctor, one administration staff, the women's health nurse and the researcher were able to enter the data on the computer when they were not undertaking their other roles.
- *Absence of Men's Well Health program*  
As men were asking to see the doctor during the women's program an established time was required for them, for example an evening session for two hours. This may be addressed by the sessions that could be provided by the local male GP at the Aboriginal health service.

- *Building the Capacity*

Further capacity building for staff to improve their knowledge to assist a primary healthcare approach in the delivery of services. Staff training was undertaken in eye testing, urine testing for ACRs, blood glucose levels, and follow through of collected urine and blood specimens.

### *PAG Critique Program 2*

The second program was held in March – April 2005

- *Follow-up of women following the program*

At the PAG meeting at the commencement of the program a system was organised for the follow-up of abnormal results. It was necessary to delegate responsibility and accountability for this within the Aboriginal health service.

- *Sexual health education for sexually transmitted infections*

This screening has identified that there was still an element of STIs requiring treatment and education for safe sex and use of condoms. A visiting Aboriginal healthcare provider trained in sexual health has joined the women's health team and health education sessions and health education sessions were better addressed.

- *Reference Group*

It was suggested that a reference group made up from a small group of staff and community women to advise the PAG on their needs and how the program will work best for them. Members of staff and community were nominated for this.

- *Access to the program by community women*

Aboriginal women continued to attend the program and there are patterns of ill health that were now being identified. The women were interested to know how

they can better manage their own health and that of their families, and there appeared to be trust developing between the women's health team and the women.

Screening from these two programs has identified the Aboriginal women's health as extremely poor. The program is starting to reach the women who have not previously, or recently had, any health screening. Three Pap smears showed abnormal cytology that required further investigation and elevated renal screens and uncontrolled diabetes have all been referred to the local GP for follow up. Discussions have been undertaken with the diabetes educator to attend the Aboriginal health service regularly to build rapport and provide diabetes education that will improve self-management.

### *PAG Critique Program 3*

- *Reference Group*

There was no report as there had not been a reference group meeting as various members of this newly formed group have been away.

- *Well Health checklist*

This is working well and was seen as a good record. There was discussion relating to a template on the computer so that the client information could be added directly to it. However, as there was not another computer in the clinic, this would make it difficult for staff to monitor clients and so both a paper copy and computer data entries were maintained.

- *Play Gym and childminding*

There was no progress in this area as the community grant had already closed, and children were minded by members of the team.

- *Dental health*

Two vehicles with 13 clients (male and female) were taken to town to the dentist. Most had X-rays and teeth extracted and one was admitted to hospital for treatment under anaesthesia. The overall costs exceeded the dental grant and future trips will need to be more cost effective.

- *Transport*

Much time has been spent by staff collecting and returning clients and also finding them. This was also compromised by the early opening time of the hotel serving alcohol at 9.00 am. There was discussion of a partition to prevent this early opening as it contravened the aims of the organisation in Aboriginal health and wellbeing. The hotel also had a variety of poker machines that were well frequented. The issue of no local community transport remains, making it difficult for some clients to access facilities.

- *Advertising the program*

Discussions were undertaken that related to advertising the program to make it more available for non-Aboriginal women. This was to be followed through by the women's health community nurse with some of the women Elders.

### *Attendance*

The doctor saw a variety of clients - women, children and still some men. The women continued to attend the health information and lifestyle sessions. A significant



number of new clients attended the WWH program and the health problems that have presented reinforced the need for the program and its importance in the community.

### *Men's health*

The CEO hopes to follow the Women's Well Health model and have an Aboriginal Men's Well Health program running shortly.

## **6.19 Leadership (domain)**

### *Holistic approach*

Leadership plays an important role through taking responsibility and accountability for achieving goals, dealing with conflict and providing direction. Leadership in this program was displayed through individual PAG members, such as the CEO, doctor, women's health nurse and community manager, Aboriginal sexual health nurse educator and the researcher. They all provided their unique skills and working in collaboration with the Aboriginal health Unit staff with the common goal of providing the holistic AWWH program

The CEO had resigned from the Aboriginal health service and reported that the PAG meeting in July 2005 was the last she would attend in that position. She asked that:

*...all staff support the new CEO and continue the program in the cheerful and willing spirit in which you have conducted yourselves. Thank you to everyone for their commitment towards improving women's health.*

The new CEO (a male) was invited by the researcher to attend the PAG meeting in September 2005 as it was thought it would give him a good overview of what the program did and how it was managed. However, it was retrospectively found that this was at the expense of three Aboriginal healthcare workers who were absent, as they were not comfortable with a male being present at "women's business", and this also limited the discussion.

There were no subsequent PAG meetings for programs five and six. Program five was postponed from December 2005 by direction of the incoming CEO and not conducted till March 2006 despite strong objections from the visiting AWWH team, the local AWWH team and the visiting doctor. Therefore there was no screening program for the best part of six months for Aboriginal women and there were many management and staff changes within the Aboriginal health service.

Leadership and governance are discussed in more detail in the discussion chapter.

#### *PAG Critique Program 4*

- *Direct entry of computer client*

There was an additional computer that could be set up for direct entry of client data onto the computer. However, the template needed to be installed on that computer. Paper copies of the well checklist will continue both in the clinic and throughout the program for easy access to monitor and document client information. The new CEO stated that he was likely to change the database system in the near future, probably to one that was used in Central Australia called 'Communicare'. This caused much concern for the doctor and team as the database was selected originally as one that the doctor was familiar with and had been used by the other local GP services. Staff were also just beginning to familiarise themselves with the health program database and statistical data collection.

- *Transport*

Transporting clients to and from the clinic placed a huge demand on the staff as the local GP was also now consulting at the Aboriginal Health Service twice a week and also throughout the AWWH program. This meant that staff resources were limited in operating two services simultaneously, and that transporting clients became more difficult. This impacted on attendance for those two days of the program. It was decided that a dedicated driver should be employed throughout the program who was not a member of the clinic team. The RN stated that the healthcare workers knew where to find the women, so it was best for them to go and collect them, and sometimes this was from places such as the hotel.

- *Child supervision and Play Gym*

The researcher had brought suitable ride-on toys and equipment from Adelaide from the Toy Library, however these still required supervision. There was still some problem with paying for a childcare minder on site and a member of the team was delegated to follow this up. At this program six children attended who had never been seen before by the Child health nurse. Their attendance provided her the opportunity to assess them and organise immunisations.

- *Dental health*

The doctor stated that 85% of women attending the program required dental care. She stated that while not everybody had diabetes, many have either diabetes and early renal impairment or cardiovascular disease. With the high incidence of dental caries, she considered that they were at risk of endocarditis

and infections that become septic. It was discussed that if referred by a doctor, the cost of dental health and transport to Adelaide can be recouped by the organisation through the funds for chronic disease management.

- *Advertising the program*

This had not been arranged for this program, as the women Elders had not been approached to give approval. There was some discussion as to whether this would restrict access in any way for Aboriginal women. The CEO asked if any advertising would need to be approved by the Board of the health service. The researcher stated that this had happened before the program was put in place. The lack of advertising was an issue for the program in the first two days as the women did not know the doctor was present till word spread. This, together with the lack of showers and transport, impacted on the number of women attending.

- *Sustainability of the program*

Other areas relevant to the program's sustainability included the need for it to be supported in the wider community, exploring better chronic disease management. The researcher had identified renal and chronic disease community programs that could be considered as being effective in other areas of SA. The managers of these programs could be contacted through the university regarding their assistance in chronic disease management in this community.

The doctor reported that it was necessary to change the women's attitudes from one of crisis management only - going to the doctor when they were really sick -

to primary healthcare focusing on how to stay well, having check-ups for prevention and early disease management, and being more accountable for their own health.

- *Diabetes*

The doctor reported that there should be a full-time diabetes nurse educator at the Aboriginal health service as diabetes is one of the biggest problems for the whole Aboriginal community. The diabetes nurse educator also needed to be on site for the local GP clinics at the health service. As soon as clients came in the door, staff should do as much testing and management of diabetes as possible as clients may not return for some time. This view was also supported by mainstream services members. It was commented that the collaboration across mainstream services and Aboriginal health was one of the strengths of the AWWH program.

### ***6.20 Resource mobilisation (domain)***

The ability to identify the required resources and negotiate these at a local level indicates the level of skill and organisation within the community.

#### ***Health sector responsibility***

##### ***Process issues***

- *Lack of client follow-up*

The researcher discovered that when she visited two months after the initial program in November 2004, the follow-up for clients from the first program had not actually occurred. Staff had taken their Christmas break shortly after completion of the first program. In the New Year, on return to work, they had forgotten about the need for follow-up with the demand of crisis management again building up in the clinic. Prior

to the second program this organisation of clients' referrals to health specialists and monitoring were then attended to as a matter of priority. Ten people were transported to Adelaide for emergency dental care; however some could not be treated, as they had not had prophylactic antibiotics.

- *Staff Illness*

Three staff members were ill and unable to assist during the second program. This put stress on the remaining staff to collect women. On the third day, a fourth member of staff was also off sick, as they had walked too much and ankle oedema was a problem. This highlighted that the staff themselves were extremely fragile with their own health issues. Another female member working as the receptionist was also off sick for a day. The Aboriginal health service is a stand alone service with very little resource support from the region and no back up for sick healthcare workers. There were no drug and alcohol or mental health workers, no active diabetes management, no oral dental health, and no podiatry or physiotherapy.

- *Participation of the whole clinic team*

There were some issues concerning the involvement of the whole clinic team. The clinic RN did not participate in the program as she was busy with routine medication management and following male clients who had seen the male GP conducting a consulting clinic at the opposite end of the organisation. The screening was left to one enrolled nurse and the women's community health nurse (mainstream) who coordinated the program extremely well.

- *The limited capacity of some staff at the Aboriginal health service*

There appeared to be a lack of coordination, management and supervision for new workers throughout the clinic. Some Aboriginal health service staff reported that they had limited capacity without further training. A new male health worker employed for drug and alcohol programs had manned the phone for two days. There were continuing difficulties in providing female drivers to transport the women to and from the clinic. Therefore the only female health worker trained in women's health was not working in the clinic, as she volunteered as a driver.

#### *The need for Child Care throughout the program*

There was some difficulty in attending to the health information needs of the women with the young children running about and requiring constant attention. A play gym was suggested but designated childcare personnel would be required to oversee this so that accidents did not occur as the children were extremely active. Funding for this was to be investigated.

### **6.21 Recommendations from the PAG**

#### *Implementing other successful components of the successfully established program*

For this program to emulate the successful Central Australian Well Women's program, other components, identified as responsible for success needed to be included. These include:

#### *A Coordinator*

A Coordinator of the program is required to assist the AWWH team to:

- Determine in collaboration the specified needs of clients in health education and promotion, for the next program.

- Assist in the organisation of the equipment for the doctor's visit and the requirements of other invited specialised health providers, and aspects of promotion of the program.
- Coordinate the health education and promotion sessions throughout the program.
- Follow up the results of clients' screens, monitor primary healthcare issues identified in the screening program and collate and computerise the information that contributes to the evaluation of the program and client needs.

#### *Health Education*

More structured presentations with specific health expertise were required to support the health education sessions to inform women and provide a forum for further discussion of any health issues (e.g. sexual health, mental health, and focusing towards well health such as healthy eating and cooking).

#### *Encouraging women's participation in activities*

The women themselves need encouragement to participate in activities leading up to the AWWH program, e.g. painting posters that express good health, perhaps some may be interested in promotion through preparing the Well Women's Health participation bags.

#### *Designated times for the younger women to attend*

The younger women require a specific time (day) to participate in the program. It was noted that some attended the first day but did not participate in activities, as the Elders were present. However, they did not return as suggested the following day.



### *School Students*

Young women still attending school also need to be included in the program through invitation and participation, for instance through a healthy women poster competition, sewing activities and promotion bags. Additionally, their ideas sought about their requirements in well health, for example this may be in the way of a prominent sporting identity visit to the school promoting health in exercise and foods.

### *Sustainability and Effectiveness*

Sustainability can be more assured by designated funding to this program with process and outcome evaluation over the long term. This may be accomplished through the formation of a reference group with definite roles to manage specific program issues, and actively demonstrating the principles of community empowerment for the women.

### **6.22 Participation (domain)**

Participation is demonstrated by the involvement of individual community members in the AWWH program so it will enable them to contribute and have greater control over the factors that influence their lives.

## Aboriginal Well Women's Health Team and Community Women



### *Integrated Services and collaboration*

The collaboration of health providers across mainstream and Aboriginal services, to organise and implement the program, was excellent. The Well Women's Health team worked together to provide a culturally acceptable and effective screening process that appeared to meet the women's expectations. The Project Advisory Group has guided the development of the program and continued to support its improvement and explore the issues of sustainability. These shared resources have fostered good working relationships across mainstream and Aboriginal health services.

*The Acceptance of the AWWH Program by the Healthcare Providers.*

### **6.23 Healthcare providers**

Both local and visiting healthcare providers were asked the same questions concerning the health of Aboriginal women and the factors that they believed would make this AWWH program work and the barriers to be overcome (questions listed in Appendix). The first block of interviews was conducted in April 2005 at the completion of the second program. The next interviews were undertaken in August-September 2005 and final interviews were completed in July 2006 fifteen months later, following the sixth program. Some of their responses to these questions have been selected to report and describe their overall views.

### **6.24 Problem Assessment and Resolution (domain)**

The identification of problems by the community and the action taken to provide solutions helps to build capacity within the group. When asked how they would describe the health of Aboriginal women in this community, healthcare providers volunteered the following information.

*April 2005*

*The group of grandmothers that live in the Aged Care complex seem to be well looked after. Some of the younger women seem to have got it together. Out on the street quite a lot of them appear to be out of control, some of the problems have been identified, but there appears to be very little if any follow up especially around diabetes. ...Aboriginal women in urban areas appear to have better access to shelter and good water, housing and access to food, those basic things.*

*The incidence of chronic disease especially diabetes and kidney problems are prevalent. Their social health is dramatic really. There is too much family violence in a community like this- and a lot we don't even hear about.*

*Alcoholism and drug use and probably infidelity as much as anything, drives the violence.*

*Of all the Aboriginal communities that I have worked with, the overall health here would be the worst I have ever seen!*

Health providers were asked what factors influence women's health? Their responses included these statements:

*The Aboriginal women here appear to be missing out on the basics. I don't know what their housing is like, and I don't know about their access to water, but there does not seem to be adequate water. If they come in here for the showering program, they obviously do not have access to water wherever they are living.*

*Listening to the stories about not having access to food, I have noticed how much more expensive food is, especially fruit and vegetables and with the alcohol problem, much of the money they do get disappears on grog and gambling. The basic needs do not appear to be available and what there is quite expensive.*

*Previously, women have not been able to access the female doctor on her infrequent visits. There is not always a woman doctor available to come with the RFDS and the time frame is too short as she needs to see the whole community. Aboriginal women have not been comfortable waiting to see the doctor in the waiting room with everyone else.*

*I think they need some guidance with regards to their food, they don't have much idea about nutrition. Nurses at the clinic try to explain it to them, but maybe that's not as good as getting a nutritionist and dietician with their knowledge, to explain. From what the nurses have seen they prefer take away food to cooking. It's not that healthy and it's more expensive as well.*

Healthcare providers were asked how they saw the AWWH program making a difference. They responded:

*If we can encourage them to come in here, even to assess their basic needs, unless there is coordination in the follow up, apart from identifying STIs and finding people with diabetes that have not been diagnosed, finding abnormal pap smears which can do a bit of good: the overall situation is probably not going to change unless there are other things put in place.*

*Hopefully it will make a huge difference, as the women will be checked to see if they are generally healthy. Some early interventions may help to extend their life span. There have been around five funerals for community women in the last couple of months.*

*It will, because the numbers coming in here were good numbers, because when the women come in they do not want to wait, and you have to convince them that they need to stay for their own good. They stayed because they own the place and feel comfortable.*

### **6.25 Resource Mobilisation (domain)**

Healthcare providers described support programs that are needed as:

*It seems that there needs to be much more in drug and alcohol support, diabetes care plans that need to be put in place, a women's healthcare worker who is there all the time who tends to coordinate and follow up things who works from the clinic, does the intensive program and has an ongoing role in the area of women's health.*

*Family violence is very bad here, part of it is anger management perhaps it can be trialled to say there are other ways to express one's anger. The problem is if the woman does not follow what the man wants, then he will start bashing her. They can live within their budget have a lovely house, but the drunks will come around and trash it and eat all the food, and then where do you start.*

*And then on the opposite side of the scale there are those families that just don't feed their children. They're on the side of the street twenty-four / seven like stray dogs.*

Healthcare providers were asked what were the main health-related problems they had identified. Responses included:

*Alcohol abuse is certainly a significant problem, family violence, dental problems, diabetes, grief and loss and that continuing trauma.*

*Physical abuse being aware of people who have been bashed even if it is not serious injuries, bruises and lacerations and then their generally poor nutritional status.*

*Family violence, housing as many of them don't have housing, they live from house to house. Some have furniture some don't. Very few have fridges or*

*washing machines. They bring their washing into the showering program I started in 2002.*

*Some asked if they could shower even if they were not sick, I said yes so that they could feel better about themselves. Socially they are more presentable and happy and less sweaty, a boost to their self esteem. They also get a change of clothes.*

Healthcare providers were asked their opinions of the elements to make the program work and be successful over the long term. They suggested:

*You probably need a full time women's health worker, who works from the clinic and someone to coordinate the program. There needs to be a full time female doctor in the health service to make a difference to women's health, as there is still a lot of crisis management.*

*I think the enthusiasm of the women who are coming along and the fact that they are telling their friends and relatives to come along and get screened. Just the fact that they are participating is going to make a difference.*

*The follow-ups and the general cooperation and participation of the women. This will make it successful. Because if they are comfortable in coming here and having these checks and they realise the value through education. And I think they do, because there has been so many of them coming here in the last couple of days.*

*Women need to be aware that the program is going on. It needs to be explained that this program is important to them.*

Barriers or threats to the program were identified by some healthcare providers as:

*The danger is in pushing it, as I really haven't got the impression that anybody owns it or wants to own it yet. The positive side is there is potential to make a difference and now with the well person's check from a financial point of view.*

*There is a financial incentive for the health service and also for each person to be able to have a regular health check up. However unless you have the resources- for example; almost everyone I have seen required dental work and so unless there are the resources to follow that through, what is the point in telling people how bad their teeth are if you are not going to be able to help fix them up.*

*I guess there is the potential to identify lots of health problems and really make a difference, there is huge potential to do that.*

*The problem is staffing levels and there staff being here at any given time.*

*Time, because we are not enough staff in here, there may not be enough time for staff to attend to it.*

### **6.26 The Roles of Outside Agents (domain)**

#### ***Working together***

Outside agents are an important and essential link between the community and external resources in remote areas. Outside resources were essential for the establishment and the continuation of the program. The original program was identified by the researcher and brought to the Aboriginal women community for consideration. The implementation of the AWWH program following their interest and acceptance, required a female GP and expertise in women's health assessment and knowledge that was not available within the Aboriginal health service.

These visiting healthcare providers from local mainstream and the city of Adelaide were required over the long-term for each program to complement the growing skills and capacity of the healthcare providers from the Aboriginal health service. This collaboration and partnerships across organisations with the common goal of improving the health of Aboriginal women in this community, through a primary health approach to prevention, detection, information and management, has provided the successful transfer of an established Aboriginal Well Women's Health program with the potential for sustainability.

### **6.27 Organisational structures (domain)**

.The level at which the organisation functions is crucial to community empowerment. Staff members require a supportive environment and a sense of belonging and

connectedness in their organisation that is displayed through their personal relationships and ability to collaborate, and show concern for each other and their roles in community issues.

## **August 2005**

### *Accountability*

It was acknowledged by the Aboriginal health service management that not only had the AWWH program identified the health needs of Aboriginal women (and more recently men) but it also identified the limitations in existing services and systems:

*The program has identified limitations that existed in providing primary healthcare and a holistic approach to the needs of Aboriginal clients. Changing the focus from crisis management to a broader holistic health model is in transition.*

*A more effective storage system for client notes, both as a database through Medical Director computer software and a physical system of all the files being moved to a central location with tighter security to meet confidentiality specifications has been put in place.*

*There is more accountability of who is responsible for specific tasks*

*More areas have been set up as examination rooms that can be used by visiting doctors, that is GPs and specialists (there was no specified area set up for doctors examinations when the program began).*

*More equipment such as a haemocrit machine has been purchased to establish haemoglobin levels*

*An extra Registered nurse has been employed on a full time basis to address primary healthcare issues and a holistic approach to healthcare. A coordinator for all healthcare programs is also being established and should commence shortly. This is a collaborative venture between the health service and community mainstream services.*

*The implementation of this program also identified a previous lack of collaboration between services eg cervical screening, breast screening and health education.*



*The adaptation of the Aboriginal Well Women's Checklist to a generic tool has identified the continuing and urgent needs of Aboriginal men in the community.*

Aboriginal health service management reported that there were still some aspects of organisational change that need to be addressed. These were identified as further training for staff in renal screening and organisation of a designated transport driver throughout the program, and some organised back up for sick workers. This was further compounded by the resignation of the CEO who had been extremely supportive of the program. Her resignation was expected to have some impact even if only temporary.

*There is still some question as to whether the renal screening is being undertaken properly and this may need further assessment and education.*

*The female health worker was again relied on for transporting clients to and from the clinic rather than working in the clinic along side the doctor and community women's nurse.*

*This program was the most extensive and comprehensive that the health service has tackled and there were challenges for all participants to overcome.*

One Aboriginal healthcare provider commented on the education and lifestyle sessions:

*We did up snap lock bags which had small pots of skin cream, small bottles of essential oils, tea candles, toothbrush/paste, comb, small bottles of shampoo/conditioner and tissues, which proved very popular with the women. We showed some videos, cooked morning tea and lunch. The doctor had a steady stream of clients, some were new, some were returning for results etc. the only thing wrong was there was not enough hands on involvement from the Aboriginal health worker and own clinic staff.*

## **July 2006**

### ***Promoting good health***

Healthcare providers were again asked how they saw the AWWH program making a difference. They responded:

*It has [increased] the awareness of the importance of well women's health and has improved the health of local Aboriginal women.*

*By attending, and advertising to other women about their experiences of the AWWH program*

*It has helped the women to learn about health issues, identifying any illness such as high blood pressure, diabetes or infection and monitored their health progress with referrals to other health service and specialists.*

*A coordinated approach to health to address the poor status of Aboriginal health. It is not only a clinic [program] but it involves health promotion and education activities. There is food for the women and children, and the community is able to access showers and clean clothes. Everyone helps everyone else, good team effort, good support for the Aboriginal health service. The benefits for the community are unmeasurable in terms of getting the service to the people, for the people. It has been a long time coming.*

An AWWH team member who had worked in the community for twenty years reported:

*What was provided was a multidisciplinary, comfortable health service, catering to the individual needs of Aboriginal women, within a facility that was suitable to their social and cultural needs.*

Observations:

- *Positiveness with which the women attending the health service displayed in contrast to them attending mainstream facilities.*
- *Health testing was well received by the women*
- *Comfortable ambience of clients*
- *Willingness, interest shown on behalf of consumers*
- *Open appointment times worked well and 'bottle-necks' were easily diverted to other times*
- *Attendance by all women was appropriate and there was no unnecessary repeat of tests such as pap smears noted.*
- *Women attending were given the choice to participate in examination/screening.*
- *Some chose not to have a pap smear and this decision was respected.*

- Overall the clinic [program] was well worth the effort, particularly as we reached those vulnerable women with genuine need.
- Positive networking and liaising between a variety of health disciplines and organisations, with the client as the centre point of attention. Some other modern programs have the provision of service the centre of attention and the consumer is secondary.

Healthcare providers thought that further information and lifestyle sessions in a variety of topics would add even more interest for the community women. These included:

**Table 13 Healthcare providers suggestions for lifestyle and information sessions**

Antenatal & Mother & baby education	Hairdressing Basic cuts, colours, head massage	Sports, softball, netball, swimming
Alcohol & other drugs - Low risk drinking & drug use	Loss & grief counselling	Nutrition- budget cooking & food recipes
Kidney health	Dancing	Mental health
Exercise programs	Family violence	Heart health

**6.28 Participation ( domain)**

*The views of participating community women*

Sixteen community women and girls who had participated in the AWWH program were asked their views. This was specifically targeted at why they attended, the program content, whether the program helped to improve Aboriginal women’s health and any barriers to women’s and girls attendance. Their views are indicated below.

*Program attendance*

This identified the age group of the client and what they knew of the AWH program why women attended and when it was best for them to attend.

**Table 14 Age groups of women responding to the best time to attend AWWH program**

<i>Age group of respondent</i>	<i>Program attendance</i>
15-20 =5	Evening or early morning
21-35=3	Early mornings Monday to Friday all week
35-55 =7	Early morning or late afternoon
>55=1	Evening Wednesday

*Program content*

*Community control*

Participating women and girls were asked what they wanted from the program and if it met any of their needs and what they would like included in the health information and social health and wellbeing sessions. When asked what they wanted from the AWWH program, women responded:

*Confidentiality and everything checked*

*Health information*

*To be kept informed and up to date with women's issues*

*To be number one well women's health*

*Need to know what's there to offer women*

*The services of a female doctor*

*To see if my health is good*

*For the health service to have the best well women's program in SA*

**One woman commented:**

*For the program to have more organisation in different information sessions, with a list, and so everyone has a turn*

She had listed every health information and activity session totalling twenty-six. It is therefore thought that this comment reflected that more variety would be useful for the women, and that they may like to make choices about which activities and sessions are to be organised, well before each program.

When women and girls were asked if the AWWH program had met their needs seven stated it had, four stated their needs were partially met but would like some other health information and this included a dietician and a diabetes nurse educator, and five did not comment.

**Table 15 Women’s responses in age groups to if the AWWH program met their needs**

AWH Program	Age group and no. of comments
Program Met needs	15-20 =2 21-35=3 35-55=1 over 55= 1 <b>Total =7</b>
Some needs not met A dietician as overweight A diabetic nurse educator not available	15-20 =1 21-35=0 35-55=3 over 55=0 <b>Total =4</b>
No needs or no comment listed	15-20 =3 no comment 21-35=0 35-55=2 no comment over 55=0 No comment <b>Total =5</b>

When asked why they thought other Aboriginal women attended the AWWH program, respondents stated:

*It's held at the Aboriginal health centre and friends and family come along together.*

*Because they [women] want to look after their health and interact with each other.*

*To get a full health check.*

*To stay healthy and check this.*

*So everyone can be healthy and sit down with the other women. It is good to sit down and talk with activities, hair care, makeup and how to socialise. At the end of the day we get a nice feed.*

#### *Helping to improve Aboriginal women's health*

Women were asked if and how the AWWH program had helped to improve their health. Not all respondents answered this question. The responses of those who did are listed below in Table 16. The women appeared to be very interested in learning about their health issues and those of their families and monitoring their health progress.

**Table 16 How the AWWH program had helped the women who responded**

In learning about health issues	8
Managing health issues	8
Treatment of injury or illness	7
Identifying any illness	8
Monitoring health progress	8
Referral to other service or specialist	8

Other responses included:

*Want follow up after program to let us know that everything is good. Not by local doctor here.*

As their interest in health sessions and activities varied across age groups, these are listed together with improvements they would like to see included in the program. The younger women and girls also requested a session when their aunts, mothers and grandmothers were not present.

*It would be good to have something in the evening where we could all come along and that way we will not meet up with our aunties and feel shame.*

**Table 17 Aboriginal Women’s comments on sessions and improvements they would like included in the AWWH program**

<i>Age group</i>	<i>Program content</i>	<i>Improvements</i>
14,15,16	Health sessions Skin care, kidney, heart, diabetes, sexual health, foot care, exercise nutrition Activities Art/painting, hairdressing, Jewellery making, dancing, sports: softball, netball, swimming	More privacy during consultation Perhaps we can use youth centre  We need to learn about health issues
21-35	Health sessions Skin care, kidney, heart, diabetes, sexual- health, foot care, nutrition loss & grief counselling, low risk drinking & drug use, Cooking & Pilates & aerobic exercise Activities Hairdressing, art/painting, jewellery, sports	More private room (was revealed that curtains were partially open) AH Workers should go out into the community Give out videos – such as domestic violence, coping with stress & gambling and use youth centre for sessions
35-55	Health sessions grief counselling, low risk drinking & drug use, child care for young children, breastfeeding for young mums Activities All listed activities and health information sessions	Tell women the week before. Have BBQ lunch Make child care available Talk out in community more Let the young ladies cook meals More notice of when the program will occur

One respondent, when asked what could be better in the program, stated:

*Being outside, reconnecting with the bush and bush medicines.*

The women were asked what they believed were the barriers to attending the program. The women who responded were able to identify some issues that they saw as a barrier to attendance of the AWWH program. These were reported as:

- *Lack of advertising*

Women stated that they were not aware the program was being conducted until other women, who had visited the health service, told them. The women suggested the program be well advertised several weeks before it commenced, so the women knew when the doctor was arriving. This would enable them to plan for attending both the clinic and the other activities.

- *The lack of transport*

The need for a health service ‘pick up and put down’ was mentioned. This was especially important in the hot weather as it was too far to walk for some women, being several kilometres from the main street. There were also several comments about more privacy and some comments about lack of privacy during consultation as on one occasion the curtain was partially open.

- *Need more varied health information and activity sessions*

There was considerable interest in a greater variety of health information and activity sessions. However, these sessions depend on the available external resources and the possibility of financial re-imburement for costs. At present most external resources, with the exception of the doctor, are volunteers, who travel a long distance to



participate in the program over the four days. Broadening the program to include loss and grief counselling, drug and alcohol issues, gambling and domestic violence tapes, more health information and providing childcare would be of great benefit for the women.

The women's comments about barriers to the program included:

*We did not know about the program till last week.*

*Women have no transport so need to supply transport*

*We do not want to be there with aunts – just young people*

*No time*

*Feel shame (embarrassment)*

*Feeling well*

*Too hot*

*I did not know about it before so reminder letters could be send out.*

We need to have a ladies day at the clinic so we can talk about issues together with health workers

### ***6.29 Strengths of the Program***

#### ***Cultural respect and acceptance***

##### *Interest and support of community women*

The Aboriginal women have demonstrated their interest and willingness by attending the Well Women's Health program over the three days. They continued to access the program throughout the screening days for monitoring and repeat screens, especially early morning urines, and blood glucose levels and continued to join in the activities and in some cases saw the doctor on more than one occasion. Women were still

coming to visit the doctor at the completion of the program right up to the plane's imminent departure.

Health information activities and lunch were provided each day in the meeting room together with competitions and lucky ticket prizes. The women who had full screenings also received a Well Women's health bag of goodies. Some women who did not have operating showers in their homes used the "shower program" before the doctor's examination. Others enjoyed the food and health and lifestyle sessions and actively participated in these. As the word spread in the community, more women walked or were transported to the clinic. From the women's response and eagerness to participate it was decided that the program was culturally acceptable and meeting the immediate needs of community women.

### ***6.30 Limitations***

#### *Problem assessment (domain)*

The identification of problems by the community and the action taken to provide solutions, builds capacity within the group.

#### *Attendance of younger women and evening clinic*

It was noted that very few of the younger Aboriginal women attended in the first four programs. Their needs appear to be different and it would seem more beneficial to provide them with their specific times early evening as most are still at school and do not feel comfortable with their elders. Several women who arrived late on day one to see the doctor, and made appointments for the following day, did not appear. Not all women were able to attend throughout the day and a late clinic may better meet their needs.

*A lack of community transport*

There is no community bus and therefore the women have relied on the health service collecting them and returning them home or walking. This has resulted in some women not having the opportunity to visit the doctor and participate in the program.

*A lack of childcare*

The issue of child minding still requires redress. The women love to bring their children and some formalised play group should be available for them to be nearby but also allow their mothers, aunts and grandmothers time to have their screening and actively participate in the health and lifestyle sessions. This issue would be easily resolved with paid child minding staff who could be employed for the week. This would also enable a child health nurse the opportunity to catch up with the children for any assessments or immunisations throughout the week. Unfortunately, there is no longer a resident child health nurse in the community. This position is being filled in a 'fly in fly out' capacity on a monthly schedule.

*Minimal human resources*

The lack of human resources has created difficulties in accessing de-identified data after the program, entering and completing patient file information on computer, and delays in submitting Medicare claims due to the other work commitments of personnel. This has also created delays in monitoring clients requiring reviews and follow-up services, as crises and sick leave have impacted on the availability of clinic staff able to attend this.

### *Links with others (domain)*

Networks and links to other people including partnerships can lead to empowerment through greater access to information and resources.

### *Lack of structured health information sessions*

Specialist health professionals are required for health education sessions such as renal, cardiac, drug and alcohol, mental health and social wellbeing. Other information segments, such as healthy cooking and eating, are required alongside the screening process. These sessions need to be tailored to meet the expectations and realities of the Aboriginal women attending.

### *Lack of a Coordinator*

A coordinator is required to assist the clinic staff in the preparation and health education, to send screens to the laboratory in a timely fashion on the daily aircraft, to follow up abnormal results for intervention, and to collect data for evaluation purposes. This requires a health provider who can also negotiate with regional health and other organisations, as well as prepare for the intensive screening days and provide timely client monitoring and referrals.

The coordinator should also be responsible for continuing collaboration across mainstream and Aboriginal health services. As the PAG has guided the AWWH program and is recognised as an established identity that would continue to augment this process, it would seem prudent to continue this group to advise, critique and evaluate future programs working with the coordinator and the local healthcare providers.

*Lack of community programs in chronic disease management and mental health*

The doctor, when asked to make some comparison with other Aboriginal communities she had worked in, described the Aboriginal women's health as "absolutely shocking". Further support, resources and capacity building are all required with the development of community programs that are continuous.

There is no local mental healthcare provider as the previous worker had ceased work due to extreme pressure after five weeks of working extensive hours, and there has been no drug and alcohol worker nor programs for women to attend. The coordinated care chronic disease management programs in place in other remote areas of SA have training programs alongside their support structures that could address this area of need.

**6.31 Concluding Remarks of Results**

**Asking Why** (domain)

'Asking why' is described in terms of critical awareness through the reflexive process of PAR in discussion and action of implementing and evaluating the program, and addressing responsibility and accountability of actions or inaction. The process of participation and reflexive action and the dynamics of the AWWH team, and the participants within the context of the remote locality, all impacted and influenced the program.

*Localised Decision Making by the Aboriginal Health Service Staff*

The governance and leadership of the Aboriginal health service have been major factors of influence throughout the successful implementation of this transferred

program. This has fluctuated with the changes of CEO and Board of governance being influenced by individuals' level of commitment and understanding of the work. However, as the continuity of the program was threatened by those in leadership roles changing priorities, it was the local mainstream health providers and those working from within the Aboriginal health service, some who were originally ambivalent, who became the staunch advocates of the AWWH program.

As their ownership became more apparent and the focus and management of healthcare changed to a more systemised and comprehensive holistic approach, the reality of empowerment became more obvious. An example of this was illustrated during the initial programs when the Aboriginal health service was pleased to accept all external visiting healthcare providers who wished to be involved in the program. As their own control and empowerment grew, members of the Aboriginal health service questioned the need, and having weighed up the benefits of visiting healthcare providers, they made more active decisions as to who they invited to help them deliver the program.

As the significantly high incidence of disease was demonstrated through the screening processes and primary healthcare approach, the Aboriginal health service recognised this service as their core business. This now resembled a community empowerment approach to Aboriginal health described by Laverack (2004) in his domains of community empowerment, and supported by Freire's (1996) concepts of hope and Stringer's (1999) community-action research.

### **6.32 Key findings**

Culturally appropriate resources and a collaborative approach are desperately required to address the screening results found in this community. The high incidence of diabetes in the Aboriginal women, was consistent with reported literature about other communities, and is presently poorly controlled. The incidence of elevated albumin and creatinine levels has required clients to be monitored more regularly, specifically for blood pressure, blood glucose levels and urine screening. A primary health care approach and follow up management plans are needed to prevent further renal impairment. Options for emergency dental treatment need to be investigated urgently as clients currently have to be transported to other major towns and require an overnight stay or longer, away from family.

#### *For the Aboriginal community women*

Despite their vulnerability, the community women were most interested in developing their knowledge about how they can undertake better health management for themselves and their families. They have ‘voted with their feet’ and actively participated in the AWWH program and have continued to return to the program. Furthermore, they have asked for further health promotion and activities that will bring them a greater understanding of their complex health problems. This AWWH program has enabled Aboriginal women in this community access to culturally acceptable holistic screening and health information that provides them with the knowledge to make choices and decisions about their health, changing the dynamics from them being disempowered to being empowered.

### ***6.33 Transfer and potential for sustainability***

The transfer of the successful elements of the established AWWH program from Central Australia appears has been demonstrated in this recipient remote community setting. The program identified the immediate health needs of the Aboriginal women who participated in this program and a structure and service model has been implemented that will nurture an intensified primary healthcare approach.

Staff capacity has been developing through a holistic primary healthcare approach used to identify and address very complex problems, with strong support from outside resources. There is the potential for long-term sustainability of this program. This will, however, depend on: firstly, the governance and leadership within this Aboriginal health service; and secondly, the strength of collaboration and partnerships across organisations and generosity of spirit.



## CHAPTER 7: DISCUSSION

### *7.1 Introduction*

This chapter discusses briefly, the issues that have informed and impacted on this research. The extremely poor health and neglect of Aboriginal people has been compounded by the lack of a systematically delivered comprehensive primary health care and adequate infrastructure to support this vulnerable population in SA. While public health issues such as vaccination have been well addressed, community awareness and health promotion programs to enable Aboriginal people living in regional and remote areas to better manage their own health have been tokenistic at best.

Past governments have much to account for, through their low expenditure for primary health care resources, education and training. Essential funding required to prepare and develop healthcare providers to deliver primary health care services and effective community health promotion programs, that can prevent and reduce the incidence of disease in Aboriginal communities, has not been provided. The seventeen-year gap in life expectancy between Aboriginal and other Australians has not been reduced, and there are indications that this may have increased. Diseases such as diabetes, cardiovascular, renal and dental disease have escalated to endemic proportions with the comorbidities of mental health and drug and alcohol problems also increasing dramatically that have continued to be reported in the (AIHW 2004b), and (Australian Bureau of Statistics 2001; Australian Bureau of Statistics 2003)

annual reports and the Aboriginal and Torres Islander Health Performance Framework (DHA 2006).

These national figures align with the incidence of diseases identified through the AWWH screening program, which were discussed in Chapter 6. The difficulty of addressing this comorbidity of disease effectively without additional financial resources, and a primary health care infrastructure, to make available effective community awareness and significant health promotion throughout the whole community remains. This enormous task at times overwhelms the small group of local healthcare providers trying to make a difference in this community.

To be effective, a holistic and systematic approach to primary health care delivery also requires that the social determinants of poor health be addressed. These determinants include such things as substandard housing with limited facilities, enduring poverty, poor educational opportunities and minimal sustainable employment, lack of safe transport and limited community facilities. This multiplicity of issues is the underlying cause of many Aboriginal families' poor mental and physical health and social wellbeing, hopelessness and continuing despair.

The social determinants of health reported by Evans and Stoddard (1990) in Chapter 1, argued that health was more than an absence of disease, or injury. It implied a much more comprehensive concept, linking people's social and physical environment as well as their lifestyle behaviour with their level of health and function, and socio-

economic capacity with their overall level of wellbeing. Therefore well health has been seen as influenced by multiple determinants that have included physical, social and environment elements that impact uniquely on each individual and group.

A ‘whole of government’ approach currently being promoted by the national government is aiming to initiate collaborative responses across government departments, such as housing, welfare, health and transport to more effectively address the health crisis of Aboriginal people, including those living in remote areas. However, this development will take a significant period of time to be fully implemented and positively effect the health of Aboriginal women living in remote communities, such as described in this research.

A frequently heard statement from today’s government is ‘we know the problems, tell us the solutions’. Atkinson and colleagues claim that research has a significant role in identifying and reporting what is happening and the reasons for this, and initiate effective strategies to address the identified problems (Atkinson, Graham, Pettit and Lewis 2002). The following discussion endeavours to address remote Aboriginal women’s health issues from this direction.

### *Primary Health Care*

The 2003 SA Generational Health Review critically evaluated the state health services and infrastructure and offered recommendations for long-term sustainable improvement. especially in comprehensive primary health (DHS 2003). As discussed in Chapters 1 and 2, the importance of Primary Health Care has long been recognised

world wide (WHO 1981; 1986) as a necessary foundation to improvement in such areas as Aboriginal health, mental health and early intervention in child abuse. These areas of health care in Australia have been neglected as State and Federal health dollars have been spent on other health priorities, particularly on acute hospital care, including better equipment, drugs, more hospital beds and elective and emergency surgery. While there is a clear need to support acute care services, the budget for health is not limitless, and the funding for acute care services may have been achieved at the cost of investment in a sustainable primary health care infrastructure, especially in rural and remote areas of SA (DHS Generational Health Review Committee 2003)

Prevention of illness and disease, and assisting people to improve their lifestyle, with accessible and affordable nutritious food such as fresh fruit and vegetables blended with daily exercise, would appear to be a far more effective strategy than only addressing these health issues when diseases like diabetes and complications of cardiovascular, renal and dental disease create a health crisis that results in admission to hospital. It appears that the health system itself is reacting to crisis management, rather than implementing a proactive approach and this is a style of health management that the general community has been following.

Well health screening, assessment, monitoring health issues and providing the appropriate health information can assist individual community members, in this instance the Aboriginal women, to better manage and control their own health,

thereby empowering them. The AWWH program is a successful example of this process.

### ***7.2 The Need for Comprehensive Primary Health Care to Address Aboriginal Health***

Community consultation and participation are essential criteria required to address Aboriginal health care. Many Aboriginal women could be better assisted with the management of their chronic illnesses; especially in cardiac, renal and diabetes, mental health issues and acute dental disease, if the infrastructure for primary health services was well developed, resourced and sustainable in their community. This would be the preference for individual women who appear to lose any autonomy and control they have over their health on admission to hospital and who also are unable to continue their family obligations. Better management of disease this would also lower the burden of hospital admissions, as chronic diseases such as diabetes are responsible for a high proportion of the admissions and readmissions from acute episodes of uncontrolled blood glucose levels, poor diet and limited exercise.

In Chapter 1, (Figure 1) has illustrated the national mortality of Aboriginal women from diabetes in 1999 to 2001 as 400 deaths per 100,000 in the 55-64 age group and over 800 deaths per 100,000 in the 65-74 yr age group (AIHW 2004a). The health system has not yet adequately addressed this preventable cause of death and in 2006, sadly, SA has the highest ratio of complications from diabetes in Indigenous people than any other Australian state or territory. These complications are notably,

cardiovascular, eye, renal and dental disease (Department of Health and Ageing 2006).

While hospitalisation rates have continually increased there has been no apparent sign of a decrease in incidence of diabetes. Risk factors for diabetes are the prevalence of smoking, unhealthy weight gain to obesity, and risky, high consumption of alcohol have not altered significantly and health improvement has not been evident. Diabetes is one example of the imbalance between the dollars spent on preventative strategies against the cost of acute hospitalisation which is 12 times greater for Indigenous people than for other Australians (Department of Health and Ageing 2006)

*Compounding issues that have delayed an effective comprehensive approach to Primary Health*

The lack of health improvement concurs with Ring and Brown (reported in Chapters 1 and 2), who stated that there had been little overall progress in the health of Aboriginal people in the ten year period 1990-2000, when the diabetes mortality ratio was then eight times higher than other Australians. They reported a lack of commitment and implementation of good policies and financial resources, especially to support good Primary Health Care initiatives and effective community programs to 'break the ill health cycle' (Ring et al. 2002).

Inaction by governments, reported by (Lomas 1997) in Chapter 1 and 3, may also be a consequence of previous research that has been undertaken in isolation from Aboriginal people, rather than in collaboration with them. Decision and policy

makers, have often failed to collaborate with local healthcare providers and the community concerned, through their Aboriginal boards of governance. However, community consultation, participation and shared knowledge are essential criteria to address Aboriginal health. This collaborative process should be ongoing through the program design, implementation and evaluation, to ensure that the program has met the needs of the community and can be adapted to suit their health needs if a reflexive approach is taken, and the evaluation is a continuing process. Lomas has succinctly pointed out that what policy and decision makers have been lacking, are the structures, processes and the people who not only are able to improve the situation constructively, but are able to build on past successes (Lomas 1997).

### ***7.3 The Strengths and Limitations of the Transfer of an effective AWWH program.***

Through extensive consultation processes, this study, has explored the health needs of Aboriginal women living in a remote community. Through a collaborative approach, an established Aboriginal Well Women's Health program was identified and the elements of its success identified. These elements were then been transferred with the AWWH program to a recipient community and adapted to meet the needs of this community in SA. The strengths and limitations of implementing this Aboriginal Well Women's Health program in this recipient remote Aboriginal community in SA are discussed here.

#### *Strengths*

The extensive evaluation has demonstrated the acceptance of this AWWH program through the participation of community women and the continued diligence of local

and external visiting healthcare providers in providing access to appropriate health information for informed consent to screening and facilitation of lifestyle sessions.

The AWWH program has built bridges across the divide, through collaboration of the local the Aboriginal health service with mainstream community services, and with the researcher. It has provided a common goal where knowledge has been shared and learnt to provide a culturally acceptable service in informed holistic health screening.

The AWWH program has provided a forum where Aboriginal women feel they are welcome. They are able to participate in health information and lifestyle sessions that are enjoyable, with information that can assist them to understand the impact of chronic diseases, such as diabetes, and discuss ways in which they can better manage their own health. Women participating in this program include those who have never attended a well health screening while others are younger women and girls who had previously not considered a well health check. The screening program has identified a high incidence and comorbidity of chronic and acute disease and the limited resources that are presently used to manage such health problems.

On a state level, the well health assessments have provided a wealth of data that are up to date and span the spectrum of physical and mental health and social well being. These data will inform planning and resources, with strategies to assist the health and welfare of Aboriginal women in this community.



However, this does not mean that the health of Aboriginal women in this community will suddenly improve. The well health assessment has identified the health issues of the attending women but other systems need to be implemented to address issues such as dental health. There is an ethical responsibility and accountability that accompanies the identification of substantial ill health and requires a collaborative approach across services that are inclusive of the Aboriginal Health Service Board members, the South Australian Dental Services and the Aboriginal Health Division of the SA Department of Health.

#### *Limitations*

During the first AWWH program in November 2004 the prevalence of comorbidity of disease was identified, which is a trend that has continued to be identified in all subsequent programs. The management and staff of the Aboriginal Health service were not aware of the great extent of chronic disease and acute illness until they were informed by the visiting female GP that the health of the Aboriginal women was “absolutely shocking” and the worst she had ever seen in any community.

Addressing the prevalence of disease in the short term was a slow and difficult process.

Negotiations were commenced with the Aboriginal Affairs Division, Department of Health, SA Dental Services and Kidney Health SA by the researcher and relevant de-identified data shared through the first preliminary report (Mitchell, Vanajek and Durdin 2005a) with the permission of the Aboriginal Health Service.

#### *7.4 Dental Health*

The results of this research show that oral hygiene and dental disease are a major issue and this leads to other complications in poor general health and high risk of endocarditis and renal disease which needs urgent redress in this community.

The town has a visiting dentist who flies in with his team of technician and nurse, every six weeks. However he rarely sees any Aboriginal clients. At the PAG meeting the clinic RN stated that women would not “go down” to the dentist who worked from the caravan attached to the school and they were unable to keep the tightly scheduled appointments. Fear is another major factor that keeps Aboriginal women and their families away from the dentist.

Negotiations were commenced with SA Dental Services, to orchestrate a management plan that would address not only the urgent dental treatment required but to provide a much needed oral health promotion program alongside regular dental services. This in turn, would reduce cardiac and renal infection from Streptococcal A infection through caries and broken teeth, and enable better nutrition. However these discussions were postponed, when the management of the Aboriginal Health Service changed. Although enquiries were made, the researcher was informed that it was “all in hand”. The second report in November 2005 (Mitchell 2005b), further informed the Aboriginal Health Services Board, the SA Department of Health and the Minister of Health of the urgent situation but still no action appeared to have been taken to improve the situation.

Now two years have elapsed since the first program, and very few women have been transported south for dental treatment, no action plan has been fully developed, and the issue remains.

This inability to instil change and provide sustainable effective Primary Health Care programs in a health system that has been paralysed by its traditional bureaucracy and lack of infrastructure and limited professional health resources continues to impact on Aboriginal people. Thomson and colleagues (1999) remark that the lack of recognition of the multiple challenges and problems that have existed, compounded by the poor social and economic conditions and prevalence of chronic diseases and comorbidities, have all contributed to the difficulty in implementing successful and sustainable health strategies.

### *7.5 Renal disease*

The AWWH program has identified early stages of renal disease through testing Albumin Creatinine ratios by urine examination by a small data 2000 computer. This screening is the outcome of an earlier research program undertaken by Dr Mark Shephard commencing in 1999. A renal screening program had been introduced into the Aboriginal Health Service “Point of Care Testing” that screened for elevated Albumin and Creatinine levels through early morning urine samples, and elevated blood sugar by finger prick blood sample, Hb1ac. The screening was able to be undertaken by health care providers in the clinic, and immediate results could help determine elements of kidney dysfunction, and probability of Type Two Diabetes through elevated blood sugar levels. This program had exhausted its funding and had not been re-supported through further Commonwealth research or health practice funding and so was abandoned. However, the researcher had continued to send cartridges to the

community to avail them of this screening, but as the cartridges needed a doctor provider number for the Medicare rebate to be reclaimed, the screening was not continued. (Shephard, Allan, Barrett, Barbara, Paizis, McLeod, Brown and Vanajek 2003).

With the introduction of the AWWH program, this technology was reintroduced (taken out of the cupboard at the Aboriginal health service) and an education session was undertaken by phone with Dr Shephard, the researcher and the female GP. This was then shared with the clinic team so everyone was familiar with the screening process. In 2006 Dr Shephard personally visited the Aboriginal health service to provide further training and information. This screening technique is now used at each AWWH program. Once any renal dysfunction is recognised a management plan is required, that involves a specific drug administration plan and regular blood pressure and urine monitoring.

This program in 2006 is now being widely rolled out across many remote communities nationally.

### ***7.6 Identifying deficits in health***

Short term funding and discontinuation of funding have caused the disruption and cessation of effective and successful programs, such as the renal screening program, which has had a continuing impact on the worsening health of Aboriginal people in remote communities. Gray and Sputore (2002) confirm that research projects that have led to successful health programs often have not been sustained because of short-term funding arrangements of governments, usually 12 months. This has made it impossible to fully establish and evaluate such programs effectively, and then

access sustainable funding within such a short time frame (Gray et al. 2002; NATSIHC 2003)

Mooney et al (1998) advocated that adequate funding needed to be established and made available to support the health priorities of the community that should then be driving the policy, rather than the reverse. Improving health services for Aboriginal people in remote areas would make a valuable contribution, particularly if these services were comparable to those available for all other Australians.

#### *Comorbidity of disease*

Renal, cardiac, respiratory and endocrine diseases (particularly diabetes), as well as cervical and breast cancer and injury from assault and accidents, are responsible for much of the high mortality of Aboriginal women, especially in remote areas (AIHW 2004 p. 332). The comorbidity of disease is further exacerbated and influenced by the physical and socio-economic environmental conditions and serious psychological health issues, often further compounded by family violence, serious drug and alcohol problems and gambling in this community.

#### *Governance*

Another factor that adds to the difficulty of providing effective health services in this remote recipient community has been the governance by the community controlled Aboriginal Health Service Board. This has been administered by a small group of community members with no governance training and no health management experience, and led by three CEO's with no health background and with different management styles over the last two years. The health issues in this community are enormous and would test the most experienced health management professional. Yet

there is not the support from Commonwealth or State bodies to support the Board and develop its capacity and to provide a strategic plan that is embedded in Primary Health Care management. Without strong leadership it is easy for the staff to become overwhelmed with the day-to-day incidences and who also suffer their own ill health.

### *Leadership*

The changes in leadership throughout the two years of the AWWH program have had a significant impact on the staff of the Aboriginal Health Service and Community Women's health mainstream services and the Project Advisory Group (PAG). The contrast in management styles and communication were extreme, and disappointingly a number of staff left the Aboriginal health service or took extended leave, which put the AWWH program in potential jeopardy.

The AWWH program set for December 2005 was cancelled, much to the distress of remaining staff and external visiting resource staff. The view of the management at the time, was that the program was not the highest priority for the Aboriginal health service whose remaining staff were trying to provide some semblance of health service. This was also very discouraging for the PAG team as the health promotion strategy that the program was trying to emit, was to provide a monitoring capability for women and the focus of preventative well health, rather than only visiting when a health emergency arose.

There was very little communication from the Aboriginal Health service with the researcher over the following six months break, with only a few staff keeping contact who also needed so a distant ear to listen. Other resource people, maintained contact

and also met with the researcher and female GP. The GP was also greatly concerned, that much of the good planning and diabetes management would disappear, and the women would feel they had been abandoned and that the Well Women's team and program had let them down.

*The demise of communication and individual contribution and voices through the PAG*

Happily the AWWH program was continued in March 2006, with the employment of new acting RN's at the Aboriginal Health Service. As one RN was male, only the female RN was involved with the program. However the PAG was not reassembled at the request of the CEO at the time. This was to have a very negative effect, as the Well Women's Health team has previously worked as an all-inclusive unit, discussing, preparing and delivering and evaluating the AWWH program. Through this lack of communication over the next two programs in March and July 2006, relationships between the local Community Women's health mainstream and the Aboriginal health service became strained. Community health mainstream was particularly careful as they had been through this experience at a previous time and had not forgotten the negative impact that it had caused and the personal relationships that had been harmed, living in a small town.

Therefore there were no PAG meetings for program five and six. However, as there had been no program for six months the AWWH program was very well received and strongly supported by the Aboriginal women. On the negative side however, their health had deteriorated as they had stopped coming in to the clinic for glucose and

blood pressure monitoring and their diabetes was said to be out of control by the female GP.

Some of the women later admitted that they wanted to come to the clinic early for checks but they had to walk, and with the new RN's the clinic did not open till nine am. The day was becoming too hot by then and the women had already moved to the hotel where there was air conditioning "pokies" and cheap food.

### ***7.7 Moving Aboriginal Women's Health Forward***

Further changes occurred with the resignation of the second CEO and the appointment of a third and the return of some of the staff that had taken extended stress and sick leave.

Communication from the Aboriginal health service with the researcher increased and the next program was planned to reassemble the PAG, to provide the forum for discussion, both prior to and post program. This was to be a celebration as the AWWH program had been in operation for two years. The Aboriginal Health service clinic team also decided they were able to conduct this program without the services of the Community Women's health nurse who had been a wonderful advocate for Aboriginal women and a great organiser and coordinator, in the absence of any other coordinator. The researcher was also invited to participate and evaluate the program and support the new team approach.

This program conducted in November 2006, is one of the reasons the completion of this thesis was delayed. As the researcher, I had some internal reservations as to how



the new WWH team would manage, but to counterbalance this, I was thrilled at the prospect that they thought they could achieve it and this added to the control and ownership of the program by both the health providers and the community. Control and ownership are essential components of a successful transferable and sustainable program and empowerment.

The original RN had returned to the Aboriginal health service, and the acting RN's had moved on. The new CEO had settled in and was happy for the AWWH program to continue in its original format, for at least one program. The researcher was invited back to support the AWWH program. by the Clinic team. With approval from the team, the researcher also invited a colleague to accompany her on this visit, who was well respected in Aboriginal women's health, as an RN in women's sexual health and fellow PhD student, who had previously worked with the female doctor in remote Aboriginal communities, This meant there was not only a skilled back up professional to assist the team but this RN had great skills in teaching women's health and great diplomacy . She was a great asset to the AWWH team and has been invited back to continue to work as a member of the WWH team for future programs.

This last program in November 2006 was extremely busy as it had been well advertised by the Social Health and Wellbeing Coordinator. More than forty women attended and many had full health assessments. The board room was available and used and all the meals were cooked in the kitchenette attached to the board room and were very well accepted by the community women and staff. The program was very

successful and the write up in the local paper (attached as an appendix) was done by the Social Health and Wellbeing Coordinator.

However, the extremely high incidence of disease continues, and diabetes is still escalating and not well controlled. Dental disease is still a major issue and renal disease still evident. Cardiac disease such as rheumatic fever or ischaemic heart disease is not specifically screened for at present. However there are plans to address cardiac screening early in the New Year.

The new CEO said he was extremely pleased with the whole event. He had not seen his staff work in such a collaborative way and with such determination and he was happy to accept the recommendations of the PAG, that dental disease was the highest priority for the community women for action, closely followed by diabetes, renal and cardiac disease.

It was arranged with the CEO and AWWH team that the researcher, although completing this research, would continue to be an advocate and work to improve the health of Aboriginal women and their families in this community.

Both state and federal finances are used to support aspects of this Aboriginal health service and these dollars may be better accounted for if more comprehensive services were provided in the community, rather than the enormous cost in wages fuel and transport, accommodation and food of transporting a few people at a time to a major city for health services such as dental treatment and eye appointments.

The lack of essential health services in dental and allied health care (such as podiatry and mental health), and poor access to specialist services, adds to the complexity and multiplicity of comorbidity of illnesses, and need for timely and available treatment intervention.

The priorities of health services in remote communities have generally had to focus on and manage multiple crisis situations that are prevalent and required most of the available health providers' time. However, to reduce the burden of disease, improved chronic disease management and reduced rates of premature death, proactive earlier detection, prevention and treatment interventions are urgently required in various primary health programs that can easily be implemented and sustained over time.

### ***7.8 Conclusion***

At the last AWWH program in November 2006, the female GP expressed her frustration with the lack of organised health management. She asked what the point of writing dental disease on the health assessment was, if nothing was going to be done. The PAG agreed that dental health was a major priority and this was reported back to the newest CEO with agreement for action.

The researcher has recently commenced a position in the Aboriginal Health Division, SA Department of Health and has written a brief supported by the Aboriginal Health Division, to the Minister of Health about the continuing extremely poor health of Aboriginal women in this community. A meeting has also been organised with the

SA Dental Services and the Aboriginal Health Division to determine urgent action to address dental disease in this community as their highest priority.

This Aboriginal Well Women's program has empowered local health care providers, through a change in practice from crisis management to primary

The collaboration of health providers across mainstream and Aboriginal services, to organise and implement the AWWH program, has been excellent. The Aboriginal Well Women's Health team has worked together to provide a culturally acceptable and effective screening process that appeared to meet the women's expectations. The Project Advisory Group has guided the development of the program and continued to support its improvement and explore the issues of sustainability. These shared resources have fostered good working relationships across mainstream and Aboriginal Health Services.

## CHAPTER 8: CONCLUSION

### ***8.1. Introduction***

Through an examination of the literature and government policy, and consulting with key Aboriginal and non-Aboriginal informants, this research identified that remote Aboriginal women's health is a priority for remote communities in both South and Central Australia. The researcher responded to this priority by examining the possibility of transferring, adapting and implementing an established Aboriginal Well Women's Health program from Central Australia, in a collaborative process, to a recipient Aboriginal community in South Australia that had similar characteristics and needs, and who was willing to receive it.

### ***8.2. The contribution of this research***

#### *A transfer model*

Through a synthesis of Naturalistic Inquiry and Critical Social Theory, a Participatory Action Research reflexive approach provided the theoretical structure for a transferable model to be identified and developed, which incorporated the essential elements of successful research transfer. This model of transfer was then used successfully to adapt and implement an effectively established Aboriginal Well Women's Health program in another remote community that had similar characteristics and needs. The Naturalistic Inquiry approach provided insight into the environmental and cultural issues that have influenced the social determinants of Aboriginal women's health in this recipient community.

#### *Evaluating empowerment*

A well reported community evaluation model was implemented to determine any positive changes in empowerment of Aboriginal community women and the local

healthcare providers throughout the adaptation and implementation of the conducted AWWH program. By using the nine domains of empowerment, specific areas of the AWWH program were examined and areas of positive empowerment demonstrated.

#### *Evaluating the program*

The program evaluation model has analysed the cultural appropriateness of the AWWH program and demonstrated through the responses of participants and local healthcare providers, their acceptance of the program. It is said that community women 'vote with their feet' and their continued attendance at the AWW health screening, information and lifestyle sessions over two years, has supported the view that they believe the program is beneficial in monitoring and improving their health. The prevalence of illness and disease amongst these women has clearly been established and changes in health management practices are now in progress to address these priorities.

#### *Change of practice to Primary Health Care*

It has been necessary for the local health providers at the Aboriginal health service to change their method of practice to incorporate a primary health care focus. This has been achieved through their use of the adapted Aboriginal Well Health Checklist throughout the intensive screening programs and in the clinic on a regular basis. This change has also required their active cooperation, support and diligence in circumstances where there are continuing crises that concurrently require redress.

The Aboriginal community women have also been encouraged to change the manner in which they view health care and health services. The aim of this program has been to change their focus from seeking reactionary care only when they are acutely ill, to attending for well health and well health checks in a proactive way, in an environment where they feel culturally safe and comfortable to attend. Therefore, a primary health focus of health screenings and information aimed towards prevention, and early detection and greater treatment options has been introduced and accepted.

### ***8.3 How this research has filled a gap in the knowledge***

The research has shown that an established remote Aboriginal Well Women's Health program can be transferred, adapted and implemented effectively in another like community if the successful elements of the original program are also identified, transferred and implemented in the recipient community. Due to its relevance and acceptability this Well Women's Health program model has been replicated in an Aboriginal Well Men's Health program in the same Aboriginal health service in SA. This program has now been in progress for over twelve months.

The recipient Aboriginal Health Service management team are also exploring how this model may also be replicated as an Aboriginal Child and Adolescent Well Health screening program. Since the Medicare holistic health screening rebate came into operation, only six Aboriginal children have been recorded as participating in this screening process throughout SA (personal communication, Department of Health Aboriginal Affairs Division).

This research has identified the very poor state of the health of Aboriginal women living in this community and the specific resources required to improve their health. Local services such as dental facilities that provide culturally acceptable care and treatment, mental health support and drug and alcohol counselling, are among those service provisions that are not currently accessible to the women in this community. Other services, such as diabetes management, are in high demand and therefore difficult for the women to access at the time when they are most needed.

The study has also determined that the local community women who have accessed the program are keen to improve their health and take better account by self-managing their own and their family's health. These women have actively participated in the program and have requested further health information in such areas as cardiac and renal health, that require additional support from external resources.

#### ***8.4 Implications***

The health of Aboriginal women in this community can be further improved through a case management approach across mainstream and Aboriginal health services. This requires the Aboriginal health service to initiate and then continue to build and maintain strong collaboration and interaction. The high incidence and comorbidity of disease has provided the impetus for a local GP service to run a clinic at the Aboriginal health service twice a week on a regular basis. However, further partnerships need to be established with external services and resources to build a multidisciplinary team that can better address the complexity of health issues that pervade this community.



Premature death is an indicator of serious ill health, and this community has seen the premature deaths of seven community women in the last nine months. As not all community women are yet familiar and comfortable with well health screening, there needs to be a significant health promotion and community awareness program in chronic disease management that is congruent with the health screening programs based in the community. Successfully established community awareness programs in chronic disease management could be transferred from other areas of SA to this community with appropriate financial and human resources.

#### ***8.5 The transferable model of an effective health program***

For an Aboriginal health program to be transferred successfully the following elements need to be addressed:

- The program is seen as the core business of the service.
- The enthusiasm of the recipient community for the adaptation, transfer and implementation of the program.
- The need for a collaborative approach across services with community ownership and control regarded as necessary in the long term.
- The program is focused on empowerment of a community group encompassing community self esteem.
- Effective leadership being continued throughout the program implementation and operation, with reciprocal respect for all stakeholders involved in the program.
- Continuing open communication and partnerships and collaboration with other agencies being facilitated so that external resources and assistance in building individual and community capacity are provided.
- Skills and knowledge transfer occur that are inclusive of policy development with service delivery to enhance and sustain the program over time.
- Financial commitment and viability are provided to ensure sustainability.

- The provision of continuous monitoring & evaluation in set time frames in a participatory endeavour.
- The program benefiting the community for whom it is intended.

The inclusion of all these elements should provide for effective and successful program transfer.

### ***8.6 Strengths of the study***

The AWWH program has been transferred successfully into the recipient remote community through a collaborative approach using critical social science in Participatory Action Research and a critical evaluation process, Naturalistic Inquiry and a community development model of empowerment.

#### *Mixed Methods*

The use of mixed method research has ensured that new and complex data has been synthesised and provides a greater understanding of remote Aboriginal women's health issues and how remote health care services can respond proactively to better meet their health needs. This now offers a tangible and acceptable way forward to reducing remote Aboriginal women's extremely poor health and premature deaths.

The Naturalistic Inquiry approach has enabled extensive knowledge of the local environment and how this has influenced the determinants of health for Aboriginal women in this community. This methodological approach has facilitated the recognition of the factors that have impacted on the physical and social health and wellbeing and the limitations in practical resources to improve health. This has been complemented by the critical social science critique that has underpinned the program's evaluation and allowed the issues arising throughout the adaptation and implementation process to be raised. The PAR approach with

reflexive action has permitted healthcare providers to critically appraise the implementation and refine the program. This critical process, together with community development, has also enabled the identification of community empowerment issues and capacity-building for the local healthcare providers within the Aboriginal health service, and women in the community. The women are responsive to their health needs, in prevention through screening processes and actioning, through the appropriate health information and services.

The collection of quantitative data has provided information about access to the AWWH program and exposed the high incidence of acute and chronic disease in those women who have participated. The opinions of some of the women who responded to interview has provided healthcare providers with information about ways in which the program can be further improved to continue to meet their health needs.

The National Aboriginal Health Principles listed below have guided this research and were identified throughout the Chapter 6 together with the Domains of Empowerment that were used to identify any issues where empowerment had been established.

<b>Health Principles</b>	<b>Domains Evaluation</b>
<i>Cultural respect</i>	Links with others
<i>Holistic approach</i>	Program Management
<i>Health sector responsibility</i>	Resource mobilisation
<i>Community control</i>	Organisational structures
<i>Working together</i>	Participation
<i>Localised decision making</i>	Leadership
<i>Promoting good health</i>	Problem assessment
<i>Building the capacity</i>	The role of outside agents
Accountability	Asking why

## ***8.7 Limitations of the Research***

### *Generalisations*

This research model of transferability is not generalisable to any community at any given time. The recipient community is required to have similar characteristics and needs as the original community where the program is successfully established. The elements that made the program successful also need to be transferred with the program to the recipient community with a project advisory group made up of the local and external healthcare providers and community representatives. It is important that this group is able to guide and critique the program in a reflexive process with a view of continual improvement through its journey of adaptation and implementation to sustainability. The recipient community must also be willing to adapt and implement the program of choice and evaluate it with a continuing commitment to sustainability through funding and human and material resources.

### *Community women's views*

Women participating in this AWWH program were invited to provide opinions as to how the program was of benefit to them, what sessions they would like to see included, and any barriers they identified in access or cultural suitability or effectiveness. However, because this was undertaken at a different time from the AWWH program there was difficulty in finding many of the women and ascertaining their views.

It was important that there was a clear distinction between the AWWH program and the general everyday running of the Aboriginal health clinic, which was not under review. The issue of 'Sorry Business' also continued during this investigation and it was essential to show sensitivity and respect for this. There was no particular 'good

time' to visit the community women as premature deaths have continued to occur in an untimely manner. As these conclusions are being written the community is again mourning the death of another woman aged in her forties.

#### *Quantitative data*

The introduction of a computer data base has enabled the addition of client statistics in the AWWH program to make some comparisons of data between its programs conducted over the two years. This has been the only program where client statistical data have been collected because of computer program availability, time and personnel limitations and so there are no comparable statistics from any other programs. The statistical data were difficult to retrieve after the conclusion of the program. This was because much of the usual work of the healthcare providers was set aside during the AWWH program to provide screening, transport, lifestyle sessions and food preparation. Therefore, the usual work of local healthcare providers needed to recommence as a matter of high priority on the completion of the program.

Without the support of an AWWH program coordinator, statistical data entry and retrieval after the program completion was difficult and therefore some statistics from some programs are minimal. Some of the areas that were continually difficult to track were mental health, drug and alcohol problems and family violence.

#### *The attendance of the researcher at all AWWH programs*

The researcher's role included the facilitation of the Project Advisory Group, the adaptation and implementation of the AWWH program and the evaluation of the program and the transfer model. The absence of the researcher from one program was thought to be a good experience for the local healthcare providers to determine how the process of empowerment was proceeding. This was a positive

experience for the AWWH team and the program and collaboration between the group continued. Moreover, the confidence of local health providers grew, as they were still supported by other external members of the team.

However as the governance and management structure changed within the Aboriginal health service, this absence was not as positive and the communication channels between the Aboriginal health service and mainstream health providers became strained. Essentially, the PAG did not meet as a forum to discuss program issues. This has implications for the sustainability of the AWWH program in the long term.

This change in relationships through the alteration of management and structure within the Aboriginal health service, has constrained communication with the researcher and limited ways forward in collaboratively addressing some of the identified health problems specifically in acute dental disease and chronic disease, especially diabetes, renal and cardiac disease.

The following recommendations reflect the views of the researcher and the participating Aboriginal Health Service management and Project Advisory Group

They are offered from the basis of particular knowledge and experience gained throughout the research and the delivery and evaluation of the AWWH program, by the PAG and the researcher.

### ***8.8 Recommendations***

1. The Project Advisory Group (PAG) should continue to evaluate, monitor and provide a forum for discussion and resolution of issues that arise in

the Well Health Women's program. A similar PAG should be established for the Well Men's program and Children's and Adolescents program.

2. The Well Health Checklist should continue to be used in the clinic on a daily basis to provide the primary health care focus necessary to address many of the community health issues, and focus on prevention and earlier detection and available treatment options.
3. A culturally acceptable dental health service that is regular and can address the disproportionate amount of dental disease should be provided in the community. This could be effected through the RFDS and South Australian Dental Health Services.
4. A dental/oral health promotion community program should be introduced that runs parallel to dental treatment to provide participatory information in strategies for healthier teeth, and to remove the fear of dental treatments. This could be run simultaneously with the Well Health programs.
5. A cardiac screening program should be provided that incorporates both cardiac ischaemia and rheumatic heart disease, to be organised in collaboration with existing programs operating in Central Australia and Darwin, Northern Territory.
6. Community awareness programs in chronic disease management should be introduced, and they should be fully resourced and implemented in the community to follow the established programs in SA's Eyre region.
7. Capacity building programs should be introduced and supported to:
  - a) extend the knowledge of healthcare providers; for example health worker education in diabetes education programs to assist the community and extend the knowledge and management of Type Two diabetes with effective individual diabetes management plans;

- b) Assist Aboriginal Health Service Board members to undertake training in governance and health responsibilities towards their community.
8. Public health issues, such as increased drinking water supplies, are resolved. For example, drinking water facilities are made available in the town centre and on the periphery for those who need to walk to access basic services.
  9. Attention to public transport is given, so that a local community bus can be operated to assist families to access essential services.
  10. Fluoridation of the drinking water should be introduced where possible to assist in the reduction of tooth decay and encourage the growth of healthy teeth.
  11. Further research studies should be undertaken in cardiac, renal and child health to provide preventative measures so that there is a renewed quality of life and healthier lives for the children and adolescents growing up in the community and an increase in life expectancy for the community. This is particularly true for the Aboriginal women who so generously shared their experiences with me and the collaborative team of the Project Advisory Group.

### ***8.9 Concluding statements***

The researcher has just returned from a very successful Aboriginal Well Women's Health program that was organised and conducted by the recipient Aboriginal Health Service Team without support of the Community women's health nurse who was unavailable. The program was extremely well organised and advertised and new health workers were introduced to the screening program. Many of the organisational issues that had arisen at the previous program had been addressed, such as ensuring there was food available to cater for this program and all food was cooked on site. The large boardroom area was available for health



information sessions and for women to eat and meet with each other during the entire program.

This AWWH program has impacted on the Medicare Aboriginal health screening figures in SA. In the 2004-2005 financial year following the introduction of the Medicare rebate (h710) in May for Aboriginal adult well health checks there were 583 Aboriginal adult well health checks completed in SA. Of these, this recipient community conducted 56 AWWH checks, which represents 10% of the total. In 2005-2006 there were 545 Aboriginal adult WH checks completed throughout SA and the recipient community through the AWWH program, conducted 54 of these again equalling 10.% (personal communication, Department of Health SA 2006). This has not included the Aboriginal Well Men's program that has been in progress for twelve months.

There are still major health issues to address in this community to make a difference to the overall health and well being of the community. However, the enthusiasm and commitment shown from this last program, with support from their management, indicates a very positive commitment and ownership of the program. Furthermore the attitudes and willingness to implement and sustain the program indicates great potential the Aboriginal Well Women's Health program to be sustainable over time.

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# **DATA TOOLS**

## **APPENDIX 1**

### *Well Women's Health Checklist*

#### **Page One**

Physical and Mental health and Social Wellbeing  
Assessment

#### **Page Two**

Mental Health continued, family history, doctors  
comments and referrals

#### **Page Three**

Sexual Health “Special Women’s Business”



Medicare no:

# Well Health Check

Umoona Tjutagku Health Service

Patient Consent


Name: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_










Community/ Address: \_\_\_\_\_ Allergies: \_\_\_\_\_

Age: \_\_\_\_\_ years old D.O.B. \_\_\_\_/\_\_\_\_/\_\_\_\_

Story: Reason for visit \_\_\_\_\_


Adult Immunisations: (year given)

	ADT -	<input type="text"/>
	Pneumovax -	<input type="text"/>
	Fluvax -	<input type="text"/>
	Hep B -	<input type="text"/>





Urinalysis	HBA1C ACR	Vision Eyes	Hearing (Whisper Test)	Height/ Weight/ BMI	Blood Pressure	Pulse	BSL & HB	Teeth	Skin/Hair
 NAD or _____ _____	HB1AC _____ ACR _____	 R:6/ R L:6/ L	 L:_____ R:_____	 Ht: cm Wt: kg BMI: _____	 / (mmHg)	 Rate: _____ Regular/ Irregular	 HB_____ BSL_____	 Teeth: Gums:	 Injury/ Infection Yes/No

**Patient Medical History** \_\_\_\_\_

**Current Medications** \_\_\_\_\_

Tick for any problems            

Cross for no problems  Heart Chest pain. Breathing y/n How often \_\_\_\_ Kidneys Burning Diabetes Other?

	yes/no	fruit 	vegies 	meat 	cereal/bread 
Diet/tucker eats well	yes/no				
Exercise	yes/no	how often.....			how much.....
Alcohol	yes/no	how often.....			how much.....
Tobacco	yes/no	how often.....			how much.....
Cannabis	yes/no	how often.....			how much.....
Inhalants (petrol)	yes/no	how often.....			how much.....
Inhalants (other).....	yes/no	how often.....			how much.....
Pitjuri	yes/no	how often.....			how much.....
Medicines	yes/no	how often.....			how much.....
Other Drugs	yes/no	how often.....			how much.....
Injecting drugs	yes/no	how often.....			how much.....
Violence - injury occurring	yes/no	how often.....			how .....

### Mental and Social Health (Circle which applies)

Have you been sleeping well over the last week? . YES NO

Are you sad or worried at present? YES NO




Is there anything that you would like to talk about? YES NO

Do you live alone? YES NO

Does anyone look after you? YES NO

Do you have friends or family you can talk/share your problems with? YES NO  
 Have you talked to another health worker/Dr about things that have changed for you in recent weeks? YES NO  
 Do you look after anyone else? YES NO  
 Do you have a home to live in? YES NO  
 Do the things in your house work for:  
 Cooking, water, lights, toilet, heating, cooling, telephone YES NO

**Family History**

Tick for any problems           
 Cross for no problems  Heart Chest pain. Breathing y/n How often \_\_\_\_\_ Kidneys Burning Diabetes Other?

	Current	Recommended		Current	Recommended
Aboriginal Health Worker	<input type="checkbox"/>	<input type="checkbox"/>	Optometrist	<input type="checkbox"/>	<input type="checkbox"/>
Registered Nurse	<input type="checkbox"/>	<input type="checkbox"/>	Social Worker	<input type="checkbox"/>	<input type="checkbox"/>
Doctor	<input type="checkbox"/>	<input type="checkbox"/>	Nutritionist	<input type="checkbox"/>	<input type="checkbox"/>
Dentist	<input type="checkbox"/>	<input type="checkbox"/>	Audiologist	<input type="checkbox"/>	<input type="checkbox"/>
O.T. / Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	Community Nutrition Program	<input type="checkbox"/>	<input type="checkbox"/>
Mental Health	<input type="checkbox"/>	<input type="checkbox"/>			

Current or potential health problems / risk factors influencing long term health

	Follow up:
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

**Other Comments**

**Intervention**

Assess patient's risk factors	<input type="checkbox"/>	Discuss results of check with patient	<input type="checkbox"/>
Discuss risk factors with patient	<input type="checkbox"/>	Provide preventive health advice	<input type="checkbox"/>
Provide intervention activity:	<input type="checkbox"/>	Initiation of treatment	<input type="checkbox"/>
Immunisation	<input type="checkbox"/>	Referral	<input type="checkbox"/>
education, advice or assistance	<input type="checkbox"/>	Other Interventions considered	<input type="checkbox"/>
(eg pre-pregnancy safer sex, social and family issues)		necessary by practitioner	
Documentation of simple strategy	<input type="checkbox"/>	Record of health check kept on file	<input type="checkbox"/>
of good health for patient			

**SIGNATURES**

Patient	AHW/ Nurse	GP
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Umoona Tjutagku Health Service

# Well Women's Check

Adapted from Flinders SON&M/DHCS

### Gynae history



Pregnancy test



Current Contraception:

Last Period:

Last pap \_\_\_\_\_ (year) /result  
Pap Register discussed: Y/N



Other operations

STIs?



### Births

Year

Outcome

Any Complications

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### Breast Check



Result: \_\_\_\_\_

Discuss Breast Health Y/N

### Abdo Palp



### External genitalia

Appearance/Comment

Discharge? Y/N

### Internal Assessment



Cervix- Appearance

Bimanual  
Painful/ not painful  
Adnexae

Continence advice Y/N

Speculum Size (Circle) **S M L**

### Action

Treatment given:



\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Menopause Symptoms:

Contact Tracing:

Named

Treatment

On Recall

Other Comments

### TESTS:

Urine



Chlamydia

Gonorrhoea

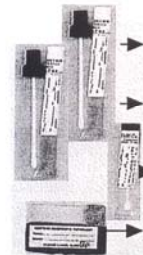
STS (syphilis)

Blood



HIV

Other



### Swabs

High Vaginal Swab (MC&S)

Endocervical Swab (MC&S)

Endocervical PCR  
(Gonorrhoea & Chlamydia)

Pap Smear (Brush Used)  
(Cervix brush & Cytobrush)

Follow up:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Referral to DMO: Y/N

Seen by: \_\_\_\_\_ AHW/RN/MO

## **APPENDIX 2**

### **First Semi Structured Questionnaire for Staff ( 2004- 2005)**

## First Semi Structured Questionnaire for Staff ( 2004-2005)

*Q1. What is your role in this AWWH program?*

*Q2. How would you describe the health of Aboriginal women in this community?*

*Q3. How does this compare with other women's health like migrant women or other Australian women in this community?*

*Q4. What do you see as the factors that influence the health of Aboriginal women in this community?*

*Q5. How do you see this Aboriginal Well Women's Health making a difference?*

*Q6. What are the main health problems you have identified?*

*Q7. What factors will make this program work?. What will make it successful over the long term?*

*Q8. What are the barriers or threats to the program from your perspective?*

*Q9. What else would you like to add?.*

Note. These questions were used as a guide and varied depending on the staff member and what they wanted to discuss.

## APPENDIX 3

### Evaluation of the Aboriginal Well Women's Health Program 2006.

4 Themes :

- **Program attendance**

Q 1. Age Group

15-25

26-36

37-55

Older women

Q2. Did you know about The Well Women's Health Program that has been held four times in the last twelve months at UTHS?

Q3. How did you hear about the WWH program?

Q4. Have you attended any of these WWH programs that have been held? Have you had a Well women's health screen?

Q5. Do you know why women are coming to AWWH program?

Q6. What days and times of day are best for you to come to the program activities?

Early or late morning? Early or late afternoon? Evening? Day of week?

Q7. What did you want from the WWH program?

Q8. Did the program meet all your needs? or some of your needs? none of your needs? Why?

Q9. What else would you like as part of the program?

*Health information sessions Social Health and well being sessions*

Kidney	Hairdressing
Heart	Massage
Diabetes	foot care
Breast health	art /painting
Sexual health	Jewellery making
Mental health	exercise program
Alcohol or other drugs	sports, softball, netball, swimming
Domestic violence	naturopathy
Nutrition	cooking & food recipes
Other	other

- **Impact on Women**

Q10. Has the WWH program had any impact on your health, or health of other women?

Finding out information? How to better manage any health issues,  
 Identifying any illness? Eg high blood pressure, diabetes, any infection,  
 Treatment for any illness? Referral to other health person or specialist?  
 Monitoring health progress ? Other?

Q11. What needs to be improved in the WWH program to make it better?

Q12. How can the community women have better control of this program ?

Q13 Where would you prefer to meet for health information and other program sessions?

- **Barriers to attendance**

Q 14. What might have stopped you or other women coming to the WWH program?

- No transport                      Did not know about it
- Too hot                                did not know doctor
- Feeling well                         Shame
- Other

Q15. How might other women be encouraged to attend this WWH program?

Thank you for taking part in this evaluation of the Aboriginal Women's Well Health Program.

*Jill Mitchell & Sharon Clarke*  
*January 2006.*