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# Supporting self-management of diabetes in Aboriginal people living with diabetes through a 5-day residential camp

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# Supporting self-management of diabetes in Aboriginal people living with diabetes through a 5-day residential camp

## **Abstract**

The aim of a 5-Day Diabetes Self-management Residential Camp was to develop, trial and evaluate a culturally appropriate model of disease self-management in a group of Aboriginal people with established diabetes and their partners, focusing on education, diet, exercise, attitudes and beliefs. The camp was effective in providing education, addressing barriers to good control of clinical signs and symptoms, fostering self-management skills, changing lifestyle behaviors and improving diabetes outcomes.

## **Keywords**

day, 5, living, camp, people, aboriginal, diabetes, self, residential, supporting, management

## **Disciplines**

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# Supporting Self-Management of Diabetes in Aboriginal People Living with Diabetes through a 5-Day Residential Camp

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**P project funded by:** NSW Health Aboriginal Vascular Program

## Introduction

A number of studies have identified the increase in incidence of diabetes amongst Australians over the last 20 years, with estimates of prevalence rising from 3.4% of the population over 25 years of age in Busselton, Western Australia (1981) to 7.4% within two decades. Prevalence rose to more than 23% amongst those members of the population 75 years or older. It is a real concern within the Australian context that more than half of the individuals identified in the this study were previously undiagnosed, indicating the insidious nature of Type II Diabetes Mellitus (T2DM).

Of even more concern is the incidence and severity of diabetes amongst Aboriginal and Torres Strait Islanders living in Australia. The Australian Institute of Health and Wellbeing (AIHW) reported that in 2001, self-reported incidence of diabetes amongst Aboriginal people was 11%, nearly 4 times that of non-Indigenous Australians, while other authors have indicated that diabetes can run as high as 26% of the Aboriginal and Torres Strait Islander populations, 6 times higher than the Ausdiab survey of other members of the population. For Indigenous people aged 35-44 years, the incidence is around 9 times that of non-Indigenous people. The median age of onset of Type 2 diabetes is much lower in these individuals than is the case in the non-Aboriginal community, and the cost to the individual and to the community is considerable, with Indigenous males recording '10 times as many hospital separations as expected for Type 2 diabetes, and nearly 15 times as many for Indigenous females'. Death rates resulting from diabetes also reflect the terrible impact of diabetes on Indigenous communities, with similar multipliers when compared to non-Indigenous populations.

The traditional models of education and treatment within urban representatives of these populations have demonstrated limited success, with many of these individuals displaying signs of diabetes complications within 5 years of diagnosis.

The UKPDS studies, demonstrated that optimum blood glucose and blood pressure controls are required to significantly reduce the risk of both macrovascular and microvascular complications, and these tight controls are not being achieved in the target population.

Population studies have demonstrated the positive outcomes resulting from effective management of dietary and physical activity interventions, in impacting on development of T2DM and on reducing incidence of T2DM. These interventions were conducted with American and Scandinavian populations with access to medical and allied health professionals involved in the design and management of their lifestyle interventions. Since many Indigenous people who do not access state-provided medical services and demonstrate poor management of diabetes, alternative delivery models are required. Community based programs have been identified as programs with potential for success. Some researchers have argued that the interventions focusing on the individual, as has occurred with most of the lifestyle related interventions noted earlier, are in fact inappropriate for Aboriginal people who have higher levels of connectedness with family, community and society. Obviously educational programs that assist Indigenous people to manage their diabetes need to include the wider Aboriginal community, be community directed and recognise and respond to local circumstances.

One such delivery model involves developing effective self-management strategies, with delivery of these strategies to be managed in an environment in which cultural sensitivity is identified and a culturally safe space is provided. The current project grew from a need to trial the effectiveness of a comprehensive package designed to educate, support and inspire the target group to better self-manage their diabetes, applying Aboriginal teaching and learning principles.

There were indications from within the Illawarra Aboriginal Medical Service (IAMS) that certain fundamental self-management strategies related to diabetes, such as taking prescribed medications effectively, and treatment schedules related to the prevention of the complications of diabetes were not being managed well by the patients.

A number of strategies had been devised and implemented in the recent past to provide a stimulus for education and support for the more than 100 Aboriginal people diagnosed with diabetes and recorded on the IAMS data base. These included the usual strategies of medical recall for assessment

and support, the involvement of Aboriginal health workers, linkages with medical and allied health practitioners from the local area Health Service and also the development of residential camps for people with cardiac pathology. These 'heart health' camps had proven to be very popular with the Aboriginal and Torres Strait Islander patients and had provided a stimulus for increased awareness of the impact of the pathology on individuals and their families. Upon return to normal living circumstances however, the usual patterns of poor self-management were evident.

It was felt that a more sophisticated program of support was required to assist the participants to implement the processes and rehearse the skills that were developed in the residential camps. It was agreed that structured educational experience, remote from the usual pressures of life, but including ongoing support on return, was required to impact on diabetes self-management strategies amongst this population. Furthermore, involvement of partners or other family members at the camp and involvement of representatives of the community in the design of the camp increased ownership of the program. The schedule of activities within the camp supported the development of increased understandings and ties to those components of Aboriginal life that provide support – these being the family, the community and **recognition of their special attachment to the land.**

**Project Aim:** To develop, trial and evaluate a culturally appropriate model of disease self-management in a group of Aboriginal people with established diabetes and their partners, focusing on education, diet, exercise, attitudes and beliefs. At the individual level, the project aims to:

1. Increase participant's self efficacy for self management of diabetes
2. Improve levels of self management adherence... and thus
3. Improve control of diabetes as evidenced by lower HbA1c scores

Intensive personal support for a period of 6 months following the residential camp was included in the project model, the purpose of which was to work in partnership with the participants and partners, health workers and service providers in managing the lifestyle changes of participants, and of the factors influencing them.

**Project Summary and Processes:** A partnership of health workers and service providers from Illawarra Aboriginal Medical Service, Department of Biomedical Science at the University of Wollongong and from the Illawarra Area Health Service, and a representative from the Aboriginal Elders was formed 6 months prior to contacting the potential participants. The partnership, The Steering Committee, was to brainstorm and plan an appropriate program for a 5-Day Diabetes Self-Management Residential Camp. The decisions about inclusion/exclusion criteria, scheduling of follow up interventions and processes for evaluation of the self-management outcomes were negotiated at these meetings. Identification and development of necessary resources as well as a comprehensive Diabetes Self-management Workbook that

took into account of the various learning styles of participants occurred within regular meetings of key stakeholders. The research project was developed and approved by the IAMS Management Committee, and by Human Research Ethics Committee of University of Wollongong/Illawarra Health.

**Recruitment:** 20 participants on the IAMS data base were recruited (1 later withdrew) for the six month project. 12 of the participants were targeted as being poorly controlled over a number of years, failing to respond to conventional medication and educational interventions. Participants were approached on the basis that they would be likely to be committed for the duration of the project (6 months). 8 males and 11 females participated, mean age and duration of diabetes for these people were 50.8 yrs and 5.7 years respectively. Ten participants had poor control of their diabetes, evidenced by their HbA1c levels above 10% despite the fact that they had undergone previous clinical interventions. Six participants had only moderate control of their diabetes with HbA1c levels 8-10%. Three of the participants were newly diagnosed or well controlled, with HbA1c levels below 8%.

All participants undertook a medical examination, obtained clearance for participation and provided informed consent. Baseline data recorded prior to attendance at the camp included: weight, BP, fasting Blood Glucose, HbA1c, fasting lipid levels, UECs ACR and liver function test. Participants were interviewed by an independent psychologist and assessed using 2 scales; SE-Type 2 and the Dass. A lifestyle assessment was also completed which included information about diabetes management as well as diet and exercise histories.

**Self-Management Camp:** The 5-day camp was held at a culturally appropriate family resort facility 200km south of Wollongong and close to significant spiritual sites. The choice of this facility was important, as the organisers of the Self-Management Camp wanted the participants to feel they were leaving their everyday problems 'at home' and embarking on a 'new journey'. Cultural sensitivities were acknowledged and a local Aboriginal Elder was invited to open the camp.

The 'heart health camps' run previously had been, by their very nature, more casual and more informal than the proposed camp. The Steering Committee believed more structure was required in order to create an environment in which the lessons related to self-management of diabetes could be learned, enjoyed and shared. It was also felt important to convey the message that effective diabetes self-management was crucial to the participants' own long-term health, and this required a more structured environment. The 5-day camp provided both the focus and the environment for delivery of strategies to self-manage diabetes. On day one, participants were provided with glucometers and pedometers, and trained in their use, thus supporting them in development of effective practices related to blood monitoring and commencing a physical activity program. The daily monitoring was supervised to ensure appropriate skills in use of this support equipment, and

participants were able to keep the glucometer and pedometer upon returning home. Participants were encouraged to attend the workshops which were held in the mornings, leaving afternoons free to participate in a range of activities, to rest, go fishing or speak with any of the educators involved in the camp, or with people in a similar situation as themselves.

The development of a shared understanding about the nature of the pathology and the impact of the pathology on each individual was considered very important to effective development of self-management strategies, and integration of the support team members. Aboriginal health workers, allied health professionals, and students from the University of Wollongong, lived with the attendees during the residential camp. Educators and allied health professionals who provided the workshop information and managed the sessions were involved in all activities at the camp including meals which were shared with the participants. This social interaction produced an atmosphere of equality, acceptance and friendliness between all involved, and provided opportunities for informal and incidental communication and discussion about strategies that could be implemented to self-manage diabetes. These interactions also provided insights into lifestyle-related behaviours that could impact on success of self-management processes such as habitual meal sizes and frequency and duration of incidental physical activity.



**Camp participants working with University students in workshops**

Workshops focused on disease management, physical activity, nutrition, stress management, relaxation training and smoking cessation and were designed around a Diabetes Self-Management Workbook (DSMW.) The Steering Committee reviewed available educational material and tailored it to the needs of this group by identifying the minimum information required for effective self-management. The Workbook included activities designed to identify the participant's own barriers to effective control, to identify issues in their own lifestyles which impact on their health outcomes and to clarify their own support networks. All sessions were designed to be interactive and were managed so they demonstrated that the views of the participants were valued. At the end of each session the participant completed a goal sheet (in the DSMW) to improve his or her own self-management. On the final day of the residential camp, participants developed their own self-management health plan using the information they had gained over the week and from their completed goal sheets. The Aboriginal health workers assisted the participants to better

understand their pathology and develop their personalised management plan in response to their particular clinical indicators. The participants also completed a self-efficacy scale for Type 2 Diabetes Mellitus self-management and also completed a measure of negative emotional states. This component of the project was managed by a postgraduate student in Psychology at the University of Wollongong, and implemented to determine the effectiveness of the self-management program at the camp in changing perceptions about the participant's ability and confidence to self manage with respect to diabetes.

### Project Outcomes

Table 1 presents information about age and duration of diabetes in male and female participants. There was no significant difference in mean ages for male and female participants although male participants had been diagnosed with diabetes for a significantly longer period of time (8.17 yrs vs 3.88 yrs). Note although 19 participants attended the self-management camp, one participant was unavailable for assessments.

**Table 1: Mean age and duration of diabetes**

	Male	Female	Total
N	8	10	18
Mean age (yrs)	47.25	53.6	50.78
Mean time with diabetes (yrs)	8.17	3.88	5.71

Much of the data were recorded at baseline and at 3 months post-residential camp. Demographic data was recorded solely at baseline, and the self-management adherence scale was collected at three months post-camp only. Self-efficacy measures and negative emotional states were recorded at baseline and upon completion of the camp. Scores recorded in each of the areas noted (self-efficacy, depression, anxiety and stress), were significantly improved at the end of the camp as compared to pre-camp measures. However, it is significant to note that these measures returned to pre-camp levels at the end of three months post-camp.

HbA1c was measured through standard pathology protocols at a single pathology service in the Illawarra. Dietary history was taken by the dietitian using the 24 hour recall method, and macronutrient content analysed using Foodworks Version 2, (Xyris 1999). Percentage of carbohydrate and fat in that profile was used as an indicator of food selection and of adherence to dietary recommendations.

Effectiveness of self management was determined using the SE Type 2 scale, and this instrument was applied by a trained psychologist. The glucometers provided for the participants

stored blood glucose levels which were downloaded to a computer for later analysis by a Diabetes Nurse Specialist, with the results being shared with each participant.

**Table 2: Changes in blood pathology over time (Mean+/- SD)**

	Pre	3 month	6 month
<b>Chol</b>	5.29 +/- 1.06	5.21 +/- 0.89	5.1 +/- 1.08
<b>Trig</b>	3.39 +/- 1.69	2.66 +/- 1.31	2.99 +/- 1.76
<b>HbA1c</b>	9.24 +/- 2.00	8.13 +/- 1.72	8.6 +/- 1.86

These data are explained below.

### 1. Improved Lipid Levels

- 12 of the 19 (63.2%) participants recorded lower cholesterol levels
- 10 of the 19 (52.6%) lowered triglyceride levels

These trends for a reduction in both cholesterol and triglycerides did not, however, represent significant reductions in these measures. (Larger numbers of participants would be needed with similar levels of change in these parameters to reach significance.)

### 1. Improved Glycaemic Control

There was a statistically significant difference in the HbA1c levels at 3 months following the self management camp. Furthermore,

- 17 of the 19 participants (89.4%) had a reduction in HbA1c levels, with those in the poorly controlled group showing the greatest degree of improvement.
- 6 of the 19 (32%) participants showed an improvement of between 1% and 4%.
- 3 of the 19 (16%) participants showed outstanding improvements of 4% or more.
- There was mean reduction in HbA1c of 1.1% in the 3 month period following the camp which, according to Stratton, equates to a 21% reduction in risks of complications from diabetes.

Collective responses related to self-management of medication, continuation of the exercise intervention, and

management of their blood monitoring and dietary plans were recorded at three months and are noted below. Although the responses indicated that some of the self-management strategies were utilised more frequently than others, all adherence strategies were utilised by more than 50% of the participants, and in fact:

- 94% of the participants reported adhering to their medication regime
- 59% reported adhering to their exercise plan
- 55% reported adhering to blood glucose monitoring plan
- 55% reported adhering to their dietary plan

These data are displayed in Fig 1 below.

Furthermore, at a more general level, 66% of the participants reported:

- They were better able to self-manage their diabetes
- Improved attitudes regarding the importance of their health
- A perception of greater control over their lifestyle since being involved in the project

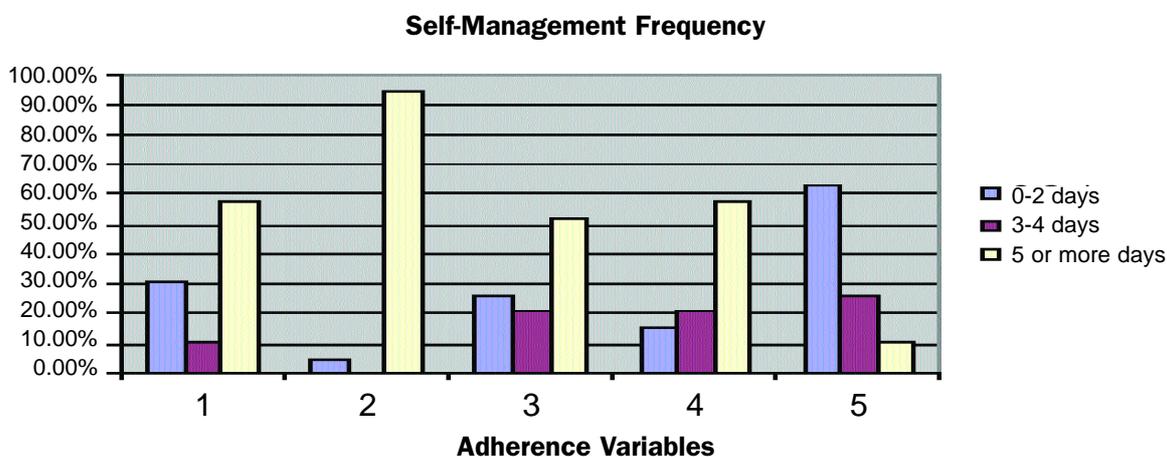
### 4. Barriers to Good Control were Identified

Anecdotal feedback from the participants regarding the barriers to self-management included: family problems, stress, illness, lack of transport, financial problems impacting on lifestyle choices including cost of fresh produce and low-fat cuts of meat. A strategy to increase self-management skills in addressing these barriers is required, and will be the focus of a follow-up research project.

### 5. Stress Management Identified as a Major Issue

This research project identified that stress has an impact on glucose levels in that those participants who reported the greatest stress in their lives also recorded above average recordings of HbA1c. Furthermore:

- 55% of participants entered the project with either severe levels of depression, or elevated levels of anxiety or stress
- 60% reported having problems adhering to their stress management plans developed during the Self-Management Camp, in the 3 months following the camp.



## Discussion

The strategy outlined to develop and manage a residential camp designed to improve self-management skills was successful, in the short term, in impacting positively on diabetes through improvement in psychosocial factors, enhanced self-management skills and metabolic control.

This initiative involved a process in which a medical challenge, identified within an Indigenous population was addressed through collaboration between a number of stakeholders.

The involvement of **Aboriginal health workers** in the planning and implementation of this initiative was considered essential – from the design of the camp and the educational materials, through to baseline data collection, and management of the residential camp. Effective tools for use within the camp were identified through similar experiences in the Heart Health camps, and through investigation of the research literature related to similar self-management residential camps for Indigenous people.

Intending participants and their partners were also involved in the design of the project as they provided information about issues impacting on effective management of diabetes, attitudes towards the various strategies that have been used in the past, beliefs about ownership of health, and the role of the Allied Health professionals. They also provided particular insights into the impact of the often complex and chronic health problems they faced. This information was used in developing the framework for the Self-Management Camp, the workshops, educational material and the Workbook layout and design.

The psychosocial state of participants was demonstrated to improve from baseline to the assessment at the end of the camp, as was self-efficacy related to management of diabetes, although these returned to baseline measures at the 3 months post-camp measurement. HbA1c levels were significantly lower at the 3 months period than at baseline and there was a trend for lipid profile to be improved.

The emphasis in this article is on the management processes related to the design and delivery of the residential camp and on innovative accessing of expertise within the community. The expertise accessed from within the community included Health Promotion experts, Allied Health workers from within specialist diabetes services, Dietitians from the Illawarra Area Health Service, and academics and students from the University of Wollongong. In each case it was important to identify positions of mutual benefit and then promote these within the respective organisations. For example, in the case of the University staff and students, the fact that community outreach from the University is considered to be an important component of service by that organisation. The fact that students are required to be exposed to research techniques and methods increased their support of this initiative. Involvement of the final year students with members of the community not known for accessing their skills and competencies also provided valuable insights into the need to develop delivery modes for lifestyle change

including physical activity for this population.

### **Development of the Workbook (SMWB) and Other Educational Issues**

The literacy skills, learning styles and strategies to engage participants in the learning process need to be considered in the design of the educational component of the camp, and in the materials that are created for participants. In the case of the SMWB, the written material used to describe and define was presented in point form to increase clarity and to highlight the crucial information that was needed to self-manage diabetes. The Workbook uses diagrams and cartoons where possible to explain underpinning medical conditions, increase accessibility, and is written in the first person when explaining the impact of the pathology (diabetes) on the participant.

### **Layout of the Workshop Room**

The layout of the environment in which the Workshops were to be conducted was controlled, with a U-shape arrangement of working tables and chairs. This arrangement provided for cross talk amongst participants, and increased involvement in both the delivery of the information and the development of the individualised responses to each worksheet. This layout also encouraged the use of Story, where individuals would outline their circumstances and have their experiences and opinions valued.

### **Support and Involvement of Aboriginal Health Workers**

Involvement of Aboriginal health workers (AHW) and other allied health professionals in the education sessions was important in confirming for the participants that this process was really important for all concerned. The AHW were instrumental in encouraging increased involvement by the participants, and supported interaction between participants and support staff. Furthermore, they were heavily involved in supporting participants with limited literacy skills or confidence in verbal communication.

### **Involvement of Partners**

The participants were encouraged to invite a 'partner' or support person to the Camp. This increased the numbers of participants with pathology being able to come, and provided a ready sounding board for the development of self-management strategies. Partners were also encouraged to consider the range of behaviour and lifestyle changes that were developed for participants as another way of supporting their partner and improving their own health.

### **Management of Educational and Workshop Sessions**

These sessions involved the setting up of the area so that individuals would be able to all provide input and communicate with group members. It also required the attendance of the AHWI's and allied health professionals, as well as a staff member dedicated to recording any special or significant comments or perspectives; topics that required clarification; and to determine when work-breaks would be taken. The information gathered by this staff member was then included

in follow-up material provided for participants during workshops.

The sessions were conducted with frequent breaks for mental relief and for refreshments. The sessions contained significant amounts of information, and the program supervisors were mindful that concentrated attention for prolonged periods of time is quite tiring, and ensured a short break at least every 30–40 minutes or so.

Provision for the use of incidental learning was scheduled into the program. Social interaction, chats, walks, and meal times all provided opportunities for participants to share their stories, and to increase their awareness of strategies of self-management and to provide opportunities for these to be put into practice.

Participants became more relaxed about the process and their involvement as the Camp continued, and it became evident that some of these individuals were facing circumstances in which further, and possibly ongoing emotional and social support was required. A number of initiatives were thus planned and implemented on return 'home'.

## Camp Innovations

This Self-Management Diabetes Camp implemented a number of innovations that played an important role in determining the positive outcome of the camp. These included:

### Meditation Sessions

Meditation had not been offered at previous camps run by the IAMS or as a service within the medical facility, but as stress and anxiety had been identified as a major barrier to effective management of diabetes, group sessions were offered daily as a coping skill at the self-management camp. The meditation sessions were provided by a trained counsellor who focused on culturally appropriate strategies such as 'connecting to the earth and spirits' for strength and guidance. Meditation proved to be of great assistance for some of the participants and a fortnightly group continued following the camp.

### The involvement of University Students

Seven student, five final year Exercise Science and Rehabilitation and two Masters of Dietetics and Exercise Science students were invited to the camp and they became Personal Exercise Support Professionals (PESPs) to individual participants during the camp. The students also supervised activity sessions and facilitated in a number of the workshops. The students were valued and welcomed by the participants. They were seen as having fresh ideas and providing inspiration and support for lifestyle change.

Students were also involved in supporting participants in their activity plans on return from the camp. Their involvement was important. It was provided free of charge, was given enthusiastically and was seen as highly desirable to be involved in an innovative program supporting individuals in the community who are at most risk of premature death or disability as a result of complex and chronic pathologies. The

experiences they gained were invaluable to an enhanced professional career.

Concerns that these students would not be well accepted by the participants proved to be unwarranted. Introduction of the students to the participants on the first day of the camp, and provision by them of information about their program of study opened the way for a number of questions by the participants. Each participant was effectively equipped with a pedometer and a personal assistant for better management of their physical activity intervention.



A small group of participants on a physical activity break. Other participants chose fishing as the activity!

## Camp Follow-up and Intervention

Follow-up after the camp has been seen as very important in supporting the participants' self-management skills. Many participants claimed to be highly motivated immediately following the camp, only to return home to be subsumed by the same problems and issues they are required to face in every day life. Post-camp evaluation showed this to be the case. Interventions offered following the camp were: supermarket tours to inform participants about food selection, meditation groups, counselling, Quit Smoking groups, supported exercise/physical activity sessions and a monthly newsletter to keep everyone in touch. At three months and six months following the camp, data was collected for evaluation and a Self-Management Booster Session was offered.

## Conclusion

This project demonstrated that camps are both a popular and effective means to increase awareness of pathology and self-management strategies in Aboriginal populations, and particularly so if family members/partners are included as it made it easier for participants to commit to the 5-day intervention. The camp was effective in providing education, addressing barriers to good control of clinical signs and symptoms, fostering self-management skills, changing lifestyle behaviours and improving diabetes outcomes. It also identified that financial, family problems and long standing symptoms of chronic stress, depression and anxiety clearly require a more intensive and specific intervention than that provided by this project and require further investigation.

Participants who have experienced significant difficulties in developing effective self-management skills are those who were identified as having high levels of depression, anxiety or stress at the pre-camp assessment. Participants with high levels of depression, anxiety or stress require more intensive

support and intervention.

This project demonstrates that intervention and support for Aboriginal people with diabetes needs to be planned and offered in a range of modalities. It needs to be offered both individually for some participants and in groups, and also on a regular basis in order to consolidate the skills provided for the development and maintenance of self-management skills. Conventional treatment and education interventions are only a bandaid approach to diabetes care for Aboriginal people with complex social and emotional issues within their daily lives.

It also shows that project partnerships – partnerships between organisations that can demonstrate a mutual benefit in developing and maintaining a close working relationship – can lead to better practice in diabetes care and a better understanding of the issues and barriers faced by Aboriginal and Torres Strait Islander people with diabetes.

## Recommendations

Management of complex and chronic pathologies requires a multidisciplinary approach for effective outcomes. A thorough understanding of the social and life-related circumstances in which the participant finds his/her self is required in order that any issues facing potential participants may be identified and addressed. Prior to attending a Diabetes Self-Management Camp, participants need to be assessed for levels of depression and anxiety and offered intervention, with individual or group counselling and stress management. In this way the participant may have identified their own barriers to good control and would be better prepared for the Diabetes Self-Management Camp and for lifestyle changes.

Upon return from the camp, contact and follow-up with the group needs to be in the first fortnight in order to confirm the strategies that are proving effective and to address barriers and issues which have arisen since returning to their own environments. It may be necessary to re-evaluate the participants' goals and self-management plans which were developed at the camp to be successfully implement them in their normal home environments.

Support through meetings, groups and phone calls should be regularly convened, at least monthly, following the first contact. Intensive support needs to be offered to the participants following the camp for those people identified as having very challenging social and emotional barriers to effective diabetes self-management. Furthermore, this support may need to be offered for some months following the camp.

A state-wide strategy to increase the range and effectiveness of self-management skills in addressing the barriers to effective self management of Indigenous people with diabetes is required. Primary health care services to Aboriginal and Torres Strait Islanders need to be funded and supported appropriately to be able to offer the intensive interventions required. **[So needed and so true - Ed.]**

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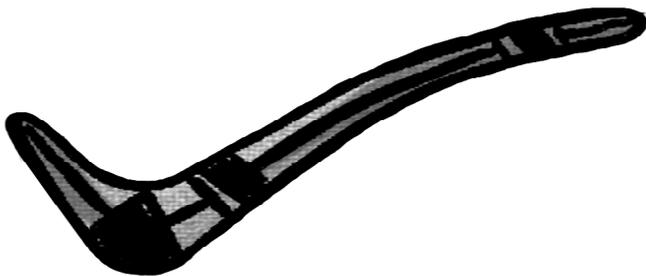
## Stakeholders and their representatives:

Aboriginal Vascular Health Program: Manager Ms Margaret Scott  
 Project Manager: Aboriginal Vascular Health Illawarra Area Health Service: Mrs Caroline Harris  
 Illawarra Area Health Service (IAHS – Illawarra Diabetes Service)  
 Diabetes Nurse Consultant  
 IAHS – Illawarra Diabetes Service – Two Dietitians: Dianne Rodgers, Shelley Mason  
 IAMS – Two Senior Aboriginal health workers : Leonie Burley, Fay Allen  
 IAMS – One Psychologist: Ms Carol Eddington  
 IAMS – one member of the Board of Directors: Aunty Mary Davis  
 IAMS – Manager: Ms Julie Booker  
 University of Wollongong : Senior Lecturer from Department of Biomedical Science/Exercise Science and seven final year students: Owen Curtis and senior students  
 University of Wollongong: Sr Sheena McGhee  
 UoW Postgraduate student in Faculty of Health and Behavioural Science, Psychology Department : Greg Konza  
 Heart Foundation – Regional manager : Mr Andy Mark  
 Local Psychologist working with Aboriginal Youth was also involved in the process.

## Postscript:

Each community has resources similar to these within them, as they included the local Aboriginal Medical Service and representatives of the Aboriginal community, and volunteers from the tertiary education sector, public health experts and allied health professionals from NSW Department of Health. These professionals and community members formed a Steering Committee, under the Aboriginal Partnership Agreement to develop strategies that would engage the local Aboriginal population, provide access to high level expertise in specific discipline areas, and develop an application for funding for the project through the appropriate funding authority (NSW Aboriginal Health Promotion Community Grants Scheme). All people involved in the project were required to attend cultural awareness training, provided through the IAHS, to increase awareness of issues requiring modification of behaviour, language or processes.

A follow-up program, Aunty Jean's Good Health Team, has been developed and conducted, with a most comprehensive evaluation framework designed and managed by Dr Sue Curtis. This project has focused on developing a suitable metaphor for effective involvement of Indigenous people, has implemented a range of evaluation strategies, and has developed a system through which changes in self-management competencies and health behaviours are identified, recognised, and then reported on through traditional public health frameworks.



- oversees, develop priorities for, and monitor communication and recruitment strategies;
- provides a focus for informed comment and debate; and
- develops and implements a work program addressing agreed and emerging priorities.

The ASAC has several Working Groups, which undertake work in specific areas. The Aboriginal and Torres Strait Islander Women's Forum is one of those Working Groups. Others include:

- Policy Review and New Technology Working Group;
- Monitoring and Evaluation Working Group;
- Quality Assurance and Workforce Working Group; and the
- Communication and Education Working Group

### ***The Aboriginal and Torres Strait Islander Women's Forum***

At its meeting in October 1999, the National Advisory Committee discussed the high mortality rates from cervical cancer of Aboriginal and Torres Strait Islander women, compared with non-Aboriginal and Torres Strait Islander women. There has been a significant amount of work done in various regions, however the NAC wanted greater emphasis and support to address this issue.

Further analysis of data available at that time suggested a higher rate of mortality in rural and remote areas, and for women who under-screened or who had never screened. The NAC agreed that a group be formed to specifically address these issues, and this group first met in Canberra in February 2000. Originally, Queensland, Western Australia and the Northern Territory were considered the most appropriate areas for representation, as they have the highest numbers of remote and rural Aboriginal and Torres Strait Islander women. NSW and South Australia were also included as there is a high population of Aboriginal and Torres Strait Islander women in those States, especially in rural and remote areas. As well, South Australia currently provides services to some parts of the Northern Territory. Also represented on the Forum was the National Aboriginal Community Controlled Health Organisation (NACCHO).

It was also agreed that Aboriginal and Torres Strait Islander women should be represented in any group formed to discuss these issues. Initially membership included some State and Territory Program Managers and the Chair of the NAC. The Forum has now been restructured and all members are Aboriginal and Torres Strait Islander women from each State and Territory, representing government, consumers, and the community-controlled sector. The Australian Government attends meetings of the Forum as an observer.

The Forum became a Working Group of the National Advisory Committee to the National Cervical Screening Program on 11 May 2000.

The February 2000 meeting of the Forum was the first time that Aboriginal and Torres Strait Islander people were included from States and the Northern Territory around the discussion table. They were able to voice their concerns and identify issues about cervical screening, both locally and at a State/Territory level that are relevant to Aboriginal and Torres Strait Islander women. It was the first time that Aboriginal and