

# **Chronic Condition Management Strategies in Aboriginal Communities:**

**Final Report 2011**



Inge Kowanko, Yvonne Helps, Peter Harvey, Malcolm Battersby,  
Bev McCurry, Russell Carbine, Jenny Boyd, Oscar Abdulla

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Note : We use the term 'Aboriginal' in this report to represent both Aboriginal and Torres Strait Islander people. We only use the term 'Indigenous' where it is a direct quote from a person or agency.

Warning: This report may contain the names and images of, and references to, people who have passed away.

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A partnership of Flinders University and the Aboriginal Health Council,  
in collaboration with Port Lincoln Aboriginal Health Council, Nunkuwarrin  
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# Abbreviations

AHCSA	Aboriginal Health Council of South Australia
CRCATSIH	Cooperative Research Centre for Aboriginal and Torres Strait Islander Health
CCRE	Centre for Clinical Research Excellence in Aboriginal and Torres Strait Islander Health
FHBHRU	Flinders Human Behaviour and Health Research Unit
PLAHS	Port Lincoln Aboriginal Health Service
RCHS	Riverland Community Health Service
LIFE	Living Improvements for Everyone, a peer support leadership program for chronic disease management, adapted for Aboriginal people
QUMAX	Quality Use of Medicines Maximised for Aboriginal and Torres Strait Islander Peoples
HbA1c	Glycosylated haemoglobin, a measure of diabetes control
BMI	Body Mass Index
HDL	High Density Lipoprotein, known as 'good' cholesterol
LDL	Low Density Lipoprotein, known as 'bad' cholesterol
GP	General Practitioner
NHMRC	National Health and Medical Research Council
Nunkuwarrin Yunti	Nunkuwarrin Yunti of South Australia Inc
POCT	Point of Care testing
PIH	Partners-In-Health scale, used in the Flinders Program™ of Chronic Condition Management
SA	South Australia
MBS	Medical Benefits Schedule



# Executive summary

## Background and rationale

### What was this project about?

This is the final report of a project called 'Chronic Condition Management Strategies in Aboriginal Communities' conducted during 2008-2011. The goal was to evaluate, and where possible develop and demonstrate effective and transferable chronic condition management strategies, and to generate research evidence about their processes, impacts and health outcomes.

### Why was this research done?

The burden of chronic conditions has increased for all Australians, especially for Aboriginal people, and significantly reduces wellbeing and productivity. Consequently, improving the prevention and management of chronic conditions has emerged as a priority, so that people can keep living well in their communities for as long as possible.

We knew from our previous research that certain strategies for managing chronic conditions could be tailored to suit Aboriginal settings and clients. Those strategies included structured care planning focused on clients' problems and goals, training in chronic disease management and self-management support for staff and peer leaders, and coordinated holistic team care. However little was known about the health impacts and outcomes, sustainability or transferability of such promising chronic condition management strategies. This project addressed these issues.

### Who was involved?

The research team from Flinders University and the Aboriginal Health Council of South Australia, worked closely with staff, Aboriginal clients and community members of Port Lincoln Aboriginal Health Service (PLAHS), Nunkuwarrin Yunti of South Australia Inc. (Nunkuwarrin Yunti) and Riverland Community Health Service (RCHS).

The project built on our previous collaborative research and relationships with Aboriginal health services in South Australia, particularly through the Centre for Clinical Research Excellence (CCRE) in Aboriginal and Torres Strait Islander Health. It was developed at the request of the CCRE partners, and supported by the Cooperative Research Centre for Aboriginal Health (CRAH, now managed by the Lowitja Institute).

## Project methods and activities

### Research design

A flexible participatory action research approach using mixed methods was chosen for the study design. The research plan was refined through the CRAH's facilitated research development process. An advisory group provided guidance and grounding, and relevant ethics approvals were granted. Capacity development opportunities for Aboriginal staff, clients and community members featured throughout the project.

## Chronic condition management strategies supported through the project

Additional chronic condition management strategies were offered and supported as part of this action research project and processes and impacts explored through direct involvement, observation and interviews. These strategies were negotiated with the three health services to suit their different approaches, priorities and capabilities. They included:

- > providing training for staff in the Flinders Program™ of Chronic Condition Management
- > facilitating the exchange of experiences and ideas between health services to support organisational change
- > development of health promotion resources with PLAHS
- > helping RCHS to develop a community support group and expo

## Data collection and analysis

Clinical data from the health service records of 36 clients involved in chronic condition management, collected over 1-10 years, were analysed retrospectively. The random effects modelling method was used to explore changes over time in key health indicators for the group as a whole. Individual clinical data were mapped against information from interviews and case notes to produce individual client graphs showing change in health indicators over time in relation to introduction of chronic condition management interventions, eg care plans, and other life events.

Semi-structured interviews with 18 clients and 12 staff explored how they approached and managed chronic conditions, and their experiences and ideas about what works, what doesn't and why. Thematic and grounded theory analysis of the qualitative data identified benefits, barriers and enablers of chronic condition management strategies.

## Key findings and outputs

### Health improvements associated with chronic condition management

Group analysis of the longitudinal clinical data from 36 clients showed statistically significant and small but clinically important improvements over time in key indicators of health: body mass index, total cholesterol, triglyceride and LDL (the 'bad' cholesterol) and HbA1c (a measure of diabetes control).

Considering graphs of individual clients' health indicators alongside their qualitative information provided richer understandings of the way that chronic condition management and other life events influenced their health trajectories.

### Benefits of chronic condition management

Benefits for clients of structured chronic condition management strategies (eg client-centred care plans and self-management support) were identified from analysis of interviews. They included:

- > New knowledge about chronic conditions and how to manage them
- > Empowerment and taking control of their own health
- > Setting and achieving personal goals
- > Reassurance and keeping track of progress
- > Feeling better and avoiding complications of chronic conditions

## Barriers and enablers of chronic condition management strategies

Through interviews with clients and staff, we identified factors influencing how chronic condition management strategies are implemented and sustained. These factors were classified into themes that were related to the health system/service, staff or clients. Most had both barrier and enabler aspects depending on the context and circumstance, eg 'transport' was a barrier to accessing health services for clients unable to drive or take the bus, also an enabler if the health service drove clients to and from the clinic. Listed below are the main enabling factors under each theme.

Health system/service-related themes:

- > Access to appropriate and affordable health services (transport assistance; mobile clinic; locally available services; cultural safety; bulk billing).
- > Effective clinical information management system (electronic patient record. system eg Communicare; compatible systems between/within services; accurate and consistent data entry; routine use by staff for monitoring chronic conditions, care plan reviews and referrals).
- > Coordination and team care arrangements (holistic, 'no wrong door' organisational approach; established care plan and review processes; clear pathways for assessment and referral; core team focusing on chronic conditions; point-of care pathology testing; multiple appointments arranged for same day).
- > Facilitation of peer support (Living Improvements for Everyone course for peer leaders; diabetes camps; support groups for specific client/community groups).

Staff-related themes:

- > Staff capacity and training in chronic condition management support (core chronic conditions team with sufficient skills; training is valued and encouraged by management; subsidised or free training; courses modified to suit Aboriginal staff and contexts; mentoring and support within the team; support to implement training into daily practice).
- > Engagement with clients and community (Aboriginal community-controlled service; taking time to develop trust and rapport; promoting local services; holistic client-focussed approach).
- > Encouragement and support for clients (support and advise clients but don't dictate; motivate clients to set achievable goals; clients set extent and pace of involvement in chronic disease management; be available and genuinely care).

Client-related themes:

- > Client knowledge of chronic conditions and their management (acceptance of chronic conditions; body awareness; desire and opportunity to learn more; information provided in appropriate forms).
- > Commitment to lifestyle change (taking responsibility for own health; complying with medications; healthy diet and exercise built in to everyday routines).
- > Family and peer support (lifestyle changes embraced by whole family; practical help with difficult tasks; role modelling; maintain emotional and social wellbeing; few other stressors allow health to be prioritised).

## Resources produced through the project

A Community Storybook about the development and activities of the Riverland Aboriginal Chronic Disease Support Group, featuring members' stories of living with chronic conditions, was developed and published as a celebration of this successful initiative and encouragement for others to address their health. Health promotion posters were developed in collaboration with PLAHS, encouraging health checks and care plans, and featuring 'self-management star' clients as role models for their community.

## Capacity development outcomes

Aboriginal staff members from each health service were engaged as project links, gaining research skills and experience, as did community links and the Advisory Group. Some co-presented at conferences, and co-authored publications. Staff skills in chronic condition management were increased through training programs provided by the project. We brought health services together to share ideas about implementing structured systems of chronic condition care. Health promotion resources and activities developed and supported by the project increased potential community capacity to prevent and manage long-term illness. This project has also informed the research team's related research proposals and modifications to training courses eg Flinders Program™ for Chronic Condition Management. The project officer was based at the Aboriginal Health Council of SA, strengthening the research capacity of that organisation and the partnership with Flinders.

## Recommendations

This project provides strong qualitative and quantitative evidence that people involved in structured chronic condition management strategies (eg care plans) improve their health and wellbeing over time. Such evidence of clinical effectiveness would strengthen bids for further funds and support for these strategies.

A range of factors were identified that enable or hinder the introduction and sustainability of chronic condition management strategies, at health service, staff or client level. Attention to these factors would enhance the likelihood of successful transfer of chronic condition management strategies elsewhere.

## Key Elements

Key elements that health services need to have in place, or to develop, in order to implement chronic condition management systems include:

- > An accessible, culturally appropriate and free health service that meets clients' needs
- > A model of chronic condition management based on principles of self-management support eg the Flinders Program
- > Systematic and coordinated service delivery, with clear clinical protocols and pathways of care
- > Sufficient staff to work with and motivate clients
- > Staff with clinical expertise, teamwork skills, and trained in chronic condition self-management support
- > An effective clinical information system, eg Communicare
- > Peer support and outreach programs
- > Organisational support for staff to implement structured client-centred care.

This project demonstrated the efforts and successes of participating health services, staff and clients in managing chronic conditions. The variety of effective strategies and the different challenges encountered highlight the importance of tailoring new initiatives to suit individual needs and local circumstances.



# Introduction

## Background and rationale

The health and wellbeing of Aboriginal and Torres Strait Islander people stills lags behind that of all other Australians [1-2], despite the efforts of all Australian governments [3]. Chronic health conditions are prevalent, particularly among Aboriginal people, and put significant strain on patients, their families and communities, and the health care system as a whole. Recent national aggregated data highlight that 50% of all Aboriginal people have a chronic condition or disability, and that chronic disease contributes to 80% of the estimated 11.5 year life expectancy gap between Aboriginal and other Australians [3-4]. Deaths attributable to all chronic conditions were 2-3 times higher for Aboriginal people than other Australians, and diabetes-related deaths were 6-7 times higher [2]. Chronic conditions include long term illnesses such as diabetes, cardiovascular disease, renal and pulmonary disease, mental illness and substance use problems. Many Aboriginal people are living with several chronic conditions at once, highlighting the need for holistic yet individualised approaches [2, 5].

To reduce the burden and cost associated with chronic conditions, various chronic condition management strategies were developed and promoted widely by government for both the general population [6-7] and for Aboriginal people in particular [8-10]. Chronic condition management strategies that are holistic, primary care approaches to enable people with chronic conditions to live healthy productive lives, are in accord with the Aboriginal community-controlled health sector's values [11-12], as well as those of the larger Aboriginal community:

*'Aboriginal health is not just the physical well being of an individual but also the social, emotional and cultural well being of the whole community in which each individual is able to achieve their full potential thereby bringing about the total well being of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life.'* [13]

However, although chronic condition management strategies seem like a good idea, and we know that some of these strategies have been implemented successfully in different settings including Aboriginal communities, little is known about their clinical effectiveness, sustainability or transferability.

## Project aim

The goal was to evaluate, and where possible develop and demonstrate effective and transferable chronic condition management strategies, and to generate research evidence about their processes, impacts and health outcomes.

## Project development

The project builds on our current and previous collaborative research and relationships with Aboriginal health services in South Australia (Table 1) [9-19], particularly through the NHMRC Centre for Clinical Research Excellence in Aboriginal and Torres Strait Islander Health [11, 14-15], a collaboration of Flinders University, the Aboriginal Health Council of SA and several Aboriginal health services in the Eyre Peninsula region of SA.

**Table 1.** Inter-related research projects on chronic conditions from this team underpinning this project

Examples of research projects in partnership with Aboriginal health services	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
SA Health Plus coordinated care trial																		
Better Medication Management for Aboriginal people with mental health, alcohol and other drug problems and their families																		
SA Chronic Disease Self-Management demonstration																		
Sharing Health Care Initiative project																		
Coordinated Aboriginal Mental Health Care																		
Centre for Clinical Research Excellence in Aboriginal and Torres Strait Islander Health																		
Chronic Condition Management Strategies in Aboriginal Communities																		
'Closing the Gap' Flinders chronic disease self-management programs																		

That research showed that some chronic condition management strategies, for example, structured and holistic client-centred care plans, point of care pathology testing and coordinated care arrangements, with appropriate supports and training, could be tailored to suit Aboriginal settings and clients, and early evidence suggested positive health outcomes and potential sustainability [14-27].

This research project was developed at the request of our Aboriginal partners to explore the transferability of such promising chronic condition management strategies, and demonstrate their effectiveness and sustainability. The project was funded by the Cooperative Research Centre for Aboriginal Health over 4 years (2008-2011) following an extensive 'facilitated research development process' [28] during 2006-2007. In this iterative process the research plan was refined through discussion with research peers and potential research users (Aboriginal community leaders, health service managers and workers, policy makers), resulting in a high quality plan meeting priority Aboriginal health needs.





# Project design and research methods

The project had a flexible, participatory action research framework using mixed methods. A similar approach was employed successfully in our previous collaborative work with Aboriginal partners [24, 29-31]. Briefly, we explored issues and contexts around the chronic condition management strategies at each of three project sites. We offered and supported additional chronic condition management strategies to suit their priorities and capabilities, conducted interviews with staff and clients and analysed clinical data, generating research evidence about the effectiveness and benefits of chronic condition management strategies, and the barriers and enablers to implementation.

## Ethics

In keeping with ethical Indigenous research principles [32-33], the project included research, capacity development and translation activities. The partnership approach to research with Aboriginal people is based on collaboration, flexibility, respect, meeting needs and participation [29, 34].

The research plan was approved by the Southern Adelaide Clinical Research Ethics Committee (Application 171/08), a joint committee of the Southern Area Health Service and Flinders University, as well as the Aboriginal Health Research Ethics Committee of South Australia (Application 04-08-246). Permission to conduct the project was also obtained from the Boards and senior staff of participating health services and community leaders. Informed consent was obtained from individual participants for interviews and access to clinical data. Information sheets and consent forms are appended (Appendix 1-4).

## Capacity development

Throughout this project, opportunities were found to develop research capacity of the research team and participating health service providers, clinical skills of health service providers, and ability of clients to manage their own health. Aboriginal health workers from participating health services were engaged and mentored as health service link people / research assistants, helping with local project activities, client engagement, data collection, conference presentations and local chronic condition management initiatives. Together with volunteer Aboriginal community link people, they participated in annual Project Advisory Group meetings.

## Advisory Group

An Advisory Group was convened to provide guidance and grounding to the project team, specialist advice, feedback on progress of the project, and input into draft reports. Participation in the Advisory Group was invited from health service providers at each of the three project sites, Aboriginal clients and community members, as well as the Lowitja Institute, Flinders University and the Aboriginal Health Council of SA. The Advisory Group met annually (Appendix 5).

## Project sites and activities

The project was conducted in three SA sites: Port Lincoln Aboriginal Health Council (PLAHS) in Port Lincoln, Nunkuwarrin Yunti in Adelaide and the Riverland Community Health Service (RCHS) in Berri. Members of the research team visited the project sites frequently, developing professional and community relationships and consulting extensively with staff, management



and Boards of the health services, clients and other Aboriginal community members to negotiate local research activities and processes, and identify health service and community link people.

The three project sites differed greatly in their client and staff profiles, governance and funding arrangements, previous involvement in and capacity for research, and ability to take on new chronic condition management initiatives. Consequently additional chronic condition management strategies offered or supported through this research project also varied between sites, and locally relevant strategies were decided through consultation with participating services and clients according to local priorities and capabilities.

### **Port Lincoln Aboriginal Health Service (PLAHS)**

PLAHS had established chronic condition management strategies in place, a skilled chronic disease team and many clients with care plans. Therefore, research activities at PLAHS focused on consolidating and enhancing those strategies, including:

- > Interviews with clients and staff to explore and document chronic condition management strategies in use, and to identify the benefits, barriers and enablers.
- > Flinders Program™ of Chronic Condition Management training refresher for staff.
- > Retrospective examination of changes in chronic condition indicators over time to demonstrate clinical benefit of PLAHS' approach to chronic condition management.
- > Development and launch of chronic condition prevention/ health promotion tools (self-management stars and care plan posters, visual representation of clinical progress towards goals over time).
- > Sharing knowledge and experience of successful chronic condition management strategies with Nunkuwarrin Yunti and RCHS.

### **Nunkuwarrin Yunti of South Australia Inc. (Nunkuwarrin Yunti)**

Project activities at Nunkuwarrin Yunti focused on supporting its evolving chronic condition management strategies:

- > Interviews with staff to explore chronic condition management strategies in use, and to identify the benefits, barriers and enablers.
- > Flinders Program™ of Chronic Condition Management training for staff, with client volunteers, and feeding back experience of the process to refine and improve this training.
- > Retrospective examination of changes in chronic condition indicators over time for evidence of clinical effectiveness of Nunkuwarrin Yunti's existing chronic condition management strategies.
- > Sharing PLAHS' experience of successful chronic condition management with Nunkuwarrin Yunti.

### **Riverland Community Health Service (RCHS)**

When the project began, chronic condition management strategies for Aboriginal people in the Riverland region were not well developed. Poor coordination between services and lack of staff capacity at RCHS were major problems. Early meetings indicated the need for staff training in chronic condition management, better engagement of health services with Aboriginal people, and a strong desire for more peer support for people with chronic conditions. Therefore, project research activities at RCHS focused on these initiatives:

- > Interviews with clients and staff to explore chronic condition management strategies in use, and to identify the benefits, barriers and enablers.
- > Working with local community and RCHS to develop and support the Riverland Aboriginal Chronic Disease Support Group.

- > Writing a community storybook featuring local clients' stories of successful chronic condition management and the support group.
- > Support for the Moorundie Ruwe Health Expo, to encourage health checks and identify and manage chronic conditions.
- > Flinders Program™ of Chronic Condition Management training for staff, with client volunteers.
- > Adapting and implementing elements of the care planning process, eg the 'action plan' based on client's long term goals.

## Data collection and analysis methods

### Participant engagement

By negotiation with senior managers of the participating health services, information about the project was provided to staff involved in caring for Aboriginal people with chronic conditions. Research team members gave presentations and project information sheets (Appendix 1) were widely disseminated. Interested people contacted the project officer and/or the health service link person, who arranged a time to meet, explain further, and obtain informed consent (Appendix 2) from staff willing to be interviewed.

Similarly, clients with chronic conditions were identified by the health services and given information about the project in written form (Appendix 3) and through presentations by research team members, followed up with further information on request. Clients were invited to participate in interviews and/or provide access to selected clinical information from the health service's clinical records, with informed consent (Appendix 4).

Health service and community link people at each service aided participant engagement by promoting the project and its activities.

Twelve staff and 18 clients participated in interviews (some more than once) and 36 clients allowed access to their clinical record (Table 2). Roles of staff participants included Aboriginal health worker, nurse, diabetes educator, nurse manager, medical officer, chronic disease nurse. All the clients and many of the staff were Aboriginal. Sixty-five per cent of all participants were female.

**Table 2.** Summary of participants who provided interview and clinical data: roles, sites, contribution.

Project site	Number of participants			
	Staff	Clients		
	Interview	Clinical data only	Clinical data and interview	Interview only
PLAHS	7	12	12	0
Nunkuwarrin Yunti	3	12	0	0
RCHS	2	0	0	6

Client participants mostly had multiple comorbid chronic conditions, some had more than ten co-existing chronic conditions recorded. Most common diagnoses were type 2 diabetes, hypertension, anxiety and depression, respiratory illnesses and cardiovascular disease. Appendix 6 provides more detail about the chronic conditions of the 36 clients who provided clinical data for this project. All the client participants were involved in some sort of chronic condition management, ranging from self-management supported by the Flinders care planning process, through GP management plans to medication support and involvement in a peer support group.

## Interviews

Interviews with staff explored how chronic conditions are identified and managed in their workplaces, knowledge training and support for chronic condition management strategies, perceptions about barriers and enablers of effective chronic condition management strategies and their implementation before and during this project, and future plans and ideas. Interviews with clients explored their experiences of living with a long term illness, their knowledge and understanding of chronic conditions, how they manage their conditions, interactions with health services, and their ideas about what works or doesn't and why.

All interviews were informal conversations that loosely followed interview guides (Appendix 7-8), and all interviewees gave informed consent. Most interviews were with individuals. Occasionally group interviews were held and several people were interviewed on more than one occasion to update or verify information. Interviews were audio-recorded and transcribed verbatim. A total of 31 interviews were conducted with staff and client volunteers across all three project sites.

Iterative thematic analysis of interview transcripts was conducted using the N-Vivo program: coding categories were based on interview topics initially, and then modified as new themes emerged and others coalesced using grounded theory approaches [35-37]. Independent analysis of selected transcripts by two researchers verified major categories. Emerging themes were considered in relation to site and interviewee characteristics. Further analysis of the combined interview data identified benefits, barriers and enablers of chronic condition management strategies.

## Longitudinal clinical data

Clinical data from consenting clients were extracted in de-identified form from the electronic patient information system (Communicare). The dataset included 24 records from PLAHS and 12 from Nunkuwarrin Yunti (Table 2), spanning the period from registration at the service to current. The clients had multiple comorbid conditions (Appendix 6). Clinical records from RCHS clients were unavailable.

The data included multiple measures of key health indicators including body mass index (BMI) and the results of point of care pathology blood tests for HbA1c (a measure of diabetes control), and blood lipid profile comprising total cholesterol, HDL and LDL (the 'good' and 'bad' cholesterol respectively) and triglyceride, all with corresponding dates. Data also included a client identification number, diagnoses, results of lifestyle assessments (diet, smoking status and alcohol consumption), prescribed medications, treatments and procedures. Significant events (eg initiation of formal care plans, diabetes camps) were added. The length of clinical records ranged from 1 to over 10 years, with some clients having as many as 80 recorded interactions with their health service.

These quantitative data were analysed in two ways: individually, and as group trends using Random Effects Modelling.

For individual clients we plotted relevant health indicators against time, and then examined those graphs alongside client interviews and other information from the clinical record (eg interventions, medications, diagnoses), looking for changes in clinical indicator values and trends associated with chronic condition management strategies and other life events as recalled by clients or noted in the record. Novel ways of presenting such information to help clients understand their progress were developed and piloted during the project (described elsewhere in this report).

Statistical analysis of group trends in clinical indicators over time was conducted using Random Effects Modelling [38-40]. The hypothesis is that chronic condition management strategies are associated with stable or improving trends in key health outcome indicators over time. This statistical method allows for the 'messiness' in the data that we have available; that is the clients have different, often multiple, chronic conditions and treatments with widely varying lengths of clinical records. Clients also differ in the number and sequence of time points for which clinical measurements are available. In short, the Random Effects Model recognises that subjects have different baseline measurements and, also, that their scores change over time in different ways. The process involves developing individual client profiles based on the most common

quantitative clinical indicators (HbA1c, BMI, cholesterol, lipid profile) for a quick visual indication of how well the model fits, followed by a group analysis to determine the significance of trends over time.

### **Integration of findings**

Other data about the implementation process, outcomes and impacts of chronic condition management strategies introduced during the project were also collected, eg notes of informal discussions and researcher field notes. This information, along with findings from staff and client interviews and clinical data, was incorporated into the narrative results/discussion.

### **Dissemination of findings**

Information about the project was made available periodically to participating organisations and their member communities through meetings and newsletters. Presentations at conferences promoted the project and its findings to wider audiences. Resources produced during the project (eg Riverland support group storybook, self-management stars posters) were formally launched to their communities where they continue to be used as health promotion tools. All project outputs are freely available on-line through the Lowitja Institute (<http://www.lowitja.org.au/craah/chronic-condition-management-strategies-aboriginal-communities>), and will be made available through the websites of the Flinders Human Behaviour and Health Research Unit ([www.flinders.edu.au/medicine/sites/fhbhru/](http://www.flinders.edu.au/medicine/sites/fhbhru/)) and the Aboriginal Health Council of SA ([www.ahcsa.org.au](http://www.ahcsa.org.au)).

# Description of chronic condition management at the project sites

## Chronic condition management at PLAHS

PLAHS is an Aboriginal community controlled organisation, providing primary health care to some 1200 Aboriginal clients in Port Lincoln and surrounding areas. The organisation is accredited by the RACGP, and includes services such as coordinated case management, clinical services, social and emotional well being, health promotion, child and maternal health, chronic disease self-management, hospital liaison, nutrition programs, a gym and fitness centre, community education and more [41]. PLAHS employs Aboriginal health workers, GPs, registered nurses and midwives, diabetes and asthma educators, and through the region's community health services it has access to a dietician, physiotherapist and podiatrist. This arrangement enables PLAHS to provide a one stop shop service. The organisation strives to deliver quality holistic primary health services that meet the community's specific needs, and are valued and utilised, resulting in improved health and wellbeing [42].

The research team and PLAHS have worked together for over a decade on a program of inter-related research informing continuous quality improvement in holistic primary health care for people with chronic and complex conditions (Table 1) [9-24]. Early evidence that chronic disease management supported by Medical Benefits Schedule funds is feasible and sustainable in Aboriginal settings was generated through pilot studies involving PLAHS [16, 18]. PLAHS also helped to pioneer the routine use of Point of Care pathology testing to monitor health and disease progress [25-26], the Living Improvements for Everyone (LIFE) peer support program for Aboriginal people with long term illnesses [27, 43], and the adaptation of the Flinders model of chronic condition self-management for Aboriginal contexts [16, 18] to become the Flinders Program™ of Chronic Condition Management which is being rolled out nationally through the Closing the Gap project [9-10].

When the project began, PLAHS had already embedded chronic condition management strategies, systems and supports into its core business. Many clients with chronic conditions had care plans, team care arrangements were established and most staff had participated in chronic condition management training. These training initiatives included the Flinders model of chronic disease self-management and specialist courses (eg diabetes education, mental health), there were established health-promoting and support activities for people with or at risk of chronic conditions (eg diabetes camps, Nunga Kids café, exercise group). The organisation's overall holistic primary care approach, clear protocols and pathways, effective communication and clinical data systems, and skilled team care arrangements underpinned PLAHS' model of chronic condition management. Information sharing within the service on a need-to-know basis is fundamental to the model of care. Collaboration between staff is encouraged through enhanced primary care team meetings to plan and discuss program development and client management.

At PLAHS, chronic conditions may be identified at adult health checks, or when clients attend the service for any other reason. Clients are referred to the chronic condition team, which includes a core group of skilled Aboriginal health workers and nurses who have earned community trust and confidence. These members of the chronic condition team each have a list of clients that they case-manage. They coordinate the whole care and do the bulk of the care planning and follow up work, organise and follow up referrals, arrange regular clinic visits and recalls for monitoring and care plan review, conduct point of care tests, use and update clients' clinical records (Communicare), advocate for clients and generally advise and support clients to manage their chronic conditions. The model is sustainable through Medical Benefits Schedule, and other government funding.

## Chronic condition management at Nunkuwarrin Yunti

Nunkuwarrin Yunti is an Aboriginal community-controlled health service in metropolitan Adelaide providing comprehensive primary health care services for Aboriginal people living in, or visiting Adelaide, at its premises in the city centre and satellite service site in the northern suburbs [44-45]. Initially the metropolitan project site was to be the Gilles Plains Aboriginal Outreach Service, a mainstream service with a clinic staffed by GPs from Nunkuwarrin Yunti, where members of the research team already had links through other projects [30-31, 46]. However, changes in the structure of the SA health system meant that was no longer possible, and Nunkuwarrin Yunti became a project site in 2009.

At that time Nunkuwarrin Yunti did not have a systematic approach to chronic condition management. Some clients with chronic conditions had GP management plans and team care arrangements, and all had medication support through the Quality Use of Medicines Maximised for Aboriginal and Torres Strait Islander Peoples (QUMAX) Program [47]. The organisation did not employ continuing specialised chronic condition staff; care was provided on an ad hoc basis. However, Nunkuwarrin Yunti was planning to introduce a more comprehensive and coordinated system of chronic condition care, requiring staff training and a defined approach.

Healthy for Life data demonstrated a marked increase in chronic disease management plans during the GP Plus nurse tenure at Nunkuwarrin Yunti. Over a 2 year period 2009-2011, the percentage of patients with diabetes mellitus having completed a GP management plan increased from 5% to 15%; and the percentage of patients with chronic heart disease having a completed GP management plan increased from 6% to 21%. For patients with diabetes, Nunkuwarrin Yunti was on par with other Aboriginal community-controlled health services in major cities. For patients with chronic heart disease, Nunkuwarrin Yunti surpassed other services in major cities.

## Chronic Condition Management at RCHS

The RCHS is a mainstream Country Health SA community health service located in the Riverland region of SA. There is no Aboriginal community-controlled health service in the region. The RCHS office in Berri houses a small Aboriginal health team which consists of several Aboriginal Health Workers, a Chronic Disease and Healthy for Life Registered Nurse, a Health Services Manager, and various allied health staff who are assigned fractional time to Aboriginal clients. Private GPs work from surgeries located in the various Riverland towns.

The Peelies Bus (originally a mobile eye clinic, hence its name) is a mobile clinic for Aboriginal people; this rotates every fortnight through the main Riverland towns (Renmark, Loxton, Waikerie, Berri & Barmera) and uses the community clinic in Gerard instead of the Bus. The Aboriginal Health Workers provide point of care testing and monitoring of clinical indicators to clients as required, support their access to the GP and make referrals as needed through the Peelies Bus clinics. Progress notes and Point of Care data is recorded on a computer in the Peelies Bus using Medical Director client management software, and a copy is placed in their RCHS health file. The RCHS uses a different patient software package, Client Management Engine.

During 2010 the Berri and Barmera Peelies Bus clinics were moved into the private medical practices of those towns providing a direct link and consultation with a GP. The Berri clinic provides access to a diabetes educator. Through the diabetes educator recall list, the RCHS Aboriginal health team is able to provide support to clients to ensure they receive their annual cycle of diabetes care and have updated GP management plans and team care arrangements. The RCHS Aboriginal health team supports clients with dietetic, podiatry, dental and other allied health referrals, making appointments, giving reminders and providing transport as required. The Barmera clinic has just started with this model of care, however there is relatively more emphasis on the Healthy for Life Registered Nurse providing support with the Aboriginal and Torres Strait Islander health checks, GP management plans and team care arrangements. There are fewer clients at Barmera than at Berri.



# Additional chronic condition management strategies supported through the project

## Chronic condition management training for staff – Flinders Program™ of Chronic Condition Management

Training in the Flinders Program™ of Chronic Condition Management was provided through this project to staff at each site. It is one of the chronic condition management strategies known from our earlier research to be feasible in some Aboriginal settings, but lacks robust evidence about transferability and health outcomes, and was therefore offered as an additional ‘intervention’ in this project.

This clinical program is based on recognised attributes of self-management for individuals with chronic conditions [48-50]. The process is conducted by an Aboriginal health worker or other health professional in partnership with a client to assess the client’s self-management knowledge, behaviours, strengths, barriers to self-management and identify the client’s highest priority life problems and goals. The medical and psychosocial interventions and steps to achieve them are summarised on a 12 month care plan that serves as a basis for follow up. The health worker motivates, supports and coaches the client to achieve lifestyle, medical and psychosocial goals. Aboriginal health workers and other health professionals learn how to use the Flinders tools in a course conducted over several days by accredited trainers from the Flinders Human Behaviour and Health Research Unit, Flinders University. Participants are required to complete 3 care plans satisfactorily to gain their certificate of competence [9-10].

PLAHS was involved in early research to show that the Flinders model could be implemented successfully in Aboriginal contexts and in pilot studies where the care planning tools were refined [16, 18]. Many PLAHS staff had already done the training in the past, but refresher training was requested and conducted at PLAHS in late 2008.

*I think it's a good opportunity to expose... new health workers as well as the more experienced health workers, just to get them thinking about how that [care planning] process works... Then when they're in the clinic they might identify people that we may have missed and then that referral process will [be set up], and there's always opportunity for the health workers to actually start doing the care planning. That's what I'd really like to see. (staff 8)*

Most staff at Nunkuwarrin Yunti and RCHS had not been exposed to the Flinders Program™ of Chronic Condition Management before joining this project. Both health services wanted to develop a more structured and coordinated approach to managing chronic conditions, and eagerly accepted the offer of staff training in the Flinders Program™. The project provided training at RCHS for eight staff in October 2009, and at Nunkuwarrin Yunti for 15 staff in December 2009 and May 2011. Five volunteer clients from RCHS and nine from Nunkuwarrin Yunti participated in the training; they benefited by having personal care planning processes initiated. At the time of writing only one staff member from Nunkuwarrin Yunti and one from RCHS had completed the training, though several others were nearing completion, and only four of the volunteers’ care plans had been finalised.

The main barrier to completing the training that was mentioned by staff was lack of time, especially to complete the three care plans required to achieve a certificate of competence:

*And it does take time you know, to get that rapport as well. I mean I sat there for three hours one day, just getting a client to respond really. Like, it was a great session but out of that three hours there was about an hour and half hiding under her hat and whatever, but, by the end of it we've got such a great rapport. ... so, to get her care*

*planned to the point of getting it signed off, probably a six hour journey. You know. It's very time consuming. (staff 6)*

Other time-related barriers to completing the training in Flinders Program™ of Chronic Condition Management included clients not appreciating the potential benefits relative to the time required, and over-extended clinicians with more urgent client care issues to deal with.

Other barriers to completing the training were also mentioned, eg:

*There are different reasons, including lack of confidence in their skills, in their abilities. They felt they hadn't had enough time, that it wasn't a streamlined approach, like it wasn't very clear. How would they fit in care plans amongst everything that they're going to do, and they've wanted more support from management, to some people even questioning the validity of using that model within this set-up. (staff 2)*

One staff member qualified as a trainer in the Flinders Program™ during the project, and undertook to provide continuing training and support for the other staff. That staff member's insights and suggested modifications have been useful in the ongoing refinement of the Flinders Program™ of Chronic Condition Management, which is now being delivered to Aboriginal health services nationally by Flinders Human Behaviour and Health Research Unit [9-10].

*They've revised this to make it a four day thing and it's really more focused on the Aboriginal health workers and building their confidence up gradually over that three days and so then on the fourth day they actually feel confident. (staff 8)*

*I think they felt more confident than when we'd done it before when the training wasn't really that suitable for Aboriginal health workers. It was a bit too quick and a bit complicated. So I think it's more friendly for Aboriginal people to work with it, like the way that you do the problems and the goals and various other things. (staff 10)*

## Chronic condition self-management education – Living Improvements for Everyone

Living Improvements for Everyone (LIFE) is a peer support and leadership program for Aboriginal people with chronic conditions, an adaptation of the Stanford chronic disease self-management program. This group program is conducted in 2.5 hour sessions weekly over 6 weeks with two peer leaders conducting the program. The aim of the course is to teach people with any chronic condition a generic set of skills including goal setting, action planning, problem solving, exercise, healthy eating and management of emotions, pain and fatigue. LIFE was developed by Spencer Gulf Rural Health School (including members of this research team) and piloted at PLAHS and some other Aboriginal health services [27, 43]. Like the Flinders Program™, LIFE was one of the additional interventions that this research team planned to offer or support through this project, in order to build on earlier research. LIFE complements care planning processes for people with any long term illness, whether through traditional GP management plans and team care arrangements, or through the more client-focused Flinders Program™.

During 2009, Country Health SA funded the delivery of LIFE to organisations in its jurisdiction. Two staff members from RCHS participated. Participation increased their understanding and interest in care planning and self-management, along with their willingness to consider novel ways to help clients help themselves.

## Implementing care planning

Commonwealth funding has been available for over a decade to Aboriginal health services that employ GPs for chronic disease prevention and management services, eg payments through the MBS for care planning, team care arrangements and review [6]. Currently health services can access additional funding through Australian Government Department of Health and Ageing Closing the Gap Indigenous Chronic Disease Package [7-8]. Previous research showed that



structured care planning funded in this way for clients with chronic conditions was feasible and potentially sustainable in Aboriginal settings [9, 11, 13, 15]. Support to implement care planning was therefore one of the additional chronic condition strategies offered to participating health services through this project.

Nunkuwarrin Yunti is an Aboriginal community controlled health service, employs GPs, and is eligible for support through the Closing the Gap Indigenous Chronic Disease Package. At the time of writing Nunkuwarrin Yunti reports making progress towards a streamlined system of chronic condition management.

It was hoped that staff training in the Flinders Program™ provided through this project would assist Nunkuwarrin Yunti to implement care planning into everyday practice, however at the time of writing most staff members had not yet completed the training (discussed elsewhere in this report). Of the 9 volunteer clients who participated in the two training sessions at Nunkuwarrin Yunti only 4 had their care plans completed. The length of time between initiating and completing these care plans was over 12 months, and not acceptable to some clients. Nunkuwarrin Yunti remains committed to offering care plans for clients with chronic conditions and making best use of Commonwealth funding through the Indigenous Chronic Disease Package, and increasing the number of clients with a care plan. This project facilitated the sharing of experiences between Nunkuwarrin Yunti and PLAHS, which has successfully incorporated client-centred care planning into its normal business (discussed elsewhere in this report).

Unlike PLAHS and Nunkuwarrin Yunti, the RCHS is a SA government funded community health service and does not employ any GPs, and therefore cannot access this funding. RCHS Aboriginal health team helps its Aboriginal clients to access GPs and allied health on the Peelies Bus, at Gerard Community clinic and private GP clinics. Some clients have GP management plans. Recognising that comprehensive care planning might be difficult to achieve in the Riverland at present, selected elements of the process were introduced to the Riverland Aboriginal Chronic Disease Support Group in 2011. Aboriginal clients who are willing and confident to take an active role in managing their chronic conditions work with a member of the RCHS Aboriginal health team to set an achievable long-term goal and develop a monthly action plan (Appendix 9). So far 2 clients have long term goals and action plans and more are on the way. They are already proving to be helpful, eg:

*I'll try and help myself. I have an action plan – to help me stay sober. I look at my action plan, it's up in my room. I look and say, good one, you've done alright today.*  
(client 13)

Whether or not members of the Riverland Aboriginal Chronic Disease Support Group increase their involvement in the goal setting and action planning exercises, this is a practical example of an initiative taken to enhance client self-management capacity, where the program could not be implemented in full. The Support Group is currently planning a chronic disease camp with most members having diabetes. At the camp there are plans to have more sessions about goal setting.

PLAHS has employed GPs and effectively accessed government funds and programs to help support its chronic condition management work for many years. Most of PLAHS' clients with long-term illnesses now have care plans, many have Flinders Program™ care plans, which include clients' personal goals as well as clinical goals, and team care arrangements are common for people with complex needs. PLAHS continues to encourage people with chronic conditions to have a care plan and has developed a simple and a streamlined way of beginning the process:

*So we would do a big heap of screenings, then we would go through using cue and response, like the Flinders tools, do an interview with those people and then we develop a bit of a care plan up around what we think they might need to stay well for that 12 month period and then we'd book them into the doctors to have that care plan signed off and they'd put on their medical goals onto that care plan and then away we go. (staff 8)*

## Care plan promotion materials

Opportunities were found within this research project for two Bachelor of Health Sciences students at Flinders University, Patricia Mitiel Gahanao and Penny van Pelt, to complete topic requirements for HLTH3003 'Health Work Internship' with the Aboriginal Health Council of SA during 2010. They worked closely with members of the research team at Aboriginal Health Council of SA and Flinders University, and with clients and staff from PLAHS to develop health promotion tools based on information already being collected for this project. PLAHS had already expressed an interest in developing such materials through this project to encourage more people with chronic conditions to get involved in the care planning process.

Penny van Pelt devised a novel visual representation of clinical data from consenting PLAHS clients. De-identified longitudinal clinical data (eg HbA1c, BMI) from individual clients were converted to charts using the Excel software program, prepared with green (ideal), amber (caution) and red (alert) overlays. Where possible, multiple measures were represented on a single chart. The green/amber/red traffic light analogy was used as a simple visual tool to assist clinicians and clients to develop and monitor self-management strategies, and as a take home reminder of progress and goals. An example is shown in Figure 1. This particular client was successfully losing weight and making good progress towards his target of 90Kg, but on viewing this chart he realised that he was still in the overweight range, and would revise his goal.

Figure 1. 'Traffic light' graph of clinical progress



Negotiations with Communicare, the patient information management software company that PLAHS uses for all its clinical records, were initiated with a view to building such chart templates into the system so that any client's clinical markers can be viewed on screen and printed out at the clinic. Unfortunately, at the time of writing there had been no further progress.

The PLAHS chronic disease staff identified three 'self-management star' clients who were managing their chronic conditions successfully. These clients were willing to be role models for their community, and Patricia Mitiel Gahanao worked with each of them to develop health promotion posters that featured their stories, paralleled with their health record data. The intent was for the posters to encourage others to get involved in care planning and self-management. The posters included the clients' images, and their goals, challenges, achievements and successes outlined in their own words. Dot points described what the client said they had gained from being on a Care Plan. The clients selected individually meaningful background images for their posters and helped refine the content and design, resulting in appealing and informative posters (Appendix 10-12).

A complementary poster 'Could you be a self-management star?' was developed by the research team and PLAHS clinic staff, encouraging people to have an adult health check, identify risk factors for chronic disease or existing problems, and initiate the care planning process at PLAHS (Appendix 13). Small information cards with chronic condition management tips from clients and corresponding facts on the reverse side were also prepared (Appendix 14).

All these health promotion materials were formally launched for the Port Lincoln Aboriginal community at the diabetes camp bush tucker night at Trinity Haven in December 2010, and to the staff and the Board of PLAHS on the previous day (Appendix 15). The posters were then displayed prominently at PLAHS in the clinic and reception areas, continuing to attract interest and positive comments from staff and community members. The following comments from one of the clients featured on the posters highlights how she is a role model to her community, encouraging her family to make healthy lifestyle choices, and countering feelings of despair among peers newly diagnosed with a chronic condition:

*Yeah, well I saw my mum, dad and sister pass away all through diabetes, and I said to myself I had to change my life so whoever's left in my family I can show them how to eat healthy. (client 7)*

*But it's sad to see lots of other people that just think that they've got diabetes now, and they say, 'Oh no, I'm menga now'. Menga means sick. 'I'm sick now, I've got diabetes.' I say, yeah, so have I. They say 'Yeah, well I'm on needles now.' [And I say] yep, well so am I. (client 7)*

A poster about the development of these health promotion materials (Appendix 16) was presented at the 14th Annual Chronic Diseases Network Conference held in Darwin September 2010 [51]. There was also media coverage about the poster launch and diabetes camp [52].

## Riverland Aboriginal Chronic Disease Support Group

Inconsistent health service provision, poor coordination between services, and lack of staff capacity are ongoing challenges in the Riverland, despite the strenuous efforts of dedicated health professionals. Consequently, Aboriginal people with chronic health problems have not always received the health care they need, with impacts on their quality of life and families. Early discussions indicated the need for better engagement of health services with Aboriginal people, staff training in chronic condition management, and a strong desire for a more peer support for people with chronic conditions. A survey conducted by the RCHS dietician confirmed the desire for a support group. Consequently the RCHS Aboriginal health team began making plans to develop and maintain such a group.

The first meeting of the Riverland Aboriginal Chronic Disease Support Group was held in May 2009 at Glassey Park community sports complex in Berri with 14 people attending. Since then, the Support Group has met monthly. This provides a regular opportunity for clients to socialise outside the home, learn more about their conditions, and to support each other. The social aspect has emerged as a high priority for the members. The group members also have access to point of care testing, guest speakers are arranged for the group on request and there is a strong emphasis on healthy eating with interactive food preparation and cooking occurring almost every month. The RCHS staff members assist by arranging visiting speakers, providing transport, hiring the venue, and supplying food and resources. Appendix 17 shows the schedule of meeting topics.

The numbers of people attending has steadily increased over the two years since it began, with new people coming each month as word spreads. During 2010, the number of people having attended the group at least once was 32, and 39 people attended up to September 2011. Over 70 people are now on the Support Group mail-out list. More importantly, over this period a core group of around a dozen participants has emerged, whose regular attendance and participation ensure its longevity and capacity for growth.

The Riverland Aboriginal Chronic Disease Support Group is unusual in that it is open to both men and women, and is community-driven. Whilst most existing support groups in other areas are specifically tailored for people with type 2 diabetes, this group set out from the beginning to cater for all chronic conditions. During the first year of meeting diabetes was the most common chronic disease, but several other conditions were also present; heart or cardiovascular issues, asthma, cystic fibrosis, kidney disease. Mental health issues were also common, and over time it came to be recognised that depression was a common co-morbidity, and that most clients were likely to be living with more than one chronic condition.

A founding member of the group gave a presentation about it to a SA Health forum in February 2010 [53]. She identified the following factors contributing to the group's success: interesting guest speakers, transport assistance, people have input into what they like and need, learning to take control of their own health, shared resources, opportunity for community and health professionals to interact in a neutral environment.

Comments from participants and staff confirm this view:

*You meet a lot of people, and you do a lot of talking, and you listen to the people's stories. You communicate and you're not sort of isolated. (client 14)*

*We just need to know when the meetings are and what's going on then we can attend. ...Part of what's good about that group, you can do what suits you... You've got speakers and that, and you either listen to them or not, you know what to expect, so, it's good in that way. (client 10)*

*It certainly helps the networking, and making sure that clients are getting that coordinated care and getting those referrals on and stuff like that, and just helping with that follow through to happen for clients. Because health is a bit of a mine field really, when you try and, you know, access different services, and you've got to jump through this hoop to do that, and all the rest of it. (staff 12)*

A Community Storybook was developed through this research project to celebrate the first two years of the Riverland Aboriginal Chronic Disease Support Group and to show how Aboriginal people from the Riverland are taking an active part in managing their long-term illnesses in partnership with health professionals [54] (Appendix 18). The idea for the Community Storybook came from community members attending initial meetings of the Support Group, where they were shown a range of leaflets and booklets about chronic conditions. One booklet in particular was of great interest: 'Look, Think, Act: Indigenous stories about living with diabetes' [55] from Aboriginal Elders living in Port Lincoln. There were several requests from Riverland Aboriginal Chronic Disease Support Group members for a similar booklet to be produced as part of the current research project, to give a voice to the Riverland Aboriginal community living with chronic conditions. People who signed informed consent to participate in the research project were very keen to have their stories recorded as part of the project. The research team worked closely with participants on the design and content of the Storybook. It tells how and why the group was formed, some achievements and benefits, and several stories and tips from individual members. It also describes how the RCHS is involved, some related activities in the region and how this work fits into this research project. It is hoped that this storybook will inspire and encourage Aboriginal people to take control of their health, and to live well despite their chronic conditions.

## Moorundie Ruwe Nunga health expo

During this project the RCHS Aboriginal Health Team organised the Moorundie (river) Ruwe (country, or land) Nunga health expo on Wednesday, May 12th 2010 at Glassey Park, Berri. Another expo was held in 2011. The idea was to promote the health services available in the region, and encourage Aboriginal clients to access them, because it had been noted that many Aboriginal people did not know about the services, or were reluctant to use them.

This research project supported the expo as a way of encouraging people to have a comprehensive health check, and raising community awareness of risks and signs of chronic conditions, and of the services and supports for managing them. This project also promoted the expo through the Aboriginal Health Council of SA newsletter [56].

There were 16 health checks at the expos that clients could engage with, including hearing, dental, nutrition, physical activity, diabetes, emotional health, smoking, alcohol, medications and sexual health. At the 2010 expo there was a GP present to review their health check and assist with referrals and appropriate follow up. At the 2011 health expo, no GP was present, so follow up of issues was left to the client to arrange with a GP of their choice. Once again, due to the RCHS not being an Aboriginal community controlled health service, access to a GP was through the private medical centres.

## Health services sharing experiences

One of the objectives of this project was for participating health services to share their experiences of implementing strategies for managing chronic conditions, and to transfer successful approaches to other settings where possible. They were kept up to date with each others' strategies and this project's activities through communiqués, and regular research visits and annual Advisory Group meetings held at the different project sites.

PLAHS already had a well established system for coordinated and comprehensive care of people with chronic conditions before this project began, whereas Nunkuwarrin Yunti and RCHS were still developing theirs. Nunkuwarrin Yunti's Strategic Plan 2010-2013 includes client and community access to coordinated services that promote continuity of care and reflect a client centred journey to health and wellbeing. Nunkuwarrin Yunti was keen to learn from PLAHS' successful experience, with a view to applying some of that learning. For example in April 2011, the project facilitated a visit by the Public Health Medical Officer and the Senior Medical Officer from Nunkuwarrin Yunti to PLAHS, where they observed and discussed the holistic, client-centred model of care that PLAHS has developed over the years. The visit focussed on organisational aspects of chronic disease care planning and review, how clients move through the various parts of the health service, the clinical information management system, how health workers engage with the Flinders care planning process and the changes that PLAHS has made to the Flinders Program™ tools. This visit was followed by two PLAHS chronic disease team staff members attending the Nunkuwarrin Yunti Flinders Program™ workshop in May 2011, where they shared their experiences and discussed strategies with the Nunkuwarrin Yunti staff being trained. These interactions were encouraging to the senior clinician responsible for the necessary reforms in implementing the chronic condition management model at Nunkuwarrin Yunti. She commented that having seen how smoothly and efficiently care planning works at PLAHS she felt more optimistic about implementing system change at Nunkuwarrin Yunti.



# Effectiveness of chronic condition management strategies – Analysis of health outcome data

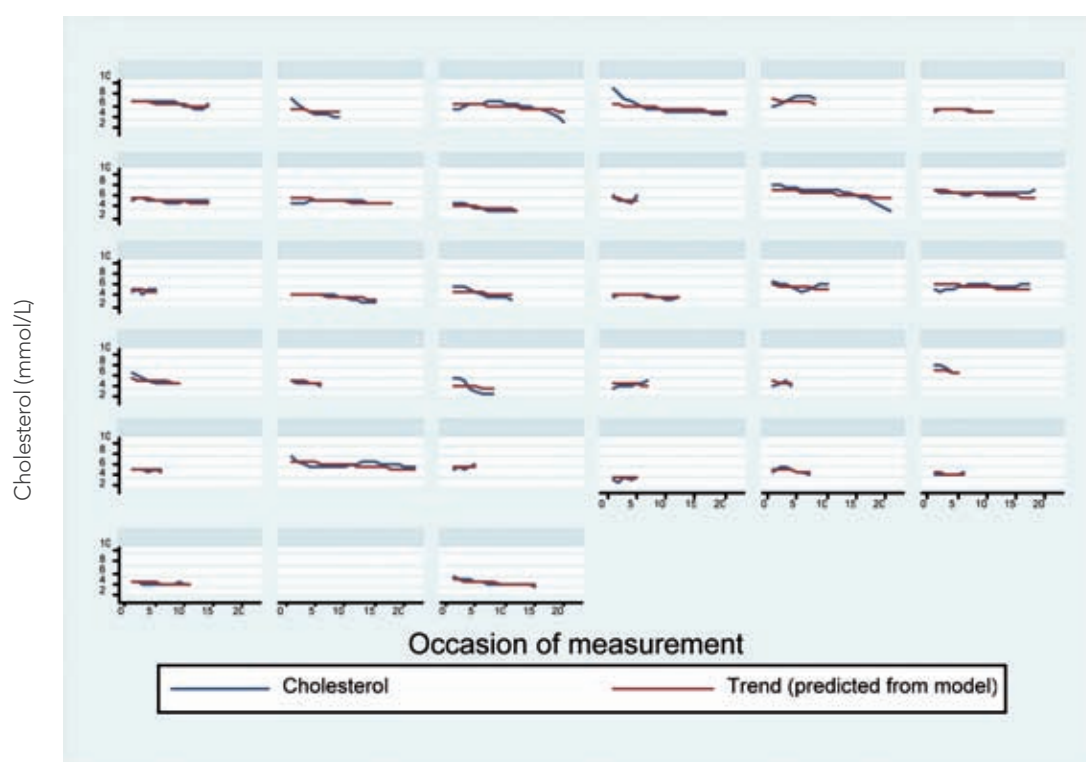
## Analysis of complete dataset

A group of clients (24 from PLAHS and 12 from Nunkuwarrin Yunti) gave consent to access clinical data from their electronic records, some spanning up to 10 years. Key clinical indicators of health (HbA1c, lipids, BMI) were measured at most client visits, these data were extracted from the core data set along with the date of the test. The combined dataset provides a longitudinal record of health status for this group, and the opportunity to demonstrate improvements that might be associated with structured chronic condition management strategies. Statistical analysis using the Random Effects Modelling method [38-40] was applied to the data to determine if there were significant trends over time.

The Random Effects Modelling method is a robust statistical technique but requires normally distributed data. Only HbA1c and triglyceride scores required log transformation as their frequency distributions were right skewed. Data from clients with less than 4 time points were excluded from analysis.

Individual client profiles were visually checked to see how well the model fits. For example, Figure 2 shows the cholesterol profiles (blue) and the trend lines predicted from the model (red) for each client. In each case the horizontal axis represents occasion of measurement. It can be seen that individual cholesterol profiles vary in how well they fit the model, but that the trend lines are mostly going in similar directions, ie decreasing over time. Similar profiles were developed for other clinical indicators (HbA1c, BMI, HDL, LDL and triglycerides).

Figure 2. Individual clients' cholesterol profiles vs occasion of measurement, actual values and predicted trend



The next step was to perform a group analysis to determine if the trends were statistically significant and clinically important. Results are summarised in Table 3.

**Table 3.** Change in clinical indicators over time, summary statistics for combined group of 36 clients from PLAHS and Nunkuwarrin Yunti

Clinical indicator	Statistical significance of change (p)	Effect size (Cohen's d) and clinical importance	Intra-cluster correlation	Change over time and 95% confidence interval
HbA1c	Significant (p = 0.000)	0.22 (small)	75%	-0.005 (-0.007, -0.003)
BMI	Significant (p = 0.000)	0.21 (small)	82%	-0.115 (-0.175, -0.055)
Triglyceride	Significant (p = 0.043)	0.15 (very small)	65%	-0.114 (-0.022, 0.0003)
Total cholesterol	Significant (p = 0.000)	0.32 (small)	45%	-0.076 (-0.103, -0.049)
LDL	Significant (p = 0.001)	0.34 (small)	53%	-0.074 (-0.105, -0.043)
HDL	Not significant (p = 0.473)	0.02 (negligible)	62%	0.002 (-0.004, 0.009)

The analysis for the combined group of 36 clients shows that the overall changes over time are negative where a drop is the desired health outcome (HbA1c, BMI, triglycerides, total cholesterol, LDL) and positive where an increase is the desired outcome (HDL). So it can be concluded that the trends are in the right direction. These changes were all statistically significant ( $p < 0.05$ ), except HDL which did not change significantly overall. Furthermore the effect sizes for HbA1c, BMI, total cholesterol and LDL, although small, were all in the range accepted as clinically important, i.e. Cohen's d effect size is between 0.15 and 0.40 [57-58]. All the clients in the group were involved in some form of structured chronic condition management, ranging from effective self-management with clinical support at one extreme to simple diagnosis and medication support at the other, over the data collection period. Therefore the results support the hypothesis that chronic condition management strategies are associated with improving health status, as has been demonstrated in other programs involving Aboriginal people [14, 16, 59-60].

## Analysis of PLAHS sub-set

The smaller group of 24 clients from PLAHS alone was also analysed separately in order to provide relevant local information to that health service. Summary results are shown in Table 4 and broadly mirror those of the larger group. Trends in all the clinical indicators decreased significantly, except the 'good cholesterol' or HDL where an increase in this value is desirable, indicating improvement in health status over time. Small but clinically important effect sizes were observed for HbA1c, total cholesterol and LDL. As in the larger group, the biggest effect sizes were seen for total cholesterol and LDL. Since PLAHS operates a well-established model of

chronic condition care with most clients involved in self-management, this is strong evidence of an association between this structured chronic condition management strategies and positive health outcomes of clients.

**Table 4.** Change in clinical indicators over time, summary statistics for subgroup of 24 clients from PLAHS

Clinical indicator	Statistical significance of change (p)	Effect size (Cohen's d) and clinical importance	Intra-cluster correlation	Change over time and 95% confidence interval
HbA1c	Significant (p = 0.000)	0.26 (small)	73%	-0.005 (-0.007, -0.003)
BMI	Significant (p =0.047)	0.12 (negligible)	89%	-0.048 (-0.0965, -0.001)
Triglyceride	Significant (p =0.044)	0.05 (negligible)	54%	-0.114 (-0.022, 0.0003)
Total cholesterol	Significant (p 0.000)	0.36 (small)	41%	-0.094 (-0.126, -0.061)
LDL	Significant (p = 0.000)	0.35 (small)	55%	-0.017 (-0.106, -0.039)
HDL	Not significant (p =0.302)	0.06 (negligible)	56%	0.004 (-0.003, 0.011)



# Effectiveness of chronic condition management strategies – Selected client analyses of health outcome data

Clinical indicators from the Communicare records from 24 PLAHS clients and 12 Nunkuwarrin Yunti clients were plotted against time, along with dates of chronic condition management interventions eg initiating care plan or GP management plan, attending diabetes camp or LIFE course. These graphs were considered alongside other information from the clinical record (eg new diagnoses, medications, procedures) and other events recalled by clients at interview (where available). The intention was to look for an association between measurable health outcomes and chronic condition management strategies. Some examples are shown below. Pseudonyms are used to safeguard anonymity and confidentiality.

## Andrew

Andrew is an Aboriginal man in his 60s and has been living with type 2 diabetes for over 15 years. In 2000 he found out he had hypertension and hyperlipidaemia as well. Although Andrew is a busy man with many community responsibilities, he is keeping his chronic conditions under control and staying well with the help of the chronic disease team at his health service.

Andrew became a client of the health service in 2000, and an initial care plan was developed in early 2002. Further care plans were developed in 2003, 2004, 2005, 2009 and 2010. Most of these were based on the Flinders model, whereby Andrew and the chronic disease team worked in partnership to develop care plans, focused on his own goals and abilities.

Andrew explained that the care plans helped him understand what was needed in his daily life, other than medications, to keep his chronic conditions controlled. Nowadays Andrew enjoys a healthier diet with more vegetables and fruit, oily fish, and leaner meats. He drinks less alcohol and doesn't smoke any more, monitors his blood sugar daily and takes medications as prescribed.

Andrew's care plan goals included making diet and lifestyle changes that he felt comfortable to make. Generally this was a compromise between the ideal recommended by the health team and what was meaningful, tasteful and acceptable to him:

*I haven't got big goals. It's what do I need to change (in my diet, lifestyle), that I feel OK about doing. It's a balance of what is recommended as ideal and what I can and want to do in my life.*

Walking more is a recent care plan goal, but is proving difficult as Andrew has poor circulation and needs to rest often. He has an exercise bike at home that he uses while watching television when he feels like it. His many commitments mean that he is often away travelling, but he intends going to the gym when he can.

Andrew appreciated the help of the chronic disease team at the health service, including reminders about quarterly care plan reviews:

*I've got someone working with me ... It's good having someone else to talk to about it.*

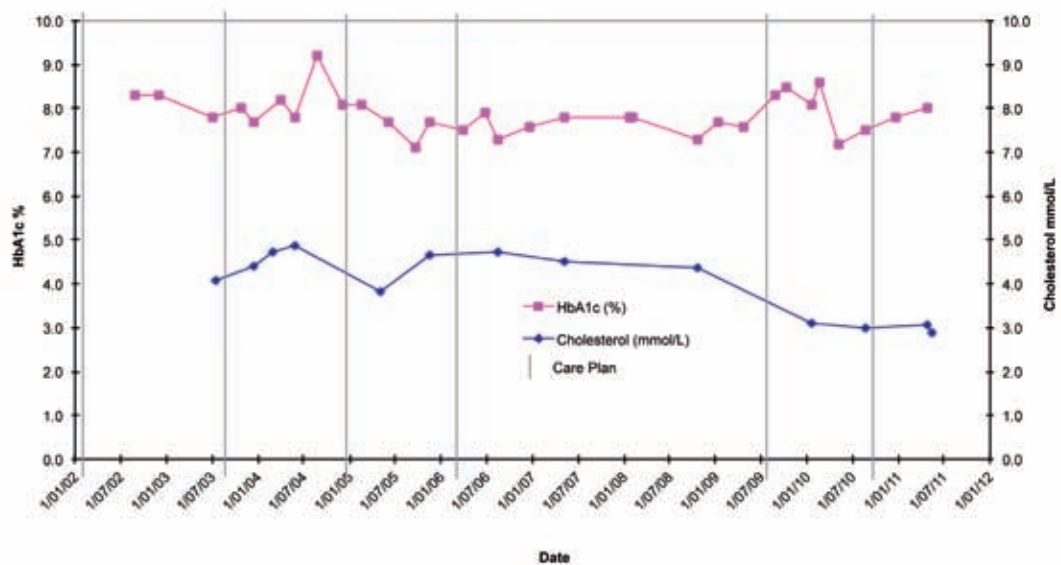
The fact that the health service is Aboriginal community controlled was important to Andrew. He remarked that compared to the rather cold atmosphere at mainstream GP clinics, the friendly environment and chatty staff at the Aboriginal health service who know and care about

him make him feel comfortable and at ease, and consequently more receptive to health advice:

*They're there to help and I'm prepared to be helped.*

As part of the care planning process Andrew had regular point of care blood tests to monitor his conditions. With his permission these data were extracted from the Communicare client record and are shown in Figures 3 and 4. Overall they show stable or improving values, explained in more detail below. Dates when care plans were initiated are marked as vertical lines.

Figure 3. 'Andrew', HbA1c and total cholesterol change over time

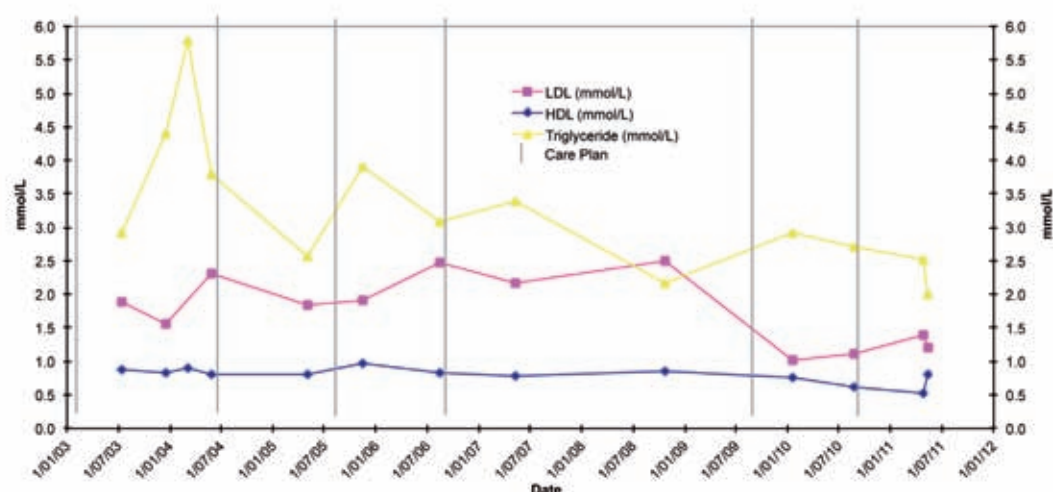


HbA1c is an indicator of diabetes control. Figure 3 shows that HbA1c readings were fairly stable at around 8% throughout, approaching the medically recommended target of <7% [61]. Clearly Andrew's diabetes management was satisfactory throughout the period of measurement.

Similarly during these years as a client of the health service Andrew's total cholesterol levels were good, trending gradually downwards over time and in the last 2 years reaching recommended safe levels of <4 mmol/L [62].

Because Andrew was diagnosed with hyperlipidaemia (elevated blood fats), a closer examination of how his lipid profile changed over time was warranted. Figure 4 shows the time courses of 'bad' cholesterol (LDL) and 'good' cholesterol (HDL), as well as blood triglyceride. It can be seen that the 'bad' LDL values trended down, and by 2009 had reached safe levels of < 2.0 mmol/L. [62]. The 'good' HDL concentrations were relatively stable throughout, approaching the recommended level of >1.0 mmol/L [57]. Triglyceride levels also trended down overall, but remained within the borderline – high risk range [62].

Figure 4. Andrew, Triglyceride, HDL and LDL change over time



Andrew's health care history and the clinical information shown in these graphs support the idea that structured care planning at his Aboriginal health service contributed to his effective chronic condition management and good clinical outcomes. Importantly, Andrew's story shows that it is OK to compromise, and that being an active partner in managing his chronic conditions and setting achievable goals helps him to stay well. Andrew says:

*I'm doing OK without busting a gut. I'm doing it the way I feel comfortable with it. ... I have a life and I live it my way. And these things [chronic conditions] I have, I will deal with as I go along.'*

Andrew acknowledged the support of his wife and the chronic disease team at his Aboriginal health service team in managing his conditions:

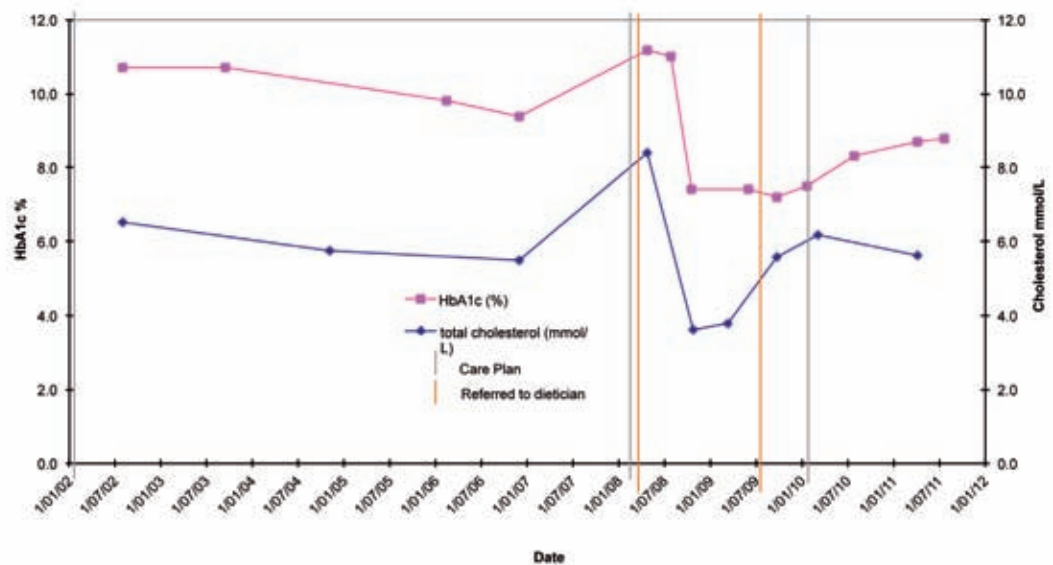
*I feel OK with what I'm doing now, with what I have around me.*

## Betty

Betty has type 2 diabetes, first diagnosed in 1996. Many of her close family members had diabetes, so she had some understanding of the disease and its long term effects. Nevertheless she considered her condition to be 'borderline' and thought it wouldn't get any worse. Although she had cared for her parents, both of whom had diabetes, and made sure they ate healthy food suitable for diabetics, she did not fully accept or address her own health problems until many years later.

She became a client of the Aboriginal health service in 2000 and was prescribed oral medication for the diabetes. In 2002 her first care plan was developed. The clinical record over the following 6 years indicates only occasional visits to the health service for monitoring and medicines. Betty recalled that during that time she was grieving for family members who had passed away, 'drowning her sorrows', in denial about her diabetes and continuing with unhealthy lifestyle habits. Figure 5 shows how this is reflected in her HbA1c levels (an indicator of diabetes control) which remained at dangerously high levels throughout this period, reaching 11.2 % in 2008. Her total cholesterol levels were also very high during this time, reaching a maximum of 8.4 mmol/L.

Figure 5. Betty. HbA1c and cholesterol change over time



The death of yet another close relative in 2008 through complications of diabetes and alcohol was a turning point for Betty. She realised the severity of her own chronic health problems, how tired and miserable she felt all the time, and resolved to make changes to her lifestyle to avoid a bleak future and early death. She began attending the diabetes clinic at the Aboriginal health service regularly and was referred to a dietitian. Insulin was prescribed to help control her diabetes, as well as statins for high cholesterol.

A new care plan was developed in April 2008. Her personal care plan goal was to change her lifestyle habits. Betty described how she gave up alcohol and fast foods completely, radically changed her diet (home-cooked meals at regular times, reduced fats and sugars, plenty of fresh vegetables, less meat, porridge for breakfast), built exercise (walking) into each day, and took medications regularly as prescribed. As a result of these efforts her HbA1c and total cholesterol levels dropped markedly to safer levels, as shown on the chart. Betty told how much better she felt in herself during this time. She credited her success to the care plan, her own determination and focus on managing her chronic condition, assistance and encouragement from the chronic disease team at the health service, and her supportive partner.

In November 2009 Betty was feeling well enough to work, and found employment in a local factory. Unfortunately, the inflexible work conditions meant that her meal and medication routines could no longer be maintained and that exercise was hard to fit in. She soon noticed her health declining as a result. The chart also shows that HbA1c concentrations stopped falling at that time and then began climbing again. Similarly her cholesterol levels began to rise again.

Betty eventually left that job in mid 2010 for the sake of her health. She resumed her healthy lifestyle routines and her care plan was updated. Within a few months the upward trend in HbA1c levels began to flatten out, and cholesterol levels dropped again.

Betty remains committed to managing her chronic condition in partnership with the PLAHS team. Giving up smoking, regular exercise at the gym and losing weight are her current personal goals. She is an advocate for the care planning process and encourages others in her community to get involved. Her story shows that she is managing her conditions effectively in partnership with the health service, guided by a care plan tailored to her goals and abilities. Betty says:

*If you control your lifestyle you are in control your life... Always be true to yourself, acknowledge your gains and losses.*

## Grace

Grace is an elderly Aboriginal lady who has been living with a number of chronic conditions for many years, and has been actively involved in the structured system of chronic disease care at her Aboriginal health service. With her consent, we accessed her clinical record from the Communicare system to find out how key indicators of her health varied over time and in relation to her care.

Grace already had hypertension when she became a client of the service in 2003, and osteoarthritis was diagnosed in 2004. Prescriptions at this time included blood pressure-lowering drugs, anti-inflammatory medications for the arthritis, and also cholesterol-lowering drugs. A Flinders model care plan was developed in 2003, and reviewed and updated in 2004, 2005, 2008 and 2009. Care plan development entailed the chronic disease team at the health service and Grace working in partnership to identify her main problems and goals and capacity to self-manage, and then agreeing on an action plan to achieve those goals and manage her conditions.

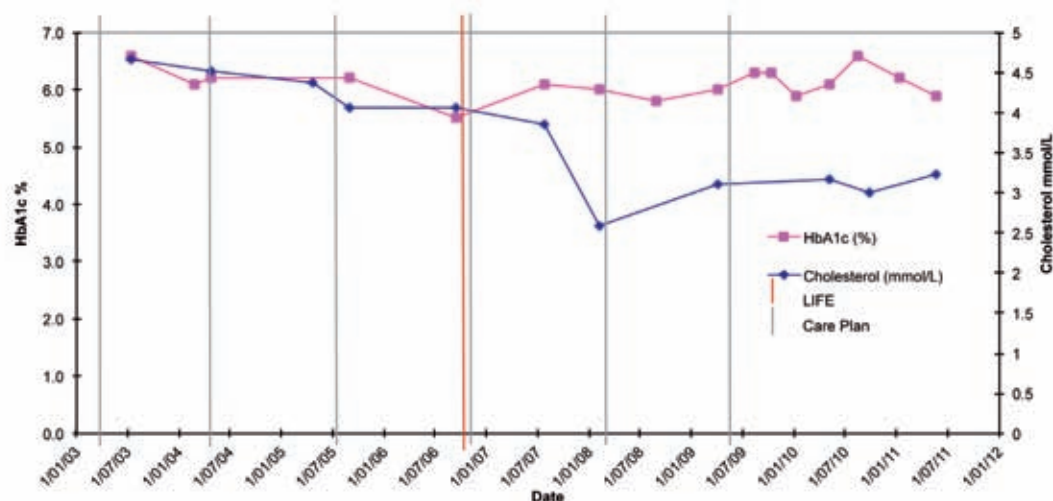
Grace participated in a Living Improvements for Everyone (LIFE) peer support program for people with chronic conditions in late 2006. This program, based on the Stanford model of self-management support, was modified to suit Aboriginal people [14, 27, 43, 59] and has now been delivered to many communities and organisations around Australia.

In 2007 Grace was diagnosed with type 2 diabetes. For the next 3 years this was managed without medications, ie with diet and exercise alone. Lifestyle assessments (diet, smoking status and alcohol consumption) were conducted twice a year from 2007 onwards; no problems requiring intervention were identified (her diet was always assessed as balanced, she was an ex-smoker and consumed alcohol within safe limits). According to her clinical record, the diabetes medication Metformin was prescribed from 2010 onwards, and insulin has not been necessary.

Care plans included the 'Partners-in-Health' tool to assess self-management capacity [63-64]. Grace's Partners-in-Health scores increased from 0 in 2003 to 3 in 2005 and 17 in 2008, reflecting increased confidence and ability to manage her own health.

Figure 6 plots her total cholesterol and HbA1c against calendar time. Dates when care plans were initiated are shown as vertical lines. The chart shows that her HbA1c (an indicator of diabetes control) was well controlled throughout the period of measurement, remaining below the medical target of 7.0%. Similarly Grace maintained healthy blood lipid levels, with total cholesterol always below the medical target of 4.0 mmol/L, and trending downward over time. This information supports the idea that structured care planning and self-management support contributes to good clinical outcomes.

Figure 6. 'Grace', HbA1c and cholesterol change over time



## Daria

Daria is an Aboriginal lady in her 70s who has been a client of the Aboriginal health service for over 20 years. During the 1990s she was diagnosed with several chronic conditions including arthritis, hypertension, asthma, emphysema and type 2 diabetes. Oral medications were prescribed to treat these conditions. The clinical record indicated that Daria visited the clinic 2-3 times a year during this time for her prescriptions, and for occasional help with other acute illnesses eg infections.

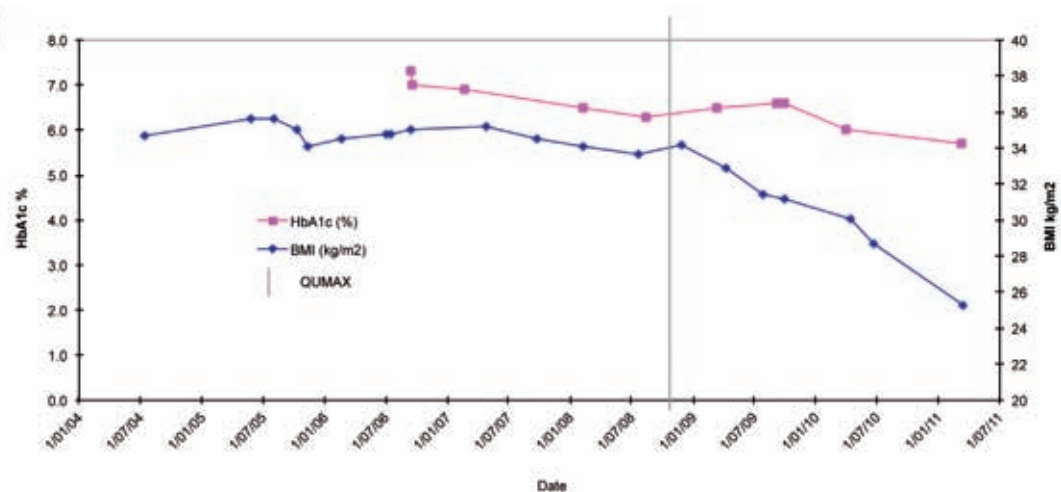
From 2005 onwards Daria visited the clinic more frequently, on average 10 times a year. Also, results of regular clinical tests were entered in the health service's Communicare system from 2005 onwards. Assessments of Daria's diet, smoking status and alcohol consumption were conducted in 2006, 2007, 2008 and twice in 2009, but no problems were identified as she was always assessed as having a balanced diet, she no longer smoked and consumed alcohol within safe limits.

Mental health conditions related to grief and loss, eg stress, anxiety and feeling run down, were diagnosed throughout the 2000s. Sadly, several of Daria's close family members died during this time. However, there were no prescriptions or interventions for these conditions noted in her clinical record.

Figure 7 below shows how some of Daria's key health indicators changed over time. HbA1c concentration, a measure of diabetes control gradually decreased over time, and was at or below the medical target of 7.0% throughout and gradually decreased over time. Clearly Daria was keeping her diabetes under control. Her body mass index was mostly in the obese range, but also gradually trended downwards over time, reaching near-normal values by 2011.

In 2008, Daria joined the QUMAX program [47], which provided medication support. There were no records of care plans or GP management plans for her chronic conditions through the health service in the available data. Nevertheless, her steady improvement in health, frequent visits to the health service for prescriptions and tests, and maintaining a healthy lifestyle, suggests that Daria has been actively involved and committed to managing her chronic conditions.

Figure 7. 'Daria' HbA1c and BMI change over time





# Benefits of chronic condition management strategies – evidence from interviews

Analysis of interviews with clients from all three sites identified five main benefits of chronic condition management strategies:

- > New knowledge about chronic conditions and chronic condition management
- > Empowerment and taking control of own health
- > Setting and achieving personal goals
- > Reassurance and keeping track of progress
- > Feeling better and avoiding complications

These are discussed below.

## New knowledge about chronic conditions and chronic condition management

Clients wanted information about chronic conditions and how to manage them. They appreciated opportunities to learn more through interaction with health professionals and through their own efforts, eg:

*But it's good that we got people coming and having discussions with us and, it's education you know, which we need, education. The right foods to eat, how much sugar is in this and if it's salty... (client 14)*

*I think the other thing there is the learning, the knowledge. I'm learning all the time. When I first got diabetes, people didn't know much about it. And now, over a long time, I've learnt lots of different things like, you know, wearing socks that are very tight can cut the circulation off to your feet. And so the learning, I think, has been amazing because from way back then, when they just told you, "You've got diabetes type 2" to now, where we know all the different things about it, about the whole thing. Like, you know, your eye sight can suffer, you can have problems with your heart. .... So I think that coming to PLAHS has been a really good thing because it's the knowledge that we're talking about all the time. And that makes a difference because then I know what sort of things I can do to help that. (client 8)*

Some clients were critical of the lack of information provided in traditional medical consultations and had useful ideas about improving the way health information is explained to Aboriginal people, eg:

*They need to tell you a little bit more nitty gritty stuff. I've been finding out slowly from different people, the effects that diabetes can have on you ... but I've learnt now that you don't have to go that way [insulin dependence], you can look after yourself more. (client 11)*

Another talked about being encouraged by her parents to seek out health information, and how she is passing that on to the next generation:

*My mum and dad they got to educate themselves, they went and said we need to know all about what we've got wrong with us so ... they learned how to manage their diabetes and they passed that on to their children. So that we were able to look at them and say well they did it, we're going to do what they did. And so that's what I did and tended to do that with my kids. ... It's better to be educated because if things go wrong you know what to do. Because otherwise if you go to the doctor when you're really half dead then it's your fault, you're to blame because you should've done it before. (client 8)*

Clients explained how regular attendance at the health service increased their understanding of clinical markers of their condition, such as blood pressure or lipid profile, and how monitoring those markers helps them self-manage their conditions:

*They say, oh you know, your sugar level's too high, your cholesterol's too high and your blood pressure's too high, and if I'd had stopped going I wouldn't have got to knowing all this, but now ... when I go down to get my check up, well I know all that and I know what I've got to do. I've got to get all the three things down and to improve my health, and yes, it's a good idea. I love it. (client 3)*

Health professionals agreed that clients gained valuable understanding of their chronic conditions and how to manage them, especially through the care planning process, with positive impact on wellbeing:

*I think that the care planning process works well. It is worker-driven a fair bit but I think with some of the actual clients that have done it for a long time they are starting to manage better, like self-manage better and understand what they need to stay well, whereas for the new people, for a lot of them it is a real learning thing and they didn't realise or they didn't know that they needed to have those sort of things done throughout the year, like for diabetes, the podiatrist, the optometrist checks, that sort of stuff, and just access to doctors on a regular basis as well, every three months. I think that is a whole lot better than what it was when they weren't on a care plan, so they might not go see a doctor for three years and in that time their condition could have worsened. So I think it actually improves their health. (staff 8)*

## Empowerment and taking control of own health

Following on from increased knowledge about their conditions and what can be done to live well despite having long term illnesses, clients gained the confidence to take more control and be actively involved in managing their health:

*I just thought to myself well I've got it and I've got to learn about it, what is diabetes. So then I started reading up, and seeing what food to eat, and how to keep it under control, so I never really panicked. Yeah, I just thought to myself, well, it's up to me to control it. (client 14)*

*But, as I've learnt, going on the care plan, it's all about looking after yourself, eating the proper foods and drinking plenty of water, and I'm doing that. (client 4)*

Increased client confidence was particularly apparent at PLAHS where care planning and support for people with chronic conditions was well established:

*And they make it seem like, you know, at the beginning when I did it and they told me I had to do all of this I've gone, Oh, God, I'm not doing that. They made it sound like it was that hard. But after sitting down with them and doing a care plan put everything into perspective and now I see where I was making mistakes. ... I think the ladies here, the care plan, when you come here and you see them and they set everything out for you it made it a bit easier for me... Yes, I thought, I can deal with this. (client 7)*



One client eloquently explained how taking control and changing the lifestyle factors contributing to her chronic conditions led to increased wellbeing:

*If you control your lifestyle, you get your life back, you're in control of your life. Then it's not like the packet of chips is in control of you, the Coke's not in control of you. I feel I'm in control of my life now, which means I feel a lot happier. I was miserable before. (client 7)*

This idea of client empowerment through involvement in managing their own health problems was echoed by health professionals, eg:

*I so believe in the concept of self-management, particularly in the Aboriginal population, because I think it serves a dual purpose. Apart from everyone who has got a chronic condition should learn to some degree how to self-manage, as far as possible to self-manage, I think for the Indigenous population, it becomes an additional empowering tool, and because chronic conditions are so much more prevalent, that to me there is an inherent benefit in being able to do that. (staff 2)*

## Setting and achieving personal goals

Once clients understood more about their chronic conditions and management, and were confident enough to take some responsibility and be active partners in their health care, they were able to set and achieve realistic goals:

*I know I'll never, I can't say, oh well I'll knock diabetes out. I know that's one thing that will never happen, but there is goals that I, that I do want to reach you know. I don't know if I will or not, you know, but I'm a strong person so when I make up my mind. (client 14)*

Some goals were specific medical goals, for example several clients with diabetes aimed to reduce blood sugar concentration to a certain level:

*My sugar was very high. It was sitting up in the elevens and twelves and I was thinking hey this is not on for me... So I've actually kept it down. I'm keeping it between six and seven, normal. (client 4)*

Other clients focused on losing weight, eg:

*I just piled on all this weight, but I'm gonna lose it, my goal is to get back to sixty five [kg]. Sixty five is good for a person my size. (client 4)*

Changing eating habits and maintaining a healthy diet were also common goals, eg:

*I have achieved a regular diet, a healthy one. (client 7)*

Other client goals included giving up smoking, cutting down on alcohol and exercising more.

When clients achieved their goals they spoke with pride of their achievements, eg:

*I've dropped back to a size fourteen, and yeah, so I need to get some more clothes. ... I feel so happy, you know, like I'd just won an Olympics. (client 4)*

*I buy stuff, I'll keep them here and it's how strong I got to be as to how long they last. So, I bought a cream bun ... and then I find it still in the fridge two days later and I chuck it out, and I don't consider that a waste of money. To me, that's me being strong and I really didn't need it. (client 11)*

## Reassurance and keeping track of progress

Regular interaction with health professionals and having a good knowledge of what the changes in clinical markers of chronic conditions mean was helpful to clients. It allowed them to monitor their progress, make adjustments where necessary to their care, or simply to be reassured that they were on the right track eg:

*That's why I think with the care plans and that it's helping me to control my life much better because if I was going to a doctor and they didn't check any of those things, how do I know what's going on with myself? (client 8)*

*It keeps a record of how my situation's going, is it improving, have I got it under control, if not well then he said, 'Right'o ... it looks like you're doing this and you need to do that' (client 3)*

## Feeling better and avoiding complications

Several clients told how much better they felt as a result of being involved in managing their chronic conditions, eg:

*I've lost nearly 8kg. I feel good now. When you bend and you can do your own laces up! (client 3)*

*I was feeling better, I could run a mile I reckon and I lost that much weight just by eating right and getting off the alcohol. (client 7)*

There were also flow-on benefits for other family members:

*It's made a difference to our whole family not just me, it's passed on to my family, my husband the same, he's lost weight and he's exercising and he's feeling a lot better. He was really excited the other day because he got his blood sugar down. (client 8)*

Another advantage of being a partner in one's own chronic condition management was knowing the danger signs for potential complications and seeking prompt help: eg:

*Like the other day I had a really sore foot, I didn't know that it was sore because I don't have a lot of feeling in my foot. I noticed a red line, came in to see the nurse and she said 'look you need to go to the doctor straight away', booked me in and got antibiotics straight away.... I've educated myself to know that I need some help here and there. (client 8)*

# Barriers and enablers of chronic condition management strategies

Integrated thematic analysis of all the qualitative information collected from clients and staff at all three sites was conducted to identify barriers and enablers of structured strategies for managing chronic conditions. A number of themes and sub-themes emerged. Themes could be classified into (A) health system and service, (B) staff or (C) client-related themes. Depending on the context, many themes had both enabling and hindering aspects, summarised in Table 5.

**Table 5.** Barriers and enablers of chronic condition management

	Themes	Enabling aspects	Barrier aspects
A. Health system and service-related themes	A1. Accessible, appropriate and affordable health services	<ul style="list-style-type: none"> <li>&gt; Transport assistance to clinic</li> <li>&gt; Mobile clinic</li> <li>&gt; Wide range of health services available in region</li> <li>&gt; Assistance with Medicare rebates and other concessions</li> <li>&gt; Aboriginal community controlled health service</li> <li>&gt; Culturally safe service provision</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Lack of transport</li> <li>&gt; No, few or inconsistent health services</li> <li>&gt; Limited access to services that bulk bill</li> <li>&gt; Racism, fear and distrust of mainstream health services</li> <li>&gt; Family and community politics</li> </ul>
	A2. Clinical information management system	<ul style="list-style-type: none"> <li>&gt; Effective clinical information system (Communicare) in routine use across the health service</li> <li>&gt; Communicare routinely used for chronic condition monitoring, client recall and care plan review</li> <li>&gt; Comprehensive and accurate data input</li> <li>&gt; Enables accurate service activity reporting</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Client information stored in incompatible clinical information systems</li> <li>&gt; Incomplete records</li> </ul>
	A3. Coordination and team care arrangements	<ul style="list-style-type: none"> <li>&gt; Holistic, 'no wrong door', 'one stop shop' approach</li> <li>&gt; Established protocols for assessment and referral</li> <li>&gt; Established care planning processes</li> <li>&gt; Core team focused on chronic condition management</li> <li>&gt; Appointments coordinated to save clients and staff time</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Ad hoc arrangements</li> <li>&gt; Poor coordination within and between the health service/s</li> <li>&gt; Care planning, referral and monitoring processes not established</li> <li>&gt; Identified health issues not followed up in a timely manner</li> <li>&gt; Organisational inertia, senior staff slow to implement a coordinated system of chronic condition management</li> </ul>

	A4. Facilitating peer support	<ul style="list-style-type: none"> <li>&gt; LIFE peer support course for Aboriginal people with chronic conditions</li> <li>&gt; PLAHS diabetes camps</li> <li>&gt; Riverland Support Group meeting clients' needs</li> <li>&gt; Walking groups, gym</li> <li>&gt; Diet and cooking groups, Nunga Kids café</li> <li>&gt; Men's, women's groups</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Support groups not available</li> </ul>
<b>B. Staff-related themes</b>	B1. Staff capacity and training in chronic condition management	<ul style="list-style-type: none"> <li>&gt; Training (eg Flinders Program™) widely available at no cost through government initiatives</li> <li>&gt; Training continually modified for Aboriginal staff and contexts</li> <li>&gt; Staff training encouraged and expected by the health service.</li> <li>&gt; Strategies learned from training implemented into routine practice</li> <li>&gt; Core chronic condition team members mentor and assist colleagues</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Shortfalls in Aboriginal and other staff numbers</li> <li>&gt; Many Aboriginal health workers lack clinical and other basic knowledge</li> <li>&gt; Training not completed due to lack of time, interest, encouragement</li> <li>&gt; Lack of confidence to implement learned strategies into practice</li> </ul>
	B2. Engaging with clients and community	<ul style="list-style-type: none"> <li>&gt; Aboriginal community-controlled service meeting community expectations and needs</li> <li>&gt; Promoting local health services</li> <li>&gt; Taking the time to develop rapport, trust</li> <li>&gt; Holistic, client focused approach</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Lack of community understanding about available services</li> <li>&gt; Poor communication</li> <li>&gt; Narrow, disease focus</li> </ul>
	B3. Encouraging and supporting clients	<ul style="list-style-type: none"> <li>&gt; Clients decide extent and pace of involvement in chronic condition management</li> <li>&gt; Staff support and advise clients, but don't dictate</li> <li>&gt; Genuinely care about clients</li> <li>&gt; Staff available to discuss problems</li> <li>&gt; Staff motivate clients to strive for realistic goals</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Lack of staff for ongoing follow up and support</li> </ul>
<b>C. Client-related themes</b>	C1. Client knowledge of chronic conditions and how to manage them	<ul style="list-style-type: none"> <li>&gt; Acceptance of chronic conditions</li> <li>&gt; Awareness of the body and how it responds to the chronic conditions and treatments</li> <li>&gt; Opportunities to learn about chronic conditions and how to manage them, and desire for this knowledge</li> <li>&gt; Information provided in appropriate form</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Denial of chronic conditions</li> <li>&gt; Lack of interest or opportunity to learn about chronic conditions and how to manage them</li> <li>&gt; Information not given in ways that client can understand</li> </ul>

	C2. Commitment to lifestyle change	<ul style="list-style-type: none"> <li>&gt; Taking long-term responsibility for own health</li> <li>&gt; Understand and comply with medication</li> <li>&gt; Healthy food choices, physical activity, avoiding alcohol, etc built into everyday family life</li> <li>&gt; Daily routines for medication, food, exercise</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Fatalistic attitude to chronic conditions</li> <li>&gt; Chaotic life, other issues prioritised over health</li> <li>&gt; Financial cost of health lifestyle choices</li> </ul>
	C3. Family and peer support	<ul style="list-style-type: none"> <li>&gt; Family joins client in healthy diet</li> <li>&gt; Exercising with family and peers</li> <li>&gt; Practical help with things client can't do</li> <li>&gt; Clients that manage chronic conditions well can be role models</li> <li>&gt; Maintain emotional wellbeing</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Chaotic life, family members and peers preoccupied with their own problems</li> <li>&gt; Inflexible work routines or unsafe environment interfere with chronic condition management</li> </ul>

In the following text, each theme is discussed in turn with examples and quotes from the interviews to illustrate both enabling and hindering aspects, so often different sides of the same coin.

## A. Health system and service - related themes

### A1. Accessible, appropriate and affordable health services

Good chronic condition management requires regular interaction with health services, and therefore clients need to be able to access the services easily and with confidence. Access is compromised if transport is a problem, where services are limited or absent, and where services are perceived as culturally unsafe or otherwise inappropriate. Interviews with clients and staff at the three project sites provided insight into the way that chronic condition management is hindered by poor access to services, as well as strategies that enable or enhance access.

#### A1.1. Transport

PLAHS, Nunkuwarrin Yunti and RCHS Aboriginal health team all provide transport assistance for clients who cannot otherwise get to their appointments:

*Transport is a big issue. You can organise as many appointments with as many different people if you like but if people can't get to their appointments, it's not going to help, so transport is a big issue... It puts a lot of strain on our transport service to try and provide transport for clinical services that we run here. (staff 1)*

#### A1.2. Limited or absent service

In the Riverland, health services for Aboriginal clients with chronic conditions are mostly provided by private GPs rostered on the Peelies Bus, which visits each of the major towns twice a month and Gerard Community clinic twice a month, or at GP's consulting rooms. Originally a travelling eye clinic developed in response to access barriers identified through earlier projects in the region, the Peelies Bus is now a mobile general health clinic for Aboriginal people operated and maintained through a service agreement between the Riverland Division of

General Practice and the Riverland Regional Health Services. The RCHS Aboriginal health team encourages and assists Aboriginal clients to access the mobile clinic, have a health check to identify risk or presence of chronic conditions, and attend for regular monitoring and review.

These arrangements have improved access to the limited health services available in the Riverland, and are much appreciated by clients, especially when recalling how difficult it was in the past:

*I think that's the biggest thing in the Riverland, transport. A lot of people haven't got transport. Do you think that the Peelies Bus sort of helps by going to the towns? It does, it does, for the people who haven't got transport, and the people who aren't confident enough to go to their doctor. (client 10)*

However, the continuity and consistency of the services offered on the Peelies Bus and at Gerard have changed over time, mainly due to funding and staffing difficulties. There were times when a GP was not available, causing frustration:

*Sometimes follow ups are an issue, cos there are breaks in between. It's very hard to get your clients back. One [client] got angry when the doctor didn't come last time, so he won't go this time. ...Or else the doctor's there, but by the time [the client] gets down there the doctor says he's waited too long and he's gone. And [the client] gets there and it's all locked up. (client 12)*

Clients often need to access GPs and other health service providers between mobile clinic visits, but waiting time can be lengthy. The Aboriginal health team ensures that timely appointments are made:

*It's quicker to go to the Peelies Bus and get an appointment done through that way because, if it comes from mainstream you've got to wait about three or four weeks to see a doctor...the only other way we can see a doctor is Emergency. (client 14)*

Services may also be limited in terms of the duration of GP appointments. Clients reinforced the importance of allocating enough time to clients with newly diagnosed chronic conditions, eg:

*I think if they're got a new patient they need to talk to the patient a bit longer, especially new diabetic patients. (client 11)*

### **A1.3. Affordable services**

Staff at all three sites helped clients to access affordable services, organising referrals to providers that bulk billed, eg:

*We make a lot of phone calls – talk to people – are you willing to do this on Medicare rebate? Do you charge a gap fee? If there's a gap fee, we don't use them. (staff 1)*

Riverland clients attending GPs through the Peelies Bus are bulkbilled, however, because the GP practices are private services, the GP may charge a gap fee at other times and locations. Cost is a significant factor in accessing other services also, including accident and emergency services in the Riverland with a \$40 gap fee for everyone, even those with concession cards.

Ensuring clients are registered with Medicare and have health care cards if eligible is another way that service providers support clients to manage their chronic conditions - by reducing or removing the cost barrier for medications.

*... and if they've got healthcare cards, so it's sort of an incentive, it takes that barrier away of the cost of medication for people and then they're more likely to actually take their medication. (staff 8)*

This was taken a step further in the Riverland where a Medicare Officer worked on the Peelies Bus alongside the clinical staff.

*A discount voucher for prescriptions dispensed on the Peelies Bus makes treatment for chronic conditions more affordable, and consultations are bulk billed. (staff 11)*

This voucher system has been replaced by the medication support provided through the Government's Closing the Gap program:

*...if they're all signed up [to the Closing the Gap program] they can get free medications. (staff 8)*

Nunkuwarrin Yunti is involved in the QUMAX program [43], which provides free medications to eligible Aboriginal people with chronic conditions.

#### **A1.4. Culturally safe service**

A recurring theme in staff and client interviews was the importance of culturally safe health service. A culturally safe health service was an enabling factor for chronic condition management, lack of culturally appropriate service was a barrier.

A history of fear and distrust of doctors and other authority figures, experience of racism, and concerns about confidentiality deterred many Aboriginal people from seeking early advice about their health, eg:

*I know that a lot of people in my family they won't go to the doctor unless something is badly wrong and they can see that something's wrong. (client 8)*

Many clients preferred to go to Aboriginal community controlled services, if available, than to mainstream services. Their way of working, with a focus on holistic, primary health care and delivered by a largely Aboriginal workforce, in order to meet the needs of the local Aboriginal client community according to Aboriginal values was generally appreciated.

*Biases existed in [mainstream] health services and health providers that made it an imperative for PLAHS that they had to produce their own workers and area specialists (eg diabetes, alcohol and other drugs, mental health) as opposed to using existing services, this need was reinforced by the Aboriginal community. (staff 4)*

*I mean with the stuff that we've been doing and it's recorded and all of that over time, it makes a difference to the whole health, my health. And I always say to my kids and that, if you go to Aboriginal medical services they actually do a lot of stuff, they will do your blood sugar and your cholesterol and all the stuff that it's better for you to know than not, because you could have a heart attack or something and you wouldn't know why. (client 8)*

However, neither Aboriginal community-control nor having Aboriginal staff were in themselves guarantees of perceived culturally appropriate health service. Family and community politics often interfered, eg:

*Some community members will not access them for political reasons, for family reasons, and would feel alienated from access to the services on offer, because the people in control at the time were not following a particular line. (staff 4)*

Many clients were not concerned with the Aboriginal status of their health service providers, as long as they were treated with respect and consideration, eg:

*That just don't count for me because they're there to help us, they're there to serve us, you know. They're there to help us and give us a better understanding of our sickness. So that's good we've got people there. That's good. I don't mind. (client 14)*



The way in which health service providers engaged with clients to develop relationships of trust was the key to perceptions of cultural safety (discussed elsewhere in this report).

## A2. Clinical information management systems

Having an accurate computerised system to manage clinical records and client recalls was a key enabler of structured chronic condition management, whereas lack of such a system was a barrier.

PLAHS transitioned from ad hoc paper records to electronic records in about 1999/2000, firstly using Medical Director software (commonly used by GPs), later Ferret, and now Communicare, the software used by most Aboriginal community-controlled health services around Australia today.

*Communicare's alright. It changes with every year. ... that's where the patients have got all their records saved and all their data and that. (staff 10)*

At PLAHS there is a computer on each staff member's desk; training and support in using the system has been provided through the software company and an information technology specialist on staff. Clinical workers at PLAHS reported entering and looking up client information on Communicare as part of their daily practice.

*We have everything on Communicare, so that is like a patient recall system. We have paperless notes here so everything's scanned into that program, all of their IMVS results come through there, doctors' notes are all in there, so it just collects. So there's different access by different people so like as a nurse I can see different things to what the health workers can but everyone can access the care plans. If they have someone present to the clinic then it's quite easy for them to open up their care plan and see what they need done. We also have that recall system so if they were due a HbA1c then as soon as they open up that file they can do the HbA1c because it's flashed in red. (staff 8)*

The Communicare system has also been helpful for service activity reporting, and PLAHS has worked hard to improve its record keeping over the years. This has helped PLAHS to gain and maintain funding for its chronic disease programs and staff, and has been a major factor in effective management of clients with long-term health problems.

Nunkuwarrin Yunti also uses Communicare to store clinical data and for managing client recalls, and to document transport episodes:

*Our drivers have got to pick up patients and bring them in. They document on Communicare. If somebody was not there when they went to pick them up, that's documented. (staff 2)*

Nunkuwarrin Yunti is aware that customised care plan templates in Communicare can be developed and how they could aid the transition to a more streamlined system of chronic condition management:

*There is lots of stuff you could do beforehand like the medical part of the Care Plan you could fit in and it would be fantastic if we could get the Care Plans into Communicare. If it becomes one of the templates, certain bits of information should just be automatically self-populated so that decreases the amount of paperwork that the Health Workers and other staff will be involved in, and I think that will make it easier to be involved in the logistics of the Care Plan. You see everyone understands at an intellectual level why it's good. If the actual implementation becomes tedious, it's hard. ... We might modify those [care plan] documents to suit our needs and ... go to Communicare and say put this in as one of templates for us, so that we can lessen the amount of this constant transcribing that we need to do. (staff 2)*

RCHS does not use Communicare; it uses Client Management Engine (CME).

*CME is a Country Health SA Government statistical data system that we have to use and account for our time. (staff 12)*

Record keeping at RCHS was inconsistent:

*We do have to report on our activities, and so as part of Healthy for Life we have to actually report on the haemoglobin A1c, and blood pressures and how many adult checks are done and how many chronic disease management plans are actually done. And we know that some of that has been done, however we haven't always recorded it... So it's about improving our processes with documentation and stuff like that, to be able to report on it. (staff 12)*

Medical Director software is used by the Riverland GPs wherever they see their clients, including on the Peelies Bus and at Gerard clinic. The CME and Medical Director systems are not compatible, a challenging situation for staff attempting to coordinate the management of Aboriginal clients with chronic conditions in the region. A participant at RCHS explained:

*We do need to record those clients that we see at Gerard or Peelies on CME, and we need to keep an accurate record and have files, I mean that's just an ethical, professional thing. Medical Director is not our data. (staff 12)*

However, she is working through the Medical Director records to clean and update them and ensure timely client recalls, with the aim of streamlining future care plan arrangements:

*I think we need to start with the base first in regards to cleaning the data, making sure that everything is up to date, getting the recall system happening, getting the three monthly diabetes checks happening and that recall system and that happening. And then I think after a few months of that happening, then look at the chronic disease management plans. (staff 12)*

Clients appreciated reminders about checkups and referral appointments, generated through the clinical information systems. Some clients also liked keeping track of their clinical progress by discussing Communicare data with the health care staff.

*Sometimes showing them their results over time is encouraging, they can gain understanding of their disease progression. (staff 5)*

The longitudinal 'traffic light' graphs of clinical indicators developed through this project (discussed elsewhere in this report) were considered more useful than purely numerical data for keeping track of progress:

*It would help a lot ... for me, to look at it like that [as a graph] is easier than looking at it like that [a list of numbers]. (client 8)*

### A3. Coordination and team care arrangements

Most clients with chronic conditions require care and assistance from a variety of health and human service providers to address their complex needs. Interviews with clients and staff confirmed that a coordinated, client-centred approach with well organised team care arrangements was an important enabler of structured chronic condition care, whereas an uncoordinated, ad hoc approach was a barrier.

PLAHS has developed a holistic model of care with a 'no wrong door' approach [23-24, 41-42]. There are systems and protocols in place for triage, assessment and referral of clients whenever they access any part of the service. When clients with chronic conditions and care plans visit

PLAHS, for planned or unplanned appointments, staff will ensure that they have any tests that are due and follow up on identified issues immediately. Established team care arrangements and the Communicare clinical information and recall computer system facilitate this coordinated approach.

Coordination of care extends beyond the clinic at PLAHS to include relevant external services, especially for people with complex health and social challenges, eg:

*I've got a [client] that has epilepsy and when he has seizures he changes, he gets quite aggro and he's gotten himself into a little bit of trouble with that. So now I think we've sort of care planned him and we've identified that's one of his biggest things, because he doesn't know he's doing it. He also is referred to community services and they work on that and then we're looking at strategies together of how we can manage that better for him. When he does have those seizures he's often been locked up and that sort of thing, so we're trying to identify a way that we can manage that where we might have to include people, like in A&E and the police. (staff 8)*

Workers' knowledge about other programs and services beyond their own immediate responsibilities and their willingness to recommend them to clients contributed to the success of PLAHS' coordinated chronic condition management system:

*You know, some of that's knowing about other programs as well. Even if I don't know about it I'll say, look okay, I'll put you on to somebody, or we're doing this there, you know, promoting it. Every time you go out you're promoting the organisation. (staff 9)*

Nunkuwarrin Yunti is making progress towards a structured and systematic approach to caring for clients with chronic conditions. Managers have recognised that an agreed service-wide system is a necessary change. A model of care and implementation strategy has been written and will be implemented:

*It is difficult to do [care planning] when you're constantly in that one-to-one clinical setting, it's got to be a bigger approach than that. And that requires a good coordinated team approach, which is something that we have not got to but that is the aim. (staff 2)*

This project facilitated the sharing of PLAHS' successful coordinated approach with Nunkuwarrin Yunti, described elsewhere in this report. Nunkuwarrin Yunti is aiming to have an integrated seamless client pathway between the different programs similar to the PLAHS' 'no wrong door' system:

*The idea is, and it's a very good idea, that it doesn't matter what point of entry they come into the organisation, once they come in they should then be able to be offered a place in Clinical Services if there is a necessity for it. The thing though that the assessment with the other program probably could be a more in-depth, a more comprehensive one. So then it becomes exactly the same – it's not actually an organisation-wide approach, it's just somebody else in the organisation identifying somebody as having a chronic condition and then just saying – well go to clinic, whereas I think it could be much more powerful if it was a collaborative approach. (staff 2)*

At RCHS, coordination of care had not yet been achieved, though efforts were being made. The existing approach and plans were described by staff as follows:

*Sort of assessing how things are being done at the moment, trying to improve the way things are being done, and trying to get better continuity of care for clients around their chronic disease, to try and improve their outcomes, because at the moment things seem to be a bit ad hoc and opportunistic. (staff 12)*

## A4. Facilitating peer support

Health services facilitated a number of health-related events and group activities for the community, eg support groups, diabetes camps, all of which were peer support strategies enabling Aboriginal people to manage their chronic conditions better. Clients could enjoy some 'time out' for themselves in a relaxed and safe environment, interact with others who have chronic conditions and support each other, with health professionals on hand to encourage and give information and practical assistance. Staff and clients from all three sites gave examples of such peer support activities and how they enabled better management of long-term health problems.

### A4.1. Living Improvements for Everyone (LIFE)

Living Improvements for Everyone (LIFE) is a structured peer support course adapted for Aboriginal people with any chronic condition, aimed at helping them to make and maintain the lifestyle changes needed to manage their health [27, 43]. Peer leaders receive advanced training and go on to train other community members. Elsewhere in this report we note that some RCHS staff participated in LIFE training during this project, and that many PLAHS staff and some clients had participated previously. Staff support and encouragement at LIFE courses helped clients put their problems in perspective, recognise and deal with grief:

*Yeah the LIFE courses were really good because of the depression and they dealt with them and with grief and things like that and they've helped a lot because you get to go and talk to other people and think well mine's not as bad as their problems and that really helped a lot. (client 8)*

and strive for goals:

*I did [LIFE] last year and it was really good because it helped to sort of give me goals that I can achieve and it wasn't something that was out of reach because that was my goal, just to be able to weed my garden which now I'm really happy that I can do... That was really good, it was fun. But also, again, the information that was coming out I could use it every day so that was good. (client 8)*

### A4.2. PLAHS diabetes camps

PLAHS has organised camps for Aboriginal clients with diabetes and their families each December for some years. The camp is held at Trinity Haven, a quiet group of cabins and communal areas on a beautiful stretch of coast about an hour drive north of Port Lincoln. A staff member described the aims and activities of the diabetes camps as follows:

*So it's – you know, we've been saying all the time, get away from everything for a while, give yourself a bit of quality time, come out there and no one bothering you. You know, you haven't got people knocking on your door or ringing you up for money. You know, you're not stressing out in town. We get other professionals around the community to come out and do some presentations there, like podiatrists, exercise, doctors.... In the mornings we go for walks, we do BSLs, blood pressures. We have bush tucker nights where we bring the cultural aspect back into it and that's a big one because that's mostly when a lot of community people come out. (staff 9)*

Clients valued the support and encouragement they gained from the diabetes camps, eg:

*Any person who's is a diabetic I'd recommend they go to these camps. It's good. You don't talk about the garbage, you talk about the positive things, how can you control it, yeah. (client 3)*

From 2011 PLAHS has broadened the scope of the camps to wellness for the wider community.

### A4.3. Other peer support activities

PLAHS also organised other regular activities for clients and community members aimed at preventing and managing long-term health problems, including an exercise group:

*Yeah, and [we] have got an exercise group at the gym so we've got about six [clients] a week attending. (staff 10)*

diet and cooking sessions:

*It is useful when you go there and everyone knows exactly what you've got to eat and what you can't and there's nothing that's there that should not be there. That helped me, that really did, like focussed me on what I had to do. (client 7)*

the Nunga kids café:

*Also I've worked with a kids café – Nunga Kids Café – that's with the junior primary, that's year sixes and seven. [We] are doing a nutrition and cooking group upstairs in the diabetes kitchen. (staff 10)*

*We do [Nunga] kids café, we had one this morning, so they did a bit of cooking up there... They can invite their parents when they're doing cooking and we give them a cook book so when they take it home they can say 'is it okay if I can do cooking tonight and do it for the family' and we take them shopping and they can read the labels, so you're doing all of that as well, so you bring all the food back and then you, one can do the chopping, the other ones can do the saucepan, so they learn a lot, they enjoy it. (client 6)*

and the Lantus group specially for people using that diabetes medication:

*I think the care plan strategy's good but other strategies as well, like the LIFE course and that, and the LANTUS group seems to be good... I've been involved in that a bit too. (staff 6)*

Nunkuwarrin Yunti staff reported on several peer support groups for their clients with chronic conditions, largely in the early stages of development:

*There is the Women's Group that we have here and a number of people who go to that have chronic conditions and this is more of a support network. We're not specifically around chronic conditions; it's about being okay with your life and what's going on, as far as I understand... There's the beginnings of a Men's Group and there's a whole bunch of people who have just gone on a men's camp around chronic condition and men's engagement with the health system. It's just starting now. It's early days. (staff 1)*

Elsewhere in this report we describe how RCHS developed the Riverland Aboriginal Chronic Disease Support Group through this project, and how that has encouraged people to make use of health services and get involved in managing their chronic conditions. As for the PLAHS diabetes camps, the emphasis is primarily on enabling people with chronic conditions to get together, enjoy themselves and support each other:

*We don't dictate. That's the only thing we don't do, we just let them come to enjoy themselves and don't think about anything, just get them out of the house for a couple of hours. (staff 11)*

Health information is available at the Riverland Aboriginal Chronic Disease Support Group for those who want it:

*Part of what's good about that group, you can do what suits you... You've got speakers and that, and you either listen to them or not, you know what to expect, so, it's good in that way. (client 10)*

## B. Staff-related themes

### B1. Staff capacity and training in chronic condition management

#### B1.1. Lack of qualified Aboriginal health workers

This research confirmed that Aboriginal health services often struggle to fill positions for Aboriginal health workers, and that many Aboriginal health workers lack formal qualifications. The Aboriginal Health Council of SA is the main provider of generic training for Aboriginal health workers in SA (Certificate III and IV in Aboriginal Primary Health Care), generally as on-the-job training with block release for course work. Staff shortfalls have become even more acute in recent years because the Aboriginal Health Council of SA did not offer this training in 2009-2010 while it updated its course structure in line with new national standards. The impact on staff capacity in Aboriginal health services has been severe:

*We're constantly struggling with staff numbers. People leave to do other things and then you can't replace them. It's not easy. ... I think the Health Council hasn't run the Primary Health Care training course for a while and so that's really made a hole in the cohort of people, and we are really noticing it now... We put an ad in a month ago and we did not get one person out of that that we could actually interview. Not one. It's really disappointing. (staff 1)*

Staff shortages meant that remaining workers had less opportunity to specialise:

*I've been doing this for years, trying to focus straight onto one thing but you can't when you get short staffed and you've got to go and do other things. (staff 3)*

Clinical skills and knowledge are not introduced into SA Aboriginal health worker training until certificate IV level. There are many Aboriginal health workers in the SA workforce who have not yet completed basic training, and have little knowledge about physiology, chronic disease processes and indicators. Some people had strong views about the lack of clinical skills training provided for Aboriginal health workers:

*So I think the health worker training, as good as it may be, I think they should scrap it and focus on training everybody to be enrolled nurses.... they're not getting taught properly the clinical stuff. (staff 6)*

#### B1.2. Staff training in chronic condition management

Interviews with staff identified staff training in chronic condition management as a key factor influencing the success or otherwise of any chronic condition management strategy introduced in health services. Self-assessment of their own knowledge and understanding of chronic conditions and how to manage them varied greatly, as did their professional experience and education; staff participant roles ranged from novice Aboriginal health workers to medical officers, and everything in between. Most had received some training about chronic condition management (eg LIFE, Flinders Program™), before or during this project. Many had also participated in other relevant training eg diabetes education, and some had nursing, allied health or medical qualifications.

At PLAHS where there is a core group of qualified, experienced staff and established chronic condition management systems and processes, novice health workers could see the value of the training and how to apply it in practice, and were keen to learn more. They were also encouraged by their more experienced colleagues:

*It would be good to train all the health workers and so we can all know what it's all about and what they actually do with the care plan. (staff 10)*

*I'd like to see more young health workers come through into this program to become diabetes educators or work in the area of chronic disease. (staff 9)*

However as discussed above, there are many Aboriginal health workers in the workforce who lack basic clinical skills and knowledge, impacting on their ability to understand aspects of chronic condition management training courses like the Flinders Program™ of Chronic Condition Management. Several people commented that staff participation in such training did not necessarily translate to clinical confidence or ability to implement what they have learned into practice:

*I think that a lot of our Health Workers go off and do some training and so they've got a bit of paper. It does not mean that they either feel competent or confident, so there is something that needs to happen between them getting their bits of paper to get into a place where they feel comfortable, and that's across the board. (staff 2)*

As opposed to most Aboriginal health workers, nursing staff participants had the clinical knowledge to identify and follow up on potential issues with the GP, enhancing timely support for clients:

*Health workers are able to do the care planning, but I really see it lacking in that, you know, the doctors need to be reminded a lot of the time to look at medication and look at what their blood pressures levels have been, and follow up on that liver function test, you know, all that knowledge that don't come with being a health worker. (staff 6)*

Perhaps not surprisingly therefore, some nursing staff felt responsible for aspects of care planning:

*Yeah, and I love the care planning idea but there is a real, this is a real negative thing and it's only my personal opinion but some of the nurses here have a real ownership thing of that group of clients and I think that needs to change, like you need to actually be able to delegate some of those things out to other people not just 'You do all of it because you know that it's going to get done,' sort of thing. (staff 8)*

## B2. Engaging with clients and community

### B2.1. Engaging the community

Staff members worked hard to promote their health services, for example in the Riverland:

*The people in the community have a misunderstanding of what these people in here do ....So there's a big misconception out there as to what these people are doing, and if they're doing anything good for them....I'm trying to get the Aboriginal people to come to the health service and make them feel welcome. (staff 11)*

Being Aboriginal and having local community connections was advantageous for staff in engaging Aboriginal clients:

*As soon as I mention my last name, like connection back, you're in... it's like that yeah. (staff 7)*

Reflecting on PLAHS' growth and development, a long-term staff member recalled how PLAHS employed and trained a core group of Aboriginal health workers as a deliberate and ultimately successful strategy to engage Aboriginal clients:



*A decision was made to employ a core team of four Aboriginal health workers and, once established, the group supported each other and shared the load. All four were fully trained and qualified, and this was a key ingredient for their sustainability. ... We deliberately chose two men and two women to be in the team of four, for obvious reasons and we found that those together were trusted. ... The community response to this approach was to use the Aboriginal health workers in preference to non-Aboriginal nurses or the GP as first line contact. The Aboriginal health workers gained the respect of their clients, and were publicly spoken about with pride by members of the community. (staff 4)*

One of the PLAHS Aboriginal staff explained his role with respect to the community:

*I'm just not a diabetes worker in the organisation. I am an employee of the community that works in the area of health so it's how I promote it to the community. (staff 9)*

A range of ongoing community-focused health promotion activities organised through PLAHS helped engage the Port Lincoln Aboriginal community with the health service, eg:

*An interesting activity was setting up a women's walking group, which helped the women to get together (the power brokers of the community). After a while the kids started to come along too, and this became an opportunity to teach them about bush tucker and the right things to eat. (staff 4)*

This research project facilitated several new community engagement strategies that we anticipate will encourage Aboriginal people with or at risk of chronic conditions to address their health, eg the Support Group and Expo in the Riverland, and the 'self-management stars' posters for PLAHS. These are discussed elsewhere in this report.

Engaging male community members with health services was especially difficult in all three project sites. However, efforts to bring more men to the services were underway. In Port Lincoln any Aboriginal men could use the PLAHS gym as long as they have a health assessment. Nunkuwarrin Yunti was just beginning a men's group:

*There's the beginnings of a Men's Group and there's a whole bunch of people who have just gone on a men's camp around chronic conditions and men's engagement with the health system. It's just starting now. It's early days. ... it's been a mission trying to get men to come back. (staff 1)*

And there is a popular men's group in the Riverland organised by the RCHS Aboriginal health team:

*Yeah, we've got a Men's Group up there. We have between 10 and 15 blokes come every fortnight. ... We don't dictate. That's the only thing we don't do, we just let them come to enjoy themselves and don't think about anything, just get them out of the house for a couple of hours. (staff 11)*

## **B2.2. Engaging individual clients**

Interviews with staff at all sites highlighted the importance of building and maintaining a trusting relationship with the clients for any chronic condition management strategy to be effective. Staff members spoke of the need to invest time and effort to build rapport and confidence:

*You have a good yarn. Sort of get them out of their shell a little bit (staff 10)*

*So it's about sitting down with somebody and listening to them, because people will talk about something else then they'll slowly get around to it, and the reason's probably down the bottom of the pit, not at the top. The community, they know that you've got time for them and you can support them or you'll get someone that can support them. (staff 9)*

The down side of strong relationships between clients and staff is that clients may approach workers, particularly Aboriginal health workers who are also community members, out of hours, leading to blurring of professional boundaries and potential burnout:

*You don't want them to be too dependent on you, because it'll be all the time. Monday to Friday 9-5 is okay. The weekend is my time. (staff 11)*

### **B2.3. Engaging clients as partners their own chronic condition management**

One client described how Aboriginal health workers engaged with him:

*They started to come and check up on me and got me to come in, keep checking up on me all the time and we had a bloke here ... He used to come around to the place there and sit down and have a drink of coffee and we'd go through everything, 'how do we feel and are we taking our medicines.' When he came around it was good. (client 3)*

All agreed that having dedicated and committed staff was vital for effective client engagement in their own chronic condition management:

*We need people who are dedicated. It's not easy work. It takes a lot of energy as well. It takes a particular type of person. (staff 1)*

When it came to involving individual clients in care plans and self-management, staff again emphasised the importance of allowing enough time for clients to get involved in managing their chronic conditions at their own pace:

*We aim for people to go on a care plan. Depends on how much people are willing to access the service, there are still barriers there, with people accepting their condition. Going slowly and building a rapport works best, so that they enjoy the process ...If you get the rapport and the trust, it's our responsibility to provide the care. (staff 5)*

*So, taking it step by step I suppose is the way to go and once you get their confidence I think you can look at addressing some of those issues. As we've seen today with some of our clients, they're taking that next step and they're willing to participate in further sort of management of their chronic illness. (staff 9)*

Interviews with staff also emphasised that their role is to support and advise, not to tell clients what to do:

*It's for us to just sort of say to them, if you have a chronic illness, I mean, you have to look out, you want to address it. That's giving them the power. I think it's giving them ownership as well. If you start saying you've got to do this, you do that, then they just back away. (staff 9)*

*Yeah it's really the relationship and not standing up there and lecturing ... just on the same level, simple words... just be genuine that you do care for their health; just let people know that you care for their health, without jumping on their lap and saying, 'I'm going to look after you', or something like that. (staff 3)*

## **B3. Encouraging and supporting clients**

The theme of health services encouraging and supporting people to manage their chronic health problems was evident from interviews with clients and staff at all three project sites. Clearly, this is an enabler of chronic condition management strategies, and most comments were positive. The Aboriginal health workers we interviewed agreed that their main role was to provide such support to clients to address their own health problems:

*We try to promote that we are here to support, not to tell people what to do. (staff 5)*

*We don't dictate. (staff 12)*

The support and encouragement given by staff encompassed: genuinely caring about the client, being available to discuss problems, keeping clients motivated, and facilitating peer support.

### **B3.1. Genuinely caring about the client**

Many of the staff interviewed, especially Aboriginal health workers, spoke passionately about their work and how it is underpinned by genuine care for their clients:

*They need to know I'm being genuine, not just 'it's a part of my job'. Forget that, be a human being and let people know that you are there to help, just not another figure, another stat number or something. (staff 3)*

Clients greatly appreciated that their health service providers genuinely cared about them, and felt less isolated as a result:

*Yeah, because they ring up, they check on you and, you know, it - to have someone that cares, you know, it makes a big difference. You're not alone, you feel. And you're not alone with diabetes anyway, because everyone has it. But when you first get diagnosed with it you feel like you're isolated. (client 7)*

### **B3.2. Being available to discuss problems**

Once clients had accepted their chronic conditions and become involved in managing them, problems and issues inevitably arose. Knowing that the workers were available to discuss issues was very helpful to clients, eg:

*She's always available and that's a really good thing. If I'm coming in she's there and she listens. ... And then she goes off and makes all the appointments for me to do things like go to see the podiatrist or the dietician or whatever from what we talk about because stuff happens. What's really good is that she's really helpful. It makes a difference. (client 8)*

Staff interviews confirmed this view, eg:

*They know they've got support if they've got a bit of a problem, if they don't understand something, that they're supported. (staff 3)*

One staff participant expanded on supporting clients living in difficult family circumstances:

*People just don't support one another enough I think and a lot of the support they get for themselves actually comes from staff in the health services because we make that time to sit down with them and have a cup of coffee and talk about some of the issues, where families these days, a lot of people just don't do that anymore. (staff 9)*

### **B3.3. Keeping clients motivated**

The support and encouragement provided by health service providers, particularly the Aboriginal health workers and nursing staff, motivated clients to be active partners in their own chronic condition management, eg:

*Sometimes I didn't even want to lift my feet to even come to the meetings, but when you've got a nice lady like [name], and she's always smiling and saying, 'Come on,*

*we can do this'. You know, part of their positive attitude, like I took on theirs and I thought, 'I can do this. Bloody oath I can.'* (client 7)

Staff understood their role in encouraging clients to maintain lifestyle changes and actions in their care plans, especially when setbacks occur:

*At some stage they might come to a point where they hit a wall and they'll fall off the truck for a while ... and when they do fall off that thing we try to give as much support as we can, and when stuff like that comes at them, we're pretty supportive of that side, so yeah.* (staff 10)

Several staff participants spoke of making sure that chronic condition management strategies are realistic and achievable, as small successes encourage clients to keep going:

*Yeah. Well, to make sure things are realistic, that you don't set yourself up to fail I suppose, because I think if you can get wins on the board, sort of for a client, then that helps keep them motivated.* (staff 12)

## C. Client-related themes

### C1. Client knowledge of chronic conditions and how to manage them

Clients were eager for more information about their health and wanted a better understanding of chronic conditions and how to manage them. The steadily increasing interest in the Riverland Aboriginal Chronic Disease Support Group, diabetes camps, Riverland Expo, care planning and self-management are all evidence of this and described elsewhere in this Report. One client explained her interest in learning more:

*So I think that coming to [the health service] has been a really good thing because it's the knowledge that we're talking about all the time. And that makes a difference because then I know what sort of things I can do to help.* (client 8)

Clients who had a good awareness of the body and how their chronic conditions and treatment affect it could sense when something is amiss, and take action to avoid complications, eg:

*I think being trained as a nurse puts you in a different perspective of things too. It makes you aware everything what's going on in your body... When I'm feeling untoward I can see I need to go to the doctor.* (staff 12)

Staff agreed that clients need and want more knowledge about chronic conditions and chronic condition management:

*Just to get them to try to actually understand the illnesses is important to them. That's all they really need I reckon. Just education, just an understanding of what their illness is and then once they know that, they've got a better understanding, they'll know what's good, what's not good, what's right, what's wrong.* (staff 10)

Clients said that health professionals did not always explain things in plain language or take enough time, leaving clients confused and ill-informed, and inhibited about asking for clarification:

*Nobody wants to feel silly by saying, what does that mean. You walk out the door and you say well what does that mean, you know.* (client 11)

## C2. Commitment to lifestyle change

### C2.1. Being strong

A recurring theme from all the interviews was client commitment to long-term lifestyle change as a key part of managing their own chronic conditions. Clients expressed their determination, eg:

*I'm just going to meet it head on and do whatever it takes to make myself better. (client 13)*

*I thought well you have to make a change in your lifestyle so that's what I actually done. (client 6)*

They knew that maintaining a healthy lifestyle in order to live well with a chronic condition meant taking personal responsibility for their health and long-term lifestyle choices, despite peer pressure:

*Nobody else can work for your health. You've got to do it yourself. You've got to work for it. So yes, anybody out there if you want to live a long life, healthy life, you work for it. (client 3)*

*I'm old enough now to realise about my life. That's why I've wanted to make a change. I'm not naive and easily pulled to one side by other people's opinions. (client 7)*

*I believe in putting temptation out there to challenge me. I don't believe in... if I give up drinking I'm not never, ever, ever going to go in a pub, that's ridiculous, you're cutting meeting people and things like that, so yeah, it's my choices. (client 11)*

Clients also spoke about being realistic, and not being discouraged about lapses and setbacks:

*Always be true to yourself, acknowledge your gains and your losses. You know, some days you lose, and some days you win, but don't let it get you down. (client 7)*

Focusing on the future was helpful in maintaining commitment:

*Some days you, you know, when you've got to wake up and give yourself a needle every morning it tends to turn you off. I don't know, some days you're up and some days you're down. Yeah, so I just look at it like, you know, if I don't have that, have this needle, well then I won't be here to see my grannies or anything like that. So I think of long-term things where, I don't know, I want to make sure I'm alive at 50. I want to make sure I'm perfect at 50, I'm healthy and happy. (client 7)*

### C2.2. Managing medications

Clients with complex chronic conditions often had to take multiple medications, and commitment to taking them regularly for life was necessary. Clients had tips and routines that helped them take their medicines regularly and at the right time and dose, eg:

*[I don't use a dosette] at the moment, I probably will I think because I tend to forget. So what we've done is because I take [insulin] every single day at half past eight, it helps because I have to take all my other medications. I do it all at once and that has helped because by the time [name] gets ready to go to school it's half past eight, ... we know that we have to have our medication and that's the way we've worked it, it's the routine. (client 8)*

However, work conditions interfered with some clients' established routines for managing their conditions, impacting negatively on health:

*But before I was working I was walking and doing everything but I just had my mind set on my diabetes... I paid attention to it, I did for about a year and brought everything that was sky high right down but with work now everything is going out the window because all my eating times have changed, my insulin times have changed. Don't know if it's worth it. (client 7)*

### C2.3. Healthy diet tips

Having a healthier diet was the most commonly mentioned lifestyle change made by clients to help manage their chronic conditions. Clients spoke of eating normal foods, but in moderation:

*I just eat normal foods and I try and regulate what I eat. (client 11)*

*No, I don't cut back on [sweets and fats]. I still eat it but the quantity has gone down. In moderation I should say. (client 3)*

Most clients we interviewed shared healthy diet tips, such as reducing portion sizes:

*I'm starting to eat smaller proportions in my meals now. I was not much of a breakfast person but, I have at least a toast or grab a banana on the way out now, and I eat a healthy lunch, I usually buy a sandwich or a juice ... I've actually lost seven kg. (client 4)*

Increasing fruit and vegetables and reducing fats were other common strategies for healthier eating:

*I try to cut the fat off and have lean meat and bought this [steamer] for myself up here. (client 13)*

*We've cut out all the fats and the butters and stuff that's not good. ... Obviously we do go out and have a meal now and again but most places will give you what you ask, sandwich with no butter on, lots of vegies. (client 8)*

*I've been reading the labels, but I don't mind shopping because I only go for certain things and that's it. [I know] what's good for me and what's not. I eat a lot of vegies and a lot of salad stuff. (client 10)*

Avoiding takeaways was another healthy diet strategy. Takeaways provide quick and easy meals, especially tempting when time is short or life is chaotic. Some clients we interviewed realised that takeaways were detrimental to their own and their families' health, and replaced takeaways with home-cooked fresh foods:

*A lot of things were happening in my life, so I was resorting to eating junk food with my children, and then I looked at my children, like you know, just not healthy for my children. I'm a full time worker and by the time I get home... you just grab a sandwich or Kentucky, it's so easy to do that, you know. As long as the children are fed, but actually I was helping to kill my children, and myself, so, yeah, we've slowed down on take away stuff and started eating more salads, you know, cold meats. With the chicken, like when I do buy a chicken, I take the skin off because that's where all the fat is held. ...I'm changing, my children are for the better too. Because my youngest daughter ..., she's overweight and I want to help her. (client 4)*

Involving family members in preparing tasty meals at home was another strategy that clients used to maintain and encourage a healthy diet:

*I can show them how to eat healthy, plus prepare dinners with me. You know, I've got them chopping things and stuff as well. But I try and show them that their taste buds don't have to just stop at KFC and Maccas. So I create different things for them. We eat a lot of fish, which is yum. (client 7)*

Some clients, particularly those with diabetes at PLAHS, had received diet education as part of their care plan, and made use of diabetic recipes and cookbooks obtained from the health service:

*It is useful when you go there and everyone knows exactly what you've got to eat and what you can't and there's nothing that's there that should not be there. That helped me, that really did, like focussed me on what I had to do. (client 7)*

*If we're going to make something we look in the diabetic one first, and you have a look, if you put a diabetic recipe next to the normal one that we're used to having, there's like ten ingredients more, but in the bad one. So when you eat the diabetic one you know exactly how much kilojoules you're getting, and stuff like that. So that's good. (client 7)*

## C2.4. Giving up alcohol

Another commonly mentioned lifestyle change made by clients as part of their chronic condition management was to give up alcohol. This quote illustrates how one client's health improved dramatically after giving up drinking:

*Every time I had a drink of alcohol you'd have a hangover for like four days, and that was because of the diabetes. Once the alcohol went, oh, it was a new life. ... Yeah, so I just said, 'No, I'm changing. And the next day I did.' Yeah, and that was the main thing, alcohol. Because alcohol made you eat things that you shouldn't eat. But as soon as that stopped then everything else just fell into place. (client 7)*

Clients described how concern from or about family members prompted them to stop drinking:

*It was me the one who wanted to give up drinking because I saw what it was doing to me and him and then our kids, and being a Stolen Generation well I thought, my kids are going to be taken away if I don't give up alcohol. (client 5)*

*I was walking down the street one day and I saw this Aboriginal lady and she had no shoes and never had her hair combed, and I thought, God, if I looked like that, that's it, and this woman was my aunty and everything. So, you know, and I thought if I look like that when I'm drunk well that's it and that's how I gave up drinking, and I think I've pressured [my husband] a little bit. ... So, yeah, that lady, you know I've never thanked her but she snapped me out of what I was doing. (client 5)*

## C3. Family and peer support

A common theme emerging from interviews with clients was the importance of having support from families and friends to make and maintain the lifestyle changes needed to manage a chronic condition.

*You must have a supporting family... because you cannot just do it on your own. Especially if your life has been used to doing things one way, then you have to change. But it's what you have at home that makes you pull through. (client 7)*



Several clients had partners and other family members who provided hands-on care and assistance to clients managing their conditions, eg:

*My husband always looks at my feet in the night and he's noticed that one of the toes was red, this little toe. And we came to health here and they're filling me up with antibiotics and that straight away because they said, 'that's really, really dangerous'. Well I didn't know...it was just lucky that he looked at it. (client 8)*

Families also helped motivate clients to stick to their care plans:

*Yeah, because everybody cuts crook at me. My family worry. (client 11)*

### **C3.1. Chaotic life**

Staff and clients acknowledged many Aboriginal people do not prioritise their own health needs because there are so many other pressing issues to cope with. Living in poverty and disadvantage, and with extended family responsibilities may leave people with little capacity or inclination to get involved in managing their chronic conditions. The effects of a chaotic life on capacity to manage chronic conditions were highlighted in interviews with staff and clients from all three sites, eg:

*If you have other problems in your household there's no way that a younger person is going to sit down and pay attention to their diabetes. (client 7)*

*You're trying to talk to someone about their problems but they've got other issues; it could be housing; it could be no money; electricity is going to be turned off or something like that; other issues come before the health. (staff 3)*

However, one client who was a good self-manager of her diabetes was able to focus on her immediate health needs as a way of getting through difficult times:

*Mainly things that you can't have control over are probably things that make life hard for you. But when those things come up you tend to focus more on your diabetes and try and get a bit of mental strength out of that. (client 10)*

### **C3.2. Role model**

A number of clients who were managing their chronic conditions quite well spoke of being role models for their families:

*I act as an elders role of a... a good teacher. A lot of people can't do that, even older than me. A lot can't do that. I got knowledge, wisdom, and I've got spirit. (client 14)*

*Yeah, well I saw my mum, dad and sister all pass away through diabetes, and I said to myself I had to change my life so I can - whoever's left in my family I can show them how to eat healthy. (client 7)*

### **C3.3. Family support for healthy diet**

Clients told us how changing dietary habits can be challenging, but achievable if the whole family embraces and supports healthy food choices. Most clients we interviewed gave examples of how their families and peers helped them to prepare and eat healthier food, and how diet changes benefited the whole family, eg:

*[My wife] is a big help and, you know [she says] oh that's no good for you, and I think, oh yes. Sometimes she gets on my nerves but when you look at the big picture, she is*

*right and so you just think, thank you . . . Yeah, we look after each other. (client 3)*

*My partner he's changed, like we don't have sugar, we have Sugarine, he has Sugarine, he hasn't even got diabetes or anything but as the doctor said it will make you live longer . . . We do the George Foreman steamer and all of that stuff we have. He's worse than what I am, if I put a little bit of salt on, [he says] don't cook with salt, you put that on after. (client 4)*

*But if there's three of you at home, and you make it good fun, I tell you, you don't know that you've just chopped all your onion, your carrots, because you're laughing. And that's all we do, is make it fun. (client 7)*

### C3.4. Financial pressures

Some clients and staff felt that the cost of lifestyle change was a barrier to managing chronic conditions.

*How can you tell somebody to check their sugar levels if they haven't got the machine to do it? . . . How can you tell them to buy healthy foods or food for the whole family if they haven't got enough money? (staff 3)*

Healthy food was also considered to be very expensive by some clients:

*But, you know the other thing that puts people off? Is to eat healthy your bill goes from \$100 to maybe \$180. It - my bill, that food shopping bill, has just doubled. And it's sad, because you're trying to look after yourself and eat healthy, and money is your first object before we do anything. And our bill's gone up like massive because we're buying the healthy vegies and stuff. You look for the cheaper version of vegies, but you can't get Black and Gold bananas, can you, you know? (client 7)*

Other clients felt that healthy food was affordable after making changes to shopping habits, and eating out less often:

*We find now we buy our food, our shopping and a lot of it is fresh vegetables and because we live on a farm we freeze everything so it's easier, so I'm not buying food every day I come to town or when I come in, I do it once a fortnight and it's a lot cheaper. I've found that we've saved a lot of money and it's good quality stuff like vegetables and of course we eat everything in the cupboard now because there was a lot of wastage before because 'I don't want to eat that today, I'll go to town and buy something', we don't do that now, we eat what's in our cupboard. (client 8)*

### C3.5. Exercising with peers and family

Several clients had made changes to their lifestyle, including introducing more physical activity to their lives. Some had exercise-related personal goals in their care plans, eg one client wanted to keep up with weeding her large garden, another wanted to go for a daily walk. The company of their families and friends encouraged and motivated them, illustrated in the following examples:

*When I'm in town me and a couple of other colleagues do a lot of walking, or we'll go down to the beachfront . . . encouraging each other. (client 6)*

*When I'm on the farm I do a lot of gardening with my partner . . . we do a lot of walking . . . or we'll go out on the boat and do a bit of fishing and catch some whiting and cook it up and take some vegies and that on the boat and camp for the night, swimming is a bit of exercising, so when it gets hot we have a bit of a swim off the boat. We usually just do that every weekend. (client 6)*

Sometimes conditions at work or other factors in the environment made exercise difficult, eg:

*But being in town I'm not as active as I would like to be, because I'm really nervous of dogs. And there's always dogs out on the street when you go for a walk, and they growl at you and stuff. And I'm real nervous about that. That's why I'm waiting for the gym down here, and then I can go down there. I feel a bit safer. (client 7)*

*Just standing [all day at work] and the doctors told me to walk on the spot but you've got these big gum boots on, big aprons on and you try and lift your little skinny diabetic legs, it's that hard. (client 7)*

### C.3.6. Emotional and spiritual wellbeing

Another theme that emerged from some of the client interviews was the importance of emotional and spiritual wellbeing, and how that influenced their physical health and their ability to manage their health, eg:

*I try not to worry about it too much, I notice when I worry too much my diabetes goes up. (client 11)*

*You got to have a positive attitude. I think that's the main thing, a positive attitude. (client 10)*

Clients drew emotional and spiritual strength in different ways, including spending time on the land and outdoors, eg:

*After I finish work I just can't wait to get home, I love it. ... I feel better in myself. (client 4)*

*We go down to the beach for walks, we get lots of sea things off the beach, at the backyard I've got a big net so I hang things on there, I love going and getting little shells to make jewellery and make other things. Play with my animals. (client 7)*

Some clients talked of needing their own space and finding it at work or in solitude; others relaxed in the company of friends or drew strength from their faith as illustrated in these examples:

*I'm an artist... Yes, [it] has helped me a lot. I'm creative, but then I get deep .... I run workshops, and in those workshops you meet a lot of people, and you do a lot of talking, and you listen to the people's stories. You communicate and you're not sort of isolated, you're not sitting there, and just dwelling on the past, move on, you're talking to other people who have gone through similar experiences what you did. It just made me strong, it's just made me stronger. (client 14)*

*I find my work is really good for me. It gives me my space away from my husband, and he can have his space and I have my own space, yeah, work is a big thing for me. (client 10)*

*At other times I sleep. Just so I don't have to talk to anyone, and no one talks to me. I come in the house and I lock the door, and I go to sleep... I love silence. (client 11)*

*That's why I come back to my God. I can have the highest blood pressure but if He is with me, I wasn't worrying. (client 5)*

# Capacity development outcomes

Throughout this project, opportunities were found to develop research capacity of the research team and participating health service partners, and the capacity of health services, staff, clients and community members to manage chronic conditions more effectively. These opportunities arose through the participatory action research design of the project, and the various project activities and interventions supported through the project. A brief summary of the capacity development outcomes follows.

Aboriginal health workers from participating health services were engaged and mentored as research assistants / health service link people, helping with local project activities, client engagement, data collection, conference presentations and local chronic condition management initiatives. Together with Aboriginal community 'link people', they participated in annual Project Advisory Group meetings.

Russell Carbine, Aboriginal health worker and project link at PLAHS developed basic research skills eg data retrieval and client engagement, through the project. This experience has complemented his studies (Aboriginal Health Worker certificate III completed in the reporting period), and developed his interest in further work around research and diabetes in his community.

Interest in the development of the Riverland Aboriginal Chronic Disease Support Group prompted an invitation from within Country Health SA to speak at a State health forum. Kathleen Sansbury, a founding member of the group, gave a presentation about it in February of 2010 in the SA Health forum 'Only the Beginning: Chronic Disease Self-Management Support Beyond June 2010' in Adelaide. She identified factors contributing to the group's success such as interesting speakers, transport, member input, learning to take control of their health, shared resources, community and health professionals interacting in a neutral environment [53]. It is notable that Kathleen was the only health consumer presenting at the conference. The presentation was produced in collaboration with RN Jenny Boyd from the RCHS.

Aboriginal community members involved in the project as health service or community links (Kathy Chisholm, Allan Wilson, Dylan Branson, Oscar Abdulla) contributed to the article in the SA Health Promotion Storybook, 'Chronic Condition Management Strategies in Aboriginal Communities' [65].

Oscar Abdulla, Aboriginal health worker and project link in RCHS, and Yvonne Helps, research officer for this project, attended the Healing our Spirit Worldwide Sixth Gathering in Honolulu, and presented a joint paper about this project, titled 'Our Health Our Way: Chronic condition management strategies in Aboriginal communities' [66]. The paper described the development of the Riverland Aboriginal Chronic Disease Support Group and the Aboriginal health worker's professional and personal development during the process.

Yvonne Helps also presented an outline of the methodology at a primary health conference in Alice Springs [67].

Patricia Mitel Gahanao and Penny van Pelt, both Bachelor of Health Science students from Flinders University and doing work internship electives with the Aboriginal Health Council of SA, developed health promotion tools based on stories and clinical data from participating clients at PLAHS collected during this project [68]. The tools they developed are the basis of a public health promotion poster campaign to attract Aboriginal chronic condition clients to engage in care plans with their clinic, launched in Port Lincoln in December 2010 (described elsewhere in this report and shown in Appendix 10-14). Patricia and Penny presented a poster describing the development of these tools at the Chronic Disease Network conference in Darwin in September 2010, entitled 'Care plan health promotion poster: A way of reading and learning chronic condition self-management in Aboriginal communities' [51] (Appendix 16). From this experience, and through links with PLAHS and Flinders University, Patricia has been

supported to adapt successful chronic condition management strategies for implementation in Morobe-Lae province, Papua New Guinea, in her role as senior nurse/midwife. In particular she is undertaking to establish a point of care testing program, through a new international collaboration with Dr Mark Shephard, Community Point of Care Services, Flinders University, which is likely to have significant benefit for screening and monitoring of a range of acute and chronic conditions and the health of people in Papua New Guinea.

Follow up training in the Flinders Program™ of Chronic Condition Management for staff of participating services was offered through the project, as described elsewhere in this report, providing opportunities for both staff and client volunteers to learn more about managing chronic conditions. Dr Annapurna Nori of Nunkuwarrin Yunti is now an accredited trainer, which will enable more staff at Nunkuwarrin Yunti to implement self-management support.

Building on this project and previous related work, members of this research team gained further funding to refine and roll out this training program through the Flinders Closing the Gap Program™ for 400 health professionals working with Aboriginal patients across Australia [9-10]. The training program is being revised in light of experience from this project to better meet the needs of Aboriginal workers and contexts. Barriers and enablers of implementing and maintaining structured systems of chronic condition care identified through this project will inform the implementation phase of the Closing the Gap Program. Quantitative methods for establishing beneficial health outcomes of chronic condition management strategies, as demonstrated in this project, can now be applied in the evaluation of this and other programs.

The project facilitated sharing of ideas about implementing care planning and other chronic condition management strategies between staff members from participating services.

Qualitative and quantitative evidence about the clinical effectiveness of chronic condition management strategies and their barriers and enablers was generated through this project. Participating services can potentially use this evidence to support submissions for the staff and resources required to continue and expand such strategies. Publication and promotion of the project and its outcomes through the Aboriginal Health Council of SA [56, 69-71], Flinders University [72], SA Health [73] and the Lowitja Institute [74] support these efforts.

This publicity, as well as media coverage of community events such as the Riverland Health Expo, the Riverland Aboriginal Chronic Disease Support Group and the PLAHS diabetes camps [52] raised community awareness of chronic conditions, and encouraged people to address their health.

Having the project officer employed by and based at the Aboriginal Health Council of SA strengthened research linkages with Flinders University. This arrangement also increased the Aboriginal Health Council's research profile and capacity to advise and advocate for other research initiatives.

# Discussion

As outlined in the introduction, this research project builds on over a decade of linked research on chronic condition management and self-management in Aboriginal communities, including the Council of Australian Government coordinated care trials [16-17] and projects conducted through the Centre of Clinical Research Excellence in Aboriginal and Torres Strait Islander Health [11, 14-15, 18, 21-24]. Also, the Sharing Health Care Demonstration project in South Australia [19, 59-60], Point of Care Testing systems [25-26] and, more recently, initiatives of the National 'Closing the Gap' programs [9-10] are related to the current project.

## Limitations and strengths of the project

This is a modest project, conducted in three very different sites, and with a small convenience sample of volunteer participants. The aim of the study was to find out what works and the barriers and enablers to chronic condition management, not to prove the effectiveness of a single element of a combined set of processes and interventions, for example through a randomised trial design. The facilitated research development process ensured a culturally acceptable and feasible methodology that addressed priority research questions identified by Aboriginal partners. The study design was action-oriented, intended to demonstrate the effectiveness and transferability of promising chronic condition management strategies selected by participants to meet their needs, in real life contexts, and to increase understanding of their barriers and enablers. Another strength of the project was the use of multiple methods to investigate these issues, enabling triangulation of findings from qualitative and quantitative approaches, and enhancing the credibility of the results. Capacity development opportunities throughout the project ensured beneficial outcomes for participating clients, staff, health services and communities.

## Chronic condition management interventions and processes

This project provides qualitative and quantitative evidence that Aboriginal people involved in structured chronic condition management strategies can improve their health and wellbeing over time. Strategies include client-centred care planning based on principles and processes that support self-management, education about chronic conditions and how to manage them, help with medications, and peer support groups.

Retrospective analysis of longitudinal clinical data showed statistically significant and clinically important improvements in common health indicators like body mass index and cholesterol levels. Interviews with clients and staff confirmed and further explored the benefits of chronic condition management. A novel aspect of this project was inclusion of all chronic diseases, and that different chronic condition management strategies were facilitated and/or evaluated in each site according to need and capacity. Previous research had shown that structured chronic condition management strategies could lead to better organisational systems and processes [75-77], and more engaged and knowledgeable clients [47, 60], but evidence about the health outcomes of such strategies was scant, especially for Aboriginal people [60, 75, 78]. This new evidence of clinical effectiveness of structured chronic condition care could also strengthen bids for further funding to support these strategies.

This project has helped refine the key elements of effective strategies that are consistent with established models of chronic illness care [48-50, 79-82], including adaptations to suit Aboriginal people [16, 18, 26-27, 43, 83]. This project confirms other research highlighting the importance of a holistic approach, meeting specific needs identified by Aboriginal clients and community groups, key roles for Aboriginal staff, collaboration and organisational support [84-86]. Key health service and system enablers identified in this project, including effective



client information systems, collaborative arrangements, well trained staff and organisational support, are similar to elements in the Wagner's model of chronic disease care [48-50]. Effective communication [79], responsive and accessible health services [80], and informal support of family and friends [87] were also confirmed as important enablers in this project. Additionally, the current study highlighted staff and client knowledge about chronic illness and capacity to change lifestyle habits and professional practice as key factors influencing the success of any strategy. This project extends what is known from the literature about factors that help or hinder implementation and sustainability of chronic condition management strategies for Aboriginal people. Attention to these factors would enhance the likelihood of successful transfer of chronic condition management strategies elsewhere.

## Recommendations

This project demonstrated the efforts and successes of participating health services, staff and clients in managing chronic conditions. Strategies explored in this project included education and training for staff and clients about chronic disease management and self-management, integrated care planning, systems and protocols to support organisational change, peer support group, health promotion and more. The variety of effective strategies and the different challenges encountered highlight the importance of tailoring new initiatives to suit individual needs and local circumstances. Recent reports confirm the need for flexible programs [84-85], particularly for Aboriginal people [76, 86].

This research identified enablers and barriers of structured client-centred system of care for Aboriginal clients with chronic conditions. Key elements that health services need to have in place, or to develop, in order to implement such a system include:

- > An accessible, culturally appropriate and free health service that meets clients' needs
- > A model of chronic condition management based on principles of self-management support eg the Flinders Program
- > Systematic and coordinated service delivery, with clear clinical protocols and pathways of care, ie 'one-stop shop', 'no wrong door' approach
- > Sufficient staff to work with and motivate clients
- > Staff with clinical expertise, teamwork skills, and trained in chronic condition self-management support
- > An effective clinical information system, eg Communicare
- > Peer support and outreach services, the LIFE program, support groups, diabetes camps
- > Organisational support for staff to implement structured client-centred care.

## The future

Leaders of Aboriginal community controlled health services have come to recognise the importance of implementing integrated strategies of chronic condition care and collecting objective data that demonstrates their effectiveness. The challenge for all services is to cope with acute demand while implementing a system for chronic condition prevention and management. This project, built on a foundation of over 15 years of collaboration with Aboriginal communities in South Australia, shows that this can be achieved. The findings provide a model for working with Aboriginal communities to implement chronic care programs as well as a systematic approach to data collection and analysis. At a time when the Australian Government is investing in national strategies to improve health outcomes for Aboriginal people [8], including the Flinders Closing the Gap Program™ for Chronic Condition Management [9-10], the research team has demonstrated what is possible in relation to the collection and aggregation of key clinical data in order to track the longer-term impacts and outcomes of structured systems of care.



As the Flinders Program™ gathers momentum and moves from a training strategy to an embedding phase, similar approaches may be used to collect, collate and analyse population level data for the clients with whom the new wave of health care providers work. This vital evidence of the effectiveness of chronic care programs will help to educate and motivate people to engage with and maintain better chronic condition management strategies, and provide the data needed to ensure that communities are funded more effectively to run programs that improve the health and wellbeing of Aboriginal people.

## Appendix 1: Information for health service staff

Chronic health conditions are prevalent, particularly among Aboriginal people, and put significant strain on patients, their families and communities, and the health care system as a whole. To reduce this burden, various chronic condition management (CCM) strategies have already been developed and are being promoted widely by government. Some of these strategies, including holistic, primary care approaches and have been accepted by Aboriginal people and Aboriginal health organizations as valuable approaches to enabling their people to live healthier and more productive lives. However, although CCM strategies appear to have merit, there is little evidence to date about their clinical outcomes, cost or sustainability.

This project will address that evidence gap with the overall goal being to develop and demonstrate sustainable and effective CCM strategies for Aboriginal communities. The project builds on the researchers' previous and current work, including through the Centre for Clinical Research Excellence in Aboriginal Health in SA, and is being supported by the Cooperative Research Centre for Aboriginal Health for 3 years (2008-2011). The Flinders University investigators are Inge Kowanko, Malcolm Battersby and Peter Harvey, working in partnership with the Aboriginal Health Council of South Australia's research officer, Yvonne Helps. The project includes research, capacity development and knowledge and skills translation activities, within a participatory action research framework. It is anticipated that the project will provide Aboriginal health services with practical information on sustainable CCM strategies to suit their needs and contexts, and ultimately reduce the burden of chronic conditions in the Aboriginal communities they serve. The project has been approved by Flinders Clinical Research Ethics Committee and the Aboriginal Health Research Ethics Committee (SA). Negotiations are underway with three project sites (the Riverland, Nunkuwarrin Yunti of SA, Port Lincoln).

This research will explore the CCM strategies that are currently used for Aboriginal people at each of the three sites, find out what works well for them and why, and what systems and supports are required. Then, according to local priorities and available resources, one or more additional CCM strategies will be offered, i.e. Care Plans supported by MBS funding, the Flinders Model of care planning based on the client's Community Health Services own life goals, and the LIFE program of peer support for self-management, along with associated training for health service providers and organizational change. The processes, impacts and outcomes of these CCM strategies (interventions) will be assessed using multiple methods including interviews with clients and service providers, changes in health status (clinical measures and self-report), audits of service provision and costs.

For further information please contact:

Mrs Yvonne Helps, Aboriginal Health Council of South Australia (AHCSA)

E-mail: [Yvonne.Helps@ahcsa.org.au](mailto:Yvonne.Helps@ahcsa.org.au)

## Appendix 2: Consent form for staff

I ....., being over the age of 18 years, give my consent to participate in

- > a focus group interview on ..... at .....
- > an individual interview on ..... at .....

I understand any personal comments used will be de-identified in reports to protect my confidentiality.

I understand the information provided. Details of procedures and any risks have been explained to my satisfaction and I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

I understand that:

- > I may not benefit directly from taking part in this research.
- > I am free to withdraw from the study at any time and I am free to decline to answer particular questions. This will not disadvantage me in any way.
- > I understand that confidentiality of information I share in Focus Group Interviews cannot be guaranteed.
- > I understand that information shared in individual interviews is kept confidential.
- > Whilst the information gained in this study may be published as explained, I will not be identified in reports.

Participant's signature..... Date .....

Male/female ..... Age in years .....

I would/would not like my participation acknowledged in reports.

I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name .....

Researcher's signature ..... Date .....

## Appendix 3: Information for clients

### Chronic condition management strategies in Aboriginal communities

The Cooperative Research Centre for Aboriginal Health (CRAH) has funded this project to examine the impacts of a number of chronic illness programmes being developed and used in Aboriginal communities. The project is a partnership with the Aboriginal Health Council of South Australia (AHCSA), and Flinders University.

As an individual who may wish to participate in this research work you will have the opportunity to:

- > meet with members of the research team to discuss your experiences of chronic condition management strategies in your community such as care planning and lifestyle education
- > meet with researchers and other patients involved in chronic condition management programmes to discuss your experiences
- > participate in interviews with researchers to provide details of your experiences of chronic illness programmes
- > consent to provision of selected clinical data from your medical record in a de-identified form to the research team to monitor the effects of chronic illness programs on the health of the community

Through these processes, all of your contributions to the research project will be kept confidential and you will not be identified in any formal reports or documents that are produced through the research programme.

If you agree to participate in the project, you will be asked to sign a consent form to indicate that you have read this information and that you understand what the research programme will involve. You are free to withdraw from this research at any time without any penalty to you. If you do choose to withdraw, we would appreciate it if you could fill out a withdrawal form for our records. If you choose to withdraw from the research programme, any information you have provided to researchers will be subsequently removed from summaries, transcripts and reports.

If you are interested in participating, please sign the attached consent form.

If you have any questions about this research process, you can contact Yvonne Helps, the research officer, on ..., or by email ...

## Appendix 4: Consent form for clients

I ..... being over the age of 18 years, give my consent to participate in a recorded

- > a focus group interview on ..... at .....
- > an individual interview on ..... at .....

I do/do not consent to making key clinical data from my medical record available in to the research team. I understand any personal data used will be de-identified in reports to protect my confidentiality

I understand the information provided. Details of procedures and any risks have been explained to my satisfaction and I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

I understand that:

- > I may not benefit directly from taking part in this research.
- > I am free to withdraw from the study at any time and I am free to decline to answer particular questions. This will not disadvantage me in any way.
- > I understand that confidentiality of information I share in Focus Group Interviews cannot be guaranteed.
- > I understand that information shared in individual interviews is kept confidential.
- > I understand that clinical data provided from my medical record will not be identifiable
- > Whilst the information gained in this study may be published as explained, I will not be identified in reports.

Participant's signature..... Date .....

Male/female ..... Age in years .....

I would/would not like my participation acknowledged in reports.

I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name .....

Researcher's signature ..... Date .....

## **Appendix 5: Project advisory group: Role and terms of reference**

### **Background**

The overall goal of this project is to develop and demonstrate effective, transferable and sustainable CCM strategies for Aboriginal communities. The project is funded by the Cooperative Research Centre for Aboriginal Health for 3 years: 2008-2010. It is being conducted by Flinders University researchers in partnership with the Aboriginal Health Council of South Australia at three sites: Nunkuwarrin Yunti of SA in metropolitan Adelaide, Port Lincoln and the Riverland. The project builds on our previous research, and was developed at the request of Aboriginal partners. It has been through a rigorous research development process and has been approved by Flinders and South Australian Aboriginal health research ethics committees. The Advisory Group was commenced in October 2008.

The purpose of the group is to provide guidance and grounding to the project, specialist advice, feedback on progress of project, and input into draft reports.

### **Terms of Reference**

1. To advise the CCM project on the most effective use of organisational resources to investigate and address better management of chronic conditions for Aboriginal people.
2. To advise the CCM project on the development and maintenance of effective partnerships with local Aboriginal clients and communities, and their health services and providers.
3. To advise the CCM project on appropriate cultural approaches in the organisations and communities.
4. To advise the CCM project of local or broader issues, priorities, plans and programs that may impact on the project.
5. To be advised about project progress in relation to planned objectives at each site and for the project as a whole
6. To comment on draft project outputs
7. To engage in the advisory group on an equal and respectful basis with all members.

### **Composition of the Advisory Group and relationship with the CCM project**

The Advisory Group has been formed by inviting participation from: the health service providers involved in each project site, organisations that support health service providers, members of the Aboriginal communities, the funding body, the academic institution leading the research, the peak body representing Aboriginal health and substance misuse services in South Australia.

### **Agencies invited to join CCM advisory group**

Participation is being sought from: Aboriginal Health Council of South Australia (AHCSA), Cooperative Research Centre for Aboriginal Health, Flinders University, Nunkuwarrin Yunti of SA Incorporated, Port Lincoln Aboriginal Health Service, Riverland Community Health Service, Riverland Division of General Practice.

### **Communities invited to join CCM Advisory Group**

Community or client participation is being sought from: Nunkuwarrin Yunti of SA, Port Lincoln, Riverland.

### **CCM project team**

Dr Inge Kowanko, Assoc. Prof. Peter Harvey, Professor Malcolm Battersby, chief investigators, Flinders University

Mrs Yvonne Helps, the Aboriginal Health Council of South Australia (AHCSA)

### **Frequency of meetings and communication**

The project advisory group will meet at least once a year face to face, with extra teleconference meetings if necessary. Written materials and draft reports will be circulated by email or post for comment and input when needed.

Contact: Mrs Yvonne Helps, Aboriginal Health Council of South Australia (AHCSA)

E-mail: [Yvonne.Helps@ahcsa.org.au](mailto:Yvonne.Helps@ahcsa.org.au)

Thank you very much for your interest in the project.

Yvonne Helps, Inge Kowanko, Peter Harvey, Malcolm Battersby



# Appendix 6: Comorbidity patterns in the clinical dataset

The clinical records (Communicare) of 24 clients from PLAHS and 12 from Nunkuwarrin Yunti were analysed. They had various coexisting chronic conditions, summarised as frequency bar graphs (Figures 8-9). These graphs were developed by noting the first ten (or fewer) diagnoses from each client’s record, grouping the diagnoses by ICD-10-AM classification [88] and then counting the number in each classification. Separate charts were developed for the Nunkuwarrin Yunti and PLAHS clients.

Clients mostly had multiple co-morbid chronic conditions, some clients’ records included more than 10 separate co-occurring illnesses. Figure 8 shows that for the 24 clients from PLAHS, the most common diagnostic classifications were circulatory disorders, and endocrine, nutritional and metabolic disorders, followed by musculoskeletal and respiratory disorders. There were fewer than expected recorded diagnoses in the mental and behavioural disorder group, based on recent national prevalence data and previous research [2, 5, 23]. However, many of these PLAHS clients were prescribed medications for mental health conditions, suggesting that our dataset might be incomplete. Our previous research with PLAHS identified documentation and sharing of client data between teams as priority areas for improvement [23].

Figure 8. Comorbid chronic conditions in PLAHS group

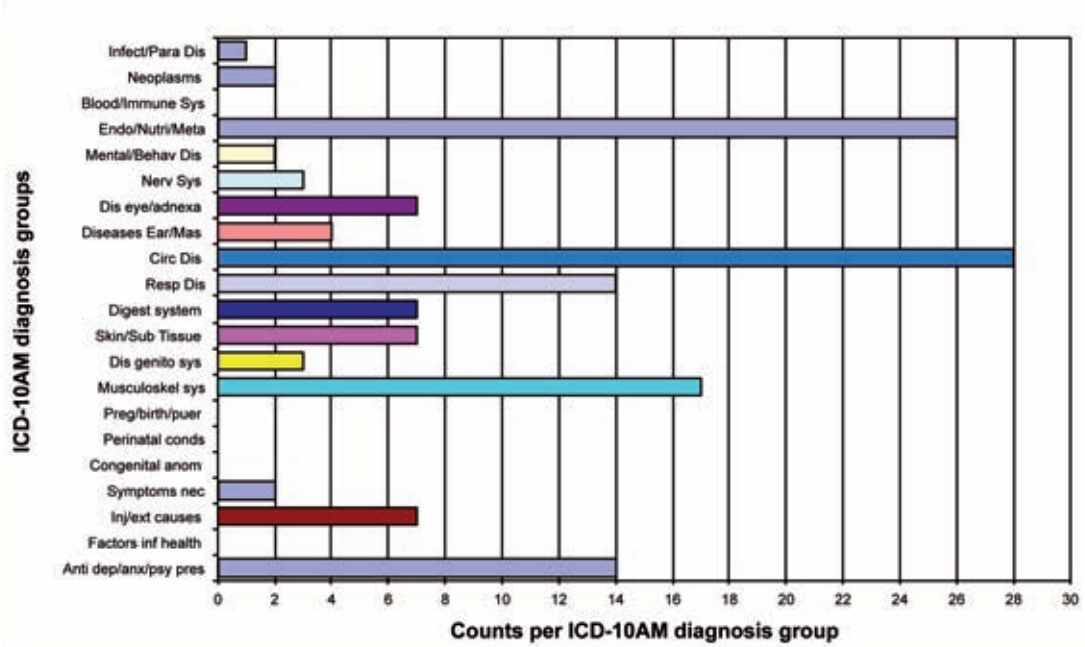
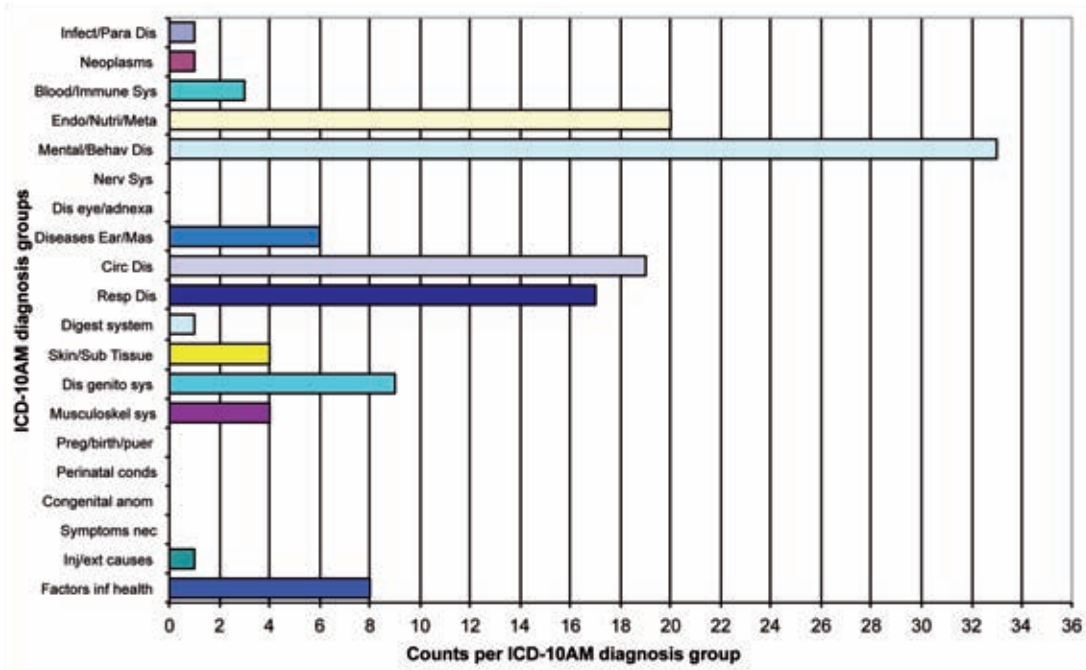


Figure 9 summarises the recorded diagnoses of the Nunkuwarrin Yunti clients. Six clients had at least 10 chronic co-morbidities, three had 9, and 1 client had 5 recorded comorbidities. Mental and behavioural disorders (including anxiety, depression, stress, grief) was the largest group of diagnoses, followed by endocrine, nutritional and metabolic disorders (includes obesity and diabetes), respiratory disorders (asthma, emphysema, chronic obstructive pulmonary disease) and circulatory diseases. Six clients had diabetes, and several of the others had risky or potential precursor conditions for diabetes, eg obesity, hypertension, stress [89-90].

Figure 9. Comorbid chronic conditions in Nunkuwarrin Yunti group



## Appendix 7: Interview guide for staff participants

How are chronic conditions currently identified, approached and managed for your Aboriginal patients?

What things influence the way in which you approach patients with chronic conditions?

What works well for you/for your patients? Why that may be so?

What are the biggest obstacles to managing chronic conditions for you/for most of your patients?

What systems and supports are needed to achieve what you currently do?

What do you think your patients' needs might be in managing their chronic condition?

## Appendix 8 : Interview guide for client participants

Please tell me a little about your experience of living with a chronic condition. How long ago were you diagnosed, do you remember how that made you feel, what did you think at this stage?

What sort of things do you do to help cope with your condition day to day?

Can you tell me about your experience of being involved in a chronic illness management programme in your community?

What made it hard/easy to participate?

Did you benefit from your involvement in the program? How? Why? Why not? Please provide an example or story to illustrate.

Are there things you understand or can do now that you couldn't before? (prompt for specific issues covered programs, eg care planning knowledge, skills, knowledge of illness, coping strategies, symptom management, goal setting and monitoring progress).

Have other members of your family been involved in the program? Can you share your experience of their involvement?

Do you know which services you can go to for help? Are they helpful, supportive, appropriate and accessible? Have they followed through? What worked well? What didn't work well?

What made it easy or difficult for you?

Do you have any suggestions for how programs might be improved?

## Appendix 9: Action plan and goal setting template used at RCHS

### Long Term Goal and Monthly Action Plan

Long Term Goal \_\_\_\_\_

Over the next 6-8 months I will \_\_\_\_\_

My confidence level is \_\_\_\_\_ (0 = not at all confident; 10 = totally confident)

### Monthly Action Planning

In writing your action plan, be sure it includes:

- > What are you going to do
- > How much you are going to do
- > When are you going to do it
- > How many days a week you are going to do it

**For example:** *this month, I will walk (what) around the block (how much) after lunch (when) three times (how many) per week*

**This month I will:**

\_\_\_\_\_ (what)

\_\_\_\_\_ (how much)

\_\_\_\_\_ (when)

\_\_\_\_\_ (how many)

**How confident are you?** \_\_\_\_\_ (0 = not at all confident; 10 = totally confident)

	Check off					Comments
	Wk 1	Wk 2	Wk 3	Wk 4	Wk 5	
Sunday						
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						

## Appendix 10: Chronic condition self-management stars poster (Wally)

# Chronic Condition Self Management Stars

Reaching for the stars through Care Planning with the PLAHS Chronic Condition Self Management Team

**Wally's Story**  
Wally was diagnosed With Type II diabetes in 2000. His wife Shirley is also diabetic. They support each other to manage their chronic conditions. His goals are to reach his target weight by the end of 2010 and to live better and longer. The support from Chronic Condition Self Management Team at Port Lincoln Aboriginal Health Service is helping him to achieve his goal.

**You can be a Star too!**  
Wally's goals are to:  
 ✦ Lose weight  
 ✦ Live longer  
 ✦ Be more active

**Wally's achievements and successes**  
 ✦ Good insulin management makes him feel better in everyday life  
 ✦ Enjoys life more  
 ✦ Controls his weight with diet  
 ✦ Has cut back on chocolate, bread  
 ✦ Improved blood circulation in feet

**Set Goals  
Feel Better  
Do More**

**The care plan is helping Wally to:**  
 ✦ Do things he couldn't do before like  
 Travel interstate  
 Walk further  
 Share feelings, yarn  
 ✦ Review and control his medication  
 ✦ Organise and attend family gatherings  
 ✦ Eat moderately, cut back on sweets  
 ✦ Improve his circulation

**Did you know...**  
 one third of Aboriginal people aged 55 and over live with high blood sugar levels or diabetes  
 Thomson N, MacRae A, Burns J, Catto M, Debuyst O, Krom I, Potter C, Ride K, and Stumpers S, 2009, Overview of Australian Indigenous Health Ret 010710 [http://www.healthinfonet.ecu.edu.au/health\\_facts/overviews](http://www.healthinfonet.ecu.edu.au/health_facts/overviews)

**Wally Pickett**

This shows Wally's progress, his goal weight and Body Mass Index, and his Care Plan dates.

Background: 'Journey', artwork on canvas by Jerny Pickett. Image courtesy of Kuju Aboriginal Arts and Crafts, Pt Lincoln

Aboriginal Health Council of South Australia Inc.  
Our health, our choice, our way

Flinders University

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## Appendix 11: Chronic condition self-management stars poster (Isabel)

# Chronic Condition Self Management Stars

Reaching for the Stars through Care Planning with the PLAAHS Chronic Condition Self Management Team

*...and over that time I've also made sure that I've been able to take my medication every day, my blood sugars are now down to between 4 and 7 every day, all the time and I'm so happy about that...*

### Isabel's Story

**Isabel** was diagnosed with Type II Diabetes when she was very young and has lived with this chronic condition for almost 22 years. She missed out on school and her social life. However, with the support of her family, Dietitian and **Chronic Condition Self Management Team (CCSM)**, Isabel is now on a **Care Plan**. Isabel has managed to live with diabetes and achieve her goal. She is a role model to her children and family.

### Take Charge Feel Better Happier

### Isabel Richards

### You can be a star too!

Be a role model to family and friends

### Isabel's achievements and successes

- ✦ Cuts down on fast foods
- ✦ Saves more money
- ✦ Blood sugar level down to normal everyday
- ✦ No pain and feels better
- ✦ No more depression
- ✦ Sleeps well at night
- ✦ Role model for her family
- ✦ Better knowledge of diabetes

### ISABEL IS A STAR

- ✦ Learns about her condition from her Diabetes Educator
- ✦ Shares decisions with CCSM Team
- ✦ Adopts healthy eating with help from the Dietician

### Did you know...

**A Care Plan helps Isabel to:**

- ✦ Access information on diseases like diabetes
- ✦ Easily access appropriate health care services
- ✦ Make positive changes to her family's health
- ✦ Plan and take medications at the right time
- ✦ Eat healthier by buying and cooking fresh food at home (often much cheaper too)

**That in a study of over 3,000 South Australians, 24% of people with diabetes also suffered from depression**  
**2004 Goldney RD, Phillips PJ, Fisher LJ, Wilson DH. Diabetes, Depression, and Quality of Life: A population study. Diabetes Care**

**Flinders UNIVERSITY**

**Aboriginal Health Council of South Australia**  
*Your health, our choice, our way*

**Aboriginal Health Council of South Australia**

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Background: Kalgoorlie's Super Pit. Photo by Brian Voon Yee Yap.



## Appendix 12: Chronic condition self-management stars poster (Jackie)

# Chronic Condition Self Management Stars

Reaching for the stars through Care Planning with the PLAHS Chronic Condition Self Management Team

*...if you control your life style you are in control of your life. Always be true to yourself, acknowledge your gains and losses...*

## Jackie's Story

Jackie was diagnosed

with border line diabetes in

1996. Jackie thought it would go away,

however, in 2008, she was diagnosed

with Type II Diabetes. She

now follows a **care plan** with

support from the **Chronic Condition**

**Self Management Team**. Her husband

is also very supportive, helping her to live

better with diabetes. Jackie's goal is to change

her lifestyle habits, which she is doing successfully.

## A care plan has helped Jackie to

### change her life style habits:

- ✦ She now has two fruits a day
- ✦ Eats salads and herbs
- ✦ Visits families and friends
- ✦ Diet has less fats and meat
- ✦ Walks on the beach
- ✦ Walks her dog



Jackie Stewart

**Follow Your Star,**  
you can do it

**Take Charge  
Live Longer  
Be Happy**

## Challenges

**It's not always easy to follow plans. It helps to:**

- ✦ Take medication on time
- ✦ Eat regular meals
- ✦ Attend appointments
- ✦ Do regular exercise

## Jackie's achievements and successes

- ✦ Gave up alcohol completely
- ✦ Cut down on cigarettes to 3 a day
- ✦ Has a regular and healthy diet

## Did you know...

**three times as many Aboriginal and Torres Strait**

**Islander people have diabetes than other Australians**

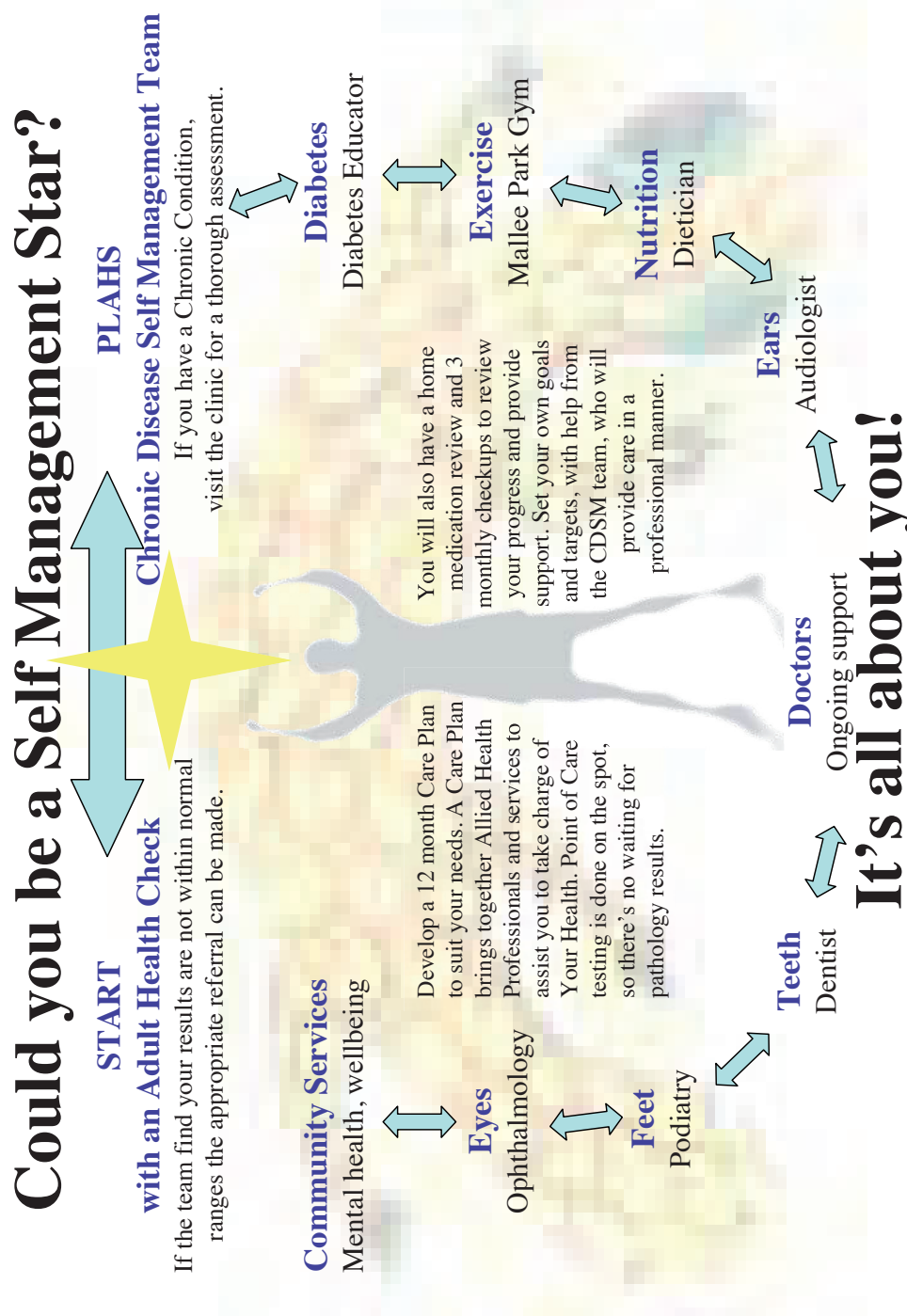
(in 2004-2005) Australian Institute of Health and welfare 2008, Diabetes,

Australian Facts, Diabetes series no. 8, CVD, Canberra: AIHW




Poster developed by Patricia Mirell Gahamao and Penny van Peit FUSA Health Work interns in the Chronic Condition Management Strategies in Aboriginal Communities project. Joint copyright held by Yvonne Helps, Inge Kowanko, Flinders University of South Australia and the Aboriginal Health Council of South Australia. May be reproduced in whole or in part for study or training purposes only. Aboriginal and Torres Strait Islander Community organisations subject to citing the source. Not for commercial use or sale. Reproduction for other purposes or by other organisations requires the written permission of the copyright holders.

## Appendix 13: Could you be a self-management star? PLAHS health promotion poster



Poster developed by Bev McCurry and Yvonne Helps in the Chronic Condition Management Strategies in Aboriginal Communities project 2010. Joint copyright held by Yvonne Helps, Inge Kowanko, Flinders University of South Australia and the Aboriginal Health Council of South Australia. May be reproduced in whole or in part for study or training purposes, or by Aboriginal and Torres Strait Islander Community organisations subject to citing the source. Not for commercial use or sale. Reproduction for other purposes or by other organisations requires the written permission of the copyright holders.

## Appendix 14: Did you know? cards



### Did you know...

#### Exercise

**Can Reduce Diabetes Risk**


For a person with diabetes exercise helps:

- Insulin to work better
- You control your weight
- Lower your blood pressure
- Reduce your risk of heart disease
- Reduce stress.

Get a health check before taking up a new activity, and start slow. Don't do strenuous activity if you feel unwell. Ideally, you should be doing about 30 minutes of exercise every day. Too much? Try 3 x 10 minutes sessions.

<http://www.diabetesaustralia.com.au/Living-with-Diabetes/Keeping-Active/>

"Shirley and I increased our steps each day, using a pedometer to count. Shirley got up to 10,000 steps! When I couldn't walk outside, I used a walking machine." **Wally Pickett**



### Did you know...

#### White Bread

**Can Increase Diabetes Risk**


White bread has a high glycemic index (GI), tending to cause big increases in blood sugar.

High-GI foods may increase diabetes risk by causing weight gain, which increases the risk Of type 2 diabetes.

Low GI foods don't do this, so it's best to eat grain bread, and maybe monitor how much bread you are eating.

A. M. Hodge, D. R. English, K. O'Dea, G. G. Giles. Glycemic Index and Dietary Fiber and the Risk of Type 2 Diabetes *Diabetes Care* November 2004 27:2701-2706;

"My target is to lose weight to help my diabetes and to feel better. I counted how many pieces of bread I was eating each day, and now I halve that amount. Shirley helps me keep on track." **Wally Pickett**



### Did you know...

#### Exercise Tips


**For Diabetics - Look After Yourself**

- Drink extra fluid before and after exercise
- Wear sun block when exercising outdoors.
- Wear comfortable and well-fitting shoes.
- Check your feet before and after exercise.
- Avoid things that cause foot stress (running)
- Wear loose, comfortable clothing
- Keep track of your blood sugar levels
- Pick an activity that makes you feel good

Ask your Diabetes Educator about adjusting your insulin or food intakes for exercise.

<http://www.diabetesaustralia.com.au/Living-with-Diabetes/Keeping-Active/>

"We go down to the beach for walks, we get lots of sea things off the beach, at the back yard I've got a big net so I hang things on there, I love going and getting little shells to make jewellery and make other things." **Jackie Stewart**



### Did you know...

#### Foot Care

**can slow Diabetes complications**

People with diabetes need to take extra care of their feet. High blood glucose can cause nerve damage, or poor blood flow. Caring for your feet helps slow down any complications.

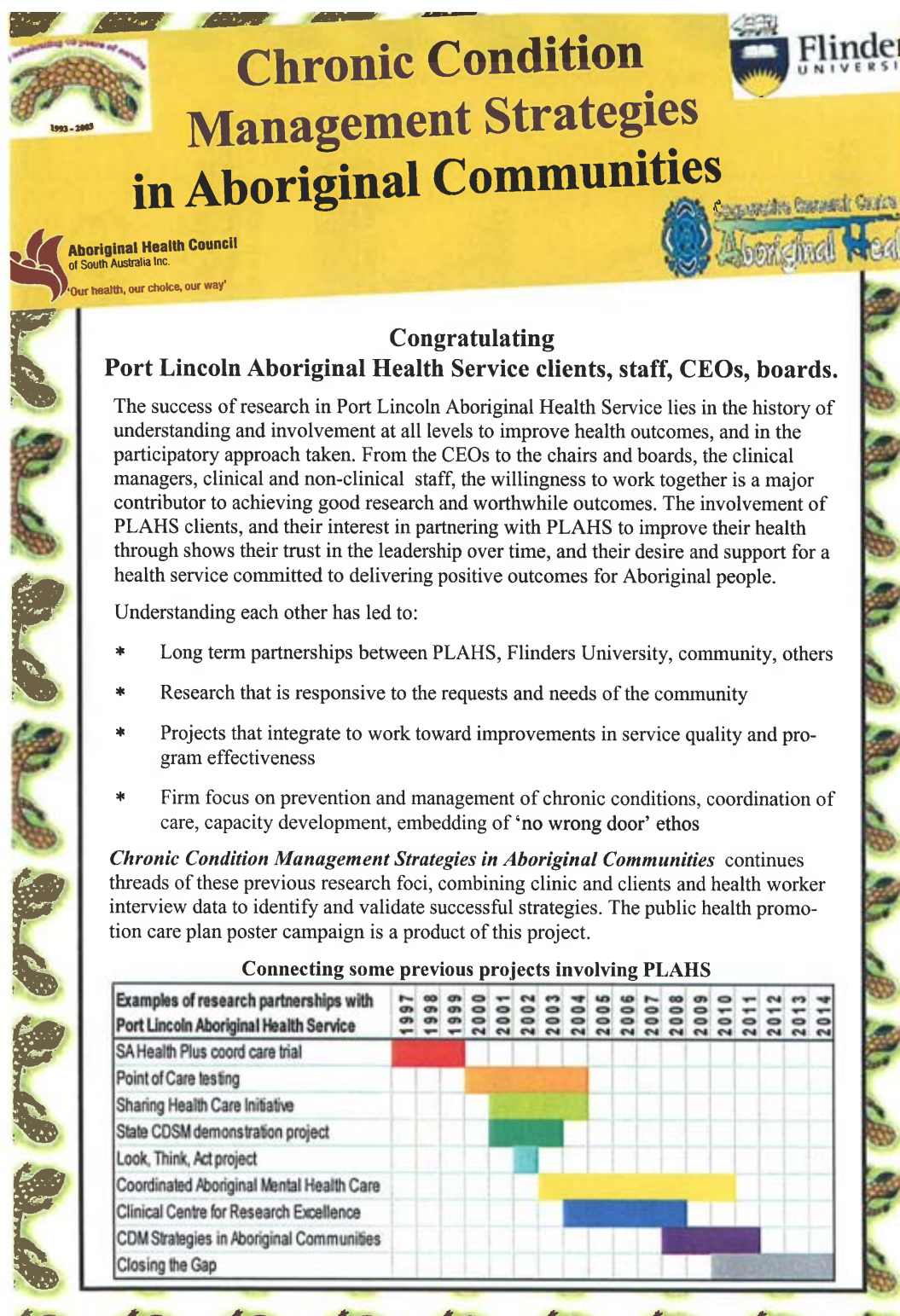
- Wash your feet in warm water every day
- Use lotion for dry skin (not between toes)
- Check feet daily for cuts, sores, redness
- Keep nails trimmed, use a mirror or ask someone else if you can't bend.

[http://diabetes.niddk.nih.gov/dm/pubs/complications\\_feet/#feet](http://diabetes.niddk.nih.gov/dm/pubs/complications_feet/#feet)

Isabel's diabetic relative had an amputation. "He always had his socks too tight. If he'd known, it might have helped him keep his limb. Howard's my health partner, he checks my feet at night for any changes." **Isabel Richards**



## Appendix 15: Chronic Condition Management Strategies in Aboriginal communities: Flyer congratulating PLAHS



### Chronic Condition Management Strategies in Aboriginal Communities

**Aboriginal Health Council of South Australia Inc.**  
"Our health, our choice, our way"

**Flinders University**

#### Congratulating Port Lincoln Aboriginal Health Service clients, staff, CEOs, boards.

The success of research in Port Lincoln Aboriginal Health Service lies in the history of understanding and involvement at all levels to improve health outcomes, and in the participatory approach taken. From the CEOs to the chairs and boards, the clinical managers, clinical and non-clinical staff, the willingness to work together is a major contributor to achieving good research and worthwhile outcomes. The involvement of PLAHS clients, and their interest in partnering with PLAHS to improve their health through shows their trust in the leadership over time, and their desire and support for a health service committed to delivering positive outcomes for Aboriginal people.

Understanding each other has led to:

- \* Long term partnerships between PLAHS, Flinders University, community, others
- \* Research that is responsive to the requests and needs of the community
- \* Projects that integrate to work toward improvements in service quality and program effectiveness
- \* Firm focus on prevention and management of chronic conditions, coordination of care, capacity development, embedding of 'no wrong door' ethos

*Chronic Condition Management Strategies in Aboriginal Communities* continues threads of these previous research foci, combining clinic and clients and health worker interview data to identify and validate successful strategies. The public health promotion care plan poster campaign is a product of this project.

#### Connecting some previous projects involving PLAHS

Examples of research partnerships with Port Lincoln Aboriginal Health Service	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
SA Health Plus coord care trial																		
Point of Care testing																		
Sharing Health Care Initiative																		
State CDSM demonstration project																		
Look, Think, Act project																		
Coordinated Aboriginal Mental Health Care																		
Clinical Centre for Research Excellence																		
CDM Strategies in Aboriginal Communities																		
Closing the Gap																		

# Appendix 16: Care plan health promotion poster – a way of reading and learning chronic condition self-management in Aboriginal communities

## Care Plan Health Promotion Poster

### A Way of Reading and Learning Chronic Condition Self Management in Aboriginal Communities

PATRICIA MITIEL GAHANAO, PENNY VAN PELT, Dr INGE KOWANKO, YVONNE HELPS

**Introduction**

- Chronic Conditions (CC) are major health concerns
- Clinical and Self-Management is often difficult
- However, some clients are very successful
- Care Planning seems to be a key part

**Aim**

- To develop health promotion posters that feature community members who successfully manage their CC.

**Working with Port Lincoln Aboriginal Health Service (PLAHS)**

- With PLAHS staff we identified 3 clients with CC who are managing well ('self management stars').
- Each client has a care plan in which they set achievable goals.
- The Chronic Condition Management team at PLAHS help clients develop actions to meet their goals.
- Allied Health areas like dietetics, podiatry, smoking cessation, exercise and medication management are incorporated in care plans.
- We approached the 3 clients about putting their success stories on posters to encourage others to manage their CC better.

**Working with Self Management Stars**

- Each client gave informed consent for use of their story and health data.
- Their goals were noted from the Care Plan.
- Quantitative data from clinical records were obtained and examined.
- Self Management Stars were interviewed to tell their story.
- We listened, read their transcribed interviews, matched clinical data (eg Point of Care test results) with the stories.



Isabel Richards



Wally Pickett



Jackie Stewart

**Developing the posters**

- The voice of the client is what appeals; we started with their image and a quote.
- Underneath that we highlighted their main goals within a star shape.
- On the left side of the poster we outlined their CCs and goals.
- We used dot points to describe what the client said they had gained from their Care Plan.
- We included relevant facts to reinforce and offer another way of learning about the seriousness of CC.
- On the right of the poster we included a meaningful chart of clinical data over time.



**Conclusion**

- Care Plans appear to assist clients and health workers manage CC.
- We developed an innovative and meaningful way of charting clinical data to help clients and health workers manage CC.
- We developed health promotion posters to encourage Aboriginal people to get involved in managing their CC, based on real life success stories from community members.
- The posters will be placed in the waiting room and reception areas of Port Lincoln Aboriginal Health Service.

**Implications**

This is an example of enhancing health literacy where people may be able to read and learn about health and wellbeing in several ways; their personal story, their improvement as evidenced in their clinical test results, in the translation of those aspects in an interpretive chart with a clearly understood analogy. The poster format can be adapted elsewhere in Australia and internationally, whether for this or almost any other topic for health promotion. As well as appealing to Aboriginal clients, this literacy approach may also be effective with migrant communities.



The research team

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Liz Aberly (Flinders University)  
Aboriginal Health Council of SA  
Lowitja Institute






**Developing meaningful charts**

- The aim is to interpret individual client clinical data that are linked to their Care Plan goals so that they can understand the effect of their actions on health indicators (eg BMI).
- The example chart shows one client's clinical data (BMI) over time, and his goal. The chart uses a traffic light analogy on the background indicating progress against accepted BMI obesity risk levels.
- The chart was improved through crosschecks with the client and health worker.
- Further consultation with the client and health workers suggested charting other clinical indicators against the traffic light background also.
- These charts can help clients monitor progress towards their goal, and strengthen commitment to following their care plans.
- A range of health workers may also find the charts useful in engaging with clients.
- All feedback received to date supports this innovative use of client health data.



## Appendix 17: Riverland Aboriginal Chronic Disease Support Group schedule of meeting topics 2009-2011

	Health topics discussed at RACDSG meetings		
	2009	2010	2011
February		-	Dental Health Care
March		-	Diabetes Outreach Service
April		Exercise and Physical Activity	Cardiovascular
May	Inaugural meeting	Stop Smoking	Diabetes SA
June	Foot Care & Diabetes Information Session	Carbohydrates and HbA1C	Foot care
July	Foot Care & Story Books	Eye Health	Virtual supermarket
August	Mental Health– Stress Management	Foot Care	Preventing falls
September	Chemist; Medication, Webster Pack, Interactions	Occupational Therapy	Measuring BSL
October	Dentist/Medicare	Emotional Wellbeing	Healing session
November	Physiotherapy– Easy Exercises	Kidney Health	Food and budgeting
December	Christmas celebration	Christmas Celebration on the River	Christmas boat trip

## Appendix 18: Riverland Aboriginal Chronic Disease Support Group: Community storybook

### **RIVERLAND ABORIGINAL CHRONIC DISEASE SUPPORT GROUP** COMMUNITY STORYBOOK 2011

Yvonne Helps and Inge Kowanko





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