

CCRE Achievements and Milestones

Centre of Clinical Research Excellence (CCRE)
in Aboriginal and Torres Strait Islander Health



Centre of Clinical Research Excellence in Aboriginal and Torres Strait Islander Health: Achievements and Milestones

Compiled by Glenn Giles

**Centre of Clinical Research Excellence in Aboriginal
and Torres Strait Islander Health (CCRE)**

The CCRE is a partnership led by the Aboriginal Health Council of South Australia Inc., with Flinders University of South Australia.





© Centre of Clinical Research Excellence in Aboriginal and Torres Strait Islander Health (CCRE) 2008

ISBN 1 876532 00 0

This work is copyright. It may be reproduced in whole or in part for study or training purposes, or by Aboriginal and Torres Strait Islander Community organisations subject to an acknowledgement of the source and no commercial use or sale. Reproduction for other purposes or by other organisations requires the written permission of the copyright holder.

Published by the Centre of Clinical Research Excellence in Aboriginal & Torres Strait Islander Health (CCRE). The CCRE is a collaboration led by the Aboriginal Health Council of South Australia in partnership with the Flinders University of South Australia. The CCRE is based at Aboriginal Health Council of South Australia. The CCRE is funded by the National Health & Medical Research Council, Grant Number 264414.

Compiled by Glenn Giles for the CCRE, November, 2008.

Cover illustration by Jillian Larking, design by Matthew Goodluck.

Graphic design by Theresa Leach.

Publication of this report supported by the Cooperative Research Centre for Aboriginal Health (CRCAH).

Additional copies of this publication can be obtained from the Aboriginal Health Council of South Australia

Website: www.ahcsa.org.au

Email: ahcsa@ahcsa.org.au



AHCSA CEO's perspective on the first Centre of Clinical Research Excellence in Aboriginal and Torres Strait Islander Health, which AHCSA hosted from 2003 to 2008.

Foreword by Mary Buckskin

Over the past five years the Aboriginal Health Council of South Australia (AHCSA) has led a partnership with Flinders University and Aboriginal community health services in the Eyre Peninsula region in the first Centre of Clinical Research Excellence (CCRE) focused specifically on Aboriginal and Torres Strait Islander Australians.

The CCRE project has built some good foundations on which to progress our aim of strengthening the Aboriginal community-controlled health sector's involvement in planning, implementing and reporting on culturally relevant evaluation and research.

AHCSA is committed to maintaining the provision of quality health services to Aboriginal communities. To achieve ongoing improvement we need to monitor, measure and evaluate the impact of these services on patients and communities. Developing the research capacity of Aboriginal health services will equip them with knowledge and skills to monitor and evaluate their own performance and to change and improve their services to meet the needs of their communities.

AHCSA is also keen to increase the involvement of the Aboriginal health sector in shaping and determining research within its own communities. Hosting and leading the first CCRE in Aboriginal and Torres Strait Islander health has enabled AHCSA to progress this agenda in a significant way. However, there is still more work to be done.

The focus of this CCRE has been on developing approaches and programmes for managing chronic diseases among Aboriginal and Torres Strait Islander Australians. This area is increasingly becoming a key priority for federal and State governments. Evidence from this project will help to inform both

governments and Aboriginal communities' responses in this crucial area of health policy and practice.

As the current AHCSA Chief Executive Officer, I would like to acknowledge some of the key people who laid the foundations of the partnerships that led to the establishment of the CCRE. Professor Peter MacDonald, head of Flinders University's then Institute of Health Research, had the initial idea of bringing researchers and AHCSA together. Ms Bernadette Anderson (then Information Officer at AHCSA) and Inge Kowanko (Flinders University) worked very hard on putting together a very competitive submission. Many other people and organisations also contributed to the work of the CCRE and are too numerous to name individually.

The CCRE project has made significant progress in its key areas of activity: research, training and translation. In particular, it developed a Certificate IV level course in research and evaluation, which has now been delivered for the first time nationally. AHCSA aims to continue offering this course as a significant part of our efforts to build the capacity of Aboriginal health services to be able to incorporate research and evaluation within their core business.

Building the research capacity of Aboriginal health services will increase their ability to engage in ongoing monitoring and evaluation, which will support improved service delivery and therefore support improved health outcomes for Aboriginal people and communities.

Mary Buckskin

Chief Executive Officer
Aboriginal Health Council
of South Australia Inc.





Comment from the other main partner in this CCRE project, the Flinders University of South Australia.

Foreword by Professor Roy G. Goldie

Flinders University, through its Faculty of Health Sciences, has a longstanding commitment to the partnership with AHCSA, in particular through its involvement with the CCRE in Aboriginal and Torres Strait Islander Health.

The Faculty and the University are delighted to be a significant part of the agenda for change and improvement in health outcomes for Aboriginal people. This agenda is progressed in a most tangible way through the CCRE and its influence to extend and build research capacity and expertise in the Aboriginal health arena within a sustainable framework.

Flinders University is particularly proud of its involvement in bringing innovative ideas to the research table. The Point-of-Care Testing project and the establishment

of programmes addressing the management and self-management of chronic disease conditions, which have for decades had a devastating impact on both the longevity and the quality of life for many Aboriginal people in Australia, are two very significant examples.

Flinders University remains committed to providing significant tangible assistance to AHCSA and its future plans to improve Aboriginal and Torres Strait Islander health outcomes. This will involve building upon the great work already completed by the CCRE collaborative.

Professor Roy G. Goldie, PhD

Executive Dean

Faculty of Health Sciences

Flinders University of South Australia

Contents

Foreword – Mary Buckskin	iii
Foreword – Professor Roy G. Goldie	v
Contents	vi
Acknowledgements	viii
Abbreviations	ix
Summary Chart for the CCRE at AHCSA	x
Guide to this report	xii
PART A THE CCRE PROJECT	1
Chapter 1: Overview	1
AHCSA wins CCRE grant	2
The aim of the CCRE	2
Research focus	3
Background to the CCRE	3
Building the research capacity of Aboriginal people	4
The future	4
Summary of the CCRE project	4
Chapter 2: CCRE Organisation & Structures	7
Links with Aboriginal Community	7
The CCRE Structure	7
CCRE Board	8
CCRE Executive Committee	12
The CCRE and its Staff	12
Education, Development and Research (EDR) Group	13
Investigators' group	13
CCRE Investigators – Profiles and Key Activities	13
Chapter 3: Aboriginal Health Service Partners of the CCRE	20
Port Lincoln Aboriginal Health Service	20
Ceduna / Koonibba Aboriginal Health Service	21
Pika Wiya Health Service	22
Chapter 4: CCRE Rationale and Key Activities	24
Research	24
Education and training	26
Translation	28
Research into the future	28
PART B CCRE ACHIEVEMENTS	30
Chapter 5: Summary of Main Achievements	30
Research projects	30
Research-related training programme	32

Contents

Scholarship and bursaries	33
Translation activities	35
Successful tenders for further work	37
Chapter 6: Workshops and Forums	40
CCRE Education, Development & Research Group	40
Aboriginal Evaluation Workshops	42
CCRE hosts Participatory Action Researcher, April, 2006, at AHCSA, Norwood	42
CCRE Symposium, September, 2006	43
Introduction to Research in Aboriginal Health Services Workshop	45
Action Research Conference	45
CCRE Planning Day	46
Chapter 7: Community Projects	48
Developing chronic illness management for Aboriginal people	48
CCRE Integrated Projects	48
Pika Wiya Health Service – Effectiveness of Chronic Disease Self-Management Programs	49
Ceduna / Koonibba Aboriginal Health Service – Enhanced data collection & effectiveness of chronic illness management strategies	50
Port Lincoln Aboriginal Health Service – Enablers and inhibitors for engaging PLAHS' Aboriginal clients in chronic condition care	51
Chapter 8: Sustainable Activities into the Future	54
Self-management training – (Living Improvements for Everyone or LIFE programme)	54
Certificate IV in Indigenous Research Capacity Building	55
PART C LEARNINGS AND REFLECTIONS	56
Chapter 9: Reflections on the Project	56
Interview with Cephas Stanley, CEO, Pika Wiya	56
Reflections on the CCRE Integrated Projects	57
Reflections from the CCRE Investigators	58
Education and training activities	59
Translation activities	61
Conclusion	61
PART D APPENDICES	64
Appendix 1: Vision and scope for the future – CCRE 2008 and beyond	64
Appendix 2: Factors affecting capacity of Aboriginal health organisations to undertake and participate in research – Summary of main points	65
Appendix 3: CCRE Investigator – Publications	68
Appendix 4: References	74
Appendix 5: Scholarship and Bursary Recipients	77

Acknowledgements

We acknowledge the traditional owners of the land that this CCRE at AHCSA is on, the Kaurna of the Adelaide area, and respect their continuing spiritual connection with their country and their ancestors, and we acknowledge all the traditional owners of the lands of the places that our work has been associated with in different parts of South Australia and Australia.

We also acknowledge the support of the many people at AHCSA, in the regional Aboriginal health organisations, and from Flinders University of South Australia and other organisations with whom we have worked. It has been our privilege to work with them all. The work highlighted and described in this report is the result of the combined efforts of the partners in the project: AHCSA, Flinders University, the Investigators and the staff of the Secretariat. This report has also been substantially contributed to by the Investigators and by the Training Officer, Dr Merridy Malin. The Translation Officer, Glenn Giles, produced the report.

For the artwork used in this report, thank you to the artist Jillian Larking and graphic designer Matthew Goodluck; and for the



Cooperative Research Centre for
Aboriginal Health

design of this report, thank you to Theresa Leach. In the final production of this report, the CCRE received invaluable support from the Cooperative Research Centre for Aboriginal Health, including in editing and printing. This CCRE was funded by the National Health and Medical Research Council (NHMRC), Grant number 264414.

Secretariat

CCRE in Aboriginal and Torres Strait
Islander Health
Aboriginal Health Council of South
Australia

Abbreviations

ACCH	Aboriginal Community Controlled Health	EDR	Education, Development and Research Group
AHAC	Aboriginal Health Advisory Committee	EPC	Enhanced Primary Care
AHCSA	Aboriginal Health Council of South Australia	FUSA	Flinders University of South Australia
AHD	Aboriginal Health Division	JCU	James Cook University
AHREC	Aboriginal Health Research Ethics Committee	LIFE	Living Improvements For Everyone
AHS	Aboriginal Health Service	NHMRC	National Health and Medical Research Council
ATSIC	Aboriginal and Torres Strait Islander Commission	PIH	Partners-in-Health
CCC	chronic condition care	PLAHS	Port Lincoln Aboriginal Health Service
CCM	chronic condition management	POCT	Point-of-Care Testing
CCRE	Centre of Clinical Research Excellence	QAAMS	Quality Assurance for Aboriginal and Torres Strait Islander Medical Services
CCSM	chronic condition self-management	SGRHS	Spencer Gulf Rural Health School, University of Adelaide and University of South Australia, Whyalla
CEO	Chief Executive Officer	VET	Vocational Education and Training
CIP	Continuous Improvement Program		
CKAHS	Ceduna/Koonibba Aboriginal Health Service		
COAG	Council of Australian Governments		
CRCAH	Cooperative Research Centre for Aboriginal Health		

Summary Chart of the CCRE at AHCSA

a partnership with Flinders University



Chart Explanation

This chart describes key elements of the CCRE, that was hosted at AHCSA from 2003 to 2008. Each of the three groups of circles presents a 'stage' of the CCRE.

The first group represents the coming together of AHCSA, with some Aboriginal health services and various researchers engaged in work with these services, to create a CCRE.

The largest group of circles summarises the work of the CCRE during its existence, 2003-2008. It indicates the work of the CCRE in research, training and translation, from the combined efforts of its staff, the investigators (researchers) and partner Aboriginal health services.

The final cluster presents these key aspects of the CCRE's work that are continuing after the end of the Secretariat at AHCSA, including capacity building activity that will continue at AHCSA, and ongoing research projects.





Guide to this report

This report of the CCRE based at AHCSA gives a broad summary of the project. It has four parts. The first part gives an overview of the structure, people, areas of activity and rationale of the CCRE. This is followed by a part describing and detailing the achievements of the CCRE. The third part consists of some reflections on the CCRE and some learnings from participants in the project. Appendices make up the final part of the report.

Part A has four chapters.

Chapter 1, the Overview, is an overview of the project, from the collaboration of AHCSA and Flinders University winning the National Health and Medical Research Council grant to establish the first CCRE focused on Aboriginal and Torres Strait Islander Australians to the aims and focus of the project.

Chapter 2 describes the organisational structure of the CCRE. It describes the links of the project to the Aboriginal community in South Australia, explains how the CCRE operated, and lists and gives brief profiles of the key people involved, describing their CCRE-related work.

Chapter 3 profiles the three regional Aboriginal health services in South Australia that were part of the initial proposal for, and the work of, the CCRE.

Chapter 4 details the work of the CCRE, and some important influences on how it has identified and pursued its aims. A key aim of the CCRE has been building the research capacity of Indigenous people and communities. In pursuing this aim, the CCRE developed three inter-related strategies or program components: community-controlled research programmes focusing on chronic illness, facilitating training and education opportunities for Aboriginal people in health-related research, and the broader translation and adoption of effective practice.

Part B of the report is about the achievements of the CCRE. It has four chapters.

Chapter 5 summarises key work of CCRE Investigators, and the work of the CCRE's Training and Translation Officers.

Chapter 6 describes workshops and forums — those organised by the CCRE Secretariat and those which the CCRE assisted in various ways.

Chapter 7 is an overview of the community projects that the CCRE planned and pursued.

Chapter 8 outlines CCRE core activities that are being continued into the future.

Part C completes the description of the CCRE.

Part C, 'Learnings and Reflections', comprises Chapter 9, which has thoughts on the project by many of the key participants in the CCRE — from the Aboriginal health services' perspective, the Chief Investigators (the university researchers), and the CCRE's Training and Translation Officers — and points to some learnings from this project. The project is summarised with a brief conclusion.

Part D has four appendices: a vision for the future of the work that has been pursued by the CCRE based at the AHCSA; a summary of some CCRE work identifying important issues affecting the ability of Aboriginal health organisations to participate in health research projects on an ongoing basis; lists of

CCRE Investigator-published papers and conference presentations; and a reference list.

This report is not academic in style - there are few direct references in the text. For those wishing to further explore some of the ideas informing the work of the CCRE, we have provided a list of useful general readings (in addition to the Investigators' papers).

Through this report, various terms are used to refer to the First Peoples of this continent called Australia: Aboriginal and Torres Strait Islander People, and Indigenous Australians (often used by academics and public servants). In this report we mostly use the term Aboriginal to encompass all Aboriginal and Torres Strait Islander Australians.





An overview of the project

- the collaboration of AHCSA and Flinders University winning the National Health and Medical Research Council grant to establish the first CCRE focused on Aboriginal and Torres Strait Islander Australians, and
- the aims and focus of the project.

Overview

The Centre of Clinical Research Excellence in Aboriginal and Torres Strait Islander Health (the CCRE) is a collaborative project in chronic condition research, led by the Aboriginal Health Council of South Australia Inc. (AHCSA) in partnership with the Flinders University of South Australia. Three Aboriginal health services of the Eyre Peninsula region (Port Lincoln Aboriginal Health Service, Pika Wiya Health Service (Port Augusta) and Ceduna/Koonibba Aboriginal Health Service), and the University of South Australia were other collaborators in the project.

This CCRE was a significant development in Aboriginal health research in South Australia and Australia. It was the first CCRE focused on Aboriginal and Torres Strait Islander health. The partnership built on relationships between some Aboriginal health organisations, including AHCSA, and several researchers based at Flinders University. (More about the development of the collaborative relationships underlying this CCRE is in another publication of the project: Mapping the Journey.)

AHCSA wins CCRE grant

The Commonwealth Government's Minister for Health and Ageing announced on 7 July 2003 that AHCSA was the successful tenderer for the first CCRE in Aboriginal and Torres Strait Islander Health. AHCSA signed a Deed of Agreement with the Commonwealth for the proposed Research Centre on 17 September, 2003. The NHMRC grant was from its Strategic Research Development Committee for a Centre of Clinical Research Excellence (CCRE) in

Aboriginal and Torres Strait Islander Health for five years (grant number 264414).

The aim of the CCRE

The overall mission of the CCRE was to improve the health of Aboriginal people.

The CCRE was established to conduct high-quality Aboriginal-controlled health research in Aboriginal communities, focusing on the prevention and management of chronic and complex conditions. In the process of conducting research projects, the CCRE aimed to build the capacity of Aboriginal communities in health research and in managing health issues at the community level. The CCRE objectives translate into the facilitation and provision of relevant training for Aboriginal health workers and community members, and using research evidence to inform primary care, clinical practice and health policy.

The objectives of the CCRE have been strongly informed by the Indigenous Research Reform Agenda, as articulated by the Cooperative Research Centre for Aboriginal and Tropical Health, now the Cooperative Research Centre for Aboriginal Health (CRAH).

The key objectives of this CCRE have been to:

- conduct clinical research focused on the management and prevention of chronic illness;
- facilitate education, training and capacity building for Indigenous researchers; and to
- transfer research findings into policy and practice.

Overview (continued)

These objectives have been supported by:

- offering bursaries and scholarships, workshops and forums, to develop research capacity of Aboriginal health workers and students;
- developing and delivering a Certificate IV level course in Research Capacity Building;
- translating and using research evidence to influence systems of health care, self-management, workforce development and training, best clinical practice and community health policy, services and practice.

Research focus

The CCRE's research focus has been on the prevention and management of the growing burden of long-term illnesses and chronic conditions among Aboriginal Australians, including diabetes, cardiovascular disease, renal diseases and mental health conditions.

The collective projects and research work of this CCRE's Investigators address several aspects of managing chronic conditions among Aboriginal Australians. These projects connected with the CCRE include:

- Point-of-Care Testing (POCT), which involves testing patient blood and urine samples and having results available within the patient's visit time;
- better medication management for Aboriginal people with mental health (and drug and alcohol) disorders;
- innovative primary health care models for prevention and management of chronic diseases (e.g. diabetes, renal and cardiovascular disease);
- developing and evaluating a chronic disease self-management model, developed with Aboriginal people to be culturally sensitive;
- co-ordinated Aboriginal mental health (and drug and alcohol) care;
- provision of evidence-based clinical, educational and community resources to inform and guide the above.

Further details are provided in Chapter 5: 'Summary of main achievements'.

Background to the CCRE

This CCRE was the first to be established in Australia under the auspices of a peak body of a State

community-controlled Aboriginal health organisation, AHCSA. Part of the brief was to build the research capacity of Aboriginal researchers, services and communities to conduct their own relevant and culturally meaningful research. This was to be achieved through a program of research focusing on the management of chronic conditions, through a research training program for Aboriginal researchers, and through mentoring and translating research findings into sustainable community-oriented practice. These three areas of activity — research, research training and translation — underpin the rationale of the CCRE and have culminated in a range of successful projects, programmes, research and workforce training, which, if continued, will directly contribute to improving the health and wellbeing of Aboriginal people in Australia.

While the CCRE's initial funding was for five years, the work of the CCRE and its partners has established a framework for conducting community-based research and research training that we believe can be sustained into the future. It is important that the Aboriginal community has control of its research, research translation and research training agendas and retains the capacity to establish, own and control its own research programmes. To date, the Aboriginal Health Research Ethics Committee (AHREC) has given AHCSA direct input into the ethical aspects of research being proposed by other bodies such as universities and mainstream health authorities. AHCSA now is developing capacity to also frame, establish and manage health and community research programmes in its own right.

The CCRE's development of a research training course for Aboriginal researchers has already provided an important pathway to formal undergraduate and post-graduate research training and graduation, building the sustainable research capacity of individuals and the wider Aboriginal community.

These developments will ensure that more equitable partnerships between AHCSA and similar organisations and mainstream education and research institutions are possible in the future. From such partnerships, improved health status for Aboriginal

Overview (continued)

people will grow and can be sustained with ongoing supportive programmes over the medium and longer term to maintain and build the capacities of the AHCSA and Aboriginal health services.

Building the research capacity of Aboriginal people

Part of the background to the creation of this CCRE is the appalling comparative state of Aboriginal health in contemporary Australia, which shames the country internationally. Additionally, there has been little impact of research on Aboriginal health. Over about the past decade or so, concern about the conduct of Aboriginal health research has grown, with calls for Aboriginal leadership and participation in, and determination of, the research.

The Commonwealth Government's primary funding body of health-related research is the NHMRC. Through the 1990s it undertook a review of its ethical guidelines relating to Aboriginal and Torres Strait Islander research. Its support for Aboriginal health research increased, with a commitment to spend at least five per cent of its research funds on Aboriginal health research (achieved, according to NHMRC reports, in 2007).

The team that produced the proposal for this CCRE impressed the NHMRC that it had the experiences, capacities and relationships to enable it to build on previous research and related projects to further develop research work (focused on chronic conditions in Aboriginal health), and the ability to increase Aboriginal participation in and determination of such research.

Increasing access to, and the effectiveness of, Aboriginal health services, particularly the community-controlled sector, is an important objective in the national agenda of addressing the disparity in health outcomes between Aboriginal and non-Aboriginal Australians. An integral aspect of improving Aboriginal health services is for the services to have capacity to monitor and evaluate the care programmes they provide for their communities.

The future

It is important for the Aboriginal community-controlled health sector to carry forward the agenda of building the capacity of Aboriginal people and organisations to be involved in research — and to conduct and determine research — about the health of their people. Building these capacities will help develop the Aboriginal health care sector's resources to utilise and learn from evidence about its systems and programmes, and incorporate initiatives based on lessons from that evidence.

AHCSA is now well positioned to maintain and build its own capacity to be directly involved in leading and conducting Aboriginal health research and related activities that it has 'hosted' over the five years of this CCRE.

As the initial five-year period of NHMRC funding of the CCRE ends, work of the CCRE partners will continue and expand upon the initial research activities. Further research project work is already underway, applying key learnings from the systems of care, care planning and self-management approaches so far developed by CCRE Investigators in a range of projects. This research will apply these approaches in other Aboriginal communities, to inform and test their transfer and effectiveness in addressing the chronic conditions, including mental health and drug and alcohol conditions, affecting many Aboriginal people and their families. Work continues in applying POCT in Aboriginal health services across the country, bringing greater capacity at the individual Aboriginal health service level to work with their communities' chronic health issues and to investigate the management of mental health care issues.

Summary of the CCRE project

In keeping with the aims and objectives of the CCRE, we developed a range of initiatives in research, research education and program translation to develop the abilities of Aboriginal people to manage their own health systems and improve their health outcomes over time. The CCRE established a number of research programmes within the communities of the initial CCRE partner organisations, focused

Overview (continued)

on managing and preventing chronic and complex health conditions such as diabetes and cardio-vascular disease.

The team has built on these programmes and expanded its activities in collaboration with the CRCAH to study other aspects of chronic illness care: the impact of 'the Flinders Model' of care planning, the systems and organisational structures that enable or hinder effective research and program implementation, and the impact of chronic condition self-management programmes in Aboriginal communities.

To enhance the ability of Aboriginal people to design, implement and manage their own health research programmes, the CCRE wrote workbooks for, and delivered the Certificate IV in Indigenous Research Capacity Building. This course has been developed in collaboration with James Cook University. In addition to this course development work, the CCRE has funded a range of student scholarships to assist Aboriginal students to complete formal pre-university and university studies including Aboriginal health worker training, nursing and graduate certificate programmes, and bursaries to support conference attendance. (See Appendix 5 for lists of recipients.)

Our translation activities have involved producing informative and culturally relevant brochures and posters, as well as ongoing research with communities into key factors affecting the uptake and maintenance of health programmes in Aboriginal communities. We have linked the workforce with relevant training such as emergency mental health, alcohol and other drugs; safe medication management in community settings; and using the newly developed national Alcohol Treatment Guidelines for Indigenous Australians. We have worked on several related projects with our partner organisations, including an evaluation of the Aboriginal Health Worker in Private General Practice project in Port Augusta and the expansion of the chronic condition self-management training program for Aboriginal communities.

Much research work in relation to Aboriginal health previously and currently tends to emphasise the priority

and importance of documenting the magnitude of disparity between mainstream and Aboriginal community functioning, income, housing and education — all aspects that impact directly on the overall health and wellbeing of Aboriginal people. The CCRE mission was different. It was to build Aboriginal community research capacity and health service delivery so as to improve the crisis of chronic diseases, both physical and mental health-related, in Aboriginal communities; it was also to serve the need for better management, including prevention, early intervention and self-management practice.

Our CCRE focused on how to better implement chronic illness management strategies. In addition, we aimed to empower Aboriginal communities and individuals through translating our efforts into programmes and strategies that local communities might implement and by training Aboriginal community leaders to set and manage their own research agendas in their own way. The mainstream research processes, which, in the main, have until now been imposed on communities, were to be modified by and for Aboriginal people to suit the way they want to work and the way they choose to study, learn about and implement approaches to care that suit their needs and their priorities.

In short, this means the promotion of community-oriented research methods, as well as formal research programmes, and it means teaching and supporting local community people to carry out relevant and meaningful research rather than implementing external research programmes that are managed and controlled by university teams, for example. These community development programmes may take longer to implement and to produce results compared with standard randomised controlled trials with a specific and more narrow clinical focus, but the results are ultimately more valid and connected to the communities involved (Carson et al. 2007: 273).

The CCRE was conceived and designed to build a research capacity within AHCSA, the Aboriginal community peak body for Aboriginal health in South Australia. This function must be retained within AHCSA into the future to continue to build Aboriginal

Overview (continued)

community control of the research agenda in Aboriginal health and to avoid replicating the past problems of external researchers conducting irrelevant and meaningless research that does not benefit the communities concerned. An independent and authoritative research program run by Aboriginal communities and supported through the peak body and guided by AHREC will help to ensure that research produces programmes and strategies that can ultimately lead to improved health status for Aboriginal people.

Describes the organisational structure of the CCRE. It describes the links of the project to the Aboriginal community in South Australia, explains how the CCRE operated, and lists and gives brief profiles of the key people involved, describing their CCRE-related work.

CCRE Organisation and Structures

This chapter describes the organisational structure of this CCRE, indicating the links of the project to the Aboriginal community in South Australia. It explains how the CCRE operated and lists the people involved, giving brief profiles of Board members, Investigators (researchers) and staff, indicating their key work and projects in the area of focus of this CCRE.

Links with Aboriginal Community

Several features of this CCRE establish strong connections between the project and the Aboriginal community in South Australia. AHCSA is the community-controlled peak organisation representing Aboriginal community-controlled health services, substance misuse services and Aboriginal

Health Advisory Committees (AHACs) in South Australia. It is the auspicing partner of the CCRE collaboration and hosts the CCRE Secretariat.

A majority of the CCRE Board members are Aboriginal people (see below). Links with the South Australian Aboriginal community have been a focus of the CCRE team in its work (see elsewhere in this report) and in the various projects of CCRE Investigators. The project has had good working relationships with the three South Australian regional Aboriginal health services connected with the project from its start: Port Lincoln Aboriginal Health Service, Pika Wiya Health Service and Ceduna/Koonibba Aboriginal Health Service.



CCRE Organisation and Structures

CCRE Board

The CCRE Board was structured to facilitate strong Aboriginal involvement in overseeing and participating in the project. The CCRE Board was set up with a total of eleven members, a majority being Aboriginal. Membership was monitored and revised as necessary, taking into consideration changes in personnel at connected organisations. It met quarterly. The CCRE Manager attended Board meetings.

Membership of the CCRE Board was made up of:

- three nominees from AHCSA;
- three nominees from Flinders University;
- one nominee from each of the partner Aboriginal health services (Pika Wiya Health Service, Ceduna/Koonibba Aboriginal Health Service and the Port Lincoln Aboriginal Health Service);
- one nominee from the Spencer Gulf Rural Health School (Whyalla);
- one nominee from the Aboriginal Health Division (AHD), Department of Health, South Australian Government.

In early 2008, the Board decided to increase its number to twelve, by inviting Jackie Ah Kit to rejoin in her new role as Director, Aboriginal Health, Country Health SA.

Through most of 2008 the people on the CCRE Board were:

John Singer:	Chair of Board of AHCSA (and Nganampa Health Council);
Alwin Chong:	(Chair of CCRE Board until early 2008): Senior Research and Ethics Project Officer, AHCSA;
Yvonne Buza:	(Chair of CCRE Board from early 2008): Vice-Chairperson, AHCSA Board (and Northern Region Aboriginal Health Advisory Committee);
Kym Thomas:	Spencer Gulf Rural Health School (Whyalla);
Harry Miller:	Port Lincoln Aboriginal Health Service (proxy Sue Mills);
Cephas Stanley:	Director, Pika Wiya Health Service;
Tauto Sansbury:	Chief Executive Officer (CEO), Ceduna/Koonibba Aboriginal Health Service;
Inge Kowanko:	Flinders University;
Malcolm Battersby:	Flinders University;
Graeme Bennett:	AHD, State Department of Health (representing then Executive Director, AHD, Richard King);
Peter Harvey:	Flinders University;
Jackie Ah Kit:	Country Health SA.

*CCRE Organisation and Structures (continued)***CCRE BOARD MEMBER PROFILES****John Singer (2005 – 2008)**

John Singer commenced working in the Aboriginal community-controlled sector at Ceduna/Koonibba Aboriginal Health Service, where he also started health worker training, which he completed at Nganampa Health in the late 1980s. He worked in community administration from 1989 to 1996, became manager of the Iwantja Clinic in 1997 and, in 2000, was appointed Director of Nganampa Health, the largest community-controlled health service in remote Australia. He has been on various committees and boards, and is currently on the National Aboriginal Community Controlled Health Organisation Board, the AHCSA Board (since 1998, including as Chair in 2005, and 2006–current), Country Health SA Board, and the Anangu Remote Health Alliance (including as Chairperson in 2005 and 2006, and he was influential in establishing it in 2005). His experiences give him a good understanding of governance, community control and government structures. Mr Singer is very committed to improving the health and wellbeing status of Aboriginal people.

Yvonne Buza (2007 – 2008)

Yvonne Buza is Chairperson of the Northern Region Aboriginal Health Advisory Council (full member of AHCSA) and is on the Country Health South Australia Forum representing all isolated Aboriginal communities in the region. Previously Secretary to the AHCSA Board, and Vice-Chairperson from June 2007, Ms Buza has represented AHCSA at many health forums and meetings at the local, state and national levels and she feels this broad representation has enabled her to be very pro-active in establishing and maintaining a unique and profound South Australian position on all health matters.

**Yvonne Buza****Cephas Stanley (2004 – 2008)**

Cephas Stanley has been CEO of Pika Wiya Health Service for nearly ten years. Pika Wiya is the Aboriginal health service in Port Augusta. Cephas started at Pika Wiya as a health worker (unqualified) in 1986, achieved his Aboriginal Primary Health Care Certificate II in 1995, progressed to become Clinic Supervisor from 1989 to 1992, Project Officer from 1992 to 1994, Services Co-ordinator from 1994 to 1995, Acting CEO 1995 to 1997, Services Co-ordinator again from 1997 to 1999, and CEO (since 1999).

**Cephas Stanley****Kym Thomas (2007 – 2008)**

Kym Thomas is head of the Aboriginal health team with the Spencer Gulf Rural Health School. He is an Aboriginal person committed to the holistic development of both individuals and Aboriginal and Torres Strait Islander communities, particularly in regard to personal development, health, employment and education. Kym is a board member of Pika Wiya and a committee member for the MiB (Males in Black is a group of Aboriginal men in the Port Augusta region striving to provide programmes to address the cultural needs of Aboriginal men in their region). Kym has worked for more than ten years in the government sector and for universities at regional, State and national levels. In the tertiary education sector he has mainly been involved in developing and presenting Aboriginal and Islander studies and cultural awareness programmes. He has presented an extensive variety of short and longer-term programmes to a range of participants from both the private and public sectors. More recently Kym has conducted cultural awareness field trips for health professionals and medical students, linking with Aboriginal medical services, the Adelaide University School of Medical Science and the School of Health Sciences at the University of South Australia.

**Kym Thomas**

CCRE Organisation and Structures (continued)

CCRE BOARD MEMBER PROFILES



Harry Miller

Harry Miller (2008)

Harry Miller was appointed CEO of Port Lincoln Aboriginal Health Service in 2007, the Aboriginal community-controlled health service in Port Lincoln.



Tauto Sansbury

Tauto Sansbury (2008)

Appointed CEO of Ceduna/Koonibba Aboriginal Health Service in April 2008, Mr Sansbury brings a wealth of experience and commitment to the role. Tauto has been employed at a senior level for more than twenty years in Aboriginal affairs and as an advocate for Aboriginal people. He also has extensive committee experience at both a national and state level. Tauto was Chairperson of both the National and South Australian Aboriginal Justice Advocacy Committees for ten years and was elected Chairperson of the Aboriginal and Torres Strait Islander Committee (ATSIC) Patpa Warra Yunti Regional Council from 2002 to 2005. For his achievements he was recognised as National NAIDOC Aboriginal Person of the Year in 1996 and received a Commonwealth Government Centenary Medal in 2003 in recognition of his work as Director of the Aboriginal Justice Advocacy Committee and the National Aboriginal Justice Advisory Committee.



Graeme Bennett

Graeme Bennett (2008)

Graeme Bennett is the current manager of the Liaison and Strategy Branch of AHD, State Department of Health. From early 2008 he represented the Executive Director of the AHD, Richard King (who was filling in for April Lawrie-Smith on maternity leave). Graeme has a background in medical science and health service management and has been working in the Aboriginal health area since 2006.

Alwin Chong**Inge Kowanko****Peter Harvey****Jackie Ah Kit****Malcolm Battersby**

are Investigators on this CCRE project. See 'CCRE Investigators – Profiles and key activities' in this chapter for brief profiles of these people.

CCRE Organisation and Structures (continued)

CCRE BOARD MEMBER PROFILES

Previous CCRE Board members have included (not in any particular order):**Wendy Edmondson**

former CEO, AHCSA (also initially a Chief Investigator), 2004–05

Brian Dixon

former Executive Director, AHD, State Department of Health, 2004–05

Brenton Richards

former Deputy Chair, AHCSA Board, and Chair, Port Lincoln Aboriginal Health Service Board, 2005–06

Colin Weetra

formerly of Spencer Gulf Rural Health School (Whyalla), 2004–06

Jackie Ah Kit

former CEO, Port Lincoln Aboriginal Health Service (also an Associate Investigator), 2004 – April 2007;
again from early 2008

Colleen Prideaux

former CEO, Ceduna/Koonibba Aboriginal Health, 2004–07

Robert Dann

former Chair, Board of AHCSA, 2005

Sandy Miller

AHD, State Department of Health, 2005

April Lawrie-Smith

(alternate, Sally Castell-McGregor) — AHD, Department of Health, 2006–07

Peter Harvey

as CCRE Manager (also a Chief Investigator) attended 2005 – late 2007; member from early 2008

Sally Castell-McGregor

AHD, State Department of Health, 2006–07

Charlotte de Crespigny

Flinders University (also a Chief Investigator), 2004 – early 08

CCRE Organisation and Structures (continued)

The role of the CCRE Board has been to:

- provide strategic direction for the CCRE;
- make decisions on recommendations from the CCRE Executive Management Committee;
- meet quarterly (unless circumstances require other meetings);
- monitor the functions and strategies of the CCRE, ensuring objectives are met;
- provide overall governance and leadership for the CCRE's research and training activities;
- develop policy, strategic direction and Aboriginal research protocols and guidance over the life of the CCRE.

The CCRE Manager reported to the Board and was the first point of contact in relation to the business of the CCRE.

CCRE Executive Committee

The Executive Management Committee was selected from the CCRE Board to carry out the business of the Board and to assist the Manager in day-to-day activities. The executive group met monthly (or more frequently if required) at a time conveniently scheduled between the meetings of the CCRE Board.

The CCRE Manager also attended the meetings of the Executive.

Members of CCRE Executive Management Committee (from early 2008):

Yvonne Buza

(Chair of this Committee, AHCSA representative)

John Singer

(AHCSA representative)

Inge Kowanko

(Flinders University)

Malcolm Battersby

(Flinders University)

Graeme Bennett

(AHD, State Department of Health)

Jackie Ah Kit

(Country Health SA)

Alwin Chong was AHCSA representative and Chair of this committee until April 2008. Jackie Ah Kit (Port Lincoln Aboriginal Health Service) was a member of this committee until April 2007 (when she became Director of Aboriginal Health, in Country Health SA). She was invited to re-join the Board and Executives and did in early 2008.

The role of the CCRE Executive Management Committee has been to:

- deal with the immediate issues of the CCRE;
- take direction from the CCRE Board;
- provide recommendations to the CCRE Board;
- provide some direction for CCRE staff.

The CCRE and its Staff

The CCRE team is based at AHCSA.

In 2008 the staff of the CCRE Secretariat were:

Luita Casey

CCRE Manager, August 2007 – June 2008

Dr Merridy Malin

Training Officer, May 2004 – present

Glenn Giles

Translation Officer, April 2004 – present

Helen Diasinnis

Administration Assistant, January 2008 – present

The start up of the Secretariat was more protracted than hoped, taking a period of time to find people to fill the positions. There has been some success in achieving the aim of employing Aboriginal staff. Manager and administrative positions have been filled by Aboriginal people for substantial periods.

Initially Angela Francisco was Senior Administration Officer (February to August 2004), and Shelley Nitschke was Administration Assistant, starting in March 2004. Glenn Giles commenced as Translation Officer in April 2004. Dr Merridy Malin commenced part-time as Training Officer in May 2004 (located in Alice Springs), going full-time from July 2004 (having moved to Adelaide). Merridy and Glenn have remained with the CCRE since they commenced. (All of these staff members are

CCRE Organisation and Structures (continued)

non-Aboriginal — they had a range of experience working with Aboriginal people.)

The CCRE had a Manager for a short period in late 2004 into early 2005, Mr Tim Agius, an Aboriginal man from South Australia. Dr Peter Harvey was Manager from early 2006 until August 2007, then Luita Casey, an Aboriginal woman, took on the role until June 2008, when she took up a scholarship at UniSA. (Dr Harvey, non-Aboriginal, was also a Chief Investigator of the CCRE.)

Shelley Nitschke moved on from the CCRE early in 2006 (being relieved for a couple of months by Jodie Sandell). Amanda Mitchell became the Administration Assistant for about a year and a half (until September 2007), followed by Francine Milera (September 2007 to January 2008) and then Helen Diassinis. (Amanda and Francine are Aboriginal.) The Secretariat also had the services of a part-time Information Officer, Ian Thurnwald, through 2005 to 2007.

Education, Development and Research (EDR) Group

In its first year the CCRE established an Education, Development and Research (EDR) Group to enable input from all those engaged in developing the CCRE proposal to have continuing input into how the CCRE was set up to pursue the objectives articulated in the submission to the NHMRC. The group was open to all Chief and Associate Investigators and representatives from the key organisations (see 'Introduction'). Three workshops were held in 2004, one in the region of each of the Aboriginal health services that were part of the CCRE original submission proposal. (Some brief information about these workshops is included in Chapter 6: 'Workshops and forums'.) In August 2004 the CCRE Board decided to refer to the EDR group as the 'CCRE workshop group'.

Investigators' Group

The CCRE established a forum for the Chief and Associate Investigators to maintain contact with and input into the development of the CCRE project. The Investigators' Group was also set up to facilitate

coordination of research and development of future research opportunities for the CCRE team. The Investigators' Group met about every six weeks and its role was to:

- provide research leadership and advise on aspects of research;
- support the research process and encourage new research activities;
- assist, as mentors and research leaders, the development of new researchers;
- share information on research activities;
- work collaboratively to promote the work of the CCRE;
- attract new funding to expand the research base of the CCRE.

CCRE Investigators - Profiles and Key Activities

This section gives brief profiles of the Chief and Associate Investigators, describing their expertise and some key developments in work associated with the CCRE project. Also included are some comments from Investigators on how and why they became involved in the project, and indications of what they brought to the project. There are some reflections on the overall CCRE project, and the future of the various activities and projects it has been engaged in.

*CCRE Organisation and Structures (continued)***The CCRE Chief Investigators were:****Ms Wendy Edmondson**

AHCSA; then Flinders University*

Mr Alwin Chong

AHCSA

Professor Malcolm Battersby

Flinders University

Professor Charlotte de Crespigny

Flinders University; April 2008 Chief Medical Officer, SA Dept. of Health

Professor Paddy Phillips

Flinders University

Dr Peter Harvey

The University of Adelaide until July 2007, then Flinders University

Dr Mark Shephard

Flinders University

CCRE Associate Investigators were:**Professor John Wakeman**

Centre for Remote Health

Dr Inge Kowanko

Flinders University

Professor Paul Worley

Flinders University

Professor Phillip Aylward

Flinders University

Ms Jackie Ah Kit

Port Lincoln Aboriginal Health Service (until April 2007; then Director, Aboriginal Health, Country Health SA)

Dr David Mills

The University of Adelaide; Investigator Clinic until January 2006

(* indicates the person left the project part way through its term).

CCRE Organisation and Structures (continued)

Ms Wendy Edmondson*

Ms Edmondson had a key organisational position in the period leading up to, and in the initial period of, the project as Chief Executive Officer of AHCSA. As an Aboriginal person, a descendant of the Badimaia people of Western Australia, with a range of experiences in the education sector and managing delivery of some government programmes to Aboriginal people, Ms Edmondson brought a strong understanding of Aboriginal societies, cultures and protocols. Ms Edmondson was for a period a member of the executive of the Cooperative Research Centre for Aboriginal and Tropical Health (the precursor of the CRAH), and has formal qualifications in teaching and management.

Mr Alwin Chong

Senior Research and Ethics Officer, AHCSA

Alwin Chong was, and is, also in a key organisational position, providing comprehensive research, planning and evaluation services to AHCSA, including as the Executive Officer to the nationally recognised AHREC, a sub-committee of AHCSA. Alwin's primary role is to monitor and promote appropriate research and research practices for the Aboriginal community-controlled health sector, rather than to see continuance of academic-driven research topics. He had experience in the late 1990s as a Research Associate at the Aboriginal Research Institute, at the University of South Australia, and had a range of responsibilities.



Alwin Chong

Professor Malcolm Battersby

Professor in Psychiatry, School of Medicine, Faculty of Health Sciences,
Flinders University

Director, Human Behaviour & Health Research Unit, Flinders University

Dr Battersby had major involvement in developing the South Australian Coordinated Care Trial. He is Director of the Flinders University Coordinated Care Training Unit (now Flinders Human Behaviour and Health Research Unit). Dr Battersby and his unit developed collaborative relationships with Aboriginal communities in Eyre Peninsula, Port Augusta, Daruk (in Western Sydney) and Katherine West, with a focus on trialling models to introduce chronic disease self-management within the routine system of care. This involved developing a culturally sensitive education program incorporating a research element.



Malcolm Battersby

CCRE Organisation and Structures (continued)

Charlotte De Crespigny

Professor Charlotte De Crespigny

Professor of Drug and Alcohol Nursing, University of Adelaide

Professor Charlotte de Crespigny (Professor at Flinders University prior to joining The University of Adelaide in June 2008) brought a national reputation for innovative research relevant to alcohol and other drugs with Aboriginal people to the project team. Key features of Professor de Crespigny's research work has been the use of participatory research methodology, developing and fostering ongoing relationships so as to work effectively with Aboriginal communities and organisations, as well as multidisciplinary collaborations. The research has always sought practical outcomes that inform policy and practice, and developing and implementing training courses informed by research findings for various health workers, other relevant workers and community members to understand, minimise harm and respond effectively to mental health, alcohol and other drug-related physical and mental health problems. She is also passionate about research informing the systems of care, taking into account the holistic needs of Aboriginal clients and their families in contact with health services.



Paddy Phillips

Professor Paddy Phillips

Chief Medical Officer, South Australian Department of Health

Professor Phillips, at the time of the original proposal, was Professor and Head, Department of Medicine, Flinders University. He had held academic appointments at The University of Melbourne and University of Oxford and had expertise in basic, clinical and health services research. Professor Phillips brought many strategic experiences to the project team—he was a foundation member of the Australian Council for Safety and Quality in Health Care; a member and Chair of the Casemix Clinical Committee of Australia (the peak ministerial committee of the Commonwealth Government responsible for casemix issues in health); a member of the Strategic Research Development Committee (SRDC, one of the four peak committees of the NHMRC) and Chair of the SRDC Evidence Based Clinical Practice Research Committee (1998–2000); foundation chairman of the Australian Centre for Evidence Based Clinical Practice; a member of, or chaired, various Royal Australasian College of Physicians (RACP) committees and a RACP Councillor; and a member of the Heart Foundation of Australia Cardiovascular Health Advisory Committee (the peak clinical committee of the Heart Foundation). He has authored 130 academic publications and has held more than \$7 million in competitive peer-reviewed research grants.

Professor Phillips became involved in the CCRE in order to help improve Indigenous peoples' understanding of research and how it leads to evidence upon which clinical decisions are made—how research can ultimately improve health and wellbeing. By increasing the understanding of the value of research and how it can ultimately improve health and wellbeing, he hoped this would lead to a greater ownership of research and to more research about Indigenous health (and ultimately improved health).

The ability of Professor Phillips to be involved in the project as much as he would have liked has been significantly constrained because of his multiple and demanding commitments, and because of the geographical spread of the sites of the regional Aboriginal health services that have been partners of the CCRE project and with whom the project has sought to maintain engagement.

CCRE Organisation and Structures (continued)

Dr Peter Harvey

Senior Lecturer and Manager, Statewide Gambling Therapy Service, Flinders University

Dr Harvey had significant experience in research on systems of health care and chronic disease management strategies. With a team of colleagues, he developed systems of care and support strategies that are sustainable and culturally appropriate to Aboriginal communities. Much of this work was conducted in the Eyre Peninsula region of South Australia where Peter had developed good working relationships with both Aboriginal and mainstream health service providers.



Peter Harvey

From these experiences, Dr Harvey could see good opportunity within the CCRE for developing the potential of the Aboriginal health services at Port Lincoln, Ceduna and Port Augusta to build their capacity to participate in research (and to undertake research themselves) about the health of their communities. As a partnership between Aboriginal health organisations and academic researchers, and by being based at AHCSA, the project offered great possibility for Aboriginal people to be in control of the research. Increasing Aboriginal determination of research about the health of their people would address the widespread criticism that much research into the health of Aboriginal Australians was not producing results of relevance to those people. One issue here is that the standard practice of researchers has been for them to not be concerned to share the results of their research with the community that was the subject of the research. There were, and are, many reasons for this. With this opportunity, through the CCRE, for Aboriginal people close to the community level to be involved in determining the research, the research should be more focused on the issues identified by community people, and should include reporting back to them.

Peter was a senior lecturer with The University of Adelaide School of Population Health and Clinical Practice until July 2007. He has worked in health research and health systems development programmes in rural South Australia since 1996, with the Spencer Gulf Rural Health School and with the University of South Australia. Peter led the rural component of the South Australian Coordinated Care Trials and the Sharing Health Care SA project. Both of these research programmes involved Aboriginal communities and focused mainly on the management and prevention of chronic and complex health conditions.

Dr Mark Shephard OAM

Director/Senior Research Fellow, Community Point-of-Care Services, Flinders University Rural Clinical School, Flinders University

Dr Mark Shephard brought seven years experience of applying point-of-care pathology testing for chronic disease prevention and management in Australian Aboriginal communities to the CCRE. He is Program Manager of a national POCT program for diabetes management called QAAMS (Quality Assurance for Aboriginal and Torres Strait Islander Medical Services), funded by the Australian Government's Department of Health and Ageing for nine years, involving over a hundred Aboriginal medical services from across Australia. More than three hundred Aboriginal Health Professionals have been trained to be qualified POCT operators of a medical device called the DCA 2000, which can perform on-site pathology tests for diabetes management.



Mark Shephard

CCRE Organisation and Structures (continued)

Dr Shephard is also Program Manager of the Point of Care Testing in Aboriginal Hands program, which has been a key community-based program supported through the CCRE.

Dr Shephard was awarded his PhD in the field of POCT in July 2007. He received an Australian of the Year Award in 2004 and an Order of Australia Medal in the 2006 Queen's Birthday Australian Honours list for contributions to public health through medical research. He is a past Chair of the Australasian Association of Clinical Biochemists (AACB) Working Party on Point of Care Testing and invited to be the AACB's inaugural Regional Travelling Lecturer in 2004/5, where he lectured at twenty regional centres in Australia and New Zealand on community-based POCT.

Professor John Wakerman Director, Centre for Remote Health (Alice Springs), Flinders University of South Australia

Professor Wakerman is a public health medical specialist and general practitioner, with a background in remote primary health care services as a medical practitioner, senior manager and researcher. He has special interests in remote health services research and health management education. He has also had substantial international experience as a public health and health service management consultant (Centre for Remote Health n.d.).



Inge Kowanko

Dr Inge Kowanko

Senior Research Fellow, Head Flinders Aboriginal Health Research

Dr Kowanko leads the Flinders Aboriginal Health Research Unit, which coordinates, conducts, supports and grows Aboriginal health research, enhances partnerships and links with Aboriginal and other stakeholders and promotes ethical research practice. Flinders Aboriginal Health Research is one of the university's competitively selected Areas of Research Focus (see <http://aboriginalhealth@flinders.edu.au>). Inge was one of a small group that developed the CCRE proposal and submission.

Dr Kowanko has considerable involvement in the CRCAH, having helped to develop the successful bid for this CRC in 2003 and increasing Flinders University's contribution to the CRCAH since. She is also currently Flinders University's Link person to the CRCAH.

Inge's current and recent research has been largely in Indigenous health. She developed the funding submission and was principal researcher for the South Australia-wide project 'Better medication management for Aboriginal people with mental health', resulting in influential reports and journal articles, established networks, and a partnership model for Indigenous research. This work led on to her other current research, such as 'Coordinated Aboriginal mental health care' and new research collaborations around safe transport needs of Aboriginal people, disability training for Aboriginal communities and about domestic violence. Inge is the Chief Investigator on a new project, 'Chronic condition management strategies in Aboriginal communities', funded by the CRCAH (over three years: 2008-10)

CCRE Organisation and Structures (continued)

Professor Paul Worley

Dean, School of Medicine, Flinders University of South Australia

Professor Paul Worley became the Dean of the School of Medicine at Flinders University in July 2007. Previously he was Director, Flinders University Rural Clinical School. A practicing rural doctor, he has a passion for increasing the profile, impact and social accountability of medical schools and their students through creating mutually beneficial partnerships with clinicians, health services, government and community agencies, the wider research community, and professional bodies. He is recognised internationally as a leader in community-based medical education and research and has a special interest in the application of point of care pathology testing by Aboriginal Health Workers in Aboriginal Medical Services.



Paul Worley

Professor Philip Aylward

Cardiology Unit, Flinders University of South Australia

Acting Director, Division of Medicine, Cardiac and Critical Care Services and at Flinders Medical Centre and Professor in Medicine, Flinders University

Professor Aylward has particular expertise in acute coronary syndromes and interventional cardiology. He is Co-Chairman of the Acute Coronary Syndrome Guidelines Committee of the National Heart Foundation of Australia. He is on the Board of the Cardiac Society of Australia and New Zealand, President of the National Heart Foundation (South Australian Division) and National Board Member of the National Heart Foundation.



Phillip Aylward

Ms Jackie Ah Kit

CEO, Port Lincoln Aboriginal Health Service (up to April 2007)

Ms Ah Kit was CEO of Port Lincoln Aboriginal Health Service until April 2007, in which time she oversaw the growth of the service, including its involvement in research projects and in setting up the CCRE. She was a CCRE Board member during this time. In April 2007 Ms Ah Kit changed employment to become Director, Aboriginal Health, Country Health SA (Department of Health), based in Port Lincoln. She re-joined the CCRE Board and Executive in early 2008 in this capacity as a senior manager in Country Health SA.



Jackie Ah Kit

Dr Peter David Mills

Investigator Clinic, Port Lincoln until January 2006

Senior Lecturer, Spencer Gulf Rural Health School, University of Adelaide and University of South Australia

Dr Mills was much involved with the Port Lincoln Aboriginal Health Service, including with developing its implementation of care-planning, working with researchers from Flinders University. In 2007 Dr Mills moved from Port Lincoln to Adelaide. Dr Mills has been a general practitioner in private practice for twenty years, and is a postgraduate and undergraduate supervisor. His major interests are in diabetes care, diabetes management and ambulatory care, and service delivery interventions for diabetes care in rural and Aboriginal communities. Ongoing research relates to each of these areas.



David Mills

Profiles the three regional Aboriginal health services in South Australia that were part of the initial proposal for, and the work of, the CCRE.

Aboriginal Health Service Partners of the CCRE

A critical element of a project such as this is the development of ongoing working relationships between Aboriginal health services, communities and non-Aboriginal researchers (usually from universities). Three regional Aboriginal health services were part of the initial submission to the NHMRC for the project and were key, on-the-ground collaborators in the CCRE: the Port Lincoln Aboriginal Health Service, Pika Wiya Health Service (the Aboriginal health service in Port Augusta) and Ceduna/Koonibba Aboriginal Health Service. Here we present some brief information about these Aboriginal health services.



Port Lincoln Aboriginal Health Service

The Port Lincoln Aboriginal Health Service (PLAHS) is an Aboriginal Community Controlled Health Organisation established in 1992.

The health service has a history that the Port Lincoln Aboriginal community has always been a part of, in particular, the founding of the service. The establishment of the health service was a result of a number of reports and submissions put to both the Commonwealth and State governments from the mid-1980s onwards.

The health service was officially opened by Lowitja O'Donoghue, the then Chairperson of ATSIC, during the International Year of Indigenous Peoples on 3 September 1993. In 1992 PLAHS employed six staff—a mixture of

administration staff and health workers. Today, PLAHS employs some forty-eight staff, across a range of disciplines, both Aboriginal and non-Aboriginal and full-time and part-time. Of the staff, approximately eighty per cent are Aboriginal and eighty-five per cent of senior management positions are held by Aboriginal people.

PLAHS provides primary health care to some 1200 Aboriginal clients in Port Lincoln and surrounding areas, across a comprehensive range of health issues. It has been involved in a range of research projects over several years, particularly in chronic disease management and mental health issues. In 2007 it established a Learning Centre as part of its operations.

PLAHS is governed by an Aboriginal board of management, elected by the community.

PLAHS Vision

PLAHS strives to maintain its autonomy and cultural identity as an Aboriginal community-controlled health service while delivering a quality holistic primary health service to all Aboriginal people.

Mission

The PLAHS mission is to provide leadership, direction and support on community health issues to strengthen the capacity of individuals, families and communities, which will result in improved health and social wellbeing of Aboriginal people.

Key Domains

PLAHS aims to achieve its mission by focusing efforts under the domains that are considered to comprise the

Aboriginal Health Service Partners of the CCRE (continued)

elements of best practice in primary health care delivery:

1. To ensure fully effective management of PLAHS while promoting respect and harmony in the community.
2. To develop and deliver a culturally appropriate range of holistic programmes to meet the specific needs of the community.
3. To maintain existing linkages and communication with all stakeholders, while exploring new initiatives and partnerships.
4. To encourage the community to participate in the development and utilisation of a service that is culturally appropriate to all Aboriginal people.

The five main program areas through which PLAHS aims to achieve its vision, mission and aims are:

- Alternative Care & Family Preservation;
- Health Team;
- Family Violence Legal Prevention;
- Social and Emotional Well Being and Kinship;
- Administration and Finance.

At PLAHS other work related to the management of chronic conditions has been undertaken, including a participatory action research project with Aboriginal community Elders, and health professionals working with them, looking at people's experiences of living with and managing diabetes. The Elders identified four main themes: nutrition (seen as critical in learning how to live with diabetes, focusing on healthy eating as distinct from 'diabetic' food); understanding diabetes (the links between nutrition, exercise and medication); education of young people (so they can avoid the negative consequences of diabetes); and support for family and community members (referring to a nurturing, caring and supportive environment for people). (Mann, S, Burgoyne, A, Coaby, J with The Elders Ambassador Group, *Look, Think, Act: Indigenous Stories About Living With Diabetes*, Port Lincoln, 2002).



**Ceduna / Koonibba
Aboriginal
Health
Service**

“Health Workers serving the Community”

The Ceduna/Koonibba Aboriginal Health Service (CKAHS) is a community-based health service designed to meet the health needs of Aboriginal people within Ceduna and surrounding districts.

The health service was established in 1978 and was incorporated under the South Australian Health Commission Act on 1 August 1986. In 2008 the CKAHS decided to become an Aboriginal community-controlled health service.

CKAHS provides primary health care, transport, referrals and preventative health care to local communities, as well as to people who are visiting Ceduna for the short term.

CKAHS has opened a low-care facility designed to meet the specific needs of elderly Aboriginal people. The Ceduna District Health Service has supported and will continue to support the new facility through the provision of staff training, exchange of intellectual information, allied health services and advice.

CKAHS Philosophy

To provide an Aboriginal health service to the Aboriginal community that is culturally appropriate and which meets the needs of the Aboriginal community.

To provide preventative health care, education programmes and a clinical service to the Aboriginal community aimed at improving their health standards to a level equitable to that of other Australians (CKAHS 2006).

Aboriginal Health Service Partners of the CCRE (continued)

**Pika
Wiya
Health
Service**

Pika Wiya Health Service is the Aboriginal health service in Port Augusta. In 2008 it decided to become an Aboriginal community-controlled health service. Its service area includes much of the northern Flinders Ranges, including the towns Quorn, Hawker, Copley, Nepabunna, Lyndhurst, Maree, Leigh Creek South and surrounding areas.

Pika (meaning 'sickness') Wiya (meaning 'no'), is derived from the Pitjantjatjara language, one of the many Aboriginal languages spoken in Pika Wiya's service area. Pika Wiya Health Service is used by nearly all Aboriginal and Torres Strait Islander people who live in, or visit, Port Augusta. Pika Wiya employs staff from most Aboriginal groups, who are able to communicate and respond in a culturally appropriate manner, who strive to achieve survival for future generations. Members of the Aboriginal community in Port Augusta can utilise both their own local general practitioner and services provided by Pika Wiya and its programmes.

Pika Wiya's purpose is not only to comprehensively service the region, but also to be a voice to support all other Aboriginal health services and to advocate and foster improvement in the health sector for all Aboriginal and Torres Strait Islander people in the country and surrounding regions of South Australia. The aim is to advance their social, spiritual, cultural and economic status and pursue better outcomes for the Aboriginal community of Port Augusta, encompassing all aspects of primary health care (PWHS 2006a).

Philosophy

Go to the people, live among them
learn from them, love them.
Start with what they know,
Build on what they have to be the best leaders.
When their task is accomplished,
the people all remark:
'We have done it ourselves' (PWHS 2006a).

Vision

Pika Wiya Health Service strives to improve social, emotional, spiritual and physical wellbeing of all Aboriginal people.

Objectives

Pika Wiya's objectives are to:

- develop a service that meets the health care needs of the Aboriginal people of the area in the most appropriate way, having regard for their total well being, and the importance of health promotion and prevention;
- assist in establishing an environment in which health care providers can render a needed service in a cooperative and satisfying manner;
- ensure that people are fully informed of the options available to them for health and local community services;
- teach people about personal health care and resources in order to encourage mutual responsibility for maintaining health;
- develop and maintain the relationships necessary to ensure coordinated and effective health service delivery in this area;
- provide integrated local community health and medical services that complement existing services;
- encourage staff to assume roles in local community development through involvement in local groups;
- maintain appropriate links with other health units, that have an impact in this area. Provide a base for health units and other agencies delivering services to the community;
- develop outreach services and special clinics where necessary;
- provide services in the form of programmes for particular client groups based on the needs in the area, combining health and hospital services;

Aboriginal Health Service Partners of the CCRE (continued)

- research the needs of the population and evaluate new and existing services;
- open up the service to foster cultural sensitivity and placement experiences to students of all disciplines to encourage them to look towards Indigenous rural and remote health as a career option (PWHS 2006b).

Living Improvements For Everyone

At Pika Wiya a more culturally appropriate chronic disease self-management model has been created for Aboriginal people, based on an United States program developed at Stanford University (Lorig et al; 2000; 2001). Two Aboriginal women, trained at Stanford University to be Master Trainers in the Stanford chronic disease self-management approach, (one a senior Aboriginal health worker at Pika Wiya and the other from the University of South Australia and Spencer Gulf Rural Health School), developed a course they called Living Improvements For Everyone (L.I.F.E.). It provides practical advice and strategies for people and families living with ongoing and complex health conditions. The course was developed with the important input of a group of local Aboriginal community patients to incorporate a culturally appropriate approach to patient self-management, and includes more general health promotion material and relies on collaboration with other staff in the local health service.

The work of the CCRE, and how it identified and pursued its aims. A key aim has been building the research capacity of Indigenous people and communities. The CCRE pursued three inter-related strategies: community-controlled research programmes focusing on chronic illness; training and education; and translation and adoption of effective practice.

CCRE Rationale and Key Activities

This chapter details the work of the CCRE and some important influences on how it has identified and pursued its aims.

In order to build the research capacity of Aboriginal people and communities, the CCRE has developed three inter-related strategies or program components: community-controlled research programmes focusing on chronic illness; facilitating training and education opportunities for Aboriginal people in health-related research; and the broader translation and adoption of effective practice.

Research

The common practice and experience with research carried out in Indigenous communities has been one of an imposed, quasi-experimental, scientific research model, which for many Aboriginal people was foreign, meaningless and degrading. Furthermore, the research has not translated into improved health service delivery. Consequently, much of this research has failed to contribute to building healthier, more informed communities. With the re-assertion through the 1970s of Aboriginal identity and, more recently, new processes for research ethics approval, new approaches have been developed for research in Aboriginal communities. Aboriginal people have increasingly asserted that it is essential that research contributes to improvements in the community and is not just carried out for its own sake or for the benefit of non-Indigenous researchers or research bodies such as universities. Research has to be meaningful and contribute to the development of real knowledge, skills and capacity building within

the communities where it was carried out. Importantly, research needs to be controlled by Aboriginal people if it is to be effective. This is a key principle underpinning the establishment and funding of the CCRE.

The fact that the history associated with research has 'had a powerful impact on the collective memories of Aboriginal communities' (Anderson cited in Henry et al. 2004:6) is widely acknowledged. In response, Aboriginal research ethics committees have been set up in an effort to make researchers more accountable to the communities they study. As Anderson (in 1996) states, 'within the Aboriginal community there is a growing, though tentative, recognition that research can be a valuable tool if deployed appropriately'.

For example, Aboriginal community-controlled health services working with us requested assistance in setting up rigorous data management systems to secure recurrent funding and hence work towards sustainability. This consciousness is emerging in the broader community and it is now acknowledged that in order to improve health service delivery and health outcomes generally, robust research evidence is required. Through the work of the CCRE, more appropriate and flexible approaches are being taken towards research in Aboriginal communities. Research methods are carefully chosen to match the questions being asked rather than simply applying routine study methods that may not be appropriate.

In the larger health care context there is a need to build sustainable health care systems. The development of more

CCRE Rationale and Key Activities (continued)

effective systems of care provision for Aboriginal people is part of this challenge, especially in rural communities. Advocates for Aboriginal research reform emphasise the importance of ensuring that research initiatives can be sustained within the community in the absence of external researchers. This objective has been a key aim of this CCRE. It will require a continuing effort involving initiatives that have been central in this project — supporting Aboriginal employees and people in the health sector with scholarships to achieve higher and professional education qualifications, and providing research training to Aboriginal employees in the health sector.

CCRE Integrated Projects

The CCRE developed research proposals with the three Aboriginal health services in rural South Australia that were involved in the original proposal for the CCRE. These CCRE Integrated Projects were to focus on aspects of chronic condition management (e.g. self-management approaches, point-of-care pathology testing and the need for routine, reliable, repeated data measuring health outcomes). These integrated projects built on previous related research in these services, as part of the Council of Australian Governments (COAG) and Sharing Health Care SA initiatives, and through grants from external bodies such as the Department of Health and Ageing, Rotary, etc.

CKAHS consulted with AHCSA about establishing routine processes for the collection, collation and reporting of key health outcome data for patients involved with the Enhanced Primary Care (EPC) health assessment and care planning process. The plan was to build a reliable longitudinal record for patients by combining hitherto disparate data sources and integrating this record management process into routine business practice within the health service. Over time, it is anticipated that the community will build the capacity to collect and utilise such data to sustain more effective primary health care programmes.

A second project involved PLAHS, where there was interest to investigate, through a qualitative research approach, the processes underlying the maintenance of successful participation in structured systems of chronic

disease care. This project aimed to produce a document on the evolution of successful practices in the community, and to train a local Indigenous registered nurse by supporting that person to complete a graduate diploma in qualitative research methods. These research skills would then remain within the community, enabling the health services to explore other community development issues in locally relevant and meaningful ways.

At Pika Wiya Health Service in Port Augusta a similar project was planned, where a local project officer would be funded to carry out research and be supported in undertaking the research by appropriately experienced and qualified mentors. The effectiveness of existing organisational and health system practices used to establish health assessments, care plans and other structured systems of care for patients with chronic and complex health needs would be looked at and investigated as to how effective they are in engaging with the Aboriginal community, and how effective they are for the Aboriginal health organisation. (Chapter 7, Community Projects, includes more description of these projects.)

CCRE Investigator Projects

The CCRE provided some funds to support some of the ongoing projects of CCRE Investigators, in particular with Eyre Peninsula region Aboriginal health services. These included:

- Coordinated Aboriginal Mental Health Care (Inge Kowanko, Charlotte de Crespigny with PLAHS and CKAHS);
- extend Mark Shephard's POCT work in the Eyre Peninsula region;
- further develop Malcolm Battersby's work on chronic disease self-management, especially with PLAHS.

Other small research projects were supported by CCRE, and including some funding for:

- an Aboriginal health worker in general practitioner services in Port Augusta;
- developing a proposal for a Whyalla maternity project;
- tracking cardiac patients (joint project with Heart Foundation at Pika Wiya). (More on this is presented in the next chapter.)

CCRE Rationale and Key Activities (continued)

Education and training

The Indigenous Research Reform Agenda challenges the ways that research has traditionally been identified, funded, controlled and undertaken. It entails increased Aboriginal control over all aspects of research affecting Aboriginal interests. Supporting this view, a number of federally sponsored reviews and reports over the past sixteen years have recommended increased Aboriginal participation and leadership in health research, including more employment and training of Aboriginal researchers. The Wills report asserted that this is a crucial step for making research effective in providing solutions to health problems.

This transfer of control over the research process can only be achieved through increasing the research capacity of Aboriginal people. The CCRE aims to contribute to this through its education and training program, which includes the provision of scholarships and bursaries for Aboriginal researchers and the development of a research training course.

Scholarships and bursaries

The thinking underlying our scholarships program has been to increase the pool of Aboriginal people with university-level education in the health field. The scholarships provided \$6000 for full-time study (pro-rata for part-time), advocacy support (for instance with university teaching staff and administration) and referrals. A condition attached to the scholarships was that candidates undertake a short course in research developed and run by the CCRE if their own courses do not contain an element of research. It is apparent that currently there are other postgraduate research scholarships designated for Aboriginal candidates and offered around Australia that are not being taken up. This CCRE had an aim of supporting doctoral-level research students, but was unable to fulfil this objective.

As of the beginning of 2008, the CCRE had supported twenty-six students in their studies, with scholarships mostly to Aboriginal people working in the health sector and pursuing a range of study programmes. Bursaries were provided to fourteen

Aboriginal people to attend and/or present papers at national and international conferences. This was part of the CCRE's capacity development strategy for Aboriginal people. (An appendix gives brief details relating to those supported.)

Researcher training

Researcher training occurred through the CCRE scholarships and bursaries program, through mentoring of individual Aboriginal researchers, through a series of workshops and through a nationally accredited Vocational Education and Training (VET) level research course.

Our consultations with practitioners in Aboriginal community-controlled health services informed us that many Aboriginal people wanted to learn more about research in order to be:

- informed about research findings that relate to their own practice;
- able to conduct evaluations of their own health service programmes;
- able to read and understand research in order to be able to judge whether
 - the research findings are founded on sound evidence and whether these are relevant to their own particular programmes
 - a particular research proposal submitted by outsiders to their health service is well conceived and will contribute to the community;
- able to understand the language of research.

Aboriginal people emphasise that they want to undertake accredited courses in research rather than short courses that offer no formal qualification. Our objective in this area has been to develop a course in research education, which will provide an educational pathway between the VET and university sectors, and lead to formally recognised academic qualifications for Indigenous researchers.

The CCRE team pursued this in collaboration with James Cook University (JCU), where two VET-level courses—a Certificate IV and a Diploma in Research Capacity Building in Indigenous Community Services—had been developed and accredited for

CCRE Rationale and Key Activities (continued)

Indigenous researchers. In developing the framework for these courses, extensive consultations were conducted with Aboriginal community-controlled services around Queensland over two years. The CCRE entered into an agreement with JCU for the CCRE to deliver the JCU course.



Curriculum Development Committee: (left to right) Jerry Moller, Amanda Mitchell, Kim O'Donnell, Christine Franks, Sonia Champion, Merridy Malin, Jason Bromley.

The Training Officer brought together a course development committee to develop the curriculum for the course in response to our South Australian needs, and developed learning resources (such as a series of fourteen workbooks). The committee was primarily made up of Aboriginal researchers, teachers and health workers. Piloting the Certificate IV course with twelve Aboriginal health practitioners began in the second half of 2007, the first time the course was offered in Australia. The pilot was completed in June 2008, with graduations occurring in August 2008.

The CCRE also entered into a partnership with the Secretariat for National Aboriginal and Islander Child Care to deliver an accredited short course in evaluation and action research. This short course draws on three of the ten competencies (subjects) from the Certificate IV in Research Capacity Building, which the seventeen students can use as electives towards their child care qualifications.

Delivery of the course is student-centred, in that each student, in addition to attending four 4-day (or two 2.5 days for the short course) block release workshops, completes course requirements by conducting small projects within their work environment, pursuing

a research question and methodology specific to that environment. Students receive on-site mentoring support with their project, ideally from locally based researchers. By developing evaluation skills and implementing 'continuous improvement to practice' strategies into their strategic plans and daily work, the students are able to strengthen their own services.

Some of the projects that students investigated included:

- The Free Spirit Project: Determining the need for palliative care and bereavement support in Port Lincoln;
- evaluation of Through Young Black Eyes information kit about family violence and child abuse;
- a needs analysis for a social and emotional wellbeing program for youth in a regional town;
- increasing the engagement of women in a regional Aboriginal women's centre.

Mentoring of individual Aboriginal researchers

The Training Officer provided mentoring support to two project research workers located in CCRE partner health services as part of their studies. These two Aboriginal health service staff were part of the CCRE Integrated Projects at their respective organisations: PLAHS and Pika Wiya Health Service. (These projects are described in Chapter 7: 'Community projects' in this report.)

A project research worker based at PLAHS was supported with intensive tutoring through a Graduate Certificate in Primary Health Care: Research and Evaluation at Flinders University. As part of her degree, she designed a research project aimed at strengthening the engagement of Aboriginal clients, which was to be implemented within the local health service (unfortunately it was cut short by a change in employment).

A project research worker based at Pika Wiya Health Service, is currently being offered supervision and mentoring support in a project funded jointly by the CCRE and the Heart Foundation. This project is tracking the journey for rural Aboriginal cardiovascular patients through the health system. The project fulfilled

CCRE Rationale and Key Activities (continued)

the student's requirements for the Certificate IV in Indigenous Research Capacity Building.

Translation

One of the key focuses that the creators of this CCRE identified is referred to as 'translation'. This emphasis was strongly influenced by the ideas formulated in the Indigenous Research Reform Agenda and articulated by the CRCAH and its precursor.

Over recent times there has been some debate about this aspect of research work and many readers will be familiar with the 'research transfer' concept. The CRCAH has advocated, and strives to achieve in practice, the ideal that research and its 'results' about Aboriginal and Torres Strait Islander health must not just be left 'on the shelf'.

A key concern has been that researchers must be accountable to the participants in their research and that reciprocity is integral to this, and that the research has positive results for the research participants and their communities: Aboriginal people. Different research projects will have different implications, but a common point within this rationale is that it is necessary to devote some resources and attention, possibly including dedicated staff, to ensuring that research can be utilised to benefit the people on whom it is focused.

There are many activities that fit within the 'translation' function. We see translation as being about using knowledge and learning developed through specific research projects to inform and improve health practice, education and health policy. The range of activities could include:

- disseminating lessons for effective clinical procedures;
- providing relevant training, practice guidelines and other workforce development strategies;
- policy recommendations (for the health service and wider social application);
- recommendations for the training of workers in the field;
- the provision of informed advice for people in the community;

- linkages and networks with other relevant services and groups locally and beyond.

In our CCRE we have focused on developing good working relationships with the Aboriginal health services that have been involved in previous research projects that contributed to creating this CCRE. These services have also been directly involved in setting up this majority Aboriginal-controlled research unit in partnership with researchers from Flinders University and other collaborating organisations.

A priority for translation activities thus far has been disseminating information about some of the lessons of key research work into the recognition and management of chronic conditions. This work has been conducted in the Aboriginal health services now involved with the CCRE and provides a foundation for further projects and ongoing research and research training.

Research into the future

Another important aspect of our experience through this CCRE is that, in striving to establish collaborative working relationships with the Aboriginal health services, we find that there are major difficulties for the services in devoting staff resources to this work. As noted in the section about training and education, another central aim of this CCRE is to help build the capacity of the Aboriginal health services, and the Aboriginal community more generally, to undertake health research and to control the health research involving their communities. Because the general experience seems to be that Aboriginal health services are commonly understaffed, due mainly to a serious shortage of appropriately qualified and experienced staff, a major part of this CCRE's work is developmental: facilitating 'upskilling' of Aboriginal staff at the health services and elsewhere in the sector. The shortage of funding to Aboriginal health services is a critical issue to be addressed in this context and in the wider context of the vast health inequities that exist in Australia generally. The importance of the funding issue is also clear when comparing Aboriginal and Torres Strait Islander Australians to Indigenous people from other parts

CCRE Rationale and Key Activities (continued)

of the world and the differential (for instance, in life expectancy) between Indigenous people and non-Indigenous people.

It is crucial for communities to gather, own and apply information, evidence and knowledge about the impacts and outcomes of the health care programmes they run if they are to secure sustainable funding into the future. The AHCSA is now well positioned to make a significant contribution to the evolution of more effective community-controlled research, research training and research translation in collaboration with Aboriginal people.

Applying narrow and intrusive research methods in Indigenous communities has been damaging and counterproductive. New and more collaborative community-led approaches have been developed and should now always ensure that research is meaningful and relevant to Aboriginal people. Indigenous community leaders are now recognising their knowledge, skills and leadership roles in deciding matters pertaining to health research and research translation needs and that research can be conducted differently and produce useful and beneficial research outcomes.

The CCRE in Aboriginal and Torres Strait Islander Health has been able to meet its goal of establishing and advancing the agenda of Aboriginal-controlled, community-based research for improvements in health and wellbeing.

Part B reports the achievements of the CCRE: this makes up Chapters 5 to 8.

Chapter 5 summarises key work of CCRE Investigators, and the work of the CCRE's Training and Translation Officers, highlighting the first delivery of a Research Capacity Building Training Course for Aboriginal Health Workers and others.

Summary of Main Achievements

This section highlights the main achievements of this CCRE's Investigators and project staff during the period of the CCRE. The two chapters following this one, 'Workshops and forums' and 'Community projects', also outline achievements of the project. The appendices include publications and presentations on CCRE-related work, and a list of students that the CCRE supported with scholarships and bursaries.

The CCRE Secretariat and AHCSA are working to secure support to maintain the activities and functions of the Training and Translation Officers, initiatives that have given new capacities to AHCSA. If AHCSA is successful in obtaining ongoing resourcing to continue to accommodate these functions, this will contribute significantly to developing the capabilities of the Aboriginal community health sector in South Australia to be more involved in, and to shape and determine, the research of their communities' health issues. Working towards this aim has been central to the CCRE project's rationale, structures and activities, and its achievement would make a significant contribution to improving the health outcomes of Aboriginal and Torres Strait Islander Australians.

Research projects **Alcohol Treatment Guidelines for Indigenous Australians**

CCRE Chief Investigator Professor Charlotte de Crespigny managed a national project that produced the Alcohol Treatment Guidelines for Indigenous Australians, which drew on several sources, including CCRE-related research work conducted with various

South Australian Aboriginal communities on mental health, substance use and medication management issues.

These guidelines are a very good example of the translation of research findings into practice at the clinical level. The project has involved delivering workshops nationally on the guidelines. Indigenous advisers and health service providers were involved in the development and implementation of these as a national resource—the first of its kind.

Better Medication Management for Aboriginal People with Mental Health Disorders, and Family and Other Carers, 2003

Researchers: Inge Kowanko, Charlotte de Crespigny, Helen Murray (Flinders University and Drug & Alcohol Services South Australia), Scott Wilson and Warren Parfoot (Aboriginal Drug and Alcohol Council SA) and Dr David Mills (Eyre Division of General Practice). The research team worked in partnership with various Aboriginal health services and community groups throughout the project. Funding was provided for this three-year research and research translation project by the Australian Government Quality Use of Medications Evaluation Program.

The Aboriginal population is sicker, younger and poorer than the non-Indigenous population, with mental health (social and emotional wellbeing) and alcohol/drug problems impacting on significant numbers of Aboriginal people. Mental health problems are often complicated by chronic physical illnesses and/or alcohol/drug disorders, often resulting in the need

Summary of Main Achievements (continued)

for multiple medications. This participatory action research state-wide project aimed to explore the particular needs, experiences and contexts of Aboriginal people diagnosed with a mental health disorder, their carers and other family members, focusing on issues relating to management of medications; to recommend strategies to improve quality use of medicines by this group, informed by the findings; and to implement and evaluate selected recommendations. Multiple research methods were used including review of literature and key documents; semi-structured interviews with clients, carers, community leaders and health and other relevant professionals in each region; a state-wide survey of service providers; a review of the most recent South Australian hospital separation statistics; and reflection on interventions made in response to findings during the project.

The research team and steering committees collaboratively considered the combined findings and formulated recommendations to improve the safe use and management of medications and related issues for Aboriginal people with mental health problems and their carers/families. Selected strategies were implemented and evaluated and included advocacy for full consultation with the Aboriginal community regarding the recent review of the South Australian Mental Health Act; education and training of Aboriginal health workers and other key workers; local community education; and publications. The project was conducted from July 2000 to June 2003, and has since been followed up with continuing research titled 'Coordinated Aboriginal Mental Health Care' under the auspices of this CCRE (2003–continuing).

The research reports on key projects conducted by this team can be accessed at <http://aboriginalhealth.flinders.edu.au/research/index.html>.

Point of Care Testing program – expanded & maintained

Since the inception of the CCRE, the Community Point-of-Care Services unit within the Flinders University Rural Clinical School has worked collaboratively with PLAHS on a program called Point-of-Care Testing in Aboriginal Hands. The project used POCT for

the prevention and management of chronic disease (notably diabetes) within the community setting. POCT enables pathology testing for markers of chronic disease (notably Haemoglobin A1c [HbA1c] and Urine Albumin:Creatinine Ratio [ACR]) in an Aboriginal health service by a trained Aboriginal health professional. POCT results are available within ten minutes, facilitating change of management on the spot by the doctor and providing a convenient and accessible service for the client with diabetes, as a follow-up visit to obtain results is not required. POCT also facilitates community control and ownership of pathology testing results.

Dr Shephard's unit developed a sound quality assured framework for POCT at Port Lincoln. A large Aboriginal Health Professional team, led by Tony Burgoyne, has been trained and is now skilled in conducting POCT on-site at Port Lincoln. Indeed, Tony's work in the field of POCT has been recognised more broadly with his appointment as the Aboriginal Leader representing South Australian and Northern Territory sites in the national QAAMS POCT Program (see Shephard 2006 in 'CCRE Investigator—Publications' in Appendix 3). Over the past three years, Dr Shephard's unit has also established and implemented a management plan for the tracking and monitoring of patient's POCT results to enable the collection of clinical outcome information. The concomitant introduction of POCT with structured chronic condition self-management (CCSM) care plans at PLAHS resulted in improved diabetes control within a group of twenty-four type 2 diabetes patients. A statistically significant reduction of Haemoglobin A1c (HbA1c) of 1.2 per cent (paired t-test, $p < 0.05$) has been observed since POCT was introduced at PLAHS. Community acceptance of POCT among key stakeholder groups, namely the service's doctor, Aboriginal POCT operators and clients with diabetes, was high. The results of this study have recently been published in the peer-reviewed international journal *Point of Care* (see 'CCRE Investigator—Publications' in Appendix 3 for details). In late September 2007 a regional POCT Training Workshop was held at Port Lincoln for a number of other Aboriginal medical services from the Eyre region and beyond; participating services included Port Lincoln, Ceduna/Koonibba,

Summary of Main Achievements (continued)

Pika Wiya and Umoona Tjutagku Health Service. Again, Tony Burgoyne from PLAHS assisted the Community Point-of-Care Services unit's scientific team in training participants to conduct POCT for Haemoglobin A1c and Urine Albumin:Creatinine Ratio (a marker for early renal disease). In total, fifteen Aboriginal health professionals received certificates as qualified POCT operators as a result of this training workshop. The workshop boosted considerably the skill base and capacity for POCT to be conducted in Aboriginal communities from the Eyre region.

Further development of testing an approach to chronic disease management, in various communities, (including use of POCT)

Dr Battersby and his Flinders Human Behaviour and Health Research Unit at Flinders University have worked on furthering the testing of an approach to chronic disease management, developed in part through the Sharing Health Care trial in South Australia, particularly in the Eyre region with Aboriginal services and communities. See 'Successful tenders for further work' later in this chapter for an outline of further work on implementing their approach to chronic disease management in a project funded by the CRCAH.

Research-related training program

The CCRE's main achievements include the development and delivery of various training programmes, including:

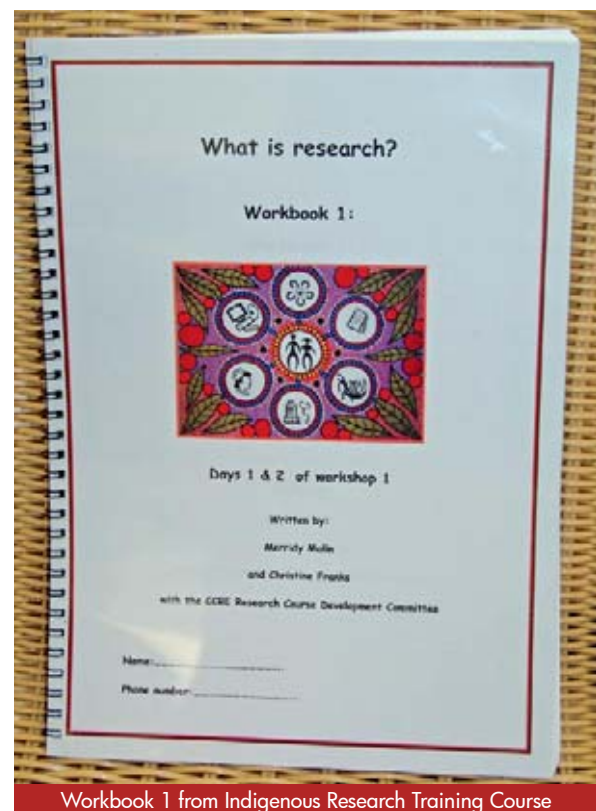
- Research Training Course (including learning materials) developed and delivered; the first time for such a research training course at vocational education and training Certificate IV level;
- key involvement in Secretariat of Aboriginal and Islander Child Care Research Training;
- Aboriginal Evaluation Workshops (in 2005 and 2006);
- Introduction to Research workshop (Nunyarra, Whyalla, December, 2006);
- Assisting Action Research Conference with Aboriginal focus (Tavondi College, Port Adelaide, August 2007).

Indigenous Research Training Course

In August 2008 twelve people graduated with the Certificate IV in Indigenous Research Capacity Building. A further seventeen completed three competencies from this same course, which they are able to credit as electives towards their various certificates in child care.

In the final of the four workshops, students presented their projects to the class, mostly choosing PowerPoint as the preferred way of communicating their findings. The projects entailed action research and evaluation (documenting, consulting and surveying) around the implementation of a particular program. For example:

- consulting Aboriginal mothers in regional and remote communities about the best way to conduct a survey into the adequacy of services during and after child birth;
- documenting the vandalism (and facilitating the restoration) of a war memorial in a rural Aboriginal community;
- conducting a consumer survey on the adequacy of a government health service in a regional town;



Workbook 1 from Indigenous Research Training Course

Summary of Main Achievements (continued)

- establishing and evaluating a nutrition program in a country primary school.

At the end of the course, the graduating group decided to establish a network of Aboriginal researchers who would be available to work in partnership with others wanting to conduct research in their respective communities. It is proposed that this network should become part of a national network facilitated by the CRAH.



Research Course Students Graduation Ceremony

The graduation ceremony was held in late August 2008 at Warriparinga (at the Living Kurna Cultural Centre in southern Adelaide) with a one hundred per cent completion rate. This was followed in September 2008 by a symposium at the Australasian Evaluation Society annual conference in Perth, where six students and three mentors involved with the evaluation and action research short course gave presentations on their projects to an international audience.

Those of us involved in the development and delivery of the course have found the whole process extremely enriching. The quality of projects conducted by the students and the confidence and skills that students displayed at the end have been inspiring.

We are hoping that we will find funding to continue the course in 2009 and, in the meantime, will scrutinise the results of the external evaluation of the course and amend the teaching resources and curriculum accordingly.

Scholarships and bursaries

The CCRE granted scholarship and bursaries, and supported students in their study programmes (described in Chapter 4: 'CCRE rationale and key activities'). The CCRE supported twenty-six students, with scholarships mostly to Aboriginal people working in the health sector to pursue a range of study programmes. Of those, thirteen graduated, six were continuing, three withdrew, and four transferred to different courses of study. These students pursued study in primary health care, health sciences, biomedical engineering, nursing, and diabetes education and management. The students have studied across the range of sectors including VET, undergraduate university degrees, graduate certificates and masters degrees. The scholarships have been used to fund study-related costs including computers, books, child care, travel and accommodation to attend classes, and university fees.

Bursaries were also awarded to fifteen people to contribute to their conference travel and registration; for study-related travel; and also to support Aboriginal researchers from the Northern Territory and regional South Australia to present at the Action Learning Action Research Conference at Tauondi College, which was co-sponsored by the CCRE.



2006 Graduate Scholarship Students from Flinders University

Summary of Main Achievements (continued)

CCRE scholarship recipient case studies

1. Tony Burgoyne (Port Lincoln Aboriginal Health Service)



Tony Burgoyne

Among the people the CCRE has supported in undertaking studies have been several staff members of PLAHS. The CCRE supported two employees of PLAHS to undertake and complete a Graduate Certificate in Diabetes Management and Education (Flinders University): Tony Burgoyne (Aboriginal) and Bev McCurry (non-Aboriginal).

It is worth noting that one strategy of PLAHS in developing its workforce is to have at least two staff participate together in training opportunities as they arise. This approach maximises the success of those taking up such opportunities. In addition to the support from teaching and tutoring staff associated with the particular program, the staff doing the study or training can support each other through it. This strategy increases the likelihood that the organisation will retain benefits flowing from some staff having undertaken the learning.

Speaking with Tony a couple of years after completing the above diabetes course, he felt there had been some very positive outcomes for PLAHS from this. Tony reported that he had received very good support from some of his non-Aboriginal colleagues at PLAHS through the course of study, including from Bev McCurry, who did the course with Tony.

Tony reported that one benefit of doing the Graduate Certificate in Diabetes Management and Education, and other related work, has been that he has been able to specialise in the diabetes area. This is positive for the client/patient

community of PLAHS, enhancing the skilled staff available to meet the needs of clients and patients. Having done the course and being deployed to focus on diabetes in his position at PLAHS, Tony has come to be recognised by his community as having an advanced level of knowledge in diabetes. He is now deployed as a Diabetes Educator, and is seen as being more than an Aboriginal health worker (which Tony has been for several years).

PLAHS has also developed its resources and facilities connected with health promotion activities, including in the area of diabetes, with a kitchen and training room and teaching resources. It has organised three diabetes camps for patients and community members over eighteen months to progress its aim of making the Aboriginal community that uses its service better informed about diabetes, its implications and how to manage the condition more effectively.

Among the other activities that Tony has been involved in is the introduction of POCT to PLAHS. Tony has also become an Aboriginal health worker leader in a national program implementing this technology in Aboriginal health organisations around the country, a program led by CCRE Investigator Dr Mark Shephard. For more information on this program, see Dr Shephard's key projects in Chapter 2: 'CCRE Investigators—profiles and key activities.'

Summary of Main Achievements (continued)

2. Anthony Ah Kit



Anthony Ah Kit

Mr Ah Kit has been another recipient of a CCRE scholarship. He has been 'extremely grateful' for the opportunity to access one of the CCRE scholarships. It enabled him to work towards completing a Master of Primary Health Care at Flinders University in Adelaide. (As of Semester 1, 2008, Anthony had three subjects remaining to complete the course requirements.)

The scholarship has supported Anthony in the following ways:

- purchase of a laptop computer;
- paying for text books and other study-related materials;
- advocacy support in dealings with the university system.

When Anthony completes the course he will go into the field of research and will do research on the topic of Aboriginal men's health. A topic of particular interest to Anthony is the importance and relevance that Aboriginal men's groups play in determining long-term and sustainable health outcomes.

Anthony would also like to add that he is extremely grateful and appreciative of the all-round support he received from the CCRE Training Officer, Merridy Malin. Merridy has assisted Anthony in times of crisis and as a friend.

Translation activities

The translation activities of the CCRE included the development, production and distribution of the following resources and materials. The primary objective of these initiatives was to communicate key points about strategies to manage long-term

illness (chronic conditions) that afflict many Aboriginal and Torres Strait Islander Australians. The CCRE email bulletin distributed monthly had several broader aims. This initiative collated and forwarded a range of information on Aboriginal and Torres Strait Islander health issues, in general trying to make information and resources more available to enhance and facilitate an increase in the capacity of Aboriginal health services to engage with research in their field.

Resources, reports, pamphlets and posters

- CCRE email bulletin: Wake Up Call;
- CCRE brochure;
- 'Long-term sickness' (chronic illness) brochure;
- 'Long-term sickness' poster and banner (see next page);
- reprint of Look, Think, Act (booklet from a participatory action research project with Port Lincoln Aboriginal Elders, and others, about living with type 2 diabetes).

Associated with CCRE research there have also been a number of workforce development programs delivered through on-site training, other training, and provision of evidence-based resources for practice.

These include:

- alcohol and other drug education;
- mental health, alcohol and other drug co-morbidity;
- safe medication management in community settings;
- emergency mental health and other drugs;
- provision of, and training in, the Alcohol Treatment Guidelines for Indigenous Australians package;
- provision of the Alcohol, Tobacco and Other Drug Clinical Guidelines for Nurses and Midwives package;
- provision of relevant community education, referral and health promotional resources;
- training in use of POCT.

Summary of Main Achievements (continued)

Long Term Sickness

Chronic Illness - Prevention and Care



Chronic Illness (Long Term Sickness) includes: Heart Disease, Asthma, Diabetes, Mental Illness and Renal Diseases

Artwork by Jillian Larking (Kuju Arts and Crafts, Port Lincoln). Poster Design by Matthew Goodluck.

Keys to improving long term health:



Equal Access

Providing more and better health services to Aboriginal communities, and increasing pathways to training and education for Aboriginal health workers.



Care Planning

Yarning, listening and working together to write care plans to help cope with or improve long term sickness.



Self-help

Looking after yourself and helping us help you.



Support Services

Knowing about support services that can help people cope with or improve long term sickness (Doctors/GPs, Aboriginal Health Services, Allied Health, Drug / Alcohol and Mental Health Services).



Healthy Lifestyle

Learning about healthy ways to keep long term sickness under control, like exercising and eating good food.



Technology

Using technology to keep a check on long term sickness to monitor and measure symptoms, for example point-of-care technology.

For more information contact this CCRE or your local Aboriginal Health Service:



*This CCRE is funded by the National Health and Medical Research Council.

Centre of Clinical Research Excellence in Aboriginal and Torres Strait Islander Health*

PO Box 787 Kent Town SA 5067
Tel: (08) 8132 6700
Fax: (08) 8132 6799
Email: ccre@ahcsa.org.au
Web site: www.ahcsa.org.au

Your Local Aboriginal Health Service:



An initiative of the Centre of Clinical Research Excellence in Aboriginal and Torres Strait Islander Health

Summary of Main Achievements (continued)

Papers and presentations to conferences and meetings

In addition to the academic and other papers and conference presentations of CCRE Investigators (a fuller list is included as Appendix 3 of this report), the CCRE Secretariat produced several academic and other papers and presentations, including to Aboriginal primary health care workers. These are listed here:

Giles, G. D. 2007, 'Factors Affecting Aboriginal Health Organisations' Participation in Research', Public Health Association of Australia, 38th Annual Conference, Mparntwe (Alice Springs), 23–26 September.

Giles, G. D. 2007, 'Promises Yet To Be Fulfilled', in N. Gillespie (ed.), *Reflections: 40 Years on from the 1967 Referendum*, Aboriginal Legal Rights Movement Inc., Adelaide, pp. 31–6.

Giles, G. D. 2006, 'World Leader in Chronic Disease Self-Management Visits South Australian Aboriginal Health Service (Pika Wiya)', *Aboriginal and Islander Health Worker Journal*, vol. 30, no. 1, pp. 26–7.

Giles, G. D. 2006, 'Participatory Action Research for Aboriginal Community Health Research', *Aboriginal & Islander Health Worker Journal*, vol. 30, no. 5, p. 16.

Giles, G. D., Malin, M. & Harvey, P. W. 2006, 'The Centre of Clinical Research Excellence (CCRE) in Aboriginal and Torres Strait Islander Health—An operational rationale and summary of early achievements!', *Australian Journal of Primary Health*, vol. 12, no. 2, pp. 97–104.

Giles, G. D., Malin, M. & Harvey, P. W. 2007, 'Improving the Management of Chronic Conditions of Indigenous Australians through Indigenous Research', 9th National Rural Health Conference, Albury, NSW, 7–10 March.

Giles, G. D. & Coulthard-Stanley, J. 2007, 'Building Aboriginal Research Capacity re Long-term Illnesses', Public Health Association of Australia, 38th Annual Conference, Mparntwe (Alice Springs), 23–26 September.

Giles, G. D. & Casey, L. 2007, 'Building Aboriginal Research Capacity in Relation to Patients with Long-term Illnesses', *Research Brokerage and Transfer in*

Primary Health Care, PHR-RED Tri-State Collaboration Event, Adelaide, 11 September.

Malin, M. 2008, 'Managing Chronic Conditions by Building Aboriginal Research Capacity', paper presented at the Aboriginal Health Research Conference: Strong Foundations...Strong Future, Cockle Bay Wharf, Sydney, April 29 & 30.

Malin, M. & Champion, S. 2007, 'Working Towards Aboriginal Research in Aboriginal Hands', paper presented at the Working Together to Close the Gap Meeting of the Australian Royal College of General Practice, Crowne Plaza, Darling Harbour, Sydney, 3 October.

Malin, M., Franks, C., Casey, L. & Champion, S. 2007, 'In Aboriginal Hands—Aboriginal research', paper presented at the Teaching and Research: Making the Connection in Health Sciences Conference, University of South Australia, City East Campus, 8 & 9 November.

Malin, M. & Warren, K., 2007, 'Aboriginal Research into Practice—the CCRE research course and the LIFE course', presentation at the Buderu Booroodu: Excellence in Aboriginal and Torres Strait Islander Health Conference, Sheraton on the Park Hotel, Sydney, 21–23 November.

Successful tenders for further work

This section indicates the continuation of key areas of research and project work, showing that important elements of the project are being extended and are achieving sustainability, offering promising and positive further development of work of the CCRE project.

1. Chronic condition management strategies in Aboriginal communities.

This is a three-year CRCAH-funded project commencing in 2008, with Inge Kowanko, Malcolm Battersby and Peter Harvey as Chief Investigators (CRCAH Project CD218). The research assistant will be based at AHCSA, providing an opportunity for continuing research activity within AHCSA.

Overall the project aims to develop and demonstrate sustainable and effective chronic condition management (CCM) strategies for Aboriginal communities. It builds on previous and current

Summary of Main Achievements (continued)

work on CCM, most especially through the CCRE. That work and other research showed that several CCM strategies known to work well in non-Aboriginal settings can be modified and implemented successfully in Aboriginal communities. This project aims to demonstrate the effectiveness, sustainability and transferability of promising CCM strategies (in particular care plans supported by Medicare Benefits Schedule (MBS) funding, the Flinders Model of care planning based on clients' own life goals, and the LIFE program of peer support for self-management).

The project is being conducted in three Aboriginal communities: Port Lincoln, metropolitan Adelaide and Riverland. The project team is being advised and guided by an advisory group of stakeholders. This research explores the CCM strategies that are currently used in each site, and to find out what works well for them and why, and what systems and supports are required. Then, according to the priorities of the participating communities and available resources, services will be offered additional CCM strategies (i.e. care plans supported by MBS funding, the Flinders Model of care planning based on clients' own life goals, and the LIFE program of peer support for self-management), along with associated training for health service providers and organisational change. The processes, impacts and outcomes of these CCM 'interventions' will be assessed using multiple methods including interviews with clients and service providers, changes in health status (clinical measures and self-report), audit of service provision and costs.

2. Collaboration with Pika Wiya and Heart Foundation: Tracking the journey of rural Aboriginal people with symptomatic coronary heart disease: Stage 1

The overall objective of this research is to improve outcomes for Aboriginal people with chronic disease through strategies of care that address health systems or service barriers. We seek to achieve this by identifying health system or service obstacles that prevent Aboriginal coronary

heart disease patients from receiving life-saving procedures, by aiding change in destructive lifestyle choices, and by providing appropriate information regarding heart care etc., whether through the health system or elsewhere. The timeline for the research is March 2008 to February 2009.

The Heart Foundation and the CCRE are providing funding and support to a young Aboriginal employee at Pika Wiya to work full time on this project and thereby build research skills and the research capacity of Pika Wiya. (The person was in the first group to complete the CCRE Indigenous Research Capacity Building Course, and will be assisted by another young Aboriginal person who was also in this group.)

A reference group will oversee the project, involving several researchers, a medical practitioner, community members and health organisation bureaucrats.

The work will look at the journey of Aboriginal cardiac patients through the health system, by talking with a number of Aboriginal coronary heart disease patients in the Port Augusta/Pika Wiya Health Service region. It will provide new information about how Aboriginal cardiac patients are treated, and offer potentially effective and sustainable CCM strategies for transferring to other settings. The project findings will be disseminated widely.



Chapter 6 describes workshops and forums organised by the CCRE, and assisted by the CCRE, focusing on developing the research and evaluation capacity of the Aboriginal community health sector in South Australia.

Workshops and Forums

Through the period of its operation, the CCRE Secretariat was involved in, and organised, several workshops and forums. On several occasions, in the setting-up phase, at the mid-point and towards the end of the project, many of the participants in the project—from the Aboriginal health services, the researchers, and representatives from AHCSA—were brought together to work collaboratively on planning the progress of the work of the CCRE research program.

The CCRE Secretariat also organised, and was involved in, various workshops and forums aiming to advance the objective of facilitating development of Aboriginal and Torres Strait Islander health research by Aboriginal and Torres Strait Islander people, particularly from Aboriginal health services.

Following is a list, and then brief descriptions, of the main workshops:

- CCRE Education, Development and Research Group;
- Hosted presentation by Participatory Action Research practitioner and teacher Ernie Stringer (April 2006, AHCSA);
- Aboriginal Evaluation Workshops (November 2005 and May 2006);
- CCRE Symposium (September 2006, Glenelg);
- 'Introduction to Research in Aboriginal Health Services' Workshop (December 2006, Nunyara Wellbeing Centre Inc., Whyalla);
- Action Research Conference (August 2007, Tavondi College);
- CCRE Planning Day (Kaurna Living Culture Centre, Warriparinga, March 2008).

CCRE - Education, Development & Research Group

In the early stages of the CCRE, an Education, Development and Research (EDR) Group was formed to enable input from all those engaged in developing the proposal for the CCRE to have continuing input into how the CCRE was set up to pursue the objectives articulated in the submission to the NHMRC. The group was open to all named Investigators and representatives from the key organisations involved in the bid—AHCSA, Flinders University, the three Aboriginal health services (as identified above). (In August 2004 the CCRE Board decided to refer to the EDR group as the 'CCRE workshop group'.)

Three workshops were held through 2004, one in each region of the Aboriginal health services that were part of the CCRE original submission.

*Workshops and Forums (continued)***Port Lincoln, March 2004**

The first CCRE EDR workshop was held at PLAHS on 11 March 2004. A key theme of comments from the CEOs of PLAHS and CKAHS was that while they were keen to be engaged in this CCRE project and in further research projects, they confronted serious barriers to their organisations' abilities to participate in further research projects. (Note: Pika Wiya was unable to be represented at this meeting.) It was recognised, and pointed out, that the NHMRC did not provide funds to cover costs for backfilling of staff (such as Aboriginal health workers) who would be required to undertake the tasks involved in doing the work of research projects or for administrative support in this project. Those attending the meeting agreed that these were important issues for the CCRE, and that it needed to develop a model for funding of further research activities. In addition, unlike for universities and other research institutes, the NHMRC did not provide funding to the host of the project (the AHCSA) to cover associated administrative costs.

Researchers gave reports of their work. The areas covered included chronic condition management and self-management; POCT in Aboriginal Hands; mental health, drug and alcohol, safe medication management, health services. A number of possible areas for future collaborative research work activities were discussed, in part based on programmes at the three Aboriginal health services involved in the CCRE. It was recognised that resources were limited and that it was going to be important to focus efforts on work that was underway and able to be developed, and to explore further possible sources for funding of future research work.

Ceduna, June 2004

The second CCRE EDR workshop was held in Ceduna, at the Ceduna Sailing Club, on 11 June 2004. (The starting time of the meeting was delayed by flights delays, one of the unpredictable aspects that can affect operations in regional and more remote areas.) One focus of the meeting was the possible focuses for future research work and further development of the chronic condition work of the Investigators involved with this CCRE.

This meeting also considered the roles of the Training and Translation Officers of the CCRE, discussed how the CCRE could support ongoing work of Investigators, and considered publicity material about the CCRE.



Port Augusta, August 2004, Colleen Prideaux, CEO CKAHS, Cephass Stanley, CEO Pika Wiya

Port Augusta, August 2004

The next CCRE large group meeting (from that point onwards referred to as the CCRE workshop group) was held in late August, at Pika Wiya Health Service in Port Augusta. This meeting had various presentations from researchers about projects associated with the CCRE. It also addressed several organisational issues, including budgeting and provisioning for support of further research work pursuing the focus of the CCRE.



Port Lincoln Workshop, March 2004

*Workshops and Forums (continued)***Aboriginal Evaluation Workshops**

Two workshops—Australian Evaluation Society Indigenous Evaluation Workshop (November 2005) and Aboriginal Evaluation Workshop (May 2006)—were run by the CCRE to offer training in evaluation for people interested in conducting evaluations in Aboriginal communities and services. The first was in collaboration with the Australasian Evaluation Society and the Spencer Gulf Rural Health School. The twenty-five participants paid a fee, which covered the costs of venue hire, catering, and payment and travel and accommodation for the guest speakers.

The theme of the workshop was appropriate evaluation practice in Aboriginal communities, and examples were provided by Aboriginal and non-Aboriginal researchers working in partnership. The speakers stressed the importance of adhering to ethical principles and cultural protocols involving the essential ingredients of two-way understanding, reciprocity, sufficient time and mutual trust.

The second workshop was organised by the CCRE, AHCSA and the Primary Health Care Research, Evaluation and Development (PHCRED) Strategy.

Paul Aylward (then Tri-State-Wide Coordinator, PHCRED Program) and Alwin Chong (Senior Research and Ethics Project Officer, AHCSA) were the presenters of this half-day session; which had fifteen participants, primarily from the local Aboriginal health sector.

The workshop addressed several aspects of evaluation, especially in the Aboriginal context, including what is evaluation and why do it; goals, objectives and strategies; and considerations about who should conduct an evaluation. Different kinds of indicators and evaluation were explained, giving indication of where various approaches might be most effective. In the session there was a particular focus on looking at the different methodologies appropriate in Aboriginal communities, and considerations that people would need to be aware of in undertaking evaluation in Aboriginal contexts.

Participants in the workshop also had opportunity to engage in an activity constructing an evaluation framework.

Feedback from participants, overall, was very positive, with most people finding the content very useful. Some attendees felt that the session was a bit rushed, considering the amount of material covered at the workshop. People very much appreciated the opportunity to ask questions and discuss ideas.

CCRE hosts Participatory Action Researcher, April, 2006, at AHCSA, Norwood

In early April 2006, the CCRE hosted a visit by Ernie Stringer, a leading exponent of participatory action research, especially with Indigenous peoples. Mr Stringer led an engaging session with a group of students and others, and we shared lunch.

Some South Australians are familiar with Ernie's approach. In 2002 PLAHS was a key partner with the Royal Nursing District Service in a participatory action research project with Port Lincoln Aboriginal Elders about their experiences of living with diabetes. The project used the research approach of Mr Stringer. It produced the booklet *Look, Think, Act: Indigenous stories about living with diabetes*.



CCRE hosts Participatory Action Researcher, April 2006, at AHCSA, Norwood

This phrase, 'look, think, act', is central to the participatory action research method that Ernie Stringer advocates and practices. 'Look' refers to finding out information about the subject of interest, especially from the people most directly involved

Workshops and Forums (continued)

in that subject or issue. For Aboriginal health research, that means obtaining information from Aboriginal people. In the session at AHCSA, Mr Stringer demonstrated the method. He began by asking for comments from the Aboriginal people attending. Many made telling, insightful comments, a common theme being that when Aboriginal people are asked by governments and their agencies about an issue, they can give very thoughtful responses, but they are mostly ignored by those governments and agencies. Outside bodies collect information from, and about, Aboriginal people, but then make their own interpretations of that information.

The second stage involves thinking about and analysing the information gathered. This will likely produce suggestions or recommendations from discussing the information with the participants, and from working with them to identify priorities.

Then the third stage is most important, and distinctive, involving putting the information into action; working out what the people themselves can do with the information, how they can use the information to strive for something in their community.

Ernie Stringer made the important point that in his work with and for Aboriginal communities, where he uses his action research approach, he employs local Aboriginal 'mentors'. He consults these mentors extensively and works closely with them so that in a period of months they become the 'boss' of the work.



CCRE hosts Participatory Action Research, April 2006, at AHCSA, Norwood

CCRE Symposium, September, 2006, (Glenelg)

As a useful milestone activity for the CCRE at about the half-way point of its initial projected term, the CCRE convened a forum for key stakeholders of the CCRE to meet to discuss current research programmes, plans for future research and practicalities of conducting research in partner organisations. The gathering commenced with presentations from key participants in the CCRE—both researchers and the Aboriginal health services involved with the CCRE.



CCRE Symposium, September 2006

Summary of key points of discussion

The forum enabled a better appreciation of some of the critical factors that influenced the way research was carried out in communities. A shared appreciation of working constraints within community-controlled health services and universities was developed, with emphasis placed upon the serious shortage of qualified staff to carry on the core health service business and the perennial problems associated with the nature of funding arrangements for these services. Short-term and fragmented funding processes meant that longer-term strategies could not be developed for chronic illness management, for example. Where more secure funding is available, the problem of recruitment and retention of suitably qualified staff is still omnipresent.

As a consequence of these difficulties, it was suggested that the nature of CCRE research activities might be modified slightly in order for the CCRE team to lend more support to communities to accumulate, collate and document essential health outcome data that could be used directly to make a case for increases in resources in areas of need (e.g. chronic illness). In

Workshops and Forums (continued)

addition, it was thought that CCRE staff could work more closely with communities to build writing and funding submission skills to ensure that opportunities to secure new funding are not lost due to an inability to address funding submission criteria or to meet submission deadlines.

An overriding concern was the tendency for community-controlled health services to be forced to work more in the mainstream system and compete for mainstream funds to run their services. This creates a difficult bind for communities that might choose to increase their access to mainstream funding systems (e.g. competitive tenders, EPC item numbers for care planning) in that success in these fields could jeopardise their existing funding arrangements and threaten their autonomy and community control.

The difficulties associated with this tension notwithstanding, members agreed that in order for communities to become more independent and to run their own affairs their way, they needed to become more proactive in collecting data, presenting findings and using their research evidence to argue for and secure successful programmes and strategies for the future. Partners also thought that future research activities might include research into and documentation of some of the wider ideological aspects of Aboriginal health system operations in order to build awareness of these social, political and economic factors that determine the extent to which community health programmes are realistic and manageable.

Document concerns raised at Symposium

Following the September 2006 CCRE Symposium, the CCRE Translation Officer worked with the Aboriginal health services that attended the forum to document issues that impede and constrain the ability of these organisations to participate in and undertake research. One aim was to provide good information about some key issues that need to be addressed to enable these organisations to participate in a sustainable way in research activities, and to build their own research capacity.

The project was entitled 'An investigation into organisational factors affecting the participation in research and research capacity building in Aboriginal health organisations'. It involved conducting interviews with seventeen staff of Pika Wiya Health Service and PLAHS, and a Board member of PLAHS. These interviews were conducted on-site at Port Lincoln and Port Augusta. An analysis of the content of the interviews was undertaken to identify the most frequently raised key points in the summarising document for use in a conference paper to the Public Health Association of Australia conference in September 2007 in Alice Springs. Comments from the audience in that forum indicated that what was found to be the situation for the Aboriginal health services in this work was also the experience of others around the country.

In this work looking at factors hampering the capacity of Aboriginal health services to participate in research activities, issues that were identified ranged across central aspects of the operations of the Aboriginal health services and various matters to do with:

- staffing (several issues were raised);
- funding arrangements (including high demand on administrative processes, particularly reporting associated with funding agreements); and
- organisational capacity issues (including in relation to information technology).

Workshops and Forums (continued)

Appendix 2 of this report is a summary of the main issues raised in the interviews.

Introduction to Research in Aboriginal Health Services Workshop, December 2006 (Nunyara Wellbeing Centre, Whyalla)

This workshop was organised by the CCRE and led by the Training Officer Merridy Malin to introduce Aboriginal health service staff to formal research. About twenty people from four Aboriginal health services in the Eyre Peninsula area attended the day. Many staff were aware of research occurring at their organisations. A key message of the day was that the Aboriginal health services could influence the research undertaken.

The day's activities involved formal presentations about research for Aboriginal health organisations by Mr Jerry Moller, Professor Paddy Phillips and Dr Tina Jones. This was followed by a discussion and questions about the ideas raised. Many of the key issues about ethical and culturally appropriate research were explained and discussed.

Participants then broke up into five groups to identify a research question and think about the steps that would be involved in undertaking a project addressing that question.

The groups reconvened as one group to consider research method, in relation to one of the questions identified by the groups. It was emphasised that, in practice, determining a research question needs to involve those to be researched, and that researchers need to gain the respect of those being researched and thereby also gain validity.

From this workshop there was a common desire to organise a follow-up series, ideally at the different sites of the participants, especially to further develop the ideas of those who were able to attend.

Unfortunately, in 2007 several factors contributed to this being unviable. However, during 2007 the CCRE commenced the first delivery of a one-year, Certificate IV Indigenous Researcher Training course. Some of

the first group of students had attended this workshop, thereby extending in a substantial way their introduction to formal research. (See Chapter 5: 'Summary of main achievements' for more information on the course.)

As this is written, the CCRE is planning sessions about research with Aboriginal community health organisations in South Australia, in significant part to assist in developing the research agenda of these organisations and their capacity to participate in and determine that research. There is an important role for the South Australian Aboriginal community health sector's peak organisation to fill, in the future of research about the health of Aboriginal South Australians.

Action Research Conference (August 2007, Tavondi College)

The national Action Learning and Action Research Association conference, 'Moving Forward Together: Enhancing the wellbeing of people and communities through Action Research and Action Learning', held at Tavondi College in Port Adelaide brought a broad range of people from around Australia and some from New Zealand to showcase and discuss ways of working in partnership to address social issues such as land degradation, diabetes, alcohol and drug misuse, healthy lifestyles, and Aboriginal ways of researching and working. There were about ninety people in attendance and more than thirty presentations. Tavondi College students and staff made a significant contribution with catering, administration, reception and information technology support for the conference. The main sponsors for the conference, apart from Tavondi, were the University of South Australia, Flinders University, AHCSA (including CCRE sponsorships for Aboriginal presenters from the Northern Territory and west coast of South Australia), the CRCs for Desert Knowledge and Aboriginal Health, and Wilto Yerlo (the Aboriginal and Torres Strait Islander academic and student support program from Adelaide University).

The CCRE sponsored Allan Wilson and Jeremy Coaby, from PLAHS, to attend. They talked about the Look, Think, Act action research project, which involved PLAHS, Aboriginal Elders of the Port Lincoln community,

Workshops and Forums (continued)

CCRE-sponsored presenters: Allan Wilson and Jeremy Cooby from Port Lincoln who talked about the Look, Think, Act action research project.



Joanne Garngulkpuy and Dorothy Yungirringa from Galiwinku. The CCRE sponsored their presentation of The Yolngu Way of Doing Action Research.

with the project managed by Dr Susan Mann (Royal Nursing District Service Research Unit). (This project is briefly mentioned above in the section 'CCRE hosts Participatory Action Researcher, April 2006'.) The CCRE also sponsored Joanne Garngulkpuy and Dorothy Yungirringa from Galiwinku, Elcho Island, to do a presentation on The Yolngu Way of Doing Action Research. Garngulkpuy and Yungirringa spoke about Yolngu ways of conducting action research, which they have been developing over the past six years through their research centre, the Manggithinyaraw Yalu (hereafter Yalu for short). The name of the Yalu means nest or womb in the Yolngu Matha language. They explained how the Yalu evolved from a CRCAH sponsored project exploring the connections between education and health. The community concluded that Yolngu people's health had deteriorated since the arrival of the Europeans and that in order to improve it, they needed to revitalise some of the Indigenous foods and associated ceremonies, combined with promoting healthy living among their communities.

CCRE Planning Day (Living Kaurna Culture Centre, Warriparinga, March 2008)

As this CCRE entered its last calendar year of funding, it held a Planning Day in early March, at the Living Kaurna Cultural Centre (Warriparinga,

south of Adelaide near Flinders University and Marion Council). The Planning Day was well attended by key people from AHCSA and key researchers (Investigators) involved in the project.

The main object of the Planning Day was to consider the priorities for the CCRE in its remaining period, and to think about the future for AHCSA of the research, training and translation activities that have been hosted by AHCSA in the CCRE project.

Key researchers with the CCRE gave brief presentations about the progress of their work connected to the CCRE research agenda of developing culturally appropriate and clinically effective health service approaches for Aboriginal patients with long-term illnesses (chronic conditions), and CCRE staff gave brief presentations about progress of their projects.

Representatives from AHCSA, including the Chairperson, John Singer, Vice-Chairperson, Yvonne Buza and CEO, Mary Buckskin, and the Aboriginal health service partners to the CCRE project were given opportunity to reflect on and comment about the reports from the researchers and staff. They made some important and useful contributions for setting the future directions.

Workshops and Forums (continued)

Some main priorities that were identified during the day were to:

- a) offer bursaries and scholarships for Aboriginal research students; build and develop the capacity of health research for Aboriginal people in their communities;
- b) conduct high-quality research in chronic conditions, e.g. point-of-care project on Aboriginal health research focusing on chronic conditions (especially diabetes), the challenge being to ensure we can apply/adapt to other communities with different needs and challenges;
- c) build Aboriginal community capacity in health research and in managing health issues (including training of Aboriginal workers and community members);
- d) maintain dissemination of information to the Aboriginal community health sector, and develop more strategies for influencing policy through research transfer, translating and using research evidence to influence clinical practice and procedures, personal and community practices and health policy;
- e) expand the reach of the CCRE across the Aboriginal community health sector in South Australia beyond the three Aboriginal health services that have been connected with the CCRE since its start. This would include consulting with the wider Aboriginal community health sector in South Australia about research priorities, and informing them about the work of the CCRE.



CCRE Planning Day, Living Kaurna Cultural Centre, Warriparinga

Chapter 7 summarises the community projects that the CCRE planned and pursued, with a focus on management of chronic conditions.

Community Projects

Developing Chronic Illness Management for Aboriginal people

Recent developments in chronic illness management for Indigenous people have involved the uptake of structured patient-centred care planning and CCSM training programmes. Both of these key elements of chronic illness management have been modified in demonstration programmes in South Australia to suit the Aboriginal communities in which they are being provided.

The question of whether CCSM programmes can be implemented successfully in Indigenous Australian communities has been answered in part through the successful work carried out by the Sharing Health Care Chronic Disease Self-management initiative run between 2001 and 2004 in the Spencer Gulf region. Building on the initial successes of the Sharing Health Care CCSM program in the key sites, a key aim of this CCRE has been to detail the processes of refining the goal setting, care planning and CCSM training programmes and examining the clinical and health-related outcomes that can be achieved through a wider roll-out of these programmes in a range of Aboriginal communities.

The CCRE's research questions and study focus have been:

1. How can CCSM approaches be adapted successfully for application in a range of rural and remote Indigenous communities and what are the enablers and inhibitors of effective programmes?
2. What impacts do various components of the current chronic condition care (CCC) models have

on patient self-management knowledge, skill, health-related behaviour and overall wellbeing? Do these programmes contribute to improved health status for the populations concerned?

3. What specific aspects of the evolving CCC models are effective in which contexts in Indigenous communities?
4. How long can the effects of these programmes be sustained?
5. What are the costs and the benefits of CCC programmes as they currently exist?
6. In what ways are Aboriginal health services evolving to meet the emerging needs of patients with chronic and complex conditions?

CCRE Integrated Projects

The CCRE Integrated Projects were developed early in the life of the CCRE to build on the partners' previous and current research and service delivery around self-management of chronic conditions across a range of sites in the Spencer Gulf and Eyre Peninsula region to:

- compile baseline data from the Sharing Health Care SA project and develop a literature base in relation to CCSM in Indigenous communities (including overseas communities);
- document developments to date (a retrospective study of the introduction, impact and modification of the CCSM program beginning with the care planning models of COAG, the CCSM pilot program established in Port Lincoln and the ongoing CCSM project work conducted via Sharing Health Care SA);
- modify the standard CCSM course approach through extensive consultation and testing, including

Community Projects (continued)

the compilation of CCSM course evaluation data and patient satisfaction feedback;

- implement the newly developed model in a variety of settings;
- evaluate the impact of this evolving model both with and without the formal care planning processes that may precede it (i.e. EPC and Partners-in-Health [PIH] methods);
- publish and promote the modified and tested models in other communities.

Through the early period of the CCRE, consultations were conducted with the three regional Aboriginal health service partners of the CCRE about developing research work to support ongoing project work at those three sites in the Eyre Peninsula area (Ceduna, Pika Wiya and Port Lincoln) focusing on chronic disease management.

Following discussions with the three project sites involved, an integrated project was planned across these sites to involve:

- development of information technology systems to enhance research capacity in Ceduna;
- documentation of community engagement processes in Port Lincoln;
- refinement of the EPC and CCSM data management processes in Pika Wiya.

These projects were planned to develop the research capacity of the Aboriginal health services to enable them to be more able to continue participation in ongoing research and monitoring of their patient community with chronic conditions. Included as part of these activities was the formal training in research skills of Indigenous health service staff who were selected to work on the Integrated Project.

As it has happened, various factors have inhibited the implementation and realisation of the program outlined above. The experiences provide some important lessons for the project, and for the pursuit of similar programmes in other places and in the future. Some of the particular circumstances of each of the three sites are described in the individual sections below.

Pika Wiya Health Service – Effectiveness of Chronic Disease Self-Management Programmes

The CCRE Integrated Project at Pika Wiya aimed to inquire into processes involved in establishing an EPC patient goal-setting, care plan and self-management model in Pika Wiya and the level of knowledge and engagement of Aboriginal patients in these processes.

Pika Wiya Health Service has been involved in developing a number of CCC strategies including a self-management training program for Indigenous people and an integrated care planning approach funded through the Commonwealth EPC program. Leading into the formal care planning process are a number of 'community-based' assessments and goal-setting strategies designed to engage and empower patients to take increased control over and responsibility for the management of their chronic conditions. This project initially aimed to focus on identifying key enablers of patient engagement in these processes and documenting trends in health-related behaviour and health status for participating patients.

A number of projects pursued in Pika Wiya have been aimed at improving chronic illness management and developing systems that provide better access for patients to early assessment and identification of health risk and disease. This CCRE project complemented existing work in this area. Specifically, this work was designed to learn about the patient engagement process and to develop more functional health assessment, goal-setting and formal care planning procedures across the organisation. It may also link to other EPC initiatives currently being developed for Indigenous people through the Division of General Practice.

A twelve-month research project was run, in conjunction with existing care planning and CCSM strategies in place in Pika Wiya, to explore the successful elements of the model being used there and to inform further training and information technology development to support the efficient collection and reporting of patient data. The project involved:

Community Projects (continued)

- a qualitative survey of the enablers of patient engagement in the EPC process;
- development of local research capacity and skills;
- improved information technology systems to support the EPC process and formal funding avenues;
- further development of the LIFE self-management program;
- establishing baseline data for patients in the PIH EPC care planning process;
- use of this formative study in the development of more formal research proposals designed to test in more detail (multi-site longitudinal study) the benefits of CCSM programmes in Indigenous communities.

In undertaking the work, a young member of Pika Wiya staff, James Coulthard Stanley, was mentored by Angela Russell (based at Pika Wiya) and Peter Harvey (then Manager of the CCRE). The project was entitled 'The Effectiveness of Chronic Disease Self-Management Programmes in Aboriginal Communities in Rural South Australia'. (The following description is from James.)

The research intended to explore, in essence, the response of Aboriginal communities to the LIFE Chronic Disease Self-Management course, and to any other CCSM programmes, and how effective they were found to be.

The results collected were rather different to what was expected, but they still provide interesting discussion points and are indicative with regards to the Aboriginal community and the management of their chronic conditions.

The major finding was that community members who had a chronic illness felt that they were already managing it, yet wanted more education about their condition and limitations they may face; a major issue raised was that clients wanted to know more about the medications they were on, why they were on them and what they did. These findings contrasted with care plans and EPC items, which were found to be less-desirable than self-management, particularly

since many community members surveyed felt that they were already managing their illnesses. (Care plans may promote self-management, but the community indicated that learning self-management was more important than plans.)

A recommendation that was made was to seek further knowledge and input from the community as to what self-management of their illnesses means to them. As the research was running, a member of Pika Wiya's Shared Health team left; thus, the program was stopped.

After the project had been completed, James had the opportunity to do a presentation about this project at the Public Health Association Australia conference in Alice Springs in 2007 (with the CCRE Translation Officer). The presentation received positive feedback from the audience, who felt that they were in similar positions. James valued the chance to network with other Aboriginal organisations, as well as hearing about other similarly-themed research projects being undertaken, and he felt that the chance to meet and discuss issues with people from all across Australia was 'priceless'.

Ceduna / Koonibba Aboriginal Health Service – Enhanced data collection & Effectiveness of chronic illness management strategies

CKAHS has also been involved in aspects of CCC, care planning and self-management as part of its core business in patient care since the inception of the COAG trial in 1996. In more recent times, the organisation has trained a range of staff and community members as peer leaders to run chronic condition self-management programmes. Consequently, the CKAHS community now has patients with access to formal EPC care plans, health assessments and Care Plan reviews and, in the near future, patients will participate in a range of CCSM support programmes designed to build their knowledge and skills in the area of self-management.

The aim of the proposed CCRE Integrated Project was to train local Indigenous staff to collect and

Community Projects (continued)

enter complete data records into existing data systems and to develop a comprehensive data set for patients involved in the various aspects of structured CCC. The proposal sought to advance the CCRE objectives of building local staff capacity around research into CCC and producing good-quality patient profiles and clinical data that can be managed and reported as required to provide evidence of changing health status resulting from improvements being made to systems of CCC. In addition, the project offered the potential for CKAHS to report on the organisational changes and developments that have been achieved over time in relation to the provision of CCC and to measure the evolution of the organisation over time.

The proposed research had three main components:

- enhancement of staff training in effective data collection, entry and reporting processes that will support local CCC programmes;
- the development of high-quality patient data records, especially for patients involved in the range of chronic illness programmes and strategies deployed at CKAHS;
- the mapping and profiling of clinical data and other lifestyle outcomes resulting from patient participation in a suite of chronic illness management strategies.

The project aimed to achieve:

- development of local data collection and reporting capacity and refinement of data sets for focus patient groups;
- improved staff information technology skills needed to support the EPC process;
- further development and application of CCSM strategies in the community;
- documentation of stages in organisational change and development at CKAHS;
- establishment of sound baseline data for patients involved in EPC and CCSM;
- application of key CCC principles to wider research programmes.

As it turned out, it was not possible to progress the Integrated Project work planned for CKAHS. The reasons for this included staff turnover, loss of particular staff skills, and difficulties in recruiting suitably

experienced and qualified people able to take on the roles involved in this work or in diverting staff with appropriate capacities (fully occupied in clinical and other duties). At that time, it was also not possible to progress the planned learning centre, which would have assisted training needs.

Port Lincoln Aboriginal Health Service – Enablers and inhibitors for engaging PLAHS' Aboriginal clients in chronic condition care

PLAHS has been involved in the COAG coordinated care trial and subsequent CCSM and care planning initiatives since 1997 and is currently undergoing other Continuous Improvement (CIP) activities across a range of core business processes in the organisation.

Over this time and range of chronic condition management activities, various forms of data, patient and consumer information have been collected through routine data collection, clinical monitoring processes and participatory action research at PLAHS. The organisation was keen to examine the impact of patient participation in the various CCC activities in PLAHS through a formal research project carried out by local staff and supported by the CCRE. This proposed analysis of the enablers and inhibitors of patient involvement and participation in chronic illness management activities might also be linked (via CIP) to other sources of longitudinal data in PLAHS, which could be made available to the researchers to build more comprehensive information about successful aspects of organisational development.

Previous project plans and submissions for CCRE funding have highlighted:

- building local data compilation and analysis capacity to examine and report on clinical outcomes for patients involved in CCC programmes;
- extending the 'Elders' Group' participatory action research program to explore ways of improving patient engagement with, and uptake of, care planning and CCSM programmes;
- carrying out qualitative research into patient satisfaction with, and engagement in, a range

Community Projects (continued)

of community-led preventive health initiatives leading to a more comprehensive understanding of which strategies and approaches to integrated care in the community are more effective in engaging and retaining patient compliance and participation.

After considering the various options, available personnel and projects that might be likely to provide the most benefit to PLAHS in the current climate, PLAHS staff decided to pursue a locally led qualitative research project, supported by mentors from the CCRE, Spencer Gulf Rural Health School (based at the Whyalla campus of the University of South Australia) and Flinders University. The main objectives of the project were to:

- recruit a local Indigenous registered nurse to learn about and conduct qualitative research into patient participation in CCC programmes and, in the process, complete a formal qualification in qualitative research/evaluation methods;
- collect and analyse data, and report to the Board with key recommendations about successful CCC strategies in PLAHS;
- link this research to other clinical outcome data pertaining to CCC programmes.

The project began in late 2005 with a trainee researcher, who would work with other staff and mentors to design a community-based model designed to identify the most successful consumer engagement strategies in CCC in PLAHS. Key research questions were:

- what are the enablers and inhibitors to patient engagement and participation in CCC programmes in PLAHS?
- what programmes are successful and why, and what corroborating clinical data exists to support qualitative assessments of successful approaches to CCC?
- how can qualitative data be used to complement other clinical outcome measures in relation to the benefits of CCC programmes in PLAHS?

The project was designed to achieve the following objectives:

- training and retention of an Indigenous postgraduate researcher in systematic qualitative research techniques that complement ongoing CIP activities and other programmes such as the organisational evaluation program;
- documentation, publication and translation of the processes used and outcomes achieved in the project;
- building local capacity within PLAHS to conduct ongoing qualitative research across the organisation to inform the application of best practice in CCC.

From the project a local Aboriginal registered nurse, based at PLAHS, successfully completed a Graduate Certificate in Primary Health Care: Research and Evaluation at Flinders University, with additional support from the CCRE Training Officer and a non-Aboriginal PLAHS employee undertaking the study course at the same time. (PLAHS puts two employees through training programmes simultaneously, with the objective that they will support each other to successfully complete the study.) As part of her degree, she designed a research project to look at the enablers and inhibitors for engaging PLAHS' Aboriginal clients in CCC. However, this person's employment with PLAHS finished soon after, with the project work unable to be completed.



Chapter 8 outlines CCRE activities that are being continued into the future.

Sustainable Activities into the Future

Over the five years of the CCRE at AHCSA, the combined work of the Secretariat and CCRE Investigators (Chief and Associate) has developed several initiatives. Building on previous and existing work and projects, further research projects are underway, aligned training programmes have been developed, some have been delivered and there are plans for the delivery of others.

These various initiatives combine to develop the capacity of AHCSA to play an important role in developing approaches to managing chronic conditions, the long-term illnesses that affect many Aboriginal people. AHCSA can play an active and central role in approaches designed by Aboriginal people and professionals to be culturally appropriate for their people. This work will increase the research capacity of Aboriginal health organisations in relation to chronic conditions, and empower the community and develop the capacity for Aboriginal leadership in research of the health issues of their people.

In addition to the above work, the CCRE has developed, and has delivered for the first time, a Certificate IV in Indigenous Research Capacity Building, an Indigenous health research course.

Self-management training - (Living Improvements for Everyone or LIFE program)

AHCSA, building on recent work in EPC promotion, and workforce and health promotion programmes, is aiming to establish a chronic condition training coordination and support role within AHCSA, continuing AHCSA's

direct involvement in the research and project agenda of the CCRE into the future. The role facilitates the involvement of Aboriginal organisations and people in shaping the health services for Aboriginal people. AHCSA has had discussions with Commonwealth and State Departments of Health in pursuit of this aim.

If funds can be obtained, this activity would enable AHCSA to have direct input into, and influence over, the roll-out of CCSM training for Aboriginal people (the LIFE program and other chronic illness management interventions) and to oversee the coordination of a range of other chronic illness management strategies now being implemented at national and State level.

This training coordination and support role would complement the existing AHCSA training capacity (within its Registered Training Organisation, the Education and Training Team) and facilitate AHCSA to lead such training and program implementation across the State and subsequently promote the program at a national level. Because South Australia has key 'Master Trainers' in the Stanford CCSM and LIFE programmes in place already, the State is in a strong position to consolidate self-management training for Aboriginal people, and to promote this in conjunction with other programmes such as the Healthy for Life program and to potentially lead these initiatives nationally. The training coordination program would run initially for three years to enable the collection of robust longitudinal data across rural and metropolitan pilot sites in order to establish the efficacy and potential

Sustainable Activities into the Future (continued)

sustainability of the LIFE program. AHCSA and CCRE researchers are well placed to respond to new research required by the Aboriginal community, conduct ongoing research into the impacts of programs and continue to be instrumental in refining the successful elements of new approaches to the management of chronic health conditions in Indigenous communities.

Certificate IV in Indigenous Research Capacity Building

This course has been added to the AHCSA's Registered Training Organisation scope of courses it is registered to deliver, thereby providing for a sustainable continuation of delivery of this significant development in research training—a first in delivery of such a course in the VET system. It provides a pathway for Aboriginal people for research in the higher education sector and beyond.

AHCSA is seeking funding for a lecturer position so the course can continue to be delivered.

Part C, 'Learnings and Reflections', comprises Chapter 9, with comments on the project from many of the key participants—the Aboriginal health services, the Investigators (the mainly university-based researchers), and the CCRE's Training and Translation Officers. This chapter points to some key learnings from this CCRE.

Reflections on the project

There has been much learning from this project, for both AHCSA and the Aboriginal health services, and the university researchers. There are lessons in the various areas of focus of the CCRE Investigators, and in process and organisational issues involved in undertaking this project.

This final chapter includes some brief reflections on the CCRE project from some of the key people involved. First, some thoughts of the CEO of Pika Wiya are presented. Then there is a section incorporating several key points made by Investigators (the researchers with the CCRE) during a discussion in early 2008.

This chapter is not a thorough and systematic evaluation of the project; there are many significant points made that can inform other similar projects. Many of the points are consistent with, and reiterate, issues raised in research undertaken by the CCRE, in a project initiated after the CCRE forum convened at the mid-point of this overall CCRE project. In that forum it was reported, by key participants from the regional Aboriginal health services involved in the CCRE, that their organisations confronted various significant issues that impinged on the abilities of their organisations to engage in ongoing research projects. The project was entitled 'An investigation into organisational factors affecting the participation in research and research capacity building in Aboriginal health organisations'. Key points from that research are summarised in Appendix 2 of this report. These points are useful in considering the range of issues that need to be considered in planning and undertaking projects aiming to involve

organisations such as Aboriginal health services. Other issues are also pointed to in the comments below.

Interview with Cephias Stanley, CEO, Pika Wiya

The following information is taken from an interview with Cephias Stanley, the CEO of Pika Wiya, in December 2007, in which he reflected on how and why Pika Wiya became involved in the CCRE project. (Glenn Giles conducted the interview.)

How did you and your organisation become involved in the CCRE?

Mr Stanley referred back to the Sharing Health Care project and Pika Wiya's involvement, which helped Pika Wiya develop an interest in a more comprehensive patient management process. Some key people involved in that project were Peter Harvey, Kate Warren and Fiona Coulthard. Cephias also referred to Better Medication Management project work with Charlotte de Crespigny, Inge Kowanko and Helen Murray. At the time of the CCRE proposal development, some members of the AHCSA Board indicated they would like to be involved—Cephias was one of those people on the AHCSA Board.

Why did your organisation become involved, and what benefits could you see for Pika Wiya?

Cephias could see some benefits for Pika Wiya in the areas of research and staff training, with potential to improve Pika Wiya's delivery of services and the functioning of the organisation. He could also see the potential for Pika Wiya to develop a more effective ability to monitor its delivery of services and thereby be able to improve its

Reflections on the project (continued)

services for the community. He hoped that being involved in the project would result in more Pika Wiya staff being trained to do research, that at least some of these newly gained skills would be applicable in other aspects of their jobs, and that across the Pika Wiya staff there would be more understanding and general interest in research.

What would you say has been positive for your organisation from being involved with the CCRE?

Through 2006 the CCRE developed Integrated Projects at each of its partner regional Aboriginal health services. Each of these projects sought to look at 'factors affecting chronic disease self-management programmes in Aboriginal communities in rural South Australia'. At Pika Wiya this project initially involved two staff being engaged to undertake some research at Pika Wiya, focusing on Pika Wiya community's knowledge of chronic conditions. Unfortunately, funds only permitted one staff member to be engaged to work on this project. Through the project that person gained some useful direct experience in undertaking research, which was a good training experience.

That staff member was also given opportunity through the CCRE (via funding and mentoring support) to give a presentation to the Public Health Association of Australia Conference in September 2007 in Alice Springs on the work undertaken in the Integrated Project. (The presentation went very well, and also was a valuable development experience.)

Another direct positive for Pika Wiya from the CCRE is that from late 2007 two people from Pika Wiya, and two others from the Aboriginal community in Port Augusta, enrolled in, and commenced, the CCRE Indigenous Researcher Training course; they were in the first group given the opportunity to participate in this course. This will contribute to building the future research capacity of Pika Wiya and contribute more broadly to the Port Augusta Aboriginal community's capacity in, and understanding of, research.

From your perspective, what have been some of the barriers for the CCRE (that may have affected it achieving its goals)?

Processes associated with getting the CCRE operating took a bit longer than we hoped. For instance, in some instances the making of decisions by the CCRE Executive and Board had been drawn out. Also, securing staff for the CCRE was a somewhat protracted process. And the CCRE could be more flexible.

What have been some of the milestones for the CCRE?

Among the milestones of the CCRE, there has been, in the first place, the success of winning the tender process for AHCSA to host the Centre; the development (and now running) of the Indigenous Researcher Training Course; building up of relationships, partnerships and Memorandums of Understanding with other organisations (e.g. with Spencer Gulf Rural Health School, UniSA); the Integrated Project at Pika Wiya.

How do you view the collaborative approach to research (e.g. between Flinders and AHCSA)?

Good to have partnerships. But it would be good to include other universities, particularly other Aboriginal people in other universities (developing other research projects and initiatives).

Anything else you would like to mention?

Very happy that AHCSA won the hosting of the CCRE, and hope that it is possible to continue to the Centre beyond its original funding.

Reflections on the CCRE Integrated Projects

As described in Chapter 7: 'Community projects', the CCRE devised three Integrated Projects to be conducted at the three Aboriginal health organisations that were part of the initial proposal. From the various experiences of pursuing these CCRE Integrated Projects, many significant points are indicated about some important difficulties and constraints faced by Aboriginal health organisations aiming to participate in ongoing research projects and activities.

The proposed project at the most remote of the three sites was unable to commence, significantly because of delays in the development of a learning centre, with which the project was integrally connected.

Reflections on the project (continued)

Another contributing factor was the relatively high turnover of staff, especially those with longer experience, thereby reducing the capacity of the organisation's staff to participate in research-related tasks, leaving aside for a moment issues about the ability of the organisation to divert staff away from other existing duties within the organisation.

In another of the CCRE projects, at a different organisation, two employees completed a Graduate Certificate in Research and Evaluation. The plan was for one of the staff, a local Aboriginal nurse, to conduct research with local people into patient participation in CCC, putting into practice learning from the completed Graduate Certificate. Unfortunately, the person conducting the research project changed employment prior to completing the project, and was not able to be replaced. In part this also points to the shortage of appropriately experienced and qualified staff able to undertake research tasks and projects.

The third project was successfully completed. Although not as much local support was achieved as planned, a significant level of support was able to be provided.

It appears from these experiences that projects like those pursued by the CCRE Integrated Projects need ongoing local support to be taken into account, among the range of significant practical considerations that have to be addressed to enable successful conclusion of such projects.

Reflections from CCRE Investigators

The following points were made by a number of the CCRE Investigators (researchers) at a group discussion in early 2008 in which they reflected on their experiences and key lessons with the CCRE. Some of the questions used to start the discussion referred to: how and why they became involved in the project; what were the most important aspects of participating in the project; what were some of the barriers to progressing the project, and what were some of its key milestones. The resulting discussion brought out some important insights about processes

involved in such a collaborative project between Aboriginal and non-Aboriginal organisations and individuals. Here we present just a brief overview of the points made. Many of the points made are similar to those made by Cephas Stanley above.

- This CCRE has found it difficult to attract suitably experienced and qualified Aboriginal people to staff the CCRE, pointing to the major need for training more Aboriginal people in research skills and giving more Aboriginal people appropriately supported experience in undertaking research projects. This is inevitably a longer-term project that needs continued programmes and funding. If the appropriate supports can be maintained, more Aboriginal people will occupy higher-level positions, particularly in research-related areas (capacity building has been a major focus of this CCRE project).
- Building, and maintaining, relationships and trust are paramount and must be valued and emphasised.
- Unfortunately, the project has not expanded as much as was hoped to reach and establish projects with other Aboriginal health organisations across regions of the State not involved in the initial group of Aboriginal health organisations associated with the project submission. However, building on the work of this CCRE, AHCSA has good prospects to be able to extend the reach of key elements of the CCRE research agenda.
- Research processes and designs need to incorporate more input from people at the Aboriginal health service and community levels. This is a central plank of the Indigenous research reform agenda that the CCRE has been following. However, it also requires Aboriginal health services to develop research as core business, which in turn means appropriate resource allocation and capacity development.
- More resources are needed to work with and support Aboriginal health services and communities for research findings to be followed through in a timely fashion and sustained so as to not lose the important gains or 'go backwards'.
- There are major systems impediments to progressing health research in Aboriginal

Reflections on the project (continued)

communities; for example, the enormous amount of time taken up in seeking funds, administering funds and reporting on short-term funding programmes, and the fact that funding is so piecemeal and uncoordinated and that resources are consumed in pursuing endless funding rounds—placing stress on already stressed communities and groups and failing to make concerted, effective advances. University researchers also face similar constraints due to their own usually short-term contracts, other project and academic responsibilities, etc.—note that all time spent by the university-based investigators on CCRE work is ‘in kind’, over and above their job descriptions.

- Recognising different priorities and responsibilities of university-based researchers and Aboriginal health organisations, often resulting from the fact that Aboriginal health organisations are commonly over-stretched. These pressures on the Aboriginal health organisations have been especially high in the context of the past few years where many Aboriginal community organisations and services were seriously undermined and even closed. One result of this has been that Aboriginal health organisations increasingly came to be seen by local Aboriginal communities as the place to go to seek assistance with a range of issues and problems that had previously been dealt with elsewhere (to the extent they were addressed).

One of the Investigators, Dr Mark Shephard, was unable to attend the discussion that produced the above points. He provided the following reflections on his work that was part of, and supported by, the CCRE. His Community Point-of-Care Services unit became involved in the CCRE through a partnership he developed with PLAHS from 2001, resulting from a mutual interest in the use of POCT for both risk assessment and management of chronic disease. Dr Shephard wanted to build the capacity of Aboriginal health professionals to become POCT Operators, and he wanted to transfer to the PLAHS health team the skill set and knowledge base required to set up and manage a sustainable, culturally and clinically effective POCT service. In doing so, POCT has provided the opportunity for PLAHS to take greater ownership

and control of diabetes management and to provide a more convenient, accessible and user-friendly service to diabetes clients in relation to pathology testing. PLAHS, originally a pioneer in this field, has now become a well-recognised centre of excellence for POCT in Australia. A key aim of this joint program was to demonstrate the ability of POCT to assist in improving diabetes control in clients with this debilitating condition.

Support from the CCRE has assisted the continuation of Dr Shephard’s POCT work at PLAHS. Too many good health projects never have the opportunity to be sustained over a period of many years, but through the support and guidance of the CCRE, this POCT model has been able to demonstrate its effectiveness and longevity.

From Dr Shephard’s perspective, the CCRE project has worked extremely well through a strong sense of long-term mutual trust and respect that has been built between his Community Point-of-Care Services unit staff members and the PLAHS health team. Tony Burgoyne (initially an Aboriginal health professional at PLAHS and now a qualified diabetes educator who received a CCRE scholarship to study for this qualification) has been inspirational in the way he has embraced his role as principal POCT Operator and worked diligently to ensure all POCT monitoring of clients with diabetes has been conducted to the highest quality and on schedule. The program has also had excellent clinical governance from Dr David Mills over a number of years (until his recent move to Adelaide) and strong managerial support from Angela Dufek as Manager of Health Programmes at PLAHS. The support of the (former) Director Jackie Ah Kit and the Board of PLAHS, together with the willingness of community members with diabetes to utilise the POCT service available, has also ensured continued success. There have been very few barriers encountered along the journey.

Education and training activities

Learnings from research course

An important learning for the Education and Training program was that Aboriginal health services in South Australia wanted resident Aboriginal researchers

Reflections on the project (continued)

within each service who were able to:

- assess the quality, relevance and potential benefit of external research submissions;
- communicate research evidence in plain language to health practitioners;
- write tender submissions and attract research activity to the centres.

There was no accredited research course appropriate for Aboriginal health workers available nationally within the VET sector until the Diploma and Certificate IV level course in Indigenous Research Capacity Building received accreditation in 2006.

The facilitators of this research course learned a great deal from its pilot. These learnings included issues specific to the teaching of the course, such as what topics needed more emphasis or clearer explanations, ways to improve the delivery of the computing components and better strategies for facilitating class cohesion. Because most of the facilitators and presenters come from university teaching backgrounds, some had a lot to learn about genuinely interactive teaching and learning and also how to ensure that the course remained relevant to people's actual work situations. The full-time facilitator is a non-Aboriginal person, and although there were several Aboriginal researchers who presented in the four workshops, we believe it would be beneficial if, in the future, an Aboriginal person co-facilitated throughout all the workshops. This would make teaching the course a genuine intercultural partnership.

The students approached the course with a great deal of interest and commitment, and although some changed their topics during the course, by the end they had each settled upon an achievable, practical evaluation or investigative project that was of particular relevance and interest to them. The inaugural graduates, with assistance from AHCSA, are planning to establish a register of Aboriginal researcher/evaluators available to contribute to research being conducted in their particular regions in an advisory or assistant capacity. They will also become part of a national network of Aboriginal

researchers established in a partnership between AHCSA, the CRCAH and other research institutes.

Learnings from the scholarship and bursaries program

Aboriginal people enthusiastically engaged with the CCRE's scholarship and bursaries program. For many people, this financial support enabled them to pursue further study, which they would otherwise have been unable to do. For some, it became the major catalyst motivating them to take up study.

It also became apparent that in order to retain students in the university system, there was the need for a strong advocate to inform university faculties of the kinds of barriers that the Aboriginal students encountered and the flexibility that was required to assist them to overcome those barriers. In order to reduce the disproportionate burden on Aboriginal students, we found that the following principles need to be included in faculty policy and then enforced by staff:

- keeping communication channels between the lecturer and the student open in order for the student's situation to be understood in an ongoing way;
- keeping assignment deadlines flexible, so that they can be extended in extenuating circumstances;
- providing students with explicit and constructive assignment feedback in writing so students are able to learn from the strengths and weaknesses of each piece of work;
- providing students with the opportunity to improve on their first submission of work in response to the lecturer's feedback.

The university-based foundation courses run between 2005 and 2007 consistently provided inadequate support to our Aboriginal scholarship students who were ineligible for additional tutorial support due to changed AbStudy regulations. We subsequently enrolled these students in courses run by Equals International, (a private Registered Training Organisation) which tailored courses to the students' needs.

*Reflections on the project (continued)***Learnings from the research and evaluation workshops offered at the community level**

There is a need to continue running research and evaluation workshops that are tailored to the specific interests and needs of Aboriginal people. Also, workshops are needed to inform outside researchers of the appropriate protocols for conducting research in Aboriginal communities. Aboriginal health services in South Australia have asked us to run workshops whereby each service can decide upon their immediate research priorities.

Translation activities

A key focus of this CCRE's translation activities was to convey information to the Aboriginal community about chronic condition management strategies and related issues, particularly those being developed by CCRE Investigators. The production of a poster and associated brochure, providing a range of information about such strategies and other services accessible at a local Aboriginal health service, was a key CCRE initiative in this effort. It is evident that it is desirable to have a multi-pronged and well-organised approach that includes effective verbal interaction with, and presentation to, Aboriginal community people directly. Time is needed to build relationships to achieve engagement with the people, along with appropriate sensitivity to the cultures of different Aboriginal peoples.

The agenda of research translation and transfer is a large one, potentially informing many areas and levels of activity. In brief, in relation to health research this can range from clinical practices and organisational arrangements, to implications for workforce training; to the setting of broader health sector policies at regional, State and federal levels. To maximise the impact of research, it is desirable to develop coordinated plans addressing the many possible sites for the utilisation of strong and relevant research findings.

Workforce development programmes related to CCRE work have been developed and delivered through onsite training, other training, and provision of evidence-based resources for practice in relation to, for example:

- alcohol and other drug education;
- mental health, alcohol and other drug co-morbidity;
- safe medication management in community settings;
- emergency mental health and other drugs;
- provision of, and training in, the Alcohol Treatment Guidelines for Indigenous Australians package;
- provision of the Alcohol, Tobacco and Other Drug Clinical Guidelines for Nurses and Midwives package;
- provision of relevant community education, referral and health promotional resources.

Conclusion

The CCRE, in its short life as a research innovation in Aboriginal health, has developed new programmes in chronic condition management and made a major contribution to building the capacity of and empowering Aboriginal people to design, manage and own their own health research programmes. Pathways have been developed for a range of Aboriginal health professionals to learn about and conduct relevant and culturally appropriate research and to pursue formal qualifications in their chosen fields.

In addition to those students who have graduated or who will graduate shortly, the research education program that has been developed, if sustained, will provide a pathway for future groups of Aboriginal health professionals to enter higher education and to help their communities take more control of their research programmes and larger research agendas in health and community development. It is envisaged that the Education and Training Team within AHCSA will continue this training program in South Australia and pave the way for more graduates to enter higher education and formal research programmes in collaboration with other organisations, universities and health services.

As this process becomes embedded in the culture of AHCSA and in the professional development processes of Aboriginal communities, a growing involvement in research programmes will serve to inform the development of more effective health services in communities and to support improved health status and health outcomes for Aboriginal people.

Reflections on the project (continued)

Levels of accountability are increasing across the health system today and Aboriginal health services, like all health care systems, will be advantaged in the future if they are able to produce reliable and robust data on the outcomes and benefits of the programmes they offer. Indeed, their potential to attract new funding or to expand their operations will be advanced by their ability to structure systems of care through which patient records are well maintained in order for health services to extract reliable data on utilisation patterns and clinical outcomes, which can be used to evaluate health care programmes and provide new directions of health service management.

The research training program developed by the CCRE will ensure that individuals and communities are supported and resourced and have the necessary human capital to create and manage complex data systems, the output of which can be used to underpin successful and sustainable business models and operations. Further, we hope that in the near future the number of graduate and postgraduate Aboriginal research students emerging from the university sector will increase markedly, bringing with it a higher profile of Aboriginal managers, researchers and community leaders to take control of and direct the health initiatives that will be required to assist, improve and sustain the wellbeing of Aboriginal people into the future.

To realise the potential of enhancing the capacities of Aboriginal communities and health organisations, it is essential that education and training programmes such as those of the CCRE are supported in the longer term and further developed through thoughtful and thorough evaluation so as to achieve sustainable development of research and organisational capacities.

Appendix 1

Part D has four appendices:

- a vision for the future of the CCRE work;
- a summary of important issues affecting the ability of Aboriginal health organisations to sustain participation in health research projects, including in an ongoing way;
- lists of CCRE Investigator-published papers and conference presentations;
- a reference list;
- and a list of CCRE Scholarship and Bursary recipients.

Vision and scope for the future – CCRE beyond 2008

Key Activity Area	Components	Expected Outcomes
Research	<ul style="list-style-type: none"> • AHCSA maintains active research programmes in South Australian communities • collaborative research maintained in partner communities and elsewhere via new projects • CCSM training capacity within AHCSA 	<ul style="list-style-type: none"> • research programmes linked to activities in all partner communities and research used to support funding bids and program implementation • CCM research maintained and expanded via new project funding • AHCSA to establish CCSM training and mentoring for metro and rural services as core business • AHCSA to obtain funds for a research coordinator to drive ongoing research and development in partnership with its constituent organisations, Flinders researchers and others. • AHCSA to enquire into the research priorities of its constituent organisations (an AHREC role?), and broker research development in these areas with Flinders researchers and others
Research training	<ul style="list-style-type: none"> • Certificate IV course sustained via AHCSA Education and Training Team • student mentoring and scholarship program continued 	<ul style="list-style-type: none"> • fund new lecturer position at AHCSA to run the research course • regular cohorts run through AHCSA Education and Training • funds managed via collaborative research grants for students and research assistants • Income from this training will be re-invested in the sector
Translation	<ul style="list-style-type: none"> • AHCSA maintains translation component as core activity in collaboration with other health promotion functions • research forums coordinated via AHCSA staff 	<ul style="list-style-type: none"> • research program feedback and program information to all partner communities • greater emphasis on face to face translation of health health-related research and program information facilitated via AHCSA
Central data management	<ul style="list-style-type: none"> • AHCSA to establish a central data compilation and outcome reporting capacity to assist health services to harness and report on their health status 	<ul style="list-style-type: none"> • AHCSA to establish a central data compilation and outcome reporting capacity to assist health services to harness and report on their health status • services to use data capacity to win increased funding for appropriate programmes (e.g. chronic illness, prevention, health checks and funding care planning)

Appendix 2

Factors affecting capacity of Aboriginal health organisations to undertake and participate in research—Summary of main points

The summary below is from seventeen interviews with allied health professionals in Aboriginal health services in regional South Australia, conducted by the Translation Officer from March until June 2007 for the project 'An investigation into organisational factors affecting the participation in research and research capacity building in Aboriginal health organisations'. Employees in a range of areas, from clinical and administrative to project work and health promotion-related work, were interviewed, mostly individually, but some in a group. They were asked to comment about factors affecting the ability of Aboriginal health organisations to undertake and participate in research. In this overview, the issues identified by those interviewed are grouped together.

The people interviewed drew on their experiences in their workplaces. The points below were invariably made by several people interviewed; most of those interviewed were not aware of what other people had said in their interviews.

It should also be noted that one of the Aboriginal health services involved in the project identified that at that time it had nearly fifty separate lines of funding, from a range of sources, with a variety of reporting requirements. (This was the normal funding situation of the organisation.) This number of funding arrangements represents a significant administrative load on a relatively small organisation. It places a major burden on the ongoing operation of Aboriginal health services, and other Aboriginal organisations.

This administrative burden on these organisations has received some increased attention in recent times, including from a 2006 Morgan Disney 'A Red Tape Evaluation in Selected Indigenous Communities' report to the Federal Government calling for major change to the system of administration of Aboriginal affairs, for instance to cut the time and efforts wasted by Aboriginal communities and organisations in having

to apply for grants, even for continuing programmes. Also during this period, the Secretary of the Commonwealth Department of Treasury, Dr Ken Henry, pointed to the 'red tape burden' (Henry 2006) weighing down Aboriginal communities and organisations, arguing that changing this situation needs to be a national priority.

The operational environments for Aboriginal health services (and Aboriginal organisations and communities more generally) need to be changed to make their continued operation more sustainable, including in their capacity to engage in research.

Aboriginal health organisations are critical to the delivery of health services to many Aboriginal people—for many, Aboriginal health services are their principal health service. (They can deliver services in the most culturally appropriate ways, thereby engaging with Aboriginal patients more effectively, opening up potential for the best results for people's health status.) It is essential that these organisations are assisted to become as effective as possible. Road blocks to this achievement have to be clearly analysed, and more effective ways (many are already known) of achieving results need to be put into policy and implemented.

What follows is a brief summary of the issues raised in the interviews conducted with Aboriginal health services personnel in the first half of 2007. This summary indicates the kind of issues that need to be dealt with.

Issues related to staff:

- **Staff shortages, need for backfill staff:**
'Staff shortages; there is no one to backfill and go out and do research. That is one of the problems'; 'There needs to be funding for back up staff'.
- **Often staff are absent due to illness.**
- **Burn out from overwork:**
We are fighting to get casuals but it is very hard. ... I am getting burnt out.'
- **Staff doing more than their job descriptions:**
'Many times people doing more than what their job statement says and there isn't actually the funding for these other jobs that need to be done that are not specifically funded'.

Appendix 2

- **Can't take on more tasks, including research:** 'A lot of other staff are really bogged down with their current workloads, as well as other things within the organisation.'
- **Issues re training staff:** limited number of Aboriginal people with levels of experience for research work.
- **Lack of funding for support people,** with a qualified person being alongside a 'trainee' to train them up.

Funding issues

- **Fund research work and projects. Need specific funding for research work.**
Should not assume that it is easily within the capacity of staff to add on research tasks; time on research task needs to be funded.
- **Specific, dedicated research person**
- **Inadequate funding all the time:**
government will direct just enough money to you for another year, and then, of course, at the end of the year you fail; ...they're setting us up to fail every time. 'Well, I just think that there is not enough staff...and there's obviously not enough funding'.
- **Services being provided to meet community needs but which aren't specifically funded.**
- **Health services not addressing fundamental problems, particularly grief and loss (responding to crises).**
- **High administrative burden in relation to the numerous funding streams:**
'Aboriginal organisations are subject to much more interrogation of their activities and performance than other organisations; which leads to the next factor, of high administrative load for relatively small organisations to cope with in legitimising/accounting for/acquitting their expenditure.'
- **Funding needs to be longer-term;**
short-term funding arrangements and numerous (simultaneous) sources of funds mean very large administrative work-load: 'But not just say, well the money is there for two or three years or whatever, because it just doesn't work, and it makes a lot of work for us, because you've got to start a project,

you've got to apply for it and make the submission for it, there's all the evidence to go with it, then you've got the reporting at the end of it. And while you're trying to report on that, you're then generating new submissions to try to get new money, and so they don't give us enough administrative capacity or funding to be able to do that.'

- **Change to tri-annual funding.**
Changes in requirements of Office for Aboriginal and Torres Strait Islander Health are positive in one way, but in another there is no gain because of the need to produce plans etc. for different projects (with separate funding streams).

Wider context of Aboriginal health/medical services

- **Aboriginal health services becoming the centre** for community people to seek help with problems they are encountering, as other avenues are closed (adds to demands on organisation, which does things not funded for).
- **The particular social circumstances of Aboriginal health services are not recognised** (e.g. very significant change in demand on service as result of other government policies, Port Augusta dialysis increase to service APY Lands people).
The extra calls made on Aboriginal health services from their community of clients, for emergency assistance on a range of matters from immediate housing need to attending family and community 'sorry business', related to frequent grieving of people (Aboriginal mortality rates being about three times higher than for other Australians).
- **Time to undertake projects properly is not appreciated,** or factored in by funding bodies. They just want statistics etc.: e.g. also, what is involved in some activities (is funded, like PATS Patient Assistance Transport Scheme for country patients and approved escorts) is not appreciated by the funders—in this sort of activity an Aboriginal health service is likely to do a lot more associated back-up organisation for a 'client' than mainstream organisations would do, and response of funders is that if you wish to do it that way, that's your choice, but this is the way it needs to be done to be culturally appropriate.

Appendix 2

Issues about research

Not surprisingly, in these interviews that asked about the research capacity of health services, a theme mentioned by many was the issue of who should be involved in doing health research of Aboriginal people. There is a high level of support for local Aboriginal control over this research and the doing of the research, and a belief that this is necessary to produce research that is more relevant to the people being researched.

- **Research not informing practice** (findings not acted upon): ‘The major problem is the research not being acted upon, the findings not being acted upon’; ‘Health checks are great—but they’re revealing various problems and issues which the Aboriginal health service is not set up, or funded, to deal with’.
- **What happens to research when it is done; community doesn’t see any results, etc.**: ‘These people [external researchers] come and go and ask us questions but nothing ever happens’; external researchers don’t provide feedback to communities.
- **Time to undertake projects properly**—not understood or factored in by funding bodies. They just want statistics etc.
- **Who does the research**: ‘I don’t think a white man can fully comprehend where an Aboriginal is coming from, or whether that Aboriginal person will open up to a white person’; Aboriginal health workers should be supported to do research in the area in which they have experience, as they are in a very good position to conduct the work with community people; ‘A lot of times people come into our community, they do research and take it away with them, it doesn’t belong to us. Whereas if we can train our people, then it is ownership, it belongs to the community, to part of the community through that person that is doing it.’

Appendix 3: CCRE Investigator – Publications

- Ah Kit, J., Prideaux, C., Harvey, P., Collins, J., Battersby, M., Mills, D. & Dansie, S. 2003, 'Chronic Disease Self-management in Aboriginal Communities: Towards a sustainable program of care in rural communities', *Australian Journal of Primary Health* (Special Issue: The Management of Chronic Disease in Primary Care Settings), vol. 9 no. 2–3, pp. 168–76.
- Battersby, M. W. 2001, *Identifying and Recommending Assessment Instruments for the Coordinated Care Trials (2nd Round)—Amended final report submitted to the Commonwealth Department of Health and Aged Care, Coordinated Care Branch, Coordinated Care Training Unit, Adelaide.*
- Battersby, M. W., McDonald, P., Pearce, R., Tolchard, B. & Allen, K. 2001, 'The Changing Attitudes of Health Professionals and Consumers Towards a Coordinated Care Trial—SA HealthPlus', *Australian Health Review*, vol. 24, no. 2, pp. 172–8.
- Battersby, M. W., Ask, A., Reece, M., Markwick, M. & Collins, J. 2003, 'The Partners in Health Scale: The development and psychometric properties of a generic assessment scale for chronic condition self-management', *Australian Journal of Primary Health* (Special Issue: The Management of Chronic Disease in Primary Care Settings), vol. 9, no. 2–3, pp. 41–52.
- Battersby, M. W. 2004, *Report on the Indiana and New York Collaboratives for the South Australian Department of Human Services*, Harkness Research Fellow, Flinders Human Behaviour and Health Research Unit. Adelaide
- Battersby, M. W. 2004, 'Community Models of Mental Care Warrant More Governmental Support', *British Medical Journal*, vol. 329, no. 7475, pp. 1140–1.
- Battersby, M. W. 2005, 'Health Reform Through Coordinated Care: SA HealthPlus', *British Medical Journal*, vol. 330, no. 7492, pp. 662–5.
- Battersby, M. W., Pols, R., Markwick, M., Lawrence, J. & Williams, A. S. 2005, *The Flinders Model of Chronic Condition Self-Management*, Flinders University, Adelaide, viewed 8 June 2005, <<http://som.flinders.edu.au/FUSA/CCTU/Hand%20out%20Flinders%20Model%20May%2005.pdf>>
- Battersby, M. W., Williams, A. S., Lawrence, J. & Markwick, M. 2005, *Evaluation of the Aggregated Data of the Flinders Human Behaviour & Health Research Unit Chronic Condition Self-Management Training Workshops*, prepared for the Australian Government Department of Health and Ageing, Flinders Human Behaviour & Health Research Unit, Adelaide.
- Battersby, M. W. 2006, 'A Risk Worth Taking', *Chronic illness*, vol. 2, no. 4, pp. 265–9.
- Battersby, M. W., Harvey, P. W., Mills, P. D., Kalucy, E., Pols, R. G., Frith, P. A., McDonald, P. J., Esterman, A., Tsourtos, G., Donato, R., Pearce, R. D. & McGowan, C. H. 2007, 'A Controlled Trial of a Statewide Application of a Generic Model of Chronic Illness Care', *Milbank Quarterly*, vol. 85, no. 1, pp. 37–67.
- Battersby, M. W., Ah Kit, J., Prideaux, C., Harvey, P. W., Collins, J. P. & Mills, P. D., in submission, 'Implementing the Flinders Model of Self-Management Support for People with Diabetes in Aboriginal Communities: A pilot study', *Health Promotion Journal of Australia*.
- Cerro, N., Zeunert, S., Boesch, L., Duff, M., Shephard, M., Jureidini, K. & Braun, J. 2002, 'Nutrition Project in a Remote Australian Aboriginal Community', *Journal of Renal Nutrition*, no. 12, pp. 102–6.
- de Crespigny, C. 2002, 'Double Jeopardy: Disadvantage and drug problems', *Australian Journal of Primary Health*, vol. 8, no. 1, pp. 70–6.
- de Crespigny, C., de Bellis, A., Cruse, S., Kowanko, I., Murray, H., Parfoot, W., Turner, M. & Wilson, S. 2002, *Better Medication Management for People with Mental Health Disorders, their Carers. Report of the pilot study*, March edn, Flinders University, Adelaide, <<http://nursing.flinders.edu.au/learningcommunity/reports/QUMEP%20Adelaide%20Metro%203July03.pdf>>.
- de Crespigny, C., Emden, C., Drage, B., Hobby, C. & Smith, S. 2002, 'Missed Opportunities in the Field: Caring for clients with co-morbidity problems', *Collegian*, vol. 9, no. 3, pp. 29–34.
- de Crespigny, C., Kowanko, I., Emden, C. & Murray, H. 2003, *Better Medication Management for Aboriginal People with Mental Health Disorders and their Carers—Report of research conducted in Coober Pedy*,

Appendix 3: CCRE Investigator – Publications

- June edn, Inprint Design, Bedford Park, viewed 15, August, 2008 <<http://nursing.flinders.edu.au/research/reports/QUMEP%20Cooper%20Pedy%20Booklet.pdf>>.
- de Crespigny, C., Emden, C., Kowanko, I. & Murray, H. 2004, 'A Partnership Model for Ethical Indigenous Research', *Collegian*, vol. 11, no. 4, pp. 7–13.
- de Crespigny, C., Kowanko, I., Murray, H. & Emden, C. 2004, 'Implementing Research Outcomes for Better Medication Management for Aboriginal People', *Aboriginal and Islander Health Worker Journal*, vol. 24, no. 4, pp. 14–17.
- de Crespigny, C., Kowanko, I., Murray, H., Emden, C., Wilson, S. 2005, 'Improving Indigenous health through better medication management: an overview', *Australian Journal of Primary Health*, vol. 11, no. 1, pp. 17–23.
- de Crespigny, C., Kowanko, I., Murray, H., Wilson, S., Ki, J. & Mills, P. D. 2006, 'A Nursing Partnership for Better Outcomes in Aboriginal Mental Health, Including Substance Use', *Contemporary Nurse*, vol. 22, no. 2, pp. 275–87.
- Ellis, R., Bottroff, V., Kowanko, I. & Hodgson, V. 2008, *Developing Training Pathways To Meet the Needs of Aboriginal People with Disabilities. Final report*, Flinders University and Disability South Australia, Adelaide, SA, ISBN 978-0-646-48913-1.
- Emden, C., Kowanko, I., de Crespigny, C. & Murray, H. 2005, 'Better Medication Management for Indigenous Australians: Findings from the field', *Australian Journal of Primary Health*, vol. 11, no. 1, pp. 80–90.
- Fuller, J., Harvey, P. W. & Misan, G. 2004, 'Is Client-centred Care Planning for Chronic Disease Sustainable? Experience from rural South Australia', *Health & Social Care in the Community*, vol. 12, no. 4, pp. 318–26.
- Giles, G., Malin, M. & Harvey, P. W. 2006, 'The Centre of Clinical Research Excellence (CCRE) in Aboriginal and Torres Strait Islander Health—An operational rationale and summary of early achievements', *Australian Journal of Primary Health*, vol. 12, no. 2, pp. 97–104.
- Harvey, P. W. 2003, 'Managing Health Care in Australia: Steps on the health care roundabout?', *Australian Journal of Primary Health* (Special Issue: The Management of Chronic Disease in Primary Care Settings), vol. 9, no. 2–3, pp. 105–8.
- Harvey, P. W. & McDonald, P. 2003, 'The Science of the COAG Coordinated Care Trials', *Australian Journal of Primary Health* (Special Issue: The Management of Chronic Disease in Primary Care Settings), vol. 9, no. 2–3, pp. 109–13.
- Harvey, P. W., Mills, P. D., Misan, G. & Warren, K. 2003, 'Small-scale Rural Pilot Programs in Chronic Illness Management—What next?', *Australian Journal of Primary Health* (Special Issue: The Management of Chronic Disease in Primary Care Settings), vol. 9, no. 2–3, pp. 114–17.
- Harvey, P. W. 2004, 'Relationship between Continuity of Care and Diabetes Control; Evidence from the Third National Health and Nutrition Examination Survey' Mainous, AG et al - a commentary', *Evidence Based Health Care*, vol. 8, no. 4, pp. 192–4.
- Harvey, P. W. 2005, 'Approaches to Population Health Care—The emerging context!', *Australian Journal of Primary Health*, vol. 11, no. 2, pp. 45–53.
- Harvey, P. W. 2006, 'Social Determinants of Health—Why we continue to ignore these factors in the search for improved population health outcomes', *Australian Health Review*, vol. 30, no. 4, pp. 419–23.
- Harvey, P. W. & Docherty, B. 2007, 'Sisyphus and Chronic Disease Self-management: Health care and the self-management paradox', *Australian Health Review*, vol. 31, no. 2, pp. 184–92.
- Harvey, P. W., Petkov, J., Misan, G., Warren, K., Fuller, J., Battersby, M. W., et al. 2008, 'Self-management Support and Training for Patients with Chronic and Complex Conditions Improves Health Related Behaviour and Health Outcomes!', *Australian Health Review*, Vol. 32, No. 2, pp. 330–38
- Harvey, P. W. & Staker, J. 2007, 'Next Steps in the Logic of Consumer-led Self-management: Translating CCSM into self-management programs for young people', *International Journal of Child Health and Human Development*, accepted October 2007, in press
- Heard, A., Kalucy, E., Richardson, D., Battersby, M. W., Frith, P. & McGowan, C. 2002, 'An Evaluation of the Care Planning Process in Coordinated Care Trials: What difference do care plans make to service provision?', *Australian Journal of Primary Health*, vol. 8, no. 1, pp. 52–6.
- Helps, Y. L. M., Moller, J., Kowanko, I., Harrison, J. E., O'Donnell, K. & de Crespigny, C. 2008, *Aboriginal People Travelling Well: Issues of safety, transport and health*, Department of Infrastructure, Transport, Regional Development and Local Government, Canberra.
- Kowanko, I., de Crespigny, C. & Murray, H. 2003, *Better Medication Management for Aboriginal People with Mental Health Disorders and their Carers—Final Report 2003*, June edn, Inprint Design, Bedford Park.
- Kowanko, I., de Crespigny, C. & Murray, H. 2003, *Better Medication Management for Aboriginal People with Mental Health Disorders and their Carers—Report on research conducted in the Port Lincoln area*, March edn, Inprint Design, Bedford Park.

Appendix 3: CCRE Investigator – Publications

- Kowanko, I., de Crespigny, C., Murray, H. & Groenkjaer, M. 2003, *Better Medication Management for Aboriginal People with Mental Health Disorders and their Carers—Report on research conducted in the Port Augusta area*, March edn, Inprint Design, Bedford Park.
- Kowanko, I. & de Crespigny, C. 2004, 'Mental Health Disorders and Associated Health Problems among Aboriginal People: A review of hospital separation data', *Australian Epidemiological Association*, Adelaide, *Australasian Epidemiologist*, vol. 11, no. 3, p. 28.
- Kowanko, I., de Crespigny, C., Murray, H., Groenkjaer, M. & Emden, C. 2004, 'Better Medication Management for Aboriginal People with Mental Health Disorders: A survey of providers', *Australian Journal of Rural Health*, vol. 12, no. 6, pp. 253–7.
- Kowanko, I., de Crespigny, C., Murray, H. & Wilson, S. 2004, 'Better Medication Management for Indigenous Australians with Mental Health Problems', 8th International Congress of Behavioural Medicine, Mainz, Germany, August, *International Journal of Behavioral Medicine* vol. 11 (supplement), p. 109.
- Kowanko, I., de Crespigny, C., Murray, H., Wilson, S. & Emden, C. 2004, 'Better Medication Management for Aboriginal People', *Aboriginal and Islander Health Worker Journal*, vol. 28, no. 2, pp. 11–13.
- Kowanko, I. 2005, 'Coordinated Aboriginal Mental Health Care—A model for best practice', *Indigenous Health Matters*, vol. 12 (June), p. 8.
- Kowanko, I. 2005, 'Working Together to Improve Aboriginal Health through Research', *Research Pulse*, vol. 1, no. 2, p. 3.
- Kowanko, I., de Crespigny, C., Murray, H., Emden, C. & Wilson, S. 2005, 'Improving Indigenous Health through Better Medication Management: An overview', *Journal of Primary Health*, vol. 11, no. 1, pp. 17–23.
- Kowanko, I., Prideaux, C., Ah Kit, J., Ordasi, L., Murray, H. & de Crespigny, C. 2007, 'Rural and Remote Aboriginal Mental Health—Meeting the challenges', in P. Hanlon, et al. (ed.), *Reach Out: Connect. Contemporary TheMHS in Mental Health Services*, TheMHS Conference Inc, Balmain, pp. 220–7.
- Kowanko, I., de Crespigny, C., Murray, H., Ah Kit, J., Prideaux, C. & Mills, D. in press, 'Improving Coordination of Care for Aboriginal People with Mental Health, Alcohol and Drug Use Problems—Reflections on an ongoing collaborative action research project', *Collegian*.
- Mills, P. D. & Harvey, P. W. 2003, 'Beyond Community-based Diabetes Management and the COAG Coordinated Care Trial', *Australian Journal of Rural Health*, vol. 11, no. 3, pp. 131–7.
- Phillips, P., Caust, C., Del Fante, P., Hodgson, J., Kroemer, D., McGowan, C., Ruffin, R., Battersby, M. & Conroy, P. 2002, 'Coordinating Diabetes Care—The SA HealthPlus trial', in *The Australian Coordinated Care Trials—Recollections of an Evaluation*, Publications Production Unit (Public Affairs), Parliamentary and Access Branch, Commonwealth Department of Health and Aged Care, Canberra, pp. 51–64.
- Pols, R. G. & Battersby, M. W. 2006, 'Chronic Condition Self-management: Is there a need for a specific curriculum for medical students? [Editorial]', *Medical Education*, vol. 40, no. 8, pp. 719–21.
- Regan-Smith, M., Hirschmann, K., Iobst, W. & Battersby, M. W. 2006, 'Teaching Residents Chronic Disease Management Using the Flinders Model', *Journal of Cancer Education*, vol. 21, no. 2, pp. 60–2.
- Shephard, M. & Tallis, G. 2002, 'Assessment of the Point-of-care Cholestech Lipid Analyser for Lipid Screening in Aboriginal Communities', *Australian Journal of Medical Science*, no. 23, pp. 4–10.
- Shephard, M. 2004, 'Point-of-care Testing in the Indigenous Rural Environment—The Australasian experience', in C. Price, J. Hicks, et al. (eds.), *Point-of-Care Testing*, American Association of Clinical Chemistry Press, Washington DC, pp. 293–301.
- Shephard, M. 2004, 'Analytical Performance Criteria for Point-of-care Testing Instruments', in *Standards for Point of Care Testing in General Practice. Incorporating POCT Trial Guidelines*, Australian Government Department of Health and Ageing, Canberra, pp. 101–40.
- Shephard, M. 2004, 'Point-of-care Testing in the Indigenous Rural Community', *Clinical Biochemist Newsletter*, no. 153, June, pp. 22–7.

Appendix 3: CCRE Investigator – Publications

- Shephard, M. 2004, 'How to Set Up and Manage a Point-of-care Testing Service', *Clinical Biochemist Newsletter*, no. 153, June, pp. 32–7.
- Shephard, M. 2006, 'Clinical and Cultural Effectiveness of the 'QAAMS' Point-of-care Testing Model for Diabetes Management in Australian Aboriginal Medical Services', *Clinical Biochemist Reviews*, no. 27, pp. 161–70.
- Shephard, M. 2006, 'Analytical Goals for Point-of-care Testing Used for Diabetes Management in Australian Health Care Settings Outside the Laboratory', *Point-of-Care: The Journal of Near-Patient Testing and Technology*, vol. 5, pp. 177–85.
- Shephard, M., Mazzachi, B., Shephard, A., Burgoyne, T., Dufek, A., Ah-Kit, J., Mills, P. D. & Dunn, D. 2006, 'Point-of-care Testing in Aboriginal Hands—A model for chronic disease prevention and management in Indigenous Australia', *Point-of-Care: The Journal of Near-Patient Testing and Technology*, vol. 5, pp. 168–76.
- Shephard, M., Allen, G., Paizis, K., Barbara, J., Batterham, M. & Vanqjek, A. 2006, 'Results of an Aboriginal Community-based Renal Disease Management Program Incorporating Point of Care Testing for Urine Albumin:Creatinine Ratio', *Rural and Remote Health*, vol. 6, Article 591, viewed 10 Sept 2008, <http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=591>
- Shephard, M. & Gill, J. 2006, 'The Analytical Quality of Point-of-care Testing in the QAAMS Model for Diabetes Management in Australian Aboriginal Medical Services', *Clinical Biochemist Reviews*, vol. 27, pp. 185–90.

CCRE Investigator – Conference presentations

- Battersby, M. W. 2003, 'The Australian Sharing Health Care Program—Education for clinicians and consumers', Perspectives on the Expert Patient, presentations from a seminar held at the Royal Pharmaceutical Society of Great Britain, London, 19 May.
- Battersby, M. W. 2004, 'Lessons from America', The Turning Tide: Actions & Improvements in Chronic Disease—Towards Building Healthier Communities, Darwin, 23–24 September.
- Battersby, M. W. 2004, 'Evidence for Implementing Self-management Support for Chronic Illness in Primary Care', Dimensions in Health Care Conference: 15th Casemix Conference, Sydney, 10–13 October.
- Battersby, M. W., Pols, R. G., Lawrence, J. & Markwick, M. 2004, 'CCSM Education and Training: A national approach', Proceedings from the National Chronic Condition Self-Management Conference, Guiding Us Forward, Melbourne, 12–14 November.
- Battersby, M. W., Reardon, L. & Rollman, B. 2004, 'Supporting Recovery: Clinical and system issues in self management', Depression in Primary Care Annual Meeting, Phoenix, AZ, United States. 29–30 October.
- Battersby, M. W. 2005, 'Evidence for Patient and Clinician Directed Self-management', Australian Rheumatology Association's 47th Annual Scientific Meeting, Melbourne, 22–25 May.
- Battersby, M. W. 2005, 'Chronic Condition Self-management Education and Training', Managing Pain Using Self-management Approaches: Evidence and implementation, Sydney Convention and Exhibition Centre, Sydney, Australia, 19 August.
- Battersby, M. W. 2005, 'Incorporating Self-management Support into Routine General Practice', National Forum on Practice Capacity for Chronic Disease Prevention and Management, Mercure, Sydney Airport, 15 April.
- Battersby, M. W. & Markwick, M. J. 2005, 'Chronic Condition Self management, Partnerships with Patients', National Primary Care Collaboratives, Melbourne, 29–30 March.
- Battersby, M. W. & Regan-Smith, M. 2005, 'Self-management Support for Chronic Conditions—The Flinders Model', International Conference on Patient Self-management, Victoria, British Columbia, Canada. 12–14 September.
- de Crespigny, C., Wilson, S., Kowanko, I., de Bellis, A., Cruse, S., Parfoot, W., Turner, M. & Murray, H. 2002, 'Better Medication Management by Aboriginal People with Mental Health Disorders and their Carers', National Medicines Symposium: Linking People, Actions and Policy for Quality Use of Medicines, Canberra, March.
- de Crespigny, C. & Kowanko, I. 2003, 'Prescribed Medication—Use and problems. An action research project to improve medication management by Aboriginal people with mental health problems, their carers and family members', National Drug and Alcohol Conference, Adelaide, May.
- de Crespigny, C., Kowanko, I., Murray, H., Wilson, S. 2004, 'Better Medication Management for Aboriginal People with Mental Health and Substance Use Problems', APSAD conference, Fremantle, November.

Appendix 3: CCRE Investigator – Conference presentations

- de Crespigny, C., Kowanko, I., Murray, H., Wilson, S. & Emden, C. 2005, 'Safer Medication Management for Aboriginal People with Mental Health and Alcohol and Drug Problems in South Australia', 23rd Quadrennial ICN Congress, Taiwan.
- Cruse, S., de Crespigny, C., Parfoot, W., Roberts, G., Wilson, S., de Bellis, A. & Kowanko, I. 2001, 'Quality Use of Medications Project: Problems associated with the use of medication by Indigenous people with social and emotional wellbeing issues and their carers', Health Care in a Complex World: An International Research Conference, Toronto, Canada, 2–4 May.
- Harvey, P. W. 2003, 'The Partners in Health Program and CDSM—Changes in patient illness management knowledge and lifestyle behaviour in the SHC SA program', National Chronic Condition Self-management Conference—Guiding us Forward, Melbourne, 12–14 November.
- Harvey, P. W., Battersby, M. W. & Misan, G. 2003, 'Chronic Disease Self-management—A health management approach for patients in rural and remote communities', 7th National Rural Health Conference, Hobart, March.
- Harvey, P. W., Battersby, M. W. & Misan, G. 2003, 'Structured Behavioural Change Strategies in Chronic Disease Self-management Programs: Early outcomes of the Sharing Health Care Model in rural South Australia', 6th WONCA World Rural Health Conference, Santiago de Compostela, Spain, 24–27 September.
- Harvey, P. W. & Blue, I. 2003, 'Sharing Health Care Education with Community', International Rural Network Conference—Taking Charge: Rural Community Empowerment in Rural Development, Rural Health and Rural Education, Inverness, Scotland.
- Harvey, P. W., Fuller, J., Gentle, I. & Misan, G. 2003, 'The Sharing Health Care SA Chronic Illness Self-management Program—Local evaluation model and early outcomes', Australian Health Outcomes Conference, Canberra, 19–21 August.
- Harvey, P. W. & Misan, G. 2003, 'The Importance of Partnerships in the Processes of Self-management in Modern Health Care!', 6th WONCA World Rural Health Conference, Santiago de Compostela, Spain, 24–27 September.
- Harvey, P. W., Battersby, M. W. & Lawrence, J. 2004, 'Integrating Patient Centred Goal Setting, Care Planning and Chronic Condition Self-management Programs for Sustainable Health Related Behaviour Change', 15th Casemix Conference, Sydney.
- Harvey, P. W., Petkov, J. & Battersby, M. W. 2004, 'Partners in Health Outcomes 2004—Perspectives on population health', Australian Health Outcomes Conference, Canberra.
- Harvey, P. W., Petkov, J. & Misan, G. 2005, 'Patient Self-management Programs in Rural South Australia Lead to Improved Health Related Behaviour and Health Outcomes for Patients with Chronic Conditions', Australian Health Outcomes Conference, Canberra.
- Harvey, P. W., Warren, K. & Coulthard, F. 2005, 'Elements of Successful Chronic Condition Self-management Programs for Indigenous Australians.' 8th National Rural Health Conference, Alice Springs.
- Harvey, P. W., Edmondson, W. & Ah Kit, J. 2006, 'Centre of Clinical Research Excellence (CCRE) in Aboriginal and Torres Strait Islander Health—An operational rationale and summary of early achievements', The Empowerment Conference—Noel Pearson, Melbourne, 16–17 May.
- Harvey, P. W. 2007, 'The SA HealthPlus Coordinated Care Model', Northern Territory Government Forum on Kidney Disease Management, Darwin, September.
- Harvey, P. W. 2007, 'Chronic Condition Self-management through Community and Health Professional Collaboration: A model for health science collaboration', The Second International Conference on Interdisciplinary Social Sciences, Granada, Spain,
- Harvey, P. W. 2007, 'Coordinated Care Models for Integrated Case Management', NT Department of Health—Chronic Kidney Disease Forum, Darwin, 5 September.
- Harvey, P. W., Berry, G., Warren, K. & Battersby, M. W. 2007, 'Chronic Condition Self-management Collaboration in General Practice', South Australians Network Annual Conference, Adelaide, 9–10 May.

Appendix 3: CCRE Investigator – Conference presentations

- Maguire, G., Freeman, H., Mahony, A., Martin, D. & Shephard, M. 2004, 'Point-of-care Diabetes Diagnosis in a Remote Indigenous Australian Community', poster presentation at the Royal Australasian College of Physicians Annual Meeting, Canberra, May, where it was awarded the Best Poster Prize—Adult Medicine.
- Kowanko, I. 2003, 'Better Medication Management for Aboriginal People with Mental Health Disorders, their Carers and Families', Uncharted Territory—A Conference Exploring the Links between Chronic Illness, Mental Health and Alcohol and Other Drugs, Darwin, 8-10 May.
- Kowanko, I., de Crespigny, C., de Bellis, A., Murray, H., Groenkjaer, M., Wilson, S. & Parfoot, W. 2003, 'Better Medication Management for Aboriginal People with Mental Health Disorders and their Carers', First international Alcohol, Tobacco and Other Drugs Nursing and Midwifery Conference, Adelaide, 17 April.
- Kowanko, I., de Crespigny, C. & Murray, H. 2003, 'Better Medication Management for Aboriginal People with Mental Health Disorders, their Carers and Families', Growing Research in Primary Health Care, 1st South Australian PHC RED Conference, Adelaide, October.
- Kowanko, I., De Crespigny, C., Ah Kit, J. & Murray, H. 2005, 'Coordinated Aboriginal Mental Health Care', CRCAH Convocation, 6-7 April.
- Kowanko, I., de Crespigny, C. & Ah Kit, J. 2007, 'Collaborative Drug and Alcohol Research with Aboriginal People', DASSA and APSAD Workshop, 26 November.
- Kowanko, I., de Crespigny, C., Murray, H., Ah Kit, J., Prideaux, C. & Mills, D. 2007, 'Improving Coordination of Care for Aboriginal People with Mental Health, Alcohol and Drug Use Problems—Reflections on an ongoing collaborative action research project', Drug and Alcohol Nurses of Australasia Conference 'Regional Perspectives in Practice', Whyalla, 11–13 July.
- Power, C., Dang, N., de Crespigny, C., Norvill, I., Kowanko, I., Murray, H., Casey, W. & Wilson, S. 2006, 'Sustainable Families: Looking at the relationship between culture, alcohol and other drugs and violence', The Second International Conference on Sustainable Heritage Development: Environmental, Cultural, Economic and Social Sustainability, Vietnam, 9–12 January.
- Prideaux, C., Ah Kit, J., Ordasi, L., Kowanko, I., Murray, H. & de Crespigny, C. 2006, 'Rural and Remote Aboriginal Mental Health—Meeting the challenges', 16th Annual TheMHS Conference, 'Reach Out, Connect', Townsville, 30 August –1 September (invited presentation).
- Shephard, M. 2004, 'Evaluation of the HemoCue Urine Albumin Device', Screening, Diagnosis and Management of Disease at Point-of-Care Workshop, 10th Asian-Pacific Congress of Clinical Biochemistry, Perth, 18–23 September.
- Shephard, M. 2004, 'Supporting Diabetes Management in Rural and Remote Aboriginal Medical Services through On-site Point of Care Testing', Diabetes: Laboratory Perspectives and Disease Management, Australian Institute of Medical Scientists (AIMS), SA/NT Branch, Videoconference between Adelaide, Darwin, Alice Springs and Katherine, 11 October.
- Shephard, M. 2004, 'Flinders University of South Australia, Graduate Certificate in Health: Diabetes Management and Education', lecture delivered on Point-of-Care Testing for Aboriginal Diabetes and Renal Disease, 29 June.
- Shephard, M. & Mundraby, K. 2004, 'Supporting Diabetes Management in Australian Aboriginal Communities through an Innovative National Education, Training and Quality Assurance Program for Point-of-care HbA1c Testing', 6th International Diabetes Conference for Indigenous Peoples, Cairns, 7–10 September.
- Shemesh, T., Piers, L., Rowley, K., Shephard, M. & O'Dea, K. 2004, 'Point-of-care Testing for Chronic Disease in a Remote Australian Aboriginal Community', poster presentation at the Australian Diabetes Society (ADA) and Australian Diabetes Educators Association (ADEA) Annual Scientific Meeting, Sydney, 25–27 August.
- Wilson, S., Mazzachi, B. & Shephard, M. 2004, 'Point-of-care Testing in Aboriginal Hands', 6th International Diabetes Conference for Indigenous Peoples, Cairns, 7–10 September.

Appendix 4: References

- Mann, S, Burgoyne, A, Coaby, J with The Elders Ambassador Group (Port Lincoln) 2002, *Look, Think, Act: Indigenous stories about living with diabetes*, Port Lincoln Aboriginal Health Service, Royal District Nursing Service Research Unit, Spencer Gulf Rural Health School.
- Carson, B., Dunbar, T., Chenhall, R. D. & Bailie, R. 2007, *Social Determinants of Indigenous Health*, Allen & Unwin, Crows Nest, NSW.
- Centre for Remote Health (n.d.) 'Professor John Wakerman', viewed March 2008, <<http://rh.flinders.edu.au/staff/johnW.htm>>.
- CKAHS (Ceduna/Koonibba Aboriginal Health Service) 2006, 'Ceduna/Koonibba Aboriginal Health Service', viewed August 2008, <http://www.erhs.sa.gov.au/5services/ck_abor_health.php>.
- Henry, J., Dunbar, T., Arnott, A., Scrimgeour, M., & Murakami-Gold, L. 2004, *Indigenous Research Reform Agenda—A review of the literature* (Mongraph), CRCATH, Cassurina, NT.
- Henry, K., 2006, "Managing Prosperity, Address to the 2006 Economic and Social Outlook Conference", Melbourne; viewed August, 2008 http://www.treasury.gov.au/documents/1190/PDF/O2_Prosperty.pdf
- Lorig, K., Holman, H., Sobel, D., Laurent, D., Gonzales, V., & Minor, M. 2000, *Living a healthy life with chronic conditions*. Palo Alto California: Bull Publishing Company.
- Lorig, K., Sobel, D. S., Ritter, P. L., & Hobbs, M. 2001, Effect of self-management programs on patients with chronic disease. *Effective Clinical Practices*, 4(6), 256-262.
- Morgan Disney & Associates Pty Ltd, 2006, A Red Tape Evaluation in Selected Indigenous Communities, Final report to The Office of Indigenous Policy Coordination, Canberra Viewed September, 2007 <http://www.oipc.gov.au/publications/> <http://www.oipc.gov.au/publications/PDF/RedTapeReport.pdf>
- PWHS (Pika Wiya Health Service) 2006a, 'Purpose of the Pika Wiya Health Service Inc,' viewed August 2008, <<http://www.pikawiya.com.au/purpose.asp>>.
- PWHS 2006b, 'Objectives', viewed August 2008, <<http://www.pikawiya.com.au/objectives.asp>>.

Other useful references for people interested in the range of issues of this CCRE

- Anderson, I, 1996, "Ethics and Health Research in Aboriginal communities", in Daly, J. (editor) *Ethical Intersections: Health research Methods and Researcher Responsibility*, Allen & Unwin, Sydney.

Appendix 4: References

- Australian Medical Association 2003, *Public Report Card 2003—Aboriginal & Torres Strait Islander Health: Time for Action*, AMA, Barton, ACT.
- Australian Medical Association 2004, *Healing Hands—Aboriginal and Torres Strait Islander Workforce Requirements*, AMA, Barton, ACT.
- Commonwealth Department of Health and Aged Care 1999, *The Virtuous Cycle—Working Together for Health and Medical Research—Final report*. (The Wills Report, Wills, P.J. Chairperson Health and Medical Research Strategic Review), AGPS, Canberra.
- Henry, J., Dunbar, T., Arnott, A., Scrimgeour, M., Matthews, S., Murakami-Gold, L., et al. 2002a, *Changing Institutions*, The Cooperative Research Centre for Aboriginal and Tropical Health, Casuarina, NT.
- Henry, J., Dunbar, T., Arnott, A., Scrimgeour, M., Matthews, S., Murakami-Gold, L., et al. 2002b, *Positioning the Cooperative Research Centre for Aboriginal and Tropical Health*, The Cooperative Research Centre for Aboriginal and Tropical Health, Casuarina, NT.
- Henry, J., Dunbar, T., Arnott, A., Scrimgeour, M., Matthews, S., Murakami-Gold, L., et al. 2002c, *Promoting the Use of Health Research*, The Cooperative Research Centre for Aboriginal and Tropical Health, Casuarina, NT.
- Henry, J., Dunbar, T., Arnott, A., Scrimgeour, M., Matthews, S., Murakami-Gold, L., et al. 2002d, *Rethinking Research Methodologies*, The Cooperative Research Centre for Aboriginal and Tropical Health, Casuarina, NT.
- Humphreys, J. 1999, 'Rural Health Status: What do statistics show that we don't already know?', *Australian Journal of Rural Health*, vol. 7, pp. 60–3.
- Marmot, M. & Wilkinson, R. G. 2006, *Social Determinants of Health* (2nd ed.), Oxford University Press, New York.
- McDermott, R. 2004, 'Catastrophic Failures of Public Health [Comment]', *Lancet*, vol. 363, no. 1551, p. 8.
- McDermott, R., Tulip, F., Schmidt, B. & Sinha, A. 2003, 'Sustaining Better Diabetes Care in Remote Indigenous Australian Communities', *BMJ*, vol. 327, no. 7412, pp. 428–30.
- Mills, P. D. & Harvey, P. W. 2003, 'Beyond Community-based Diabetes Management and the COAG Coordinated Care Trial', *Australian Journal of Rural Health*, vol. 11, no. 3.
- Ring, I. & Brown, N. 2002, 'Indigenous Health: Chronically inadequate responses to damning statistics', *MJA*, vol. 177, no. 11, pp. 629–31.
- Smith, J. D. 2004, *Australia's Rural and Remote Health—A Social Justice Perspective*, Tertiary Press, Melbourne.
- Smith, L. T. 1999, *Decolonising Methodologies: Researching and Indigenous People*, University of Otago Press, Dunedin.
- Thomas, D. 2004, *Reading Doctors' Writing—Race, Politics, and Power in Indigenous Health Research 1870—1969*, Australian Institute of Aboriginal and Torres Strait

Appendix 4: References

Islander Studies, Canberra.

Thomas, D., Condon, J., Anderson, I., Li, S., Halpin, S., Cunningham, J., et al. 2006, 'Long-term Trends in Indigenous Deaths from Chronic Diseases in the Northern Territory: A foot on the brake or a foot on the accelerator', *MJA*, vol. 185, no. 3, pp. 145–9.

Thomas, D. P. & Anderson, I. P. 2006, 'Getting the Most from Indigenous Health Research', *MJA*, vol. 184, no. 10, pp. 500–1.

Thommasen, H., Patenaude, J., Anderson, N., Mc Arthur, A. & Tildesley, H. 2004, 'Differences in Diabetic Co-morbidity between Aboriginal and non-Aboriginal People Living in Bella Coola, Canada', *Rural and Remote Health* (online) (319).

Trudgen, R. I. 2000, *Why Warriors Lie Down & Die: Towards an understanding of why the Aboriginal people of Arnhem Land face the greatest crisis in health and education since European contact: Djambatj mala*, Aboriginal Resource & Development Services Inc., Darwin.

Wilkinson, D. & Blue, I. (eds) 2002, *The New Rural Health*, Oxford University Press, Melbourne.

Wilkinson, R. G. 2005, *The Impact of Inequality—How To Make Sick Societies Healthier*, The New Press, New York.

Wills, P.J. (Chairperson Health and Medical Research Strategic Review) 1999, *The Virtuous Cycle – Working together for health and medical research*, Commonwealth Department of Health and Aged Care, AGPS, Canberra.

Appendix 5: List of Scholarship Recipients 2005 – 2008

Name	Level of Study	Field of Study	Institution	Part/Time Full/Time	Period of support
Anthony Ah Kit*	Masters	Health Sciences	Flinders	P/T	3.5yrs
Graham Berry	Grad Cert	Research & Eval	Flinders	F/T	1 yr
Eileen Bloomfield*	Bridging	Foundation studies	UniSA	P/T	1 yr
Judith Borg*	Grad Cert	PHC: Research & Evaluation	Flinders	F/T	1 yr
Sari Bryant*	Certificate IV	Enrolled nursing	Spencer TAFE	P/T	1.5 yr
Tony Burgoyne*	Grad Cert	Diabetes Education	Flinders	F/T	1 yr
Luita Casey*	BN & HS Grad Dip	Health Sciences Grief & loss Counselling	Flinders	F/T	2 yrs
Shane D'Angelo*	BBM	Business management	Gibaran	P/T	3yrs
Justin Gladman*	Masters	Clinical Education	Flinders	F/T	3.5 yrs
Alwyn Graham*	Grad Cert	diabetes educn & management	Flinders	F/T	1 yr
Kylie Hampton*	Associate Degree	Indigenous Com Dev & Mngmnt	Curtin	F/T	2 yrs
Wendy Lawrie*	Grad Cert	Mental Health Promotion	Flinders	P/T	1.5 yrs
Beverly McCurry	Grad Cert	Diabetes Education	Flinders	P/T	1 yr
Anthony Milera*	Bridging	Foundation studies	Bridging course	F/T	1 yr
Gladys McKenzie*	BN	Registered Nursing	Uni SA	P/T	1 yr
Ricky Mentha*	Grad Cert	Remote Practice - Research	Flinders	P/T	2 yrs
Kim Morey*	BA	Policy & Mangmnt Human Services	Uni SA	P/T	3 yrs
Kim O'Donnell*	Masters	Health Sciences	Flinders	F/T	0.5 yr
Shereen Rankine*	BN	Nursing	Uni SA	P/T	1.5 yrs
Jaime Reed*	Grad Dip	Social Sciences, Counselling	Uni SA	P/T	3 yr
Gilbert Rigney*	BN	Nursing	Uni SA	P/T	1 yr
Courtney Thompson*	Honours	Bio-Medical Engineering	Flinders	F/T	1 yr
Muriel Wanganeen*	Short Course	Food Inequities Workshop	Flinders	P/T	1 yr
Naomi Willis*	BN	Nursing	Uni SA	F/T	1 yr
Maria Wilson*	BSc	Environmental Health	Flinders	P/T	3 yr
Tarni Wilson*	BBS	Behavioural Sciences	Flinders	F/T	3 yr

* Indicates Aboriginal

Appendix 5: List of Bursary Recipients 2005 – 2007

Name	Activity	Year
Anthony Ah Kit*	Healing Spirit Conference, Canada	2006
Jackie Ah Kit*	Healing Spirit Conference, Canada	2006
Tony Burgoyne*	Healing Spirit Conference, Canada	2006
Yvonne Clark*	Healing Spirit Conference, Canada	2006
Jeremy Coaby*	ALARA Conference presentation	2007
Joanne Garnggulkpuy*	ALARA Conference presentation	2007
Justin Gladman*	Travel to study	2007
Alwyn Graham*	Diabetes Forum	2006
Colleen Prideaux*	Healing Spirit Conference, Canada	2006
Brenton Richards*	Healing Spirit Conference, Canada	2006
Major Sumner*	Healing Spirit Conference, Canada	2006
Margaret Kemare Turner*	ALARA Conf presentation	2007
Muriel Wanganeen*	Diabetes Forum	2006
Allan Wilson*	ALARA Conference presentation	2007
Dorothy Yunggiringa*	ALARA Conference presentation	2007

* Indicates Aboriginal



Achievement and Milestones

