

Elements of successful chronic condition self-management program for Indigenous Australians

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BACKGROUND

The Commonwealth Government Sharing Health Care chronic disease self-management (CDSM) initiative was established in 2001 across all states of Australia. This demonstration and research program has resulted in the testing and refining of a range of new approaches to chronic illness self-management including the application of patient centred care planning, use of Enhanced Primary Care (EPC) Medical Benefits Scheme (MBS) item numbers to fund care planning and the introduction of peer-led chronic illness self-management training program.

The South Australian Sharing Health Care project (SHC SA) focused on rural and remote communities in Whyalla, Port Lincoln and Port Augusta, including Pika Wiya Aboriginal Health Service where modified forms of the Stanford University CDSM course were introduced. Following the conclusion of the Sharing Health Care project local CDSM course leaders have continued to apply and expand self-management principles in Aboriginal Communities. All of these activities have been integrated to form the LIFE (Living Improvements For Everyone) model of chronic disease management.

In South Australia it is estimated that 450 000 people over the age of 20 have at least one preventable chronic disease and the burden is growing. In Indigenous Australian communities, there are higher levels of chronic disease which occur much earlier in life. (1)

This paper outlines the processes involved in the introduction and acceptance of self-management as a key component of chronic illness management at the Pika Wiya Health Service and highlights some of the successes of this program to date. Data from the National Evaluation and Local Evaluation programs of the SHC SA project are also presented in relation to achievements in health outcomes and organisational change in the communities involved and an outline of continuing research is provided.

Throughout this paper, the term 'Indigenous' is used to describe Aboriginal and Torres Strait Islander people of Australia, but more specifically, the Aboriginal community of Port Augusta and surrounding areas. It is acknowledged that some of the methods used in the development of the LIFE model may not suit all Indigenous groups across Australia but may be easily modified.

GENERAL OVERVIEW OF THE SHARING HEALTH CARE PROJECT

The Sharing Health Care SA (SHC SA) initiative in Whyalla, Port Augusta and Port Lincoln was based on the initial findings of the Eyre Peninsula co-ordinated care trials and a chronic illness management pilot program conducted in Aboriginal communities in Port Lincoln and Ceduna (2). The project was also consistent with developments elsewhere that have shown that chronic disease, much of which can be prevented and/or managed, has become a major burden upon our health systems. In the United States (US) the impact of chronic diseases such as

diabetes, coronary heart disease, hypertension and asthma, for example, already account for 70% of the nation's health care costs (3) and this burden is set to rise by 15% by 2010 and by an estimated 60% by 2050 as the population ages.(4) In Australia, approximately 70% of the national burden of disease is attributed to chronic conditions and predicted to rise to near 80% by 2020 if present trends in health care continue.(1) When comparing with the rest of the population, life expectancy for Indigenous South Australians (SA) is unacceptably low. In 1998–2000, the adjusted life expectancy for Indigenous males in SA was 55.3 years – 21.3 years less than that of the total male population. Life expectancy for Indigenous females was 61.2 years – 21.1 years less than that of the total population. (5) A recent study of the mortality rates of clients of Pika Wiya Health Service (deaths that occurred between 1995 and February, 2004) found that the median age at death was 44.5 years. (6) Through improving chronic condition management, it is hoped to reverse or at least slow the impact of chronic disease on mortality and morbidity rates amongst local Aboriginal Australians.

It is now becoming clear that the effective management of such chronic conditions is a major health system challenge and that our health efforts will need to focus increasingly on illness prevention, population health management and community and patient partnerships (7) as well as maintaining acute care delivery. The challenge is to identify, and manage, not only emerging chronic illness, but also to intervene at the social, economic and environmental levels to prevent much of this illness at its source (4, p586) through more population based approaches to the management of community and individual well-being.

SELF-MANAGEMENT APPROACHES

Self-management, in the context of this study, refers to a patient's ability to understand their condition and to manage and organise their access to key elements of their care. A patient who understands their illness, how to recognise early warning signs and take appropriate action, how to manage their lifestyle for optimal health outcomes and how to work effectively with health care providers and carers is seen to be a good self-manger of their condition.

Self-management does not imply that patients need to manage their illness by themselves or in isolation from mainstream services or having to manage their own treatment plan. Quite the contrary, a good self-manager knows what services to access, how and when in order to maximise their potential for well-being. This implies an effective partnership between patient, carer and health service provider to ensure that essential elements of care are available when needed and that the various providers involved in a patient's care are informed about key aspects of this care and are able to work together to ensure the best possible outcomes for patients (8).

RATIONALE

Lorig and Fries, and others, have demonstrated that major contributors to reducing the cost of care for chronic illness sufferers and increasing health outcomes for this group are illness management awareness initiatives, self-management training and support programs (4, 9–19). In addition, it is widely recognised that where communities and consumers of health services participate meaningfully in the process of accessing and using those services; that is share in the process of health care, improved health outcomes are more likely than in situations where this sharing does not occur (20, p155).

The key hypotheses of the SHC SA project were that:

- Sharing Health Care would help improve health-related quality of life for people with chronic conditions, particularly those with co-morbidities
- Sharing Health Care will help to facilitate improvements in awareness and understanding about the benefits of self-management, as well as improving communication and collaboration between General Practitioners, people with chronic conditions and their families and other Health Professionals
- The Sharing Health Care initiative will result in more appropriate use of health services

The SHC SA project was designed to trial the application of self-management principles for a group of patients with complex chronic conditions over a three-year period and to explore whether these approaches lead to...

- improved health outcomes for the enrolled population
- the development of improved patient knowledge about their condition and improved uptake and application of self-management and self-help skills in the enrolled population
- improved access to and use of relevant health care services for the enrolled population

The self-management training and support provided for patients encouraged and developed patients' knowledge of their conditions and empowered them to manage their care more effectively whilst the formal research element of SHC SA acted as a driver for organisational change in the health system. The SHC SA project also encouraged health care providers to respond more effectively to the needs and demands of the individuals who, through their involvement in the program of care, became more empowered and more able to self-manage within the system beyond the formal project stage of the work.

PATIENT POPULATION

Three project sites were selected in which ATSI patients of 35 years or over and non-ATSI patients of 50 years and older with one or more chronic conditions requiring multi-disciplinary care were enrolled in the intervention group. Most patients were recruited through the GP led EPC and MBS care planning process with SHC SA research project staff working in collaboration with practice nurses and allied health staff to prepare care plans, administer standard patient assessment tools and implement patient centred chronic illness management initiatives.

By June 2003 the following formal recruitment had been achieved.

Project Site	Enrolled
Whyalla Project	241
Port Augusta Project (Pika Wiya Health Service)	98
Port Lincoln Project	69
Total Project Recruitment	408

INTERVENTIONS AND SUPPORT SERVICE SUMMARY

- Aged health assessment and care plan under MBS criteria applying CDSM approaches and problem and goal systems for planning and behaviour change.
- Formal care plan defining regular services to address health needs.
- Cue and response questionnaires to determine existing patient skills and knowledge and their readiness to engage in self-management of their illness.
- Pharmacy review where appropriate (Home Medication Review – via EPC).
- Initial health assessment – condition specific.
- Modified Stanford 2000 health assessment tool, incorporating the Kessler 10 depression scale and other demographic tools and well-being measures.
- Education and information packages delivered by project officers at individual sessions with enrolled patients.
- Self-management training and group support sessions run by peer leaders and allied health teams in collaboration with project officers.
- Participation in self-help groups.
- Formal EPC care plan reviews where appropriate.
- Participation in regular survey and data collection along with some random sampling as part of local evaluation process.

THE 'LIFE' (LIVING IMPROVEMENTS FOR EVERYONE) PROGRAM

Care Planning and annual Aged Health Assessments improve health problem identification and prevention of disease through early intervention and promote self-management, which, as a result, improves health status (11, 12, 14, 19, 21-27). The self-management assessment tool developed by Flinders University, the Partners in Health framework, has undergone significant testing and evaluation since its development through the Council of Australian Governments (COAG) trials. This process now forms the basis of care planning and patient self-management programs being developed for ATSI clients of Pika Wiya Health Service in Port Augusta, South Australia.

Pika Wiya Health Service is ideally placed to provide holistic health care to the clients it serves through using many and varied resources including components of the EPC package available through the MBS, namely Care Plans, Aged Care Health Assessments and more recently the Adult Health Check. The service is ideally structured because many of the multi-disciplinary services needed to address issues identified through the processes of self-management skills assessment (Flinders model), health assessments and care planning are presently available on location at Pika Wiya. This fact makes a 'whole of service approach' to planning the social, emotional and medical care of Aboriginal people with chronic conditions, a feasible and attainable goal. Along with a modified self-management course and group education sessions on health related topics, Pika Wiya Health Service is developing a holistic and comprehensive program of chronic condition management including self-management.

Emphasis so far has been on building the capacity of the organisation to deliver this service through an integrated, team approach. Systems such as supporting IT software, internal and external referrals have been developed. The provision to health service staff, including GPs, access to relevant training and education is well under way. Involving the community it serves has also been a priority of Pika Wiya, through information sessions, one-on-one interviews and the commencement of Aged Health Assessments, Care Plans and Adult Health Checks for eligible patients. Many issues have been identified and steps taken to improve the health of the people involved. So far, members of the community who have participated have enjoyed the interactive nature of the process and readily suggest ways to improve the model, which has now been modified several times to better suit the needs of the community.

The evolving model outlined here consists of three main components; patient centred care planning and health assessments, a modified self-management training course and other related population health programs. The model aims to integrate a self-management assessment tool, use of the EPC package, a culturally appropriate self-management training course and ongoing health promotion and education to improve ATSI health. This paper outlines the evolving model of chronic disease management in Pika Wiya Health Service and also summarises the early achievements of the community engagement and integrated self-management program being developed there.

DETAILS AND PROCESSES

The Commonwealth Government introduced the Enhanced Primary Health Care Package in 1999 through new item numbers for provision of Aged Health Assessments, Care Plans and Case Conferences. Each has eligibility criteria and the overall aim is to promote health through early detection and co-ordinating interventions. More recently, an adult health check for Aboriginal and Torres Strait Islander (ATSI) people aged 15–54 has been introduced through the MBS system to provide an early detection and intervention process for chronic disease.

Pika Wiya Health Service is a rural Aboriginal health service located at Port Augusta, South Australia. Pika Wiya comes from the Pitjantjatjara language, Pika (pronounced Bika) meaning sick or pain and Wiya (pronounced wee_a) meaning no, so translated, literally means no sickness or pain. (28) The Health Service has a large catchment area, and has small clinics in outlying towns as far away as Copley; around four hours drive from Port Augusta. According to Pika Wiya Health Service statistics and the most recent census, it is estimated that the service caters for in excess of 3000 Aboriginal people across the region. This does not include many transient clients who come and go. The Indigenous population experiences a high incidence of chronic disease, low socio-economic backgrounds, high levels of unemployment and mixed literacy and education levels. In addition, higher than average incidence of disease results in higher mortality and morbidity rates in the community (29, 35)

This situation, coupled with a different 'rural health care ideology' means that the overall quality of life and well-being of traditional rural populations is poorer than for urban populations and this quality declines, especially in relation to Indigenous communities, in proportion to the degree of remoteness experienced in these communities (30). Rural people are therefore 'probably poorer, and certainly less healthy, especially if (they) are also Indigenous' (31, p65).

The impact of chronic disease on the Aboriginal population is enormous. (32, 33, 34). There is an obvious need for change in the way chronic illness is managed in Aboriginal Health generally and at Pika Wiya Health Service specifically, it is fundamental to the ongoing survival of the Aboriginal community. Previous strategies to reduce mortality and morbidity, through predominantly a medical model, have had impacts in areas like immunisation, eye

and ear health, however, overall has failed to impact on disease burden and rate of death (35). Strategies have concentrated on prevention and have greatly improved immunisation rates and early childhood education, however with Indigenous people experiencing the highest rate of chronic conditions, and rising, in Australia, more emphasis needs to be placed on chronic condition management and building the Aboriginal population's overall ability to self manage and to be more independent in their quest for improved health and well-being.

HOW THE LIFE PROGRAM EVOLVED

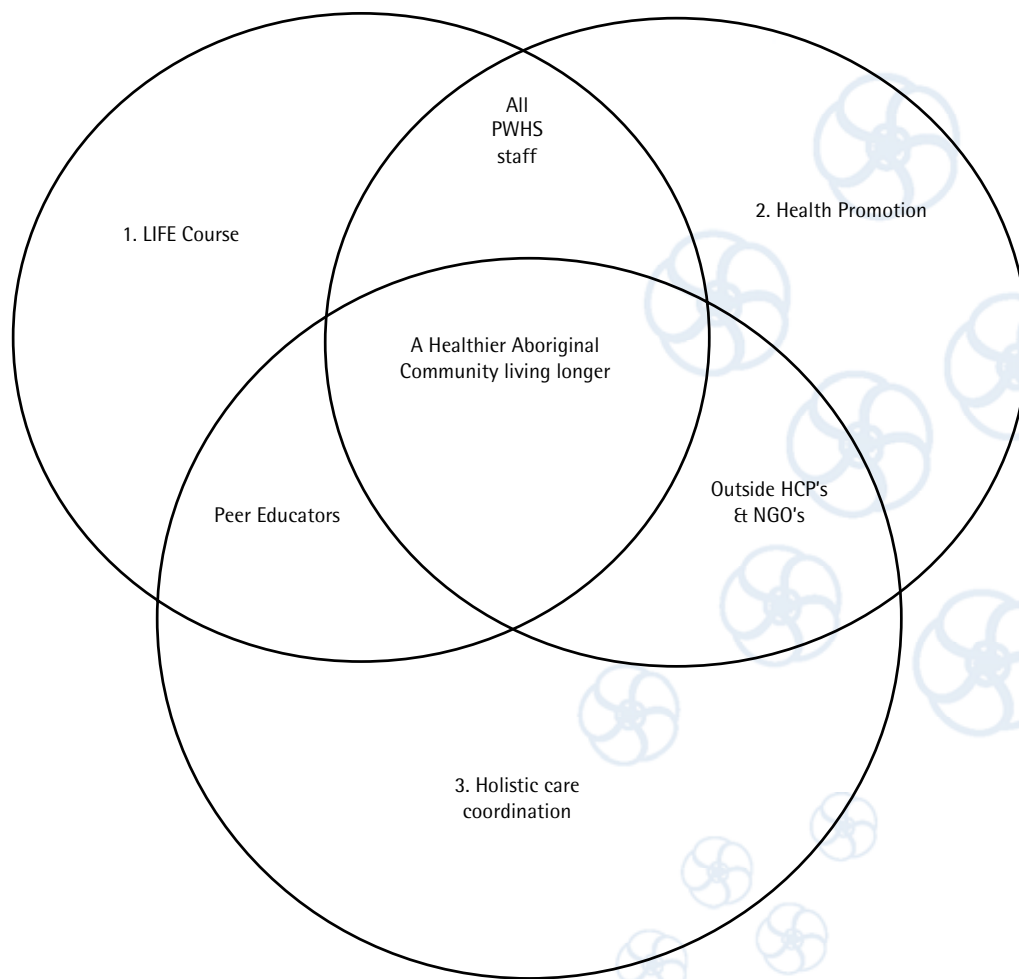
Evidence for an integrated method of managing chronic illness is growing. Literature suggests that a multi-faceted, multi-sectorial, co-ordinated approach is likely to improve health status amongst not only Aboriginal people but the population generally. (24, 32).

The Sharing Health Care SA Project provided an opportunity for the Pika Wiya community to examine, via the demonstration project, possible methods of engaging the local Aboriginal community through a more integrated approach to their health care.

Sustained effort resulted in clients attending the clinic routinely every fortnight. This then progressed to weekly attendance at education sessions. All clients recruited into the project were interviewed using the Partners in Health framework designed by Flinders University to assess self-management skills and plan holistic care. This information was then used to develop a medical care plan using the Medical Director software program, ensuring that the social and emotional health issues were included in the medical model creating holistic care and an integrated plan. The clients were also introduced to the six-week Stanford Chronic Disease Self-management course via the education sessions. This course was renamed the 'LIFE' course, which is an acronym for **Living Improvements For Everyone**. In this way several new elements to managing health were introduced to clients in a seamless and unthreatening way. It is an inclusive program (For Everyone) and LIFE was seen to be a more marketable and user friendly than Chronic Disease Self Management Program (CDSMP), the name given by the original designers at Stanford University, USA.

Thus the Pika Wiya LIFE Model consists of three main elements depicted by the large circles; the overlapping sections denote the key stakeholders with the target population in the centre and the contributing parties on the outer:

Figure 1 LIFE: an integrated model of chronic disease management



1. LIFE Course

The modified Stanford Chronic Disease Self-management course is a culturally appropriate course being developed and piloted for clients of Pika Wiya Health Service. Master trainers are available and planning to train health workers and community members in regional SA. The course itself is run over six weeks for approximately two and a half hours once per week. People with different chronic conditions attend together and share their experiences with trained leaders facilitating the group interaction following a basic script. Topics covered include (among others):

- techniques to deal with problems such as frustration, fatigue, pain and isolation
- appropriate exercise for maintaining and improving strength, flexibility and endurance
- appropriate use of medicines
- communicating effectively with family, friends and health professionals
- nutrition.

Self-management is a goal to work towards, however in our experience, many people are not ready for it. There are huge issues surrounding grief and loss to the extent that we have decided to include a new activity in the Stanford course on the subject. Many people are so preoccupied with tragedy, they have difficulty self managing their chronic conditions because it is not a high priority in their life. We have introduced the grief cycle similarly to how the symptom cycle is portrayed in the course and then, reinforce the message that many of the techniques that can break the symptom cycle can also break the grief cycle, even for a short time.

Other course modifications include more extensive scripting to encourage leaders confidence and ability to facilitate future courses. Language was changed to ensure no jargon or complex ideas without the opportunity for clarification. Many Aboriginal people who attended the course spoke English as a second or third language so it was recognised that the more effort they needed to exert to understand the principles and ideas, the less likely comprehensive understanding would occur. The modified version emphasises the need for leader support from peers and it is hoped that future trained Aboriginal leaders will form a network of communication and debriefing to ensure ongoing development and interest.

To train Course Leaders, Master trainers need to provide a structured outline of the course manual with several practical teaching sessions for each prospective Leader – this takes four full days of training and requires the text book *Living a Healthy Life with Chronic Conditions* (Lorig et al) plus a copy of the course manual for every Leader. Studies done by Kate Lorig and others at Stanford University suggest that a course facilitated by Leaders who are Health Professionals result in the participants **knowing** more, whereas a course facilitated by trained peer educators resulted in participants **doing** more (ie more healthy lifestyle changes such as regular physical activity, healthy dietary changes, regularly using stress relief and relaxation techniques.) So what we are aiming for are courses led by either a health professional and peer educator or by two peer educators. The process by which the course is delivered is considered to be the key to its success, not just the content. The emphasis is on group sharing of problems, learning problem solving principles and applying them as a group.

2. Health promotion

Health promotion consists of health related education focusing on prevention and promoting healthy lifestyles. Some of this content has been presented by Pika Wiya Health Service staff, SHC Project staff, or by guest expert speakers invited to talk to the community on specific health related issues for example, cancer prevention, heart disease, kidney disease and diabetes etc. Other health promotion activities included involvement in 'Health Expos' and the resultant promotion of project activities to the community, Chronic Disease Camps where the community was invited to participate in a structured, but informal education event involving guest speakers, participation in healthy food preparation, and sitting under the trees yarning about health and illness prevention.

3. Holistic care co-ordination

- Flinders Model of Chronic Condition Self-management
- Enhanced Primary Care Package (EPC)
 - Care planning
 - Aged Health Assessments
 - Adult Health Checks
 - Home Medication Reviews

Sustainability of the model was always important and therefore the initiation of a 'train the trainer' approach to the program was crucial. To date twelve health workers have been trained in the Flinders Model of CCSM and one Aboriginal project worker has been trained as a master trainer capable of leading courses to train other leaders. Training is available for health workers (PIH) and is planned to be ongoing for the future. A procedure manual is being developed for use by any Indigenous health service – this will reflect the models and IT systems used by Pika Wiya Health Service. A team approach is imperative for this model to work and to be sustained in the long term fully supporting the multi-disciplinary care philosophy of the EPC package.

PROGRESS AND OUTCOMES TO DATE

Aunty X is a Diabetic lady who at the end of one session said:

If you don't have diabetes now, then eat proper food so you don't get it.

Aunty Y said during a session:

You know, our mob don't talk much about these things but it is good for us.

Miss Z during a session (about her third) that she couldn't read or write so that makes life difficult for her. It took a lot of courage for her to admit that, especially in front of the group. We encouraged her to continue and supported her when written charts or whiteboard brainstorming were used, making sure to read things out several times. She interacted with the group and gradually became quite confident to speak out about issues. In the beginning she would often look at the ground and say nothing.

Mr W told us about when he was a child, his mother would colour his arms with charcoal – being half Afghan, he was considered half caste and the police would search for half caste children all the time to take them away. Once he and his brother were so frightened they ran to the bush where they lived for several weeks, eating goanna. ("Good tucker")

During a session talking about grief:

We feel real bad, y'know **real** bad. Lots of people have died but we are still alive.

Especially when the young ones die – we don't know why?

If we knew why they were dying, maybe we could try and fix it.

Ms A, a lady with Diabetes, Asthma, high blood pressure, and has also had a heart attack. She had a care plan prepared near the commencement of the SHC Project. She attended most sessions and both camps and formed friendships with other ladies in the group. She recently participated in care plan review and all her clinical measures had improved markedly: BP had reduced, weight had reduced, cholesterol was lower, HbA1c was lower (from 8 to 6.5).

After several sessions many people agreed:

I wish I knew then what I know now, perhaps I could have prevented myself getting these things.

Maybe we could have stopped other people getting things too. (Referring to family members)

During the first chronic disease self-management course, we were discouraged by the response in week one to the idea of making action plans. We thought we hadn't got through and that no

one understood or wanted to complete their plan. That week, one of the course leaders was approached by two ladies from the sessions, who were bubbling over with excitement because they had finished their action plan and couldn't wait to get to the next session to report their success.

After several sessions of the course, a few of the ladies got together and have walked regularly since. They joined a church walking group and healthy eating and cooking group. They seemed to be more confident to join in activities such as these since starting to attend the sessions at Pika Wiya.

Earlier in the project, an elderly man was interviewed using the Partners in Health scale and cue and response. He couldn't carve boomerangs anymore because it triggered his asthma. It was suggested he try a face mask, which he did quite successfully.

The same solution was applied to a man who had stopped carving emu eggs because of the fine dust. He successfully used a face mask. He really enjoyed carving and was extremely happy to start doing it again after a long break, during which he was clinically depressed and was unable to do any other activity.

One of the first interviews was with a Grandmother, who was looking after three grandchildren, living with friends, had a very low self-esteem and no support from her daughter. She was living with friends because she had no electricity at home; it was turned off because she couldn't pay her bill. When she arrived, she was depressed, teary, didn't know what to do. She felt she had worn out her welcome at her friend's house and she was having trouble sleeping. She was referred to emergency relief worker to work out a way to get power put back on in her house. She wanted to take her grandkids back home. She was also referred to the GP and Social and Emotional Well-Being program. After six months, she was able to talk to her daughter to arrange some support for the kids. They came to an agreement and share responsibility for their care. She gained a part time job and has recently purchased a car, which gives her more independence. Her self-esteem has improved to the point where she attended training to be a CDSM Leader. Now the challenge is to free up enough time for her to facilitate CDSM courses.

A lady came back to Port Augusta from interstate. Her son had multiple problems as well as being an uncontrolled Diabetic with extensive retinopathy which is making him blind. She was at a loss as to what to do for her son. She had previously lost two sons to suicide, and this son found both of them. She was a pensioner. During her cue and response interview, she revealed she wanted a part time job to help herself and her son. She thought her pension would stop her from doing this. Her name was networked through Pika Wiya and several other agencies. She obtained a job as a youth worker and is no longer on a pension. She is more confident now to deal with issues that come up and keeps in contact with SHC workers at Pika Wiya.

Many of the participants at the sessions saw the importance of going back to their families to share the things they had learnt. They also voiced that it was good to get out of the house, getting information and come together to share a nice lunch.

CONCLUSION

The Sharing Health Care Project, including the LIFE Program, have clearly been of benefit in facilitating clients with chronic conditions to become more informed about their health conditions, and, for many, greater involvement in their own health care. While it took some time for many clients to catch on to the concept of self-management, the client centred care planning approach and the use of groups and camps have been successful strategies. One of

the main benefits has been to help clients come to terms with living with a chronic condition and the social and emotional impacts of the condition. This appears to be a pre-requisite to self-management.

The uptake of the Enhance Primary Care items have increased significantly at Pika Wiya Health Service since the early stages of the project where the necessary organisation change processes needed to be implemented to support the new approach to chronic disease management including self-management. These changes include the introduction of Medical Director software, making the development of disease specific care planning templates an easier and more efficient alternative to paper based systems, changes in health workers roles to include assisting GP's with aged health assessments and care plans, and an ongoing education and in-service program for staff to update on best practice chronic disease interventions. A planned approach to monitoring peoples health and disease progression in this way has provided another opportunity to collect clinical data to track changes over time. This work is continuing to be developed.

The modified CDSM course (LIFE course), with support from the Department of Health and Ageing, is in the process of being developed, piloted and evaluated. It is envisaged that the completed manual will be available for distribution across Australia.

And as stated on more than one occasion by clients attending the LIFE course,

We need to get the young ones in 'ere to listen to this.

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PRESENTERS

Kate Warren was, until recently, the Project Officer for Sharing Health Care SA Demonstration Project and through transitional funding is now the Regional Chronic Condition Self-Management Training Co-ordinator. She is a Registered Nurse and Stomal Therapy Nurse with extensive experience in Nursing Management. Kate recently returned from Stanford University as a Master Trainer in Chronic Disease Self-Management. Kate is also certified to train health professionals in the Flinders Model of Chronic Condition Self-Management. She graduated with a Bachelor of Nursing via distance education in 1995 and is currently studying Chronic Condition Self-Management at Flinders University.

Fiona Coulthard is an Adnyamathana woman from the Northern Flinders Ranges region in South Australia. She has 15 years' experience working in the health field, beginning at Pika Wiya Health Service as a Receptionist progressing through to Data Processor to where she is now, working in the chronic disease management program (an evolution from the Sharing Health Care Demonstration Project) called the LIFE (Living Improvements for Everyone). In April this year, Fiona returned from the Stanford University as a Master Trainer in Chronic Disease Self Management. She is, at this point, the only Indigenous Master Trainer in the World.