

**National Evaluation of the sharing Health Care
Demonstration Projects**

Final Report – Executive Summary

June 2005

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KEY LEARNINGS

Overall, people participating in the Sharing Health Care Initiative demonstration projects reported:

- improved health outcomes;
- a better quality of life; and
- reduced use of health services.

The trend occurred across all eight demonstration projects, with the most significant changes occurring between the middle and baseline data collection points. These trends were also found in Indigenous and culturally and linguistically diverse (CALD) client groups.

A longer time period will be needed to fully assess the outcomes of the projects. However, the results will contribute to a growing body of evidence on the efficacy of self-management. Given that the aim of the Initiative was to test the effectiveness of self-management interventions in real life settings, lessons from the process evaluation are as important as the outcomes.

Process learnings

Projects best able to meet the challenges of implementing self-management into the community:

- were organisationally mature, with good infrastructure and support;
- had strong relationships with key stakeholders (eg community groups and Divisions of General Practice);
- established or capitalised on pre-existing relationships with a range of health service providers including general practitioners;
- were very flexible in their approach and design and able to respond to client feedback;
- employed a variety of approaches to recruitment and implementation, depending on the target group; and
- built capacity from an organisational perspective, most notably in the areas of network partnerships and knowledge transfer.

Implications for wider implementation

Program characteristics with the greatest potential for increasing effectiveness of self-management include:

- flexible approaches with tailoring of interventions to meet client need in terms of content and mode of delivery;
- ability to identify and respond to client need through the use of appropriate planning tools at the start of the program, reinforced by ongoing coaching and follow-up; and
- ability to provide appropriate and structured support to clients, finding the balance between over-dependence on the support on offer and being isolated from the program.

EXECUTIVE SUMMARY

This summary presents the main findings of the National Evaluation of the Sharing Health Care Initiative demonstration projects, in terms of clients, carers, community, health service providers and the health system. It also gives some recommendations for future implementation of self-management in Australia.

Background

Chronic conditions such as arthritis, osteoporosis, asthma, heart disease, stroke and diabetes represent one of the greatest health challenges for Australia in the 21st century.

Evidence in Australia and overseas suggests that self-management programs can assist those with chronic conditions to improve their quality of life, by equipping them with the knowledge, skills and confidence to better manage condition-related problems. Self-management interventions have the potential to bring about long-term systemic benefits that could lessen the burden of chronic disease in Australia.

Activities associated with self-management cover a broad range of areas including regular physical activity, healthier eating, improved social functioning and symptom control. 'Self-efficacy' — the belief in one's own ability to successfully perform health behaviours — is an important prerequisite for such behaviour change.

In Australia, chronic condition self-management (CCSM) programs are mainly provided by a range of non-government chronic disease organisations and private health insurance groups. Self-management programs have been successfully developed and implemented in a number of Aboriginal Medical Services and several different culturally and linguistically diverse (CALD) communities.

The medical profession in Australia is increasingly supportive of the concept of self-management with its focus on patient-centred care. State and Territory governments are starting to incorporate self-management programs for consumers into their chronic disease management strategies. They are now looking to the Commonwealth to provide national strategic direction in this area.

The Sharing Health Care Initiative

The \$36.2 million Sharing Health Care Initiative (SHCI) has tested a range of chronic condition self-management models that could be suitable for the Australian health care system. The outcomes of the SHCI will feed into the National Chronic Disease Strategy (NCDS), which is currently being developed by the National Health Priorities Action Council.

The SHCI's evaluation of CCSM in the Australian context aims to provide a 'road map' of how such models can be implemented more broadly in Australia. Eight demonstration projects were established (one in each State and Territory). In addition to being directed at those over 50 years of age with a chronic condition, in the project's local area, a number of projects also targeted participants from CALD backgrounds, and two projects also targeted Indigenous people aged over 35 with a chronic condition. In addition to the National Evaluation, the projects were supported by a range of education and training materials.

The National Evaluation of the SHCI examined the effects on clients, their carers, the community, local health service providers and the health system. The process evaluation, which underpinned the impact and outcome evaluation, showed useful findings in terms of recruitment, implementation and sustainability. These findings will provide helpful lessons for future policy development.

This document is the summary and discussion of the final evaluation report. A final technical report and appendices provide greater detail and analysis.

The demonstration projects

The demonstration projects covered a broad spectrum of metropolitan, urban, rural and remote Australia and operated out of a range of organisations. Each project was implemented by its own consortium of groups comprising consumers, health service providers and community organisations. The range of self-management activities for clients explored by the demonstration projects is summarised below.

Planning	Training	Support
<ul style="list-style-type: none"> • Self-management action planning eg problem and goal setting • Care planning, including medication review, health service review 	<ul style="list-style-type: none"> • Six-week Stanford course • Disease-specific courses (eg diabetes, cardiovascular disease) • Healthy eating shopping trips • Cookery and nutrition classes 	<ul style="list-style-type: none"> • Telephone coaching • Support/self-help groups • Walking groups • Tai Chi classes

The demonstration projects had a variety of designs, approaches and target groups, and offered different combinations of these interventions. An analysis of the interventions and the level of client support being offered by the projects identified four main intervention models (see Discussion for more detail).

Key results for clients, carers and the community

A number of key results were identified for those who had participated in demonstration project self-management intervention programs. Using focus group feedback from clients and health service providers, the following key findings emerged:

- clients reported both positive psychological and physical benefits from participating in the demonstration projects, such as increased knowledge about their conditions and their management, increased sense of empowerment and undertaking more physical activity; and
- health service providers reported that their clients appeared to be more knowledgeable and confident, and that they had also improved psychologically and physiologically.

Although not the primary focus of the demonstration projects, carers felt that their involvement in the self-management demonstration projects was of benefit to them and the people they cared for.

Projects that used a targeted approach to community engagement as well as capitalising on existing community networks found greater

success. Such an approach enabled the demonstration projects to extend their reach and recruit participants from targeted CALD background communities.

The community development models pursued by the Indigenous demonstration projects explored some innovative approaches, such as employing Aboriginal health workers and community support workers. These workers helped to build community capacity to manage and support community members with chronic conditions.

Key results for health service providers and the health system

Many of the implications identified for general practitioners (GPs) and other health service providers reflect broader health system issues, including:

- while GPs were generally very receptive to the concept of self-management, and found participation in the SHCI a rewarding experience, constraints on their time were a significant barrier to their more active involvement in the program;
- the role of other health service providers (for example, practice nurses, community nurses, allied health professionals and Aboriginal health workers) provided much of the energy and impetus in the demonstration projects;
- education and training of GPs, specialist doctors and other health service providers in self-management techniques will have a critical role in helping to ensure its integration into everyday clinical practice; and
- for projects with a high level of health service provider turnover, it was difficult to retain the necessary level of self-management knowledge within their health service provider group. Providing ongoing training and support was necessary, even though this was recognised as being resource intensive.

Several factors reduced the demonstration projects' capacity to bring about health system change and/or increased integration within local health systems. Some examples of potentially sustainable initiatives came out of the SHCI and will be important indicators of sustainability. However, a range of systemic barriers to self-management will need to be overcome before it can be integrated more widely within the health system. These include transport for clients, coordinating multidisciplinary care processes without duplication, high staff turnover, the need for networks/relationship building and issues in education and training.

Recommendations for future implementation of self-management

There are a number of key recommendations arising from the National Evaluation:

- it is important to be clear about who audiences are and target them appropriately, through mechanisms such as existing trusted community networks, engaging with local community groups, reviewing patient lists and working with the community to build its capacity for self-management;
- specific program features should be considered in future self-management policy initiatives:
 - a flexible approach, both in terms of the interventions being tailored to meet client need (so that every component of the program is not compulsory) and in the mode of delivery (eg telephone coaching) which could facilitate ongoing participation;
 - ability to identify and respond to client need through the use of appropriate tools (for example the Stages of Change approach); and
 - ability to provide appropriate and structured support to clients, so that they do not become overly dependent on the support on offer but nor do they feel isolated from the program;
- GPs must continue to be an important source of referral to self-management programs in the future. Their pivotal role in the primary care setting means they are well placed to act as facilitators for developing and encouraging self-management in their clients;
- the role of practice nurses, community nurses, allied health professionals and Aboriginal health workers should be acknowledged as being essential to the ongoing embedding of self-management principles and techniques into the health system;
- beginning self-management education of doctors and other health service providers at university could promote early interest and uptake;
- providing regular training updates to practising health service providers (eg through Divisions of General Practice and other professional bodies) about the benefits of self-management would raise awareness and encourage further interest; and
- for quality assurance purposes, it will be important to actively monitor the training records of health service providers and lay trainers who are involved in structured CCSM education and training of clients.

DISCUSSION

This Discussion aims to:

- *provide the key results arising from the National Evaluation of the Sharing Health Care Initiative demonstration projects; and*
- *discuss the implications for chronic condition self-management arising from the National Evaluation.*

Background

Self-management has been defined as an “individual’s ability to manage their symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition.....to maintain a satisfactory quality of life” (Barlow et al 2002).

Self-management approaches cover a broad range of areas including active decision making about treatment and management of conditions, regular physical activity, healthier eating, improved social functioning and symptom control. An important pre-requisite for such behaviour change is ‘self-efficacy’— the belief in one’s own ability to successfully perform a health behaviour.

Chronic diseases make up more than 70 per cent of Australia's overall disease burden due to death, disability and reduced quality of life. This is expected to increase to over 80 per cent by 2030, at a cost of more than \$51.5 billion to the Australian community.

Evidence in Australia and overseas suggests that self-management programs can assist people with chronic conditions to improve their quality of life, by giving them knowledge, skills and confidence to better manage disease-related problems.

To be effective, chronic condition self-management (CCSM) needs to be part of a high quality, comprehensive approach to prevention, detection and management of chronic diseases.

There are a number of suggested underlying principles on which self-management programs are based. These state that for effective self-management, people with chronic conditions should:¹

- know about their condition(s) and the various treatment options available;
- be actively involved in decision-making about treatment and management of their condition;
- follow the treatment or care plan developed with their health service providers;
- monitor their symptoms and take appropriate action to manage and cope with the symptoms;
- manage the physical, emotional and social impact of the condition(s) on their life; and
- adopt a healthy lifestyle.

The Sharing Health Care Initiative

The national Sharing Health Care Initiative (SHCI) is part of a wealth of activity in self-management in Australia and internationally.

The \$36.2 million SHCI evaluated, across a series of demonstration projects, a range of CCSM models that could be suitable for the Australian health care system. In addition to the National Evaluation, the demonstration projects were supported by a range of education and training materials. Together with other evidence-based research, the evaluation will guide the broader implementation of CCSM nationally.

The SHCI was designed to improve health-related quality of life for people with chronic conditions, to encourage people to use the health care system more effectively and to enhance collaboration between

¹ Based on the work of the Flinders Human Behaviour and Health Research Unit

individuals, their families and health care professionals in the management of chronic conditions.

There is a strong evidence base surrounding the *efficacy* of self-management interventions (as measured through randomised controlled trials). The aim of the SHCI was to test its *effectiveness*, by:

- demonstrating the roll-out processes of a range of self-management service delivery approaches in the wider Australian context; and
- understanding their effectiveness in a practical setting.

The context

The importance of CCSM has been recognised around the world and many countries are exploring how to implement self-management more broadly through both system-wide approaches and local programs.

In Australia, there is much activity in self-management which is contributing to the CCSM evidence base. A range of research studies have been undertaken by various research groups and universities, including randomised controlled trials and evaluated projects at jurisdictional and local levels. These include randomised controlled trials of the *Coaching Patients on Achieving Cardiovascular Health* (COACH) Program (Vale et al 2002) (see box in margin) and of peer led self-management of chronic illness programs for people from culturally and linguistically diverse (CALD) backgrounds (Belfrage 2003).

There are also many self-management activities being undertaken by community organisations (such as the Arthritis Foundation of Australia), service providers (eg the Silver Chain Nursing Association in WA), and the health insurance sector (eg the CareLink program in NSW). The medical profession is increasingly supportive of self-management, and its focus on patient-centred care is already integral to teaching within medical and health sciences schools in Australia.

All levels of government have recognised the importance of chronic condition management and prevention, with each State and Territory having developed some form of strategy or framework to address these issues. The majority of these documents also acknowledge the importance of CCSM as a part of any chronic condition management and prevention model. Jurisdictions are now looking to the Commonwealth to provide strategic direction in this area.

The SHCI is the most comprehensive government CCSM initiative within Australia, with the outcomes of the National Evaluation feeding into the National Chronic Disease Strategy (NCDS). Self-management is proposed as one of the four key action areas in the NCDS, which is currently being developed by the National Health Priorities Action Council.

***Efficacy:** the ability of an intervention to achieve its intended effect in individuals who comply with it under optimal conditions; ie its effect in an ideal world.*

***Effectiveness:** the ability of an intervention to achieve its intended effect in those to whom it is offered; ie its effect in practice or in the real world.*

(Hawe & Hall 1990)

COACH program

The program is based on empowering patients (through coaching) to obtain the best care from their usual treating doctor. The multicentre randomised controlled trial in Victoria showed that coaching achieves significant risk factor reduction in patients with heart disease.

The trial also claims to be the first hospital/community disease-management program that has been successful in significantly reducing risk factor levels in patients with heart disease without involving the prescription of medication directly to patients. Coached patients also reported feeling less anxious, healthier and happier than usual care patients.

(Vale et al 2002)

The demonstration projects

Between July 2001 and June 2004, twelve demonstration projects were funded to develop locally-based self-management service delivery approaches. Eight of these projects (one from each State and Territory) were included in the National Evaluation, and are listed below.

The demonstration projects focused on adults, aged 50 years and older or 35 years and older for Indigenous populations, with one or more of the following chronic and complex conditions:

- cardiovascular disease (including stroke and hypertension);
- diabetes;
- arthritis;
- osteoporosis;
- respiratory disorders; and
- depression (where it exists as a comorbidity).

The demonstration projects covered a broad spectrum of metropolitan, urban, rural and remote Australia, operated out of a range of organisations and had a variety of designs, approaches and target groups. Each project was implemented by its own consortium of groups comprising consumers, health service providers and community organisations.

Location	Name	Sponsor
NSW	South Western Sydney Chronic Disease Self-Management Demonstration Project	South Western Sydney Area Health Service
Vic	The Good Life Club	Whitehorse Division of General Practice
Qld	Sharing Healthcare	The Arthritis Foundation of Qld
WA	HealthPartners	Canning Division of General Practice
SA	Our Health in Our Hands in Our Region	SA Centre for Rural and Remote Health and the Spencer Gulf Rural Health School
Tas	Whose Health is it Anyway?	University of Tasmania Department of Rural Health
ACT	Health Partners ACT	ACT Division of General Practice
NT	Katherine West Health Board Chronic Disease Self-Management Project	Katherine West Health Board

Each demonstration project tailored its interventions to suit the particular population it was targeting. In addition to being directed at those over 50 years of age (or over 35 years of age for indigenous communities) with a chronic condition, in the project's local area, a number of projects also targeted participants with specific backgrounds, such as Arabic speakers (NSW project), Spanish speakers (ACT project), the Polish community (Tas project) or the Chinese community (Vic project). Other projects targeted Indigenous communities (NT, SA), or groups such as those with a lower socio-economic background (WA, SA) or those in rural or remote communities (SA, QLD).

Indigenous projects

While the Indigenous and non-Indigenous demonstration projects shared some similar experiences during the implementation of the SHCI, there were also significant differences as a consequence of their settings. To reflect the importance of these contextual issues on the reported findings, key results for the Indigenous projects have been separated in this Discussion (see Chapter 3).

Distinct from the SHCI, the Katherine West Aboriginal Health Board undertook a clinical audit based on their project. The results will be available in late 2005.

CCSM interventions used in the demonstration projects

The major intervention models used as part of the Initiative were:

- the Stanford Chronic Disease Self-Management (Lorig) model (Lorig et al 2000), which involves a six-week generic self-management course. The courses are led by trained lay-leaders and health professionals, who teach techniques for illness management, including problem solving and goal-setting skills, and offer mutual support;
- the 'transtheoretical Stages of Change' model (Prochaska & DiClemente 1983), which assesses a person's readiness to make changes to their life. The aim of this model in terms of CCSM is to enable patients' perceptions and goals to be formally included as part of the care planning process. A range of education and training materials has been developed by the Flinders Human Behaviour and Health Research Unit to assess self-management status and identify self-management problems and goals;
- a telephone coaching model which involves a 'coach' who, through motivational interviewing techniques, encourages adherence to treatment, negative effect management, improved self-efficacy and consolidated social support (Kelly et al 2003); and
- a combination or adaptation of these models, as well as other supporting activities such as 'clubs', web sites, supermarket tours to promote purchase of healthy foods, and exercise groups.

The specific intervention models used by the demonstration projects are described in Chapter 1.

Demonstration project methodology

Within the self-defined context of each demonstration project, the focus was to:

- develop and refine solutions to bring about change and improvement in identified systemic problems;
- develop and strengthen partnerships between relevant stakeholders; and
- be responsive and appropriate to their environmental context.

As a result, the projects were not efficacy trials (eg randomised controlled trials) of self-management interventions. Rather, their

purpose was to improve understanding about how to effectively deliver self-management programs in the Australian context and to provide Australian-specific information for future policy options to improve the management of chronic conditions.

The methodology allowed demonstration projects to respond to data collection and client feedback and refine their approaches during implementation.

The National Evaluation

PricewaterhouseCoopers undertook the National Evaluation of the SHCI between July 2002 and June 2004. The National Evaluation aimed to:

- monitor the implementation of each demonstration project;
- determine the extent to which the intervention models were taken up, effective and sustainable in real world rather than research settings; and
- understand the extent to which projects reached and benefited their target populations.

Data from the SHCI demonstration projects were collected and analysed at the beginning, middle (six months) and end (12 months) of each project, to provide evidence of change over time in terms of clients, families and carers, communities, health service providers and health services systems. The evaluation was structured around the following questions:

- 1 Which recruitment strategies are most successful in recruiting which clients/groups of clients?
- 2 Which clients/groups of clients are most likely to participate in which programs?
- 3 What other factors influence participation rates and in which direction?
- 4 How and by how much does the form/structure of self-management education influence the health behaviours and health outcomes of clients?
- 5 How and by how much does the type, intensity and frequency of client support and follow-up influence the health behaviours and health outcomes of clients?
- 6 How and by how much does the SHCI intervention components influence community outcomes?
- 7 What is the level of client and carer/family/significant other satisfaction associated with each program? What factors influence this?
- 8 What is the level of behaviour modification by health service providers? What factors influence this?
- 9 What factors effect the sustainability of the program?

Given the demonstration project design of the SHCI, the 'evolution' or progression of the processes was an overarching theme of the National Evaluation. Process evaluation was therefore a critical component, enabling monitoring of project implementation as well as providing a context for the impact and outcome evaluations. Process learnings also contributed to an understanding of what was successful and why, which will help to inform potential areas for further policy development and the roll out of future programs.

The framework, strengths and limitations of the National Evaluation are described in Appendix A. Further details of the methods and results of the National Evaluation are available in the final technical report and appendices.

1 Implementation and reach of the demonstration projects

This chapter discusses aspects of the implementation of the demonstration projects, including refinement of methodologies over time, and the effects of this on participation levels and client processes.

1.1 Evolution of marketing and recruitment approaches

Successful marketing strategies

- ❖ *Targeting consumers directly through pamphlets, posters, videos, presentations to community groups and media announcements.*
- ❖ *Proactive community engagement.*
- ❖ *Targeting specific groups with appropriate marketing material (eg TV, local radio, cartoons in newspapers).*
- ❖ *Word of mouth recommendations.*

Successful recruitment strategies

- ❖ *Recruiting clients into support groups or training courses before formal recruitment into demonstration projects.*
- ❖ *Establishing or capitalising on pre-existing relationships with health service providers.*
- ❖ *Opportunistic referral or recruitment during GP consultation.*

All the projects had some marketing and recruitment strategies in common – for example, targeted community presentations, mail-outs and media releases. Most had to refine their approaches over time to increase participation and extend their reach to specific groups.

Marketing

Throughout the development and implementation phase, the demonstration projects continued to develop their methods of marketing directly to clients, for example through pamphlets, posters, videos, presentations to community groups and media announcements. Marketing strategies that proved most successful were those that were targeted to specific groups – for example, clients from CALD backgrounds. This targeted approach was facilitated by ensuring marketing material was suitable for these groups. In addition, as the projects progressed, word of mouth became an increasingly successful method of marketing.

Active community engagement was also explored by some of the projects as a way of reaching their client base. This is discussed in Section 2.3.

Recruitment

As with marketing, many of the demonstration projects departed from their planned recruitment strategies (eg through health service provider referral) and examined more creative ways to improve recruitment numbers. For example, projects began to recruit clients into project-led initiatives (such as support groups or formal education and training eg the Stanford CDSM course) before formal recruitment into the demonstration project self-management programs.

Establishing or capitalising on pre-existing relationships with local health service providers was identified as being a successful recruitment strategy. Recruitment was also made easier if it could occur opportunistically, for instance, when GPs either referred or recruited clients at the same time as a GP/client consultation. However, given the difficulties in engaging GPs in client recruitment (discussed further in Section 2.4), the benefits of this approach could not be fully realised within the time available for the National Evaluation.

Recruitment in the Indigenous demonstration projects

In recruiting specific clients to their self-management programs, the Indigenous projects were able to use their links with their respective Aboriginal health service organisations, asking them to identify from patient records which clients were likely to benefit from participating in their projects. One project also pursued a less targeted recruitment approach as it progressed which seems to indicate that it was necessary to explore more creative ways to encourage recruitment. In addition, both projects undertook broader health promotion activities (see Section 3.3) which also resulted in some self-referrals to the projects, although their main purpose was to increase awareness within the communities about self-management.

While formal recruitment was important to the Indigenous demonstration projects, it was not necessarily their primary concern. In some cases it is difficult to estimate how many clients were formally recruited into the demonstration project and hence make any judgment about the success or otherwise of its recruitment strategies from an evaluation perspective.

Key points

- Most demonstration projects had to refine their recruitment approaches over time to increase participation, especially of harder to reach groups (eg those with lower socioeconomic status and those from CALD backgrounds).
 - Using a variety of innovative, proactive approaches to marketing and recruitment (eg cartoons in local newspapers, local radio, TV), together with capitalising on pre-existing relationships with the health service provider community, were found to be successful strategies.
-

1.2 Intervention models

The demonstration projects explored a range of self-management interventions as part of the roll-out of the SHCI, with most combining a number of CCSM interventions.

- *Care plans* — most projects incorporated some form of care plan or action plan aimed at identifying the needs of each participant. These included generalised self-management education and training, referral to other health service providers, or condition-specific advice. The care plans were either multidisciplinary Enhanced Primary Care (EPC) care plans or care plans worked out between participants and their health service providers. A number of projects utilised the Flinders Human Behaviour and Health Research Unit *Partners in Health* tools as part of the care planning process.

- *Training and education* — All projects offered some form of self-management training and education. Mostly this was the Stanford course, often with other options such as condition-specific education (eg diabetes education), one-on-one training, or education on issues such as nutrition and physical activity.
- *Support* — The projects offered varying degrees of ongoing support. This was integral to some projects where ‘clubs’ were formed (eg the Good Life Club in Vic, the Live Life Club in WA). Telephone coaches, buddy systems or regularly scheduled activities were other support options. There were also more informal support groups or activities, some of which were initiated by project participants.

An analysis of the interventions and the level of client support being offered by the projects identified four main intervention models. (summarised in Table 1 below). Participation and demographic profiles are discussed further in Section 1.3.

Table 1 Summary of participation by intervention model

Description of intervention models	Demographic profile*	Key partners
Intervention model 1: training (especially the Stanford course) was the main intervention with relatively high levels of participation. No client planning and limited support was provided.	<ul style="list-style-type: none"> • More people with arthritis • More females • Broad age range, towards the younger 	<ul style="list-style-type: none"> • Non-government organisation • University
Intervention model 2: a complete suite of interventions was provided comprising client planning, training and support. A very high percentage of clients participated in all three activities. The majority of clients attended a Stanford course as part of the training component of the intervention model.	<ul style="list-style-type: none"> • Older age group • More females • More from CALD backgrounds • More with no qualifications • More in supported accommodation • More with a carer 	<ul style="list-style-type: none"> • State health authority • Division of General Practice
Intervention model 3: participation in activities was based on client need and was voluntary. Only approximately half of the clients participated in client planning and training activities and only a minority attended a Stanford course, with other training activities being on offer. A high proportion of clients sought support from the demonstration project self-management programs.	<ul style="list-style-type: none"> • Less university educated • More smokers <p><i>In all other instances the demographic profile was consistent with the average SHCI cohort.</i></p>	<ul style="list-style-type: none"> • University • Division of General Practice
Intervention model 4: Telephone coaching was the main intervention based upon the Stages of Change approach. None of the clients received Stanford training. There was a high level of participation by clients in all demonstration project activities – planning, training and support.	<ul style="list-style-type: none"> • More males • More from CALD backgrounds • More university educated • More living with family • More employed • Broad age range • More non-smokers • More people with diabetes 	<ul style="list-style-type: none"> • Division of General Practice

* The relative comparisons made in this table eg ‘more’ or ‘less’, refer to the proportionate representation which any particular characteristic has in relation to the overall distribution.

Key point

- There are many different self-management interventions. Self-management cannot be 'pigeon-holed' into just being about client education or delivering a course but also has significant implications for prevention and health promotion through a range of client planning and support activities.
-

1.3 Participation in the demonstration projects

From the National Evaluation's perspective, it was only possible to measure the participation rate of those who also took part in the evaluation. Participation in the interventions varied from project to project, depending on its design and intention — for example:

- whether participation in an intervention was voluntary or compulsory;
- the type of training offered (eg the six-week Stanford course as opposed to one-off disease-specific training); and
- the extent to which the intervention was customised over time to meet client need.

Demonstration projects (non-Indigenous)

The majority of the participants were female and most of the cohort was aged 66 years or older. A spread of educational backgrounds was reported although those with university qualifications were least represented in the sample.

While the participants came from the 'non-Indigenous demonstration projects', approximately 2 per cent reported being of Indigenous background. This is consistent with the overall proportion of people from an Indigenous background as reported in the 2001 Australian Census (Australian Bureau of Statistics 2002). Approximately 15 per cent of the cohort spoke a language other than English at home, indicating that they came from a CALD background.

Arthritis was reported most frequently as the condition which had the most impact on life. This was followed by diabetes and cardiovascular disease.

A summary of the cohort's demographic and health-related characteristics at the baseline and middle measurement points is given in Figures 1 and 2.

Figure 1 *Demographic characteristics of non-Indigenous demonstration projects' clients*

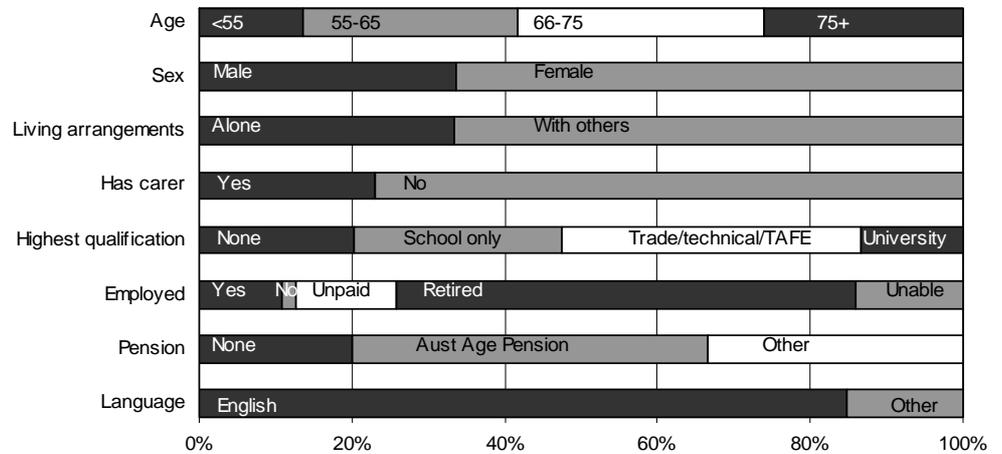
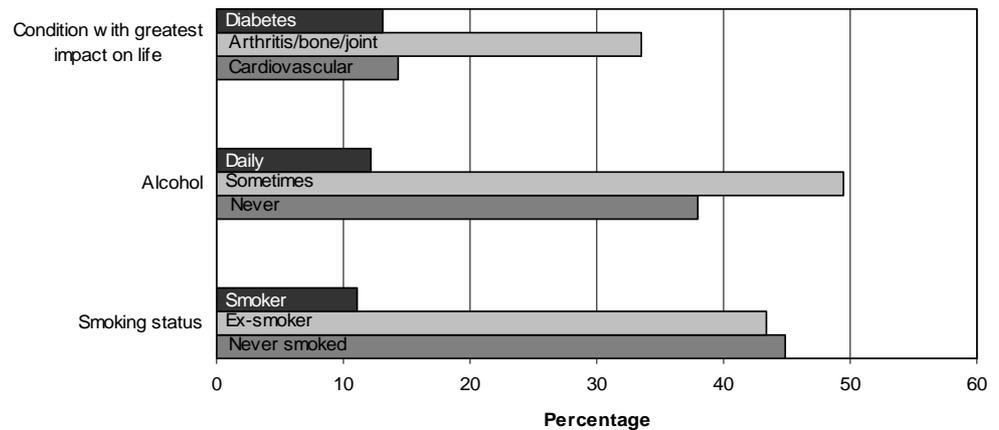


Figure 2 *Health-related characteristics of non-Indigenous demonstration projects' clients*



Impact of loss to follow-up

Figures 1 and 2 do not include clients who were lost to follow-up (ie clients for whom data at the three measurement points were not available). Understanding the profile of those who were lost to follow-up may therefore also give an indication as to which sorts of people the demonstration projects were *not* assisting given their decision to drop out before the program finished. These profiles were:

- *Demographic profile:* clients in the younger age category (<55 years of age) were somewhat more likely to be 'lost to follow-up', as were those in intervention model 4. There were no other significant

demographic differences between the groups in terms of loss to follow-up.

- *Health status profile:* clients lost to follow-up had a slightly higher mean Health Distress score at baseline compared to clients who remained in the study. There were no other significant differences in the health variables between the groups.

The reasons noted by the demonstration projects for client drop-out from their self-management programs ranged from the clients being too busy or lacking sufficient interest to attend, through to ill health preventing attendance. Death, relocation and ‘too many questionnaires’, were cited as reasons for dropping out of the evaluation.

However, some methods of follow-up were more successful than others (eg face-to-face interviews compared with mail-outs), which implies that not all dropouts from the evaluation were necessarily unhappy with the process but rather the follow-up was not active enough.

Factors affecting participation

A key characteristic of the demonstration projects was diversity with respect to their design and approach, target groups and location. As a consequence, it is not surprising that different groups of clients participated in the projects. The main reasons for this include:

- Different groups of people were attracted to different demonstration projects as a result of the interventions on offer. For example, intervention model 4 which offered telephone coaching appealed more to men (compared to the approaches on offer by the other projects), whereas intervention model 2, which offered more intensive structured support, attracted those with higher needs — as shown by the fact that their client profile was older, more lived in supported accommodation and more reported having a carer.
- The recruitment profile of the various demonstration projects also reflected the different client recruitment strategies undertaken. Intervention model 4 targeted those with diabetes and targeted members from the local Chinese community, whereas intervention model 1, through its links with the local Arthritis Foundation, attracted more clients with arthritis.
- The location of the projects also potentially influenced the types of clients participating since it is an indicator of socio-economic status. For instance, it would appear that the clients from intervention model 2 came from a lower socio-economic background. This is significant because of the inter-relationship between social economic status and a client’s existing health status and their potential capacity to self manage (Commonwealth Department of Health and Aged Care 2001).

Demonstration projects — non-Indigenous

Facilitators to participation

- ❖ *Opportunity for social interaction with other participants was reported as being the main incentive for continued involvement.*
- ❖ *Clients consistently reported a very high level of satisfaction with the courses provided by the demonstration projects, which encouraged ongoing participation.*

Barriers to participation

- ❖ *Lack of transportation, long waiting lists and the costs associated with accessing allied and other health services were consistently reported by clients as being barriers to participation.*

Indigenous demonstration projects

Facilitators to participation

- ❖ An important contributor to client satisfaction was the ability of the demonstration projects to respond positively to early challenges.
- ❖ Constructive and positive relationships between clients and demonstration project staff encouraged ongoing participation.

Barriers to participation

- ❖ As with the non-Indigenous demonstration projects, lack of transportation, long waiting lists and the costs associated with accessing allied and other health services were identified as barriers to participation.
- ❖ These barriers are likely to be more acute for those living in Indigenous communities, particularly in rural and remote areas (Commonwealth Dept of Health and Aged Care 2001).

Indigenous demonstration projects

As with the other demonstration projects, the extent to which clients participated in the self-management programs varied both within and across the Indigenous projects. The extent to which clients participated depended on their capacity and readiness for participation and the ability of the demonstration projects to respond to these different needs. For example, most of those approached by a demonstration project may have completed some form of problem and goal setting discussion, but not all those people would have had this formalised into a care plan, and even fewer would have had formal education and training (eg adapted Stanford training). However, all clients were still considered to be participants in the demonstration projects. Participation in the demonstration project self-management programs also occurred at the broader community level which is discussed in more detail in Section 3.3.

The main similarity between the Indigenous and non-Indigenous demonstration projects was that the majority of clients in the Indigenous projects were female. In the Indigenous projects, the level of schooling reached by clients tended to be lower, while the cohort was younger with the age range of clients distributed more evenly across the age categories (<35 years to 65 years plus). Also, the vast majority of respondents reported that they did not speak English at home and that they lived with their families (95 per cent compared to 65 per cent). Diabetes and cardiovascular disease (compared to arthritis for the non-Indigenous demonstration projects) were the most common conditions reported.

A summary of the cohort's demographic and health-related characteristics at the baseline and middle measurement points is given in Figures 3 and 4.

Figure 3 Demographic characteristics of the Indigenous demonstration projects' clients

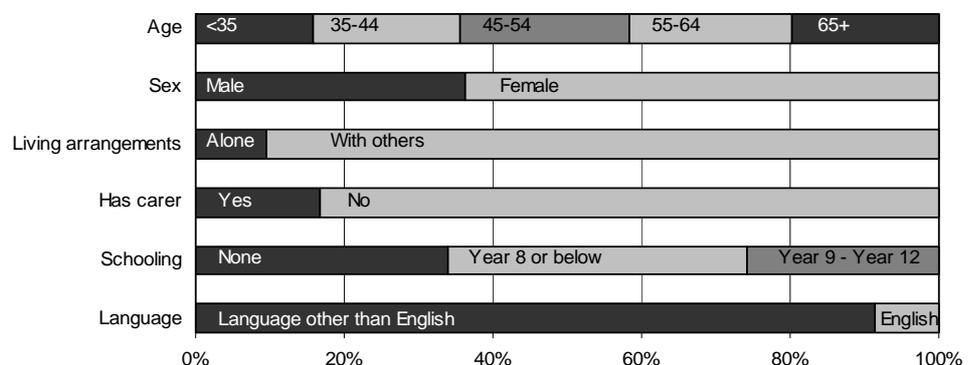
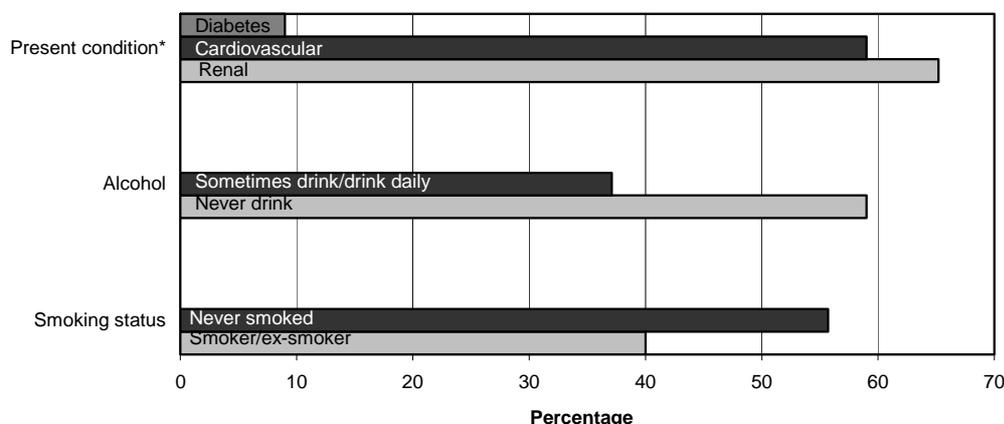


Figure 4 Health-related characteristics of the Indigenous demonstration projects' clients



Impact of loss to follow-up

Some difficulty was experienced by the Indigenous demonstration projects in following up clients for evaluation purposes. This was due to issues associated with staff resources and turnover, and client willingness to participate. Despite this, surveys found that the clients lost to follow-up were not significantly different from those who continued to participate in the study – in terms of both demographic profile and health status (details can be found in the technical report).

Key points

- The demonstration projects differed according to design, approach, target group(s) and location. As a result, the clients they attracted had quite different demographic profiles.
 - Participation in the demonstration projects varied according to the appeal to clients of the interventions on offer, recruitment strategies and degree of targeting within the local area.
 - Lack of transportation, long waiting lists and the costs associated with accessing allied and other health services were identified as barriers to participation in both Indigenous and non-Indigenous projects.
 - Face-to-face interviews were found to be more successful as a follow-up technique than less direct method such as mail-outs.
-

1.4 Client processes — planning, training and support

The process evaluation mapped out the processes undertaken by the demonstration projects and how these changed over time. To understand the impact of the SHCI on the health behaviours and outcomes of participants, the three main 'care-related' process issues need to be considered — client planning, training and support.

Demonstration project-led education and support

A club was established by a demonstration project which provided monthly information/education sessions on health-related topics (eg pain management, healthy foods, medications and finances) and was open to both community members and demonstration project clients across two sites. Club participants began to volunteer to undertake club duties (eg choosing topics for presenters, setting up for the club, and coordinating the sessions) and the demonstration project helped them to form a committee with the aim of running the club post-demonstration project.

Telephone coaching approach

One demonstration project used a coaching model where allied health professionals or practice nurses in community health services provided support to clients. The coaching model aimed to develop self-management capacity over time, facilitate access to services and promote partnerships with GPs. The coaching model involved monthly telephone contact over a period of 12 months.

Demonstration projects (non-Indigenous)

Planning

While most of the projects undertook post-recruitment self-management 'action' planning with clients to help them set their self-management goals, not all had a formal care planning process which involved a health service provider. At the outset, most projects had intended to have formal care planning, anticipating the care planning Medicare Benefits Scheme (MBS) item to be an important incentive for GP involvement and a potential sustainable approach. However, the demonstration projects' limited success in engaging health service providers, and the extent to which they wished to be involved in the care/self-management planning process, meant that this was not possible.

As the demonstration project self-management programs progressed, the focus moved to the follow-up and review of care plans. Clients in projects that did not have the direct involvement of a GP were encouraged to take their plans along to future GP visits and be proactive in engaging their GPs in this way.

Training

The primary focus of demonstration projects with an early emphasis on formal education and training was on educating clients in the Stanford self-management course. However, as the projects progressed, clients requested more group education and in response to this demand, the majority of projects introduced further education and training options for their clients (eg Tai Chi classes, cooking courses and computer training).

Support

Similarly, the extent and scope of support offered/facilitated by the projects broadened as the SHCI progressed, which was again in response to client demand. Initially, the primary support mechanism offered to clients was a support group which had either grown out of the Stanford courses themselves or was already established in the community. By the end of the SHCI, the available support options had extended to a wider range, including walking groups and buddy support systems. In some instances though, support was the *main* intervention offered and it tended to include elements of planning and education on an ongoing basis — for example the demonstration project-led education/support group format or the telephone coaching approach (see boxes in margin).

Indigenous demonstration projects

The two Indigenous demonstration projects implemented broadly similar self-management programs, although some local variation was observed due to the specific needs of the communities, the objectives of the projects and the level of resources available to them. They included whole of community health promotion activities, but also used a range of CCSM-specific interventions. The Indigenous projects

were most similar to intervention model 3. For the Indigenous projects, less distinction was made between client-related activities and community-related. For example, many of the support activities undertaken had much more of a community focus.

Reflecting the demonstration projects' responsiveness to client need, the Indigenous projects incorporated interventions and adapted their self-management programs to try to better meet their clients' needs and to support them in self-management. The steps taken by the projects to do this are discussed below. However, while this adaptation to client and community need appeared to be of some benefit, the limited length of the SHCI, together with the incomplete nature of the quantitative data, meant that it was not possible to fully assess the effectiveness of these approaches, in terms of improvements in health outcomes, as part of the National Evaluation.

Planning

Both Indigenous demonstration projects recognised the significant influence that broader social issues had on their clients' overall wellbeing. For example, as part of the problem and goal setting in the planning process, clients were asked to identify which problem had the most impact on their life and often they identified social issues (eg problems with their electricity supply or child care responsibilities), rather than health-related issues. It was reported that in many instances, addressing the social issue first often had a positive effect on their clients' wellbeing and/or their capacity to more effectively manage their health. For one of the Indigenous projects, this process was formalised into a social care plan.

Another innovative approach taken by one of the Indigenous projects to enhance the planning process was the establishment of a CCSM clinic. At these clinics, care plans were developed by a multidisciplinary team of their GP, nurse and the community support worker in conjunction with the client. This enabled specific time to be devoted to the care planning process in a supportive environment for the client. In addition, the care planning tools used by both projects continued to evolve over the life of the SHCI, in terms of being made more culturally appropriate and user-friendly for clients (eg through the use of pictures to help explain medical terms).

Training

In order to meet the diverse needs of the community, culturally appropriate training for community members was critical, and meant that both Indigenous projects needed to adapt their training to make it more specific to the Indigenous context and perceived client/community need (see box in margin). For example, where the Stanford course was trialled (which occurred to varying degrees between the two demonstration projects), the content and format of the education and training program were adapted as the courses were conducted. The projects also included group education sessions, activities including exercise groups, cooking lessons and healthy food

Innovative approaches in Indigenous communities

- ❖ *Addressing social issues through a social care plan*
- ❖ *Care planning in the supportive environment of a CCSM clinic*
- ❖ *Making education, training and resources culturally appropriate*
- ❖ *Providing client support through Aboriginal health workers and community support workers*

Making CCSM work for Indigenous communities

The education and training within one demonstration project was broad ranging, covering a wide range of health issues. Education was provided through weekly education sessions where a health professional spoke to community members about health issues — these sessions also acted as an informal support group. The Stanford course was adapted to be made more culturally appropriate and these changes were recorded as a future resource for the Aboriginal health service.

shopping trips and care plans or referrals to allied health service providers.

Support

Client-specific support was provided through ongoing informal contact with the Aboriginal health workers and community support workers from each of the respective Indigenous demonstration projects. Some care planning follow-up with GPs also occurred. The roles of the Aboriginal health workers and community support workers were central to the development of the projects, and are discussed in more detail in Section 3.4.

Key points

- Overall, the process evaluation showed that demonstration projects evolved in both form and structure, reflecting their responsiveness to client need. As a result, the projects became more diverse over time, as they incorporated new interventions and adapted their self-management programs to better support their clients in their progress to self-management.
 - Client demand led to an increased range of education and support options being offered by the non-Indigenous demonstration projects. In the more successful projects, support was the main intervention offered and it tended to include elements of planning and education on an ongoing basis.
 - In the Indigenous demonstration projects, broader social issues had a significant influence on clients' overall wellbeing. Addressing these social issues first often had a positive effect on clients' wellbeing and/or their capacity to more effectively manage their health.
-

2 Demonstration projects (non-Indigenous) — key results

This chapter looks at key results of the non-Indigenous demonstration projects, in terms of processes and outcomes, for clients, carers, communities, health service providers and the health system. Key results of the Indigenous projects are in Chapter 3.

2.1 Clients

Effects of the interventions on health behaviours and outcomes

Whole group

Overall, people participating in the SHCI showed improved health outcomes, reported a better quality of life and had reduced service utilisation. While most of this improvement occurred between the baseline and middle measurement points, this change was usually sustained between the middle and last measurement points.

Small but consistent effect sizes indicating improvement were observed for a number of health status indicators², health distress, coping with symptoms, psychological distress (Kessler 10) and times in hospital. A trend for improvement was also observed in general health (SF-1), satisfaction with life and self-efficacy, and there was a reduction in the number of GP visits. These observations were confirmed through feedback from the clients and health service providers in focus groups. A longer time period would be needed to fully assess the outcomes of the projects.

As the SHCI progressed, clients reported specific psychological and physical benefits from participating in the demonstration projects (for example, increased knowledge about their conditions and their management, increased empowerment, increased physical activity). Health service providers also reported that their clients appeared to be more empowered and confident, and that they had noticed psychological and physiological improvements in them.

Table 2 provides a summary of the changes in health behaviour, outcome and utilisation measures over the life of the SHCI. Health status measures where there was a statistically significant ($p < 0.005$) improvement over time are shown by an arrow. The direction of the arrows indicates whether this improvement was as a result of an increase or decrease in the scores of the scales used.

² Details of health status indicators and client questionnaires can be found in the technical report of the National Evaluation

Table 2 Changes in health behaviour, outcome and utilisation variables

Variable	Baseline – 12 mths			Baseline - last		
	Mean diff.	p	Change	Mean diff.	p	Change
General health (n=864)	-0.103	<0.0005	↓	-0.068	ns	na
Psychological distress (n=819)	-0.795	<0.0005	↓	-1.357	<0.0005	↓
Satisfaction with life (n=744)	0.391	ns	na	0.452	ns	na
Health distress (n=817)	-0.207	<0.0005	↓	-0.205	<0.0005	↓
Coping with symptoms (n=657)	0.169	<0.0005	↑	0.217	<0.0005	↑
Social functioning (n=757)	-0.914	ns	na	-0.349	ns	na
Self-efficacy (n=733)	0.330	<0.0005	↑	0.165	ns	na
Visits to GP (n=845)	-0.215	ns	na	-0.336	ns	na
Times in hospital (n=844)	-0.190	<0.0005	↓	-0.147	0.001	↓

Notes: Differences significant at $p < 0.005$; ns = not significant; na = not applicable

These findings are consistent with the literature. Table 3 compares the changes in health status variables from baseline to the last measurement point for the SHCI with the results from the Lorig et al study (2001) at 12 months.

Table 3 Comparison of SHCI results with Lorig et al (2001) study at 12 months

Variable	Baseline	Last	P value	Significant changes Lorig et al (2001)
	Mean ± SD	Mean ± SD		
Health status				
General health [#]	3.40 ± 0.9	0.07 ± 0.9	0.018	
Psychological distress	19.27 ± 7.8	1.36 ± 6.5	<0.0005	*
Disability	0.35 ± 0.4	0.01 ± 0.3	ns	*
Health distress	1.67 ± 1.2	0.20 ± 1.1	<0.0005	*
Social activity limitation	2.93 ± 1.6	0.02 ± 1.6	ns	
Social functioning	3.47 ± 1.6	0.43 ± 1.4	ns	*
Fatigue	4.89 ± 2.7	0.12 ± 2.6	ns	*
Shortness of breath	3.20 ± 3.0	0.15 ± 2.5	ns	*
Pain	4.55 ± 3.2	0.43 ± 2.8	<0.0005	*
Self efficacy	6.1 ± 2.4	-0.18 ± 2.4	0.034	
Service use				
Visits to GP	5.93 ± 5.1	0.35 ± 6.2	ns	
Visits to emergency	0.27 ± 0.9	0.03 ± 1.1	ns	
Visits to hospital	0.46 ± 1.3	0.15 ± 1.5	0.004	

[#] Measure not identical but focused on same phenomenon

* Lorig et al (2001) reported significant change at 12 months

Notes: Differences significant at $p < 0.005$; n values range from 833 to 874

Intervention model

All the intervention models were associated with an improvement in most health behaviour, health outcome and utilisation indices.

Overall, once adjusted for initial presentation, clients in intervention models 3 and 4 appeared to improve more consistently than those in intervention models 1 and 2. For example, clients in intervention model 1 and 2 improved significantly less than those in intervention models 3 and 4 for a number of measures – general health, health distress, coping with symptoms, self-efficacy and social functioning. Also, the reduction in number of visits to the GP was significantly lower for intervention model 1 compared to intervention models 2, 3 and 4. One reason for this could be the existence of stronger support mechanisms in models 2, 3 and 4 compared with model 1.

It is also worth noting that the type of intervention model did not significantly influence health outcomes or behaviours except for coping with symptoms, where participation in models 1 and 2 was a positive indicator for improvement in this measure. This is not surprising given that both intervention models had high participation in the Stanford course which focuses on cognitive coping behaviours.

However, unlike self-efficacy, the other health behaviour measure, a change in coping with symptoms was not a predictor of improvement for the other health outcome measures.

Key points

- Overall, people participating in the SHCI showed improved health outcomes, reported a better quality of life and had reduced service utilisation at the end of the demonstration project compared with the beginning. A longer time period would be needed to fully assess the outcomes of the projects.
 - Once adjusted for initial presentation, clients in intervention models 3 and 4 appeared to improve more consistently than those in intervention models 1 and 2.
 - The findings related to changes in health status are consistent with results reported in the literature.
-

2.2 Carers

For the National Evaluation, a ‘carer’ was defined as a person who may be a family member, friend, relative or other who regularly helped clients, formally or informally, with managing their life. This definition was made broad to incorporate the importance of the extended family for some of the target groups in the SHCI (eg those from Indigenous or CALD backgrounds), and also to recognise that while many of the clients had a chronic condition, they were not yet in high need circumstances requiring intense carer assistance.

From the process evaluation, it became clear that the demonstration projects’ capacity to specifically target the needs of carers in addition to those of clients was limited. It was not possible to identify separate processes to the client domain as part of the process mapping,

Barriers for carers

As identified by clients — transport, access to health services and their associated costs were considered to be the main barriers to carers benefiting from the SHCI.

reflecting that the carer domain was not a primary focus of the projects. This was not surprising given that the nature of the cohort was relatively well, with only 21 per cent of the clients from the non-Indigenous demonstration projects reporting having a carer.

Nevertheless, carers who were contacted as part of the projects reported satisfaction with the project, their relationships with project staff, and the opportunities the project provided for interaction with other carers. As the self-management programs progressed, they felt that clients became less isolated and increased their knowledge.

Carers reported that the demonstration project self-management programs had increased their skills to manage their own lives:

- the projects increasingly met their needs as well as those of the clients;
- they learned to manage their frustrations and were more informed in their role; and
- over time, self-management programs promoted understanding between carers and clients.

Despite these improvements, carers continued to feel burdened by the caring role. This result could be considered to be analogous to the non-significant change in general health for clients — the carer burden did not change because the health of the people they were caring for did not alter.

Key points

- The carer domain was not a primary focus of the demonstration projects, reflecting the fact that only 21 per cent of the clients from the non-Indigenous projects reported having a carer.
 - However, carers who were contacted reported positive results from the demonstration projects for themselves and those they cared for.
 - In the future, it will be important to explore opportunities for carer-specific training and support activities in self-management, so that carers are better equipped to look after themselves as well as those they care for.
-

2.3 Community

There was a clear distinction between the Indigenous and non-Indigenous demonstration projects in their approach to and understanding of community engagement. For the Indigenous projects, community engagement and capacity building mechanisms were necessary pre-requisites for effective introduction of the self-management concept to clients and the broader community (discussed further in Chapter 3).

Concept of community

The concept of community and its engagement were not well developed for many of the non-Indigenous demonstration projects, even though a number intended to target specific groups within the community (eg those from CALD backgrounds). However, the pressing need to engage the community in some form quickly became apparent as the demonstration projects recognised its importance as a facilitator for client recruitment. Significant variability existed across the projects in how strategic they were in their approach and how they tried to operationalise their approach to community engagement. Some projects tried to actively integrate the community into their self-management program, for example, through ongoing consultation and inclusion in decision making. Other projects only made contact with the community for certain purposes (eg client recruitment).

There were clear examples of effective community engagement among non-Indigenous projects. Several of the projects successfully engaged community groups from CALD backgrounds (eg Polish, Arabic, Chinese and Spanish). These groups were offered interventions which ran in parallel to the mainstream clients. This included a translated version of the Stanford course in each of the CALD communities. One demonstration project was also particularly successful in obtaining the participation of consumer and self-help organisations (see box in margin).

However, only one non-Indigenous demonstration project had a formal 'whole of community approach' the focus of which was on developing community groups to enable the groups to continue to provide self-management support to community members after the completion of the project (see box in margin). They also pursued health promotion activities (eg medication management workshops, falls prevention workshops, youth workshops and grief workshops), with a view to raising the awareness and importance of self-management at the wider community level.

For the other projects, community engagement was primarily client driven for recruitment purposes. However, as they progressed, some began to recognise the potential role of community beyond recruitment and began to undertake some broader health promotion activities (eg health fairs, supermarket tours, weight loss forums). The purpose of these activities was to raise awareness of self-management, and to assist the community in accessing self-management once the projects had finished.

Reach

Although many of the demonstration projects evolved into more community-focussed programs, the effectiveness of community engagement was compromised for many due to limited planning from the start. In focus groups, community members consistently expressed the view that information about the demonstration projects was not effectively reaching the community. A full assessment of the extent to which the projects were able to reach into the community

Extending the reach into the community

One demonstration project had a strong focus on consumer and self-help organisations in order to support self-management in the region. For example, they were involved in the development of a Sector Development Plan which responded to identified training needs in the self-help sector and they developed and maintained a self-help directory which was used by participants, members of the self-help sector and health professionals.

Community Development Fund to support community groups

One demonstration project which aimed to develop and support community groups established a Community Development Fund. This fund allowed amounts of up to \$1000 (based on certain criteria) to be delegated to community groups. Examples of the type of activities supported included Tai Chi training, the training of Stanford course leaders and diabetes cooking classes.

was outside the scope of the National Evaluation. Nevertheless, important observations were made about the focus of the projects and how this affected their reach into the community.

Impact on capacity building

Given the demonstration projects' primary focus on clients, the extent to which capacity was built within the community setting was limited in the time available. The capacity which the demonstration projects were able to build was more organisationally focused and is discussed in more detail in Section 4.3.

Key points

- When the SHCI began, the concept of community and its engagement were at an early stage of development for many of the non-Indigenous projects. Over the course of the Initiative, most projects recognised the importance of extending their reach through community engagement.
 - One of the demonstration projects had a formal 'whole of community approach' the focus of which was to develop and support community groups through a community development fund.
 - Other examples of effective community engagement included focusing on consumer and self-help organisations in order to support self-management in the region, and engaging community groups from CALD backgrounds by offering culturally appropriate interventions which ran in parallel to those offered to mainstream clients.
-

2.4 Health service providers

Given the GP's key role in chronic condition management in the primary care setting, there were substantial ambitions for their involvement in the demonstration projects. This was exemplified by the projects' intention to use the existing health care system framework, most notably the EPC item numbers for care planning, to encourage GP input. However, the actual involvement of GPs was less than originally anticipated and projects had to adapt their self-management programs accordingly. The contribution made by other health service providers (eg practice and community nurses) was essential to the successful roll-out of the self-management programs.

The majority of the weighting for data collected as part of the National Evaluation was on measuring client outcomes, and understanding the extent of and motivations for health service provider involvement could not be measured to the same degree. Nevertheless, consistent themes emerged from the systematically collected qualitative data of the National Evaluation and these are discussed below.

Health service providers involved in the demonstration projects

The term 'health service provider' covered a broad range of people who were formal members of the health system, with a health related qualification. These included GPs, nurses (practice, primary health, community, clinical nurse managers and specialists), health educators, Aboriginal health workers, allied health professionals (eg physiotherapists, occupational therapists, dieticians, podiatrists) and to a lesser extent pharmacists, psychologists and speech pathologists.

There were also a number of other professionals who were actively involved in the self-management programs and took on many of the health service provider functions, but did not have formal 'health' qualifications— for example, social and welfare workers, counsellors, community support and development workers.

Health service providers' roles

Health service providers' roles in the projects were wide-ranging and included the following:

- referring clients;
- participating in the care and/or self-management planning process;
- providing support to clients;
- participating in education and training; conducting education and training (for health service providers and/or clients);
- telephone coaching;
- active participation on demonstration project steering committee and other demonstration project specific committees;
- advisory roles; and
- providing input to the development of, and conducting other demonstration project activities (eg walking groups, information sessions and cooking classes).

Some projects directly employed health service providers (eg practice nurses, primary health nurses) to assist with the roll-out of their self-management programs (see box in margin).

In other cases, occupational therapists, nurses and social workers were employed as staff. These staff already had relevant self-management skills that could be utilised by the demonstration project, such as having worked with the target group previously (for example, those from CALD backgrounds), care planning and self-management planning skills, and providing support to clients.

Impact on working life

In the first instance, health service providers felt that the activities of the demonstration project increased their workload without the benefit of additional resources. However, by the end of the demonstration project, they felt that the experience had assisted in developing their role as facilitators (rather than educators) of self-management. As a consequence, they felt that their roles had

Nurses assisting clients with self-management

One demonstration project was based within a Primary Health Nursing team, where the role of the Primary Health Nurse was to assist the client to identify needs and issues relating to their chronic condition and to improve the communication between the client and the GP.

Organisationally, this facilitated the development and integration of self-management skills within the work practices of the Nurses, as demonstrated by the establishment of a Primary Health Nurse CCSM intervention for clients not participating in the demonstration project.

What worked well for health service providers?

- ❖ *Development as facilitators of self-management*
- ❖ *Broadening and improvement of skills*
- ❖ *More holistic approach to work*
- ❖ *Professional networks strengthened*

What problems were encountered?

- ❖ *Potential for duplication in care planning*
- ❖ *Planning expectations of demonstration projects too high*
- ❖ *EPC funding model does not cover costs for GPs*

Engaging GPs

- ❖ *Build on pre-existing relationships*
- ❖ *Establish relationships with targeted GPs*
- ❖ *Proactive GP 'champion' advocating for involvement in demonstration project*
- ❖ *Financial incentive for referrals to demonstration project*
- ❖ *Placing of demonstration project staff within GP practices.*

broadened and that they had a more holistic approach to their work. Health service providers also reported that their professional networks with other health service providers had improved. The role of networks is discussed in more detail in Section 4.3.

However, reservations continued to be expressed throughout the SHCI about care planning, in particular, the potential for duplication in care coordination processes between the demonstration projects and health service providers. The care planning expectations of the demonstration project self-management programs were also reported to be too burdensome, with the current EPC funding model not covering the costs to GPs. This observation is discussed in more detail in Chapter 4 with respect to impact on the future roll-out of chronic condition self-management within the health system.

Interaction between health service providers and clients and carers

Clients and carers reported that their interactions with health service providers improved as a result of the SHCI. This was due in part to the clients' sense of increased empowerment from the interventions, but also to the fact that their health service providers were responsive to this change in their outlook. Clients also noted that Stanford course leaders (most of whom were health service providers) were knowledgeable, friendly and committed. However, some carers noted that they would welcome more advice and support from health service providers about how to look after themselves and the person they cared for.

Engaging GPs

Often, pre-existing relationships (eg through the first round of the Coordinated Care Trials) were the most successful way of encouraging proactive involvement of GPs in self-management activities (eg referral, care planning). Cold calling, even if based on a formal 'institutional connection' between the demonstration project and the GPs (like the demonstration project operating out of a local Division of General Practice), was not effective. Where no previous relationship or network existed, it was necessary to take the time to build the relationship with the targeted GPs before they would be willing to consider participation. Another contributor to the successful engagement of GPs was the presence of a proactive GP champion/advocate of the demonstration project self-management program. The GP champion was able to promote the demonstration project and the concept of self-management more informally within the given GP community. Other strategies explored by projects that were successful included providing additional monetary incentive for referrals to the projects' self-management programs, and the placing of project staff within GP practices.

Role of other health service providers

For the most part, the majority of demonstration project self-management activity was undertaken by health service providers other than GPs, for example, nurses, health educators, Aboriginal health workers and other allied health professionals. As a consequence, the key role these health service providers played in the rollout of the demonstration project self-management programs, and their activities, cannot be over stressed. The 'other' health service providers were a heterogeneous group and their participation in the demonstration projects occurred on both a voluntary and paid basis. Activities undertaken on a voluntary basis included participation in education and training, Stanford course leaders, and advisory and committee member roles. Activities for which health service providers were paid (over and above those who were employed by the projects) included telephone coaching, the provision of education and training, and input into the care/self-management planning process.

In some cases, activities were undertaken by health service providers in addition to their existing full-time or part-time jobs, which placed additional stress on the individuals. However, the nature of the work, the potential beneficial outcomes for clients, and the broadening and improvement of their skills were seen to be rewarding.

The involvement of these health service providers in any ongoing education and training program for self-management will be important in ensuring the sustainability of self-management in the broader health service provider community; this is discussed in more detail in Chapter 4.

Volunteers

In addition to health service provider involvement in the SHCI, the contribution made by volunteers in community organisations such as self-help groups cannot be underestimated. Involvement ranged from assisting in presentations and health promotion through to establishing a health resource centre which was preparing for incorporation as a community agency.

Key points

- Overall, health service providers found that involvement in the demonstration projects was rewarding, due to the broadening and improvement of their skills and the potential benefits for patients.
 - GP involvement was less than originally anticipated for a variety of reasons. Even where the demonstration project was operating out of a Division of General Practice, capitalising on a pre-existing relationship or taking time to build a relationship was the most successful method of engaging GPs.
 - Involvement of a wide range of health service providers, on both a paid and voluntary basis, was essential to the success of the demonstration projects.
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2.5 Health system

Capacity building and sustainability were integrally linked in the National Evaluation Framework. Capacity building was defined as development work which *'strengthens the ability of a network to build their structures, systems, people and skills so that they are better able to define and achieve their objectives and engage in consultation and planning, manage demonstration projects and take part in partnerships and community enterprises'* (Bush et al 2002). Four domains to capacity building and ultimate sustainability were used: network partnerships; knowledge transfer; problem solving; and infrastructure.

Capacity building

The demonstration projects achieved successes in building capacity from an organisational perspective, most notably in the areas of network partnerships and knowledge transfer.

While many of the projects were based on a consortium of different organisations, throughout the life of the SHCI they had to work continually to maintain and develop these network relationships, as well as establish new ones to meet the challenges which arose. However, a key indicator of ongoing sustainability would be the projects' capacity to integrate their self-management program, or aspects of it, into the mainstream practices of network partners (see box in margin). None of the demonstration projects had successfully achieved this by the end of the evaluation.

However, it should be noted that those State and Territory health authorities that were involved in the demonstration projects have now moved to actively incorporate and implement self-management strategies, as have the Divisions of General Practice. In addition, local self help groups and other self-management organisations have been further encouraged to continue and expand their work.

A key element of the SHCI was the education and training of health service providers. The major investment which the Australian Government Department of Health and Ageing put into the education and training of health service providers, and the formal focus that the demonstration projects placed on training clients, both had a significant impact on successful knowledge transfer around self-management. However, continued investment in the education and training of health service providers would be required to ensure the movement becomes self propelling so that it does not in essence rely on the goodwill of a few well-intentioned individuals, which is unlikely to be sustainable in the long run.

The projects' problem solving capacity (being able to use recognised methods to identify and solve problems in a sustainable way) was less well developed due in part to the short-term nature of the projects. That is, the problems encountered were primarily operational rather than strategic in nature, and hence problem-solving mechanisms more

Building strong network partnerships

One demonstration project developed a link with its local Second Round Coordinated Care Trial, in which the Trial referred their clients to the demonstration project to undertake the Stanford course. This resulted in the demonstration project running more courses than originally anticipated for longer with the possibility being considered that the Trial would continue to run courses post-demonstration project. The existence of strong network partnerships was an important factor in facilitating this development, for example, the demonstration project and Trial shared many consortia members.

sophisticated than those using existing management structures had yet to be developed.

Sustainability

Initially, the demonstration projects did not take a particularly strategic or planned approach to the ongoing sustainability of their respective self-management programs. This is illustrated by the fact that for the most part they only began to seriously consider this issue towards the end of the SHCI. The lack of ongoing funding was consistently cited as the main barrier to long-term sustainability. However, another important difficulty encountered in ensuring sustainability was the relatively limited size, scope and longevity of the demonstration projects, which gave them reduced capacity to bring about health system change (for example, increasing GP involvement) and/or increased integration within local health systems. These factors also influenced the extent to which the demonstration projects were able to attract and retain staff. High turnover and the overloading of health service providers and other staff were significant issues for the projects.

Lack of coordination between members of the multidisciplinary team at the local level was another issue. For example, while referrals to allied health professionals were made in care plans for clients participating in the SHCI, the existing waiting list made it difficult for them to see the health service provider in a timely way in the public health system. The high cost of health care then became a barrier if they sought to move outside the public health system.

Nevertheless, some potentially important steps towards maintaining certain aspects of the demonstration projects were made during their period of operation or closely after. For example, the State and Territory health authority Primary Health Nurses (see box on page 33) whose roles were embedded within the working practices of some projects have since taken their skills back into the acute and community sectors to further promote the principles of self-management. Furthermore, the consumer resource centre (see box in margin), and the community development fund (see box on page 31) were other examples of potentially sustainable initiatives that came out of the SHCI. It should be noted that the Department of Health and Ageing provided a small amount of funding after the demonstration projects ceased their National Evaluation data collection to assist them with embedding successful elements of their demonstration projects within the broader health system. This process was outside the scope of the National Evaluation.

Consumer resource centre engages community members

A health resource centre was established by a demonstration project in partnership with a local GP champion. The centre was developed to allow community members easy access to a range of health related information as well as education and training opportunities. As the health centre developed, it built a strong volunteer base of community members who operated the centre and undertook training activities along with a number of community groups, under the direction of the demonstration project and GP champion. Towards the end of the demonstration project, the volunteer leaders of the centre were preparing it for incorporation as an independent community organisation.

Potentially sustainable initiatives

- ❖ *Primary Health Nurses in a demonstration project have taken their skills in facilitating self-management back into the acute and community sectors*
- ❖ *The strong volunteer base of the consumer resource centre (see box above) will maximise its chances of becoming an independent community organisation*
- ❖ *The support given to community groups by the community development fund (see box on page 31) aimed to enable them to continue to provide self-management support to community members after the demonstration project finished*

Key points

- While demonstration projects worked continually to maintain network relationships and develop new relationships to meet the challenges of implementing the program, none was able to successfully integrate self-management into the mainstream practices of network partners in the time available.
 - However, the work begun by the demonstration projects is now being carried on by many of those involved, including State and Territory health authorities, Divisions of General Practice and local self-help groups.
 - Education and training of health service providers, and the formal focus that the demonstration projects placed on training clients, both had a significant impact on successful knowledge transfer around self-management. Continued investment in the education and training of health service providers is required to maintain the momentum achieved by the demonstration projects.
 - The relatively limited size, scope, longevity and funding of the demonstration projects reduced their capacity to bring about health system change and/or increased integration within local health systems. However, examples of potentially sustainable initiatives came out of the SHCI and will be important indicators of sustainability.
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3 Indigenous demonstration projects — key results

This chapter looks at key results of the Indigenous demonstration projects, in terms of processes and outcomes, for clients, carers, communities, health service providers and the health system. It was not possible to undertake the same degree of analysis for the Indigenous as the other demonstration projects due to the lack of sufficient and appropriate quantitative data. However, some information can be gathered from the qualitative data collected for the National Evaluation (eg process mapping, focus groups and key informant interviews).

3.1 Clients

Effects of the interventions on health behaviours and outcomes

The results from the analysis of the questionnaire data for the Indigenous demonstration projects suggest that benefits were experienced as a result of the demonstration project self-management program. This interpretation of the quantitative data was supported by:

- the responses given in the client focus groups, which indicated that the SHCI was having a positive impact on their lifestyle (eg increased walking, healthier eating and increased health knowledge and medication management); and
- observations made by health service providers.

However, there is currently little appreciation or understanding about how the questions were interpreted by clients, and what the responses to the questions mean from an Indigenous perspective. To be certain of valid and reliable data, the questionnaires would require ethnographic development and translation, which was outside the scope of the evaluation.

Due to the differences between the two types of questionnaires and concern over the validity and reliability of the questionnaires, it was not possible to compare the self-reported health of clients from the Indigenous demonstration projects with those from the other demonstration projects. On the other hand, this was the first attempt to collect such data and it has provided an indication as to the potential benefits experienced by the clients as a consequence of the SHCI.

3.2 Carers

The experiences reported by carers within the Indigenous demonstration projects were very similar to those from the other projects. In particular, the opportunity the projects gave them for

social interaction with other carers was greatly appreciated. In addition, carers felt better equipped as a consequence of the demonstration project self-management programs to care for their 'clients' and themselves. However, despite the good relationships established with demonstration project staff, (and also echoing the need for greater carer-specific support by those involved in the non-Indigenous demonstration projects), carers in the Indigenous demonstration projects felt that the provision of more carer-focused training would particularly assist them in managing the stress of the carer role, which they continued to be burdened by.

Interestingly, although a large proportion of clients reported living with others, only 23 per cent reported actually having a carer helping them with their condition, which was very similar to the figure reported by the non-Indigenous demonstration project participants. This is somewhat surprising given the importance of the extended family in providing social support in Indigenous communities and the purposefully broad definition of the term used in the National Evaluation. However, this reflects the need, as with the questionnaires, to undertake a validation of its meaning in the Indigenous context.

Barriers

As for clients, lack of transportation, waiting lists for health service providers and costs associated with healthcare were all identified as barriers to accessing, or making the most of the demonstration project self-management program.

Key points

- The quantitative and qualitative data suggest benefits to clients in the Indigenous demonstration projects. However, uncertainty about the cultural appropriateness of the evaluation tools limits comparisons between the reported health status of clients in the Indigenous and other demonstration projects
 - The benefits of and barriers to participation in demonstration projects for carers were similar in the Indigenous and non-Indigenous demonstration projects
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3.3 Community

The resources and scope of the two Indigenous demonstration projects varied. This was primarily due to the fact that one of the projects was a satellite to a non-Indigenous demonstration project, rather than a project in its own right. Consequently, the amount of initial community consultation it was able to carry out was less than that undertaken by the primary Indigenous demonstration project. Nevertheless, as the projects progressed, the importance of the project became increasingly recognised by its Aboriginal health service so that it was able to extend its community consultation and involvement.

Community engagement

To build trust, support and ownership of the demonstration project self-management programs in the communities, the projects needed to be innovative in their efforts to engage the community. One element of this was the development of appropriate health promotion material (eg posters, pamphlets, videos on specific topics such as self-management and healthy eating), and support activities (eg education sessions, community groups such as men's and women's walking groups and healthy weight groups), as well as communication about the demonstration project in general by word of mouth. All of these activities built understanding and trust in the project self-management programs.

The other important factor was to have the right people deliver the message to the communities in a culturally appropriate way, which also facilitated further penetration into the communities. Both the Indigenous demonstration projects achieved this, employing different strategies. One of the projects had two dedicated Aboriginal health workers working on a part-time basis. The other project specifically created the role of the community support worker, who worked in conjunction with project staff to approach and discuss the self-management program within their respective communities (see box in margin). These effective engagement strategies were subsequently reflected and further enhanced by taking up community ideas. Unsurprisingly, ideas that came from the community (eg women's walking and healthy weight groups) were found to be more sustainable than project-initiated ideas.

Reach

Over time, community members felt that the projects became more successful at disseminating information to the appropriate people within the community. However, even at the last measurement point, it was generally felt that the projects could have benefited from wider dissemination of self-management program-related information. In this regard, the use of videos was thought to be a very effective way of conveying information to the communities, particularly those in more remote areas. This comment was also echoed by the health service providers involved with the projects. As the demonstration projects progressed, community members also observed that the community at large was benefiting from the programs. Community benefits included increased knowledge about chronic disease, a greater awareness of the importance of healthier lifestyles, and a proactive approach to managing conditions.

Capacity building

The roles of the community support worker and Aboriginal health worker were a very important mechanism for building community capacity within the project communities. As part of their respective positions in the projects, they underwent extensive training and education in self-management. Also, more intangible benefits were

Community support workers provide vital link between demonstration project and community

The role of the community support worker was non-health professional, aimed at developing the capacity of community members and providing a link between the demonstration project and the community. The role of the community support worker was defined by multilingual skills, 'belongingness' to community, community based training and literacy. The community support workers received basic training in a range of areas including the principles and practices of health promotion, chronic conditions and computer skills. The community support workers played a vital role in engaging the community and recruiting them into the demonstration project and subsequently providing support to both the clients and community.

observable in the workers as the programs progressed; for example, increased confidence, self esteem and community respect. By the end of the demonstration projects, community support workers knew how to take blood pressure and blood sugar levels. One of the Aboriginal health workers had completed the Stanford Master Trainer self-management course in the United States, making her currently the only qualified Indigenous person in the world to be able to train other leaders.

However, a critical barrier to maintaining capacity was high staff turnover. Not only did this place a significant burden on the demonstration projects in terms of finding resources for more education and training, but it also affected the projects' capacity to deliver their self-management programs. Turnover was particularly pronounced among the male workers, and in their absence it was not possible to reach male members of the community.

Key points

- Community engagement was a key feature of the Indigenous demonstration projects. Activities such as dissemination of culturally appropriate health promotion materials and community support groups (eg walking groups) built understanding and trust in the self-management programs and had wider benefits within the community.
 - Community support workers and Aboriginal health workers provided vital links between the community and the demonstration project.
 - The roles of the community support worker and Aboriginal health worker were a very important mechanism for building community capacity in self-management, although high staff turnover reduced the demonstration projects' ability to deliver programs.
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3.4 Health service providers

Engagement of GPs and other health service providers

Despite both of the Indigenous demonstration projects being located within whole-of-service Aboriginal health services, the projects still experienced some difficulties in engaging GPs and other health service providers into their self-management programs. Once again, the importance of building strong relationships between the demonstration projects and health service providers was a critical first step for successful engagement. Although they were salaried employees, the GPs in these organisations experienced many of the same pressures on their time as their self-employed counterparts in the 'mainstream' system. Also, the demonstration projects needed to overcome the risk of being perceived as 'just another project' by the health service providers within these organisations. As for the non-Indigenous projects, the Indigenous projects were able to use GP champions to try and engage other GPs and health service providers in the Aboriginal health service.

The GP champions also demonstrated self-management being put into practice and working well in the community. However, staff turnover (which is a particular feature of the rural and remote health service delivery setting) hampered implementation and the gains made by GP champions were often lost or diminished when they moved on.

Health service providers in remote locations also reported that they only received limited information about the demonstration projects. Unsurprisingly, projects found it harder to engage health service providers in remote areas as a consequence of the 'tyranny of distance' and difficulties this placed on achieving effective communication.

Turnover of health service provider staff

As indicated above, high staff turnover in communities was a significant problem for the Indigenous demonstration projects. The engagement, orientation and education and training effort for health service providers which the demonstration projects undertook at the beginning of the self-management program was often lost, and they had to try to maintain their health service provider education and training over the life of the demonstration project as new health service providers, particularly GPs, arrived. This was obviously very resource intensive and the projects were able to maintain the standard and quality of training to varying degrees. As noted in the health service provider focus groups towards the end of the demonstration projects, while they felt sufficiently supported and appreciated by project staff earlier on in the demonstration project, they would have benefited from further training as the self-management programs progressed.

Impact on working life

Health service providers, like their mainstream counterparts, were initially concerned that the self-management models would create additional work. However, by the end of the demonstration projects health service providers reported that the projects had assisted in decreasing their clinic workload, and had extended their networks with other health service providers. They also felt supported in their role by project staff. However, as for the non-Indigenous projects, concern was expressed around the potential risk of service duplication, particularly with regards to care planning. The improvement in the health service providers' working life was also felt by the health service providers' clients and their carers. Both felt that their relationship with their health service providers improved over time – they felt more listened to, and carers also reported feeling more supported in their role. Clients thought that this improvement was in part due to their becoming more assertive in communicating with their health service provider.

What worked well for health service providers?

- ❖ *Clinic workload decreased by end of demonstration project*
- ❖ *Broadening and improvement of skills*
- ❖ *More holistic approach to work*
- ❖ *Professional networks strengthened*

What problems were encountered?

- ❖ *Time pressures on GPs*
- ❖ *Distance limited communication between demonstration projects and health service providers in remote locations*
- ❖ *Potential for duplication in care planning*
- ❖ *Gains continually lost due to high staff turnover*

Key points

- Overall, health service providers found that involvement in the Indigenous demonstration projects was rewarding, due to the broadening and improvement of their skills and the potential benefits for patients.
 - As for the non-Indigenous demonstration projects, GP involvement was less than originally anticipated for a variety of reasons. Establishing strong relationships between the projects and health service providers was the most successful method of engaging GPs. This was more of a challenge where the communities were in remote areas.
 - Staff turnover in the communities was a significant problem for the Indigenous demonstration projects.
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3.5 Health system

Capacity building

A low level of community capacity is recognised as a significant barrier to improving the health and wellbeing of Indigenous people (Commonwealth Department of Health and Aged Care 2001). Consequently, a core aim of the Indigenous projects was to progressively build the capacity of both their communities and their respective organisations.

Given the specific challenges of building capacity within the Indigenous context (eg high staff turnover and the possible remoteness of the settings) progress was difficult to maintain. These issues are explored in more detail below.

The main area of achievement for the demonstration projects was in relation to knowledge transfer – in particular the steps taken to train and up-skill the community support workers and Aboriginal health workers – since this also helped to bring the concept of self-management into the targeted communities. High staff turnover was a major barrier in maintaining this capacity both within the Aboriginal health service and in engaging the communities.

Meanwhile, the projects had more mixed success in building network partnerships. Importantly, stronger networks were developed in the communities themselves as key community members (eg health service board members) became actively involved in the projects. Overall, it was felt by the communities that the projects had been beneficial and should be continued. Reflecting the observation that the community-led initiatives within the Indigenous demonstration projects appeared to have greater durability, the communities thought that this ‘bottom-up’ approach to self-management was likely to be more sustainable in the long run.

A problem identified with respect to making and maintaining networks was the limited range of partners with whom to ‘network’ in the more rural and remote areas of Australia. Also, despite the need to maximise the available resources, there was still a tendency to view the work of the demonstration projects in isolation and not make the

necessary linkages with other projects to develop a broader chronic condition management strategy within the Aboriginal health service.

As for the non-Indigenous demonstration projects and for the same reasons, the problem solving capacity of the demonstration projects was not well developed.

Sustainability

Despite the capacity issues raised above, the Indigenous demonstration projects had a more realistic opportunity to make self-management 'core business' compared to many of the non-Indigenous demonstration projects, given the existing infrastructure offered by their respective Aboriginal health services (eg administrative and IT support). On the other hand, the lower level of community capacity from which the Indigenous demonstration projects were starting was a significant barrier. As a result, the limited size, scope and longevity of the projects held similar difficulties for the Indigenous projects with respect to sustainability, without appropriate transitional planning.

The specific actions identified by the evaluation as being important to ensuring the sustainability of self-management programs – in some form – both within the communities and the Aboriginal health services/broader health system, were as follows:

Community

Support and buy-in from the Aboriginal health service boards and local communities were critical to the success of the Indigenous demonstration projects. This support will need to be maintained to ensure the ongoing sustainability of the self-management concept. An important way of achieving this will be through the provision of regular feedback to the community about the progress of any subsequent self-management program. Based on the feedback obtained through the National Evaluation, this will need to be done in the context of a community empowerment focused health promotion model in which innovative approaches to health are driven by the community.

Aboriginal health services/health system

Health service providers who took part in the focus groups expressed the view that self-management could be included as part of the existing population health and/or disease specific programs currently operated by the Aboriginal health services. However, strong leadership, management and coordination will be necessary for this to occur.

The EPC Medicare items provide a framework for a multidisciplinary approach to health care including self-management through the care planning process. While the existence of the EPC items proved insufficient to encourage wide-scale GP participation in the non-Indigenous demonstration project environment, this is a source of revenue which has yet to be explored by the Aboriginal health services. This opportunity to embed self-management principles into

the work practices of the Aboriginal health services would be further encouraged if it was supported by the ongoing education and training of health service providers, particularly in the more remote communities.

Lastly, the position of the community support worker (or any equivalent community focused worker) will need to be clarified if the role is to be sustainable into the longer term. The role provided an opportunity to develop stronger links between Indigenous people and local clinic staff. However, if confusion arises about the roles of the community support worker and Aboriginal health worker, it is possible that Aboriginal health workers may be less inclined to cooperate with the community support workers and any related program in which they are involved (eg self-management). Also, community support workers may have inappropriate expectations placed upon them by community members, resulting in stress and disappointment on both sides.

Key points

- Increasing the skills of community support workers and Aboriginal health workers helped to bring the concept of self-management into the targeted communities. However, high staff turnover was a major barrier in maintaining this capacity both within the Aboriginal health service and in engaging the communities.
 - A 'bottom-up' approach to self-management, with implementation of community-led initiatives, is more likely to be sustainable in the long run.
 - As in the non-Indigenous demonstration projects, the limited size, scope and longevity of the demonstration projects hampered their ability to ensure the sustainability of their programs. In the Indigenous demonstration projects, this was associated more with a low initial level of community capacity.
 - The key to implementing self-management in Indigenous communities will be a model in which innovative approaches to health are driven by the community.
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4. Implications for chronic condition self-management

Key implications for broader implementation of chronic condition self-management can be drawn from the National Evaluation of the SHCI. These are considered below in terms of reach, implementation and sustainability.

4.1 Reach

While most demonstration projects shared some recruitment and marketing strategies, differences in their approach and design affected the extent of their connection with their target populations, particularly with groups who are more difficult to reach (eg CALD communities, those from lower socio-economic groups).

Those demonstration projects that took a more strategic approach generally found greater success. In particular, it was important to be clear about who the audience was and target them appropriately. This was done most successfully by projects which targeted certain types of clients through existing trusted community networks, engaging with local community groups or reviewing patient lists.

The community development models pursued by the Indigenous demonstration projects were the most innovative in this regard, particularly with respect to building capacity within their communities.

Some of these learnings may also be used when exploring how the concept of self-management can be introduced into the broader community, for example in schools or in the workplace. This is of particular importance as the issue of prevention of chronic conditions becomes more acute for the wider population, as illustrated by the recent rise in childhood obesity.

4.2 Implementation

Implementation of the demonstration projects posed many challenges. Demonstration projects that were organisationally mature and had strong existing networks within the community were better placed to face these challenges in the time available for the projects. Other enablers of implementation included:

- experience in delivering new models of care;
- strong, committed leadership;
- skills in project management; and
- good infrastructure and administrative support.

Experience of clients

Over and above the influence of baseline, all intervention models showed improvement over the life of the SHCI. The key features of intervention models which appeared to have the greatest impact on client health outcomes were those which were:

- more flexible in their approach, both in terms of the interventions being tailored to meet client need (so that every component of their program was not compulsory) and in their mode of delivery (eg telephone coaching) which could facilitate ongoing participation;
- able to identify and respond to client need through the use of appropriate tools (eg the Stages of Change approach); and
- able to provide appropriate and structured support to their clients, so that on the one hand, the client did not become overly dependent on the support on offer but nor did they feel isolated from the program.

It is recommended that these program features be incorporated as aims in any future self-management policy initiatives.

Role of health service providers

Many of the implications of the information obtained through the National Evaluation for health service providers are closely linked to broader health system issues.

Implications of the challenges in engaging GPs to the projects include:

- the constraints on GPs' time were a significant barrier to their participation and without radical health system change it is unlikely that GPs will be in a position to willingly 'drive' self-management within the primary care setting;
- GPs who participated found the experience rewarding — it is important to identify how GP involvement can be used most effectually in the future. Based on the findings of the evaluation, GPs should continue to be a source of referral to self-management programs; and
- ongoing education and training of GPs remains an important area to pursue, as GPs are able to identify clients who would potentially benefit from self-management and also to provide support to clients who participate in self-management programs. Divisions of General Practice may be a suitable forum in which to provide such education and training. At this stage, given the constraints on their time, GPs' participation in care planning should remain optional.

The role of health service providers other than GPs is critical to ongoing roll-out of self-management in the community. However, the level and formality of their involvement varied widely in the SHCI, making it difficult to draw firm conclusions about their ongoing role. While it may be optimal to standardise their involvement, it was observed that much of the energy in the self-management arena comes from health service providers who give education and support to clients over and above their existing duties.

In future, this contribution should be adequately recognised and remuneration commensurate with their role and position in promoting self-management behaviour. For some health service providers this might mean continuing professional development points, for others it may be formal payment.

4.3 Sustainability

Promoting sustainability of their self-management programs beyond the life of the demonstration project was even more of a challenge than implementation, given the limited size, scope, longevity and funding of the projects. These factors reduced the demonstration projects' capacity to bring about health system change and/or increased integration within local health systems. Some examples of potentially sustainable initiatives came out of the SHCI and will be important indicators of sustainability. However, a range of systemic barriers to self-management will need to be overcome before self-management can be integrated more widely within the health system.

Transport

Lack of transport was cited as a common barrier to accessing self-management interventions and also other health services. Service delivery options such as telephone coaching may be worth exploring, although this may not be suitable for all clients (eg the hard of hearing). Innovative approaches such as petrol vouchers and taxis to assist with transport have been used although it is not clear how sustainable they would be in the long run.

Coordination of care

While one of the benefits of the EPC care planning package is its multidisciplinary approach to care, lack of coordination at the local level between GPs, allied health professionals and community nursing can be a major barrier to its use.

In some ways, the 'project-based' approach of the SHCI did not allow the demonstration projects to overcome this 'fragmented' health service delivery approach, since it relied on the projects on the ground to support a multi-disciplinary approach. Many projects found it difficult to achieve such integration into the broader health system given their available resources and time.

The SHCI demonstrated that the activities encouraged by the EPC package can be more effectively included into daily working practices, (eg the employment of practice nurses to do much of the care planning activity for clients). Also, for the Indigenous demonstration projects, this was the first time that they had considered using the EPC items for care planning in their Aboriginal health services.

In any future roll-out of self-management, the risk of duplication between GP and other health service provider activity would have to be minimised, especially in care planning. This would reduce any

confusion in the minds of the GP, other health service providers and clients, and minimise the risk of inefficient use of resources.

Networks/relationship building

Pre-existing networks and relationships, irrespective of their geographical location, were crucial to the success of the more effective demonstration projects. The role of the State and Territory governments and the Divisions of General Practice will be important in identifying and facilitating such networks to maintain their capacity to deliver self-management programs.

Education and training

Ongoing self-management education and training for health service providers is essential for the future success of self-management in Australia. In this way, health service providers are kept informed about the benefits of self-management. Also, a rolling program of self-management education and training would minimise the problems associated with high staff turnover.

It would be beneficial if self-management education for all health service providers (including GPs and specialist doctors) began at university, since this would encourage it to become embedded in the clinical practice of health service providers entering the profession. For those health service providers participating in the education and training of clients, it will be necessary to actively monitor their training records to ensure quality assurance standards are maintained.

4.4 Recommendations for future implementation of self-management

There are a number of key recommendations arising from the National Evaluation:

- it is important to be clear about who audiences are and target them appropriately, through mechanisms such as existing trusted community networks, engaging with local community groups, reviewing patient lists and working with the community to build its capacity for self-management;
- specific program features should be considered in future self-management policy initiatives:
 - a flexible approach, both in terms of the interventions being tailored to meet client need and in the mode of delivery;
 - ability to identify and respond to client need through the use of appropriate tools; and
 - ability to provide appropriate and structured support to clients;

- GPs must continue to be an important source of referral to self-management programs in the future. Their pivotal role in the primary care setting means they are well placed to act as facilitators for developing and encouraging self-management in their clients;
- the role of practice nurses, community nurses, allied health professionals and Aboriginal health workers should be acknowledged as being essential to the ongoing embedding of self-management principles and techniques into the health system;
- beginning self-management education of doctors and other health service providers at university could promote early interest and uptake;
- providing regular training updates to practising health service providers (eg through Divisions of General Practice and other professional bodies) about the benefits of self-management would raise awareness and encourage further interest; and
- for quality assurance purposes, it will be important to actively monitor the training records of health service providers and lay trainers who are involved in structured CCSM education and training of clients.

Appendix 1 Abbreviations

CALD	culturally and linguistically diverse
CCSM	chronic condition self-management
DOHA	Australian Government Department of Health and Ageing
EPC	Enhanced Primary Care
GP	general practitioner
IT	Information Technology
MBS	Medicare Benefits Scheme
NCDS	National Chronic Disease Strategy
NEF	National Evaluation Framework
SHCI	Sharing Health Care Initiative

Appendix 2 National Evaluation framework

The hypotheses and the evaluation questions for the SHCI were developed in close consultation with the demonstration projects. These are outlined in the table below.

Hypotheses	Evaluation Questions
1. That learning self-management principles will improve: <ol style="list-style-type: none"> the health-related quality of life for people with chronic diseases, particularly those with co morbidities; the carer/family/significant others perceptions and experiences of the health related quality of life for people with chronic diseases; and the health/wellbeing of communities. 	EQ 1) Which recruitment strategies are most successful in recruiting which clients/groups of clients? EQ 2) Which clients / groups of clients are most likely to participate in which programs? EQ 3) What other factors influence participation rates and in which direction? EQ 4) How and by how much does the form/structure of self-management education influence the health behaviours and health outcomes of clients? EQ 5) How and by how much does the type, intensity and frequency of client support and follow-up influence the health behaviours and health outcomes of clients? EQ 6) How and by how much does the SHCI intervention components influence community outcomes? EQ 7) What is the level of client and carer/family/significant other satisfaction associated with each program? What factors influence this?
2. That learning self-management principles will help facilitate among health service providers improvements in awareness and understanding about the benefits of self-management and consequent behaviour changes as well as improving communication between GPs, people with chronic conditions and their families, and other health professionals.	EQ 8) What is the level of behaviour modification by health service providers? What factors influence this?
3. That learning self-management principles will result in more appropriate use of health services.	EQ 9) What factors affect the sustainability of the program?

The National Evaluation Framework (NEF) which was developed to address these hypotheses and evaluation questions was built five domains, identified as being the key participants/features of the SHCI: 1) Client; 2) Carer/family/significant other; 3) health service provider; 4) Community; and the 5) Health service system. The starting point for the framework was the public health approach to program evaluation, from which three core components were specified:

- *Process evaluation*: monitored program implementation from the perspective of program delivery (e.g. care related processes) and broader organisational factors at both a demonstration project and health system level. Also provided contextual information for the impact and outcome evaluations, helping to explain what was successful and why.
- *Impact evaluation*: measured changes in modifiable risk (e.g. health behaviours) and protective factors (e.g. perceptions and experiences of the demonstration project self-management program) as well as community capacity and the potential for ongoing sustainability.
- *Outcome evaluation*: measured changes in the health and wellbeing of the target population(s) or program participants.

For each of these components a set of measurable dimensions were then identified to complete the overall structure of the NEF.

Methods

Given its scope and structure, the most appropriate quantitative and qualitative data collection methods were used in the National Evaluation. A robust approach was taken to the development of the instruments used in the evaluation, ensuring that where appropriate the measures were valid and reliable.

Figure 1 below illustrates how the data collection methods linked in with the overall NEF components and their relevant dimensions and measures.

National evaluation components and associated data sources

Evaluation components	1 Process	2 Impact	3 Outcome
Dimensions and markers	<p>Care-related:</p> <ul style="list-style-type: none"> Marketing (Client & HSP) Recruitment (Client & HSP) Education and training (Client & HSP) Care/SM planning (Client) Support (Client, Carer, HSP & Community) Education and training of SM personnel (Client) Health promotion (Community) <p>Organisational:</p> <ul style="list-style-type: none"> Organisational development Workforce development Infrastructure development Governance and management Integration 	<ul style="list-style-type: none"> Self-management behaviour (Client) <ul style="list-style-type: none"> Self-efficacy Coping with symptoms* Perceptions, experiences & satisfaction (Client, HSP, Community) Sustainability (Health Service System) 	<p>Client:</p> <ul style="list-style-type: none"> Health-related QOL: <ul style="list-style-type: none"> General health (SF1) Health distress* Symptoms* -Functional status: <ul style="list-style-type: none"> Physical activities* Physical abilities* Social functioning* Psychological distress (K10) Satisfaction with life Service use: <ul style="list-style-type: none"> No of GP visits Times in hospital <p>Carer:</p> <ul style="list-style-type: none"> Burden
Data sources	<ul style="list-style-type: none"> Process mapping Key informant interview Project reports 	<ul style="list-style-type: none"> CIQ & CHQ Questionnaire data Focus groups Key informant interviews 	<ul style="list-style-type: none"> CIQ, CHQ & CSUQ Questionnaire data

* Modified Stanford 2000 Questionnaire

Strengths of the National Evaluation

The main strengths of the National Evaluation of the SHCI are described below.

Evaluation Framework

The conceptual framework provided a comprehensive and logically integrated approach to the evaluation of the SHCI. The triangulation of data sources also increased the robustness of the evidence base of the evaluation. A range of data was sought for the evaluation, using a variety of methods (eg interviews, questionnaires, process mapping) and sources (eg national evaluator collected, local evaluator collected and demonstration project collected).

Process mapping

In recognising the demonstration projects' capacity for 're-invention' during the life of the Program, process mapping was a critical component of the National Evaluation. The information collected as part of the process mapping visits enabled the National Evaluation team to monitor Program implementation as well as providing a context to the impact and outcome evaluations. The process mapping also contributed to an understanding of what was successful and why, which helped to inform potential areas for further policy development and the roll out of future programs.

Action research approach

The workshops held by DoHA across the life of the Program not only allowed the National Evaluation team to feed back its findings on a regular basis but also enabled the demonstration projects to discuss their progress and share their experiences with all those involved in the roll-out and evaluation of the SHCI at both a national and local level. From this mechanism for communicating progress and lessons learned, it was possible to identify areas of best practice and potential areas for improvement going forward.

Quality and completeness of questionnaire data

While the follow-up rate varied from demonstration project to demonstration project (82.6 per cent being the highest to 41.8 per cent, the lowest) for the non-Indigenous demonstration projects, sufficient data were collected across all of the demonstration projects to undertake robust analyses over the three measurement points.

Development of self-management questionnaires for Indigenous communities

For the reasons discussed in Section 2.3.2, it was not possible to undertake the same level of analysis of the questionnaire data for the Indigenous demonstration projects as for the non-Indigenous

demonstration projects, nevertheless, some meaningful comparisons were possible.

This was also the first attempt to collect self-management questionnaire data from Australian Indigenous communities. While further time and resources will be required to ensure that these questionnaires are valid and reliable from an ethnographic perspective, the data collected provides an opportunity for further analysis, for example, comparing the results to other available longitudinal data such as chart audits.

Limitations of the evaluation

Study design

Without the existence of a control group or at least a controlled allocation of clients to similar demonstration projects, it was not possible to satisfactorily analyse the individual effects of specific interventions, nor was it possible to link outcomes to particular groups of people. So, whilst the identification of the intervention models attempted to increase the specificity of the analysis, it was still a relatively crude approach. As a consequence, it was also not possible to determine the extent to which other influencers of change such as socio-economic status or the presence of certain risk factors had an impact on the clients' capacity to improve. Due to the delays in the commencement of the demonstration projects, the period of follow-up was limited in most cases to approximately 12 months. So whilst, it appears that the observed improvement in the health status variables was maintained to the 12 month measurement point, it is not known if these movements were maintained beyond that and any consequent clinical outcomes (see below).

Measurement issues

Whilst every attempt was made to use valid and reliable instruments, it seems that the measures may not have been sensitive enough to detect subtle change over time, particularly in those who were at the better end of the scale to begin with. The evaluation was also limited in the extent of the measures it could use. For example clinical assessments were not available, hence it was necessary to rely on health reported health status. Whilst self reported changes would, for the most part be internally consistent, it was not possible to determine whether the significant changes reported had clinical significance or whether the presence of clinical risk factor influenced outcomes. In addition it was not possible to determine, based on the measures used, the extent to which other life events over the course of the evaluation may have influenced self reported health status.

Data collection issues

The overall completeness and quality of the data used in the evaluation was a considerable strength to the evaluation. However, the Project Reports was one area where there was considerable inconsistency in the quality and completeness of information supplied to the National Evaluation team. Whilst they were not a major data source, the differences in format and content (despite the proforma provided) increased the time it took to analyse the data and limited the extent to which these data could be used in the final analysis.

For different reasons, the number of community or board members interviewed as part of the key informant interviews for the National Evaluation was limited for the Indigenous demonstration projects. For the demonstration project which was operating within the larger non-Indigenous demonstration project, there was neither the time nor the scope to explore the impact of the demonstration project with a broader selection of community members. For the other demonstration project, while interviews with board members were planned for each visit, local project management issues meant they did not take place.

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