

Implementing chronic disease self-management in community settings: lessons from Australian demonstration projects

Caitlin F Francis, Anne-Marie Feyer and Ben J Smith

Abstract

The evaluation of the Sharing Health Care Initiative addressed the translation of different models of chronic disease self-management into health and community service contexts in Australia. Across seven projects, four intervention models were adopted: (1) the Stanford Chronic Disease Self Management course; (2) generic disease management planning, training and support; (3) tailored disease management planning, training and support, and; (4) telephone coaching. Targeted recruitment through support groups and patient lists was most successful for reaching high-needs clients. Projects with well developed organisational structures and health system networks demonstrated more effective implementation. Engagement of GPs in recruitment and client support was limited. Future self-management programs will require flexible delivery methods in the primary health care setting, involving practice nurses or the equivalent. After 12 months there was little evidence of potential sustainability, although structures such as consumer resource centres and client support clubs were established in some locations. Only one project was able to use Medicare chronic disease-related items to integrate self-management support into routine general practice. Participants in all projects showed improvements in self-management practices, but those receiving Model 3, flexible and tailored support, and Model 4, telephone coaching, reported the greatest benefits.

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CHRONIC CONDITIONS, such as circulatory system disorders, diabetes, arthritis, cancer and mental disorders are the major contributors to Australia's burden of disease.¹ The 2001 National Health Survey found that 52% of Aus-

What is known about the topic?

The rising prevalence of chronic diseases is the greatest source of demand upon the Australian health care system. A range of generic and disease-specific programs to equip individuals with chronic disease self-management skills have been developed, but there is limited information about the extent to which these can be transferred into routine health care settings.

What does this paper add?

The evaluation of the Australian Shared Health Care Initiative provided the opportunity to compare the quality of implementation of four established models for facilitating chronic disease self-management delivered across a wide variety of settings. This highlighted aspects of participant recruitment, program design, organisational structure and service networks that improved the reach, delivery and impact of different approaches.

What are the implications?

All models appeared to facilitate improved disease self-management, but it is clear that ongoing development of skills, service partnerships and infrastructure are required for the successful implementation of chronic disease self-management programs.

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tralians live with at least one of these major conditions,² and this number is likely to increase as the proportion of the Australian population who are over 65 years of age doubles within the next 50 years.³ In 2000–2001, total health care expenditure on chronic disease, excluding injuries and oral health conditions, was about \$26 billion,⁴ equivalent to about 42% of national health spending in that year.⁵

Because chronic conditions can be alleviated but not cured by medical interventions, there is a need for management strategies that are effective and acceptable for those living with a disease. Self-management is the goal of these strategies, and refers to an: “individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition ... to maintain a satisfactory quality of life”.⁶ (p. 178)

Activities associated with self-management include health behaviours such as exercise and healthier eating, the management of negative emotions and symptoms, and collaborative planning with health care professionals.⁷ An important prerequisite for effective self-management is self-efficacy, or the belief in one’s own ability to successfully perform an action to achieve a desired outcome.⁸

There is extensive literature to support the efficacy of self-management interventions which have been tailored to the needs of specific conditions.^{9–11} For diabetes and asthma, the focus of these interventions has been on symptom control, whereas for arthritis, patients have needed strategies to deal with pain and the consequences of disability. Their success in assisting people with chronic conditions to improve their quality of life and reduce their health service use appears to hold irrespective of the approach taken (eg, group versus individual-based interventions)⁶ or setting (eg, city versus rural location).¹²

An alternative to the disease-specific approach are interventions which focus on developing a generic set of core skills like self-efficacy, problem solving and coping skills based upon Social

Cognitive Theory, which are intended to achieve a similar result for a range of chronic conditions. The Chronic Disease Self-Management Program developed at Stanford University is an example of this approach and, while this has been subject to less evaluation than disease-specific strategies, there is evidence that it can bring about improvement in chronic disease management skills.^{13–15}

A weakness of the evaluations of chronic disease self-management interventions is the limited attention that has been given to the transferability of the approaches tested to community settings and the generalisability of their impacts to the population. Key indicators of the public health relevance of these interventions include their reach to the range of population sub-groups in need, their ability to be implemented with available services and resources, and the availability of mechanisms to enable their sustainability. These dimensions of public health interventions are identified in the “RE-AIM” evaluation framework developed by Glasgow and colleagues.¹⁶

Given the increasing burden of chronic diseases in Australia, the effective implementation and institutionalisation of self-management interventions into the real-world context is of great importance. The national review of the Sharing Health Care Initiative (SHCI), funded by the Australian Government Department of Health and Ageing, provided the opportunity to evaluate the extent to which different models of chronic disease self-management could be translated into community settings. The findings of this review are presented here and, based on this, issues are highlighted which will determine the potential effectiveness of self-management strategies in the Australian context.

Methods

Chronic disease self-management demonstration projects

The SHCI was a national program, operating from July 2001 to June 2004, which aimed to demon-

I Range of client self-management activities undertaken by the projects

Planning	Training	Support
Self-management planning eg, problem solving and goal setting	Stanford self-management course	Telephone coaching
Care planning, including medication review, health service review	Disease-specific courses eg, diabetes, cardiovascular disease	Support/self-help groups
	Healthy eating shopping trips	Walking groups
	Cookery and nutrition classes	Tai chi classes

strate the implementation of a range of self-management interventions in community settings for people with chronic and complex conditions. From a total budget of \$14.4 million, seven demonstration projects were funded for the purposes of: increasing collaboration between clients, their families and health service providers in the management of chronic conditions; improving the health-related quality of life of clients; and reducing health service utilisation.

The projects were undertaken through a range of agencies, including regional health services, non-government agencies, community controlled health services, Divisions of General Practice and universities. It was common for each project to have multiple delivery sites. The core approaches adopted in the demonstration projects can be grouped under three headings, (1) planning; (2) training, and; (3) support. The range of activities encompassed within these approaches is shown in Box 1.

For the purposes of comparison, and to de-identify individual sites, the projects have been grouped in terms of the different methods of planning, training and support activities that they adopted. Across the seven projects, four broad intervention models were identified:

- Stanford Chronic Disease Self-Management Program, a group-based education program for participants with diverse chronic diseases, based on social cognitive theory,^{8,13} with no individual client planning and limited follow-up support;
- generic planning, training and support, which included a mix of services that were delivered in a standardised format;

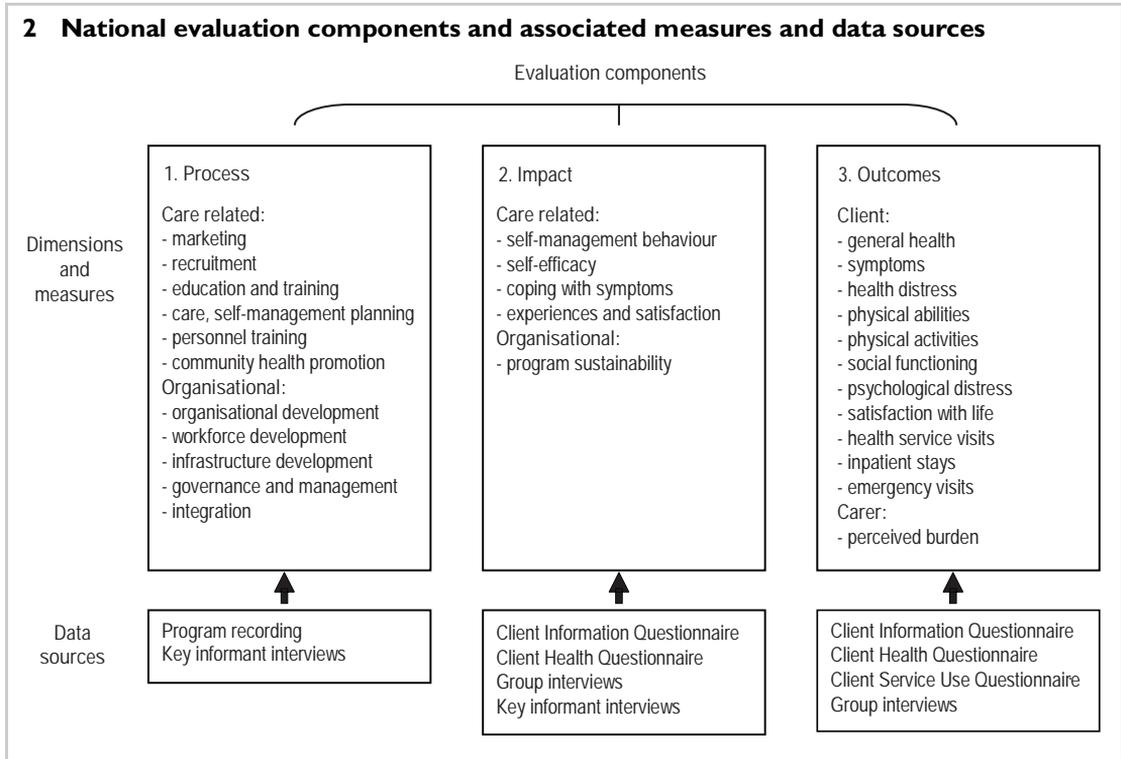
- tailored planning, training and support, where the nature and composition of services was adapted to individual disease status and circumstances; and

- telephone coaching, involving periodic telephone support that was guided by the Stages of Change model.¹⁷

The projects used a range of strategies to recruit participants, which included targeted community contacts and presentations, mail-outs and media releases. Some projects offered training and support to clients before formal inclusion in the services provided.

Evaluation approach

Both organisational and individual dimensions were incorporated in the national evaluation. At the organisational level, the potential public health benefits of the projects were measured by the extent to which: (1) relevant settings (eg, health service providers, health care practices, and/or communities) took up the program; (2) the program could be delivered outside the confines of the research setting, under real-world conditions; and (3) the program became sustainable. At the individual level (including clients and to a lesser extent, their carers), evidence was obtained to understand the extent to which the projects were able to reach their target populations, the features inherent in health promotion impact, such as satisfaction and quality of life, and the efficacy of the projects. However, given that the efficacy of the different approaches had been tested in previous studies, the purpose of the impact and outcome evaluations was to monitor the extent



to which observed improvements in health behaviours and outcomes were in the expected directions.

Box 2 summarises the dimensions, measures and data sources that were included in the evaluation at the process, impact and outcome levels. These are described further below.

Process evaluation

The purpose of the process evaluation was to collect information on the methods of intervention delivery, the number of participants, their characteristics and their level of participation in different types of intervention.

Data about program participants was collected using a Client Information Questionnaire (CIQ) which included measures of chronic condition severity and complexity, health-related behaviours and socioeconomic status. All of the items, with the exception of those relating to chronic disease status, were taken from established instruments for which Australian normative data were

available.¹⁸⁻²⁰ CIQ data were collected by the projects at baseline and 12-month follow-up. The mode of data collection varied across the projects and included face-to-face interviews, supervised self-completed questionnaires and mailed questionnaires.

To understand how clients were reached and the implementation methods used in each project, the national evaluator visited each project to discuss, observe and document the program activities. The aspects of the projects that were examined included care-related processes (eg, recruitment, awareness raising, and methods of delivering planning, training and support) and organisational processes (eg, development of local networks, management structures and workforce and infrastructure development). Key informant interviews were undertaken at each site with the project leaders, project advisory committee members, health service providers, and local advocates for self-management programs. The structure of these interviews was based on the Community

Capacity Index²¹ and addressed establishment of local partnerships, knowledge transfer about program content and delivery strategies, problem solving mechanisms and the development of program delivery infrastructure. Process data were collected at the baseline, mid-point and end of each project.

Impact and outcome evaluation

The purpose of the impact and outcome evaluations was to monitor the extent to which those who received the interventions demonstrated improved management of their chronic conditions. Two questionnaires were used to measure change in self-management behaviours and health status. The Client Health Questionnaire recorded self-management behaviours and health status measures including self-efficacy, symptom control, health status, health-related quality of life, functional status, social functioning, psychological distress and overall wellbeing. It was developed from valid and reliable instruments: the Stanford 2000;²² Kessler 10;²³ and the Satisfaction with Life scale.²⁴ A Client Service Use Questionnaire was developed to record the number of visits to health service providers (eg, general practitioners, specialists and community nurses) and admissions to hospital and emergency departments in the previous 6 months. These questionnaire data were collected by each project at baseline and 6-monthly intervals. The longest follow-up period was 18 months.

Group interviews were undertaken with clients, carers, local communities and health service providers by local evaluators at each site to examine client access to health services, involvement in the self-management planning process, communication, relationships with project staff and overall satisfaction with the program. Health service providers were also asked about how self-management had impacted on their working lives and carers were asked to comment on the extent to which they felt burdened by their role. As with the questionnaires, the interviews took place at 6-monthly intervals, with respondents selected according to their length of engagement in the projects. The local evaluators received guidance concerning interview questions from the national evaluator

(following the dimensions of the overall evaluation framework) and were able to examine additional issues of relevance to their projects.

Models for facilitating chronic disease self-management

Stanford chronic disease self-management course

Two projects adopted the Stanford course as their primary intervention. These courses ran for 6 weeks, for 2.5 hours per week, with up to 15 participants meeting at local community venues. Courses were facilitated by two trained leaders who were usually health service providers (eg, a community nurse) and/or lay people who had chronic conditions.

The target populations for recruitment were people over 50 years who had diabetes, arthritis, osteoporosis or a respiratory disorder. The projects reported that presentations to local community groups, eg, bowling clubs and Returned and Services League Clubs, as well as word-of-mouth, were the most effective recruitment methods. Wider promotional efforts included newspaper and magazine articles and advertisements, mail-outs to potential clients, and pamphlets and videos left in GP surgeries. There were 569 people recruited across the two projects, compared with initial expectations of 1100. Compared with the overall SHCI projects, participants in this model came from a broader age range (46% over 65 years), with females (75%) and those with arthritis (49%) strongly represented.

Across the two projects, 94% of the client group completed some training and nearly three-quarters attended the Stanford course for 4 weeks or more. Holding courses at a range of community venues and on evenings as well as day times increased their accessibility. While the Stanford model is a generic group education program, in response to client feedback one of the projects began to offer supplementary disease-specific training as well support activities, like grief management workshops and tai chi groups.

An important factor influencing implementation was the availability of good quality trained leaders to run the courses, who were usually community nurses. The projects, therefore, had to maintain good working relationships with community health services, especially in rural areas. In order to establish a supply of leaders within the community, one of the projects used funds from the Community Development Fund it had established to provide ongoing training of Stanford course leaders.

One of the projects built links with the local Coordinated Care Trial,²⁵ with whom it shared many of the same consortia members, for new referrals. This resulted in the project running courses more frequently over a longer period but, unlike the other project, no steps were taken to facilitate adoption of self-management programs within the community itself.

There was substantial variation between the follow-up rates achieved by the two projects (58% and 76%) for the evaluation of client impacts, reflecting the efficacy of the different follow-up methods used (ie, mail-out versus face-to-face interviews). The findings indicated that clients from this model achieved lesser improvements in health status, health-related quality of life, symptom control, self-efficacy, and number of GP visits than those who participated in the tailored and telephone coaching models.

Generic self-management planning, training and support model

The two projects in this model offered a complete suite of interventions (planning, training and support) to clients over a 12-month period. All clients received a self-management plan which was developed using a formal framework ("Partners in Health" and "Cue and Response" tools²⁶) to identify health management problems and set goals to address these. This was undertaken by primary health nurses seconded from local Area Health Services. In most cases, clients had two face-to-face follow-up contacts within the clinic or at home within 3 to 6 months of the initial planning session. The Stanford course was an additional element in both projects, with adapta-

tion to increase its suitability to clients from culturally and linguistically diverse (CALD) backgrounds. The project which was run from an area health service offered additional one-to-one training by primary health nurses for those with particular medical needs (eg, cardiac rehabilitation, diabetes management). Following the planning and training, both projects provided ongoing support through phone calls or referral to support groups or other health service providers.

The target groups for both projects were people aged over 50 years who had at least two chronic conditions. The project run from the area health service relied on primary health nurses to recruit those on existing patient lists, and also promoted the service to local Arabic community groups and GPs. The project based in a Division of General Practice was unsuccessful in engaging with GPs to provide referrals because of the limited time available to raise GP awareness and establish referral linkages, and the various projects competing for GP involvement. A more effective approach that was adopted was promotion to local self-help groups and community groups for the Spanish-speaking population.

There were 563 clients recruited in these two projects, which exceeded their more modest combined target of 356 clients. Compared with the other models, the participants in these projects were older (70% were 65 years or older), with significantly more living in supported accommodation (16%) and having a carer (32%). Given the high level of planning, follow-up and support on offer, the appeal to this higher needs group could be expected. More clients in these projects were from a CALD background (24%) and 72% were women. The most common chronic conditions reported by clients were arthritis (36%) and cardiovascular disease (17%).

A very high rate of client participation was recorded, with 98% of clients having a self-management plan, 94% attending training, and 95% receiving ongoing support. The majority of clients (64%) attended at least four sessions of the Stanford course. The project based in the area health service had the organisational capacity and infrastructure to offer a more comprehensive

program which included, for instance, a medication and health service review for all clients. The pre-existing networks that it had established with practice nurses, GPs and allied health professionals were also beneficial; they facilitated cooperation and did not place excessive demands on particular providers in recruitment or care planning. The other project placed greater care planning expectations upon GPs, which were not met. It was believed that the availability of Medicare Benefits Scheme (MBS) reimbursement for formal chronic disease care plans would encourage GP involvement, but this was not realised.

Both projects undertook client evaluations through face-to-face interviews which were integrated into the support services provided, hence good follow-up rates (73% and 80%) were achieved. Again, clients in these projects improved less than those in the tailored and telephone coaching models in all of the outcome measures. The lower socioeconomic status and poorer health status of participants in these projects may have contributed to the smaller improvements in the self-management outcomes achieved.²⁷

Tailored self-management planning and support model

The two projects in this model offered a suite of planning, training and support interventions tailored to the disease characteristics and needs of clients. In one of the projects the self-management planning was similar to that undertaken in the generic model described above, whereas the other project developed an action plan for each client which became a tool for monitoring the client's progress. Both projects offered training activities in addition to the Stanford course, for example, disease specific courses, healthy eating shopping trips and nutrition classes. Different community-based models of support were adopted, with one project establishing a club which offered monthly information sessions on health-related topics and organised exercise groups for club members. The other set up a health resource centre in partnership with a local GP to increase access to health-related informa-

tion (eg, via the Internet, brochures) and provide training and support. Both programs engaged clients and community members in operating the support services.

One project was conducted through a local rural medical school and, building on existing relationships with local GPs, was able to recruit clients through a combination of direct referral by GPs and a review of their patient lists. The other project was coordinated by a Division of General Practice, but experienced difficulty in engaging the GPs for client recruitment. This may have been due to its initial focus on establishing formal partnership and referral mechanisms rather than building relationships with GPs and engaging them to promote the project among peers. This project changed its recruitment approach to community-based strategies (eg, shopping centre stalls, newsletters, media releases), promoting the services offered by its support club.

The projects sought to recruit people aged over 50 years with one of a variety of chronic diseases, and together recruited 492 clients against an initial target of 1150. Among participants there was a fairly even spread of conditions, although arthritis was most common (34%), and women (57%) and university educated people (13%) were less strongly represented than the other projects.

About half of the clients who took part in this model participated in self-management planning (50%) and training activities (55%) and about one-third attended four or more weeks of the Stanford course. A high proportion (83%) of clients received support through a club or resource centre, or participated in exercise groups like tai chi or walking.

The project which offered both self-management and individual action plans for clients was able to increase its sustainability by having the costs of the nurse-delivered services reimbursed by MBS payment following completion of a client and GP agreement. Formal face-to-face follow-up interviews also occurred every 3 to 6 months.

There was substantial variation (from 42% to 83%) in the client follow-up rates achieved by the projects; in one the measurements were com-

pleted as part of usual follow-up whereas the other relied on questionnaires being voluntarily returned by participants. The findings suggest that participants in these projects improved significantly more than those in the generic and Stanford models in general health, health distress, coping with symptoms, self-efficacy and social functioning. While these results need to be treated cautiously, with just 79 clients providing follow-up data in one of the projects, interviews with project staff indicated that clients particularly valued the tailored approach to planning and training and the innovative support services that were offered.

Telephone coaching model

There was one project which offered self-management planning and ongoing telephone coaching as its main intervention. The initial planning was undertaken by a nurse or health educator in consultation with the client and, for the medical management plan, with the client's GP. Once the management plan had been developed, each client was allocated a coach, such as a community nurse or allied health professional, who would contact them by telephone about once a month over 12 months, for 15 to 20 minutes each time. This coaching aimed to develop the self-management capacity of clients by using strategies matched to their stage of readiness,¹⁷ facilitating access to services and promoting stronger client and GP partnerships. Stanford training was not offered, but as the project progressed extra training programs (eg, cookery classes for diabetics, disease-specific courses, supermarket tours) were offered in response to client demand.

While this project was run from a Division of General Practice it had limited success in obtaining referrals from GPs, possibly because it was one of three new projects being undertaken by the Division and there was some confusion about where to refer patients. Originally the project had sought referrals from GPs who were required to have partially completed the care plans, however, as the rate of GP participation fell the medical management plan was developed as a less resource intensive way to engage GPs. Project staff built links

with local health service providers for referrals, and formalised the roles and responsibilities of these providers, as well as GPs and officers of the Department of Veteran's Affairs, through memoranda of understanding (MOUs). The project was also promoted directly to clients via local diabetes support groups, Chinese community groups, brochures, media releases and its website.

The target population for this project was people 50 years and older with diabetes or cardiovascular disease. There were 350 clients recruited, against an initial expectation of 1000. Compared with the characteristics of participants across all of the projects, there were significantly more men (43%), clients with diabetes (48%) and people of CALD backgrounds recruited.

The level of compliance achieved in this project was very high; 99% of clients had a self-management plan developed, 97% received some degree of telephone coaching and 92% attended training. Effective engagement with the local health service provider network was found to be critical, both for providing the coaching and for raising awareness about the self-management support available across the community health network. The MOUs were a useful tool for clarifying ways in which the project's interventions could be integrated into local health service provision, especially since they described practical and acceptable methods of multidisciplinary cooperation.

There was a 50% follow-up achieved for evaluation of client impacts, which was undertaken by self-completed questionnaire. As previously stated, recipients of this model of support showed significantly greater improvements in general health, health distress, coping with symptoms, self-efficacy and social functioning than those receiving the Stanford and generic models of self-management. The generally better health status of clients in this model at baseline may have increased their capacity to adopt the disease self-management strategies.

Discussion

This evaluation of the SHCI highlighted several features of the projects that were most successful

in translating chronic disease self-management strategies into community settings. Of particular importance were well developed organisational structures, infrastructure support and having in place health system networks with GPs and other health service providers.

The generic and tailored models, which used the more resource intensive approach of reviewing patients lists to identify potential clients, appeared most successful in recruiting participants with greater support needs. All the projects had less success than anticipated in reaching community members with chronic disease who did not have previous contact with health services or support groups, highlighting a need for the development of innovative community recruitment strategies. The success of the tailored and telephone coaching projects in recruiting the highest proportions of men was noteworthy. Men have been a traditionally hard to reach group in community health interventions^{28,29} and the characteristics of programs which achieve greater male participation warrant further examination in Australia. In this case the individual, as opposed to group-based, aspects of these projects, as well as the flexibility in the times at which they were offered, are likely to have been important factors.

Projects which had strong relationships with local health services were better able to achieve multidisciplinary cooperation from GPs, community nurses and allied health practitioners. While GPs were important facilitators of client referral and care planning, the constraints on their time were a consistent barrier to their more active participation. The projects which recognised this and developed networks with other paid and non-paid primary health care workers were more likely to be implemented according to plan.

Given that the present evaluation was concerned primarily with the transferability of self-management interventions into community settings, control groups were not used in the evaluation of the impacts of each project upon indicators of client disease management. In addition, a mixture of measurement techniques were used and varying follow-up rates were achieved,

reflecting differences in the emphases placed on measuring client outcomes across the projects.

Notwithstanding these limitations, it is worthwhile considering the aspects of the programs that appeared to be associated with greater benefits for clients. There was some evidence that clients responded more positively to interventions which gave them the opportunity to have some control over the development of their self-management skills (eg, the tailored and telephone coaching models). Using appropriate planning tools (eg, "Partners in Health" tool) at the commencement of programs, and combining generic training (eg, the Stanford course) with disease-specific advice appeared to be a beneficial aspect of some interventions. Delivering structured support, which reduced isolation but did not foster a high level of dependency by clients upon the services provided, was also important. This was well illustrated by the positive client response to the telephone coaching and support club approaches offered by some of the projects. This is contrary to the principle adopted in the Stanford course, that self-management supports are most beneficial when they are self-generated by participants.

The 12-month duration of the evaluation provided an opportunity to examine whether mechanisms for sustainability were being developed by the projects. None of the projects established themselves sufficiently well within their local health networks during the SHCI to continue with their self-management programs without additional support from either state or federal governments. The use of the MBS items related to chronic disease care by GPs was envisaged as a mechanism for the integration of self-management support into routine general practice. However, only one project was able to fully integrate Medicare eligible care planning into their program and all projects had unrealistic expectations of GPs' availability to undertake care planning. It is likely that the future implementation of self-management programs in general practice will require the support of a practice nurse or the equivalent.

To assist with the integration of self-management into the health system, there needs to be recognition of the importance of such interventions within national standards of care. In addition, if self-management interventions are to be more widely adopted in health care, skills such as group facilitation, problem solving, goal setting, and cognitive behavioural techniques need to be included as part of health service providers' training.

The SHCI has helped to address the need in Australia to examine how chronic disease management strategies can be integrated into existing service delivery systems to deal with the growing disease burden that this country is facing. It is likely that diverse self-management strategies, covering the range of approaches funded under this initiative, will be required to cater for the varying needs and circumstances of individuals living with a chronic disease. This initiative has highlighted key factors affecting the reach, delivery and effectiveness of approaches that can be used at the community level and is an example of the types of evaluation that contribute to the advancement of public health practice in Australia.

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Competing interests

The authors declare that they have no competing interests.

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