

**South Western Sydney Area Health Service Chronic  
Disease Self Management Demonstration Project  
Sharing Health Care Program**

**Chronic Disease Self Management Project Follow Up Study  
Final Report  
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## Executive Summary

Chronic disease self management (CDSM) is a healthcare strategy where professionals support clients to develop skills in managing long term health conditions. A recent systematic review of chronic disease management conducted by this Centre found that patient self management support was the most commonly used and most effective intervention for chronic disease care.

A model of CDSM developed by Stanford University (USA) involves the clinician and client working in partnership to identify problems, set goals, problem solve and monitor health outcomes. The partnership is facilitated by a self management education process in which patients develop skills in identifying and managing problems which may or may not be related to disease.

Between 2002 and July 2004 the Australian Government Department of Health and Ageing (AGDHA) funded twelve demonstration CDSM projects. A consortium including representatives from local Divisions of General Practice, services within the South Western Sydney Area Health Service and the University of New South Wales developed and implemented the SWSAHS CDSM Demonstration Project. The SWSAHS project focused on the interface between clients, primary health nurses and general practitioners. The Project involved four main activities:

1. Assessment and prioritization of clients health issues using the Flinders University (AUS) ‘Partners in Health Scale’ and ‘‘Cue and Response’’ forms by community health based clinicians;
2. Collaborative development of a care plan between the community health clinician, the clients and general practitioners;
3. Referral of clients to the CDSM Program and disease specific education sessions with specialists where appropriate; and
4. Three monthly follow up by the community health clinician.

The program was overseen by four coordinators and involved collaborative training and work with consumers, primary health nurses, hospital based nurses and general practitioners. The Program ended in 2004 because the Program license expired.

The UNSW Research Centre for Primary Health Care and Equity was commissioned by the newly formed Sydney South West Area Health Service in November 2006 to undertake a follow up study of the local CDSM project. The follow up study was conducted approximately two years after the Program ended. The main objective was to assess the views of clinicians on the integration of CDSM into the routine clinical activities and identify issues for sustainability. The methods were qualitative using semi-structured face to face interviews and focus groups with community health clinicians and who were involved in the CDSM Project. A total of six face to

face semi structured interviews and two focus groups were undertaken. Audio-tapes from both the focus groups and interviews were transcribed verbatim and a thematic analysis was undertaken.

The study found widespread support by clinicians for the South West Sydney CDSM project. Participants in the study were very satisfied with the quality of the CDSM model and its congruence with their values and clinical roles. They also found the training effective in developing their own skills and confidence in providing self management education.

Clinicians identified few barriers to the implementation of the project. The most important was the inflexibility of the program to deal with the needs of different cultural and linguistic groups in the local population. Lack of small amounts of flexible funding to support the conduct of group classes was also a problem in Community Health services.

Most had attempted to continue providing SM education as part of their clinical roles even after the program had ceased. However, very little group education for clients had been sustained. Most importantly the licensing restrictions meant that the education programs could not continue to be run. Other barriers to sustainability included the other work pressures on staff especially the reorientation of their roles to provide greater support for post acute care and the declining nursing workforce. Integration with general practice was quite limited and this meant lost opportunities to enlist their support and resources.

## ***Recommendations***

### ***1. National and State policy:***

- 1.1 There is a need to continue to support funding for CDSM initiatives especially the development of culturally appropriate programs.
- 1.2 CDSM programs need to be better integrated with other initiatives in PHC especially between Commonwealth and State funded services such as between general practice and State community health services.
- 1.3 There is a need to introduce models of CDSM education which substitute peer educators for the role of professionally trained staff. This is to address the workforce pressures and to ensure that it is culturally appropriate.

### ***2. Local Health delivery***

- 2.1 There is a need to license or develop a program which can continue to be delivered as a part of routine health care and is not subject to the same restrictions which operated in this project associated with use of the Lorig Program.
- 2.2 A coordinator position needs to be established to facilitate the integration of CDSM into the work of all PHC services and to train and support all staff and volunteers to provide CDSM education group education sessions.

- 2.3 Limited flexible funding needs to be available to Community Health staff to provide group education or to train / support peer educators.
- 2.4 CDSM programs need to link with and utilize the resources of Non Government Organisations (NGOs) and Divisions of General Practice (DGP) to support CDSM.
- 2.5 The performance of health managers should include ensuring access to CDSM by all patients with chronic illnesses utilizing the Area Health Services.
- 2.6 The job descriptions of all PHC staff should include CDSM assessment and education as a core role
- 2.7. Staff development should including training to support staff in acquiring and maintaining competencies in CDSM assessment and education.
- 2.8 IT systems which support community care should prompt and record CDSM education especially in patients undergoing care planning.

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## Introduction

Chronic disease self management (CDSM) is a strategy by which health care professionals support the role of patients/clients in managing their conditions through a combination of health assessment and client education using principles of adult learning. The goal of self management is “that people will have the confidence to deal with medical management, role management and emotional management of their condition” (McGowan 2005, p 3). It is defined by a partnership between clinicians and patients and involves a combination of elements including:

- Engagement in activities that protect and promote health;
- Monitoring and managing signs and symptoms of illness;
- Managing the impact of disease on functioning, emotions and interpersonal relationships;
- Adhering to treatment regimes; and
- Adapting new perspectives and generic skills that can be applied to new problems as they arise and practicing new health behaviours.

Numerous CDSM programs have been implemented both internationally and within Australia including the Stanford Model, the Expert Patient Program and the Flinders Model. Elements that have been highlighted as contributing to effective implementation of the programs include a collaborative approach between the patients/clients and clinicians, clinician self management education and ongoing training, informed choice, behavioural and lifestyle changes and follow up. Self-management education can be undertaken on a one to one basis between client and clinician or in group settings led by either health professionals or lay persons (McGowan 2005). The role of non traditional health care providers and the optimal training of health educators is yet to be determined (Norris 2001). For disadvantaged patients/clients, engagement of local community networks (social support) is an important component (McDonald 2004). The Stanford Model developed by Kate Lorig and colleagues at Stanford University (US), shows the clinician and patients/clients working in partnership in identifying problems, goal setting, problem solving and monitoring health outcomes. The partnership is facilitated by self management education (normally conducted over six weeks) in which patients/clients develop skills in identifying and managing problems which may or may not be related to the disease.

In a systematic review of chronic disease management it was found that patient self management support was the most commonly used and most effective intervention used. These outcomes included professional adherence to guidelines, patient adherence to



treatment, patient quality of life, patient health status, patient satisfaction and functional status. The most effective self management interventions identified in the review were patient group education sessions and patient motivational counseling. (Zwar et al 2006). Zwar and colleagues also performed a review of eleven systematic reviews investigating self management support and found successful interventions focused on client empowerment and therapeutic interventions. Motivational counseling was the main contributing factor to an intervention being effective and that the activity was most effective in a group setting. Client self management undertaken within community or church groups was found to be most effective because the sessions could be “culturally specific.”

Studies however report variability in the effectiveness of CDSM in regards to economic and health service usage outcomes. A systematic review of the effectiveness of self management training in Type 2 Diabetes reported that of the studies that examined economic and health care utilization outcomes many failed to demonstrate improvements in outcomes of interest (Norris 2001). Researchers that evaluated a self management education intervention for persons with one or more different conditions found the intervention effective in increasing healthy behaviours, maintaining or improving health status and decreasing rates of hospitalization. However the authors conclude that because most CDSM programs have not been “formally evaluated” the effectiveness of these programs against single disease orientated programs can not be determined (Lorig, 1999).

People from lower socio-economic groups are more likely to report suffering from chronic disease (Robbins 2001). CDSM programs are thought to be able to be tailored to the specific needs of groups from different cultural backgrounds (Brown, 1995) and social contexts (Riley 2001). Nine factors have been shown to impact positively on the success of CDSM programs for disadvantaged patients/clients including:

- Understanding the health beliefs and expectations of the groups involved and adapting programs to meet these beliefs;
- Increasing levels of health literacy and tailoring information and materials;
- Improving the communication skills of providers;
- Working with the person with chronic conditions, their carers, families and communities;
- Addressing issues related to affordability in program design, so that it presents no barrier to uptake;
- Addressing poverty and other environmental issues;
- Improving access to PHC services;

- Employing people from the target group including Aboriginal health workers and bilingual health workers; and
- Ensuring that language barriers are addressed through the use of interpreters and translation of materials (McDonald 2004).

Of the studies that have reviewed the effectiveness of CDSM programs, the majority have not sought the views of participating clinicians in regards to the facilitators and barriers to successful uptake and long term sustainability of the programs. One study by Fuller et al (2004), reports findings of a qualitative evaluation of a chronic disease self-management project in rural South Australia. The study had a particular focus on client centred care planning as an aspect of self management programs. It was reported that in general both clinicians and clients were supportive of the care planning process and that both client-centred care planning and self-help support were both important in overall CDSM. However it was found that clinician time was a barrier to performing care planning, particularly in relation to workload pressures and that the process would need to be streamlined as the clinicians found it difficult to integrate it into their work. The study also reported that referral and feedback letters were considered appropriate means of communication between allied health workers and GPs.

CDSM is considered a health policy priority internationally. In Australia, CDSM is listed as a health service priority by the Coalition of Australian Governments (COAG) for action. It has also been identified as a priority by the NSW Health Department in its Chronic Care Program (NSW Health Chronic Care Program Strengthening Health Care for People with Chronic Disease phase 1: 1999-2002, phase 2 2003-6 [NSW Health 2004]) which includes a number of principles that relate to or support the development, implementation and sustainability of CDSM within Area Health Services including:

- The nomination of senior managers within Area Health Services to take responsibility for the development of chronic care;
- Staff access to education and training in general principles of chronic disease management by December 2007; and
- the provision of professional development and systems to provide mentoring to area health service staff leading or developing chronic care activities by June 2007.

## **Background South West Sydney Chronic Disease Self Management Demonstration Project**

Between 2002 and July 2004 the Australian Government Department of Health and Ageing (AGDHA) funded twelve demonstration projects under the Sharing Health Care Initiative. The projects were designed to develop and implement models of chronic disease self management (CDSM) in urban, rural and remote health settings within Australia. A consortium including representatives from local Divisions of General Practice, services within the then South Western Sydney Area Health Service and the University of New South Wales developed and implemented the South West Sydney Chronic Disease Demonstration Project .

The South West Sydney Chronic Disease Demonstration Project aimed to:

- Develop, implement and assess a model of community support for patients/clients with chronic conditions; and
- Support GPs to plan the care of patients with a chronic disease over a 12 month period.

The project focused on the interface between patients/clients, primary health nurses (PHNs) and general practitioners (GPs) and involved four main activities:

1. Assessment and prioritization of patients/clients health issues using the Flinders University ‘Partners in Health Scale’ and ‘‘Cue and Response’’ forms by community health based clinicians;
2. Collaborative development of a care plan between the community health clinician, the patients/clients and general practitioners;
3. Referral of patients/clients to the chronic disease self management (CDSM) Program (the Lorig Program, developed by Stanford University, USA) and disease specific education sessions with specialists where appropriate; and
4. Three monthly follow up by the community health clinician

Patients/clients were assessed for eligibility for inclusion in the project based on:

- Having at least two chronic conditions;
- Being 50 years or older;
- English or Arabic speaking background;

- An absence of mental health problems including drug and alcohol issues;
- Client support from their General Practitioner; and
- Commitment to be part of the CDSM Program for 12 months.

The CDSM project was overseen by a project manager supported by four local PHN coordinators and involved collaborative training and work with consumers, primary health nurses, hospital based nurses and general practitioners. The CDSM Project implemented three different types of training including:

1. The Flinders Model: this was a 2 day “train the trainer” program that originally was designed for the program coordinators. In the CDSM project the Flinders Model was adapted and used as in-service education for the primary health nurses (general training) in understanding self management and the use of the program related tools;
2. “Leader” training which was train the trainer workshops for clinicians and consumers to allow them to facilitate the CDSM education program for patients/clients (Lorig Program); and
3. Implementation of the Lorig Program- a six week CDSM education program for patients/clients.

In addition to the training, patients/clients were provided with both written resources and follow up support during the CDSM Project. One project coordinator and a consumer also travelled to Stanford University (US) to undertake the Master Training in the Lorig Program as part of a sustainability strategy and to support their further involvement in the SWSAHS future CDSM initiatives.

## **CDSM Follow Up Study**

A National Evaluation of the Sharing Health Care Initiative was commissioned by the Australian Government Department of Health and Ageing in 2004 and was undertaken by the Consultancy Firm Price Waterhouse Coopers.

The UNSW Research Centre for Primary Health Care and Equity was commissioned by the newly formed Sydeny South West Area Health Service in November 2006 to undertake a follow up study of the CDSM project previously implemented. The follow up study was conducted approximately two years after the CDSM project had ended due to licensing issues around using the Lorig Program for patients/clients.

### ***Objective***

The objective of the follow up study was to explore the views of clinicians around the integration of CDSM into the routine activities of clinicians and issues for sustainability.

### ***Aims***

The follow up study aimed to explore the views of clinicians who participated in the SWSAHS Chronic Disease Demonstration Project in regards to their understanding and confidence in delivering self management education for patients with chronic disease and how sustainable CDSM is in the work of community health clinicians.

The study was based on three research questions:

1. What training have primary and specialist community based nurses received in self management education and what is their perceived knowledge, attitudes and confidence in providing self management education for patients with chronic illness?
2. What factors do primary and specialist community based nurses perceive which act as facilitators or barriers to the ongoing provision of self management education for patients with chronic illness as part of routine care and how sustainable is CDSM?
3. What particular issues are involved in self management education for disadvantaged patients? How can these be addressed?

## **Methods**

This was a qualitative study using semi-structured face to face interviews and focus groups with community health clinicians and managers located within the SWSAHS (Western Zone) who were involved in the CDSM Project.

### ***Participant Sampling and Recruitment***

To be eligible to participate in the study, participants had to be clinicians or managers who had undertaken training or been involved in the implementation of the CDSM Project.

Information about the study and an invitation for eligible clinicians and managers to register their interest in participation was emailed by the Project Manager (who was also the Clinical Manager of the Western Zone Critical Care Services). The email was followed up by a telephone call by the administrative assistant of the Project manager to participants who had not yet responded to the email. This recruitment process was carried out over a period of one month, until a minimum number of clinicians and managers were recruited to support two focus group discussions.

Once clinicians had been recruited they were telephoned by a member of the research team who asked whether they were currently working in a management or clinical role for the purposes of assigning them to either an interview or focus group. It was considered important to run focus groups with clinicians only and to interview managers separately. This was completed, so as not to censor the discussion of clinicians by having their manager present whilst discussing issues.

### ***Interviews***

Face to face semi-structured interviews using a proforma were conducted at a time and location convenient with participants. Those clinicians working in a managerial role were asked to participate in an individual interview. Clinicians that could not attend the focus groups due to work commitments at that time were also given the opportunity to have an interview. Interviews on average took 45 minutes to complete.

Each participant was given a study information sheet prior to the interview and were asked to complete a consent form. Permission was sought from each participant to audio-tape the interview for the purpose of analysis.

### ***Focus Groups***

Focus groups were conducted at Liverpool Hospital as being a central location for participants. The focus groups were conducted by an experienced facilitator using a proforma and an observer also recorded discussions.

Each participant was given a study information sheet prior to the interview and were asked to complete a consent form. Permission was sought from each participant to audio-tape the interview for the purpose of analysis. Focus groups ran for approximately 1.5 hours.

### ***Analysis***

Audio-tapes from both the focus groups and interviews were transcribed verbatim and checked by a researcher for accuracy against the notes recorded during the sessions.

A thematic analysis was undertaken, governed by a flexible coding framework that allowed themes to emerge throughout the process of analysis. The material from the interviews and focus groups were coded separately and then triangulated by one researcher. The coding framework was then reviewed by a second researcher for consistency and divergence of codes.

### ***Ethics***

An ethics application to carry out the follow up study was obtained from the UNSW Ethics Secretariat: No. 067060 and the Sydney South West Area Health Service Human Research Ethics Committee (Western Zone): No. 2006/100.

## **Results**

Findings are related to characteristics of clinicians who participated in the study, specific feedback related to implementation of the CDSM Project and issues around the incorporation and sustainability of CDSM in the routine activities of clinicians. This included links with general practitioners and issues associated with implementing CDSM with disadvantaged patients/clients.

### ***Participating Clinician Characteristics***

A total of six face to face semi structured interviews were undertaken. Participants had either participated in the CDSM training or provided support to the project. Current roles of the clinicians/managers involved in the interviews included Acting Director of Community Health, Acting Nursing Unit Manager of Aged Care, Area Community Health Educator, Enrolled Nurse, and one clinical nurse consultant discharge planning. One of the original local CDSM Coordinators also took part in an interview,

Two focus groups were conducted. The first focus group was attended by five primary health nurses, and two nurses that were employed at the hospital, one working in aged care and the other working in cardiac rehabilitation. The second focus group was attended by six clinicians which included three PHNs, one ethnic health worker, one nursing working in the Aged Care Assessment Team (ACAT) and a clinical nurse consultant in pain management. Two of the original local CDSM Coordinators also attended the focus groups.

The majority of the clinicians involved in the interviews and focus groups participated in the in-service education and were involved in client assessment, care plan development and referring patients/clients to either the CDSM group education sessions or other specialist services. In addition, the majority of clinicians were currently working in a different role to when the CDSM project was operating. None of the clinicians had previously had training in chronic disease self management.

### ***General Feedback on the CDSM Program***

Feedback from participants on the CDSM Project addressed five main themes including:



- Types of training undertaken by clinicians who participated in the interviews or focus groups;
- The role individual clinicians undertook associated with the Program;
- The assessment and care plan process;
- The client education sessions based on the Lorig Program; and
- Team support for the Project.

## **Types of training**

Participants reported that there were three main types of training undertaken as part of the Sharing Health Care Initiative: (1) Master training (2) Leader training and (3) In-service education to all staff (general training). The majority of the participants in the follow up study received the in-service education, a smaller number had leader training and one clinician underwent the Master training at Stanford University in the United States.

## **Clinician roles associated with the Program**

Three clinicians working within the SWSAHS at the time underwent Leader training and became one of the four local project coordinators for the Project across the area health service. The coordinators were reported to perform a multitude of roles including patient assessment, in-service education and ongoing support for health service staff related to implementation and evaluation of the Project, promotion of the project with local general practitioners, client/patient follow up/support, as well as running the Lorig patient/client education sessions, usually with assistance from a consumer who was closely involved in the project from its inception.

*“And with the coordinators they have the one on one with them as well so that was good too, where usually they had gone and done their assessment, referred them onto us, the team, we follow it on and the coordinator would go back at some stage too, to see how things are going”  
[Clinician: Focus Group1]*

In-service education for clinicians such as the primary health nurses involved training related to performing clinical assessments of the patients/clients, development of a care plan through liaison with the GP and referral of patients/clients to the group education sessions. These clinicians in general, were not trained to run the education sessions with patients/clients.

Clinicians indicated that patients/clients were routinely followed up at 3 – 6 monthly, even if this was sometimes thought to be un-necessary:-

*“I then just followed up on those long term patients/clients and rounded up 3 months and 6 monthly check ups. By then, most of the patients/clients didn’t have much really, they had the*

*chronic illnesses but some of them seemed to have been resolved, so there wasn't really much you could add on or take out of it, so if you went to them at 3 months, there was no change after 6 months" [Clinician: Focus Group1]*

Clinicians commented that their involvement in the CDSM initiative dropped off over time because of either the selection criteria for eligible patients/clients to participate in the group education sessions (which meant that their patients/clients were not eligible to attend) or because *"most of the patients/clients had already gone through the Program" [Clinician: Focus Group1].*

## **Assessment and Care Planning Process**

### **Client Assessments**

In general participants commented on the lengthy process of undertaking the standardized assessments specific to the CDSM Project. The assessments were initially specific to the Project, but clinicians in the focus groups commented that they were time consuming to complete and that they often duplicated information contained in the routine assessments undertaken by the PHNs.

### **Care Plan development**

In general, clinicians gave positive feedback in regards to the logistics of completing the standardized electronic care plan. The care plan was perceived by one clinician as an avenue for increasing contact with the patients/clients and their GPs and also legitimizing the time spent with patients (in development of the care plan) that is difficult to justify since the end of the CDSM Project. In addition, the development of patient care plans highlighted the lack of referral services in the area related to chronic disease management. Clinicians discussed some difficulties with the care plan development which were generally concerned with the interface between the community health clinicians and GPs and these difficulties are elaborated later in the report.

*" it has again decreased our involvement with GPs and also with the client because being able to sit down doing a really good care plan with the patients/clients, liase with the GPs and other services around the place.....the funding went and I mean I had the time to go and spend and hour with the client if they wanted to, now we're lucky if we have time to do that." [Clinician: Focus Group 2]*

*"one thing that.....did highlight about the care plans are the lack of services because we were doing a whole list of assessment of patients/clients and instead of just going in and doing what we were sent to do the care plan required it a sort of whole list of assessments and the things like.....podiatry, no podiatry or an OT assessment at home, no community OT, physio therapy, no physio therapists, community transport, no transport so it highlighted a hell of a lot of services that we didn't have and still don't have." [Clinician: Focus Group 2]*

## Client Education Program based on the Lorig Program

Clinicians had differing opinions on using the Lorig Program. Some found the material too prescriptive to be able to address the particular needs of the patients/clients attending the sessions. Others found the structured nature of the program useful, particularly when first beginning to run the education sessions, and in being able to get through all of the material on time. One clinician stated that the length of the CDSM group education sessions allowed patients/clients to develop trust in the health staff and the clinicians got to know patients/clients well and “pickup stuff”. Other clinicians commented that the eligibility criteria for patients/clients to participate in the Lorig Program and because of the nature of the local population many people of non-English speaking background were not eligible.

*“We were supposed to just follow the Program we had to be strict about it, but in a lot of times it actually wasn’t appropriate some of the concepts in it” [Clinician: Focus Group1]*

*“I think the structure was quite good, from our point of view” [Clinician; Focus Group 2]*

*“Sometimes they would want something [and it wasn’t available in the Lorig material] and it was hard for us” [Clinician: Focus Group1]*

*“The criteria was quite strict we found, for eligible patients/clients for the programme, because especially out our way there’s a lot of non English speaking background people, so it meant that if they did not have basic English they were not able to participate in the group so actually the patients/clients involved in the study was quite limited” [ Clinician: Focus Group]*

*“because you were working with a group for 4 weeks you could pick up things like, we have one of the patients/clients has actually has mild depression.....when working so close with people I think then you pick more things up and once they feel comfortable with you I think that’s very important” [Clinician: Focus Group1]*

## Team Support

Clinicians talked about having good internal team support for the project. It would seem that different teams organized CDSM differently but there was a general theme of it being well supported at the team level.

*“ And the team supported, when we ran the groups, we’d pick up our workload for the morning, you’d only have an afternoon workload and that was seen as very appropriate because it was part and parcel of the workload. You were either doing the work or you were doing your clinical load or whatever and the rest of the team supported those of us that were doing it” [Clinician: Focus Group1]*

## ***Integration and sustainability of CDSM in the routine activities of clinicians***

The participants highlighted both facilitators and barriers to the integration and sustainability of CDSM within routine activities and possible areas where solutions might be found.

### **Integration of CDSM into the routine activities of clinicians**

Discussions highlighted several elements that could be seen as facilitating the integration of CDSM activities into the routine activities of clinicians and these were largely related to why CDSM was seen as a priority for their team or service and the perceived relevance of CDSM to patients/clients.

Chronic disease self management was considered a priority by both clinicians and managers for four main reasons:

- The role of clinicians working in community health;
- Types of patients/clients seen in a community health setting;
- The perceived benefits to patients/clients; and
- The perceived benefits to the health service/system.

#### *The role of clinicians working in community health*

CDSM was a priority because it could be integrated into the routine aspects of clinical work. Education of patients/clients was also seen as a focus for clinicians, particularly early in the illness phase. CDSM was perceived as a “facilitator” in enabling clinicians, in particular primary health nurses, to provide holistic care to their patients/clients through both early intervention and education. Clinicians reported being positive about their involvement in CDSM activities and that they had gained confidence as a result of the CDSM Project. Clinicians also found that the skills were transferable to other areas. Some clinicians found that they also benefited from being involved in the client group education sessions. One manager considered CDSM as part of the core business of primary health nursing.

*“the nursing staff actually loved coordinating and facilitating them and being part of those groups” [Interview 3: manager]*

*“For me, I suppose I was very enthusiastic with the project, it wasn’t just that it got me out of doing my normal role, it was something new and I found exciting um I found job satisfaction” [Clinician: Focus Group 2]*

*“...we were able to spend that bit more time in educating them and looking at those aspects of the management holistically which is basically what we should be doing in primary health care but unfortunately a lot of it tends to go to just an acute kind of service....” [focus group 1: clinician]*

*“I think it’s mmm incorporated into everything that we do within the primary health nursing team” [Interview 3: Manager]*

*“Every time you went into the group you came out yourself having learned something new yourself” [Clinician: Focus Group1]*

*“I’ve changed roles completely ....and I use those skills quite often.....so we use the skills all the time’ [Clinician: Focus Group1]*

### ***Types of patients/clients seen in community health***

For some participants CDSM was a priority because of the type of patients/clients that used their service, mainly elderly patients/clients with existing chronic disease. Other managers and clinicians felt that CDSM was important for all patients/clients using the service regardless of age, illness or presenting reasons.

*“.....chronic patients/clients here from 65 years old...” [Interview 2: Manager]*

*“I just say its self management for everyone now”[Interview 3: Manager]*

### ***Perceived benefits for patients/clients***

Both managers and clinicians thought that involvement in CDSM had benefits for the patients/clients, with some stating that they could see the positive impact that participation in the CDSM education groups had on the patients/clients and this made them feel good and to see CDSM as important. Overall CDSM was reported to have four main benefits for patients/clients which included:

- Allowing clinicians to intervene early in the disease cycle and slow the progression of the illness;
- Participation in CDSM programs helped patients/clients to avoid hospital admission;
- Participation in CDSM programs provided patients/clients with the opportunity to develop skills to manage their condition; and
- CDSM Program empowers patients/clients to take control of their health and to communicate health needs with other health professionals such as general practitioners and this contributes to continuity of care received.

*“We try to encourage our patients/clients to take on as much of the management of their health as they can and to give them skills to communicate with their GP an with other health professionals, other health services”[Interview 5: Manager]*

*“We’d like to meet people earlier in their chronic disease, the nature of the system and the service often means that we’re not meeting people until they’ve got more active symptoms after symptoms and um we’d like to meet them earlier so that we can help them with those skills and perhaps slow the deterioration of the condition” [Interview 5: manager]*

*“The positive feedback you got.....you could see people grow during the group and the group moulding”[Clinician: Focus Group1]*

*“so they were more aware of that they were in control because they had a copy of the plan and, so, then you get better continuity of care because the person themselves know that they’re in control because they’ve got the piece of paper and they can flash it to whoever. The communication is not through the specialist it’s through them, it’s just gives them that, and then.....a bit more, you, they then are more likely to report to us, feed that back.” [Clinician: Focus Group 2]*

### ***Perceived Health Service Benefits***

Both clinicians and managers thought that one of the main benefits of CDSM is that it reduced hospital admissions and the number of visits by primary health nurses.

*“About teaching people to read their own bodies and to be able to read their symptoms so they know when the right time is to seek help whether it be medical health or from our service um with the understanding that often if symptoms are caught early then we can deal with them at home and avoid the necessity of people having to come into hospital” [Interview 5: Manager]*

*“They have become more independent and less home visit from the PHN” [Clinician: Focus Group1]*

*“It was good for the community to have that, it broke down the barrier where they felt like they were having to come back to hospital and be burden, like they’d learnt skills and they then new an appropriate time to come back into hospital, because a lot of it was giving learning and giving them a plan”[Clinician: Focus Group 1]*

## **Relevance of CDSM to clinicians**

All clinicians and managers perceived CDSM to be relevant to the role of clinicians. Reasons for relevance identified included client base and health service gains.

It is very relevant because the kind of patients/clients that we have can really get education” [Interview 2: Manager]

“It’s part and parcel of the role, it’s very important” [Interview 3: manager]

## **Client base**

CDSM was seen as relevant to the patients/clients seen in community health because of their age and health conditions and the health and social gains they receive from attending the Lorig Program through being empowered to take control of their health and health management.

*“isolated people here from overseas then they come over here and then there’s no one for them and then they get a disease as well and it’s just, they’re locked in the house so it could do a world of good over here. Well, better health, if you get them moving and motivated and not depressed that means their wounds are healed better, faster, socially they start to look, looking after themselves they’re eating better, they’re exercising so in the role of PHN it would be immensely helpful.” [Interview 4: Clinician]*

## **Health Service gains**

CDSM was considered relevant to the health service as it was thought to help provide a more effective and efficient service and also because it shifts the focus of care from the hospital back into primary care, particularly general practice.

*“encouraging patients/clients to self-manage helps us to provide a more effective and sufficient service um and provide a contribution to the broader health care system” [Interview 5: Manager]*

*“Enables me to empower people to use GPs as primary care provider instead of using the hospital” [Interview 6: Clinician]*

*“Give people empowerment to take control of their own disease process, knowledge of how and when to get help, improve care between GP, patient and family.” [Interview 6: Clinician]*

## **Relevance to Patients/clients**

All participants thought that CDSM was relevant to patients/clients, many stating that they received positive feedback on the Project verbally and via the session evaluation surveys. Client empowerment (helping patients/clients to take control of their lives and overcome problems e.g. depression) and client support were the two most frequently discussed benefits for patients/clients attending the Program.

*“Patients – very relevant – it empowers them.” [Interview 6: Clinician]*

*.....”so it’s teaching them to look after themselves and their health so they, they benefit because they lose that depression because they get out and they socialize....” [Interview 4: Clinician]*

*“you know, they really um had a benefit from attending the group you know in managing their um illness, trying to change something within the, within the, practice of it a lot, so the feedback was always very, very good.” [Interview 3: Manager]*

Reducing client readmission to hospital was another benefit frequently raised benefit by participants.

*“you find that they manage their symptoms better, they stay out of hospital for longer, they are not bouncing back into hospital because of that big fear factor because they have actually have control, they know what to do and they’re able to contact their service providers, they’re able to make their way through this incredible network that we’ve created in our hospitals you know, they*

*know who to phone, they know what steps to take, they've actually got written action plans to follow, so the least they've showed that patients/clients actually did not bounce back into hospital when they were truly self managing" [Interview 1: manager]*

One participant commented that both the education component and the group interactions were relevant and beneficial to the patients/clients.

*"obviously the education component is very important um in providing the skills in a capacity for people to self-manage but I think as well the group nature of interactions are very positive and the facilitation by the PHN and the consumer with a chronic illness really worked quite well and we really got a lot of positive feed back from patients/clients about that and from staff as well" [Interview 5: manager]*

## **Barriers to incorporating CDSM into routine clinical practice**

Several barriers were raised that prevent CDSM being incorporated into routine clinical practice including:

- Clinician workload issues and time constraints;
- Logistics concerned with CDSM Program implementation;
- CDSM competing with priorities of acute care;
- Client acceptability;
- Traditional approaches to clinical care by some clinicians; and
- Outcomes of self management are not readily identifiable.

## **Clinician Workload issues and time constraints**

Four main issues were highlighted relating to clinician workload issues and time constraints that both clinicians and managers felt were barriers to incorporating CDSM into routine practice. These included:

- Complexity of care required and volume of patients/clients seen by clinicians;
- Ineffective systems/processes between hospital and community care;
- Self management adds another component to clinicians already overloaded workload; and
- A high turnover of community health staff.

Complexity of care required and volume of patients/clients seen by clinicians working in community health, was thought to reduce available time to implement CDSM. It was perceived that CDSM requires time to implement it effectively and do it well.

*"one of the main barriers is time, um it does take time to support patients/clients with self-management um" [Interview 5: Manager]*



Ineffective systems/processes between hospital care and community care were thought to add to the workload of clinicians and reduce their ability to complete self management initiatives. In addition, one clinician commented that poor linkages between the hospital and community health resulted in a lack of continuity of care being achieved.

*“They’re pushed to have people discharged from hospital, they’re pushed to um,.....acute.....beds in hospital, the complexity of the patients/clients, so and that, I mean, that leads to the time factor cause the patients/clients are more, you know, years ago they wouldn’t have come home on day 3, they’d have come home on day 10 or 12 so the complexity of looking after them at home, some of those systems are still not right you know, we don’t get a lot of information, nurses spend a lot of time ringing, chasing up, you know, discharge summaries or medication for patients/clients, things like that so it’s those kind of things that really impact on them” [Interview 3: Manager]*

*One of the .....of the project is that they didn’t manage to link with hospitals as well, continuum care is something that we really, we talk about a lot but we don’t actually seem to kind of do too much about it, um our care plans went to GPs but the didn’t necessarily go with the patients/clients back into hospital so it wasn’t that formalised link”[Clinician: Focus Group 2]*

It was perceived that self management added another component to clinician workloads, and this issue is coupled with an increase in the size of the local population which has resulted in larger case loads for clinicians (nurses) and a further expansion of their roles but no extra staff to assist. In addition, some community health workers were reported to have to cover wide geographical distances to see patients/clients and the travel time was seen to impact negatively on the time available to spend consulting with patients/clients.

*“They were talking about human resources, because the nurses already have a .....on their role and now they have CDSM & ....on their role and it’s just everything is being put onto them, huge um population areas building up in Liverpool area, large birthrates, families moving in, schools popping up everywhere and the role was getting bigger and bigger and there was just no extra positions that were being added on.” [Interview 1: Manager]*

*“we have a huge geographical area and the nurses have to um travel, you know it’s up to an hour to patients/clients sometimes so that hinders their time spent at the patients/clients house too.” [Interview 3: Manager]*

Participants commented that a high turnover of community health staff in recent times has resulted in workforce shortages, difficulties in recruiting nurses, and employment of new staff who often have to take on an increased workload. Taking part in CDSM requires that the staff would need to have training, but this is difficult to achieve amongst the demands of the job in times of workforce shortages. In addition, participants commented that at times it has been difficult for staff to be released from clinical duties to run the self management group programs.

*“it’s their knowledge and that goes to the knowledge basis because you have to educate people again um and try to do that while you’re trying to give them a work load and say come on you’ve got to get out and see whatever number of patients/clients you have for the day.” [Interview 3: Manager]*

*“at the moment we’re so short staffed so it’s not a good question to ask, we, they wouldn’t have the time for, for anyone to be doing it” [Interview 4: Clinician]*

Participants stated that many of the clinicians who had been initially trained in CDSM associated with the Sharing Health Care Initiative had since either changed roles within the Area Health Service or had ceased to be employed by the Area Health Service. It was observed by the participants that therefore relevance of CDSM to these clinicians in different roles was unknown.

*“we’ve had such a change in the team now that it would be interesting to do a little survey and ask them what they, how they feel” [Interview 3: Manager]*

## **Logistics concerned with CDSM Program implementation**

Three main barriers related to logistics of implementing the self management group education sessions were identified by participants including:

- Lack of available public transport to get patients/clients to the group education sessions;
- Lack of program funding available to cover insurance costs associated with providing alternative transportation and for the hire of a venue to run the group education sessions; and
- Lack of funding to support the acquisition of additional client education resources.

Clinicians discussed the difficulties that some patients/clients faced in accessing public transport to attend the group sessions. Lack of available public transport and long waiting periods to access public transport were two issues raised. Some clinicians commented that if they wanted to pick the patients/clients up using the work vehicle there were insurance implications, that were costly and time consuming in solving.

*“the only other barriers is maybe transport, we found that it was really hard to get some of the patients/clients to the groups because we had no transport for them..... we had to get special permission to get a car to travel, to pick up patients/clients to take to the group which took months to get because it’s matter of insurance and things like that apparently.” [Interview 4: Clinician]*

*“it’s a 40 minute run.....we couldn’t be allocating that amount of time for picking up....so transport is major issue” [Clinician: Focus Group1]*

*“oh yeah, there’s community transport, you should be able to get in” but if they live at Bankstown, I can’t get them here on community transport which is.....and even here to get the community transport, it’s you know like 3, 4 week waiting for an.....to get on so it seems that there are so*

*many delays out there that identifies this problem and you know that this could really help but there's nothing that you can do about changing it.[Clinician: Focus Group 2]*

*"No funding to get resources that you need." [Interview 6: Clinician]*

## **CDSM competing priority with acute care**

Some participants felt that acute care service delivery had become a higher priority over recent times and this reduced the clinicians ability to be involved in CDSM activities. Clinicians perceived that they were expected to see a certain number of patients a week and this conflicted in being able to firstly include CDSM in routine activities, but also the ability to do CDSM activities well. One clinician gave the example, of a client needing an intravenous drip attended to – this activity would have higher priority to attend than an activity related to CDSM.

*"Second thing is time constraints because it appears that managers are more interested or the health service is more interested in numbers, how many patients/clients we've seen because that gives you money but with chronic disease self management you can't aim at the amount of patients/clients, it's better to take a few patients/clients and do them well than trying to take on a whole lot of patients/clients and do it poorly, it just sets the whole thing up for failing. You need time to do this"[Interview 1:Manager ]*

*"I see it as a priority, acute care takes priority over chronic care so particularly when they're out in the community and there is an IV that's got to go up at 10 o'clock, it is much more important than seeing a client with a chronic illness who needs to self manage" [Interview 1: Manager]*

*"The roles are changing as well, like our roles in the community is changing, I've got a lot of acute patients/clients now so therefore you concentrate on acute client but what about the chronic you know" [Clinician: Focus Group 2]*

*"I'm quite cynical, I mean I guess I'm happy that it's gone in the sense that if it was there and the workload that we've got because it requires so much, being such a good programme, it's like "oh no, not another chronic patient, I can't do this care plan" there's just no time for it at the moment." [Clinician: Focus Group 2]*

One participant commented that the CDSM activities that were undertaken as part of the CDSM project were seen by some in a management position as being a project with a limited time span, rather than something that could be done routinely as part of care and this was thought to impact on clinicians and create a barrier to the routine uptake of self management related activities.

*"the health service providers themselves, they're attitudes and just um the lip service that is given to CDSM, you know, this ah but we are doing this approach and we've done this and we've done that but truly it was not taken seriously and it was not implemented seriously. It was something, it was a project and it was going to come and go and when the project was over it was, you know let*

*go of it now the project's gone so I don't believe that self management was viewed seriously enough." [Interview 1: Manager]*

## **Client acceptability**

One clinician during the interviews raised the issue of the acceptability of CDSM to different types of patients/clients. In their opinion it was thought that some patients/clients still only wish to take a passive role in the management of their health and therefore were not initially supportive of activities related to CDSM. This notion was also raised independently by clinicians in the focus group in particular reference to aged care patients/clients. In addition, one clinician commented that the content of the Lorig Program often challenged patients/clients and that it was necessary for clinicians to relate the material back in a relevant way for the patients/clients.

*"another barrier potentially is consumer acceptance of the concept of self-management. I think that's changing over time and I think we'll never get to a situation where we'll have 100% of people understanding that it's their role as a consumer of health services to be involved but I think we're moving forward and I think people um there's still a barrier, there's still patients/clients who just will not participate in self-management, they see health care as about providing clinical treatment to them and that they're a more passive recipient of that care rather than active and participant in their own health" [Interview 5: Manager]*

*"A lot of the older Australians were told that you work we'll pay your pension and when you get older we'll look after you and that's what the government is saying to them and all the elderly are saying well it's not my, you know, you're responsible for my health and it's very hard to turn it around but the care planning and that involving them actually....turns that around and they realise that because in a care plan they're included so they have responsibility and thing to do as well." [Clinician: Focus Group 2]*

*"A lot of them have been a passive participant in their health for years um and when you when you actually give them options, they're afraid of it, part of the Lorig programme was telling them that they had to set goals and that was very difficult for them because that's not a terminology that they're used to, so when you tell them how to set a goal they were just blown away and then when you take it down to something like well ok by next week we want you to actually buy some knitting needles and some wool and start knitting and "oh well that's easy, I can do that"*

## **Traditional approaches to clinical care by some clinicians**

One participant commented that individual clinician perceptions about how they provide care or manage patients/clients has a direct impact on the uptake of self management activities. For those clinicians that operate more traditionally and see the client as a passive recipient of health care, they are less likely to uptake CDSM activities into their clinical activities or empower patients/clients to take an active role in the management of their health.

*'I mean it would be insincere of me to suggest that all of the staff, I mean there are still staff who come from a .....provider recipient perspective as well, they're in a minority unfortunately in our team but I think that's another barrier as well, people who are actually providing care who see that's in their role and they've to all the knowledge and their client is a passive recipient of that care so I think that's still a barrier.'* [Interview 6: Clinician]

*"I see it relevant in the fact that Chronic Disease Self Management is an approach, it's a philosophy and in order to change people's thinking we've got to change their attitudes, so if you look at health service providers for so many years they have unwittingly dis-empowered patients/clients and taken the control especially when patients/clients come into hospital so I see that my role is vital in helping to change the attitudes of staff and to challenge their thinking on how they miss and why they do certain things and make them aware of how their values, their beliefs, their attitudes impact on a patients/clients ability to self manage."* [Interview 1: Manager]

In addition, one clinician commented that for patients to successfully self manage they have to be able to communicate well with their medical practitioner, and this can sometimes be a barrier.

*The medical profession to some extent can be a barrier as well, although maybe less so than previously because it's important for the participants or the people who self-manage to be able to interact constructively with their medical practitioner and obviously they aren't able to do that .....so that's potentially another barrier.*[Interview 6: Clinician]

## **Outcomes of self management are not readily identifiable**

Although the majority of participants commented on how they could readily see positive changes in the patients/clients behaviour or attitudes from attending the self management education programs and that this added to their acceptance of the concept, one participant commented that the outcomes associated with self management were not readily identifiable, and as such posed a barrier for clinicians uptaking CDSM activities.

*"You need time to do this and do it well, you're not going to see initially um anything other than, you're not going to be able to look at it at 2 weeks times and say wow, look what we've accomplished 1,2,3,4,5 it's not comfortable but you can look down 6 months down the track and say what a difference, I've put a lot in now but it's made a huge difference down the track and that is what, it's"* [Interview 1: Manager]

During one of the focus groups a comment was made that there was little formal feedback to clinicians concerning the overall number of patients/clients that took part in the CDSM assessments and group education and what outcomes were achieved. In addition, a clinician commented that after doing client assessments and having involvement in the group education sessions, there was not a sense of completion associated with the activities.

*" At the end of the day there was no feedback to say...how many patients/clients of what the outcomes were"* [Clinician: Focus Group1]

*“We all went out and did this very conscientiously, got everything, and come back and dotted the dots and things like that but everybody says oh what’s happening now, like, where do we go from here” [Clinician: Focus Group1]*

## **Factors to facilitate clinician’s ability to incorporate CDSM into routine practice**

Participants discussed factors that related to the initial acceptance and uptake of CDSM by clinicians and factors that may facilitate the integration of CDSM into routine clinical activities. Comments were related to seven main areas:

- Workforce availability;
- Referral process;
- Program Support;
- Evidence based practice;
- Ongoing Education;
- Broaden the approach to CDSM; and
- Comprehensive training for PHNs.

### **Workforce availability**

Workforce issues including the need for more staff and different health professionals that are willing to be involved in the CDSM activities were raised. It was stated that more staff, may allow individual clinicians more time to spend with patients/clients and free up other clinicians to run the self management group sessions. In addition, the availability of resources and volunteers to help run the group programs was also considered important.

*“more staffing would help um they generally would like to do the CDSM but they just don’ have the time” [Interview 4: Clinician]*

*“Resources available – booklets, tapes – to support the work, having volunteers that are willing to continue on, having different health professionals willing to be involved.” [Interview 6: Clinician]*

### **Referral Process**

Participants suggested that having an identified referral process into the program, coupled with a good relationship with the hospital is important for the functioning of a CDSM program. It was also considered important that clinicians should have knowledge of local services for client referral & support associated with CDSM.

*“I knew a lot of contacts anyway so that in itself was a benefit because I already knew a lot of services in the area and I was in contact with a lot of services um so that helped” [Interview 4: Clinician]*

*“...able to link in with a hospital and that’s very important for something....to work” [Interview 1: Manager]*

## **Program Support**

Both organizational support from senior management and leadership support were considered important factors in increasing clinicians ability to incorporate CDSM into routine practice. Senior management support was thought necessary to foster clinician involvement in the group education sessions by allowing release from other duties. The importance of leadership support through the role of the four local nurse coordinators was a theme raised throughout the follow up study. Participants thought it was important for the coordinators to be based in teams and to guide and support clinicians, patients and to contact and promote CDSM programs with local GPs.

*“if you’re empowering people in the clinical areas and the managers are not convinced of it then they often don’t allow for the time that is need or, um, for the processors that are needed to be put in place for this to work.” [Interview 1: Manager]*

*“you actually have someone that’s available for teams and they’re not just coming and going all the time, they actually become part of the team and support the team” [Interview 3: Manager]*

*“support and leadership is important.” [Interview 5:Manager]*

*“the organization was very supportive of it um at the health service, our director at the time was very supportive of it, I don’t know, to be supportive and it’s the training and it’s the resource of having someone around that will guide the nurses and go out on the road with them and contact & **promote it** with GPs.” [Interview 3:Manager]*

## **Evidence based practice**

One participant stated that if clinicians understood the success of the Demonstration Projects and that the principles of CDSM were based on evidence (& therefore work) they would be more likely to participate in CDSM activities.

*“once they see that there is a need and that it does work I think there would be more willing to try and apply it into the clinical world, there is enough research on that to show” [Interview 1: Manager]*

*“Seeing success of the demonstration projects” [Interview 6: Clinician]*

## Ongoing education for staff

Ongoing education and training was considered important in terms of orientation for new staff, particularly in times of high community health workforce turnover, and ongoing in-service education for existing staff to maintain and update skills.

*“the nature of the workforce is that we have a bigger turnover so it’s important that we have some ongoing education that’s available to access for staff because it’s important” [Interview 5]*

In addition, one clinician commented that it might be useful to incorporate CDSM into the undergraduate training for GPs and nurses.

## Broaden the approach to CDSM

Clinicians considered that broadening the approach to CDSM where it can be offered to all patients/clients and carers, not just those with a chronic disease would assist clinicians to incorporate it into routine practice.

*“One universal implementation of it will help”[Clinician: Focus Group1]*

## Comprehensive PHN training

One clinician commented that it might be important for primary health nurses to receive additional ‘leader’ training to enable them to undertake client education. It was thought that this would allow PHNs to do more comprehensive CDSM apart from assessments, care planning and referral and that this might be particularly useful in cases where there is no funding to run specific client group education programs.

*“if it’s part of your thinking and it’s been seen as that is appropriate but it’s not the quickest one and get the dressing done it’s actually stopping and take time but doing it while you’re actually doing the dressing, so it’s not a separate thing, just do it as part and parcel of your role, that takes time and it’s a confidence and it’s a learn and I think this course actually does offer the advanced skills but you need to do the whole course, and I would have.....that that’s accepted.”[Clinician: Focus Group 1]*

*“But I was thinking that if there was no funding to run groups, these people who have the skills can implement it, they can spend a few minutes with the patient.....to assess and see the client”[Clinician: Focus Group1]*

One manager also thought that seeing GPs and pharmacists become more involved in patient management and seeing patients become less reliant on community health staff would also contribute to the interest of clinician involvement.



## ***Sustainability of CDSM***

The following eight issues were raised commonly by participants and considered important in sustaining CDSM activities in community health:

- Health Service commitment to CDSM as a priority for service delivery;
- Having a support person/coordinator;
- Ongoing education and training in CDSM for staff;
- Access to Resources;
- Access and knowledge of referral services;
- More time;
- More staff; and
- Availability of the Lorig Course.

The need for CDSM to be seen as a health service priority and part of the core business of clinicians, having a support person or coordinator to oversee the implementation of the activities locally and ongoing training for staff were considered important issues in sustaining CDSM. In addition, access to resources, access to and knowledge of referral services, more staff and time were common needs identified.

*“Resources, .....resources, staff attitudes, and a true commitment from people high up in the health service.” [Interview 1: Manager]*

*“you do require somebody to keep it in the face and keep it going and that, and because we have such a changeover of staff um, the girls who were trained have all gone and the majority of girls who went through the training .....like we’ve had staff changes particularly .....um so a lot of those aren’t.....so it’s something you need to continue to maintain...and seeking GPs support and stuff is something you just don’t have time to do in a normal role and has to be ongoing.[Clinician: Focus Group 2]*

*“More in servicing, able to go to courses that you know helps them with identifying CDSM strategies and someone behind them to support them if they need to ask questions, so some sort of leader.” [Interview 4: Clinician]*

*“More services” [All Clinicians: Focus Group 2]*

*“yeah it takes a lot of time to find the services, to get them to link in and you know to overcome simple things like transport.....Finding a specific language group for somebody who’s Syrian or is, they’re out there it’s just, that takes a lot of time to actually do all of that so having the services but also the time and the facilities.[Clinician: Focus Group 2]*

*“integration, it’s about making it part of your core business, part of what you do, your interactions with all patients/clients” [Interview 5: Manager]*

Apart from the support role of the coordinator, one clinician commented that a support role under the nurses would also be useful.

*“In an ideal world there’d be another tier under the nurses in the community, not necessarily a, being a registered nurse but be able to do those extra things, sit with them a little bit longer, give them that little bit of extra support and maybe do their care plans and that sort of stuff so they’d be qualified to an extent but didn’t necessarily have the acute training um and you know just to fit in and sort of work with them, that’s my ideal world anyway.[Clinician: Focus Group 2]*

During both the interviews and the focus groups a large number of participants commented on the need to have a self management program like the Lorig program available to run the CDSM education groups, and that this was essential in sustaining chronic disease self management.

Other issues thought to be useful in sustaining CDSM activities in community health included:

- Nursing retention strategies;
- Change in staff attitudes to support CDSM;
- Health Service commitment to CDSM as a priority for service delivery; and
- Common health record across community health.

*“I don’t know what we’ll do about recruitment, um I think ask the nurses what they, you know, we try and do the exit interviews and things like that but we don’t get around to it, we’d like to get feed back on those, you know, ask the nurses why they left” [Interview 3: Manager]*

*“I think it’s more, we need, we need to move up into the electronic age and it’s more, I mean our computers, when we get.....care plans were on computers, there would be no difficulty in actually sending a copy of those to the hospital.....and all that would lead to having central numbers so that, we’ve got different numbers in the community to the medical local numbers in the hospital” [Clinician: Focus Group 2]*

*“you’ve got a different medical record number to the hospital” Fairfield has got a different medical record to Liverpool, they are linked then you’re sending them down and you’ve got to have them inter linked and.[Clinician: Focus Group 2]*

## **Links with General Practice**

Most participants discussed links with GPs being largely informal and around the development of the care plan. There was varying opinion on how engaged the clinicians found the GPs in terms of joint development of the care plan and in the concept of CDSM. Some GPs worked collaboratively with the clinicians to develop the care plan and provide feedback to community

health on the ongoing management of the client, other clinicians reported less active involvement from the GP involving “signing off” the care plan, whilst others reported finding it difficult to engage the GP at all. One reason given for lack of GP involvement was that often GPs and other professionals are reluctant to become involved in new initiatives that are unlikely to be sustained into the future.

*“A lot, we actually had signed referrals, we actually sent the doctor the care plan and he had to sign off and agree with it and if he didn’t agree he’d ring me and let me know and we’d change it to suit whatever medication or whatever you know he might not want her to do something you know, so we’d conference, so yeah we had a lot to do with the doctors, we’d make sure that they went to their doctors appointment and have a check up.....the doctors were really keen about the care plan.” [Interview 4: Clinician]*

*“It was good with the care plan, where we worked closely with the GP...we use to do most of it and send it to them and they used to sign it”[Clinician: Focus Group1]*

*“You still try and promote it but the doctors just aren’t interested “who are you, you’re the nurse” so its really gone back to that archaic thinking again that we don’t know what we’re talking about” [Clinician: Focus Group 2].*

*“ I found the opposite, I did finally increase my contact with the GPs when the programme was running and I’m still in touch and they still do plans and I do plans for the patient” [Clinician: Focus Group 2).*

*“I think too with everything that gets people frustrated, people are reluctant to get on board with things is that we put these things out and they’re great and then they’re pulled, like with the GPs are getting frustrated when we say we want you to get involved in this and they’re going “yeah but for how long, I’m going to get all my patients/clients signed up for this and then you’re going to pull it and I’m going to be the one left with that oh but” so that’s the other thing, that they get really weary about working with us and you get really weary about selling something because you turn around and it’s changed or pulled completely and you look like a.....and yeah it’s just really frustrating”. [Clinician: Focus Group 2]*

Clinicians that reported existing links (meetings) with Division continued to use those links to promote and support the CDSM program by promoting the work the community health clinicians were involved in, attending joint training sessions with GPs and access the Divisions newsletter to promote the self management education groups.

## ***Working with disadvantaged patients/clients***

### Issues

Participants raised six main issues associated with implementing CDSM Programs with disadvantaged patients or clients:

- Only English speaking patients/clients were eligible to participate in the Lorig Program education sessions
- Lack of appropriate written resources to support the Lorig Program education sessions
- Patient/client education levels
- Patient/client access to public transport
- Supply and ability to use interpreters
- Social factors

Participants commented that many of their clients had reduced literacy skills and that there was a distinct difference between being able to speak English compared to being able to understand or read English. These factors have a great impact on being able to deliver a CDSM Program that is designed for English Speaking persons. A comment was made that this is further complicated by the general lack of available culturally appropriate written resources to reinforce messages received during the education sessions. Participants also commented that to be able to take part in group education sessions, patients/clients need to have a basic understanding of their condition. Participants commented on the shortage of local interpreters to assist in running the group education sessions and logistic difficulties of accessing them (long waiting lists) for individual client sessions.

One participant commented that the concept of CDSM remains “alien” to some cultures and that patient/clients need a lot of encouragement to gain acceptance of the idea of self management amongst those populations.

*“The concept of self management is not always received, its not received in the same manner by different cultures, so obviously there are cultures where self management are quite alien and a lot of acceptance is needed” [Interview 5: Manager]*

### Potential strategies to address issues

When asked to think of possible ways to address the above issues participants discussed two main methods including running group education sessions in locations close to public transport and where participants will not have to pay for parking and implementing different education strategies. It was thought that different education strategies might need to be implemented depending on the education level of participants. One participant suggested that for some Non English Speaking clients one on one education sessions might be more appropriate than group sessions.

*“Someone with a lower education level would not in the group say I don’t know what you mean or I don’t understand that or wouldn’t disclose their lack of understanding” [Interview 1: Manager]*

Another participant commented that when working with clients from Non English Speaking Backgrounds there was a need for more intensive home follow up to ensure that the messages received from the CDSM Program are reinforced. Another strategy suggested was to implement the CDSM education sessions within GP practices.

## Discussion

This follow up study has demonstrated widespread clinician support for the SWSAHS CDSM Project. Key reasons for the perceived success of the program include:

- The congruence between the philosophy of the program and the values of Primary Health Care workers.
- The quality of the Lorig Program which has improved staff confidence in providing CDSM education to their clients.
- The clear and easy to follow Lorig Program procedures

The study identified facilitators, barriers and sustainability issues to the Projects development and implementation. Each will now be discussed and recommendations made in light of the findings.

### Facilitators

Staff perceived a lack of conflict with other models of disease management or patient education. This consistency was an important factor facilitating their involvement. Many clinicians expressed disappointment on the Project ending, but this tended to be expressed in relation to the client group education sessions rather than the assessment or other activities (resource provision etc) associated with the Project. Support for the Lorig Program varied between clinicians: those with less confidence in running the group education sessions or experience tended to view the program more positively.

### Barriers

Health staff reported few barriers to patient/client uptake of CDSM and believed that it fostered greater activation of patients in their own management. However they found that some patients especially the elderly were reluctant to give up their role as passive recipients of health care. This had a negative effect on how successfully they could be engaged in self management.

A strong theme emerged concerning the inability of clinicians to adapt the program to suit group needs due to the licensing restrictions which mandated the use of standardized materials and procedures. This issue was amplified in South West Sydney with a diverse non-English speaking population. Only clients who spoke English were eligible to participate in the program, so therefore, large numbers of clients were not eligible to participate. Evidence suggests that this population would have a higher need for chronic disease management<sup>1</sup>. There is evidence that culturally appropriate self management programs can significantly improve patient outcomes (Brown et al 2002). Future uptake of the Lorig or other CDSM Programs in Areas with similar population characteristics would need to address this issue. Failure to do so will only enhance inequities of access to the program by disadvantaged patients.

While sufficient staff were trained to deliver the program, the availability of these trained staff restricted the number and location of education sites. This increased the necessity for transport of clients to and from the education sessions. Had a broader range of PHC staff been trained, there may have been less necessity to transport clients to central locations for CDSM education.

The principle funding barrier was the inflexibility of Community Health budgets to provide small amounts of funding for venue and catering costs etc. This was an important factor in limiting the capacity of staff to conduct more self management group education. However in contrast to the US where funding for staff to deliver self management education was not a major barrier (1).

Streamlining Project components and processes is important and can be achieved through collaboration. Streamlining components such as the clinical assessments and care plans into current clinician work activities, rather than as separate activities may reduce the workload and thus the potential job satisfaction of the clinicians. Streamlining the process of the care plan development will be important as the care plan serves as a facilitator for the development of a patient provider relationship (particularly with general practitioners) and has a direct impact on achieving continuity of care. Collaboration with GPs in the streamlining process may be important in ensuring their engagement, particularly if the development of the care plan proforma and process can be linked to the Medicare Benefits Scheme Chronic Care Disease Items.

### **Sustainability**

The program has formally ceased to operate because the terms of the license agreement with Stanford University (US) did not allow continued use of the Program materials. Despite this, clinicians indicated that CDSM education continues informally through assessments, one to one education, provision of information resources and referral to local services where available. However clinicians are no longer formally developing the specific CDSM care plans. This has resulted in less communication between community health clinicians, GPs and other service providers and a potential increase in duplication of activities associated with client management.

Since the formal project ended, client group education sessions have also ceased. Although clinicians report undertaking individual education with clients and have indicated that they continue see this as part of their role, previous research suggests that client group education sessions are more effective in achieving desired behaviour or health related outcomes than individual education (Garrett et al 2005).

Participants report an increasing necessity to focus on early discharge and post acute care. This reportedly resulted in increased workloads and reduced the time available to undertake CDSM activities. Workforce shortages increased pressure and reduced available time. Thus measures to address these shortages as well as streamlining of program components such as assessment and care planning were seen to be essential to the continued role of clinicians in supporting CDSM.

The strategy of using lay peer leaders to run the client education groups has been implemented overseas (e.g. in the UK (Tyreman 2005) and US (Von Korff 1998). This would reduce the reliance on the already overtaxed existing PHC workforce and would be especially appropriate for the development of more culturally-sensitive CDSM programs (Griffiths et al 2005). However the development of such models has been quite limited in Australia and would require intensive resourcing and evaluation.

Provision of a local CDSM facilitator to provide ongoing support to clinicians around CDSM, particularly in program promotion, accessing resources, developing an updating a local service referral directory and facilitating the client group education sessions would be important for both uptake and sustainability. The role of such as position would not be to deliver a separate CDSM program but rather to support the incorporation of CDSM into routine care.

Wider scale promotion of the concept of self management and the evidence that supports it will be important in engaging those clinicians or clients/patients that are yet to find it acceptable. In particular, promotion of the concept and program to local GPs might be important in engaging them effectively in the process. There was little evidence of effective engagement of GP staff in the CDSM project to date and this appeared to lead to some duplication in areas such as care planning and a lost opportunity to enlist the resources of general practice in support of CDSM. One reason given for lack of GP involvement was the lack of clarity about whether the initiative would be sustained into the future. Thus the sustainability of such programs is a key factor in the wider adoption.

This study was a qualitative evaluation of the views of staff participants in the CDSM program in South Western Sydney. As such it is unable to demonstrate the impact of the program on the health outcomes or health service use of patients who were recipients of CDSM education. As a qualitative study, it provides insights into the range of views of staff and the reasons behind these. However it does not provide quantitative information about how commonly such views were held. Further research evaluating the impact on health outcomes is needed along with continuing monitoring of routine implementation of CDSM by health services in Sydney South West.



# Recommendations

## **1. National and State policy:**

- 1.1 There is a need to continue to support funding for CDSM initiatives especially the development of culturally appropriate programs.
- 1.2 CDSM programs need to be better integrated with other initiatives in PHC especially between Commonwealth and State funded services such as between general practice and State community health services.
- 1.3 There is a need to introduce models of CDSM education which substitute peer educators for the role of professionally trained staff. This is to address the workforce pressures and to ensure that it is culturally appropriate.

## **2. Local Health delivery**

- 2.1 There is a need to license or develop a program which can continue to be delivered as a part of routine health care and is not subject to the same restrictions which operated in this project associated with use of the Lorig Program. .
- 2.2 A coordinator position needs to be established to facilitate the integration of CDSM into the work of all PHC services and to train and support all staff and volunteers to provide CDSM education group sessions.
- 2.3 Limited flexible funding needs to be available to Community Health staff to provide group education.
- 2.4 CDSM programs need to link with and utilize the resources of Non Government Organisations (NGOs) and Divisions of General Practice (DGP) to support CDSM.
- 2.5 The performance of health managers should include ensuring access to CDSM education by all patients with chronic illnesses utilizing the Area Health Services.
- 2.6 The job descriptions of all PHC staff should include CDSM assessment and education as a core role
- 2.7. Staff development should including training to support staff in acquiring competencies in CDSM assessment and education.
- 2.8 IT systems which support community care should prompt and record CDSM education especially in patients undergoing care planning.

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