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## **6 Discussion**

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The purpose of the Discussion is to address the nine evaluation questions of the SHCI based upon the results outlined in this Technical Data Report. The future policy implications for chronic condition self management given these results are also considered.

## 6.1 Introduction

The overall trend for people participating in the SHCI was that they had improved health outcomes, a better quality of life and reduced service utilisation. This trend occurred across all DPs with the most pronounced changes occurring between the baseline and middle (approximately six months post recruitment) data collection points, and then being maintained to the end of the self-management Demonstration Project (DP) programs.

Collectively, for all of the DPs, 1,964 clients completed baseline measurement point questionnaires. However, as the analysis could only be performed for clients with complete data at all three measurement points, the sample size for the whole group analysis was reduced to 882 clients; nevertheless, this sample size was still deemed acceptable to achieve adequate statistical power. An additional unspecified number of clients were recruited by the DPs but chose not to participate in the National Evaluation and hence the effect of the SHCI is not known and has not been reported here.

### **What is self management?**

Self-management has been defined as 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* (5) as opposed to seeking a clinical improvement in their chronic condition.

Activities associated with better self-management include regular exercise, healthier eating, improved social functioning and symptom control. An important pre-requisite for such behaviour change is ‘self efficacy’ which is the belief in one’s own ability to successfully perform a health behaviour. Clients with greater self-efficacy tend to be more proactive in the management of their conditions with their health service providers (HSPs).

### **Effectiveness not efficacy**

Given the existing strong evidence base surrounding the efficacy of the self-management interventions (11), the SHCI was about the implementation of self-management approaches in the wider Australian context with a view to understanding the potential population-based impact of widespread dissemination of such a public health innovation i.e. its effectiveness. The way in which this was operationalised was through the funding of eight DPs, (one in each State and Territory covering a range of locations from

metropolitan to remote areas including culturally and linguistically diverse and Indigenous populations) to demonstrate a variety of self-management service delivery approaches covering a number of chronic diseases.

## 6.2 National Evaluation Framework

The hypotheses and the evaluation questions for the SHCI were developed in close consultation with the DPs. These are outlined in Table 122 below:

**Table 122 Hypotheses and Evaluation Questions**

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

The National Evaluation Framework (NEF) which was developed to address these hypotheses and evaluation questions was built five domains, identified as being the key participants/features of the SHCI: 1) Client; 2) Carer/family/significant other; 3) HSP; 4) Community; and the 5) Health service system.

The starting point for the framework was the public health approach to program evaluation, from which three core components were specified:

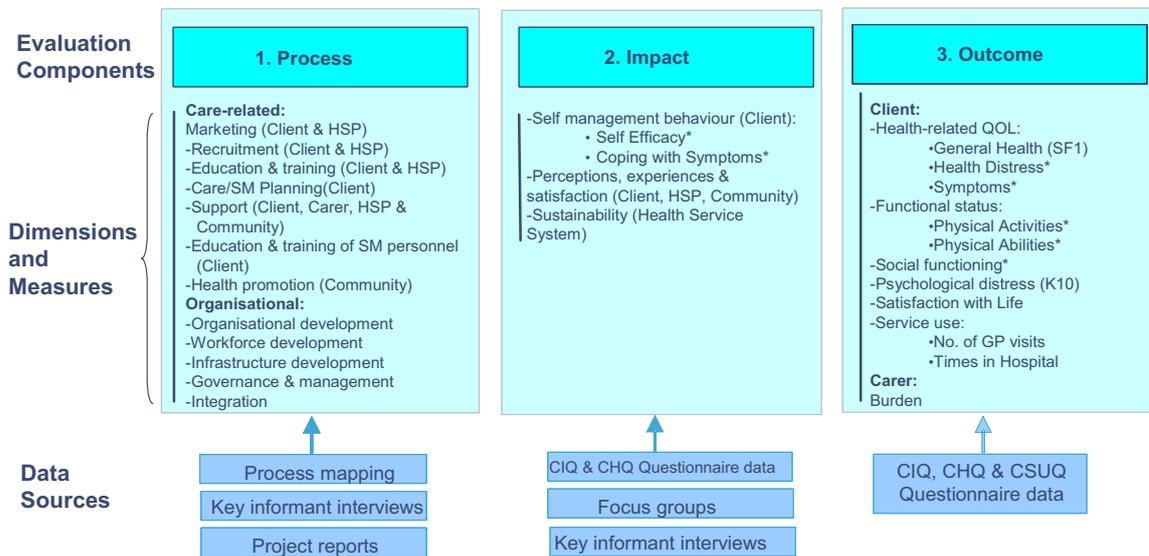
- **Process evaluation:** monitored program implementation from the perspective of program delivery (e.g. care related processes) and broader organisational factors at both a DP and health system level. Also provided contextual information for the impact and outcome evaluations, helping to explain what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

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

## 6.3 Methods

Given, its scope and structure, the most appropriate quantitative and qualitative data collection methods were used in the National Evaluation. A robust approach was taken to the development of the instruments used in the evaluation, ensuring that where appropriate the measures were valid and reliable. Figure 61 illustrates how the data collection methods linked in with the overall NEF components and their relevant dimensions and measures.

**Figure 61 National Evaluation components and associated data sources**



\* Modified Stanford 2000 Questionnaire

## 6.4 Key learnings

In this Discussion, each of the National Evaluation questions are considered in turn under each of the relevant domains (client, carer/family/significant other, community, HSP and health service system) that reflect the range of players involved in the SHCI. Relevant anecdotes from each of the DPs have also been included throughout the Discussion to highlight areas of innovative practice and interest.

Given the demonstration project design of the SHCI, the ‘evolution’ or progression of the Program is an overarching theme running throughout this Discussion. Two influential factors in determining the Program’s evolution were:

- Lack of time was consistently cited as a limiting factor to the DPs. As the DPs went ‘live’ later than was intended, this put pressure on them to achieve what they had originally set out to do in the more limited time available. Whilst this led to some innovative approaches being implemented, it also resulted, in some instances, to movement away from the DPs’ original project plans.
- The DPs’ starting point in terms of existing organisational structures, infrastructural support, networks and community engagement greatly influenced the DPs’ ability to operationalise their plans effectively and in particular their capacity to interact with overall health system, such as the local HSP community.

Whilst the Indigenous and non-Indigenous DPs shared some similar experiences during the implementation of the SHCI, there were also significant differences as a consequence of their setting. To reflect the importance of these contextual issues on the reported findings, the examination of each the evaluation questions has been separated out into non-Indigenous and Indigenous DPs.

## 6.5 Client

### 6.5.1 Non-Indigenous Demonstration Projects

***EQ1: Which recruitment strategies are most successful in recruiting which clients / groups of clients?***

For the most part, the initial recruitment expectations of the DPs in terms of client numbers were quite ambitious. However, given the acute window of recruitment (due to the truncated timeline of the DPs) and the challenges posed by the recruitment process, most of the DPs had to revise their estimates of recruitment downwards once they went ‘live’. The demonstration project design of the SHCI gave the DPs the freedom to do this because they were not reliant on achieving the ‘power’ of recruitment numbers, which would have been the case if they had been trials.

However the DPs still faced a number of issues relating to the recruitment of both clients and HSPs, in particular GPs.

#### **Role of the GP in recruitment**

Most of the DPs initially looked to engage GPs as the primary source of client referrals and to provide input into the care planning process. However, the success of GP engagement varied across the DPs, as did the reasons for success, for example, the utilisation of established GP relationships with the DP and the provision of GP incentives. Generally, the DPs reported that GPs were interested in the concept of self-management; however their busy schedules did not allow time for active participation in the DP self-management program. As a consequence, those DPs who had intended to rely primarily on GPs for the referral of clients, were required to open up the DP to self-referrals, or needed to increase their focus on self-referrals.

#### **Evolution of marketing approaches**

In response, in part to this difficulty in engaging GPs, the DPs continued to develop their methods of marketing *directly* to clients, for example through pamphlets, posters, videos, presentations to community groups and media announcements. Those marketing strategies which proved most successful were those that were targeted to specific groups of interest to the DP, for example, clients from Culturally and Linguistically Diverse (CALD)

backgrounds. This targeted approach was facilitated by ensuring marketing material was suitable for these groups. In addition, as the DPs progressed, word of mouth became an increasingly successful method of marketing.

Pro-active community engagement was also explored by some of the DPs as a way of reaching their client base. This is discussed in Section 6.7.1.

### **Evolution of recruitment approaches**

As with marketing, many of the DPs departed from their planned recruitment strategies (e.g. through HSP referral) and examined more creative ways to increase recruitment numbers. For example, DPs began to recruit clients into DP-led initiatives (such as support groups or formal education and training e.g. the Stanford Chronic Disease Management (CDSM) course (19), prior to formal recruitment into the DP self-management programs.

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

***EQ2: Which clients / groups of clients are most likely to participate in which programs?***

***EQ3: What other factors influence participation rates and in which direction?***

### **Sample characteristics**

The majority of the participants were female and most of the cohort were 66 years or older. A spread of educational backgrounds was reported although those with university qualifications were least represented in the sample. Whilst the participants came from the 'non-Indigenous DPs', approximately 2% (29) reported being of Indigenous background. This is consistent with the overall proportion of people from an Indigenous background as reported in the 2001 Australian Census. Also, approximately 15% of the cohort spoke a language other than English at home, indicating that they came from a CALD background. Arthritis was reported most frequently as the condition which had the most impact on life. This was followed by diabetes and cardiovascular disease.

A summary of the cohort's demographic and health-related characteristics at the baseline and middle measurement points is given in Table 123 below.

**Table 123 Demographic and health-related characteristics of the non-Indigenous DPs' clients**

**Demographic characteristics of non-Indigenous participants at baseline and last**

Characteristics	Baseline (n=1974)		Last (n=1097)	
	n	%	n	%
<b>Highest Qualification</b>				
None	314	15.9	150	13.7
School only	418	21.2	207	18.9
Technical / Trade / TAFE	603	30.5	341	31.1
University education	206	10.4	120	10.9
<b>Employment Status</b>				
Employed	210	10.6	93	8.5
Unemployed	36	1.8	18	1.6
Unpaid work	248	12.6	140	12.8
Retired	1153	58.4	655	59.7
Unable to work	269	13.6	147	13.4
<b>Pension</b>				
None	370	18.7	183	16.7
Australian Age Pension	853	43.2	562	51.2
Other allowance	611	31.0	303	27.6
<b>Sex</b>				
Male	662	33.5	349	31.8
Female	1311	66.4	748	68.2
<b>Age</b>				
<55	268	13.6	129	11.8
55-65	557	28.2	320	29.2
66-75	636	32.2	385	35.1
75+	513	26.0	262	23.9
<b>Language</b>				
English only	1674	84.8	925	84.3
Other	300	15.2	172	15.7

Characteristics	Baseline (n=1974)		Last (n=1097)	
	n	%	n	%
<b>Living Arrangements</b>				
Live alone	656	33.2	381	34.7
Live with others	1303	66.0	711	64.8
<b>Accommodation</b>				
Private	1765	89.4	980	89.3
Supported / other	188	9.5	109	9.9
<b>Has a Carer</b>				
Yes	406	20.6	232	21.1
No	1352	68.5	779	71.0
<b>Condition that impacts most on life</b>				
Diabetes	282	14.3	140	12.8
Arthritis / Joint/Bone Condition	661	33.5	375	34.2
Chronic Respiratory / Lung	162	8.2	69	6.3
Cardiovascular Disease	258	13.1	140	12.8
Renal Disease	10	0.5	3	0.3
Depression	63	3.2	25	2.3
Osteoporosis	53	2.7	45	4.1
Other	283	14.3	140	12.8
<b>Smoking Status</b>				
Never smoked	885	44.8	502	45.8
Ex-smoker	856	43.4	486	44.3
Smoker	220	11.1	102	9.3
<b>Alcohol Consumption</b>				
Every day	237	12.1	118	10.8
4-6 days a week	123	6.2	69	6.3
1-3 days a week	262	13.3	151	13.8
Fortnightly or less	110	5.6	75	6.8
Monthly or less	477	24.2	244	22.2
Don't drink	751	38	435	39.7

**Definition of participation**

From the National Evaluation's perspective, it was only possible to measure the participation rate of those who also participated in the evaluation. It was not possible to measure clients' participation in the DPs if they did not complete the evaluation questionnaires, which was certainly the case for some of the DPs.

Also, participation in the interventions on offer by the DPs varied from DP to DP. This depended on the design and intention of the DP for example:

- Whether participation in an intervention was voluntary or compulsory;

- The type of training on offer, for example, the six week Stanford course as opposed to one-off disease specific training; and
- The extent to which the intervention was customised over time to meet client need.

### Range of interventions delivered

The DPs explored a range of self-management interventions as part of the roll-out of the SHCI. Whilst one of the most commonly used interventions was the Stanford CDSM course (19) developed by Professor Kate Lorig of Stanford University in the United States <sup>7</sup>, it was usually used in conjunction with other client planning and support mechanisms. Also, for most of the DPs, attendance at such courses for their clients was not a compulsory part of the intervention and one of the DPs chose not to use this intervention at all but instead explored a telephone coaching approach. This indicates that self-management cannot be ‘pigeon-holed’ into just being about client education or delivering a course but also has significant implications for prevention and health promotion activities through client planning and support activities.

The range of self-management activities for clients explored by the DPs is outlined in Table 124 below.

**Table 124 Range of self-management activities undertaken by the Demonstration Projects for clients**

Planning	Training	Support
<ul style="list-style-type: none"> <li>▪ Self-management action planning e.g. Problem and goal setting</li> <li>▪ Care planning, including medication review, health service review</li> </ul>	<ul style="list-style-type: none"> <li>▪ Six week Stanford course</li> <li>▪ Disease specific courses</li> <li>▪ Healthy eating shopping trips</li> <li>▪ Cookery classes</li> </ul>	<ul style="list-style-type: none"> <li>▪ Telephone coaching</li> <li>▪ Support/self-help groups</li> <li>▪ Walking groups</li> <li>▪ Tai Chi classes</li> </ul>

An analysis of these interventions identified four distinct ‘Intervention’ Models for the non-Indigenous DPs, a description of which is given in Table 125 below together with their demographic profile and key network partners. The DPs were sponsored by a range of partners, and held a number of network partnerships in the roll-out of their self-management programs. These organisations included: Divisions of General Practice; Non-Government Organisations (NGOs); Universities; and State Health Authorities.

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<sup>7</sup> This course is licensed for use in nearly 20 countries, including the United States, the United Kingdom, Canada, Mexico, Italy, Holland, South Africa, New Zealand, China, Singapore and Australia.

**Table 125 Summary of who participated by Intervention Model**

Description of Intervention Models	Demographic profile <sup>8</sup>	Key partners
<p><b>Intervention Model 1:</b> training (especially the Stanford course) was the main intervention with relatively high levels of participation. No client planning and limited support was provided.</p>	<ul style="list-style-type: none"> <li>▪ More arthritis</li> <li>▪ More females</li> <li>▪ Broad age range, towards the younger</li> </ul>	<ul style="list-style-type: none"> <li>▪ NGO</li> <li>▪ University</li> </ul>
<p><b>Intervention Model 2:</b> a complete suite of interventions was provided comprising client planning, training and support. A very high percentage of clients participated in all three activities. The majority of clients attended a Stanford course as part of the training component of the Intervention Model.</p>	<ul style="list-style-type: none"> <li>▪ Older age group</li> <li>▪ More females</li> <li>▪ More from CALD backgrounds</li> <li>▪ More with no qualifications</li> <li>▪ More in supported accommodation</li> <li>▪ More with a carer</li> </ul>	<ul style="list-style-type: none"> <li>▪ State Health Authority</li> <li>▪ Division of General Practice</li> </ul>
<p><b>Intervention Model 3:</b> participation in activities was based on client need and was voluntary. Only approximately half of the clients participated in client planning and training activities and only a minority attended a Stanford course, with other training activities being on offer.</p> <p>A high proportion of clients sought support from the DP self-management programs.</p>	<ul style="list-style-type: none"> <li>▪ Less university educated</li> <li>▪ More smokers</li> </ul> <p><i>In all other instances the demographic profile was consistent with the average SHCI cohort, see Table 123.</i></p>	<ul style="list-style-type: none"> <li>▪ University</li> <li>▪ Division of General Practice</li> </ul>
<p><b>Intervention Model 4:</b> Telephone coaching was the main intervention based upon the Stages of Change (24) approach. None of the clients received Stanford training. There was a high level of participation by clients in all DP activities – planning, training and support.</p>	<ul style="list-style-type: none"> <li>▪ More males</li> <li>▪ More from CALD backgrounds</li> <li>▪ More university educated</li> <li>▪ More living with family</li> <li>▪ More employed</li> <li>▪ Broad age range</li> <li>▪ More non-smokers</li> <li>▪ More diabetes</li> </ul>	<ul style="list-style-type: none"> <li>▪ Division of General Practice</li> </ul>

### Indigenous Demonstration Projects

The two Indigenous DPs implemented broadly similar self-management programs to each other, although some local variation was observed given the specific needs of their respective communities, the objectives of the DPs and the level of resources available to them. In terms of Intervention Model, the

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<sup>8</sup> The relative comparisons made in this table e.g. ‘more’ or ‘less’, refer to the proportionate representation which any particular characteristic has in relation to the overall distribution

self-management DP programs were most similar to Intervention Model 3 described in Table 125 above.

### **Selection**

A key characteristic of the DPs was their diversity with respect to their:

- Design and approach;
- Target group(s); and
- Location.

As a consequence of these factors it is not surprising that as indicated by Table 125, different clients/groups of clients participated in the different DPs. This was due, in part, to the fact that different groups of people were attracted to different DPs as a result of the interventions on offer. For example, Intervention Model 4 which offered telephone coaching appealed more to men (compared to the approaches on offer by the other DPs), whereas Intervention Model 2 which offered more intensive structured support, attracted those with higher needs as demonstrated by the fact that their client profile was older, more lived in supported accommodation and more reported having a carer.

However, the recruitment profile of the various DPs also reflected the different client recruitment strategies undertaken by the DPs. Intervention Model 4 targeted those with diabetes and targeted members from the local Chinese community, whereas Intervention Model 1, through its links with the local Arthritis Foundation, attracted more clients with arthritis.

The location of the DPs also potentially influenced the types of clients participating in a given DP since it is an indicator of socio-economic status. For instance, it would appear that the clients from Intervention Model 2 come from a lower socio-economic background. This is of significance because of the inter-relation between social economic status and a client's existing health status and their potential capacity to self manage (31).

### **Impact of loss to follow-up**

Table 125 does not include those clients who were lost to follow-up i.e. those clients for whom data at the three measurement points (baseline, middle and last) were not available. Understanding the profile of those who were lost to follow-up is may therefore also give an indication as to which sorts of people the DPs were *not* assisting given their decision to drop-out before the self-management DP program's conclusion.. These profiles were:

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

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

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

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

However, some methods of follow-up were more successful (for example, face-to-face interviews) than others (for example, mail-outs), which implies that not all drop-outs from the evaluation were necessarily unhappy with the process but rather the follow-up was not proactive enough. This lesson ought to be borne in mind for future Australian Government Department of Health and Ageing (DoHA) initiatives.

#### **Facilitators to participation**

The opportunity for social interaction with other participants was reported as being the main incentive for continued involvement in the DP self-management program. Also, clients consistently reported a very high level of satisfaction with the courses provided by the DPs, which encouraged ongoing participation.

#### **Barriers to participation**

Lack of transportation, long waiting lists and the costs associated with accessing allied and other health services were consistently reported by clients as being barriers to participation in the DP self-management program. The implications of these barriers in relation to self-management are discussed in more detail in Section 6.10.5.

***EQ4: How and by how much does the form / structure of self-management education influence the health behaviours and health outcomes of clients?***

***EQ5: How and by how much does the type, intensity and frequency of client support and follow up influence the health behaviours and health outcomes of clients?***

The process evaluation component of the National Evaluation mapped out the processes undertaken by the DPs. Three clear ‘care-related’ client processes were identified: 1) Client planning; 2) Training; and 3) Support. So in responding adequately to the above evaluation questions and understanding the Impact of the SHCI on the health behaviours and outcomes of participants, client planning also needs to be considered.

Overall, the process evaluation showed an evolution in the form and structure of the DPs, this reflected the DPs' responsiveness to client need and as a consequence the DPs increased in diversity over time. The DPs incorporated new interventions and adapted their self-management programs to better meet their clients' needs, and to support them in their progress to self-management.

## Planning

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

As the DP self-management programs progressed, the DP focus moved on to the follow-up and review of the care and self-management plans. Clients in those DPs that did not have the direct involvement of a GP, were encouraged to take their plans on their future GP visits and be pro-active in engaging their GPs in this regard.

## Training

The primary focus of those DPs that had an emphasis on formal education and training in the earlier stages of the SHCI was on educating clients with the Stanford self-management course. However as the DPs progressed, clients requested more group education and in response to this demand, the majority of DPs introduced further education and training options for their clients (for example, tai chi, cooking courses and computer training).

## Support

Similarly, the extent and scope of support offered/facilitated by the DPs broadened as the SHCI progressed, which was again in response to client demand. Initially, the primary support mechanism on offer to clients was a support group which had either grown out of the Stanford courses themselves or was already community established support groups. By the end of the SHCI, the available support options had extended to a wider range, including walking groups and buddy support systems.

In some instances though, support was the *main* intervention offered and it tended to include elements of planning and education on an ongoing basis as part of this, for example the DP-led education/support group format (See Box 1) or the telephone coaching approach (See Box 2).

### Box 1

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

### Box 2

*One DP used a coaching model where Allied Health Professionals or Practice Nurses in Community Health Services provided support to clients. The coaching model aimed to develop self-management capacity over time, facilitate access to services and promoting a partnership with GPs. The coaching model involved monthly telephone contact over a period of 12 months.*

## Measuring the effects of the interventions on health behaviours and outcomes

### 1. Whole Group

Overall, people participating in the SHCI showed improved health outcomes, reported a better quality of life and had reduced service utilisation. Whilst the majority of this improvement occurred between the baseline and middle measurement points, this change was usually sustained between the middle and last measurement points. Small but consistent effect sizes indicating improvement were observed for a number of health status indicators: Health Distress, Coping with Symptoms, Psychological Distress (Kessler 10)<sup>9</sup> and Times in Hospital<sup>10</sup>. A trend for improvement was also observed in General Health (SF-1), Satisfaction with Life, Self Efficacy<sup>3</sup> and there was a reduction in the number of GP visits<sup>4</sup>.

These observations were confirmed through feedback from the clients and HSPs in their focus groups. As the SHCI progressed, clients reported specific psychological and physical benefits from participating in the DPs (for example, increased knowledge about their conditions and their management, increased empowerment, increased exercise). HSPs also reported that their clients appeared to be more empowered and confident, and that they had noticed psychological and physiological improvements in them.

Table 126 provides a summary of the changes in health behaviour, outcome and utilisation measures over the life of the SHCI. Those health status measures where there was a statistically significant ( $p < 0.005$ ) improvement over time have been highlighted in blue. The direction of the arrows indicates whether this improvement was as a result of an increase or decrease in the scores of the scales used.

**Table 126 Change in health behaviour, outcome and utilisation variables**

Variable (n)	Baseline-Middle				Change	Baseline-Last				Change
	Mean difference	95% Confidence Interval		p		Mean difference	95% Confidence Interval		p	
		Lower Bound	Upper Bound				Lower Bound	Upper Bound		
General Health (n=864)	-0.103	-0.165	-0.041	<0.0005	↓	-0.068	-0.133	-0.004	ns	na
Psychological Distress (n=819)	-0.795	-1.300	-0.290	<0.0005	↓	-1.357	-1.830	-0.880	<0.0005	↓
Satisfaction with Life (n=744)	0.391	-0.070	0.860	ns	na	0.452	-0.060	0.960	ns	na
Health Distress (n=817)	-0.207	-0.290	-0.130	<0.0005	↓	-0.205	-0.290	-0.120	<0.0005	↓
Coping with Symptoms (n=657)	0.169	0.090	0.250	<0.0005	↑	0.217	0.140	0.030	<0.0005	↑
Social Functioning (n=757)	-0.914	-1.980	0.150	ns	na	-0.349	0.780	-1.480	ns	na
Self-Efficacy (n=733)	0.330	0.150	0.510	<0.0005	↑	0.165	-0.370	0.040	ns	na
Visits to GP (n=845)	-0.215	-0.630	0.200	ns	na	-0.336	-0.830	0.160	ns	na
Times in Hospital (n=844)	-0.190	-0.280	-0.100	<0.0005	↓	-0.147	-0.250	-0.050	0.001	↓

**Notes:**

Differences significant at  $p < 0.005$

'ns' means 'not significant'

'na' means 'not applicable'

<sup>9</sup> All used in the Client Health Questionnaire, see Appendix 16 of the Final Technical

<sup>10</sup> Used in the Client Service Use Questionnaire, see Appendix 17 of the Final Technical Report

## **2. *Intervention Model***

All Intervention Models were also associated with an improvement on most health behaviour, health outcome and utilisation indices. Overall, once adjusted for initial presentation, Intervention Models 3 and 4 appeared to improve more consistently than Intervention Models 1 and 2. For example, clients in Intervention Model 1 and 2 improved significantly less than those in Intervention Models 3 and 4 for a number of measures – General Health, Health Distress, Coping with Symptoms, Self Efficacy and Social Functioning. Also, the reduction in number of Visits to GP was significantly less for Intervention Model 1 compared to Intervention Models 2, 3 and 4. One outstanding factor for this could be the existence of stronger support mechanisms in Models 2, 3 and 4 compared to Model 1.

It is also worth noting that the type of Intervention Model did not significantly influence health outcomes or behaviours except for Coping with Symptoms where participation in Models 1 and 2 was a positive indicator for improvement in this measure. This is not surprising given that both Intervention Models had high participation in the Stanford course which focused on cognitive coping behaviours. However, unlike Self Efficacy, the other health behaviour measure, changes in Coping with Symptoms was not a predictor of improvement for the other health outcome measures.

## **3. *Who benefits most***

In order to effectively target resources, it would have been an optimal outcome of the evaluation if it could identify which groups of clients benefited most from which interventions, as well as considering how and when they are offered to clients. However, as all of the DPs undertook planning, training and support (or some combination thereof) to a greater or lesser degree, it was not possible to satisfactorily analyse the *individual* effects of planning, training and support, nor was it possible to link outcomes to particular groups of people. The identification of the Intervention Models attempted to increase the specificity of the analysis, but it was still a relatively crude approach. Nevertheless, some broad conclusions can be drawn from the analysis.

Overall, the observed changes over time were driven by the ‘worst’ scorers for each measure (i.e. the clients, who at baseline had furthest to move). One interpretation of this result is that the SHCI mainly benefited those at the more severe end of the spectrum. However, it is worthwhile considering whether the measures used in the National Evaluation were sensitive enough to detect subtle change in those who were at the better end of the scale to begin with. Also, if the evaluation had continued, it may have been possible to detect whether the health status of this ‘better’ group was *maintained* over time (as opposed to improving), which still would have been a positive result for the Program.

However, another possible implication of this result is that this ‘better’ group was represented by the ‘worried well’, who although they had volunteered to participate in the Program (‘self selection’), in reality they had little room for improvement. This appears to be supported by the fact that those clients who reported having good health (as indicated by them having better General Health; lower Psychological Distress; higher Satisfaction with Life; and being younger (Age)) at the middle measurement point also reported having good health at baseline. Nevertheless, it is also worth noting that the self-reported General Health (SF-1) of those participating in the SHCI *was* slightly poorer in comparison to the general population for similar age groups (as reported in the National Health Survey, 2001).

Finally, whilst there was a significant change (in statistical terms) in the General Health for the overall group from baseline to the middle measurement point, 55% of the cohort reported no change in their self reported health status over this period. This seems to indicate that for a majority of clients who reported an improvement in the management of their condition (as indicated by changes in Self Efficacy and Coping with Symptoms) and in their sense of well-being (or decreased Psychological and Health Distress), these factors did not necessarily improve their actual health status i.e. these clients still had their chronic condition(s), but they were managing them more effectively.

However, it is not possible to gain any further insight into these or other observations (such as a deterioration in self reported health status) because the evaluation was not able to measure everything, for example, clinical change or other life events which may have influenced health outcomes over and above the clients’ chronic condition status. Also, without the presence of a control group (or equivalent mechanism for measuring change) it was not possible to determine the extent to which other influencers of change such as socio-economic status had an impact on the clients’ capacity to improve.

The limitations of the evaluation are discussed in more detail in Section 6.12.

#### ***4. Comparison with other studies***

The findings described above are consistent with the literature. Table 127 below compares the changes in health status variables from baseline to the last measurement point for the SHCI with the results from the Lorig, Sobel et al study (7) at 12 months.

**Table 127 Comparison with Lorig, Sobel et al (2001) at 12 months**

Variable	Baseline	Last	P value	Significant changes Lorig et al (2001)
	Mean ± SD	Mean ± SD		
<b>Health Status</b>				
General Health	3.40 ± 0.9	0.07 ± 0.9	0.018	
Psychological Distress <sup>1</sup>	19.27 ± 7.8	1.36 ± 6.5	<0.0005	*
Disability	0.35 ± 0.4	0.01 ± 0.3	ns	*
Health Distress	1.67 ± 1.2	0.20 ± 1.1	<0.0005	*
Social Activity Limitation	2.93 ± 1.6	0.02 ± 1.6	ns	
Social Functioning	3.47 ± 1.6	0.43 ± 1.4	ns	*
Fatigue	4.89 ± 2.7	0.12 ± 2.6	ns	*
Shortness of Breath	3.20 ± 3.0	0.15 ± 2.5	ns	*
Pain	4.55 ± 3.2	0.43 ± 2.8	<0.0005	*
Self Efficacy	6.1 ± 2.4	-0.18 ± 2.4	0.034	
<b>Service Use</b>				
Visits to GP	5.93 ± 5.1	0.35 ± 6.2	ns	
Visits to Emergency	0.27 ± 0.9	0.03 ± 1.1	ns	
Visits to Hospital	0.46 ± 1.3	0.15 ± 1.5	0.004	

**Notes:**

<sup>1</sup> Measure not identical, but focused on same phenomenon

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

Differences significant at p<0.005

n values range from 833 to 874

### 6.5.2 Indigenous Demonstration Projects

For the Indigenous DPs, less distinction was made between *client*-related activities and *community*-related. For example, many of the support activities undertaken by the DPs had a much more community focus; hence these are discussed in more detail under ‘community’.

The two Indigenous DPs implemented broadly similar models in terms of process<sup>11</sup>, although there were some important differences which are discussed below.

It was not possible to undertake the same degree of analysis as for the non-Indigenous DPs due to the unavailability of sufficient and appropriate quantitative data. As a consequence, the importance of the qualitative data collected for the National Evaluation (for example, process mapping, focus groups and key informant interviews) needs to be re-emphasised.

***EQ1: Which recruitment strategies are most successful in recruiting which clients / groups of clients?***

In recruiting specific clients to their self-management programs, the DPs were able to use their links with their respective Aboriginal health service organisations and use the patient records to identify which clients were likely to benefit from participating in their DPs. One of the DPs also began to pursue a broader, less targeted recruitment approach as it progressed which seems to indicate that it was necessary to explore more creative ways to

<sup>11</sup> See Process Model ‘C’ described in Section 4.3 of the Final Technical Report

encourage recruitment as time went on. In addition, both DPs undertook broader health promotion activities (which are described in more detail in Section 6.7.2) which also resulted in some self-referrals to the DPs, although their main purpose was to increase awareness within the communities about self-management. Indeed, whilst formal recruitment was important to the DPs, it was not necessarily their primary concern. This is perhaps most clearly illustrated by the fact that one of the DPs stopped collecting questionnaire data on new participants five months into the DP. This has made it difficult to estimate how many clients were formally recruited into this DP and hence make any judgment about the success or otherwise of its recruitment strategies from an evaluation perspective.

***EQ2: Which clients / groups of clients are most likely to participate in which programs?***

***EQ3: What other factors influence participation rates and in which direction?***

### Sample characteristics

As for the non-Indigenous DPs, the majority of clients in the Indigenous DPs were female, although this was the main similarity between the two groups. For example, the level of schooling reached by clients tended to be lower, whilst the cohort was younger with the age range of clients distributed more evenly across the age categories (< 35 years to 65 years plus). Also, the vast majority of respondents reported that they did not speak English at home and that more lived with their families (95% compared to 65%). Diabetes and cardiovascular disease (compared to Arthritis for the non-Indigenous DPs) were the most common conditions reported.

A summary of the cohort's demographic and health-related characteristics at the baseline and middle measurement points is given in Table 128 below.

**Table 128 Demographic and health-related characteristics of the Indigenous DPs' clients**

Characteristics	Baseline (n=210)		Last (n=60)	
	n	%	n	%
<b>Schooling</b>				
None	66	31.4	22	40.0
Year 8 or below	78	37.1	26	47.3
Year 9 to Year 12	50	23.8	7	12.7
<b>Sex</b>				
Male	76	36.2	25	41.7
Female	134	63.8	35	58.3
<b>Age</b>				
<35 years	31	14.8	6	10.7
35-44 years	39	18.6	14	25.0
45-54 years	45	21.4	11	19.6
55-64 years	43	20.5	14	25.0
65+ years	39	18.6	11	19.6
<b>Language spoken at home</b>				
Language other than English	192	91.4	58	96.7
English	18	8.6	2	3.3

Characteristics	Baseline (n=210)		Last (n=60)	
	n	%	n	%
<b>Living Arrangements</b>				
Live alone	20	9.5	3	5.0
Live with family / friends	189	90.0	57	95.0
<b>Has a Carer</b>				
Yes	34	16.2	14	23.3
No	168	80.0	46	76.7
<b>Present condition (can have more than one)</b>				
Diabetes	137	65.2	35	58.3
Cardiovascular Disease	124	59.0	32	53.3
Renal Disease	18	9.0	5	8.3
<b>Smoking Status</b>				
Never smoked	117	55.7	42	72.4
Smoker / ex smoker	84	40.0	16	26.7
<b>Alcohol Consumption</b>				
Never drink	124	59.0	39	65
Sometimes drink/drink daily	78	37.1	20	33.3

Some occasional missing data - percentages may not total to 100%

### Definition of participation

As with the non-Indigenous DPs, the extent to which clients participated in the self-management DP programs varied both within, and across the Indigenous DPs. The extent to which clients participated depended on the clients' capacity and readiness for participation and the DPs were able to respond to these different needs. For example, most of those approached by a DP may have completed some form of problem and goal setting discussion, but not all of those people would have had this formalised into a care plan, and even less would have had formal education and training, for example, adapted Stanford training. However, all clients were still considered to be participants in the DPs.

Participation in the DP self-management programs also occurred at the broader community level which is discussed in more detail in Section 6.7.2 of the discussion.

### Impact of loss to follow-up

Some difficulty was experienced by the Indigenous DPs in following up clients for evaluation purposes. This was due to a variety of reasons including DP staff resources and turnover and client willingness to participate. Despite this, the clients lost to follow up were not significantly different from those who continued to participate in the study – both in terms of demographic profile and health status.

### Facilitators to participation

Overall, clients reported that they were satisfied with the DP self-management program and an important contributor to this level of satisfaction was the ability of the DPs to respond positively to early challenges. For example, to begin with, there was mixed satisfaction with DP staff, but by the end of the DP self-management program relationships between clients and DP staff were described as being constructive and positive which encouraged ongoing participation.

## Barriers to participation

As was the case for the non-Indigenous DPs, lack of transportation, waiting lists for HSPs and costs associated with healthcare were all identified as barriers to accessing, or making the most of the DP self-management program. However it is recognised that these barriers are likely to be more acute (31) for those living in Indigenous communities, particularly those in rural and remote areas.

***EQ4: How and by how much does the form / structure of self-management education influence the health behaviours and health outcomes of clients?***

***EQ5: How and by how much does the type, intensity and frequency of client support and follow up influence the health behaviours and health outcomes of clients?***

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

## Planning

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

Another innovative approach taken by one of the Indigenous DPs to enhance the planning process was the establishment of a Chronic Condition Self-Management clinic. At these clinics, care plans were developed by a multi-disciplinary team of their GP, nurse and the Community Support Worker (CSW) in conjunction with the client. This enabled specific time to be devoted to the care planning process in a supportive environment for the client. In addition, the care planning tools used by both DPs continued to evolve over the life of the SHCI, in terms of being made more culturally appropriate and user-friendly for clients, for example, through the use of pictures to help explain medical terms.

### Box 3

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

## **Training**

In order to meet the diverse needs of the community, the need for culturally appropriate training for community members was predominant, and meant that both Indigenous DPs needed to adapt their training to make it more specific to the Indigenous context and perceived client/community need (see Box 3). For example, where the Stanford course was trialled (which occurred to varying degrees between the two DPs), the content and format of the education and training program were adapted as the courses were conducted.

## **Support**

Client-specific support was provided through ongoing informal contact with the Aboriginal Health Workers (AHWs) and Community Support Workers (CSWs) from each of the respective Indigenous DPs. Some care planning follow-up with GPs also occurred. The roles of the AHWs and CSWs, were central to the development of the DPs, and are discussed in more detail in Section 6.7.2.

## **Measuring the effects of the interventions on health behaviours and outcomes**

The results from the analysis of the questionnaire data for the Indigenous DPs suggest benefits were experienced as a result of the DP self-management program. This interpretation of the quantitative data was supported by the responses given in the client focus groups, which indicated that the SHCI was having a positive impact on their lifestyle (for example, increased walking, healthier eating, and increased health knowledge and medication management), and was supported by observations made by the HSPs.

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

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

## 6.6 Carer/family/ significant other

***EQ7: What is the level of client and carer / family / significant other satisfaction associated with each program? What factors influence this?***

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

### 6.6.1 Non-Indigenous Demonstration Projects

From the process evaluation, it became clear that the DPs’ capacity to specifically target the needs of carers in addition to those of the clients’ was limited. This was illustrated by the fact that it was not possible to identify separate processes to the client domain as part of the process mapping, and reflecting that the carer/family/significant other domain was not a primary focus for the DPs. This was not surprising given that the nature of the cohort was relatively well, with only 21% of the clients from the non-Indigenous DPs reporting having a carer.

Nevertheless, carers, who were contacted as part of these self-management DP programs, reported satisfaction with the DP self-management programs and their relationships with DP staff. As the self-management programs progressed, they felt that the DPs increasingly met their needs as well as those of the clients. Carers reported that the DP self-management programs had increased their skills to manage their own lives. For example, they reported that they had learned to manage their frustrations and were more informed in their role. They also observed that clients were becoming less isolated and had increased their knowledge since joining the DP self-management program. Over time it was felt that the self-management programs had promoted understanding between carers and clients.

Despite these improvements, carers continued to feel burdened (which was the key outcome variable in the National Evaluation) by the caring role. This result could be considered to be analogous to the non significant change in General Health for clients in that the carer burden did not change because the health of the people they were caring for per se did not change.

#### **Barriers**

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

### 6.6.2 *Indigenous Demonstration Projects*

The experiences reported by carers within the Indigenous DPs were very similar to those from the non-Indigenous DPs. In particular, the opportunity the DPs gave them for social interaction with other carers was greatly appreciated. In addition, carers felt better equipped as a consequence of the DP self-management programs to care for their ‘clients’ and themselves.

However, despite the good relationships established with DP staff, (and also echoing the need for greater carer-specific support by those involved in the non-Indigenous DPs), carers in the Indigenous DPs felt that the provision of more carer-focused training would particularly assist them in managing the stress of the carer role, which they continued to be burdened by.

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

#### **Barriers**

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

## 6.7 Community

A clear distinction was observable between the Indigenous and non-Indigenous DPs with regards to their approach to and understanding of community engagement. For the Indigenous DPs, community engagement and capacity building mechanisms were necessary pre-requisites for the effective introduction of the self-management concept to the clients and the broader community. The non-Indigenous DPs tended to be both less deliberate and strategic in their attempts to engage the community, since their understanding of the role of the community at the outset was less clear.

***EQ 6: How and by how much does the SHCI intervention components influence community outcomes?***

## 6.7.1 Non Indigenous Demonstration Projects

### Concept of Community

#### Box 4

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

At the outset of the SHCI, the concept of community and its engagement were at a very early stage of development for many of the non-Indigenous DPs, even though a number of the DPs were intending to target specific groups within the community, for example, those from CALD backgrounds. However, the pressing need to engage the community in *some form* quickly became apparent as the DPs recognised its importance as a facilitator for client recruitment. Nevertheless, significant variability existed across the DPs in terms of how strategic they were in their approach and how they tried to operationalise their approach to community engagement. Some DPs tried to actively integrate the community into their self-management program, for example, through ongoing consultation and inclusion in decision making. Other DPs, only made contact with the community for certain purposes, for example, client recruitment.

There were however, clear examples of effective community engagement among non-Indigenous DPs. Several of the DPs successfully engaged community groups from CALD backgrounds (for example, Polish, Arabic, Chinese and Spanish). These groups were offered interventions which ran in parallel to the mainstream clients. This included a translated version of the Stanford course in each of the CALD communities. One DP was also particularly successful in obtaining the participation of consumer and self-help organisations (see Box 4).

#### Box 5

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

However, only one of the non-Indigenous DP had a formal 'whole of community approach' whose focus was on developing community groups to enable the groups to continue to provide self-management support to community members after the completion of the DP (see Box 5). They also pursued health promotion activities (for example, medication management workshops, falls prevention workshops, youth workshops and grief workshops), with a view to raising the awareness and importance of self-management at the wider community level.

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

### Reach

Although many of the DPs evolved into more community focussed programs, the effectiveness of community engagement was compromised for many of

the DPs due to limited planning up front. The views expressed in the community focus groups tended to support this observation since community members consistently expressed the view that information about the DPs was not effectively reaching the community. However, a full evaluation of the extent to which the DPs were able to reach into the community was outside the scope of this evaluation. Nevertheless, important observations were made about the focus of the DPs and how this affected their reach into the community, which has been described above.

### **Impact on Capacity Building**

Given the DPs' primarily client-focused, the extent to which capacity was built within the community setting was limited in the time available. The capacity which the DPs *were* able to build was more organisationally focused and is discussed in more detail see Section 6.9.1 on Sustainability.

## **6.7.2 Indigenous Demonstration Projects**

As indicated above, the resources and scope of the two Indigenous DPs varied. This was primarily due to the fact that one of the DPs was only a satellite to the main SHCI (non-Indigenous) DP, rather than a fully fledged DP in its own right. Consequently, the amount of initial community consultation that the DP was able to undertake was less than that initiated by the primary Indigenous DP. Nevertheless, as the DPs progressed, the importance of the DP self-management program became more recognised by its Aboriginal health service so that it was able to extend its community consultation and involvement during the life of the DP.

### **Community engagement**

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

The other important factor was to have the right people try and deliver the message to the communities in a culturally appropriate way, which also facilitated further penetration into the communities. Both of the Indigenous DPs achieved this, employing different strategies. One of the DPs had two dedicated AHWs working on a part-time basis on the DP self-management program. The other DP had specifically created the role of the CSW, who worked in conjunction with DP staff to approach and discuss the DP self-management program within their respective communities (see Box 6).

These effective engagement strategies were subsequently reflected and further enhanced by the taking up of community ideas. Unsurprisingly, those ideas that came from the community (for example, women's walking and healthy weight groups) were also found to be more sustainable than the DP initiate ideas.

#### **Box 6**

*The role of the Community Support Worker (CSW) was a non-health professional role, aimed at developing the capacity of community members and providing a link between the DP and the community. The role of the CSW was defined by multi-lingual skills, 'belongingness' to community, community based training and literacy. The CSWs received basic training in a range of areas including the principles and practices of health promotion, chronic conditions and computer skills. The CSWs played a vital role in engaging the community and recruiting them into the DP and subsequently providing support to both the clients and community.*

#### **Reach**

Over time, community members felt that the DPs became more successful at disseminating information to the appropriate people within the community. However, even at the last measurement point, it was generally felt that the DPs could have benefited from wider dissemination of DP self-management program-related information. In this regard, the use of videos was thought to be a very effective way of conveying information to the communities, particularly those in the more remote areas. This comment was also echoed by the HSPs involved with the DPs.

As the DP self-management programs progressed, community members also observed that the community at large was benefiting from these programs. Community benefits identified included increased knowledge about chronic disease, a greater awareness of the importance of healthier lifestyles, and a proactive approach to managing conditions.

#### **Capacity Building**

The roles of the CSW and AHWs were a very important mechanism for building community capacity within the DPs' communities. As part of their respective positions in the DPs, they underwent extensive training and education in self-management. Also, more intangible benefits were observable in the workers as the DP self-management programs progressed, for example increased confidence, self esteem and community respect. By the end of the DP self-management programs, CSWs knew how to take blood pressure and blood sugar levels and one of the AHWs had completed the Stanford Master Trainer self-management course in the United States, making her currently the only qualified Indigenous person in the world to be able to train other leaders.

However, a critical barrier to the maintenance of capacity was the high turnover within both the AHW and CSW roles. Not only did this place a significant burden on the DPs in terms of finding resources for more education and training, but it also affected the DPs' capacity to deliver their DP self-management programs, as turnover was particularly pronounced amongst the male workers and in their absence it was not possible to reach male members of the community.

## 6.8 Health Service Providers

As already indicated the involvement of HSPs, and in particular GPs, did not evolve as was originally planned by the DPs during the operationalisation of their self-management programs. Understandably, given their key role in the primary care setting of chronic condition management, the DPs had substantial ambitions for GP involvement in the self-management concept. This was exemplified by their intention to use the existing health care system framework, most notably the EPC item numbers for care planning, to encourage GP input. However, the DPs had to respond and adapt their self-management program to reflect the actual involvement of GPs, which was less than originally anticipated. On the other hand, the contribution made by other HSPs, for example, practice and community nurses, was essential to the successful roll-out of their self-management programs.

It is worth noting however, that given that the majority of the weighting for data collected as part of the National Evaluation was on measuring client outcomes, understanding the extent of and motivations for HSP involvement was not be measured to the same degree. Nevertheless, consistent themes emerged from the systematically collected qualitative data of the National Evaluation and these are discussed below.

### 6.8.1 Non-Indigenous Demonstration Projects

***EQ8: What is the level of behaviour modification by Health Service Providers? What factors influence this?***

#### Box 7

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

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

#### Definition

The term ‘HSP’ covered a broad range of people who were formal members of the health system, with a health related qualification. These included GPs, nurses (practice, primary health, community, clinical nurse managers and specialists), health educators, AHWs, Allied Health Professionals (for example, physiotherapists, occupational therapists, dieticians, podiatrists) and to a lesser extent pharmacists, psychologists, and speech pathologists.

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

The HSPs’ role in the DP self-management programs was broad and wide-ranging and included the following: referral of clients; participation in the care and/or self-management planning process; provision of support to clients; participation in education and training; conducting education and training (for HSPs and/or clients); telephone coaching; active participation on DP steering committee and other DP specific committees; advisory roles; and

providing input to the development of, and conducting other DP activities, for example, walking groups, information sessions and cooking classes.

Some DPs directly employed HSPs (for example, practice nurses, primary health nurses) to assist with the roll-out of their self-management programs (see Box 7). Occupational therapists, nurses, social workers were directly employed as staff. This gave those DPs an advantage in that these staff already had relevant self-management skills that could be utilised by the DP. These skills included having worked with the target group previously (for example, those from CALD backgrounds), care planning and self-management planning skills, and the provision of support to clients.

### **Impact on working life**

In the first instance, HSPs felt that the activities of the DPs had increased their workload without the benefit of additional resources. However, by the end of the DP self-management program they felt that the DPs had assisted in developing their role as a facilitator (rather than an educator) for self-management. As a consequence, they felt that their roles had broadened and that they had a more holistic approach to their work. HSPs also reported that their professional networks with other HSPs, following their involvement in the DP self-management programs, had improved. The role of networks is discussed in more detail in Section 6.9.1 on Sustainability.

However, reservations continued to be expressed throughout the SHCI about care planning, in particular, the potential for duplication in care coordination processes between the DPs and HSPs. The care planning expectations of the DP self-management programs were also reported to be too burdensome, with the current EPC funding model not covering the costs to GPs. This observation is discussed in more detail in Section 6.10.3 with respect to impact on the future roll-out of chronic condition self-management within the health service system.

### **Interaction between Health Service Providers and clients and carers**

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

### **Engagement of GPs**

Often, pre-existing relationships (for example, through the first round of the Coordinated Care Trials) were the most successful way of encouraging proactive involvement of GPs in self-management activities (for example, referral, care planning). Cold calling, even if based on a formal 'institutional connection' between the DP and the GPs (like the DP operating out of a local division of General Practice), was not effective. Where no previous

relationship or network existed, it was necessary to take the time to build the relationship with the targeted GPs before they would be willing to *consider* participation. However the DPs were often required to seek alternative ways of recruiting clients.

Another contributor to the successful engagement of GPs was the presence of a *proactive* GP champion/advocate of the DP self-management program. The GP champion/s was able to promote the DP and the concept of self-management more informally within the given GP community.

Other strategies explored by DPs which were successful included the provision of additional monetary incentive for referrals to the DP self-management programs, and the placing of DP staff within GP practices.

### **Role of other Health Service Providers**

For the most part, the majority of DP self-management activity was undertaken by HSPs other than GPs, for example, nurses, health educators, AHWs and other Allied Health Professionals. As a consequence, the key role these HSPs played in the roll-out of the DP self-management programs, and their activities, cannot be over stressed.

The 'other' HSPs were a heterogeneous group (see 'definition of HSPs') and their participation in the DPs occurred on both a voluntary and paid basis. Activities undertaken on a voluntary basis included participation in education and training, Stanford course leaders, and advisory and committee member roles. Activities for which HSPs were paid (over and above those who were employed by the DPs) included telephone coaching, the provision of education and training, and input into the care/self-management planning process.

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

The involvement of these HSPs in any ongoing education and training program for self-management will be important in ensuring the sustainability of self-management in the broader HSP community; this is discussed in more detail Section 6.10.3.

### **Volunteers**

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

## **6.8.2 Indigenous Demonstration Projects**

### **Role of Aboriginal Health Worker**

The role of the AHWs is considered in Section 6.7.2 as part of the Capacity Building discussion within the Community context.

### **Engagement of GPs and other Health Service Providers**

Despite both of the Indigenous DPs being located within whole-of-service Aboriginal health services, the DPs still experienced some difficulties in engaging GPs and other HSPs into their DP self-management programs. Once again, the importance of building strong relationships between the DPs and HSPs was a critical first-step for successful engagement. For example, although salaried employees, the GPs in these organisations experienced many of the same pressures on their time as their self-employed counterparts in the ‘mainstream’ system. Also, the risk of being perceived as ‘just another project’ by the HSPs within these organisations, needed to be overcome by the DPs.

As for the non-Indigenous DPs, the Indigenous DPs were able to use GP champions to try and engage other GPs and HSPs in the Aboriginal Health Service organisation. The GP champions were also demonstrating self-management being put into practice and working well in the community. However, staff turnover (which is a particular feature of the rural and remote health service delivery setting) hampered implementation and the gains made by GP champions were often lost or diminished when they moved on.

HSPs in remote locations also reported that they only received limited information about the DP self-management programs. Unsurprisingly, the DPs found it harder to engage HSPs in the remoter areas as a consequence of the ‘tyranny of distance’ and difficulties this places on achieving effective communication.

### **Turnover of HSP staff**

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

## Impact on working life

HSPs, like their mainstream counterparts, were initially hesitant about the self-management model in terms of it creating additional work. However, by the end of the DP self-management program HSPs reported that the DPs had assisted in decreasing their clinic workload, and had increased their HSP network. They also felt supported in their role by project staff. However, again as for the non-Indigenous DPs, concern was expressed around the potential risk of service duplication, particularly with regards to care planning.

The improvement in the HSPs' working life was also felt by the HSPs' clients, and their carers. Both felt that their relationship with their HSPs improved over time – they felt more listened to, and carers also reported feeling more supported in their role. Clients thought that this improvement lay, in part, due to the fact that they had become more assertive in their communication with their HSP.

## 6.9 Health Service System

**EQ9: What factors affect the sustainability of the program?**

### 6.9.1 Non-Indigenous Demonstration Projects

The conceptualisation of capacity building and sustainability in the National Evaluation Framework were integrally linked. Capacity building was defined as development work which '*strengthens the ability of a network to build their structures, systems, people and skills so that they are better able to define and achieve their objectives and engage in consultation and planning, manage DPs and take part in partnerships and community enterprises*' (32). Four domains to capacity building and ultimate sustainability were used; network partnerships; knowledge transfer; problem solving and infrastructure.

#### Capacity Building

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

Whilst many of the DPs were established based on a consortium of different organisations, throughout the life of the SHCI they had to work continually to maintain and develop these network relationships, as well as establish new ones to meet the challenges which arose as part of DP self-management program implementation. However, a key feature of ongoing sustainability would be the DPs' capacity to integrate their self-management program, or

#### Box 8

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

aspects of it, into the mainstream practices of network partners (see Box 8). None of the DPs had successfully achieved this by the end of the evaluation.

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

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

The DPs' problem solving capacity of being able to use recognised methods to identify and solve problems in a sustainable way was less well developed due in part to the short term nature of the DPs. That is, the problems encountered were primarily operational rather than strategic in nature, and hence more sophisticated problem solving mechanisms other than through the existing management structure had yet to be developed.

#### **Box 9**

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

#### **Sustainability**

Initially, the DPs did not take a particularly strategic or planned approach to the ongoing sustainability of their respective self-management programs. This is illustrated by the fact that, for the most part they only began to seriously consider this issue towards the end of the SHCI.

The lack of ongoing funding was consistently cited as the main barrier to long term sustainability. However, another important difficulty encountered in ensuring sustainability was the relatively limited size, scope and longevity of the DPs, which gave them reduced capacity to bring about health service system change (for example, increasing GP involvement) and/or increased integration within local health systems. These factors also influenced the extent to which the DPs were able to attract and retain DP personnel. Staff turnover and the overloading of HSPs and staff were significant issues for the DPs.

Nevertheless, some potentially important steps towards maintaining certain aspects of the DPs were made during their period of operation or closely after. For example, the State and Territory health authority Primary Health Nurses (see Box 7) who were embedded within the working practices of some of the DPs have since taken their skills back into the acute and community sectors to further promote the principles of self-management.

Furthermore, the consumer resource centre (see Box 9), and the community development fund process (see Box 5) were other examples of potentially sustainable initiatives which came out of the SHCI.

It should be noted that DoHA provided a small amount of funding after the DPs ceased their National Evaluation data collection to assist them with embedding successful elements of their DPs within the broader health service system. This process, however, was outside the scope of this National Evaluation.

## **6.9.2 Indigenous Demonstration Projects**

### **Capacity Building**

The low level of community capacity is recognised (31) as being a significant barrier to improving the health and well-being status of Indigenous people. Consequently, a core aim of the Indigenous DPs over the life of the SHCI, was to progressively try and build the capacity of both their communities and their respective organisations. However, given the specific challenges of building capacity within the Indigenous context, for example high staff turnover and the remoteness of the setting, progress was difficult to maintain. These issues are explored in more detail below.

The main area of achievement for the DPs was in relation to knowledge transfer and in particular the steps taken to train and up-skill the CSWs and AHWs since this also helped to bring the concept of self-management into the targeted communities. However high staff turnover was a major barrier in maintaining this capacity both within the Aboriginal health service and in engaging the communities.

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

However, one problem which was identified with respect to making and maintaining networks was the limited range of partners with whom to ‘network’ in the more rural and remote areas of Australia. Also, despite the need therefore to maximise the available resources, there was still a tendency in some instances to view the work of the DPs in isolation of the rest from their Aboriginal health service and not make the necessary linkages with other projects to develop a broader chronic condition management strategy.

As for the non-Indigenous DPs and for the same reasons, the problem solving capacity of the DPs was less well developed.

### **Sustainability**

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

Specific actions which were identified as part of the evaluation as being important in ensuring the sustainability of self-management programs – in some form – both within the communities and the Aboriginal health services/broader health system were as follows:

#### ***1. Community***

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

#### ***2. Aboriginal health services/health service system***

Those HSPs who took part in the focus groups expressed the view that it would be possible to include self-management as part of the existing population health and/or disease specific programs currently operated by the Aboriginal health services. However, strong leadership, management and coordination will be necessary for this to occur.

The EPC Medicare items provide a framework for a multidisciplinary approach to health care including self-management through the care planning process. Whilst the existence of the EPC items proved insufficient to encourage wide-scale GP participation in the non-Indigenous DP environment, this is a source of revenue which has yet to be explored by the Aboriginal health services. This opportunity to embed self-management principles into the work practices of the Aboriginal health services would be further encouraged if it was supported by the ongoing education and training of HSPs, particularly for those in the more remote communities.

Lastly, the position of the CSW (or any equivalent community focused worker) will need to be clarified if the role is to be sustainable into the longer term. Whilst the role of the CSW (or equivalent) provided an opportunity to assist in the development of stronger links between Indigenous people and local clinic staff, there is risk that confusion could arise between the role of the CSW and the AHW. One potential risk of this therefore is that AHWs may be less inclined to cooperate with the CSWs and any related program which they are involved in (e.g. self-management). Also, CSWs may have inappropriate expectations placed upon them by community members, resulting in stress and disappointment in equal measure on both sides.

## **6.10 Future implications for chronic disease self-management**

Based upon the findings from the national evaluation of the SHCI, the implications for the chronic disease self-management are considered below for each of the five domains (Client; Carer/family/significant other; HSP; Community and Health Service System) in turn.

### **6.10.1 Client**

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

- More flexible in their approach, both in terms of the interventions being tailored to meet client need (so that every component of their program was not compulsory) and in their mode of delivery (e.g. telephone coaching) which could facilitate ongoing participation;
- Able to identify and respond to client need through the use of appropriate tools (for example the Stages of Change approach (24)); and
- Able to provide appropriate and structured support to their clients, so that on the one hand, the client did not become overly dependent on the support on offer but nor did they feel isolated from the program.

It is recommended that these program features be incorporated into future self-management policy initiatives.

### **6.10.2 Carer / family / significant other**

Although carers were not the focus of the DPs, overall, carers felt that the experience of the SHCI was of benefit to them. However in the future, it would be important to explore the opportunities for carer-specific training

and support activities in self-management, so that they are better equipped to care for themselves as well as their 'loved ones'.

### **6.10.3 Health Service Providers**

Many of the implications of the information obtained through the National Evaluation for HSPs are closely linked to broader health service system issues, this is particularly true for the role of the GP in self-management.

#### **Role of GPs**

Although it is accepted that GPs have a potentially important role to play in encouraging self-management behaviour in their clients, the practicalities of achieving this proved challenging to the DPs. Given the current health system environment, the constraints on GPs' time was a significant barrier to their participation and without radical health system change, it is unlikely that GPs will be in a position to willingly 'drive' self-management within the primary care setting. However, GPs found the self-management experience rewarding and were very receptive to the concept. As a consequence, it is important to identify how GP involvement can be maximised and be used most effectually in the future.

Based on the findings of the evaluation, GPs should continue to be a source of referral to self-management programs. As a consequence, the ongoing education and training of GPs remains an important area to pursue. A fully informed GP would not only be able to identify clients who would potentially benefit from self-management but also be able to provide the appropriate support to their clients who participate in self-management programs. The Divisions of General Practice may be a suitable forum in which to provide such education and training, since they would be aware of the most effective ways of attracting GPs to participate in such training.

At this stage, given the constraints on their time, GPs' participation in care planning should remain optional. The reasons for this recommendation are described in Section 6.8.

#### **Role of other Health Service Providers**

As described in Section 6.8, the role of HSPs other than GPs is critical to the on-going roll-out of self-management in the community. However, the level and formality of their involvement varied widely in the SHCI, making it more difficult to draw some firm conclusions around their ongoing role. Indeed, whilst it may be optimal to try and standardise their involvement, it was observed as part of the National Evaluation that much of the energy in the self-management arena comes from those HSPs who provide education and support to clients over and above their existing duties within the health service system.

Nevertheless, in future their contribution needs to be adequately recognised and commensurate with their role and position in promoting self-management behaviour. For some this might mean continuing professional development points, for others it will be formal payment.

### **Education and Training**

A recurrent theme identified in the National Evaluation of the SHCI is the importance of ongoing self-management education and training for HSPs. In this way, not only are HSPs kept informed about the benefits of self-management, but also, a rolling program of self-management education and training would minimise the problems associated of high staff turnover, which was a significant issue for the DPs involved in the SHCI, particularly those based in rural and remote locations.

Observations from the National Evaluation also indicate that it would be beneficial if self-management education for all HSPs (including GPs and specialist doctors) were to commence at university since this would encourage it to become embedded in the clinical practice of those HSPs entering the profession.

Finally, for those HSPs participating in the education and training of clients, it will be necessary to actively monitor their training records to ensure quality assurance standards are maintained.

## ***6.10.4 Community***

Those DPs that took a more strategic approach generally found greater success in terms of community engagement. In particular it was important to be clear about who your audience was and target them appropriately, often through existing trusted community networks. The community development models pursued by the Indigenous DPs were the most innovative in this regard, particularly with respect to building capacity within their communities.

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

## ***6.10.5 Health Service System***

### **Systemic barriers to self-management**

Many of the barriers identified by clients related specifically to systemic or infrastructural issues. For example, the lack of transport was cited as a common barrier in terms of accessing self-management interventions and

also other health services. To try and address this, other service delivery options may be worth exploring, for example the telephone coaching model. However this may not be suitable for all clients, such as the hard of hearing. Some DPs also explored using petrol vouchers to assist with the transport issue and the trials in the Second Round of Coordinated Care Trials have used their funds to pay for taxis to take clients to and from treatment. Whilst these are innovative approaches, it is not clear how sustainable they would be in the long run.

The other main barriers identified by clients were the waiting lists for health services and the costs related to health care. Whilst one of the benefits of the EPC package is its multi-disciplinary approach to care, the lack of coordination at the local level between GPs, Allied Health Professionals and Community Nursing is a major issue. For example, whilst referrals to Allied Health professionals were made in care plans for clients participating in the SHCI, the existing waiting list made it difficult for them to see the HSP in a timely way in the public health system. The high cost of health care then became a barrier if they sought to move outside of the public health system.

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

### **Networks/relationship building**

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

### **Enhanced Primary Care**

The SHCI has demonstrated that there are still opportunities for exploring ways in which the activities encouraged by the EPC Package can be more effectively included into daily working practices, for example the employment of practice nurses to do much of the care planning activity for clients. Also, for the Indigenous DPs, this was the first time that they had considered using the EPC items for care planning in their Aboriginal health services

However, in any future self-management, the roll-out, the risk of duplication between GP and other HSP activity would have to be minimised, especially in care planning. This would reduce any confusion in the minds of the GP,

other HSPs and clients and ensure that the risk of an inefficient use of resources was minimised.

## **6.11 Strengths of the National Evaluation**

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

### **Evaluation Framework**

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

### **Process mapping**

In recognising the DPs capacity for ‘re-invention’ (25) during the life of the Program, process mapping was a critical component of the National Evaluation. The information collected as part of the process mapping visits enabled the National Evaluation team to monitor Program implementation as well as providing a context to the impact and outcome evaluations. The process mapping also contributed to an understanding of what was successful and why, which helped to inform potential areas for further policy development and the roll out of future programs.

### **Action research approach**

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

### **Quality and completeness of questionnaire data**

Whilst the follow-up rate varied from DP to DP (82.6% being the highest to 41.8%, the lowest) for the non-Indigenous DPs, sufficient data were collected across all of the DPs to undertake robust analyses over the three measurement points.

### **Development of self-management questionnaires for Indigenous communities**

For the reasons discussed in Section 6.5.2, it was not possible to undertake the same level of analysis of the questionnaire data for the Indigenous DP as for the non-Indigenous DPs, nevertheless, some meaningful comparisons were possible.

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

## **6.12 Limitations of the evaluation**

### **Study design**

Without the existence of a control group or at least a controlled allocation of clients to similar DPs, it was not possible to satisfactorily analyse the individual effects of specific interventions, nor was it possible to link outcomes to particular groups of people. So, whilst the identification of the Intervention Models attempted to increase the specificity of the analysis, it was still a relatively crude approach. As a consequence, it was also not possible to determine the extent to which other influencers of change such as socio-economic status or the presence of certain risk factors had an impact on the clients' capacity to improve.

Due to the delays in the commencement of the DPs, the period of follow-up was limited in most cases to approximately 12 months. So whilst, it appears that the observed improvement in the health status variables was maintained to the 12 month measurement point, it is not known if these movements were maintained beyond that and any consequent clinical outcomes (see below).

### **Measurement issues**

Whilst every attempt was made to use valid and reliable instruments, it seems that the measures may not have been sensitive enough to detect subtle change over time, particularly in those who were at the better end of the scale to begin with.

The evaluation was also limited in the extent of the measures it could use. For example clinical assessments were not available, hence it was necessary to rely on health reported health status. Whilst self reported changes would, for the most part be internally consistent, it was not possible to determine whether the significant changes reported had clinical significance or whether the presence of clinical risk factor influenced outcomes. In addition it was not

possible to determine, based on the measures used, the extent to which other life events over the course of the evaluation may have influenced self reported health status.

### **Data collection issues**

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

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