



Chronic
Illness
Alliance

Report

Knox Community Health Service

**Consumer perspectives of chronic disease management and self-
management in the City of Knox.**

Analysis of Focus Groups

March 2007

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Executive Summary

1. The objective of this project was to explore consumer/carer perspectives of chronic disease management and self-management in the City of Knox.

Key issues covered:

- Local examples of good healthcare
 - Positive experiences of support through management of chronic disease
 - Consumer/carer understanding and response to the concepts of self-management, care coordination, comprehensive assessments and care planning
 - Experiences of, and responses to self-management interventions
 - Perceptions of the role of community health services in the care of people with chronic and/or complex care needs.
2. Four focus groups were held between November 2006 and March 2007. One focus group consisted of people who were regular users of KCHS services; another focus group had both people who used the services as well as those who did not. Two more focus groups were held in Boronia and Rowville to capture views of people living at a distance. All people who attended had a chronic illness or were caring for someone with a chronic illness. In some cases participants had both roles.
 3. Focus groups were recorded, transcribed and analysed.
 4. People who attended KCHS for care of their chronic illnesses, including diabetes, heart conditions and other conditions were more likely to be satisfied with their level of care; to feel better informed and to demonstrate more confidence in their abilities to manage. They were more likely to be motivated into maintaining an exercise and healthy eating program.
 5. People who did not attend KCHS regularly or at all, were more likely to access services privately; to feel they required more information and to consider the costs of services a factor. Some people who had received most of their care privately, especially attending private hospitals were likely to express a sense of isolation and abandonment. It was harder to remain self-motivated.
 6. **(a) Local examples of good healthcare:** William Angliss Hospital and Knox Community Health Service received consistent praise from those who used their services regularly. Regular users of these services demonstrated stronger skills in self-management, goal-setting and coordinating their own care.
(b) Positive experiences of support: people who had attended an allied health professional and then group education sessions were more likely to appear confident in their own abilities; were more likely to continue in support groups and maintain their health programs. People who had not had positive experiences of support were aware that they lacked information and to feel more isolated.
(c) Consumer, carer understanding and response to the concepts of self-management, care coordination, comprehensive assessments and care planning.
 Overall focus group participants expect to receive the coordinated services, care planning and comprehensive assessments as a matter of course. Some

participants had received care plans from their GPs as a result of the new MBS items and they were pleased they could access allied health services at the MBS rate, even though it was on a limited basis.

People who attended KCHS were more likely to expect a level of assessment but most just saw that as 'good luck' in attending KCHS rather than something they should expect from all service providers.

People who saw private health practitioners were more likely to talk of their failures in meeting goals and to see self-management in negative terms of self-discipline and self-denial. Some of them had made little attempt to meet goals and portrayed a passive attitude towards their health. People who had attended group sessions were more likely to see self-management in positive and enjoyable terms.

(d) Perceptions of the role of community health services in the care of people with chronic and/or complex needs.

Most focus group participants were vague about the role of community health services in this area. Those who attended KCHS just considered themselves fortunate to be there and recognised that they received a good service.

There was recognition of the value of having a range of services under the one roof but this was more because of the convenience rather than the contribution of coordinated services in care of chronic and complex conditions.

People who did not attend KCHS on any regular basis were less aware of the value of the services and the convenience of having them under one roof. For people living further away from KCHS, any value in having access to the range of services was outweighed by the distance, except in those cases where private practitioners had proved too expensive to continue.

1. Objectives

The principal objective of this project was an in-depth exploration of consumer/carer perspectives of chronic disease management and self-management in the City of Knox. Based on this the key issues to investigate were:

- Local examples of good healthcare
- Positive experiences of support through management of chronic disease
- Consumer/carer understanding and response to the concepts of self-management, care coordination, comprehensive assessments and care planning
- Experiences of, and responses to self-management interventions
- Perceptions of the role of community health services in the care of people with chronic and/or complex care needs.

2. Focus group methodology

Focus groups aim to collect views and perspectives across a range of people rather than collecting data on the relative frequencies about the people who hold those views.

Each focus group was comprised of 4 to ten people, all of whom had one or more chronic illnesses. In some cases, participants were also carers of other people with chronic illnesses.

In accordance with established practice focus group participants signed a consent form following an explanation of the reason for the focus group and the need to record answers. As part of this established practice they were each given an honorarium to cover their costs in attending, and to show appreciation for their contributions.

A small number of open-ended questions was developed in association with Knox CHS staff to ensure that focus groups best meet the objectives of Knox CHS.

Responses were audiotaped and manually recorded to ensure all responses were captured.

Following focus groups, the data were transcribed and analysed using the focus group questions as the main themes.

3. Target population for focus group recruitment

The target area was the City of Knox. Focus group participants were consumers who have a chronic and /or complex illness. Carers of consumers were also welcome.

Three focus groups were held in different locations in the City of Knox in November and December 2006. One was at KCHS and comprised people who regularly used the services provided there. Another was at Knox Civic Centre with the greater number of people who had never used the service. A third focus group was held at the Boronia Over-50s group. One member of this group regularly used KCHS and another member had used the services in the past but had lost contact.

In March 2007, a fourth focus group was held in Rowville, with a small number of people living a distance from KCHS, who do not always use KCHS.

4. Demographic information

Ages ranged from 42 to 80. People came from across Knox, including Boronia, Wantirna, Ferntree Gully, Rowville and Bayswater. There were 18 women and ten men.

4.1 Chronic Illnesses

Most participants had diabetes or heart disease including one person with cardiomyopathy and another with type 1 diabetes. Some people reported that arthritis was their major diagnosis. A number of women had breast cancer as well as diabetes and arthritis. Other participants reported co-morbidities such as diabetes, arthritis and heart disease. One man had had a stroke, while one woman had asthma and COPD as well as lymphoedema. Another woman had asthma and Chronic Heart Failure. Two women were carers of children; one child with Type One diabetes and two children with asthma.

5. Analysis

Focus groups provide information about people's views and perceptions of services. The analysis is therefore aimed at finding out consistent themes from the focus group participants. In these focus groups these themes are grouped under the broad areas explored through the questions.

The transcripts and notes were searched for the themes that emerge as important to the participants of the focus groups. Each new theme is recorded as it emerges. As the theme is repeated or expanded on by other participants this is recorded as a sub category or as a thematic development. In some cases, themes are developed in terms of the divergent opinions expressed in relation to them, while in other cases themes emerge because of the high level of agreement. Both dissenting views and agreeing views are recorded. The themes that are of greatest importance to the participants and interviewees emerge in terms of the amount of discussion generated when someone first mentions them and how often people return to them.

Analysis continues until no new themes emerge and remaining data fit in the categories already created by the themes either in terms of providing new views of the same theme, divergent opinions, or as illustrations of the theme.

6. Results

6.1 Those who attend KCHS

6.1.2 Pathways of referral

Most people with diabetes were referred by their GP to KCHS for the services of the diabetes nurse educator, the podiatrist and dietician. Others, such as those with heart conditions who were under the care of a specialist had found out about KCHS by other means, generally a family member or friends and neighbours. One woman was advised by her sister who is a pharmacist to attend a community health service for her diabetes care. In a couple of cases, men reported that they had been left to manage on their own for many years before they found KCHS. Several people had been referred from Wm Angliss Hospital to KCHS for specific services.

'It's the luck of the draw if you get a GP who refers you here.'

6.1.3 Services that people accessed from KCHS

People with diabetes reported on accessing the DNE, the dietician and the podiatrist. A smaller number mentioned using the services of the optician. People with heart disease had been in exercise programs and had seen the dietician. Others were attending the physiotherapist. Many of the participants had found out about the dental service later and had put their names on the waiting list. One woman was on the waiting list for the arthritis self-management program, while another had received assistance for both herself and her mother from the occupational therapist.

All those who were regular users of the KCHS services considered that they were extremely good and reported high satisfaction with the services they received. Two men expressed views that being able to form a bond with a DNE who spent time listening to them was a great benefit. A small number were critical of the waiting lists and some suggested that having health professionals who only worked part-time made it difficult to make appointments. One woman who was employed said that the times were not suitable for her to attend an exercise class since it was during working hours.

6.1.4 Support that is most helpful in managing a chronic illness

Information was identified by the more recently diagnosed people as being very important, as was being able to access someone to answer questions. People more recently diagnosed with type 2 diabetes found support from the DNE most helpful at this point. Those who had lived longer with type 2 diabetes considered that regular follow up with the various allied health professionals gave them most support. Being able to set regular appointments for each service was highly valued.

Most people who attended KCHS regularly saw its services, along with the GP, as central to their support needs.

Although it was never expressly articulated there was strong support for being able to see an allied health professional with whom they had formed a relationship and who was familiar with their histories. For instance, when asked how central KCHS was to their health care many people responded that they would phone up a health professional at KCHS first if they required information.

Having good relationships with health professionals supported people in their own efforts. People with type 2 diabetes recognised that diet and to lesser extent, exercise were important to maintaining their health. They spoke of the need for information on the right foods to eat, how to read labels and the support they required to stick to a diet. One man who had attended KCHS in the past spoke of the value of a weight loss group he had attended where they had become part of a 'buddy' system to support one another outside the group. Some people recognised that their emotions played a role in their ability to manage. One woman said that she had been in tears trying to reduce her blood glucose level on her own; while another woman said that she had suffered grief on being diagnosed with type 2 diabetes since she loved food and it was 'now her enemy'. Others pointed out that 'diet fatigue' could set in after years of denying oneself. The main exercise undertaken by people with diabetes who were attending KCHS was walking, with some people belonging to the Knox Walkers.

Participants with heart conditions tended to emphasise exercise more than diet. This was largely because those participating in the focus groups were involved with self-help exercise groups. They recognised that they were successful in their exercise plans because they each supported one another to do the amount of exercise they each could tolerate. Exercise in groups could fill social needs whereas dieting was less likely to do so.

6.1.5 Goal setting

Goal setting is an important aspect of managing chronic illnesses. It particularly relates to developing a sense of personal control in dieting and establishing an exercise regime. People who regularly attended KCHS were asked if any of the health professionals, including those external to KCHS talked to them about goal setting. Some focus group participants did not think this had been the case, with one newly diagnosed person saying that he was so overwhelmed with information he may have missed it. Another person said that if this had happened when she had first attended it would have put her offside as she felt too grief stricken to deal with it. However others spoke of health professionals who had done this with them in glowing terms. A woman with arthritis said the dietician at KCHS had talked with her about goals to reduce weight to assist the pain of her arthritis. She had found it a great help. Another woman had experienced this at the Victorian Rehabilitation Centre. Several had had their GPs talk to them of goal setting in weight loss. One woman who attended KCHS said that the dietician, the podiatrist and her GP had all talked of goal setting. Additionally she had been involved in The Good Life Club through Whitehorse Division of GP and had been told about goal setting at their information sessions as well as working with the telephone counsellor on it.

6.1.6 Self-management

The discussion of goal setting led on to the related concept of self-management in the groups. People who regularly attended KCHS were well aware of the concept of self-management. Some expressed it as being responsible for themselves while others expressed the view that it was getting information and learning the strategies that would most assist them to adopt a responsible strategy. They applied to themselves in terms of the areas they needed to concentrate on and set their own goals. For many of the people with type 2 diabetes self-management meant being responsible for their diets.

'Someone from here-I can't remember who-talked about self-management-they could not do the work for me...but the person who said that to me made me think that if I was going to do it properly I'd have to do it myself.'

'We started our program (to reach our own goals). We started out by buying some equipment with the help of KCHS and then we can follow our own plans. We have intensified our programs. In the supervised group you tend to be held down. In an hour you have 4 people and the supervisor hasn't got the time to give you individual attention. We now set out own goals. We get there and chuck a ball around for 45 minutes which makes a difference to our reflexes-the oldest in our group is 84, and set the goal that our quality of life will be as good as last year's.'

A number of people with type 2 diabetes placed a more limited and negative meaning on self-management by seeing it in terms of self-discipline in diet.

6.1.7 Other issues raised by focus group participants who use KCHS regularly
 People who used KCHS regularly commented that it was not a visible service. Many people did not know of its existence, the services it offered and who could use it. The comments demonstrate that even though these focus group participants were regular users of the services at KCHS some of them were unsure.

'and who is eligible to come here? When I first came here I thought it was just for pensioners and then I found out it wasn't just pensioners. I still don't really know.'

One woman lived close by and walked across. Another woman travelled from Wantirna and was concerned that she would soon be too old and incapacitated to drive there. A common comment was that it was not central for all of Knox and that given the lack of public transport it made it inaccessible to people who did not drive.

Comments also demonstrated that problems of visibility related to the services it offered. Several participants commented that it was 'not until you got inside that you found out all it had to offer'.

Other comments related to lack of knowledge on who was eligible to use KCHS. Some people thought it was income-related, others that it was only available to pensioners and others that it was open to all Knox rate-payers. Still others considered it was open to Knox residents. One person pointed out that there was a perception that KCHS did not provide high quality services. She said a neighbour would not use the dental service at KCHS. It must be a poorer service because it was not expensive.

6.2 Those who don't attend KCHS

6.2.1 Referral pathways

Most people didn't use KCHS because they had not been referred there.

'There's a real gap. It's amazing that you all see a GP and specialists and none of them have referred you on and told you about the services'

Some of them were aware of the existence of the community health service but had concluded they were not eligible; others did not realise that it provided services relevant to their needs. One man had used the service and then stopped. This was largely because he had been overseas for some time. One woman who has asthma as well as a heart condition, used KCHS for dental care, Wm Angliss and Box Hill Hospitals for her heart condition and a private consultant for asthma care. Families from Rowville considered that KCHS was just too far away, though it was worthwhile travelling to KCHS for the dental care, they otherwise could never afford.

For this group of people the GP was more central to their care. It was the GP who told them to lose weight and who recommended them to see various allied health professionals. Many of the participants had set off in search of other services or had seen advertisements in the local newspapers and had followed them up. For the parents of children in Rowville, one with Type 1 Diabetes and the other with two

children with asthma, the GP was also very important. The child with Type 1 diabetes saw an endocrinologist and allied health professionals at Monash Medical Centre but there were times when they wanted more immediate help and the GP was most appropriate. The mother of the children with asthma said that she would prefer specialist help but could not afford it. As her children's health improved and specialist visits were further apart she relied on the GP for advice on medications and any problems that might arise. The GP gives advice on new medications and treatments and she is able to compare this with the specialist's response when they have a regular appointment.

A man who had had a stroke explained that following his release from hospital he was sent home without any follow up services and consequently felt very isolated. It was only by exploring support groups on the internet that he found assistance. This had taken him a long time to achieve, since the stroke had 'frazzled' his brain. Another woman with chronic heart failure said the specialist had told her she did not need rehabilitation and had given her no referrals. She had felt very isolated and had looked for self-management activities. She phoned Heart Support Australia who had referred to the branch in Ferntree Gully. A woman with cardiomyopathy had received no assistance until her specialist received a letter from the Queensland branch of Cardiomyopathy Association of Australia by chance and passed it on to her. She in turn contacted them and found the branch that meets in Melbourne. A guest speaker at one of meeting had informed her about the Heart Failure Clinic at Caulfield General where she has attended. Still another woman diagnosed with COPD had found a Lung Foundation pamphlet in her specialist's waiting room and had phoned the contact number. As there is no support group in the Knox area she has begun to establish one herself.

One woman who has type 1 diabetes is involved with the local diabetes support group. She reported that while she used some of the services available at KCHS, she also accessed services privately, as did other members of the diabetes support group. This was because of the waiting lists and the extent of their individual needs. The mother of the child with Type 1 diabetes said that there were not so many pharmacies in Rowville where she could access the products her daughter required. She needed to travel for these and had recently joined the NDSS. She could see the value of KCHS being closer to Rowville.

A number of people who had been through Knox Private Hospital and had attended rehabilitation there had then been referred back to their GP. They had never been informed of services at KCHS. A man involved with stroke support said that nearly all of the other stroke support group people he came across were simply discharged without any follow up services and without any information.

One woman who described herself as a borderline diabetic with glaucoma, high blood pressure and arthritis said that she saw both a diabetes nurse educator and podiatrist privately, having been referred by her GP.

6.2.2 Information

When participants were asked what kinds of support they would most benefit from, many responded that more information would be helpful. Information should be provided at diagnosis: about services available in the local community; about their

condition and about support groups. It was also important to know which services and which health professionals were qualified and quality services. Participants felt that GPs, hospitals and specialists could be more active in providing material to their patients. Some people thought the Knox City Council should provide more information about health services including KCHS in the locality. One person suggested that when people moved into the area they should be provided with information about KCHS by Knox Council. There was some suggestion that KCHS should take more responsibility in informing local residents of its services and of people's eligibility for them.

Much of this opinion was based on participants' own experience of coping without adequate information and having to find it on their own. Some people were motivated to provide information to newly diagnosed people by leaving it in GP and hospital waiting rooms. They received little encouragement to do this.

'I firmly believe that you have got to be in the system to find out about the services.'

In conclusion, people who had not been referred to Knox demonstrated that they were more likely to travel further afield for various services and that they were more likely to have to coordinate their own services.

6.2.3 Support services

At the same time participants said they would like more services but could not necessarily afford them. Several person wanted more hydrotherapy and massage, but could not afford to pay for them. A number of people had recently been referred by their GP for services under the new MBS items. They were pleasantly surprised to find out they were eligible for them but most said the four sessions per year were not enough for things like massage and hydrotherapy when one had a long term illness.

Participants were asked if they could nominate services that would assist them. Most people wanted more access to the same services they already knew existed such as massage, hydrotherapy and chiropractic. Access was limited by the cost.

'I don't know what's available for arthritis from the Council. I'm in the position of being on a fixed income. So I don't know what's available and there's the cost factor in it.'

'I'd like to access any of the services. My husband works and we have private health insurance and it still costs me more-we get a double whammy- and they send me to a private person. I'd like to be able to access some cleaning from the Council but because my husband works they take my name and put me on a list. And nothing happens.'

Some of the women participants wanted to have more domestic help but knew they were not eligible for more. The man who had a stroke pointed out that for many people with chronic illnesses especially neurological problems, depression was never far away and there were few services to access in the community especially after hours. The cost of private counselling meant it was out of the question. He also pointed out that the degenerative nature of many chronic diseases meant that people were going to face the additional expenses of needing wheelchairs or scooters. Other

participants agreed with this and pointed to the fact that shopping at Knox City was difficult for people with minor disabilities, let alone major ones.

Parents of children with a chronic illness were looking for support that was close to home and was also school-based. An 'Asthma Friendly' school was an important advantage as was a school where the needs of a child with Type 1 diabetes were well understood. Counselling for the child with Type 1 diabetes could be required, though once it was well controlled then both the child and her family could return to normal. However the mother of this child thought that support groups would be a benefit to herself and her husband as well as her daughter. It provided them with people in similar situations to talk to and share experiences. Social work services might also be a real benefit in the future, though the Juvenile Diabetes Foundation was very good for support at the moment.

6.2.4 Goal setting

Several focus group participants who do not attend KCHS said their health professionals, including the GP, podiatrist and diabetes nurse educator had talked of goal setting. This largely related to weight loss. A man with a heart condition said his specialist had just told him to lose weight but he was unmotivated and found it too difficult to think about. People with type 2 diabetes were aware of the value of exercise and talked of the difficulty of maintaining a routine of regular walking. One woman who did not attend KCHS explained that she had become aware of the Knox Walkers through someone who attended KCHS who shared a lot of information with her.

Other women who did not receive services from KCHS said that they had heard about goal setting at the Caulfield Heart Failure Clinic and the Springvale Rehabilitation Centre. A man who had attended KCHS for weight loss but was no longer attending, described the strategies there and said the buddy system was very helpful in meeting one's goals. A woman who had attended Maroondah Hospital for treatment of asthma said that once this had finished she had really missed the support and had no incentive to set goals. Following her heart attack she had set new goals and had found support through cardiac rehabilitation.

Most participants agreed goal setting was a helpful strategy but made the point that it required follow up and additional support measures such as a support group or a buddy system. Goal setting did not work on its own.

'Yes, that's one of the problems with setting goals. You can promise yourself that you will walk each day but then something happens. You get a cold or get sick and you can't do it and you then go backwards so it is a vicious circle.'

'The interruptions are not the problem; it is the restarting.'

6.2.5 Self-management

Many of this group were familiar with the terms self-management. They equated it with self-discipline and self-denial. Self-management meant that one stuck to a diet or learnt self-discipline. For this group the discussion was largely in terms of the difficulties of doing this. Except for the man who had attended the weight loss

program at KCHS some time ago, there was an assumption that it was an individual exercise.

7. Discussion

7.1 Patterns of referral-pathways to self-management services

A comparison of focus group participants who were attending KCHS and those who were not, demonstrated that those who did not attend were more likely to have to find their own pathways to services. They were more likely to accept referrals to private practitioners from their GP or specialist or go without.

Where participants explored services for themselves, they were more likely to go further afield. Participants reported seeking services through the Internet, replying to letters from Queensland and travelling to Caulfield. Some people travelled across the Eastern suburbs, including Ringwood and Box Hill for services.

People who did not attend KCHS regularly were likely to go without services, having been told by specialists to go home and lose weight. They saw it as their own responsibility.

People who attended KCHS regularly recognised that they had been lucky to be referred there and that it depended on the medical practitioner. The view that 'it was the luck of the draw if you got referred here' was expressed several times.

7.2 Information

People who attended KCHS and those who did not, considered that access to information was of paramount importance. However, those who attended KCHS regularly had access to information and were more likely to argue that information needed to be delivered in a timely manner. Lack of information and lack of an identifiable place to seek information was more of a problem for people who did not use KCHS.

People who did not use KCHS generally received information about health services in an opportunistic manner, that is they saw notices by chance in the local newspaper, on walls, in practitioner waiting rooms or were told about services by friends and family

People who did not use KCHS appeared to have less information about their conditions, though this view should be thoroughly tested. Men who did not use KCHS, in particular were more likely to have a passive attitude towards their condition and not follow any program to address issues such as exercise and weight loss.

7.3 Coordination of services

People who attended KCHS were able to organise appointments and tests with a degree of ease. There were some comments about the length of waiting lists and booking cancellations as well as the difficulties of fitting in with part-time staff. Education and information sessions were seen as substitutes for one on one sessions, to increase throughput. Limits on the number of appointments a person could have as well as not qualifying for some services at KCHS created inconvenience as well as leading to less coordination.

One person who was aware of coordination issues argued that while KCHS education and information sessions were extremely valuable they needed to be followed up with an appointment. She also argued that in complex conditions such as diabetes there should be someone to coordinate all the appointments a person required. At present the responsibility fell on the client or carer and some people were not able to take on that role for themselves.

People who did not attend KCHS clearly had fewer expectations. They expected to organise appointments and find services themselves. Having more services that were local such as hydrotherapy and having services that were centrally located in Knox (such as KCHS being more central) were seen as solutions.

7.4 Costs

Costs were an issue for both people who attended KCHS regularly and those who did not attend KCHS. Where people were accessing a number of services at KCHS the small amounts they paid all added up. When they had reached the limit on the number of particular services they were entitled to, some people then sought services privately and consequently paid full fees.

The costs of services were far more onerous for people seeking all their health care privately. One person spoke of the relief she received from arthritis pain with massage. She had recently paid \$55 for a session and had to save up before she could afford another one. Counselling for depression was limited by income.

Some people had benefited from the new MBS items and were able to see a physiotherapist or chiropractor several times a year for a small cost. People who did not attend KCHS had been referred to private therapists for such sessions by their GPs and similarly some people at KCHS were supplementing their KCHS care with private health care through the new MBS items.

7.5 Goal setting

Many of the focus group participants had been introduced to goal setting by health professionals including GPs, diabetes nurse educators and dieticians. There were distinct differences between those who regularly attended KCHS and who had undertaken group programs and had continued to seek group programs and those who had either just completed a rehabilitation course at a hospital and/or been told to manage their ongoing care individually.

People who attended KCHS and continued in group programs were more likely to report continuing good outcomes and confidence in their own skills. They were also demonstrated an ability to seek out new activities and new strategies to meet their goals. People who were trying to reach their goals individually were more likely to have a passive approach; more likely to express dissatisfaction with meeting their goals and more likely to show complacency about their health status.

7.6 Self-management strategies

The ability to self-manage was expressed along similar lines to the ability to meet goals. Those who had been referred to private health professionals and were managing on an individual basis rather than as part of a group were more likely to

define self-management in limited terms of self-discipline in terms of diet. Most people in this category expressed self-censure in that they were not meeting goals. In contrast, those men in the focus groups who were part of a self-help group expressed confidence in their own abilities to improve their quality of life as well as demonstrating a sense of enjoyment of self-management activities. They had adopted self-help strategies and were prepared to share them in a non-competitive environment.

Some people were not as committed as the men in the heart support self help groups. They had attended diabetes education programs and had then continued on to attend other groups. They also showed a level of confidence in themselves and a willingness to explore new groups and new strategies to assist themselves.

Where people were involved in group activities there was a strong sense of altruism. For example, people created support groups to assist others, distributed information and pamphlets, provided information on activities to their friends and neighbours.

8. Conclusion

This conclusion summarises the focus group findings in terms of the objectives.

8.1 Local examples of good healthcare.

In terms of providing people with strategies to manage their conditions, KCHS and William Angliss Hospital were local examples of good healthcare. Focus group participants who had received services at these institutions demonstrated that they had information on which to base their actions; they had the confidence to keep exploring new strategies of management; they knew who to contact for further help and did not feel isolated.

In the focus groups, costs of healthcare emerged as an issue. While costs were discussed by all participants, those who were seeing health professionals privately expressed the greatest level of concern.

8.2 Positive experiences of support.

It became clear from the analysis of the focus groups that positive experiences of support were defined by ongoing services and group education. Those focus group participants who had been referred from a GP, specialist or acute care facility to an allied health professional and then to group education or information sessions were active participants in their own healthcare. Some had maintained their levels of activity through support groups and/or had joined other programs many years after the initial support had been given.

For those who received no ongoing support, negative experiences were defined as lack of information about support services and being discharged home to cope on one's own. In some cases, individuals expressed a sense of abandonment from which they had to recover by themselves.

8.3 Consumer, carer understanding and response to the concepts of self-management, care coordination, comprehensive assessments and care planning.

Overall focus group participants did not demonstrate that they expected to receive the coordinated services, care planning and comprehensive assessments as a matter of

course. Only one woman suggested people were entitled to expect their services be coordinated and her views received no support from other participants. Some participants had received care plans from their GPs as a result of the new MBS items and they were pleased they could access allied health services at the MBS rate, even though it was on a limited basis.

The costs that some people faced in attending for private consultations suggested that referral patterns by GPs and specialists had changed little over the decades and were not reflective of shifts in policy to greater care planning and coordination.

People who attended KCHS were more likely to expect a level of assessment but most just saw that as 'good luck' in attending KCHS rather than something they should expect from all service providers.

There were clear distinctions between those who had attended KCHS and other group education settings and those who saw GPs and specialists privately when it came to goal setting and self-management. People who saw private health practitioners were more likely to talk of their failures in meeting goals and to see self-management in negative terms of self-discipline and self-denial. Some of them had made little attempt to meet goals and portrayed a passive attitude towards their health. People who had attended group sessions were more likely to see self-management in positive and enjoyable terms, as well as continuing self-management activities.

8.4 Experiences of and responses to self-management interventions

As above

8.5 Perceptions of the role of community health services in the care of people with chronic and/or complex needs.

Most focus group participants were vague about the role of community health services in this area. Those who attended KCHS just considered themselves fortunate to be there and recognised that they received a good service. Not all of those who attended KCHS were aware of the basis on which they were referred there. Many people in the focus groups, including those who attended KCHS were confused and unsure of the eligibility criteria.

There was recognition of the value of having a range of services under the one roof but this was more because of the convenience rather than the contribution of coordinated services in care of chronic and complex conditions. Those participants who required a range of services were also aware that the community health service was able to provide many of these services at far less cost than if they had to access them privately. For many this made all the difference.

People who did not attend KCHS on any regular basis were less aware of the value of the services and the convenience of having them under one roof. For people living further away from KCHS, any value in having access to the range of services was outweighed by the distance, except in those cases where private practitioners had proved too expensive to continue.