



REPORT

Consumer perspectives on managing chronic illnesses

**A report on focus groups
conducted on behalf of HealthWest**

by

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EXECUTIVE SUMMARY

Aims:

- conduct in-depth exploration of consumer/carer perspectives of chronic disease self-management in the catchment areas of Westbay Alliance and Brimbank/Melton PCPs.

Methods:

- Focus groups were conducted to collect views and perspectives across a range of people accessing services in the areas covered by Westbay Alliance and Brimbank-Melton PCP.
- The focus groups had a minimum of 6 participants and a maximum of 11 participants, all of whom had one or more chronic illnesses. In some cases, participants were also carers of other people with chronic illnesses.
- Focus group questions related to the impact of illness on their lives; the services and supports they accessed and self-management activities they undertook.

Results:

- A large proportion of the participants had type 2 diabetes. Participants in the Vietnamese group were well informed and actively working to minimise the effects of their diabetes. It appeared that the Vietnamese participants had all been diagnosed when their diabetes was well advanced. Participants in the Italian focus group were suffering depression which was related to their life circumstances and this created a barrier to their active participation in their care. The women participants in the English speaking group held at Western Region Health Centre demonstrated that the Living Well program and social supports were assisting them manage their health. English-speaking participants at the focus groups held at ISIS were less well-informed about their conditions and not actively participating in managing their health.
- All focus groups emphasised that social support as well as health professional support was an important adjunct to health care to assist them actively self-manage. Rapport with health professional and verbal information were also important means.
- Depression was an important factor in limiting people's ability to access and benefit from services generally.

Recommendations:

- Develop strategies for 'hard to reach' people
- Focus on depression at time of intake
- Explore developing support groups as part of discharge strategy
- Information is best given in multiple formats.

1. BACKGROUND.

1.1 The Early Intervention into Chronic Disease Initiative (Living Well Program):

People with chronic illnesses require multiple services. This may mean that they need to access services from a number of agencies or health professionals. Better health outcomes may be achieved when access to these services is planned in partnership with consumers and their families. The Department of Human Services has funded the Early Intervention in Chronic Disease Initiative in Community Health Services, which is delivered by ISIS Primary Care and Western Region Health Centre as the Living Well program. This program forms part of the continuum of services for people with chronic disease.

HealthWest (Westbay Alliance and the Brimbank-Melton Primary Care Partnership) is undertaking service systems redesign of the Living Well program in partnership with ISIS, WRHC and other key stakeholders. Extensive planning and development is being undertaken to meet the objectives of providing better planned and coordinated services for people with chronic diseases, such as diabetes and cardiovascular disease, which constitute the predominant chronic illnesses in the local government areas served by the two Primary Care Partnerships.

1.2 Community profiles:

The communities served by the Living Well program are extremely complex. Brimbank is an area of social disadvantage; is culturally diverse and has poor community participation rates. Melton is an expanding area with young families and low incomes. It also has low community participation possibly due to the need to concentrate on work and caring for young families. Both areas have higher than Victorian average rates of depression, diabetes, heart disease and obesity.

Westbay Primary Care Partnership covers the local government areas of Wyndham, Hobson's Bay and Maribyrnong. Hobson's Bay presents a profile of a more established, less diverse community, with lower projected growth rates. However, there are pockets of social disadvantage throughout the area. Maribyrnong in contrast, is culturally diverse, socially disadvantaged, and is characterised by low incomes. It has an ageing population. Its population is expected to increase over the next 20 years.

Wyndham differs from the other areas significantly. It is less socially disadvantaged than Maribyrnong but is not as advantaged as Hobson's Bay. Its population is projected to increase at more than three times the rate of the total Victorian population increase in the next twenty years. Wyndham has a far younger average population than the other two areas; is less culturally diverse, has higher average incomes and less unemployment.

HealthWest has identified that diabetes, mental health, COPD and a range of other problems related to sedentary lifestyles and poor nutrition are health factors to be addressed. The Alliance has also identified that its partner agencies must deal on a daily basis with problems relating to domestic violence, refugee trauma, and drugs and alcohol.

Living Well seeks to support clients at medium to long term risk of hospitalisation achieve lifestyle changes. While care planning and case management may be involved program funding is focused on early intervention in chronic disease management and life style changes. Overall the aim is to make management of chronic disease responsive to the clients' individual needs and to assist the client to take a more active role in managing their conditions.

In order to ensure that HealthWest meets the broad objectives of responding to clients' needs and assisting clients to take a more active role in their own care, four focus groups were run with community members to explore their understandings of the role of self-management in chronic disease and to identify any barriers and enablers to participating in such approaches.

2. AIMS.

2.1 More specifically the aims of the focus groups were to: -

- conduct an indepth exploration of consumer/carer perspectives of chronic disease self-management in the catchment areas of Westbay Alliance and Brimbank/Melton PCPs.

The focus groups investigated:

- 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.

3. 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.

The focus groups run on behalf of HealthWest had a minimum of 6 participants and a maximum of 11 participants, 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 HealthWest staff to ensure that focus groups best meet the objectives of the HealthWest Living Well program. Responses were audiotaped and manually recorded to ensure all responses

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

Focus Group Questions.

Introduction: Introducing the facilitator. Explanation of the focus group, the consent forms, recording process, how privacy will be maintained including that information gained in the focus group will not be associated with any individual and will not be prejudicial to the person's care from any health professional.

1. You have an illness. Can you tell me a little about the kind of care you need because of this illness.
2. What are some of the important activities you (and/or your family) need to do on a daily basis to care for yourself? How did you learn these things?
3. What advice, information or programs have you received from health professionals to help you manage your own health?
4. Which health professionals have given you the most useful advice? How is it useful? (Has anyone ever used the term self-management?)
5. What is the most useful thing you have learned that helps you (or your family) take care of yourself? Where did you learn it?
6. How do think health professionals can assist best so that your health does not deteriorate?
7. Is there anything else you think HealthWest should know to assist them work with people like yourselves?

4. SUMMARIES OF FOCUS GROUPS.

4.1 Four focus groups were run:

- Two focus group in English; one held at ISIS Sunshine and one at WRHC. ISIS focus group had 11 participants (3 men)
WRHC focus group had 6 participants (2 men).
- Italian focus group (ISIS Sunshine) had 7 participants (2 men).
- Vietnamese focus group had 9 participants (5 men).
- Ages ranged from late-twenties to mid-eighties, with the majority of participants in late middle-age.

4.2 English-speaking focus group held at ISIS PC Sunshine:

This group had 11 participants, 3 of whom were men. English was not the first language of many of those participating in this group. Participants were from the Sudanese, Vietnamese, Turkish and Italian communities as well as from the Anglo-Australian community. The majority were middle-aged to early elderly, with one woman in her late twenties. Several people had part time jobs but no-one was in full time work, some having retired and others having left work due to ill-health.

Participants reported they had diabetes, depression, heart conditions, high blood pressure, high cholesterol, back problems, COPD, sleep apnoea, osteoporosis, arthritis, thyroid problems and problems with eyes and feet, a 'fatty liver' and bi-polar condition. Those participants reporting diabetes had had this for many years, in one case for 20 years. Two people with diabetes reported that they had not taken their diabetes seriously until they were hospitalised for emergency care.

Most people identified that the most important daily activity they undertook to care for themselves was walking as often as possible. All understood the value of exercise, with several people attending a gym and swimming pool, while one person cycled up to 17 kilometres each day.

Good nutrition was given far less emphasis. One person complained that having diabetes made it difficult to socialise because of all the food that was present, while another woman said it was difficult to observe a diet when she prepared food for young children, whose needs came before her own. Living alone meant one person was less motivated to adopt a good diet. On the whole the group appeared to have a poor understanding of diet and nutrition generally. There were discussions that Vietnamese food and a high intake of rice was a healthy diet.

Some participants identified barriers to adopting healthy routines. Several people had depression and one woman said her challenge was to get out of bed each day while another said her depression made it hard to carry out the domestic functions to care for her children, let alone anything else. Others identified that poor motivation was a strong factor, including not taking diabetes seriously until their health had deteriorated. The costs of using the gym and the swimming pool were barriers to regularly accessing these forms of exercise.

Only one man was highly motivated and had also integrated his exercise into his daily routine; he distributed advertising material to households and cycled every day to do this. This man was a new arrival and not eligible for Medicare. He saw this as an additional reason to remain as fit as possible.

While a good diet seemed low on the list of daily activities people undertook to care for themselves, some people identified the dietitian as a valuable source of information, providing them with recipes, advice on what to eat and what to avoid, and being able to answer any questions relating to food. The preferred way of getting this information was to present the dietitian with questions relating to meals. Most others identified their GP

as the best source of advice. Those with depression were more likely to rely on a psychologist or counsellor to answer their questions. Most were agreed that while written information had its place, being able to ask questions in a one to one situation was the best means to get information.

Problems with gaining information led some participants to miss out on services. Some participants had been referred to private specialists in the past. One woman who had sleep apnoea had seen a specialist and had found it difficult to pay his fee. She had not been able to follow his advice about purchasing a CPAP machine due to its expense. Several others in the group who had attended the clinic at Western Health told her about the rental scheme available to public patients.

Six participants had been part of Living Well. They described it as supportive since a health professional took the time to listen to them and provide them with the services that most helped. One woman who was severely disabled considered that the support she had received through the program had made the difference between staying in her own home and being in a hostel or nursing home. Others identified that the interest shown in them was a good motivator.

“I feel comfortable to talk about things. People take the time to explain things and you learn a lot more.”

“Living Well person has taught me a lot about diet. She’s not a dietitian but she spends the time teaching you things. She says I can ring her anytime.”

“Just the fact that you visit someone who focuses on your particular problem helps you get through it. Makes it easier to manage diet and exercise at home.”

“She’s very good because she finds out if I’m keeping up with exercises and that I’m going to the classes regularly and then she tries to find out why I am not coping well with my diabetes. Just a general chat which is nice. She tells me off too.”

Most participants considered that another good form of support and information sharing was through support groups. Most however did not belong to them or to any community groups.

It should be noted that those participants who were part of the Living Well program were receiving better coordinated services but no-one in the group identified formal self-management activities or strategies such as goal-setting as a means to caring for themselves. Participants in this group had poor knowledge of their conditions and many of the indicators of the level of their disease eg taking blood glucose measurements.

4.3 English speaking focus group held at WRHC:

This focus group had six participants, two of whom were men. This group was the least successful as the two men were not able to contribute a great deal. One man who was 84 had very poor English and a correspondingly poor understanding of his health. The other man had communication problems possibly due to mental illness. Both men had diabetes ('a little bit of sugar') and both played down the effects it had on their lives. They were only aware of the medical services they received and the medication they were on though possibly neither could name those medications. This suggested they may not have accessed other services.

The health problems represented in the group were depression, asthma, obesity, diabetes, myasthenia gravis, emphysema and heart problems, osteoarthritis, rheumatoid arthritis, back injury, high blood pressure, high cholesterol, glaucoma and osteoporosis.

All the women participants were aware of the need for ancillary services. Several had regular physiotherapy and one saw the podiatrist regularly. Two with severe depression saw a psychologist while one woman was being assessed for hydrotherapy at Western Health.

Three of the women were involved in the Living Well program. The two women coping with problems related to obesity including diabetes and musculoskeletal problems as well as depression, considered the Living Well program to be the most helpful program they had engaged in. Previously they had found their problems overwhelming. Judgmental attitudes towards their motivation and their achievements had driven them away from seeking help in the past.

Both women demonstrated they had internalised some of the key objectives of the Living Well program. They both spoke of goal setting and of taking small steps to achieve realistic goals. All three women spoke of the way in which the Living Well program gave them motivation and support to continue. For one woman it was simply that she had made a commitment to attend an exercise class and this got her out of bed several days a week, for the other women the level of support they received motivated them to continue.

"I have learnt to set goals for myself. I have someone to help me. She showed me different ways to cope with my illnesses so I didn't have to go to hospital. Getting up and doing something like the exercises is one of the ways of coping she showed me. Going for 10 minutes walks and then gradually lengthening the walks. Going on a short bike ride several times a day to stretch your muscles and gradually strengthen them. It made me feel really good to achieve those things".

"I go to a group session at Braybrook. It's at 9 am and that's good because it gets me out of bed. We mostly do exercises program---gives incentive because I often feel tired. I'm always tired so the group is good---Also do walking---

Disappointed not able to do more after a month. ‘Spouse it is the heart operation and the tablets or I expect too much at my age.’

“LW has given me incentive and motivation. Setting goals is like doing homework. Have trouble doing exercises, getting the motivation. LW workers are very supportive and understand the need for taking small steps and achieving them. It’s rare to find this understanding. It is hard when health professionals don’t understand that you need to take small steps and I have found this a hindrance in previous years.”

For one woman the support she was receiving from Living Well was extending into other facets of her life. She had recently taken up swimming as an exercise and now loved it and looked forward to it. She was also considering joining a book group and participating in some further study.

The fourth woman who was not engaged in the Living Well program was engaged in community work. She ran knitting classes at a refugee group and gave English classes for new arrivals. This provided some diversion from the pain she experienced while providing her with incidental exercise.

The women participants suggested that finding information in Footscray could be difficult because people did not always know where to start. When one was depressed it was even more difficult. They considered that the local newspapers could carry more information about conditions and health services in the area.

4.4 Vietnamese focus group held at WRHC:

There were nine participants in this group, five of whom were men. In this group participants had diabetes, heart problems, high blood pressure, asthma, arthritis and glaucoma.

Participants generally demonstrated knowledge of their diagnoses and their treatments. One man was waiting to have heart surgery and he described that the time he spent waiting was spent positively by building up a positive attitude, exercising and getting fit. He saw his doctor as his support while he, himself was the manager.

All the participants were strongly of the opinion it was their responsibility to be active. Most walked each day, while others also swam or did gardening. Some described the shock of learning they had diabetes. One man did not want to end up using needles (insulin) so began to learn as much as possible so he could prevent this happening. Another participant felt the same way:

“When told she had diabetes she was very worried –felt like life is dark for her /unhappy; but when it was explained to her she gradually understood. Understands that it is not the end of the world and she is not the only one; could get worse so listens so she can understand how to care for self.”

Another man who does not have diabetes understood the risks of developing it and has learnt about it in order to take a preventive approach.

Participants considered information about these risks (diabetes, heart disease) was important and they took steps to gain the information themselves. There was a general view that information in Vietnamese was not hard to access and that members of the community were likely to distribute amongst themselves. One participant for instance made a point of photocopying any information he received and passing it on to others.

The Vietnamese people were also in community groups where they shared food and talked of recipes and several were in arthritis support groups.

4.5 Italian focus group held at ISIS PC Sunshine:

There were seven participants, two of whom were men. Four participants had diabetes; one had arthritis, one had osteoporosis and one had MS. One of the men with diabetes also had heart failure and was waiting for a heart transplant. One man was the carer of his wife with MS. One woman had had cancer and a work related injury.

Participants in this group were all clearly depressed about their health and social situations. All expressed disappointment at where they were in their lives either because of their personal circumstances or because of their health. There was a clear relationship between some participants' social circumstances and the state of their health.

One woman was grieving for her adult daughter who died some two months before. Her diabetes was uncontrolled. The woman with MS felt that cheated that her condition had taken away her quality of life. She expressed disappointment that her expectations of a comfortable retirement had long disappeared. Similar expressions of disappointment in life were expressed by the woman with osteoporosis. The woman with cancer had a tragic life generally. Her husband had died before her youngest child was born, her older son was 'in trouble', which was undefined. She had been unable to work after having had surgery for RSI which produced an adverse result.

Some participants considered that even though they had been born in Australia they were culturally Italian. This meant that some of the responses from health professionals to their needs were inappropriate. One woman travelled to Preston on a regular basis to see an Italian counsellor. Another woman said that the suggestion by ISIS that she put her mother in a nursing home was culturally inappropriate. (Note: this suggestion was made some years ago). She and her sister had worked shift hours in order to care for their mother as long as possible. Not all the participants held this view of ISIS and some participants acknowledged they had received support for both health problems and their complex family problems.

Support was important. The bereaved woman whose diabetes was uncontrolled said that she had started a diabetes education course several months earlier but this had been interrupted by her daughter's illness and death. She had found the support she received

to diet and exercise very helpful; she now needed to renew that commitment. She seemed to be too stressed to take the first step towards seeking the help again. Someone to be a guide for a person with diabetes was important until the person could take charge of the strategies themselves. The man with heart failure sought support from friends and community groups. He preferred to seek diversion from his troubles. Both he and his wife attended an Italian social each week where they met their friends. The woman with cancer was a volunteer with her local church, which gave her several days a week occupation. She saw this involvement as a 'blessing'. The woman with MS attended a support group at the MS Society in Footscray. She went once a month but said that it was limited in its value as it was not facilitated by a health professional and they tended to 'wallow in their own misery'. This woman considered that she received far less support than she required. She regarded herself as 'trapped within her body' and that few people could support her as they did not know what MS was.

Most participants in this group knew one another and had a history of providing one another with some level of support. Some participants said they would also like to be able to talk with someone when they felt the need.

The man who cared for his wife also cared for his mother in law who was aged and frail.

"Not many son-in-laws are like me!"

He was aware he needed to care for his own health. He received physiotherapy and exercised on a regular basis as he described himself as pre-diabetes.

Some participants did not know of other services they could have accessed. For instance, those who could have benefited from Carers Victoria had no knowledge of it. All agreed that the best way to receive information was either in group sessions or in a one-to-one session, where it was possible to ask questions. One person made the point that receiving written information was of limited value, especially when the person was depressed.

Costs were something of a problem. Several of the participants were in a family situation where there were several people with a health problem. Medication could be expensive even at concessional rates. One participant complained about the cost of medication for osteoarthritis and said that there were times when she did not take them due to the cost.

Stress and depression were obstacles to participants engaging in self-management strategies. One woman said that when she was stressed she forgot to take her medication, she was also unable to keep to a routine and would eat a lot of sweets, even though she knew she should be dieting. Others said that they were not able to absorb information that was given them, while several said that the stress of family situations meant they ignored their own health issues. Most participants were so depressed that they viewed their futures and anything they could do to help themselves in a very negative light.

5. ANALYSIS

5.1 Illnesses and the kind of care people perceived they needed:

A large proportion of those attending all the focus groups had type 2 diabetes. They were aware of its progressive nature and that they had a role to play in managing it and stabilising it.

People perceived they needed

- access to information,
- support from health professionals and their own families,
- routines to assist them with behaviour changes related to diet and exercise.

There was a range of other conditions associated with the same risk factors in type 2 diabetes. These were cardio-vascular conditions, high blood pressure, high cholesterol, obesity. These participants, and others with arthritis and osteoporosis, were similarly aware that these conditions required similar strategies.

Depression and mental health problems were also evident in all the focus groups, except perhaps the Vietnamese group. In three cases depression was being treated in its own right, with participants receiving counselling and/or medication. Depression was generally bound up with other health issues, such as obesity, diabetes and life events. Its presence meant the person was less able to adopt routines to improve their physical health. Most participants demonstrated awareness of the role depression played in their health and quality of life.

5.2 Important daily activities:

Most participants had undertaken some behaviour change and adopted daily activities. Walking on a daily basis was the most consistently reported, followed by changes in diet. Smaller numbers of people had taken up cycling or swimming. Use of the local gym appeared very limited due to its continued cost. The Vietnamese participants also included exercise classes and Tai Chi, through their own community groups.

Some people mentioned that taking medication was an important part of their daily routine

5.3 The relationship between information and performing daily activities:

Participants had adopted these daily routines following advice from health professionals. In some cases this was the GP but generally it was a health professional in ISIS or WRHC. In approximately half the cases participants had been referred to Living Well. Most people had positive experiences of this learning experience, particularly the one-on-one relationship and developing a relationship with a health professional.

Participants consistently identified that the most useful way to receive information was verbally. When this was in the context of a supportive relationship information could be understood and put into action. Relationships with health professionals that were comfortable meant that a person could ask questions and return to ask more questions, as

they put the strategies they learned into practice. This context provided the best information. Printed information on its own was not very effective; it was best as a reminder. Vietnamese participants were more likely to actively gather information, especially printed information and distribute it amongst friends and family as a form of educating themselves. Only one person volunteered that she used the Internet as a source of information.

5.4 The role of personal support:

Personal support emerged from all the focus groups as the hallmark of any relationship which aims to introduce lifestyle changes. Participants did not discriminate on which health professional offered the best support; it just needed to be someone they could relate to. When people felt supported by health professionals it meant they could ask questions without feeling they would be judged; they could talk of other matters in their life that affected their health; they would receive the services that assisted them manage better and the health professional would acknowledge it was hard to change one's lifestyle. Several participants cited how they made greater efforts such as walking longer and further, or keeping their appointments when they were in such supportive relationships. In a supportive relationship being 'told off' for backsliding was okay. Few people reported they had experienced unsupportive relationships either at ISIS or WRHC, though staff changes had impacted on one person, and another thought the doctors were 'clockwatching'. Perception that there were waiting lists at the Community Health Centres made people feel their needs would not be met readily.

All groups identified that support groups were a valuable means to share information and to gain support from other people in similar circumstances. For some participants support groups would provide a means of helping other people. Support groups would be an adjunct to the personal support they were receiving from health professionals. Additionally it would provide an opportunity to seek more emotional support. Most people did not explain how they saw a support group working, however the woman who attended one regularly at MS Victoria in Footscray considered support groups should be facilitated by health professionals to avoid people 'wallowing in misery'.

Unusually, few participants in any of the groups spoke of receiving support from family members. One woman acknowledged her husband as her principal carer. Others did not speak of the need for family support to maintain diets or exercise or help them to get to appointments. Only members of the Italian focus group reported they received emotional help from their families and the Italian community generally. Italian participants had a history of assisting one another in life events, as well as receiving support from community groups and the Church.

Those women who were providing support and care for other family members were more likely to note that this role prevented them from caring for themselves adequately. Several women found meal preparation for the family onerous; others were caring for school children, while others had adult children who required assistance. One woman was the sole carer for her intellectually disabled daughter who could 'go off the rails' and take some weeks before she was stabilised. One woman had cared for her adult daughter

until her recent death. This had meant she had neglected her diabetes care and her diabetes was now out of control. Her sister was encouraging her to return to ISIS for professional support.

Those who had participated in The Living Well Program considered they had received excellent professional support. It was marked by patience and concern for their welfare. Most people had learnt a lot from it. One person described how she had gradually increased her ability to exercise. She was now taking short bike rides and walking to the shops each day. Another person said that she had gone from barely being able to walk to now walking on a regular basis and had taken up swimming. She would never have had the confidence to swim, which she found she loved, without Living Well. Both reported that this assistance meant they had learnt strategies to improve their own health. Taking 'small steps' or adopting achievable goals meant Living Well was very helpful to them. Similarly, another woman described Living Well as providing her with someone who was a guide until she could manage on her own. Finally the Living Well program had assisted another woman to stay in her own home instead of having to consider a nursing home. She was extremely relieved to retain her independence.

5.5 The role of self-management:

The majority of participants understood that self-management meant they should take active responsibility for their health and that this was a partnership approach with health professionals. This understanding did not automatically translate into action. Some people found that they lacked the motivation. In some cases this was due to family circumstances, in others it was due depression and in others it was poor routines. Once again the support of the Living Well program demonstrated that it could assist in this area. English-speaking and Italian participants who had not undertaken Living Well did not use goal setting or adopt a formal routine. In a small number of instances they were not accessing many services and did not know where to seek information. For some participants in this situation, they were more likely to seek services through Western Health or through private specialists.

Some of those who were part of Living Well programs demonstrated that they had adopted a self-management perspective and were practising strategies they had learned from Living well such as goal setting and integrating self-management strategies into their everyday lives. Some of them were finding this perspective was a general benefit in their lives as it built up their self-confidence and their feelings of well-being improved.

5.6 Costs:

Some participants in the English-speaking and Italian focus groups held at ISIS Sunshine found that costs were a barrier to the better management of their conditions. For several people costs of the use of the Local Government Leisure Centres meant their exercise was limited to walking.

One woman had been referred to a specialist for COPD. The specialist recommended a CPAP machine but she could not afford to purchase one. She had not been told of the rental scheme operated by Western Health. Other participants in these groups

complained of the cost of seeing private specialists, since the gap between Medicare rebate and the fees was prohibitive. Many of the participants in these groups were generally unaware of the services available through GP Management Plans or through Community Health Services which would have saved on costs.

Finally one woman found the total costs of family prescription medicines onerous and she saved by not always taking her medication for osteoporosis, which was costly in its own right.

5.7 Differences between the groups:

There were marked differences between the groups in their abilities to self-manage. Members of the English-speaking group at Sunshine were less well-informed about their conditions, the available services and self-management strategies. The women members of the English-speaking group at WRHC were better informed about their conditions and the available services. The women were accessing and benefiting from the services such as Living Well.

In contrast the two men in the group appeared socially isolated and possibly with mental health problems. They had lower understandings of their health and the services available. Their responses suggested the more traditional passive approach to caring for themselves, which does not include early interventions.

Members of the Vietnamese group were the most actively involved in all aspects of their healthcare. These differences may be related to cultural values in the Vietnamese community that favour active exercise to maintain both physical and emotional health. Vietnamese participants did not consider their cultural differences created a barrier to accepting services from Anglo-Australian agencies or health professionals.

The Vietnamese participants demonstrated they had community connection, spending time together in groups where they shared information to support one another to maintain their health.

However they were the group most likely to have had their diabetes and other health conditions diagnosed when they were more advanced. There were no explanations apparent for this.

Members of the Italian group also had high levels of community connectdness. They knew one another and supported one another. They participated in Italian community social occasions, attended church and church social activities. Whereas Vietnamese participants perceived these activities as a means to improving their health, Italian participants saw the advantage of community activities in providing them with distractions from their health related problems. Some of the Italian participants considered Anglo-Australian health services were not culturally sensitive, and this created a barrier for them to access the services. This was not a consensus view, with most people accessing some of the services at ISIS Primary Care while others had a long history of involvement with ISIS.

The depth of depression exhibited by all Italian participants may not be representative of the broader Italian community however it was demonstrative of the barriers that depression itself creates to undertaking active participation in caring for oneself. Interestingly, the history of strong emotional support Italian participants provided for one another did not seem to alleviate the negativity of their depression.

6. KEY RESULTS

6.1 Information delivery:

The way information was delivered was seen as important for all focus group participants. There was strong consensus that the most effective way to receive health information was in either group sessions or personal consultations with health professionals.

When information was delivered by a health professional in a one to one session, it was most effective when the person could develop a strong supportive relationship, where asking questions and returning to hear the same information was permissible. Being able to return with more questions as the person began to understand the complexities was greatly valued. Group sessions were also important as they allowed people to learn from the experience of others and to appreciate they were not alone and learn from role models.

Combinations of these forms of information delivery were seen as very helpful by all participants.

6.2 The role of support groups:

Support groups were not only valued as a means to learn more about one's health but as important forms of support. Some people saw group activities as morale boosters and a means to develop a routine. Others saw groups in functional terms of providing group exercises and activities to promote health, while others thought they were useful as distractions from feeling isolated by illness.

Most participants did not specify how support groups should be organised and facilitated though one woman considered professional facilitation was most effective.

6.3 Hard to reach people:

There were indications from the focus groups that socially isolated men and people with mental illnesses were less likely to access services and that they were more at risk of missing out on any early interventions. Social isolation and mental illness meant there was little motivation to inform themselves about their conditions and to take positive steps to improve their health. They, therefore, were at greater risk of developing complex chronic conditions.

6.4 Health problems are integral to the social situation:

The focus groups demonstrated that there was a strong interrelationship between participants' health and their social situations. In some instances social situations had made their health worse. For example, grieving over the recent death of a daughter had made one woman ignore her diabetes. Another example was that another woman spent time caring for her intellectually disabled daughter and was not able to care for herself. Previous examples of isolated men are also relevant here. Carers were often juggling their own health needs with the needs of the person they were caring for.

In other instances, participants' health had affected their social situation. For example one woman was not able to work following a work-related injury and another had stopped working following a diagnosis of MS. Some people who were DSP were not able to afford all health-related costs. Some people had become more socially isolated as a direct result of becoming ill.

6.5 Depression is an important barrier to dealing with other illnesses:

While depression is an important illness in its own right, it was clear from the focus groups that it is a barrier to dealing with other chronic illnesses. Participants who were depressed reported they found it difficult to be motivated, for example to establish routines to exercise and to keep appointments; they were more likely to maintain behaviours they knew were risky, such as overeating and eating poorly. Some of the participants were severely depressed though they did not seem to be having counselling specifically for the depression. They were extremely negative about their health and their prospects, generally. They could see no point in caring for themselves.

Some other participants who had long-term problems with depression were receiving counselling and significant emotional support. They were concentrating on basic daily tasks such as getting out of bed and preparing a meal. One person said that additional tasks such as walking for exercise to assist her diabetes were unthinkable for her.

For less severely depressed participants however, the supports in the Living Well program provided overall benefits. People who were setting realistic goals around exercise and diet found their moods were lightened and their motivation greatly improved. In some cases, participants recognised their self-esteem was greatly improved.

6.6 Self-management of chronic diseases:

Only some participants had clearly adopted a self-management process. Most were aware that their health would greatly benefit from taking more responsibility but had not advanced much more beyond that. Some could be said to be 'pre-contemplative' and likely to move towards self-management in the future.

Those English-speaking people who had set their own goals and were pursuing routines acknowledged they did so with a great deal of support from the teams at ISIS and WRHC. The Vietnamese participants appeared to have internalised the goals of Living Well and to be the models for others. However, based on previous research (Walker

2005) this may be as much a cultural response to personal illness as the role of Living Well or other self-management approaches.

7. RECOMMENDATIONS

These recommendations are based on the results of the focus groups. Some of the recommendations may be well-entrenched already in the programs, so that the recommendation is redundant. If this is the case, then the focus groups have simply provided confirmation that the directions programs are taking are concordant with consumers' views of their own needs.

7.1 Develop strategies for 'hard to reach' people:

For example it could be possible to consult with some of the people from focus groups who were 'hard to reach' in the past to ask their help and advice. Strategies might be related to social isolation rather than health. Some women had had drug and alcohol problems in the past which had meant they were in the 'hard to reach' category. Their insights into their own behaviour would be invaluable in identifying those strategies, tools and supports that assisted others like them to enter a health program.

'Hard to reach' people occasionally see one health professional, for example, a GP. Such a tool could assist GPs to refer them to other services.

7.2 Focus on depression at time of intake:

Depression clearly created problems for some people to care for themselves. The level of depression amongst the focus groups participants was also alarmingly high. This may mean that for some people more counselling is required while for others it might mean that the level of emotional and social support in other programs such as diabetes education needs to be increased. On this basis we recommend that checklists and tools such as the Kessler 10 be used at intake to document the extent of depression and plan for the level of emotional support that may be required.

7.3 Explore developing support groups as part of discharge strategy:

Participants consistently recommended the value of support groups, both in the community health centres and in the wider community. They were seen as multi-functional: providing information, motivation, emotional support and a means to experience greater community integration. On this basis, we recommend that support groups that are either professionally or peer-facilitated be developed along best practice guidelines. Such support groups would then be part of a discharge plan.

Were this strategy to be adopted, planning should be undertaken in consultation with consumers and community members to ensure they were developed to meet people's needs. We recommend that this consultation identify community leaders and assist them to make the links between Living Well, support groups and their communities.

7.4 Information is best given in multiple forms:

This was confirmed by the responses of all focus group participants. It was clear that ISIS and WRHC were doing this and its continuation is recommended. There was also great value in being able to return to hear information repeated and to ask questions to clarify information. Written information was valuable when it was delivered as an accompaniment to these methods of information delivery.