

Menzies Centre for
**Health
Policy**



Report of the Evaluation of the Blue Mountains GP Network Chronic Disease Self- Management Project

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Abbreviations

BMGPN	Blue Mountains General Practitioners Network
CRG	Consumer Reference Group
GP	General Practitioner
MCHP	Menzies Centre for Health Policy
NSW	New South Wales
SCIPPS	Serious Continuing Illness Policy and Practice Study

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Executive Summary

The Blue Mountains GP Network (BMGPN) received funding from the Federal Department of Health and Ageing through the Chronic Disease Self-Management/Lifestyle and Risk Modification Grants program to implement the Chronic Disease Self-Management Project from 1 July 2009 to the end of May 2010.

The BMGPN Chronic Disease Self-Management Project developed a number of objectives and initiatives aimed at increasing awareness of self-management programs and techniques in the local area, including implementing 'Moving On', a generic self-management course developed by Arthritis NSW and designed to increase people's knowledge and skills to enable them to self-manage their chronic conditions more effectively.

The Moving On program was structured into seven sessions conducted over seven weeks in three hour blocks. The sessions covered: managing fatigue and physical activity; healthy eating and leisure; coping; stress management; relaxation; sleeping; medications and working with the health care team. Each Moving On session was facilitated by a health professional and a lay leader. The lay leader was someone with a chronic condition who could provide input from their personal experience and could provide a positive role model for participants. The health professional leader contributes their technical knowledge and skills plus ensures that information was evidence-based, verifiable and correct.

An evaluation of the BMGPN Chronic Disease Self-Management Project was undertaken by members of the Serious Continuing Illness Policy and Practice Study (SCIPPS) team based at the Menzies Centre for Health Policy (MCHP), University of Sydney.

The SCIPPS evaluation employed qualitative methods for data collection supplemented by small-scale surveys and evaluation forms generated by the project itself.

The two aims of the SCIPPS evaluation were to:

- Qualitatively evaluate changes in the local setting pre and post project implementation; and
- Qualitatively evaluate the Moving On program.

Fourteen semi-structured individual interviews were conducted with BMGPN and project staff, consumer reference and professional working group members, local GPs, and health professional and lay leaders of the Moving On program.

Three focus groups were run during the course of the evaluation, one immediately before, one after, and another six months after the program was run.

Summary of Findings

The Chronic Disease Self-Management Project

- The project met its stated objectives.
- A Consumer Reference Group (CRG) to inform the development and implementation of the project was established and a project coordinator was appointed.
- Evidence gathered from evaluation activities indicated that the CRG met its stated terms of reference, including to: provide advice and consumer input on activities and strategies of the project and its evaluation including the implementation of Moving On; to produce a register of

chronic disease self management support groups and initiatives (see Project Objective 2); produce a list of barriers to access (see Project Objective 5) and assist with strategies to develop effective communication between GPs, health professionals, consumers and the wider community.

- The CRG and the project coordinator worked closely within the BMGPN and with local health professionals improving connection and communication between these groups and the wider community (including advertising the public information morning and Moving On in the local newspaper, and in support group and BMGPN newsletters.)
- Project objectives related to raising awareness among community members and health professionals were also met. The activities of the project generally, and in particular running Moving On, have played a significant role in increasing awareness of chronic disease self-management support groups and initiatives amongst health professionals, consumers and members of the local community.
- Those health professionals more closely involved or linked to the activities of the BMGPN were more likely to know about the project and Moving On, particularly those who referred patients or who were involved with the CRG or the Network Board.
- Time constraints on health professionals, due to insufficient numbers of GPs to service the local area, limited their ability to assess patients' needs and refer to support groups or self-management initiatives and also made it difficult to get their attention on an issue such as chronic disease self management.
- Barriers identified by the project to accessing chronic disease self-management initiatives included: availability and proximity of public transport; availability of parking; venue comfort and accessibility; knowledge of, and dissemination of information about, chronic disease self-management initiatives and support groups; and cost.

Moving On

- Moving On exceeded participants' expectations and participants recommended Moving On to family and friends.
- An informative, well-thought out program, technically skilled health professional and lay leaders with personal experience in self-managing a chronic condition established a cohesive learning environment underpinned by proactive coordination and support by the BMGPN.
- A collaborative interactive process provided opportunities for group learning and the sharing of challenges and successes in self-managing a chronic condition including: a shared understanding; new learning; the uptake of new activities; group support and social networks.
- Shared experiences in a supportive group environment boosted participants' confidence and reduced feelings of isolation and despair.
- Participants observed an improvement in the self-management of their chronic condition. The Moving On leaders also observed a change in participants' self-management of their chronic condition.
- The challenge for participants will be to adhere to their self-management action plan and build upon and maintain their self-management progress in collaboration with their health care practitioners.
- Program content and course materials were well received although content areas that could be further developed were also identified.
- Chronic conditions are often invisible and partners, spouses, carers, families and friends may not understand the daily challenges for someone living with a chronic condition.
- Those living with a chronic condition may not understand its impact on those close to them.
- Support groups – either formal organised groups or informal social networks - are critical for people living with a chronic condition.

Recommendations/Next Steps

Recommendations for the Chronic Disease Self Management Project

- The activities of the project generally, and in particular running Moving On, have played a significant role in increasing awareness of health professionals, consumers and members of the local community.
- Raising awareness is a continuing process that requires further input on an ongoing basis. Feedback from the CRG and Moving On participants has indicated that the terms 'self-management' and 'chronic disease' are not necessarily recognised or understood by consumers and members of the public, even if some may be practicing self-management techniques. Consideration should be given to this when future promotional activities are being planned.
- Word of mouth communication from those involved in the project within the BMGPN or through Moving On has also increased awareness and created a momentum that continuing to run Moving On in the local area could capitalise upon.
- The CRG is continuing to work on funding applications within the BMGPN to establish the CRG on an ongoing basis. A permanent CRG would make a substantial contribution to the capacity building undertaken by the project and to the sustainability of local chronic disease self-management initiatives.
- Time constraints on health professionals, due to insufficient numbers of GPs to service the local area, limited their ability to assess patients' needs and refer to support groups or self-management initiatives and also made it difficult to get their attention on an issue such as chronic disease self management. Consideration should be given to strategies that would ensure self-management remains on the agenda for health professionals in the local area beyond the life of the project.
- The continuation of the work begun by the project coordinator and the CRG within the BMGPN in implementing the project would be ensured by the establishment of an ongoing position focussed on self-management issues in the Network (or incorporating this agenda into the tasks of an existing position if limited resources do not allow for the establishment of a full-time position).

Recommendations for Moving On

The experience of implementing the Moving On program in the Blue Mountains raises the following considerations for the BMGPN and Arthritis NSW in regard to the on-going development of the program and its sustainability:

- The workbook and readings are valuable resources. However they could be further developed to include more information on: mental health and wellness; chronic condition support groups, activity programs and other community resources available in the Blue Mountains; available social service links and packages; quality of life with partners, spouses and/or carers; and alternative therapies.
- The language uses in Moving On could be reviewed to replace language denoting illness and sickness to more neutral terms, for example chronic condition and not chronic illness.
- As signalled by Arthritis NSW Moving On is currently designed for middle Australia. There are plans to extend it to other people living with a chronic condition in the Blue Mountains and to other areas in NSW and Australia. It is worth considering that Moving On could be endorsed for use in residential facilities (such as nursing homes, community centres and hostels).
- Consideration could also be given to how to adapt the program for different groups such as lower socio-economic; Indigenous, culturally and language diverse groups; young adults, teenagers and children; carers and/or partners and spouses. It may be that Moving On establishes links with other organisations, programs or experts in these fields who provide input to the Moving On program or one-off information sessions where appropriate, rather than the program itself addressing or absorbing all these diverse interests and perspectives.

- Adaptation of the Moving On program may involve specific activities for different groups, the development of applicable support materials and the training of health professional and lay leaders from each group, including older children and teenagers as role models or leaders.
- Consideration could also be given to gender demographics and chronic conditions. An evidence-based understanding of why more woman than men were involved in Moving On as leaders and participants would assist when developing strategies targeting self-management and those living with a chronic condition. It may be worth considering how to tailor Moving On to engage men in general, especially those living with a chronic condition, who may not access prevention or treatment services.
- A focus group conducted with Moving On participants six months after the conclusion of the program found that overall it was successful at providing effective self-management information, strategies (realistic pragmatic goal setting) and also broader social support.
- The more enduring aspects of Moving On discussed by final focus group participants included: acceptance of self and of one's illness; self-confidence; 'inner strength'; 'inspiration'; motivation; the value of sharing a range of things, both health and non-health related; and an increased awareness of others with chronic conditions who may be 'worse off' (sicker, more disabled or in more pain).
- Moving On action plans that were completed at the final session of the course were useful for further referrals and maintaining changes made during or after the program was completed for some final focus group participants and were also helpful for improved communication between health professionals and patients about management of chronic conditions.

Introduction

The social and economic burden of chronic conditions is set to increase in western societies over the coming decades because of ageing populations, an increase in numbers of those with chronic conditions^a, and associated escalating health costs. Chronic, non-communicable diseases make up 80 per cent of the total burden of illness and injury in the ageing Australian population¹ and account for 70 per cent of health expenditure.²

Searching for appropriate and cost effective treatment, care and management of chronic conditions will become increasingly important.³ Further exacerbating the problem, one person may suffer from more than one chronic condition.⁴ In response to this challenging situation, self-management interventions have been developed that allow people to better manage their conditions by taking substantial responsibility for the day-to-day decisions associated with their care. Self-management can be 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.” (p. 178)⁵ and can include managing medications, making lifestyle changes, or engaging in preventative behaviours.⁶

Internationally, a number of different approaches have been used for delivering self management programs and include the influential Stanford Model developed by Kate Lorig at the Stanford School of Medicine⁷, other generic and disease specific models, and individual face-to-face or telephone coaching. Most are based on the principles of adult education and self efficacy derived from Bandura,⁸ which Francis, Feyer and Smith (2007) define as “the belief in one’s own ability to successfully perform an action to achieve a desired outcome” (p. 500).⁹ In Australia, the Flinders Human Behaviour and Health Research Unit have developed the Flinders program of chronic condition self-management, a generic set of tools and processes that enables clinicians and consumers to assess self management behaviours, collaboratively identify problems, set goals and develop individualised care plans.¹⁰

Background to the BMGPN Chronic Disease Self-Management Project

The Blue Mountains GP Network (BMGPN) received funding from the federal Department of Health and Ageing through the Chronic Disease Self-Management/Lifestyle and Risk Modification Grants program to implement the Chronic Disease Self-Management Project from 1 July 2009 to the end of May 2010.

The BMGPN Chronic Disease Self-Management Project has developed a number of objectives and initiatives aimed at increasing awareness of self-management programs and techniques in the local area, including implementing Moving On, a generic self-management course developed by Arthritis NSW and designed to increase people’s knowledge and skills to enable them to self-manage. The Participants’ Workbook of Moving On describes the aim of the program as helping “... participants manage their chronic illness by challenging unhealthy behaviours and attitudes as well as providing the knowledge and skills you need to create positive changes in your life.”¹¹

a We use the term chronic condition instead of chronic illness to illustrate that while a person is said to have a long term illness or disease that person may not be ill or bed-ridden. It was evident that the participants we spoke to did not see themselves as ill, and were determined not to be ill, therefore we use the broader term of chronic condition instead of chronic illness. ‘Chronic health conditions’ is defined as those conditions which are long term (lasting more than six months) and which have a significant impact on a person’s life. Chronic conditions can affect people of all ages. Many chronic conditions can be managed to minimise the severity of the symptoms and the impact on a person’s life. Health Insite. An Australian Government Initiative http://www.healthinsite.gov.au/topics/Chronic_Conditions_and_Injury Accessed 1 May 2010 Moving On Participants Workbook. A Self Management Program for People with a Chronic Illness, Arthritis NSW (2008).

The Evaluation of the BMGPN Chronic Disease Self-Management Project

An evaluation of the BMGPN Chronic Disease Self-Management Project was undertaken by members of the Serious Continuing Illness Policy and Practice Study (SCIPPS) team based at the Menzies Centre for Health Policy (MCHP), University of Sydney. The MCHP is committed to promoting, through research and scholarship, the development of policy for the care of people with chronic conditions. SCIPPS has a long-term objective to describe current chronic disease management strategies and evaluate new interventions designed to enhance the quality of life of people with these conditions.

The SCIPPS evaluation employed qualitative methods for data collection supplemented by small-scale surveys and evaluation forms generated by the project itself (see also Section Three). Ethics approval for the SCIPPS evaluation was gained from the South West Sydney Area Health Service Human Research Ethics Committee (Westmead Campus).

The two aims of the SCIPPS evaluation were to:

- Qualitatively evaluate changes in the local setting pre and post project implementation; and
- Qualitatively evaluate the Moving On program.

Qualitatively evaluate changes in the local setting pre and post project implementation

The main aim of the BMGPN Chronic Disease Self-Management Project was to identify, connect and promote local chronic disease self-management initiatives and support groups to consumers, GPs, and allied health professionals. The project developed a number of objectives in order to meet this aim. These objectives were:

- establish a consumer reference group to inform the development of the project and oversee its implementation by the BMGPN project facilitator;
- identify and collate information about local self management groups and activities including current use of one-to-one self-management by general practitioners;
- raise consumer awareness of chronic disease self management and local self-management initiatives;
- raise chronic disease self management awareness amongst health professionals and increase referral to local self-management initiatives and health services by working with general practitioner membership of the BMGPN, health professionals and local pharmacists. Identify the needs of GP and health practitioners with regards to promotion of chronic disease self management in the Blue Mountains;
- identify access issues and barriers for the local community to participate in chronic disease self-management initiatives;
- implement in the local area "Moving On: A Self-Management Course for people with Chronic Illness";
- conduct an evaluation of the whole project including qualitative evaluation of the local implementation of Moving On; and
- build on local activities to increase the long-term sustainability of local chronic disease self-management.

To evaluate changes in the local setting pre and post project implementation the evaluation must take into consideration how the BMGPN Chronic Disease Self-Management Project has addressed these objectives, and what impact the project has made in the Blue Mountains setting in relation to these objectives. The SCIPPS evaluation conducted individual interviews with BMGPN and project staff, local GPs, consumer reference and professional working group members, and also collected and assessed other relevant information generated by the project in order to determine if, and to what extent, the project had met its stated objectives. These findings are presented in *Changes in the Local Setting*.

Qualitatively evaluate the Moving On program

As part of an overall assessment of if, and how, the project has promoted self management in the local area, the evaluation qualitatively evaluated the implementation of Moving On, a generic self-management course designed to increase people's knowledge and skills to enable them to self-manage. Four health professionals and four lay leaders (people living with chronic conditions) were trained by the project to be facilitators of the Moving On program.

In order to evaluate the success or otherwise of the Moving On program, individual interviews were carried out with project staff, consumer reference group and professional working group members, as well as health professionals and lay leaders about the implementation and impact of Moving On. Focus groups were also conducted with participants of Moving On. Three streams of Moving On were run concurrently by the project over a seven week period in three locations in the Blue Mountains, Katoomba, Hazelbrook and Springwood. Participants from each stream were included in focus group discussions.

Evaluation Methods

Consultation

A consultative approach has been taken by the evaluation team throughout all phases of research planning and evaluative activity. This process was led by the BMGPN and has included consultations with the project coordinator and BMGPN CEO in formulating the evaluation plan, carrying out the research and reviewing the evaluation report. In addition, an evaluation team member attended Consumer Reference Group and Professional Working Group meetings and a public consumer information session run in Katoomba by the project in November 2009.

Individual Interviews

Fourteen semi-structured individual interviews were conducted with BMGPN and project staff, consumer reference and professional working group members, local GPs, and health professional and lay leaders of the Moving On program. Twelve of these interviews were face-to-face and two were conducted by telephone.

Interviews lasted between 30 minutes to an hour and were conducted and electronically recorded by one member of the evaluation team while the other team member summarized the discussion on a laptop computer.

BMGPN and project staff	4
Consumer Reference and Professional Working Group members	2
Health Professional Leaders of the Moving On program	3 (2 by telephone)
Lay Leaders of the Moving On program	3
Local GPs	2
Total	14

Semi-structured schedules were used to maintain consistency of issues covered for the above groups interviewed but were modified according to each group and their differing roles in the project (see Appendix One).

Broad subject areas and specific questions from the interview guides formed the framework for analysis. Summaries of interviews were also used in the analysis with electronic recordings providing further depth and detail where necessary.

Focus Group Discussions with Participants of the Moving On Program

Two focus groups were run during the course of the evaluation, one immediately before and the other immediately after the Moving On program was run. The rationale for this approach was to explore changes in self-management motivation and practices.

Eight participants (seven women and one man) were recruited from the three course streams to take part in the focus groups—Katoomba (four), Hazelbrook (one), Springwood (three). For comparative purposes, the same people attended both focus groups. The pre-Moving On discussion focussed on people's current experience of living with chronic conditions and their expectations of Moving On. The post-Moving On discussion focussed on various aspects of the course itself – health professional and lay leaders, the Moving On workbook and readings, the experience of being in the groups themselves – as well as any changes in self management motivations and practices resulting from participating in the courses (see Appendix Two for focus group discussion guides).

A further follow up focus group will be conducted with the same participants (if possible) six months after the program has been completed to explore sustainability and durability of change in self management practices as a result of participating in the Moving On program. Findings will be presented as an addendum to this report.

The two focus group discussions were an hour and a half to two hours in duration and were conducted and electronically recorded by one member of the evaluation team. The other team member summarized the discussion on a laptop computer. As with the individual interviews, broad subject areas and specific questions from the discussion guides formed the framework for analysis. The two summaries of the focus group discussions and the recordings provided further detail.

Project Surveys, Evaluation Forms and Documentation

Two small-scale surveys and two evaluation forms were generated by the project. Information from these sources is used in the report to supplement qualitative data collected in individual interviews and focus groups.

Surveys:

- GP and Practice Nurse survey
- Consumer Awareness survey conducted at the beginning of the Consumer Information Session November 2009

Evaluation forms:

- Moving On Evaluation
- Evaluation of the Consumer Information Session

The evaluation team also reviewed project documentation to provide further detail and clarification of project activities. This information is integrated throughout the report where appropriate.

Changes in the Local Setting

The main aim of the BMGPN Chronic Disease Self-Management Projects was to identify, connect and promote local chronic disease self-management initiatives and support groups to consumers, GPs, and allied health professionals. The project developed a number of objectives in order to meet this aim (see *Qualitatively evaluate changes in the local setting pre and post project implementation*).

This section will examine project objectives and discuss the extent of their implementation and impact. This discussion is informed by individual interviews with BMGPN and project staff, local GPs, consumer reference and professional working group members, project initiated surveys and evaluation forms and relevant project documentation.

Two objectives will not be included in this section as the first of these, the implementation of Moving On in the local area, will be discussed in Section Four and the other, carrying out an evaluation of the whole project including qualitative evaluation of Moving On, is the subject of this report.

Project Objectives

Project Objective 1: Establish a Consumer Reference Group (CRG) to inform the development of the project and oversee its implementation by the BMGPN project facilitator.

The BMGPN (formerly the Blue Mountains Division of GPs), fully supported by its Board, is committed to consultation with and inclusion of consumers in its activities and structures either as representatives of people living with particular illnesses or conditions, or as carers. Previous to the implementation of the project consumers had been involved in the Network's Quality Use of Medicines and mental health shared care committees. A CRG had evolved through this and other consumer involvement in various mental health initiatives of the Network. In November 2008 consumer groups had also played key roles in the Division's Chronic Disease Self Management conference. The Division's Strategic Plan 2008 – 2010, written in 2006, had a key stakeholder focus and the Network has since developed a key stakeholder forum ensuring these groups have a voice within the BMGPN.

The formation of the project CRG was an extension of these processes. The Quality Use of Medicines committee consumer representative encouraged the Network, already aware of Commonwealth chronic disease initiatives, to apply for funding for the project. The Network contacted members of local chronic disease support groups inviting representatives of each group to meet to put together an application – Arthritis NSW Blue Mountains Branch, Blue Mountains Branch of Diabetes Australia (NSW), Blue Mountains Airs (Chronic Obstructive Pulmonary Disease support group), Nepean/Blue Mountains Cardiac Support Group, Blue Mountains Cancer Help. In keeping with the BMGPN key stakeholder focus, the application was drafted from a consumer viewpoint, with input and assistance from a local GP who was also a diabetes specialist. If successful, the funding would establish a CRG for the project, provide for the compilation of a register of self-management initiatives and support groups in the local area (see Projective Objective 2), and facilitate the implementation of Moving On. The funding was successful and shortly after (July 2009). Initially, as a project coordinator was yet to be appointed, another BMGPN staff member was the facilitator of the CRG's first two meetings. These meetings established the CRG's terms of reference and the project's frameworks and timelines.

The BMGPN employed a project coordinator in September 2009. In October it was decided the CRG would form a smaller Professional Working Group (PWG), consisting of three of its members. Working with the project coordinator, the smaller PWG guided the implementation of Moving On. The CRG's clear consumer focussed view of the aims of the project also assisted the project coordinator to carry

out the steps necessary to fulfil the project's other objectives. As the project draws to a close at the end of May 2010 Moving On has been successfully run in three Blue Mountains locations (Katoomba, Hazelbrook and Springwood) with the CRG having met five times, and the PRG meeting two times to oversee this and other project activities (with the project coordinator providing both groups with ongoing support and feedback in the form of minutes of meeting, regular updates and other information relevant to the activities of the project such as brochure mock-ups and draft editorials for the local newspaper). Without the CRG there would not have been significant input into the project from Blue Mountains chronic disease support groups - and the valuable insights they bring to chronic disease self-management from a consumer perspective. The BMGPN is now seeking further funding to establish the CRG permanently within the Network. As with previous funding activities, the CRG is involved in developing these submissions.

Project Objective 2: Identify and collate information about local self management groups and activities including current use of one-to-one self-management by general practitioners

Identification and Collation of Information about Local Self-Management Groups and Activities

Several of the key informants commented in the interviews that the Blue Mountains has a strong sense of community, despite stretching along 100 kilometres of highway and consisting of 26 towns or "villages." Because of this sense of community and associated high levels of participation and interest, health and other community-based initiatives are often enthusiastically embraced in the Blue Mountains. However, this can sometimes lead to replication of services across locations and disparities in how various initiatives are, or are not, integrated and promoted. It is hoped the creation of a register of chronic disease support groups and self-management initiatives in the Blue Mountains will alleviate this problem in the area of chronic disease self-management.

Because of its connections to GPs and other health professionals in the local area, and its commitment to consumer inclusion and advocacy, the BMGPN was ideally placed to compile a register of chronic disease support groups and self-management initiatives and activities and disseminate this information to consumers, chronic disease support groups, and its GP members. During the course of the project a register containing this information has been collated and disseminated to local support groups, the Blue Mountains City Council, and GPs and health professionals in the area. This was a project outcome for this objective. The register will exist as a laminated card and also be accessible via the BMGPN website. It is hoped this register will be regularly updated and disseminated by the BMGPN beyond the life of the project. The project is exploring the possibility of making this register more widely available on-line with a facility for regular updates by support groups themselves. However, the Network may not be able to pursue this option because of limited accessibility of currently available IT platforms.

Current Use of One-to-One Self-Management by General Practitioners

In order to access current use of one-to-one self-management by general practitioners, and other self-management related issues, the project developed a nine question survey – the Chronic Disease Self-Management GP and Practice Survey 2009 (see Appendix Three). Sixty-five surveys were distributed to the Network's 65 GP members. Nineteen surveys were returned (29 per cent response rate).

Of the 19 respondents returning the survey, all carried out some form of individualised assessment of their patients' self-management education needs although 12 of these 19 responded that their assessments were not standardised and did not consistently include "most self-management components." Three respondents replied that their assessments were standardised, fairly comprehensive, documented and taking account of patients' personal context (language, literacy levels, cultural context, existing levels of self-management knowledge). A further four indicated that their assessments of their patients' self-management education needs were an integral part of planned care and resulted in systemic documented reassessment.

Replying to a question concerning the extent of patient involvement, all respondents indicated that some patient involvement occurred. However, six responded that involvement was passive with only occasional patient input while a further 13 replied that involvement was either central to

decisions about self-management goals (nine respondents) or an integral part of the system of care, explicit to patients and accomplished in collaboration with health professionals taking into account environmental, family, work and community resources and barriers (four respondents). When asked how many of their patients with chronic conditions had self-management plans four responded "none", ten replied "few", three "many" and two "most."

Responses to other questions concerning patients' social support and links to community resources indicated that while all people surveyed took account of these issues to some extent, the majority were not able to engage in extensive assessment of needs or systematic and coordinated referral to social or community resources.

Overall, the survey results indicated that while most respondents did engage in one-to-one self-management practices only a minority were able to engage in the most comprehensive one-to-one self-management approaches with their patients.

Project Objective 3: Raise consumer awareness of chronic disease self management and local self-management initiatives

The project organised and held an information session open to consumers and members of the public to raise awareness of local chronic disease self-management initiatives in the area. This public information morning was held on Saturday November 21st 2009 at the Lawson Community Centre (close to public transport and wheel chair accessible) and involved presentations from health professionals on chronic disease and self-management as well as information on local support groups and the Moving On program about to be run in the area.

The project designed a nine question survey with assistance from the evaluation team to distribute to attendees before the information session began (Appendix Three). Twenty-nine surveys were returned from an estimated audience of 30 people. The audience consisted of mainly people living with chronic conditions but carers, health professionals, a Moving On leader and an Arthritis NSW employee also attended. Prior to information being given about chronic disease self-management at the session, the majority of attendees said they knew what self-management was and were already self-managing. When asked what they did to self-manage people responded with a range of activities including: managing medications and diet, exercising (including hydrotherapy) and regular visits/check ups with GPs. Most attendees were aware of the chronic disease support groups in the Blue Mountains with 20 people responding that they belonged to one of these groups. However, over half the people responding to the survey said they had not attended any chronic disease self-management programs.

The project also designed a six question evaluation form to distribute to attendees at the end of the information session (Appendix Three). Twenty eight surveys were returned. The majority responded that the session had met their expectations (24 people), that the content was presented at the right level (24 people) and relevant to them (21 people) although some only partially agreed that the content of the session was relevant (six people). Only one person felt that the content was not relevant. There was less agreement among attendees as to whether there was enough time for general discussion at the session, although over half responded that sufficient time had been given.

Most of the audience at the information session were members of Blue Mountains chronic disease support groups which may account for why respondents commented that they knew about self-management and were already self-managing. However, some of these people went on to participate in the Moving On program and, as section four illustrates, found that there was more to know and learn about self-management techniques and practices.

Some BMGPN staff commented that a longer lead in time and more advertising in local publications or at a range of community services or venues may have led to greater attendance by members of the public not associated with support groups or health services. The project coordinator also thought that "self-management" is not necessarily a concept that people immediately recognise or understand.

The project has made inroads in raising public awareness about chronic disease self-management through the information day, but also through the running of Moving On and the training of the

Moving On leaders. Comments made in individual interviews, and focus groups with Moving On participants, indicate that word of mouth dissemination of information about Moving On, self-management and Blue Mountains chronic disease support groups has occurred throughout the life of the project. It is very likely that the project can capitalise on this and continue to build awareness in the local area if it runs further Moving On courses in the future. The project coordinator was also of the view that regular editorials in the local newspaper discussing 'taking control of your health' and 'looking after yourself' rather than 'self-management' with each support group getting some focus would be valuable in keeping the topic current and continuing to raise community awareness of chronic disease self management in the area.

Project Objective 4: Raise chronic disease self management awareness amongst health professionals and increase referral to local self-management initiatives and health services by working with general practitioner membership of the BMGPN, health professionals and local pharmacists. Identify the needs of GP and health practitioners with regards to promotion of chronic disease self management in the Blue Mountains

Before the project began the BMGPN gained funding through General Practice NSW (a state based education and support organisation for the 33 Divisions of General Practice in NSW) to run an active learning module on chronic disease self-management. The project has promoted this event to Network members. Professor Gary Egger and Southern Cross University Health Promotion team, experts in the field, will run the session in late May 2010.

In order to assess chronic disease self management awareness amongst health professionals, assess their needs in the area, and increase referral to local self-management initiatives, the project used information gathered from the Chronic Disease Self-Management GP and Practice Survey 2009 (see Appendix Three). Sixty-five surveys were distributed to the Network's 65 GP members. Nineteen surveys were returned (29 per cent response rate). The project coordinator also visited Arthritis NSW to discuss and assess self-management needs and to get a general sense of the issues involved. Time constraints did not allow for the project to engage in workshop and interview work with GPs and practice nurses to further assess needs in the area.

As section Project Objective 2 has discussed, the survey results indicated that while most respondents did engage in one-to-one self-management practices only a minority were able to engage in the most comprehensive one-to-one self-management approaches with their patients. When asked how many of their patients participated in chronic disease support groups or self-management initiatives 15 responded "few" and three "many". One respondent said they didn't know. Asked if they consistently referred patients to chronic disease support groups or self-management programs or initiatives, ten respondents said they did not refer patients, four said they referred to support groups and five said they referred to self-management programs or initiatives. Referrals were made by letter, verbally, or paper-based information was given to the patient directly. Of those who did not refer patients, impediments to making referrals were given as: lack of information about resources available; changing criteria of eligibility; the complexity of patient's problem; patient lacking motivation to self-manage; cost to patient; patient too busy or lack of time. The most common response was lack of knowledge of information about resources (support groups and programs) available.

When asked how making referrals could be improved the majority said up-to-date information on resources that could be accessed on-line or computer-based templates would help. As Project Objective 2 discussed, the project is exploring the possibility of making a register of chronic disease self-management support groups and initiatives available on-line with a facility for regular updates by support groups themselves. However, the paper based register generated by the project and distributed to health professionals will, to some extent, address this issue. The provision of this register would assist health professionals in making referrals to self-management support groups and initiatives.

As previously discussed, the activities of the project generally, and in particular running Moving On, have played their part in increasing awareness of health professionals in the area. The project

coordinator visited most local practices to deliver Moving On pamphlets and fact sheets, giving a face to the project and promoting its activities. Those health professionals more closely involved or linked to the activities of the Network were more likely to know about the project and Moving On, particularly those who referred patients or who were involved with the CRG or the Network Board. Regular news items about Moving On and the project in the Network's monthly GP newsletter have also contributed to raising awareness. As with community awareness of chronic disease self management and support groups, word of mouth communication from those involved in the project within the Network has also increased awareness amongst health professionals and created a momentum that continuing Moving On could capitalise on.

The project coordinator was particularly aware of the time constraints on health professionals and how this not only limits their ability to assess patients' needs and refer to support groups or self-management initiatives but also makes it difficult to get their attention on an issue such as chronic disease self management and keep it "at top of mind." This presents challenges as to how to ensure self-management remains on the agenda for health professionals in the local area beyond the life of the project.

Project Objective 5: Identify access issues and barriers for the local community to participate in chronic disease self-management initiatives

Availability and proximity of public transport was identified by the project and the CRG as a potential barrier to consumers and members of the local community participating in self-management initiatives. To address this, in consultation with the CRG and the PWR, the project decided to run Moving On in three separate locations (Katoomba, Hazelbrook and Springwood) to reduce travelling times. The courses were run on both weekdays and weekends to give some choice of hours of attendance for participants, and so the program could be fitted in with participants' other responsibilities and commitments. Venues were chosen for their proximity to public transport, their accessibility (including wheelchair access), availability of parking and their comfort (e.g. air conditioning). Consumer needs were also taken into consideration by the project in providing tea and coffee and healthy food options.

BMGPN staff and CRG/PWR members also identified short lead in times to advertise or promote project activities, including Moving On, as an issue for raising awareness of self-management initiatives within the local community. Short timeframes for implementing project objectives were somewhat inevitable given the short duration of the project's running time. As discussed in Project Objective 3, the project coordinator also identified that use of the phrase "self-management" as a possible barrier to participation as it is not necessarily a concept that people immediately recognise or understand.

Time constraints, competing interests, and the lack of up-to-date information for health professionals to refer members of the community to local support groups and self-management initiatives was also identified by the project as a potential barrier to participation as Project Objective 4 discussed.

Other access barriers identified by the project and CRG included: cost (many participants of the Moving On program were pensioners or in receipt of other social welfare benefits so on limited incomes); lack of oxygen tank transport for people with C.O.P.D (Chronic Obstructive Pulmonary Disease) or lack of easily accessible toilets at venues. The CRG and the project compiled a list of access barriers for local community participation in chronic disease self-management initiatives. This was a project outcome for this objective.

Project Objective 6: Build on local activities to increase the long-term sustainability of local chronic disease self-management

The success of future funding applications to continue the CRG past the life of the project is pivotal to the sustainability of local chronic disease self-management initiatives in the area. The continuation of the work begun by the project coordinator and the Network in implementing the project would also be ensured by the establishment of an ongoing position focussed on self-management issues in the Network (or incorporating this agenda into the tasks of an existing position if limited resources do not allow for the establishment of a full-time position).

Plans to run Moving On again and possibly extend it to other groups in the community, such as veterans, Indigenous groups and groups in harder to reach lower socio-economic areas, are also essential to keeping up the momentum generated by the project, as well as sustaining and continuing to raise awareness amongst the local community and health professionals. The Moving On leaders (accredited to run Moving On courses for two years), the past participants of Moving On, the CRG and PWR members, and the local health professionals involved in the project to date are a valuable resource in terms of word of mouth communication about self-management. Many are enthusiastic advocates of self-management and involvement with local support groups due to their participation in project activities. Support groups involved in the project are also more aware of each other's activities and perspectives, the work of the Network and its numerous connections and links to a wide range of other health and community-based initiatives. The project has done well in generating these networks and connections between these groups and this will ensure some degree of sustainability beyond the life of the project. This synergy and resultant capacity building could also be capitalised on by the continuation and extension of Moving On in the local area.

The Objectives of the Project: Summary Remarks

The project met its stated objectives. It established a CRG to inform the development and implementation of the project along with the project coordinator. Evidence gathered from evaluation activities indicated that the CRG met its stated terms of reference, including to: provide advice and consumer input on activities and strategies of the project and its evaluation including the implementation of Moving On; to produce a register of chronic disease self management support groups and initiatives (Project Objective 2); produce a list of barriers to access (Project Objective 5) and assist with strategies to develop effective communication between GPs, health professionals, consumers and the wider community.

The CRG worked closely within the Network and local health professionals improving communication between these groups and the wider community (including advertising the public information morning and Moving On in the local newspaper, support group and BMGPN newsletters.) The CRG is continuing to work on funding applications along with the Network to establish the CRG on an ongoing basis. A permanent CRG would make a substantial contribution to the capacity building undertaken by the project and to the sustainability of local chronic disease self-management initiatives.

Project objectives related to raising awareness among community members and health professionals were also met. Raising awareness is a continuing process that requires further input on an ongoing basis. Feedback from the CRG and Moving On participants has indicated that the terms 'self-management' and 'chronic disease' are not necessarily recognised or understood by consumers and members of the public, even if some may be practicing self-management techniques. Consideration should be given to this when future promotional activities are being planned.

The activities of the project generally, and in particular running Moving On, have played a significant role in increasing awareness of health professionals, consumers and members of the local community in the area. Those health professionals more closely involved or linked to the activities of the BMGPN were more likely to know about the project and Moving On, particularly those who referred patients or who were involved with the CRG or the Network Board.

Time constraints on health professionals, due to insufficient numbers of GPs to service the local area, limited their ability to assess patients' needs and refer to support groups or self-management initiatives but also made it difficult to get their attention on an issue such as chronic disease self management. This presents challenges as to how to ensure self-management remains on the agenda for health professionals in the local area beyond the life of the project.

Other barriers to accessing chronic disease self-management initiatives identified by the CRG and the project included: availability and proximity of public transport; availability of parking; venue comfort and accessibility; knowledge of and dissemination of information about chronic disease self-management initiatives and support groups; and cost.

Word of mouth communication from those involved in the project within the Network or Moving On has also increased awareness and created a momentum that continuing to run Moving On in the local area could capitalise upon.

The continuation of the work begun by the project coordinator and the CRG within the Network in implementing the project would also be ensured by the establishment of an ongoing position focussed on self-management issues in the Network (or incorporating this agenda into the tasks of an existing position if limited resources do not allow for the establishment of a full-time position).

The 'Moving On' Program

Background

In 2004 Arthritis NSW saw a need to develop a local self-management program for people with chronic health conditions after licensing complications reduced the use of the Lorig model in NSW. This new self-management program was tailored to the Australian context and called Moving On.

Moving On provides people with information to self-manage their chronic conditions. Arthritis NSW conceived of a new self-management model by basing the new program on adult learning principles¹² (Appendix Four), introducing a health professional leader to minimise any potential harm and centring the program in the Australian context. Adult learning principles assume an individual is internally motivated and self-directed to change, drawing on life experience to make these changes through practical and relevant goal setting. Each Moving On module incorporated goal setting and problem solving elements.

The Moving On modules were designed in consultation with experts in each topic area and informed by the authors' professional expertise and personal experiences of managing a chronic condition. Moving On aims 'to help participants manage their chronic illness by challenging unhealthy behaviours and attitudes' while providing the knowledge and skills to support people to make positive changes. To achieve this aim the program is based on the stages of change model¹³ (Appendix Four), namely that participants are at or near the point to make and maintain changes. Underpinning the program is the belief that people with a chronic condition should be able to manage their condition safely by developing skills and knowledge about all aspects of their health such as understanding how the health system works, to have knowledge of and confidence in their medicines, and to be able to work proactively with their health-care team. A key feature of Moving On is the support given to participants to develop personal self-management action plans to share with their GP or other health professionals.

The Moving On program is structured into seven generic sessions conducted over seven weeks in three hour blocks. The sessions cover the following topics:

- An introduction to the program
- Managing fatigue and physical activity
- Healthy eating and leisure
- Coping with chronic illness
- Stress management, relaxation and getting a good night's sleep
- Working with your health care team and getting the most out of your medicines
- Putting it all together

Each Moving On session is facilitated by a health professional and a lay leader. The lay leader is someone with a chronic condition who can provide input from their personal experience and can provide a positive role model for participants. The health professional leader contributes their technical knowledge and skills plus ensures that information is evidence-based, verifiable and correct. Training on how to facilitate Moving On is run by Arthritis NSW. Support materials are integral to the program and include a participant's workbook, readings and a guideline for the leaders.

Moving On currently caters for older Australians. Arthritis NSW believes Moving On could easily be adapted for Indigenous Australians, people from culturally and linguistically diverse backgrounds and those from lower socio-economic groups.

The BMGPN and Moving On

In mid-September 2009 the BMGPN employed a coordinator three days a week to oversee the implementation of the BMGPN Chronic Disease Self-Management Project. The employment of the coordinator to implement Moving On pushed the program forward. The BMGPN and CRG's clear vision and outputs enabled the coordinator to quickly establish the steps required to inform the community about Moving On, recruit and train health professionals and lay leaders, recruit participants plus arrange and manage the logistics for the Moving On sessions. Three Moving On streams were organised according to location (Katoomba in the upper mountains, Hazelbrook in the middle mountains and Springwood in the lower mountains).

It was clear from discussions with key informants and focus group participants that the lead-time to implement Moving On was short and ideally more time was required in each step of the preparation process. Despite the lead-time constraint feedback showed that the coordination was conducted skilfully, respectfully and in accordance with people's needs. For example, different days and times were selected according to feedback, venues were chosen for comfort, accessibility and at locations convenient to public transport. Key decisions on all aspects of the program were made in consultation with the CRG.

The Moving On program was provided free. The leaders received some payment and the support materials for participants cost \$1100 for 15 sets. For future leader training or further Moving On sessions to be run some payment by participants may be required.

Participant Recruitment

Thirty-five people (26 women and nine men) enrolled in Moving On and 25 people completed the courses (19 women and six men). Participants were referred to the program through their general practitioner, the practice nurse or pharmacist. The Consumer Information Session, posters in pharmacists and general practitioners rooms, editorials in the Blue Mountain Gazette, information on the radio and targeted information to support groups and general practitioners were designed to inform people with a chronic condition about Moving On. Staff at the BMGPN used their networks and suggested to general practitioners that they could refer suitable clients to the program. It was suggested by the Moving On leaders that the BMGPN could be further utilized to recruit health professionals as referrers.

The post-program evaluation – 18 out of the 25 participants completed this evaluation – showed that the majority of participants were aged between 65 and 74 years (ten people) with the youngest participants aged between 35 and 44 years (two people). One person was aged over 75 years.

Participants were asked to name the chronic condition or conditions they were living with. While there was some similarity in the chronic conditions among the participants it was evident that everyone's situation differed. For example, 13 of the 18 respondents named two conditions or more while the remaining five named one condition. Two participants had the same condition while the other 16 participants' mix of chronic conditions varied.

Leader Recruitment

In response to a newspaper advertisement in the Blue Mountains Gazette for the lay and health professional leaders 90 inquiries were received for the leader positions. Twenty-six applications were received, 12 people were interviewed and eight selected. Of the eight people selected, four were health professionals and four were lay people with a chronic condition. While only six leaders were required eight were trained with two of the trained leaders being available if required.

The project coordinator and the Moving On coordinator from Arthritis NSW conducted the selection interviews. The health professional leaders chosen were able to demonstrate their professional health background, experience using adult learning principles with groups and knowledge of behaviour change principles. The lay leaders needed to be self-managing their chronic condition and have experience in group work and working with people. Both groups of leaders needed to show passion for the concept of Moving On, be self aware and have a desire to support others. Eight women were chosen to be leaders.

For the lay leaders becoming involved in Moving On was driven by their personal experience of managing a chronic condition. One leader commented that she has managed her chronic condition for over forty years and believed she could be a role model. Another lay leader commented that working in the health sector was a driver for her, "In my work in the hospital it is fantastic to see people self manage as opposed to always coming through as patients."

The health professional leaders were motivated by their professional knowledge of, and interest in, self-management and wished to extent their knowledge and experience. One leader was keen to meet community members and integrate into local networks while another leader was motivated by her experience living with a chronic condition as well as her professional background.

Learning about Moving On

The public information session held at Katoomba on 21st November 2009 explained self-management and outlined the Moving On Program. Out of the 30 plus attendees, 28 session evaluations were received with 15 people indicating that learning about Moving On was relevant for them.

Of the 18 participants in the Moving On program who completed an evaluation three had attended the consumer information session. Other participants heard about the program through their general practitioner (five), the BMGPN (five), or through their support group networks (five). Some learnt about the program through the radio or the newspaper. Four people heard about Moving On from one or more sources.

The Moving On Program

This section consolidates the experiences of participants, leaders and BMGPN staff of the Moving On program. Information was gathered from the participants' evaluation forms, the pre and post Moving On focus group discussions and key informant interviews with Moving On leaders and BMGPN staff.

Leader training

The leader training was conducted over two days by Arthritis NSW in January 2010. Once trained the leaders are accredited to run Moving On sessions for two years. Both the lay and health professional leaders complimented the two day leader training program. The key points of interest were: training by an author of the program, who "was passionate and knowledgeable"; opportunities to practice what was learnt; the opportunity to share and learn from the other trainees; and the focus on the stages of change model. The leaders also valued the integration of the experiences of health professionals and lay people in the training and how the trainers of Moving On leaders modelled the Moving On process. The two days required for the training was said to be an adequate amount of time, although intense with much material to cover and situations to role-play.

Both health professional and lay leaders did not know who they would work alongside until after the training. However, because of the integrity of the selection process it was said that all the leaders were compatible. Through the training of Moving On leaders a network was formed and the leaders have plans to regularly convene.

The Three Moving On Venues

Effort by the project coordinator to locate suitable venues, although they varied in comfort, was reflected in the participants' evaluation forms. All respondents found the venues to be convenient to get to and the majority thought that the access was suitable, the venue was comfortable enough and the catering suited their needs.

The Leaders from the Perspective of Moving On Participants

During the post-Moving On focus group discussion participants commented that the leaders were well-organised, informed and competent facilitators. The post-Moving On evaluation whole heartedly reflected these comments with all evaluations commending the facilitation skills of the leaders. The engagement of a health professional and a lay leader was highly valued.

The lay leaders' experiences of living with a chronic condition was said to engage participants by providing examples from their own experiences while the health professionals provided technical knowledge and validity. Both the lay and professional leaders commented that they had learnt a lot, enjoyed the sessions and would happily lead other sessions.

A mid-Moving On meeting enabled the leaders to share experiences and clarify process issues. Learning from this meeting led to some changes in the way the Moving On sessions were conducted.

The Group Dynamic

All participants in the Moving On sessions valued the use of adult learning principles, learning in a group situation, the leaders' supportive facilitation, the opportunity and space to have a voice, and be listened to, and the opportunity to make friends. Participants from each of the three Moving On streams complimented the open, supportive approach of the leaders and the development of a supportive group dynamic. As one woman said it was... "good to be accepted and acceptance was helpful" for her self-management. Another participant said Moving On "outweighed my expectations especially the diversity of conditions...and I was spurred on by others in the group."

The Moving On leaders commented that working in a group broadened participants' perspectives of the challenges for others and "helped an understanding about people in the world who are ill, but we may not see it." Tensions and difficult situations were monitored and resolved by the group and through responsive facilitation. From both the leaders' and participants' comments participants were happy to share personal stories and feelings. Humour was also mentioned by the leaders as a positive aspect of the group dynamic.

It was evident in the post-Moving On focus group discussion that participants were brighter, more open and highly supportive and understanding of each other's situation. A common theme throughout this discussion and the post-Moving On evaluations was the significance of being in a situation where participants had a variety of chronic conditions and in many cases multiple conditions. The fact that Moving On was a generic self-management program enabled people to understand the complexities of other peoples' lives, showed how others coped, what resilience strategies people used and reminded participants that their condition did not need to isolate them. As two participants said, "the impact of having others coping with similar or related issues let me see I'm not unusual or alone", "It's always good to hear other ways of dealing with your problem in an understanding environment." In one group a positive dynamic enabled a younger participant to "come to the realisation that she was no different from the rest of the group" and that others also managed multiple chronic conditions. In another group, "one woman was isolated and coming to the group made her realise it ... self disclosure could have been hard yet the group made it easier because they supported her."

Participants in the largest group (13 people) said the group was "intimate" despite the numbers and that they "made good friends," and that these friendship were a "wonderful thing." A number of participants have established informal monthly meetings since the program. A book group was also established and contact details exchanged among some participants.

Moving On Content

Readings and the Workbook

Overall the readings and workbook were a useful and well presented resource. The workbook personalised the material, was a useful tool and easy to read. The materials were read by the majority of participants (14) and some participants' partners. Five of the eight focus group participants completed the readings at some stage of the program. Often the readings were used as a reference, for example, one participant referred back to the healthy eating module for guidance while watching a weight loss television program. Most participants did not complete the readings prior to the sessions with some preferring to read the material after the session. The workbook was actively used by some participants and marginally by others.

There was a lot of material available and the leaders commented that it was difficult to complete the course content in the time available. The amount of reading was considered too much and at times too difficult to absorb, especially the module on 'getting the most out of your medicines'. Some participants and leaders described readings as repetitious, and using flowery language and too many words.

Participants often asked in-depth and technical questions and consequently the leaders needed to expand upon the readings and information in the workbook. For example, one leader conducted a quiz to check participants' knowledge of food groups after speaking to an external nutritionist. Leaders also provided extra handouts on specific information and books on nutrition and relaxation. In the post-Moving On evaluation all participants rated the information provided by the leaders during the workshop as useful.

Participants believed that the emotional challenges linked to having a chronic condition, in particular depression, were not addressed to the required depth. While depression was discussed in the session under 'coping with your emotions' more time and information on emotional and mental health and wellness was suggested. It was also noted by leaders and participants that some participants used or were interested in alternative therapies and that this topic area should be covered in the Moving On program.

For many participants the educational aspect of the program was less important, or less interesting, than activity-based practical learning such as how to use a pedometer in the physical activity session. Some participants and leaders also commented that parts of the program were considered to be prescriptive, that more group work would have been beneficial and that more time for participants to share their experiences needed to be factored into the Moving On sessions.

Other content areas that were identified as missing from the Moving On resources are as follows:

- A list of chronic condition support groups, activity programs and other community resources available in the Blue Mountains.
- More in-depth information about local support groups.
- Information on what social services packages are available for someone with a chronic condition on a limited income, for example the home modification service. It was suggested an eighth session could cover this topic.
- A session on enjoying quality of life with your partner and/or carer (see also *Family, Friends and Social Support*)
- The inclusion of different tools to support self-management such as an activity journal.

Goal Setting

Overall the concept and practice of goal setting was useful for participants in different ways. For example, one participant was aware he had not reached a goal, but was always mindful of reaching it. For some goal setting was a part of their life already while others needed to be reminded of what

a goal was. The continual focus on goal setting was considered repetitive and at times laboured by some. It was noted in the project evaluation forms of Moving On that goal setting does not necessarily bring about behaviour change.

By the end of the Moving On program participants said they understood the purpose of the goal setting approach, yet the speed with which all the different modules were brought in the 'pulling it all together' session was considered too fast. Some participants and leaders also commented that more discussion about the end action plan should have been incorporated at the outset of the Moving On to clarify for participants the overall aim of the program.

The Action Plan

During the final Moving On session participants had the opportunity to complete their action plan and give it to the leaders to pass on to the participants' general practitioner or other referring health professional. Some participants preferred to reflect on, and complete, the action plan in their own time. These participants also wanted ownership of the action plan and to share it with their general practitioner personally. Out of the 18 post-Moving On evaluation forms completed, 13 participants said they would share the action plan with their general practitioner, five with another health professional and five with a family member or friend. Three participants in the focus group discussion did not feel confident to share their action plan with their general practitioner and questioned if a general practitioner was the best person in a health care team to work with on their action plan. One participant believed that her general practitioner thought it was good for her emotionally, but it was not his business. Another said while her general practitioner was encouraging s/he was busy and that the patient could work on her own goals. A third had taken her action plan to the general practitioner who browsed it and returned it commenting that "it was more relevant for her than him." Many in the focus group had not yet discussed the plan with their general practitioner.

Participants and Moving On

Motivation

Participants were personally motivated to participate in Moving On for self-education and to assist them to adjust to the challenges that living with a chronic conditions presents. As one focus group participant summed it up prior to the program beginning, "I have a chronic disease and I am interested in knowing how to live." One participant felt coerced by her general practitioner to attend the program. However the leaders of her group observed that she benefited from the sessions.

Thirty-five people began the program with ten participants (seven women and three men) either not commencing or completing the sessions. The reasons for not completing the course ranged from child care demands to ill health. A man who was enrolled by his wife did not complete the course because of a lack of interest.

Expectations of Moving On

Focus group participants were asked what their expectations of Moving On were prior to the program beginning. One woman responded that she did not know, but believed that there must be things to learn because "I don't think anyone stops hoping for something." Another participant commented that "we will learn something new and reinforce what we already know." It was also said that "it's not just what we learn, but the support for each other."

The post-Moving On evaluation form also asked what participants' expectations were prior to attending the program. Along with the expected learning, reinforcing of knowledge and mutual support already mentioned participants expected Moving On to: provide an opportunity to share ideas about coping with a chronic condition; be offered assistance on how to deal with specific conditions; encourage better self care; help improve partner relationships; assist relaxation and assist with recovery from surgery. A number of people (seven) had no expectations as they did not know about Moving On or had never participated in a similar program before. The project evaluation forms showed that overall Moving On met participants' expectations with eight people saying that the program exceeded

their expectations and eight stating that the sessions 'very much' met their expectations. Participants praised Moving On and examples of the general response were " a great well-balanced, informative and comprehensive program" and "the program covered much more than I expected."

The leaders indicated that participants' expectations of the program was a 'you will tell us' approach as opposed to interactive learning from each other.

Self Management

Prior to participating in the Moving On program participants returning evaluation forms rated their self-management skills as good in some areas (12 people), as having skills in many areas (four) while two participants said they had basic skills only. After participating in the program there was a noticeable shift with participants rating themselves as having better self management skills with 12 rating themselves as skilled in many areas and eight as having good skills in some areas.

Participants identified that while they knew about self management prior to participating in Moving On they did not have the skills to apply their knowledge. As one participant commented, "I have been very interested in the field of preventive medicine and optimum health for many years, but [am] very poor at applying it." Another participant observed that to be skilled in the many areas of self-management "I must work on the implementation, although I now have more knowledge and self awareness to tackle this."

Self managing a chronic condition was described in the focus group discussion held prior to Moving On as "pretty challenging because whenever you do anything you have to think what I am going to need? ... sometimes it's frustrating and when you get overcommitted things start to fall apart a bit." Participants who had reached a self-management plateau prior to Moving On were re-invigorated by the program. Moving On sharpened participants' existing self-management techniques while providing them with new knowledge and skills. As noted by one participant "my existing range of skills has been re-enforced and expanded." Another commented that "I already had much of the information, but I am more mindful of what I do." In key informant interviews the Moving On leaders also observed that those experienced in self-management benefited from the program.

As well as giving participants the opportunity to learn about or review their self-management practices Moving On gave participants the confidence to re-focus and change these practices as required. For some participants realising they could change how they managed their chronic condition and gaining the confidence to make a positive change was critical. Participants in the post-Moving On focus group observed that Moving On gave you confidence to move yourself, I saw the change ... I was not happy – Moving On came at a good time for me and helped me... to make some decisions I needed to be aware and address the right thing for me and find a balance between work, life and family."

Changes Observed and Perceived

A number of participants implemented changes through the Moving On program. One commented that now there "was nothing left to work on." For others the goal setting was a tool they used consistently through the sessions to help them map the steps they were going to take. One person set a goal in the first session to try and reach a healthy weight, "I went home and worked out my BMI [body mass index] and wrote down my current weight. I weighed myself yesterday and I have loss nine kg. Success!"

The leaders observed that participants moved from a position of gaining knowledge to asking "what we do next ... what we can do with this knowledge". Participants' confidence gain enabled them to look at a problem in new ways. The use of positive language by the BMGPN and leaders, a positive group environment, plus a focus on turning negative statements to positive was said to support participants to look at "what they can do ... not what they can't."

Changes came about when participants realised there was another option. For example through Moving On one woman realised she was isolated and decided to make things happen for herself and enrolled in a class to assist her self-management progress. Practical tools such as a sleep diary helped

some participants understand their sleep patterns more clearly and make changes as necessary.

Quality of Life

Participants experienced improvements in themselves and their life-styles because of Moving On. In the post-Moving On evaluation forms all respondents said that the program had helped them to identify what influences their health and quality of life. The switch to a more positive attitude towards managing and accepting their chronic condition was said to come from a supportive group environment and being accepted. Interacting with others with chronic conditions assisted in boosting participants' confidence, to not feel guilty about their chronic condition and gave them the knowledge that they did not need to be isolated. The leaders gave examples of participants who had multiple chronic conditions and/or were in pain yet kept on smiling. The leaders also noticed that having time to reflect enabled participants to slow down and take time to determine their next steps.

Participants were said to be empowered to make a change in old patterns and improve the quality of their home life by communicating with a family member or partner more effectively. For others the goal of engaging in a physical activity has taken them back to exercise classes, even when their chronic condition prevents them from fully participating in the class.

The social aspect of the program was important to participants and being affirmed by the group was seen to improve peoples' well-being. Making new friends and social networks improved the quality of life for some while others cited improvements because they accessed different therapy groups or programs suggested through the program. Sharing personal information and experiences of managing a chronic condition was also said to help improve daily living.

Some participants' goals were not focused on managing their chronic condition, but improving their lifestyle, for example, one participant's goal was to sew again. For another participant - whose partner and carer attended the program – communicating more positively with her partner was said to improve their life as they were both stimulated to make a change.

Using positive and practical problem solving techniques assisted participants to look at how to improve their lifestyle. For example, one participant felt unable to continue gardening but with support from the Moving On leaders she was able to redesign her gardening beds to enable her better access. Another woman found that using a diary to organise daily commitments has already made improvements in her busy life.

Family, Friends and Social Support

It was evident in both the pre and post-Moving On focus group discussions that participants' expectations of their spouse or partner were a concern to them. The impact on their partners (who may also be their carers) was central to participants' lives. While participants acknowledged the support of those close to them some said their families were not interested in their chronic condition or their experience of Moving On.

Participants acknowledged that it was difficult for their partner or spouse to understand and respond to the needs associated with their chronic condition every day. It was commented that while family members listened to the challenges of living with a chronic condition family members could not truly understand, or were too busy, to provide support. However, the program allowed time for participants to reflect on the difficulties of being a carer or living with someone with a chronic condition. A story was recounted whereby a participant deliberately thanked her husband and acknowledged his input and support. This action eased the tension between them.

In one Moving On stream where a participant and her carer (who in this situation was also her partner) attended it was observed that communication between the two became easier as the sessions progressed. While this situation raised questions about the suitability of carers and partners attending the same session it validated the relevance of Moving On for carers and partners. As mentioned above a session on enjoying life with your partner would be beneficial (see *Readings and the Workbook*).

When a person's chronic condition is in the acute stage family, friends and community support is readily available. When a person's condition is not visible, support and understanding is less forthcoming. Participants tended not to talk to friends about their condition because of a lack of understanding. As one participant explained, "most of the time I feel alright, but sometimes I do not feel alright and a lot of friends say, but that [the accident/treatment/illness] was ages ago. They don't understand ... it is frustration as the expectation is that I am alright, but I am not." As another participant commented "because you look okay, they seem to think you are okay." Families were often dismissive of a person's chronic condition as were partners with participants commenting that "others did not understand...or really listen." In the post-Moving On focus group discussion participants commented that they had new friends from the program and for some, "family" now.

From the pre and post Moving On focus group discussions it was evident that chronic condition support groups are highly valued. Support groups are popular because people with a chronic condition "can meet with no judgment ... we all understand each other so it is wonderful."

Relationship with the Health Care Team

For someone with a chronic condition interactions with health care professionals are necessary and often exacting. For all participants interacting with health professionals was generally challenging including: finding a responsive professional; accessing consulting rooms; and being able to comfortably sit in waiting rooms and to be able to communicate effectively. Moving On provided a space where people could share good and bad experiences of the health care system and providers, and find solutions.

Some members of the pre-Moving On focus group discussion found communication between health professionals was often lacking and access to health professionals difficult. One participant however found their general practitioner and specialists communicated regularly and appointments were productive. From responses on the post-Moving on evaluation forms it was evident that Moving On had enabled participants to share information about how they interacted with the health system, in particular their general practitioner. Issues of accessing allied services, trust, communication, being heard and understanding medications were some of the areas where information was shared and valued.

The Moving On sessions assisted people to engage with new health professionals if they were dissatisfied with, or wanted to extend, their current care. Participants in the post-Moving On focus group described self-management and working with their health professionals as "needing to ask the general practitioner to do things ... and to take the initiative ourselves."

Two general practitioners interviewed supported the Moving On initiative especially as they saw "people trying hard and not succeeding" to self-manage. Both these general practitioners supported people having good skills to self-management their chronic conditions. It was evident in the interviews that these general practitioners have a high case load, continually deal with crisis cases, and generally do not have the time to discuss self-management of chronic conditions in the standard 15 minute appointment. These general practitioners had not yet seen a Moving On action plan, but considered them to be useful.

Moving On: Summary Remarks

The response to the Moving On program by participants, leaders and staff at the BMGPN was overwhelmingly positive. An informative, well-thought out program, technically skilled health professional and lay leaders with personal experience in self-managing a chronic condition set a positive tone for the Moving On sessions. A cohesive environment was underpinned by proactive and responsive coordination by the BMGPN while collaborative interactive processes provided positive opportunities for group learning, and a space to think, reflect and practice new skills. Difficult situations in the Moving On sessions were dissipated through good facilitation or monitored and resolved by the group.

Sharing the challenges and successes of self-managing a chronic condition, or a number of chronic

conditions, with others in a similar situation prompted shared understanding, new learning, the uptake of new activities, group support and social networks. Sharing experiences in a supportive group environment also boosted people's confidence and reduced participants' isolation and feelings of despair. The relevance of the sessions for participants who were managing their chronic condition, or conditions, was well evident.

These participants valued the reiteration of knowledge, new knowledge, new skills and new tools. Participants have recommended the program to both family and friends and the leaders would happily facilitate more sessions.

The Moving On program exceeded participants' expectations with participants noting a marked improvement in their self-management practices. The leaders also observed progress towards, or changes in, participants' self-management practices. The challenge for participants will be to adhere to their self-management action plans and build upon and maintain their self-management progress. Communicating self-management needs and progress, plus being supported by a general practitioner or health care team, will be important to help maintain the momentum of Moving On.

While the program content and course materials met participants' and leaders' needs these materials were considered dense, at times overwritten and repetitive. Covering the course content in the time available was difficult when ensuring participants had time to interact and share their experiences. Participants and leaders identified areas in the program that could be extended such as how to communicate with your general practitioner, complementary therapies, enjoying quality of life with partners and carers and mental health and wellness – in particular depression. More information on practical tools, support groups and social service packages would also enhance the program. The generic focus of the Moving On, as opposed to being focused on a specific chronic condition, is noteworthy.

Addressing relationship complexities – with a partner, carers, family, and friends – surrounding living with a chronic condition or conditions will be ongoing for participants. These relationship complexities are exacerbated by the invisibility of many chronic conditions and the general misunderstanding about chronic conditions and the daily challenges these conditions present. Support groups – either formally organised groups or informal social networks - are critical for people living with a chronic condition to share how to cope with and address such complexities. While Moving On provided a space for participants to start to explore how to improve relationship dynamics, ongoing opportunities to further this aspect of health and wellness could be considered. The six month post-Moving On focus group discussion will explore the progress and maintenance of participants' self-management, the value of their action plans, and discuss the on-going impact of Moving On on their quality of life including their relationship with their health care team, their partner, carer, family and friends.

Recommendations/Next Steps

The experience of implementing the Moving On program in the Blue Mountains raises the following considerations for the BMGPN and Arthritis NSW in regard to the on-going development of the program and its sustainability.

1. It is suggested that the value of action plan is reviewed with general practitioners as well as the focus group participants in October 2010 to assess if the action plan worked or not. It would be pertinent to find answers to the following questions:
 - Is the general practitioner the best person to work with on the self-management action plan?
 - Are there other members of the health care team who are suitable, and available, to work with an individual on their self-management action plan.
2. The workbook and readings are valuable resources. However, as 'living and responsive documents' they could be further developed. Considerations for further development include the following points.
 - The inclusion of more information on:
 - Mental health and wellness
 - A list of chronic condition support groups, activity programs and other community resources available in the Blue Mountains
 - Available social service links and packages
 - The inclusion of a section on:
 - How to enjoy quality of life with your partner, spouse and/or carer
 - The pros and cons of alternative therapies
 - The reduction in repetition and the amount of reading
 - The inclusion of more suggestions for practical self-management tools
 - The attendance of a local general practitioner to discuss the situation from their perspective and how they can assist with self-management
3. It is suggested that the language uses in Moving On is reviewed to replace language denoting illness and sickness to more neutral terms, for example, chronic condition and not chronic illness.
4. As signalled by Arthritis NSW Moving On is currently designed for middle Australia. There are plans to extend it to other people living with a chronic condition in the Blue Mountains and to other areas in NSW and Australia. It is worth considering that Moving On could be endorsed for use in residential facilities (such as nursing homes, community centres and hostels).
5. Consideration will also need to be given to how to adapt the program for different groups such as:
 - Lower socio-economic
 - Indigenous
 - Culturally and language diverse

- Young adults, teenagers and children
- Carers and/or partners and spouses

It may be that Moving On establishes links with other organisations, programs or experts in these fields who provide input to the Moving On program or one-off information sessions where appropriate, rather than the program itself addressing or absorbing all these diverse interests and perspectives.

Adaptation may involve specific activities for different groups, the development of applicable support materials and the training of health professional and lay leaders from each group, including older children and teenagers as role models or leaders.

6. Consideration could also be given to gender demographics and chronic conditions. An evidence-based understanding of why more women than men were involved in Moving On as leaders and participants would assist when developing strategies targeting self-management and those living with a chronic condition. It may be worth considering how to tailor Moving On to engage men in general, especially those living with a chronic condition, who may not access prevention or treatment services.
7. In October 2010 participants and leaders will meet socially. It is worth considering a facilitated session to review how people's self-management is progressing, encourage motivation and provide any essential support.
8. Sustainability
 - Sustainability of participants' behaviour change. The changes made by participants will be reviewed in October 2010

Overall program sustainability

All project objectives, including those related to raising awareness among community members and health professionals, were met. The activities of the project generally, and in particular running Moving On, have played a significant role in increasing awareness of health professionals, consumers and members of the local community in the area.

Raising awareness is a continuing process that requires further input on an ongoing basis. Feedback from the CRG and Moving On participants has indicated that the terms 'self-management' and 'chronic disease' are not necessarily recognised or understood by consumers and members of the public, even if some may be practicing self-management techniques. Consideration should be given to this when future promotional activities are being planned.

Word of mouth communication from those involved in the project within the Network or Moving On has also increased awareness and created a momentum that continuing to run Moving On in the local area could capitalise upon.

The CRG is continuing to work on funding applications along with the Network to establish the CRG on an ongoing basis. A permanent CRG would make a substantial contribution to the capacity building undertaken by the project and to the sustainability of local chronic disease self-management initiatives.

Time constraints on health professionals, due to insufficient numbers of GPs to service the local area, limited their ability to assess patients' needs and refer to support groups or self-management initiatives and also made it difficult to get their attention on an issue such as chronic disease self management. Consideration should be given to strategies that would ensure self-management remains on the agenda for health professionals in the local area beyond the life of the project.

The continuation of the work begun by the project coordinator and the CRG within the Network in implementing the project would also be ensured by the establishment of an ongoing position focussed on self-management issues in the Network (or incorporating this agenda into the tasks of an existing position if limited resources do not allow for the establishment of a full-time position).

Addendum: Focus Group with Moving On Participants Six Months after the Completion of the Program

A focus group was conducted with Moving On participants six months after the conclusion of the program. Six of the same participants who had taken part in the earlier two evaluation focus groups took part in this final focus group discussion (see *Focus Group Discussions with Participants of the Moving On Program*). Two participants from the previous two focus groups could not attend. The main purpose of this final focus group was to gain overall impressions of Moving On six months down the track, including aspects most remembered by participants, but also to follow up on the use of Moving On action plans.

This final focus group found that overall Moving On was successful at providing enduring effective self-management information, strategies (realistic pragmatic goal setting) and also broader social support. Focus group participants talked about a number of different aspects to Moving On. While the step by step pragmatic goal setting and session specific information stuck in some people's minds, for example information about nutrition and healthy eating, it was the more general aspects of Moving On that were most often identified as enduring, those things that six months later still stuck with participants about Moving On. These included:

- acceptance of self and of one's illness;
- increased self-confidence;
- 'inner strength';
- 'inspiration';
- motivation;
- the value of sharing a range of things, both health and non-health related;
- an increased awareness of others with chronic conditions who may be 'worse off' (sicker, more disabled or in more pain); and
- the value of lay leaders in co-facilitating program sessions.

For some, Moving On had given them what they described as inner strength. One participant explained Moving On had allowed her "to be more forceful to get health professionals to do their job". Others described this or similar sentiments as having greater self confidence or being enabled to speak up for oneself. For one participant this had a motivational aspect as well, as she put it, "to get it together again". For another person the inner strength aspect was tied to knowing she was not the only one dealing with chronic illness. As she said:

I must admit, having done this [Moving On] and meeting up with people, it gives you a strength, an inner strength, of knowing you're not the only one. Other people are battling these similar things and to try and keep that perspective.

For others, Moving On had given them the benefit of feeling they were not alone, of getting together in a group and sharing experiences, whether specifically related to living with chronic illness or not. As one person put it:

The fact that people wanted to get together. I think that's a great thing. I suppose you'd call it group therapy I suppose. But just the fact that everyone has their pain and their problems and that type of thing. And it is great just to share. Doesn't matter what it is, how big, how little, whatever.

Another aspect of Moving On that participants discussed was the use of lay leaders in co-facilitating program sessions. Several participants noted that they valued the empathetic input of the lay leaders because they had personal experience living with chronic illness, as one participant put it, the lay leaders "weren't outsiders telling you what to do."

Action Plans (see also *The Action Plan*)

During the final session of the Moving On program participants had completed an action plan that identified both short and long term goals for managing their chronic illness. Steps taken to reach these goals were also outlined, as were barriers to making the change, triggers for unwanted behaviours and ways to minimise or eliminate these triggers.

In the final focus group discussion participants were asked about the progress of their long term goals, the value or otherwise of the action plan in this process, and whether their GP or other health professional had seen or been involved in discussing their goals or action plans.

For three participants in the group serious new medical problems not related to their chronic illnesses had overwhelmed them since completing Moving On so using their action plans or achieving long term goals had been low on their list of priorities. However, for three other participants the action plans had proved useful. One person had made a long term goal, noted in her action plan, to plan and carry out regular exercise two days a week. She was happy that she had achieved this goal and was working towards increasing regular exercise to three days a week. The action plan had also assisted the practice nurse at the general practice she attended to develop a care management plan as part of an Enhanced Primary Care package.

For another participant long terms goals had included finding alternative pain relief to morphine based medications, improving health and fitness and returning to Tai Chi classes. By the second focus group (immediately after completing the Moving On program) she had stopped using morphine based medication and by the final focus group this change had been maintained. The return to Tai Chi had been a longer journey as conventional Tai Chi classes had proved too difficult for muscles weakened by surgery. However, this participant is now doing a modified version of Tai Chi so has achieved this goal. After discussion with her GP, prompted by the Moving On action plan, it was suggested she use a TENS machine to relieve pain as an alternative to medication.

Another participant had seen a practice nurse at the general practice she attended and used the Moving On action plan to get a referral to a nearby hospital pain clinic. This had been on advice from a Moving On leader. She had visited a chiropractor four or five times also prompted by her action plan. This participant had suffered loneliness and isolation before attending Moving On. By the second focus group (immediately after completing the Moving On program) this situation had been significantly alleviated and by the final focus group this change had been maintained with the participant also joining a choir to keep up social contacts and to relieve and/or take her mind off her ongoing pain.

Post Moving On Survey of GPs and Practice Nurses

A brief survey (see Appendix Three) was faxed to GPs and practice nurses in the local area in October 2010, six month after Moving On had been run. Fifteen practices responded. Of these, four practices had a total of seven patients who attended Moving On while ten practices reported they had no patients who had attended the course (one respondent was unsure whether any of their patients had attended or not).

Of the four practices with patients who had attended Moving On, one practice had three patients attending, another had two patients attending and two further practices had only one patient attending.

The practice with three patients who attended Moving On reported that the course's action plans had been seen and discussed with these patients and that this process had helped in the management of the patients' chronic conditions. This respondent also commented that discussing Moving On goals and/or action plans with patients had given a greater understanding of chronic disease, assisted both the health professional and the patient in better understanding their respective roles and that this

allowed the patient to take on some of the responsibility for the management of their illness which in turn helped health professional and patient.

While the practice with two patients who had attended Moving On reported that action plans and Moving On goals had been discussed with patients this had not been particularly helpful in the management of chronic disease as similar discussions had already taken place with these patients.

Of the two practices with one patient who had attended Moving On, both indicated that action plans or Moving On goals had not been discussed with these patients. However, one respondent commented that the patient had reported that while the course "was great" she probably would not put Moving On goals into action as she had "a lot to tackle in the immediate future."

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Appendix One: Individual Interview Schedules

Interview Schedule for Blue Mountains GP Network Chronic Disease Self Management Project staff

1. History and specific details and processes of the policy development and implementation process behind the Chronic Disease Self Management Project
2. Barriers and facilitators to the implementation, both organisational and with regard to specific roles

Did the setting/context have an impact, if so what?

Coordination of the project
3. Ways of sustaining chronic disease self management programs and strategies in the region

Interview Schedule for Blue Mountains GP Network Chronic Disease Self Management Consumer Reference Group, Professional Working Group members and GPs

1. Why members first became interested in participating in the project
2. Participation in chronic illness support groups before and during the project
3. Chronic illness support group referral processes (how members contact and/or are recruited to support groups and programs);
4. Barriers and facilitators to the implementation of the Chronic Disease Self Management Project

Did the setting/context have an impact, if so what?
5. Ways of sustaining chronic disease self management programs and strategies in the region
6. 6) Value of CRG/PWG – felt consulted? Process valuable and worthwhile or ‘just attending a meeting’

GPs Only

1. Chronic illness support group referral processes (how patients are referred to other health professionals, allied health, pharmacists, chronic disease support groups and programs)
2. Perception of self management and Moving On, do some patients already do it?
3. Do they have any patients who have participated in Moving On, of so, have they noticed any changes and what are they?
4. Sustainability of self management behaviour changes

how to support/maintain behaviour change (care plans)

links to health care environment,

role of family, carers, friends

Interview Schedule for Blue Mountains GP Network Chronic Disease Self Management

'Moving On' Facilitators (Health Professionals and 'Lay Leaders')

1. motivation to become a leader
2. the effectiveness of the training process of Moving On
3. Moving On - what worked best and why, what didn't work so well and why?
Workbook
Readings
Course - running it, for people attending, and for associated social activities (groups, outings etc)
4. Did you note changes in the participants, if so what?
knowledge acquisition and its relationship to behaviour change(enablers and barriers to behaviour change, support to continue/maintain healthy behaviours)
5. Any change in social support and quality of life from participating in the Moving On program?
6. How satisfied with Moving On were the participants?
7. Would you do it again?

Appendix Two: Focus Group Discussion Guides

Focus Group Schedule for Blue Mountains GP Network Chronic Disease Self Management Project – Participants of the Moving On program

(pre-program focus group)

1. How are you managing your illness at the moment?
(What do you do to manage your illness at the moment?)
2. Are you self-managing? What does self managing involve?
3. Experience of living with and/or managing chronic illness
 - medication
 - exercise
 - sleep
 - nutrition
 - coping
 - setting and attaining goals
4. Who, if anyone, has been involved/supported your self management?
 - doctor
 - pharmacist
 - peer/friend
 - family/carer
 - allied health
 - social worker
 - support group
 - other
5. How is behaviour/lifestyle change maintained/ supported
(support networks? referral networks?)
6. Knowledge acquisition (information) and its relationship to behaviour change
 - enablers and barriers to behaviour change
 - support to continue/maintain healthy behaviours

Focus Group Schedule for Blue Mountains GP Network Chronic Disease Self Management Project – Participants of the Moving On program

(post-program focus group)

1. Moving On - what worked best and why, what didn't work so well and why?

Workbook – goal setting, problem solving, how helpful or not

Readings

Course – leaders (health prof vs lay), associated social activities (groups, outings etc), social vs info evening?

relationships and chronic illness (carers/spouses attending, splitting spouses, spouse also has chronic illness)

2. Changes in the participants, if so what?

personal motivation to change

knowledge acquisition and its relationship to behaviour change(enablers and barriers to behaviour change, support to continue/maintain healthy behaviours)

spouse with same/diff chronic illness- barrier/support?

3. Any change in social support and quality of life from participating in the Moving On?

support groups, eligibility rules, enabler for change?

4. How satisfied with Moving On were the participants?

5. Was the course what you had hoped for? (expectations fulfilled?)

6. Would you recommend Moving On to others?

Appendix Three: Project Surveys and Evaluation Forms



Please help us better meet your needs by filling in this anonymous survey BEFORE the session begins.

1. Are you living with a chronic condition?
 a carer?
 a Health Professional? Please specify

other? Please specify
2. What are your expectations for today?

3. Do you know what **chronic disease self-management** is?
 Yes. Please go to question 4. No. Please go to question 6.

4. If you are living with a chronic condition, do you self-manage?
 Yes. Please go to question 5. No. Please go to question 6.

5. Please list 3 ways that you self-manage: (1)
(2)
(3)

6. Are you aware of **chronic condition support groups** (eg local branch of Diabetes Australia - NSW) **or programs** (eg CALM – Chronic Airflow Limitation Management) in the Blue Mountains?
 No. Please go to question 7.
 Yes. Can you name any?

7. Do you belong to any chronic condition support groups?
 No. Please go to question 8.
 Yes. Which ones?

8. Have you ever attended any chronic condition self-management programs (eg CALM)?
 No. Please go to question 9.
 Yes. Which ones? **Thank you.**

9. Can you tell us why you haven't attended a chronic condition support group or self-management program in the past?
.....
.....
..... **Thank you.**

Evaluation Form

Information Session

21 Nov 2009

1. *How much do you agree with the following statements? (Place a tick against Disagree, Partially agree or Agree. Use the lines below to provide more information if you wish)*

- a. This information session met my expectations
- b. The content of the session was relevant to me
- c. The content was presented at the right level
- d. There was enough time for discussion generally
- e. The venue was suitable, accessible and comfortable

Disagree Partially Agree
Agree

(Optional) More information

2. *What part of the session was most relevant to you?*

- Presentations from health professionals
- Finding out about local self-management support groups
- Learning about the new *Moving On* program
- Hearing from a past participant and leader of the *Moving On* program
- Other, please specify _____

3. *What have you learnt about self-management today?*

4. *Is there anything from today that you are likely to follow up and do? If so, what?*

5. *If you live with a chronic condition, what do you need help with most in managing your condition?*

6. *What is the single most important improvement that could be made to chronic disease self-management in the Blue Mountains?*

Thank you for completing this evaluation form – please hand in before you leave

CDSM GP and Practice Nurse Survey 2009

Name: _____ (optional)

Characteristic	Please indicate to what extent these activities occur in your practice (place an X on the scale for each characteristic)		
1. Individualised assessment of patients self management education needs	... is not done	...is not standardised and or does not consistently include most self management components	...is standardised, fairly comprehensive and documented prior to initial goal setting; takes into account language, literacy and culture; assesses patient's self management knowledge, behaviours, confidence, barriers, resources and learning preferences
<i>Place an X:</i> 2. Patient involvement	...does not occur	...is passive; clinician or educator directs care with occasional patient input	...is an integral part of the system of care; is explicit to patients; is accomplished through collaboration among patient, team members and physician, and takes into account environmental, family, work or community barriers and resources.
<i>Place an X:</i> 3. Patient social support	...is not addressed	...is discussed in general terms, not based on an assessment of patient's individual resources	...systems are in place to assess needs, link patients with services and follow up on social support plans using household, community, or other resources.
<i>Place an X:</i> 4. Linking to community resources	...does not occur	...is limited to a list or pamphlet of contact information for relevant resources	...system in place for coordinated referrals, referral follow up and communication among practices, resource organisation and patients.

Based on the Robert Wood Johnson Diabetes Initiative, March 2006

5. How many of your patients with a chronic disease **participate** in chronic disease support groups or self-management initiatives?
 None Few Many Most Don't know
6. How many of your patients with a chronic disease have a **self-management plan** in place?
 None Few Many Most Don't know
7. Do you consistently **refer** patients to chronic disease support groups or self-management programs / initiatives?
 No – go to Q.8 Yes – support groups Yes – programs/initiatives
 How do you make these referrals? _____
8. What are the impediments to making these referrals? _____
9. Can you see a better way of making these referrals? _____



Thank you. Further comments welcome on a separate page.
 Please fax back to Serena at Blue Mountains GP Network on Fax: (02) 4758 9722



Evaluation Form

Moving On: Katoomba Program

February – March 2010

ENROLMENT

1. How did you hear about the Moving On Program?

- My Doctor
- Other health care provider. If so, what kind of provider? _____ (eg nurse, pharmacist, physiotherapist etc)
- Local newspaper
- Information Session in November 2009
- Directly through the Blue Mountains GP Network
- Through a friend
- Other, please specify _____

2. How much do you agree with the following statements? (Place a tick against Disagree, Partially agree or Agree)

	Disagree	Partially Agree	Agree
a. I was able to choose a program that suited my availability			
b. I was able to choose a program that was located conveniently for me			
c. The enrolment process was smooth and clear			

(Optional) More information

EXPECTATIONS AND PRIOR KNOWLEDGE

3. What were your expectations of the Moving On Program prior to attending?

4. Did Moving On meet your expectations?

- Not at all Somewhat Mostly Very much It exceeded my expectations

(Optional) More information

5. Prior to attending Moving On, how would you rate your self-management skills?

- Poor or few skills Some basic skills Good skills in some areas Skilled in many areas

(Optional) More information

PROGRAM – General

6. How much do you agree with the following statements about the program content?

	Disagree	Partially Agree	Agree
a. I completed all of the pre-reading			
b. I found the pre-reading valuable and informative			
c. The content provided by the leaders during the sessions was useful			
d. I found the majority of exercises worthwhile			
e. I enjoyed the group interaction			

(Optional) More information

7. How much do you agree with the following statements about the program leaders?

	Disagree	Partially Agree	Agree
a. The program leaders were well organised			
b. The program leaders were able to respond to the needs of the participants			
c. The program leaders gave everyone a chance to speak if they wanted to			
d. The program was well led in general			

(Optional) More information

8. How much do you agree with the following statements about the venue?

	Disagree	Partially Agree	Agree
e. The venue was easy/convenient for me to get to			
f. The venue was comfortable and appropriate			
g. The catering was suitable and met my needs			
h. The duration of each of the sessions was appropriate			

(Optional) More information

PROGRAM CONTENT – Specific

Please give each session a rating for its content, exercises and usefulness to you. Please add specific comments if you choose.

Session 1 – Introduction to the Program

Poor Fair Good Very good Excellent Did not attend

Comments:

Session 2 – Managing Fatigue & Physical Activity

Poor Fair Good Very good Excellent Did not attend

Comments:

Session 3 – Healthy Eating & Leisure

Poor Fair Good Very good Excellent Did not attend

Comments:

Session 4 – Coping with Chronic Illness

Poor Fair Good Very good Excellent Did not attend

Comments:

Session 5 – Stress Management and Relaxation & Getting a Good Night's Sleep

Poor Fair Good Very good Excellent Did not attend

Comments:

Session 6 – Working with Your Health Care Team & Getting the Most Out of Your Medicines

Poor Fair Good Very good Excellent Did not attend

Comments:

Session 7 – Putting it all Together

Poor Fair Good Very good Excellent Did not attend

Comments:

OVERVIEW

9. *Attending the Moving On Program has:*

Disagree Partially Agree Agree

- a. Increased my self-esteem and self-confidence
- b. Helped me to identify what influences my health and quality of life
- c. Helped me to make decisions about my health
- d. Encouraged me to set and reach goals
- e. Enabled me to develop (or enhance) self-management skills

Disagree	Partially Agree	Agree

10. *After completing Moving On, how would you rate your self-management skills?*

- Poor or few skills Some basic skills Good skills in some areas Skilled in many areas

(Optional) More information

11. *What was the most valuable part of Moving On?*

12. *What was the least valuable part of Moving On?*

13. *Overall how would you rate the Moving On Program?*

- Not suitable Fair Good Very good Excellent

Please tell us why you gave that rating?

14. *Would you recommend Moving On to a friend or family member?*

- Yes No

15. *Do you have any further comments??*

Thank you for completing this evaluation form. Please hand in before you leave, or return by post using the stamped, addressed envelopes provided.



Attn: Practice managers: Please copy to all GPs and Practice Nurses. Thank you.

Post MOVING ON survey for GPs and Practice Nurses

1. Do you have patients who attended Moving On – a self-management program for people with a chronic illness (in February-March 2010)?
 NO – Thank you for your time. **YES** - If yes, how many? _____

2. Have you seen these patients' Moving On Action Plans?
 NO – Thank you for your time. **YES** - If yes, how many have you seen? _____

3. Have you discussed your patients' Moving On goals and/or Action Plans with them?
 NO – Thank you for your time. **YES**

4. Has discussing your patients' Moving On goals and/or Action Plans helped in the management of their chronic conditions?
 YES - If yes, in what way(s) has it helped? _____

 NO – If No, why did it not help? _____

Thank you very much for your time. Please fax this survey back to the Blue Mountains GP Network on (02) 4758 9722.

Yours faithfully,

Serena Joyner
 Project Coordinator, Chronic Disease Self-Management
Blue Mountains GP Network
 12 November 2010

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Appendix Four: Adult Learning Principles and Stages of Change

Adult Learning Principles

Adult learning values the process of learning and uses approaches to learning that are problem-based and collaborative rather than didactic. The study of adult learning was pioneered in the 1970s by Malcom Knowles who defined adult learning as 'the art and science of helping adults learn'. Knowles identified the following six principles of adult learning.

1. Adults are internally motivated and self directed
2. Adults bring life experiences and knowledge to learning experiences
3. Adults are goal oriented
4. Adults are relevancy oriented
5. Adults are practical
6. Adult learners like to be respected

Learning and Teaching Information Retrieved 12:5:2010 <http://www.learningandteaching.info/learning/knowlesa.htm>

Transtheoretical (Stages of Change) Model

This model describes and explains the different stages in behaviour change processes. The five basic stages are listed below.

Stage 1: Precontemplation (Not Ready)

At this stage someone does not intend to start the healthy behaviour in the near future (within six months), may be unaware of the need to change or are consciously intending not to change.

Stage 2: Contemplation (Getting Ready)

Individuals at this stage, are considering to make a change within the next 6 months.

Stage 3: Determination or Preparation (Ready)

A person is ready to start taking action within the next 30 days. They make a serious commitment to change.

Stage 4: Action

Behaviour change is started at this stage.

Stage 5: Maintenance

An individual changed their behaviour more than 6 months ago and are sustaining it. There are predictable health gains. Relapse may also be the fifth stage.

Nutbeam D, Harris E Theory in a Nutshell. A Guide to Health Promotion Therapy. McGraw-Hill Companies Inc. Australia, 2001.

Pro-change Behavior Systems Inc. (Founded in 1997 by James O. Prochaska). <http://www.prochange.com/about>. Retrieved 12:5:2010

Menzies Centre for
**Health
Policy**



THE UNIVERSITY OF
SYDNEY



ANU

THE AUSTRALIAN NATIONAL UNIVERSITY

Report of the Evaluation of the Blue Mountains GP Network Chronic Disease Self-Management Project

The Menzies Centre for Health Policy is a collaborative Centre between The Australian National University and the University of Sydney. It aims to provide the Australian people with a better understanding of their health system and what it provides for them. The Centre encourages informed debate about how Australians can influence health policy to ensure that it is consistent with their values and priorities and is able to deliver safe, high quality health care that is sustainable in the long term.

The Menzies Centre:

- produces and publishes high-quality analyses of current health policy issues;
- delivers public seminars and education programs on a wide variety of health policy topics;
- undertakes comprehensive research projects on health policy issues.

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