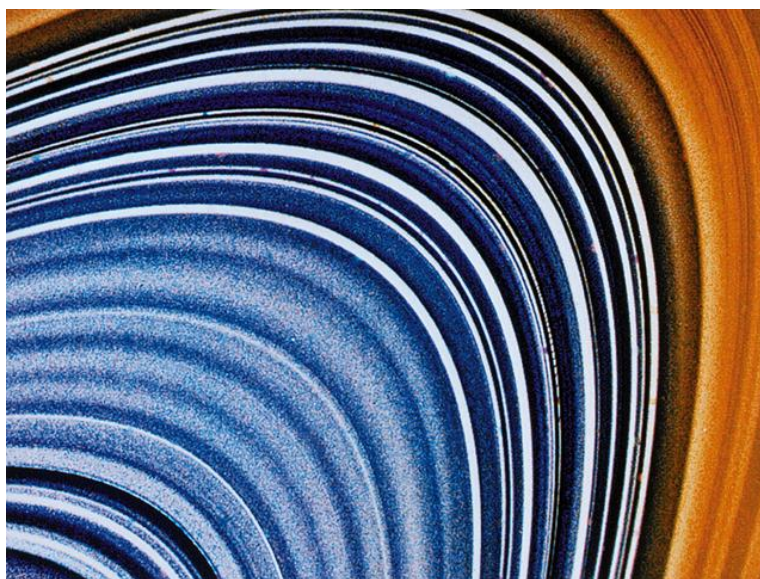


STATEWIDE CHRONIC DISEASE SELF MANAGEMENT DEMONSTRATION PROJECT

INFORMED PARTNERSHIPS FOR EFFECTIVE SELF-MANAGEMENT OF CHRONIC AND COMPLEX LUNG DISEASES



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Abbreviations

BMQ	Beliefs about Medicines Questionnaire
CCSM*	Chronic Condition Self Management
CDSM	Chronic Disease Self Management
COPD	Chronic Obstructive Pulmonary Disease
DATIS	Drug and Therapeutics Information Service
EPC	Enhanced Primary Care
FMC	Flinders Medical Centre
FUDGP	Flinders University Department of General Practice
FHBHRU	Flinders Human Behaviour & Health Research Unit
GHQ-28	General Health Questionnaire 28 items
GP	General Practitioner
HMR	Home Medicines Review
RCT	Randomised Controlled Trial
RGH-DP	Repatriation General Hospital, Daw Park
SDGP	Southern Division of General Practice
SIMS	Satisfaction with Information about Medicines Scale
PIH	Partners in Health scale
PIP	Practice Incentive Payment Chronic Disease Self Management
SGRQ	The St George's Respiratory Questionnaire

* CCSM and CDSM are used somewhat interchangeably in the report. At the time of development of the original project the term chronic disease self management (CDSM) was used however as the project as developed the FHBHRU has clarified that the preferred term is CCSM due to its emphasis on the holistic experiential construct "condition" rather than a specific disease.

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Executive Summary

Rationale

Chronic lung disease has a major impact on community health resources, is responsible for a high rate of hospital admissions and contributes significantly to rising mortality rates due to COPD, especially in women. This disease burden will increase, not lessen, in forthcoming decades. More than one-third of hospital case-mix expenditure in South Australia in 2002-3 can be attributed to four chronic diseases groups one of which is asthma/COPD.⁹

The release of the COPDX Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease has heightened awareness of COPD and will increase recognition and diagnosis of this condition in our community. It also emphasizes the need for patients to play an active role in their health and the need for patients to have a self-management and support plan agreed to by them, their GP, specialist and other health workers.

An important aspect of quality care for patients with chronic disease are strategies that reinforce the role of integrated care planning and self-management.

This demonstration project sought to address this growing COPD burden using an innovative self-management approach and to increase availability of a system for self management.

Goals

The primary aims of this study were:

- to build sustainable health care partnerships which support informed patient/ GP self-management approaches;
- to help maximize self-management capacity of people with chronic lung conditions;
- to improve health outcomes of patients and their carers through more effective self-management.

A concomitant goal was to explore and report back on the challenges and progress relating to integrating this CCSM model as a part of routine practice in the changing context of general practice.

Study Overview

The study was conducted as a prospective unblinded randomised controlled trial (RCT) to compare the effectiveness of a multifaceted chronic disease self management program specifically designed for patients with chronic airways disease versus a control group receiving usual care in the southern region of Adelaide.

The intervention group received the Flinders Sharing Health Care Self management programme which included the use of Flinders Partners in Health Scale, Cue and Response interview, and Problems and Goals to negotiate a plan of care (ie care plan). General Practitioners and practice nurses also received training from the Flinders Human Behaviour and Health Research Unit in the use of the Flinders tools and self-management.

Patients in the intervention group received the RGH Pulmonary Rehabilitation programme which provides a comprehensive education and exercise training conducted over 8 weeks and involved one education session of 2 hours per week and exercise sessions of 30 minutes, twice a week.

Followup was conducted over 12 months. The control group received usual care from their general practitioner.

Patients aged 50 year or more with moderate to severe airflow limitation, severe chronic asthma, pulmonary fibrosis or bronchiectasis and at least one concurrent condition, including mood disorder, cardiovascular disease, osteoporosis, diabetes, or arthritis managed in the community setting were invited to participate. People with chronic medical conditions likely to impose severe exercise restriction unrelated to respiratory disease or shorten survival and those with known presence of cancers likely to be fatal within 12 months or who had severe cognitive deficit were excluded.

Results

In this Demonstration Project significant clinical gains were achieved with respect to exercise endurance and physical functioning of patients in the intervention arm of the study.

⁹ Chronic Disease: prevention and management opportunities for South Australia, Department of Human Services, January 2004.

Increased patient knowledge about their condition and medications was also achieved. The majority of patients were able to take ownership of their chronic disease health problems and work in partnership with their doctors as a consequence of the intervention while GPs were empowered to support them.

A clinically significant improvement in the “six minute walk” was achieved in this Demonstration Project. This is a very encouraging result as it is a measure of the improvement in physical function of the intervention group. A clinically significant improvement is considered to be 50 metres in this study an improvement of 75 metres was seen in the intervention group at 12 months which translates into clinically significant improvement in activities of daily living for people with COPD. No clinically significant improvement was seen at either 6 months or 12 months in the control group. As an objective measure the six minute walk was a powerful motivator for patients and should be promoted to GPs as a measure of functional capacity for COPD patients. In a recent systematic review of self management education programs in chronic disease which included 71 trials the authors noted that self-management education programmes had a greater effect in certain diseases. The authors hypothesized that diseases such as asthma and diabetes in which patients can learn to monitor outcomes in an objective manner may have greater positive benefits on outcomes.¹⁰

The participants’ principal personal goal was to improve physical tolerance to exercise and in some cases to return to some sports and this type of goal was reported on 93% of the care plans. This goal was achieved by 40% of people in the intervention group who were actively continuing in the community based exercise programmes initiated as part of their care plans at 12 month followup. They have also motivated the GPs to refer other patients to these community based exercise programmes.

The use of the Flinders CCSM tools, (PIH and Cue and Response) provided insight into the social, emotional and physical health needs of the patients and these were incorporated into the care plans. The study implemented the Flinders Model of Self Management using the PIH scale, Cue and Response interview and problems and goals and care plans. 15 care plans using the Flinders model of self management were completed for intervention patients (79%).

¹⁰ Warsi A, Wang PS, LaValley M, Avorn J, Solomon D. Self-management Education Programs in Chronic Disease. Arch Intern Med 2004;164:1641-1649.

The mean number of medications in the intervention and control groups at baseline were 7 and 8.2 respectively and at 12 month followup the mean number of medicines were 7.3 and 7.6 respectively. The most common concomitant drug therapy prescribed in addition to medicines to manage their respiratory conditions were medicines to treat and prevent osteoporosis. An increase in physical functioning through increased exercise may have potential benefit in this at risk patient group for osteoporosis and fracture risk.

Appropriate use of medicines is important to the self-management of many chronic illnesses in this study we utilised the Beliefs about Medicines (BMQ) Scale which has been validated for use in the chronic illness setting. This scale comprises two 5 item scales assessing patients' beliefs about the necessity of prescribed medicine for controlling their illness and their concerns about potential adverse consequences of taking it. In this study of patients with moderate to severe respiratory disease the BMQ revealed that 24% had strong concerns about their medicines based on beliefs about the dangers of dependence or long-term effects.

The majority of GPs had reservations about elements of the EPC items. While most were very successfully implementing the health assessment items with the support of practice nurses they considered the complexity of requirements for care plans and case conferences a barrier. The GPs considered that they were providing the required care but were not claiming payments because of the perceived onerous nature of the process. Support for care plans was provided by the project team including the provision of lung function test results to the GPs, provision of a template for the COPD patient to assist them in formulating their individual care plans, and the CCSM workshops which highlighted how to write and develop care plans using the Flinders PIH and Cue and Response approach. These approaches greatly facilitated the completion of the 15 care plans in the intervention group. An important observation was that the control practices in the second six months of the study also initiated care plans as part of EPC (n=6). Despite making Respiratory Specialists available the GPs did not initiate any case conferences with them.

The role of practice nurses in delivery of CCSM models needs further exploration. In the study inclusion of the practice nurse in the CCSM model with joint training with GPs resulted in a 100% of care plans being developed in those practices in which the care plan was facilitated by the practice nurse.

Discussion

People with chronic respiratory disease are known to deteriorate gradually with time, and physiologically, this is greater if people continue to smoke. The effect that this physiological

impairment has on their everyday symptoms and functioning is not always predictable, and other factors impact on exercise capacity including muscular and cardiovascular fitness, self-efficacy for exercise and psychological well being. Overall health status in such populations has been related to all these factors as well. Indeed, the prognosis (survival) for people with COPD has been shown to be closely related to a combination of the following factors (acting independently): nutrition, airflow limitation, dyspnoea/disability and exercise capacity.

Observations from this study demonstrate the expected decline in lung function (increased airflow limitation) over the 12 months in both groups. The level of airflow limitation observed is typical of patients enrolling in COPD intervention projects, meeting criteria for severe impairment. Despite the severity of airflow limitation, patients in both groups had good functional levels, with six-minute walk distances in the second lowest quartile of predicted for age and gender. Health related quality of life was determined from the health status (SGRQ Total Score), and was found to be generally moderately reduced.

In treating people with COPD, it is expected that a correct diagnosis is made and that pharmacotherapy is optimised. For people with optimised therapy for COPD it has been widely shown that pulmonary rehabilitation, which includes exercise training, education and cognitive-behavioural approaches to improve self-efficacy, is highly beneficial even without effect on the level of airflow limitation. Best practice therefore determined that patients should enrol in such a program in the model of care proposed in this project. One proven draw-back of this type of intervention, however, is that the effects of a standard 8-week course usually last for up to six months and benefits wane if patients do not maintain a regular exercise training regimen.

Few randomised controlled studies of self-management interventions have been published in the area of respiratory disease. Monninkhof and colleagues¹¹ evaluated a program that addressed fitness over 2 years and a 4-month self-management education course (including action planning), in comparison with a control group (usual care). They observed no differences in SGRQ scores within or between groups over one year, and no differences in symptom scores or 6-minute walk distance in either group. Exacerbations were more frequently reported by members of the intervention group, but were managed early and at home. In the present study the intervention was different in that it was more integrated with primary care and designed to encourage better decision making and autonomy. It was also smaller, but did demonstrate significant improvement in 6-minute walk distance in the intervention group. The patients in this group continued positive social interactions with each

other and an ongoing involvement in self-driven exercise, which would have contributed to at least maintenance of well being and exercise endurance.

In a recent systematic review of self-management from COPD, Monninkhof and colleagues¹² found few positive results. The nine controlled studies (which described quite variable processes) showed no effect of self-management education on lung function, hospital admissions or emergency department visits, or days lost from work. The results on health-related quality of life were inconclusive: studies using the SGRQ showed better health status in the patients in the intervention group, but only in the activity component, and heterogeneity between the two studies included was seen. Inconclusive results were observed on symptoms or use of other health care resources. There was a reduced need for rescue medication in the intervention groups, and earlier use of courses of oral steroids and antibiotics for exacerbating respiratory symptoms.

The observed changes in the present study imply that the intervention was better than routine medical care in knowledge acquisition and in coping with exertion, physical endurance, and evidence of using medications more effectively (and with closer adherence). Improvements in overall health status were seen in both groups. The improvement in the control group may have been due to increased use by GPs of care planning (and concentration on socially relevant issues as well as appropriate reactive care of medical symptoms). In the intervention group, there was a group-linked decision to enrol in a community based exercise program, probably as a result of improved self-efficacy, and this was sustained over the 12 months of study (unlike usual isolated pulmonary rehabilitation).

The outcome measures used in this study were considered a priori to be among the best, most responsive and relevant to the hypotheses. The COPD Self efficacy Scale has not been widely used to evaluate response to standard comprehensive pulmonary rehabilitation, but some studies have shown positive changes, while others have not. It may not be highly responsive to change, and this may have limited its use as an outcome measure in the present study. The SGRQ, on the other hand, has been very widely used as an outcome measure in pharmaceutical research and in evaluating pulmonary rehabilitation. It is responsive to interventions, but clinically relevant changes are not uniformly found following PR. The six-minute walk distance is also in widespread use for PR assessment, and

¹¹ Monninkhof EM, van der Valk J, van der Palen J, van Herwaarden C, Zielhuis GA. Effects of a comprehensive self-management programme in patients with chronic obstructive pulmonary disease. *European Respiratory J* 2003;22:815-820.

¹² Monninkhof EM, van der Valk J, van der Palen J, van Herwaarden C, Partridge MR, Walters EH, Zielhuis GA Self-Management education for chronic obstructive pulmonary disease Systematic Review Cochrane database of systematic Reviews 4, 2004.

clinically relevant improvements are usually described. Our findings are not in conflict with available studies.

Cue and Response and Partners in Health scales were acknowledged by GPs to be relevant to caring for patients with chronic respiratory disease. However, in terms of monitoring patients in such programs both for assessment and motivation there was a feeling among GPs that this process was too time-consuming to be of routine help. This reluctance could be addressed by utilising Practice Nurses more for these assessments, as well as for helping drive the care planning process and acting as both liaison and change agents between GPs, community organisations, tertiary care and the patient/family partnership.

The intervention was multi-factorial, and multi-disciplinary. General practitioners were empowered to refer patients directly to pulmonary rehabilitation, but also trained to conduct cue and response interviews of their patients with chronic complex respiratory disease. Some facets of the intervention concentrated on generic psychosocial issues, while others were more focussed on enhancing self-management for the patients' respiratory conditions. This is one of the first studies to demonstrate significant and sustained advantages in favour of self-management for people with severe chronic lung diseases from such an intervention. Strengthening the ties between primary and tertiary care in a shared-care model, with emphasis on identifying more clearly the patients' real problems for functioning and addressing them comprehensively, provide background changes that should convert over time to greater independence and reduced handicap and disability for patients with these conditions. Health economic evaluation with understanding of health care utilisation would be helpful in determining the societal impact of such an intervention.

Patients with chronic respiratory conditions have a systemic illness that affects more than their lung function. They can have effects over a range of organ systems (eg cardiac function, osteoporosis, muscle weakness, malnutrition) as well as on their psychosocial status. While pharmaceutical treatment has improved especially over the past three years, there is substantial evidence that comprehensive pulmonary rehabilitation (with attention to exercise training, nutrition and knowledge acquisition) improves health status and both physical and psychological well being. Giving greater attention to training patients for capacity to take an active role in shared care (self-management) may have longer lasting benefits that impact not only on the patient but also on societal health care provision and costs. It appears feasible to incorporate cross-sectoral and inter-disciplinary approaches, with simple enabling systems (involving human and electronic resources), that will allow more universal and seamless use of proven treatment packages.

Background

This project focussed on adults with chronic disabling lung diseases. In Australia Asthma and Chronic Obstructive Pulmonary Disease (COPD) affect 1,507,000¹³, COPD and asthma rank second in disability¹⁴, admissions for COPD and asthma rank fourth¹⁵, readmission rates are unduly high¹⁶, and mortality rates for COPD are high, rising¹⁷, and excessive¹⁸. In Australia, only heart disease and stroke contribute more to the overall burden of disease. COPD ranks fourth among the common causes of death in Australian men and sixth in women.

Smoking is the most important risk factor for COPD. Smoking-related diseases are increasing substantially in women, and death rates from COPD in women are expected to overtake those in men. The death rate from COPD among Indigenous Australians is five times that for non-Indigenous Australians, and smoking is a leading cause of healthy years lost by indigenous people. Smoking affects virtually all organ systems, and 10% of all years of life lost from premature mortality and disability can be attributed to smoking.¹⁹ Public health promotion and assistance with smoking cessation are necessary to reduce the prevalence of smoking-related diseases, and to improve the control of chronic lung diseases.

There are high rates of mental health disorders in people who have asthma²⁰ or COPD²¹ (especially depression in COPD²²), and psychosocial factors are associated with 40-50% of unplanned COPD admissions²³. Inadequate home supports²⁴, older age²⁵ and poor medication adherence²⁶ are significant factors in hospitalisation and death in older people with asthma. Confidence in self-monitoring disease and responding appropriately to early changes in symptoms can reduce hospitalisations and unplanned or emergency health presentations for asthma²⁷. The risk of admission for asthma is higher in people who prefer not to take decisions on changing treatment in an exacerbation²⁸, and hospital reattendances

13 Australia's Health 2000. The seventh biennial health report of the Australian Institute of Health and Welfare. AIHW Cat. No. 19.

14 Australia's Health 2000

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26 McCarren M, McDermott MF, et al 1998. Prediction of relapse within eight weeks after an acute asthma exacerbation in adults. *J Clin Epidemiol* 51: 107-118.

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28 Adams RJ, Smith BJ, Ruffin RE 2000. Factors associated with hospital admissions and repeat emergency department visits for adults with asthma. *Thorax* 55:566-573

are related to incapacity to self-manage asthma²⁹. These psychosocial factors are important in a wider context of concurrent conditions (comorbidities and complications) seen in many people with chronic asthma and COPD, highlighting the need to take these complexities into account when assessing and managing such patients.

The ABS estimates that around 2.3 million (1 in 6) Australians provide care to a person who is frail aged, disabled or has a chronic physical or mental illness. Of these, 19% are primary carers (e.g. spouse) who provide substantial informal assistance. Carers are more vulnerable to physical and mental health problems³⁰, and we have found in the only existing study of the consequences of caring for patients with lung disease that over 30% of the carers met the criteria for 'psychiatric caseness'³¹. The high levels of strain and psychological morbidity reduced following pulmonary rehabilitation³⁶. The benefits that can accrue for the carer from building patient self-management capability need emphasis. Existing programs may need further development to incorporate the needs of carers, and evaluation of the effects of such programs is urgently needed.

COPD costs the Australian community an estimated \$818–\$898 million annually.³² This is a conservative estimate, based on 1993–1994 figures extrapolated to the year 2001. The addition of hidden costs, such as those related to carer burden, loss of productivity from absenteeism and early retirement, could increase the estimate to more than \$1 billion per annum. Because it is considered incurable, self-inflicted and relatively resistant to treatment, a sense of nihilism about COPD prevails. However, much can be done to improve quality of life, increase exercise capacity, and reduce morbidity and mortality in affected individuals.³³

This COPD CDSM project was informed by the COPDX Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease, the objectives of the plan being to: Confirm diagnosis, Optimise function, Prevent deterioration, Develop a self-management plan and manage exacerbations, refer Appendices Supplement.

These guidelines are the outcome of a joint project of the Thoracic Society of Australia and New Zealand and the Australian Lung Foundation. The guidelines aim to: effect changes in clinical practice based on sound evidence; and shift the emphasis from a predominant reliance on pharmacological treatment of COPD to a range of interventions which include patient education, self-management of exacerbations and pulmonary rehabilitation.

29 Wakefield M, Staugas R, et al 1997. Risk factors for repeat attendance at hospital emergency departments among adults and children with asthma. *Aust NZ J Med* 27:277-284.

30 Keele-Card, G, Foxall, MJ, Barron, CR 1993. Loneliness, depression, and social support of patients with COPD and their spouses. *Public Health Nursing*, 10: 245-251

31 Cafarella P, Frith P 2000. Pulmonary rehabilitation reduces carer strain and psychological morbidity. *Respirology* 5 (suppl):A43.

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33 (McKenzie D, Frith PA, Burdon JGW, Town GI. The COPDX Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease 2003 *MJA* 2003; 178(6 Suppl 17 Mar): S1-S40.

Aims and Objectives

The primary aims of this study were:

- to build sustainable health care partnerships which support informed patient/ GP self-management approaches;
- to help maximize self-management capacity of people with chronic lung conditions; and
- to improve health outcomes of patients and their carers through more effective self-management.

A concomitant goal was to explore and report back on the challenges and progress relating to integrating this CCSM model as a part of routine practice in the changing context of general practice.

Location and Team

The project was located at the Department of Respiratory Medicine and DATIS, Repatriation General Hospital, Daw Park.

Key members of the team working on this project included:

- Dr Peter Frith; Director Respiratory Medicine, Flinders Medical Centre and Repatriation General Hospital, Daw Park;
- Paul Cafarella, Clinical Psychologist, Repatriation General Hospital, Daw Park;
- Debra Rowett, DATIS Director, Repatriation General Hospital, Daw Park;
- Shalini Simmons, Project Officer;
- Brenda Hamilton, Rehabilitation Coordinator, Repatriation General Hospital, Daw Park;
- Karin Nyfort-Hansen, Clinical Pharmacist, Repatriation General Hospital, Daw Park;
- Dr Helena Williams;
- Professor Louis Pilotto; and
- Dr Kerry Hancock, GP.

Study was proposed by:

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Project Design

This is a prospective unblinded randomised controlled trial (RCT) to compare the effectiveness of a multifaceted chronic disease self management program specifically designed for patients with chronic airways disease versus a control group receiving usual care in the southern region of Adelaide.

Patients were invited to participate if they were aged 50 year or more with moderate to severe airflow limitation; severe chronic asthma; pulmonary fibrosis or bronchiectasis and at least one concurrent condition, (including mood disorder, cardiovascular disease, osteoporosis, diabetes, or arthritis) managed in the community setting. People with chronic medical conditions likely to impose severe exercise restriction unrelated to respiratory disease or shorten survival and those with known presence of cancers likely to be fatal within 12 months or who had severe cognitive deficit were excluded.

Carers of patients enrolled were also invited to participate.

The patient, carer or GP could withdraw from the programme at any time at their request. If there was a new acute medical crisis patients would be withdrawn from the study.

CCSM Intervention Care Plans were developed for all patients in the intervention arm using EPC Item Numbers for Care Planning (720-728). The project offered the opportunity to GPs in the intervention arm for respiratory physicians and other relevant health professionals to be available to case conferences in the community.

FHBHRU provided 3 hour 'Overview' and 6 hour training programmes in CCSM to GPs and other health professional respectively.

Assessment of psychosocial supports and capacity for self-management were used to formulate Care Plans.

Methods for integrating self-management assessment and training into care planning were established by consultation between GPs and specialist services.

Enrolment

The study was promoted through the Southern Division of General Practice and Flinders University Department of General Practice (FUDGP).

The Respiratory Departments of RGH and FMC undertook promotion of the programme within the hospitals in the region.

A GP reference group was established to facilitate patient and GP enrolment and to ensure the project goal of building a sustainable framework of health care partnerships to help maximise self-management capacity of people with chronic lung conditions was achieved.

Dr Kerry Hancock, a highly regarded GP in the SDGP in the area of airways disease and member of the COPD CDSM GP reference group visited the GPs in their practices and gave a brief promotional presentations for the study to seek their enrolment in the study. Dr Peter Frith (Chief Investigator) also visited GPs in their practices to promote the study and invite GP participation.

Patient recruitment was initiated by the GP who had consented to participate in the study. After a patient had been consented by their GP, liaison was then facilitated by the project officer together with practice staff.

Randomisation was at the level of the GP practice in a randomised, clustered design – a standard design aimed at avoiding allocation and contamination bias. Once a doctor's practice group was randomised in the study, all subsequent eligible patients cared for by that practice group were randomised to the same arm.

The primary outcome measure for the study was the St George's Respiratory Questionnaire (SGRQ). On the basis of previous published RCT data a sample size calculation estimated that at least 17 patients were required in each group or 34 patients in total to show a change in the SGRQ of 15 points from baseline (standard deviation = 13) with 90% at the 5% significance level. However, because the study design randomises to GP practice then there is a design effect which causes a doubling in sample size to 68.

Evaluation tools – patients and carers

St George's Respiratory Questionnaire

The St. George's Respiratory Questionnaire (SGRQ) is a self-complete Measure of Health Status for Chronic Airflow Limitation.⁴² This 78-item questionnaire was developed to measure health in chronic airflow limitation. The SGRQ generates 3 component scores based on symptoms, activity and impact on daily life, plus a total score. The reported coefficient of variation is 19%. Changes in the SGRQ over one year correlate with disease activity.

Flinders Partners in Health Scale (PIH)

The PIH used in the study contains 12 questions, covering the following scales, an earlier version was an 11 item scale and the scale remains under review:⁴³

- Patients knowledge about their illness
- Patients level of involvement in decisions made in relation to the management of their illness
- Patients adherence to treatment
- Observing and recording of symptoms
- Responding to symptoms
- Lifestyle

A nine point rating scale was used for each item to be rated according to the individual's perception of their level of self-management '0' indicated good self management and '8' poor self management. A nine point rating scale provides as close to a continuous variable as possible and allows a broad range of possible responses.

⁴² Jones PW, Quirk FH, Baveystock CM, Littlejohns P. A Self-complete Measure of Health Status for Chronic Airflow Limitation. The St. George's Respiratory Questionnaire. *Am Rev Respir Dis* 1992; 145:1321-27

⁴³ Battersby MW, Ask A, Reece M, Markwick M, Collins J. The partners in Health Scale: The development and psychometric properties of a generic assessment scale for chronic condition self management. *Australian Journal of primary Health* 2003,9: 41-52.

Flinders Cue and Response Interview

The Flinders Cue and Response interview⁴³ is an extension of and uses the same categories as the Flinders Partners in Health Scale. Under each item are a number of cue questions that aim to elicit information from the patient about each item. The Flinders Cue and Response interview form is completed by the general practitioner with the patient in order to identify a patient's self-management status and can be used to formulate a care plan.

Health Questionnaire (GHQ-28)

The General Health Questionnaire is a widely used measure of psychiatric morbidity and has been used regularly with respiratory patients. It contains 28 items and takes 5 to 10 minutes to complete.

It contains the following scales:

- Depression
- Anxiety
- Social Impairment
- Hypochondriasis

COPD Self-Efficacy Scale

This questionnaire contains 34 items and assesses patients' confidence regarding their ability to avoid breathing difficulty in the following areas.⁴⁴

- Negative affect
- Intense emotional arousal
- Physical exertion
- Weather/environment
- Behavioural risk factors

Carer's Questionnaire

This questionnaire contains the following domains.⁴⁵

- Cognitive status
- Problematic behaviour
- Overload
- Relational deprivation
- Family conflict
- Job-caregiving conflict
- Economic strains
- Role captivity
- Loss of self
- Caregiving competence

⁴⁴ Wigal JK, Creer TL, Kotses H. The COPD Self-Efficacy Scale. CHEST 1991; 99(5): 1193-1196.

⁴⁵ Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. The Gerontologist 1990; 30 (5): 583-594.

- Personal gain
- Management of situation
- Management of meaning
- Management of distress
- Expressive support

Beliefs about Medicines Questionnaire (BMQ)

Appropriate use of medication is an important aspect in the self management of many chronic illnesses. There have been a few studies which have attempted to investigate patients' beliefs about their treatment, particularly their views about medicines. A study involving 1200 participants, representing a range of chronic illness groups showed that patients' beliefs about the specific medication prescribed for them (specific medication beliefs) could be grouped under two core themes. These were their beliefs about the necessity of the prescribed medication for maintaining health now and in the future, and concerns about the potential adverse effects of taking it. This work has resulted in a new validated questionnaire based method for the quantitative assessment of beliefs about medication the BMQ.⁴⁶

The Beliefs about Medicines Questionnaire (BMQ) utilised in this Demonstration project is included in the Appendices Supplement.

Satisfaction with Information about Medicines Scale (SIMS)

The SIMS provides a valid and reliable tool for assessing how well the needs of individual patients for medicines information are being met and provides a method for investigating the impact of our intervention. Identifying deficits in satisfaction provides a target for interventions designed to tailor information provision according to individual needs.⁴⁷ A copy of the SIMS utilised in the Demonstration project is included in the Appendices Supplement.

⁴⁶ Horne , Weinman J, Hankins M. The Beliefs about Medicines Questionnaire (BMQ): the development and evaluation of a new method for assessing the cognitive representation of medication. *Psychol Health* 1998; 14:1-24.

⁴⁷ Horne R, Hankins M, Jenkins R. The Satisfaction with Information about Medicines Scale (SIMS): a new measurement tool for audit and research. *Quality in Health Care* 2001;10:135-140.

Project Implementation

Duration of the Project

The project ran for 26 months to allow collection and evaluation of all 12 month follow-up data as part of the CCSM study.

Recruitment

Recruitment of GPs to this study was difficult and resulted in four practices being recruited to this study (2 intervention and 2 control practices). We had aimed to recruit six practices in total. The reasons for poor uptake have been considered in depth and are included in the discussion. In addition, having identified practices and gained GP consent only a few GPs went on to recruit patients for the study. The new privacy legislation introduced in December 2001 influenced this process. The research team was not in a position to assist in this phase of recruitment given the privacy restrictions and also the interpretations of the privacy law in this first year of operation by GPs, practice managers and practice nurses as they came to understand the implications of the new legislation. In some practices we had great support and commitment from GPs in identifying patients from lists and then these patients were contacted by letter by the GP. This recruitment approach was used in the practice where the number of patients consented was lowest. The highest proportion of patients who consented to participate came from a practice where the GPs identified patients who presented on clinical grounds and if the GP considered the patient eligible for inclusion they discussed the study with the patient at the time of the consultation. This was time consuming but yielded the highest number of consented patients. Interestingly, the practice with the lowest number of consenting patients from those approached was a practice where there was already a strong commitment to care planning and patients may have been reluctant to participate on the basis they were already visiting their GP for anticipatory care.

Recruitment was March 2002 to 30 June 2003. A variety of strategies were utilised to recruit GP practices, which included personal presentations by a Respiratory specialist and/or a GP who provided information about the study often at practice meetings, (see flyer in Appendices Supplement)

Sixteen of the medium to large practices in the metropolitan and outer urban areas of the SDGP were approached. Initial recruitment of the GP practices was difficult due to the problems of accessing the GPs to speak about the study. After the initial telephone approach to the practice information often had to be sent by fax. This usually required a follow-up phone call to see if there was any interest. This process from initial contact to decision of involvement in the study took up to 4 weeks. The 16 practices invited to participate comprised 114 GPs. Four practices were recruited 25% of the sample and 6 GPs participated 5% of the sample. In the four practices recruited to the study there were 33 eligible GPs. The participation rate was 18% by the GPs in the recruited practices.

The patients that were interested in the study were seen individually by the study nurse and the project was explained in person, mostly at the GPs' surgeries. A few patients were seen at home. Consent at this point was obtained from 33 of a total of 42 patients identified by GPs (80%). Patients found it more comfortable to have the first interview in the GP surgery as it implied to them that their GP agreed with being part of the trial.

A summary of the baseline characteristics of the study participants is included in Table 1 below.

Table 1 Baseline characteristics of study participants

Demographic Variable	Total sample n=33	Intervention n=19	Control n=14
Age (mean) years	71	71	70
Gender (male : female)	47 : 53	50 : 50	43 : 57
Place of residence own home	88%	88%	86%
Pensioner	94%	88%	100%
Aged care pension type	62%	66%	64%
Indicated had a carer	38%	27%	50%
Attended a disease support group	Nil	Nil	Nil
Study participants with cardiovascular disease as a co-morbidity	46%	57%	38%

Issues associated with recruitment

- The Practice manager or practice nurse had to be willing initially to obtain a list of potential patients (from the “Medical Director” computer software) and share this information with the involved GP to identify patients eligible for the project. One GP did this entire process herself.
- Due to time constraints GP’s were slow (from a couple of weeks to 2 months) to identify eligible patients according to the inclusion/exclusion criteria from the initial lists of CLD patients given to them by their staff.
- One practice (an intervention group practice) used opportunistic recruitment (no screening of practice database). This practice identified 15 patients by 3 GP’s and 14 patients consented. This was also slow, taking many months. However, this practice had the highest intake. The GPs mentioned the study to their patients at consultation, sent a letter and then the patients contacted the project study nurse.
- Many of the patients who declined to consent were unwilling to commit to 8 weeks of the rehabilitation program. Many stated they had “busy lives”
- Some patients perceived they had to be unwell to participate in program. After clarifying this issue most were still unwilling to change their decision.

Intervention

All intervention patients completed the RGH-DP pulmonary rehabilitation program. Two programmes were conducted to accommodate the intervention patients. These were intensive interactive educational sessions conducted by the respiratory team and included talks from a Respiratory Physician, a Respiratory Clinical Nurse consultant, psychologist, physiotherapist, clinical pharmacist, nutritionist, and occupational therapist. Exercise sessions were supervised by a physiotherapist in a gym and included arm and leg strengthening and endurance exercise as well as bike riding and treadmill walking. The exercise programmes were tailored to each individual after a medical evaluation. All baseline lung function tests and questionnaires as outlined in the study protocol and amended study protocol 29 November 2002 were completed. Patient assessment from the first group to complete the pulmonary rehabilitation programme indicated a high level of satisfaction with the programme, (refer Appendices Supplement).

The Flinders PIH tool was used at baseline and at 6 months as part of the study intervention. The cue and response and problems and goals were implemented as part of the study intervention. A model care plan was developed and provided to participating GPs and practice nurses in the intervention arm trained in the principles of CCSM using the PIH and Cue and Response tools to develop the care plan (see Appendices Supplement). In one of the intervention practices the GPs elected to undertake the PIH questionnaire, Cue and Response and the care plan development. The other intervention practice utilised the practice nurse trained in the PIH and cue and response and the GPs developed the care plan using the practice's care plan template. A pack of the PIH, cue and response, sample care plan and the EPC rules for care plans was prepared and forwarded to each GP in the intervention arm. The patients full respiratory function tests were also made available to the GP.

Training of GPs and Practice Nurses in the principles of CCSM

Two successful training programmes were conducted at the International Hospice Studies Unit at RGH- Daw Park. The first was held on 1 April 2003 and both GPs and Practice nurses attended. The GP reference group for the project had commended the concept that training be undertaken with GPs and practice nurse conjointly. Other members of the pulmonary rehab team who had not been able to attend previously also attended including two Occupational Therapists, the specialist incontinence nurse, and dietician. The second training programme was conducted on the 8th April at the same venue for practice nurses and the members of the pulmonary rehabilitation team to focus on the skills development for undertaking the PIH and cue and response questionnaires leading to the development of a care plan. This second programme with the practice nurses provided a great insight to the enablers and barriers for the sustainability of the implementation strategy for the self management care plans. All GPs and practice nurses attending were remunerated for their attendance.

These training sessions were in addition to the CDSM training convened in collaboration with the SDGP mental health CDSM project at which members of the pulmonary rehabilitation team attended. The project officer, Shalini Simmons and Debra Rowett also attended a training programme at the commencement of the study.

Medication Management Questionnaires

The Satisfaction with Information Scale (SIMS) tool and Beliefs about Medicines Questionnaire (BMQ) were completed at baseline, 6 months and 12 months for all

participants. Appropriate use of medication is an important aspect in the self- management of many chronic illnesses. This project explored the use of compliance aids and the impact on self-management skills on adherence with medicines. The majority of patients in this study indicated that they managed their own medicines without carer support and that they used a particular routine which enabled them to take or administer their medications in preference to a 'compliance aid'. Some strategies had an associated risk for medication misadventure. Further the 'trigger' for taking the medicine was the breathing distress which prompted medication use. A common aid in this patient setting were the various inhaler devices being utilised to facilitate the delivery of the inhaled bronchodilators and corticosteroids. The ability to differentiate between 'preventers' and 'relievers' was very low in those on combination corticosteroid/long acting beta agonist preparations. Only one patient volunteered they had a medication management plan from their GP and no Home Medicines reviews had been completed at the commencement of study.

Consumer involvement and protection

A consumer was appointed to the GP reference group and contributed to these meetings. The consumer representative was involved in planning and implementing the project and trialling the instruments to be used in the study and provided feedback.

Ethical clearance was sought and obtained from Repatriation General Hospital- Daw Park Research and Ethics Committee. All participants were made aware of their rights to access to these committees to raise any concerns about the project. For any publication, dissemination or education and training purposes, participants' rights of confidentiality and anonymity were clearly stated in the participant information sheet. Support, liaison and linkage to relevant agencies/services were to be offered to those participants who, for whatever reason, withdrew from the project, or who may have needed additional support in the case of deterioration in their mental health.

Participants were advised that only de-identified group data would be recorded for project related reports (see Appendix Five, Appendices Supplement).

Results

A total of 33 patients were enrolled in the study. Follow-up data were available at 6 months for 18 intervention and 13 control patients and 12 months data was available for 18 intervention and 11 control participants. One intervention patient withdrew due to social reasons (n=1) and three control patients withdrew due to declining health status due to respiratory disease (n=3) with one being admitted to a residential aged care facility.

We analysed data on an intention to treat basis. We made no attempt to impute “missing” data from those participants who were lost to followup.

Quality of life: The St George’s Hospital and Respiratory Questionnaire (SGRQ)

Data summarised in Table 2 were analysed with repeated measures analyses of variance (ANOVAs), and indicated that there was not a statistically significant time x group interaction effect for the intervention group relative to the control group at 6 or 12 months ($p>0.05$) on the SGRQ total score or any of the subscales.

Table 2: St George’s Hospital Questionnaire (Descriptive Statistics)

St George Respiratory Questionnaire Subscale		N	Mean	Std Deviation
Symptoms (baseline)	Control	13	46.32	23.37
	Intervention	19	45.35	20.92
Symptoms (6 month follow up)	Control	13	40.40	29.47
	Intervention	18	45.65	18.12
Symptoms (12 month follow up)	Control	11	42.28	32.48
	Intervention	18	44.02	22.69
Activity (baseline)	Control	13	63.85	20.55
	Intervention	19	64.08	22.28
Activity (6 month follow up)	Control	13	63.13	21.05
	Intervention	18	64.36	20.54
Activity (12 month follow up)	Control	11	53.16	20.29
	Intervention	18	66.36	24.95
Impact (baseline)	Control	13	37.29	23.98
	Intervention	19	32.92	16.67
Impact (6 month follow up)	Control	13	32.07	23.20
	Intervention	18	26.53	13.04
Impact (12 month follow up)	Control	11	27.83	22.27
	Intervention	18	29.42	16.18
Overall (baseline)	Control	13	46.84	21.35
	Intervention	19	44.44	16.46
Overall (6 month follow up)	Control	13	42.87	22.08
	Intervention	18	41.17	12.53
Overall (12 month follow up)	Control	11	37.92	21.04
	Intervention	18	43.04	17.47

However, the results of the ANOVAs also revealed a significant time effect for the Total SGRQ score over the initial 6 month period, $F(29) = 5.45$, $p < 0.01$, which was not maintained at 12 months ($p > 0.05$). This indicated that the quality of life of patients in both groups improved over the first 6 months of the trial. As can be seen in Figure 1, the control group also displayed clinically significant changes between 6 and 12 months. This warrants further

investigation as the general practitioners in the control group between 6 and 12 months implemented a number of care plans for their patients as part of usual practice (n= 6).

Repeated measures analyses of variance (ANOVAs) also revealed a significant time effect for the Impact subscale over the initial 6 month period, $F(29) = 10.81$, $p < 0.01$. As can be seen in Figure 2, Both the control and intervention groups recorded significant improvements in this domain and this was maintained at 12 months, $F(26) = 4.2$, $p < 0.05$.

Statistical analyses did not reveal any statistically significant changes for either group on the other subscales (Activity, Symptoms) of the SGRQ.

Figure 1: Mean SGRQ Total Scores at baseline, 6 and 12 months

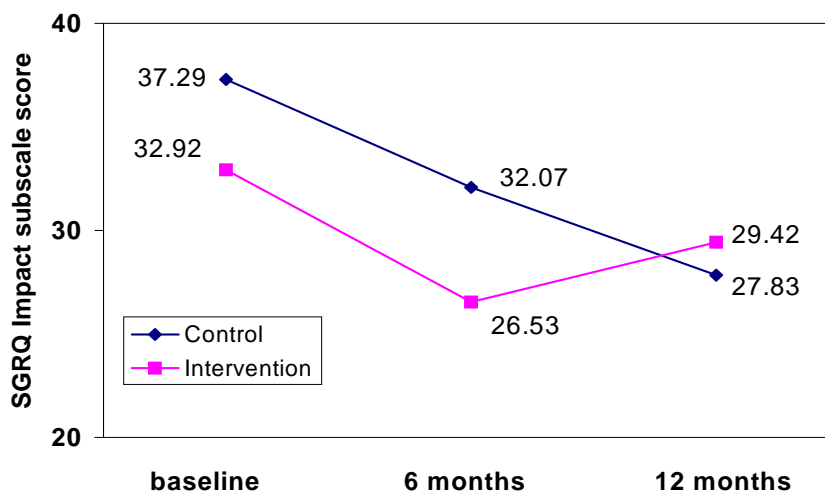
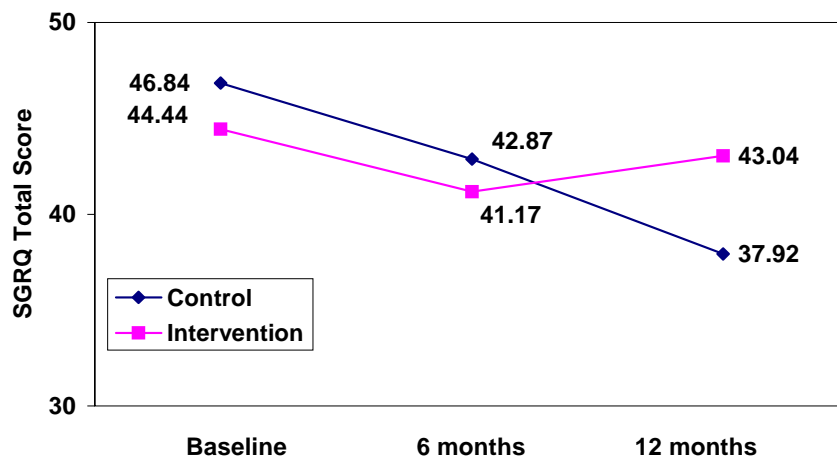


Figure 2: SGRQ Impact Scale Score at baseline, 6 and 12 months

Exercise tolerance: The 6 Minute Walk Test

Examination of the data revealed a clinically significant (>50m) improvement in CDSM patients' 6 minute walk distance at 6 months (58.38 metres) and this was further improved at 12 months (75 metres) . Participants in the control group did not achieve a clinically significant improvement at 6 months (21 metres) or at 12 months (35.3 metres). This clinically significant improvement in the "six minute walk" achieved in this Demonstration Project is a very encouraging result as it is a measure of the improvement in physical function of the intervention group. As an objective measure the six minute walk proved to be a powerful motivator for patients. Further analysis of this material is the subject of an Honours thesis. Interestingly, there was significant negative correlation ($r = -0.4$, $p < 0.05$) between age and best 6 minute walk distance at baseline. However at 6 and 12 months the relationship between age and 6 minute walk distance was not significant, suggesting that improvements in exercise tolerance are not associated with age. This is an important observation if physical function and exercise endurance can be improved irrespective of age given the burden of disease in the older age groups.

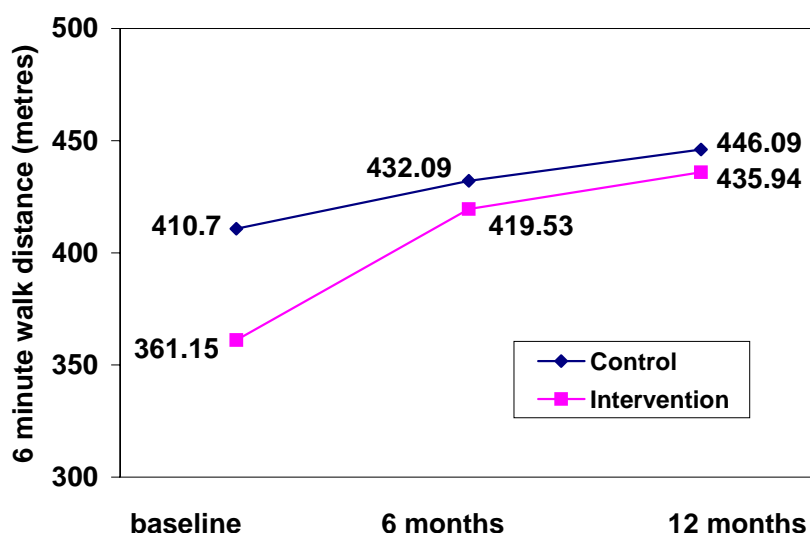


Figure 3: Mean 'Best' 6 minute walk distance (m) at baseline, 6 and 12 months

Psychiatric morbidity: General Health Questionnaire

Overall levels of psychiatric morbidity

At baseline, there was no significant difference between the control and intervention group in terms of levels of overall psychiatric morbidity ($p > 0.05$).

Repeated measures ANOVAs indicated that there was not a statistically significant time x group interaction effect for the intervention group relative to the control group at 6 or 12 months ($p > 0.05$). Nevertheless, the trend was that morbidity did increase for the control group between 6 and 12 months, albeit to a statistically non-significant degree.

Table 3 Mean GHQ scores

	GHQ Baseline	GHQ 6 months	GHQ 12 months
Control	n= 13	n=9	n=11
mean	4.23	2.33	3.18
SD	5.05	2.82	5.28
Intervention	N=19	N=17	N=18
mean	3.52	2.76	2.66
SD	3.93	3.96	3.64

T- tests for independent samples indicated that there was not a significant difference between the control and intervention groups at baseline.

Frequency of cases reporting clinically significant distress

However, in terms of caseness there was some discrepancy as 8 of the 19 participants in the Intervention group (42.1%) met the criteria of clinically significant psychiatric distress at baseline. Only four of the 13 control group members also met the criteria for caseness at baseline (30.7%).

At 6 months, the rate of caseness reported by the intervention group reduced from 43% to 23.5%. The prevalence of cases meeting the criteria for clinically significant distress increased slightly in the control group over this time (from 30.7% at baseline to 33.33% at 6 months).

However, the marked benefits seen at 6 months for the Intervention group in comparison with Control patients diminished at 12 months. At this time, the prevalence of cases reported by the Intervention group rose slightly to 27.7% whilst examination of rates amongst the Control group revealed similar levels (27.27%).

Self-efficacy: The COPD Self efficacy Scale

Repeated measures ANOVAs indicated that there was not a statistically significant time x group interaction effect for the intervention group relative to the control group at 6 or 12 months ($p>0.05$) on any of the CSES subscales.

As can be seen from Figure 4, significant time effects were evident at 6 ($F_{24} = 13.17$, $p<0.01$) and 12 months ($F_{22} = 4.80$, $p<0.05$) for the Physical Exertion subscale. This indicated that patients became more confident (lower scores indicate more confidence) in their ability to manage physical exertion. There was not a statistically significant result.

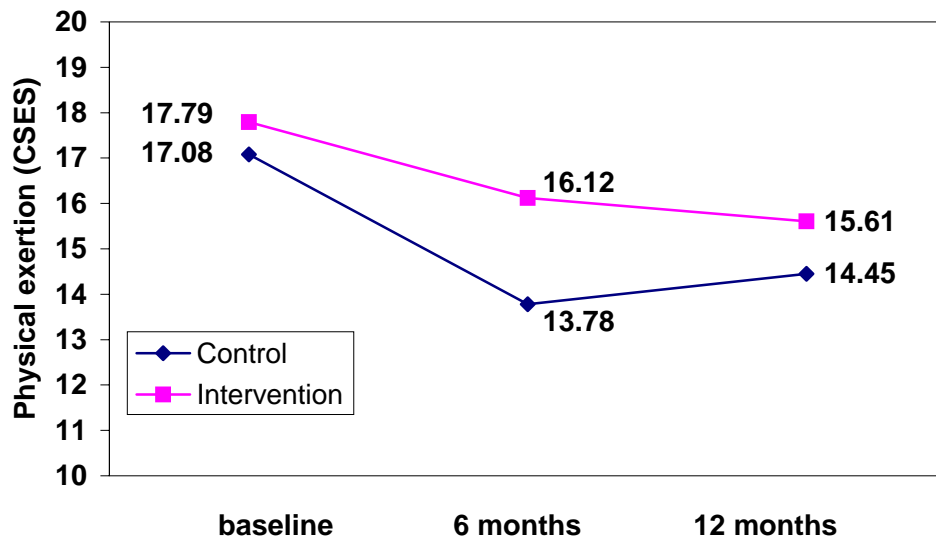


Figure 4: Time effect for Physical Exertion subscale of the COPD Self-Efficacy Scale

Figure 5, displays the significant time effects demonstrated at 6 ($F_{,24} = 9.29, p < 0.01$) and 12 months ($F_{,22} = 5.68, p < 0.01$). This indicates that patients were more confident (lower scores indicate more confidence) in their ability to handle risk.

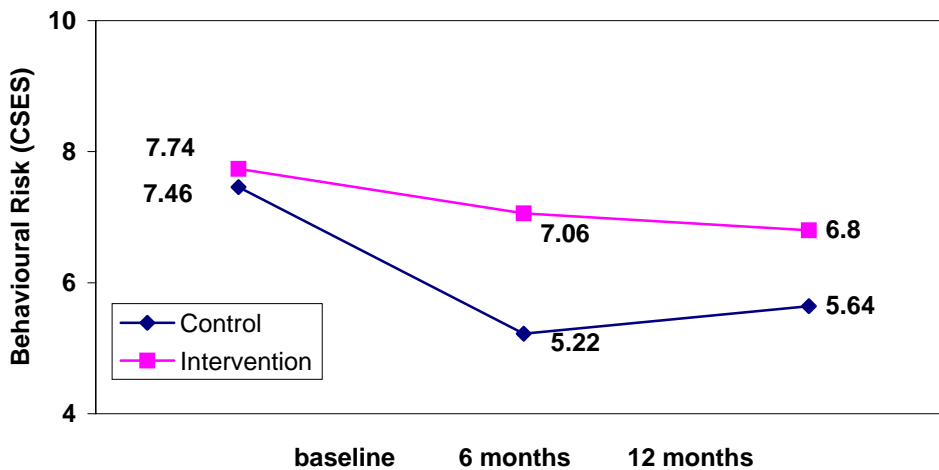


Figure 5: Time effect for Behavioural Risk subscale of the COPD Self-Efficacy Scale

Lung Function Tests

Repeated measures ANOVAs indicated that there was not a statistically significant time x group interaction effect for the intervention group relative to the control group ($p > 0.05$) when considering scores on the lung function tests.

However there was a significant time effect for FEV1 at 12 months, $F(26) = 6.18$, $p < 0.01$.

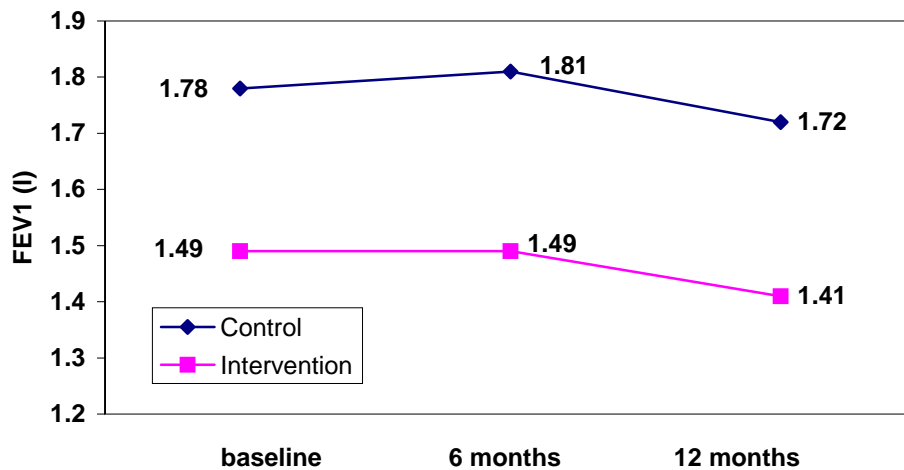


Figure 6: Mean FEV1 scores at baseline, 6 and 12 months

The analyses also revealed significant time effects for Inspiratory Capacity at 6 months, $F(23) = 6.48$, $p < 0.05$

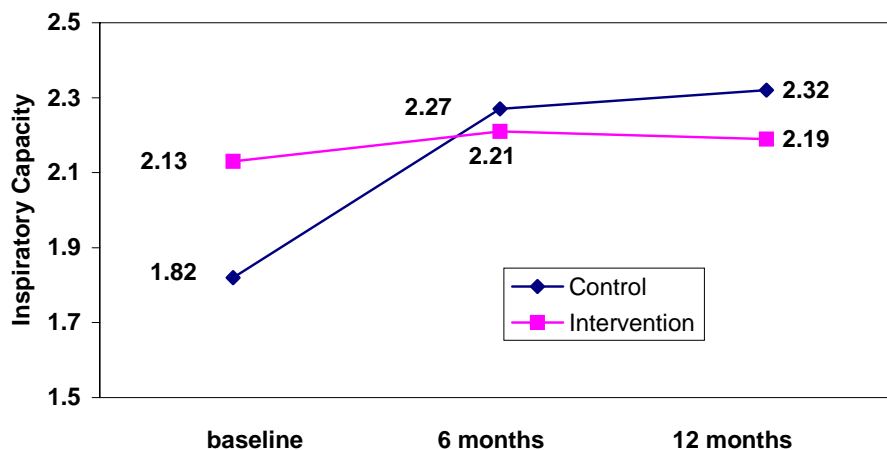


Figure 7: Mean Inspiratory Capacity scores at baseline, 6 and 12 months

A summary of the descriptive statistics associated with FEV1 and Inspiratory Capacity can be seen in Table 4.

Table 4: Mean FEV1 and Inspiratory Capacity scores at baseline, 6 and 12 months

Forced Expired Volume in 1 second FEV1		N	Mean	Std Deviation
FEV1 (baseline)	Control	12	1.78	.61
	Intervention	18	1.49	.77
FEV1 (6 month follow up)	Control	12	1.81	.51
	Intervention	18	1.48	.75
FEV1 (12 month follow up)	Control	11	1.72	.60
	Intervention	18	1.41	.76
Inspiratory Capacity				
IC post-bronchodilator (baseline)	Control	9	1.82	.71
	Intervention	17	2.13	.75
IC post-bronchodilator (6 month follow up)	Control	12	2.27	.67
	Intervention	18	2.21	.77
IC post-bronchodilator (12 month follow up)	Control	11	2.32	.82
	Intervention	18	2.19	.86

Partners in Health Scale

The PIH was administered as part of the intervention and was utilised in conjunction with the cue and response and problems and goals to develop the individual patient's self-management plan. The PIH scores indicated an improvement in knowledge about their health condition from 4 to 1.5 and about the treatment of their health condition from 1.5 to 0.5. All patients indicated at both baseline and 6 month followup that they always take their medicines as asked by their doctor. Items 7, 8 and 9 which relate to monitoring and managing symptoms and signs of their condition all move towards an increase in the PIH score from baseline. The higher scores immediately post the pulmonary rehabilitation programme and prior to the implementation of their care plans may reflect a greater knowledge and awareness of their disease and signs and symptoms they should have been monitoring and a recognition that they were not recording and documenting these symptoms. The correlation of these PIH results with the other measures used in the study is the subject of further analysis as part of an Honours thesis.

Table 5: PIH scale scores at baseline and 6 months in the intervention study arm

Item Number	Item description	Baseline Total (median score) n=18	6 month Followup Total (median score)
1	What I know about my health condition	4	1.5
2	What I know about the treatment of my health condition	1.5	0.5
3	I take my medication as asked by my doctor	0	0
4	How I share in decisions made about my health condition	0	1
5	I arrange appointments and attend appointments as asked by my doctor or Health Service Provider	0	0
6	My understanding of why I need to check and write down my symptoms	1	2
7	I check and write down my symptoms	4	7.5
8	My understanding of what to do when my symptoms get worse	1.5	2
9	I do the right things when my symptoms get worse	0.5	1.5
10	How I deal with the effects of my health condition on my physical activities	1.5	2
11	How I deal with the effect of my health condition on the way I feel and how I mix with other people	0	0
12	My progress towards living a healthy life	1	1

(Scale: 0 Very Good; 4 = Fair 8 = Very poor.)

Table 6: Results of Cue and Response at initial assessment by health professional and patient in intervention study arm

Item Number	Item description	Intervention Baseline Health Professional (median score) n=13	Intervention Baseline Patient (median score) n=13
1	Knowledge of Illness	2	2
2	Knowledge of Treatment	1	1
3	Ability to take Medication	0	0
4	Ability to share decisions	1	1
5	Ability to arrange and attend appts	0	0
6	Understanding of why the need to observe	2	2
7	Ability to observe, measure and record symptoms	4	6
8	Understanding of what to do when symptoms get worse	1	1.5
9	Ability to take the right action when symptoms get worse	1	1.5
10	Ability to manage the impact of the condition on physical activities	2	1.5
11	Ability to manage the social and emotion aspects of my life.	1	0.5
12	Progress towards adopting habits that improve my health	1	1

(Scale: 0 is very good; 8 = very poor.)

Beliefs about Medicines Questionnaire

Appropriate use of medicines is important to the self-management of many chronic illnesses in this study we utilised the Beliefs about Medicines (BMQ) Scale which has been validated for use in chronic illness setting. This scale comprises two 5 item scales assessing patients' beliefs about the *necessity* of prescribed medicine for controlling their illness and their *concerns* about potential adverse consequences of taking it

Examples from the *necessity* scale

"My health at present depends on my medicines"

"My medicines protect from becoming worse"

Examples from the *concerns* scale

" I sometimes worry about the long term effects of my medicines"

"I sometimes worry about becoming too dependent on my medicines"

Refer Appendices Supplement for the scale. It is proposed that adherence decisions are influenced by a cost-benefit assessment that the patient makes in which their personal beliefs about the *necessity* of the medicine for maintaining or improving health are balanced against *concerns* about the potential adverse effects of taking it. In this study of patients with moderate to severe respiratory disease the BMQ revealed that 24% had strong concerns about their medicines based on beliefs about the dangers of dependence or long-term effects. This has important implications for adherence to pharmaco-therapy with 1 in 5 patients in this group of COPD patients where the concerns about their medicines outweighed the perceived benefits. There were no differences between the two groups in this regard at baseline, at 6 months in the intervention group this had improved to 1 in 10 but had risen again at 12 months to 1 in 5. The control group did not change across the study.

Table 7 below highlights that overall the patients' core beliefs and attitudes about perceived risk and benefit from their medicines was largely unchanged across the study. The relationship with the finding in the PIH score were all intervention patients indicated that they always took their medicines as asked by their doctor warrants further investigation.

Table 7: BMQ scores for necessity and concerns scale

	Baseline	6 months	12 months
Intervention	n=19	n=17	n=18
Necessity scale	9.47	8.82	9.5
Concerns	16.78	19.11	17.94
Control	n=13	n=13	n=11
Necessity scale	10.23	9.92	10.18
Concerns	19.15	19.00	18.27

- lower scores on the necessity scale indicate higher levels of perceived necessity for the medicine ie benefits
 - higher scores on the concerns scale indicate lower levels of perceived concerns for the medicines
- Table 8 provides a summary of selected medicines in the intervention and control groups. Interestingly, in this at risk population for osteoporosis in the control group at the start of study there were 3 women receiving HRT and they continued on therapy at 12 month followup. In the intervention group 2 patients were receiving HRT at the start of the study the

patient receiving the Premarin® formulation ceased during the study. During the course of this study the randomised controlled trials regarding the role of HRT were published sparking an international debate which resulted in changes to guidelines with respect the role of HRT for long term use for osteoporosis. The table highlights the different pharmacotherapy prescribing patterns of the two groups, for example the much higher rates of medicines for the prevention of osteoporosis and fracture may indicate a greater focus on prevention by the doctors in the control group or simply reflect a higher prevalence of patients with osteoporosis. Also in light of the improvements seen in the control group at 12 months it is interesting to note the 50% decrease in antidepressant use and also that there were no patients on oral steroids.

Table 8 Summary of selected medicines at baseline, 6 months and 12 months

Medication	Baseline %		6 month %		12 month %	
	Intervention n= 19	Control n=14	Intervention n=18	Control n=13	Intervention n=18	Control n=11
Inhaled corticosteroids	74	57	61	69	61	64
Seretide*	53	21	39	15	44	9
Antidepressants	16	36	11	23	16	18
Benzodiazepines	11	14	11	15	5	18
LABA	68	29	61	54	56	36
Oral prednisolone	5	14	0	8	11	0
PPI^	26	29	28	23	39	36
HRT	11	21	5	21	5	21
Bone resorptive, calcium and Vitamin D	22	43	17	54	22	64
Tiotropium (Spiriva)	11	7	67	38	67	36

*Seretide® is a combination long acting beta-agonist and corticosteroid and comes in different strengths and delivery devices

^ LABA – long acting beta-agonist, includes salmeterol, eformoterol

Case Studies

Case Study 1

The participant is a 65-year-old man living with his wife who is very supportive. His diagnoses are asthma (probable), COPD/ emphysema, epilepsy (last seizure 5 years ago), glaucoma, osteoarthritis and osteoporosis. He has smoked (5/day) from the age of 21 and stopped at age 35. No family history of asthma. He is easily prone to develop upper respiratory tract infections. His chest X-ray suggests COPD. He develops a wheezy state with anxiety, frustration, excess dust, soap, perfume, cleaning agents and sprays. He produces morning sputum which is sometimes discoloured or streaked red.

His current medications include:

Carbamazepine (Tegretol[®])
100mg twice daily
Salbutamol inhaler (Ventolin[®])
2 puffs when required
Xalatan[®] Eye Drops
1 drop both eyes at night
Glucosamine (Osteo-Eze[®])
Garlic/horseradish
Multivitamins
Vit C 1000mg/day

His CCSM assessment included:

- Flinders Partners in Health scale (PIH)
- Flinders Cue and Response Interview and Problems and Goals Assessment
- These were completed by the practice nurse and CCSM study nurse.

Partners in Health scale

This was completed at the GP surgery.

It revealed that the patient perceived he had a fair to very good knowledge of his condition and treatment, understanding of recording symptoms and response to worsening symptoms. He only rated "fair" for dealing with the effects of his disease on physical activities.

Cue and Response Interview form

This revealed that the patient did have a good understanding of his condition and treatment as good or better than revealed in the PIH.

Problems and Goals Assessment

The patients identified his main problem as lack of exercise and rated this as a 5 (0-8) on the scale of interfering with daily activities. His stated goal was to join group exercise once per week for 1 hour.

Care Plan

This was formulated by his GP using his practice care plan procedure. It stated goals as increasing exercise (primary goal), maintain maximal level of independence, and use his acquired knowledge from pulmonary rehab to improve his CCSM.

Both the patient and his wife attended all the sessions in the pulmonary rehab program. The patient was very motivated and was very pleased with the learning from the educational sessions. He was very motivated to do the exercise program associated with the pulmonary rehab program, tailored to suit his needs. He stated that the self-management techniques learned through the program had a "huge improvement" of his condition. The lectures gave him new ideas and the exercises were "invaluable".

His wife stated she found participating in the lectures has eased the panic she used to experience when the patient had episodes of breathlessness and feels more at ease with the problem.

Post Rehabilitation Program Assessment (Pulmonary Rehab Nurse)

After completing the study (RGH pulmonary rehabilitation programme the following had been noted.

He was walking for 30mins every second day and if uses salbutamol puffer prior to exercise then his exercise tolerance is improved. No cough/wheeze/chest pain/shortness of breath. His GP noted the following:

- Seasonal rhinitis
- Phlegm minimal and clear
- Aware of signs of infection
- Correct open mouthed puffer technique
- Excessive use 8-9 times some days
- Practices deep breathing exercises

Management of breathing adequate was noted by the pulmonary rehabilitation nurse.

Discussion

Of special note is that this patient was enthusiastic to continue exercise and the CCSM study nurse was able to provide him with information of a suitable supervised program. The patient was empowered to take this information to his GP, and request a referral in keeping with the shared decision making and goal setting from the processes of assessment and care planning. His first appointment in this exercise program has occurred and the feedback is positive. It has been rewarding to follow this patients progress.

Figure 8 Study Participants undertaking exercise program as part of pulmonary rehabilitation program



Case Study 2

The participant is a 67 year old married woman. Her diagnoses included COPD, hypertension, anxiety, gastro-oesophageal reflux disease and osteoporosis. She first noticed shortness of breath and developed bronchitis 11 years ago. She ceased smoking 20 cigarettes per day 10 years ago.

Her occupation was shopwork and caring for the family. Her breathlessness interferes with housework and walking. She worries about going on holidays. She usually has required a course of oral steroids once a year.

Her current medications include:

Enalapril (Renitec[®]) 20mg bd

Indapamide (Natrilix[®] SR) 1.5mg daily

Alendronate 70mg (Fosamax[®]) once weekly

Seretide accuhaler[®] 500/50 powder 1 puff twice daily

Oxis Turbuhaler[®] 12mcg 1 inhalation twice daily

Diazepam (Ducene[®] 5mg) ½ daily prn

Prednisone 25 mg twice daily

Atrovent UDV[®] adult Solution 500mcg 1 via nebuliser four times a day when required

Tiotropium (Spiriva[®]) capsule 18mcg 1 cap inhaled each morning

Ventolin nebules 5mg/ 2.5ml 1 nebule 4hrly when required

Allergies and side-effects:

Erythromycin- vomiting

Verapamil (Isoptin[®]) - rash

Penicillin- anaphylaxis

Trimethoprim- Nausea

Her CCSM assessment by the GP included:

- Flinders Partners in Health scale (PIH)
- Flinders Cue and Response Interview
- Problems and Goals Assessment

Partners in Health

This was completed by the GP at his surgery.

It revealed that the patient perceived herself to have very good knowledge of her health condition and treatment and was compliant. She was not regular at writing down symptoms and only "fair" at dealing with the effects of her health condition on physical activities and social life.

The Cue and Response

The GPs assessment scores in the cue and response were generally congruent with the patient's scores. The GP thought however the impact of the condition on the patient's physical activities, was dealt with better by the patient than the patient's own assessment.

Problems and Goals Assessment

The identified problems were inability to measure and record symptoms, lack of confidence and dyspnoea. These prevented her travelling and impacted on her social life. This

generates feelings of frustration. She rated these as problems that often interfere with daily activities.

She desired increased independence and confidence with activities.

Her goals were set at increased walking and exercise tolerance.

Care Plan

This was formulated by her GP using his practice care plan procedure.

Problem: Unable to have short walks

Goals: to improve exercise tolerance and work around disability

To optimise treatment

To improve ability to assess and manage breathlessness

Management Steps

To educate and understand illness and medications

To encourage compliance

Check device techniques

Treat exacerbations early

Problem: Unable to attend Crows Footy games. Low confidence due to breathing problems experienced frustration

Goals: To overcome inferiority complex and embarrassment

To accept illness and work around disability

Management Steps: Counselling

Relaxation

Breathing techniques

Referral to a psychologist specializing in conditions associated with COPD.

Progress The patient attended all the sessions in the pulmonary rehabilitation programme

The patient was very motivated and was very pleased with the learning from the educational sessions.

She stated that she was pleased to learn ways to deal with her anxiety. She realized that even with her breathlessness she was able to exercise. This improved her general well being.

Post Rehabilitation Program Assessment (Pulmonary Rehab Nurse)

The patient found the course very helpful.

At the time of assessment the patient had a chest infection.

It was noted she had an inspiratory wheeze with green sputum

Her cough was productive and moist.

She had increased SOB at present with the infection.

She had no swelling of ankles or nocturnal dyspnoea.

She had some chest tightness.

Generally the patient stated after the education and training she has had less problems with walking & SOB

A little more SOB was present with the current infection.

She made a positive step in her self-management by joining a gym with her sister, attending once/week.

She practices deep breathing exercises when she remembers.

Applies pursed lip breathing with effect. These techniques were learned at the pulmonary rehabilitation course.

She was more independent with cooking and cleaning.

She suffers anxiety. The respiratory nurse noted she takes her medication regularly and practices relaxation.

Discussion

This patient requested at the end of the course for information on places where she could continue to exercise. It was this attitude with a fellow participant that encouraged others in the group to make similar efforts. Currently there are a group of study participants that attend a central community based exercise program.

It has been rewarding to follow this patient's progress and her developing positive attitude that is reflective of a group of the study participants who have displayed positive changes to their CCSM.

Figure 9 Study Participants as part of supervised exercise programme developed by physiotherapist in the pulmonary rehabilitation programme.



EPC and PIP – funding changes in general practice

Introduction

In 1999, the Federal Government made significant reforms to primary healthcare by introducing a number of general practice incentive programs that recognise and reward comprehensive primary care. In particular, extra Commonwealth payments were allocated in addition to other income earned by the GPs and their practices, such as patient payments and Medicare rebates.⁴⁸

Uptake of the programmes have been variable and a number of barriers have been identified which include: administration, cost, complexity of the requirements, time, poor communication, location, practice size, practice accreditation, personal and professional beliefs, practice systems, outcomes research, patient factors and other health service providers.

Some factors enable uptake of the programs. These factors include: payments, time, communication, professional practice, patient satisfaction, new items, practice nurses, workload management, streamlined administration, peer support and review and information technology.

The Enhanced Primary Care (EPC) package was introduced to improve preventive healthcare and facilitate co-ordination of care between GPs and other health professionals⁴⁹. The package consisted of a range of Medicare items that came into effect on 1 November 1999.

These new Medicare items address:

Annual health assessments for people aged 75 years and over (and Aboriginal and Torres Strait Islanders aged 55 years and over)

Adult health checks for Aboriginal and Torres Strait Islanders aged 15 to 54 years of age

Care planning for patients with chronic conditions and complex care needs (including discharge from hospital)

Case conferencing between GPs and other health professionals

Home medicines review (also known as HMR or DMMR).

The Practice Incentives Program (PIP) rewards comprehensive, quality care. Practices receive quarterly payments based on:

The use of information technology (IT)

Access to after hours care

Student teaching

Participation in the National Prescribing Service (NPS) quality use of medicines program

Rural loading

Practice nurses.

Practices can only receive PIP payments if they are accredited or working towards accreditation against the Royal Australian College of General Practitioners' (RACGP) *Standards for General Practices*.

As part of the PIP, the government also introduced Service Incentive Payments (SIP). SIP items are claimable for:

Annual cycle of care for people with diabetes

3+ visit plan for asthma

Cervical screening

Mental health initiative.

⁴⁸ http://www.hic.gov.au/providers/incentives_allowances/pip.htm

⁴⁹ Blakeman, TM; Harris, MF; Comino, EJ and Zwar NA. *Evaluating general practitioners' views about the implementation of the Enhanced Primary Care Medicare items*. MJA 2001; 175:95-98.

EPC and SIP items are targeted specifically at the provider and aimed at directly influencing patient care. In contrast, PIP items are more practice based.

Although the number of general practices signed up for the PIP continues to increase slowly, August 2004 statistics show that there are still only 4670 practices signed up to the program and a recent survey of 148 GPs found that 20% were not participating in PIP or EPC initiatives at all.

As at August 2004, sign on to the SIP program has been promising, but the number of payments claimed has been small.

Of the EPC items, health assessments are more popular than care planning or case conferencing. This reflects the relatively easier implementation of health assessments – most are straightforward and are not associated with difficulties encountered when liaising with other healthcare professionals.⁴⁵ In the first two years of the items being available, 18% of the population 75 years and over had a health assessment. Health assessments are generally seen as acceptable, practical and appropriately remunerated.

When the EPC items were first implemented, 10% of GPs were responsible for 50% of the health assessments claimed and 10% claimed 80% of all care plans. Case conferencing has not been extensively used and has been described as too complex, time consuming and poorly remunerated for the effort involved.

In order to streamline their ease of use, the programs have had several amendments since their introduction. A government 'Red Tape Taskforce' was set up to review the burden of red tape in general practice. The recent administrative changes to the EPC and PIP programs are underpinned by the recommendations of this taskforce. Significant changes to the programs have not yet occurred and GPs are still faced with several barriers to their successful implementation.

Further improvements to the PIP and EPC will also be developed and implemented towards the end of 2004, including chronic disease management items at two levels, simplifying arrangements for PIP registration, and updating current requirements for IT and after-hours service payments. This will be important for developing the CCSM.

Barriers to uptake of government incentives

Administration

There is an increasing burden on GPs arising from paperwork, forms and compliance tasks. The Productivity Commission⁵⁰ describes an *Australian Doctor* survey that says in Australia about 27% of GPs spend more than seven hours a week on unpaid Commonwealth and State Government paperwork and other administrative requirements, 31% spend from four to seven hours, and 42% spend three hours or less. In a similar survey on the Practice Incentives Program, 49% reported spending three hours or more a week, and 39% reported spending up to two hours a week doing paperwork associated with the program.

A 2002 study also suggested that almost every GP consultation would incur some type of paperwork or administrative task. Some doctors estimate the time spent on paperwork and associated tasks at 5 hours to 2 days per week, with other doctors suggesting they spend half their working week attending to administrative tasks. These administrative tasks are mostly unpaid and completed on a doctor's own time¹⁶.

It is no surprise then that a large number of GPs find the 'red tape' associated with government initiatives such as EPC and PIP as an extra burden for small or no remuneration. A recent survey of 148 GPs found that 50.7% found EPC red tape and 37.8% found PIP red tape "heavy and unmanageable".

The GPs feel that the time taken in administrative tasks could be better spent on patient care.

⁵⁰ Productivity Commission. *General practice administrative and compliance costs, research report*. Canberra: Commonwealth of Australia, March 2003.

The Productivity Commission found that incentive programs aimed at encouraging GPs to provide comprehensive quality care, e.g. vocational registration, PIP and EPC accounted for over three-quarters of a GPs annual administrative costs.

There are also other unpaid red tape demands on GPs including the government's new MedicarePlus initiative where GPs co-ordinate referral of patients on EPC care plans to allied health professionals and dental services.

GPs generally see EPC activities such as health assessments as appropriately remunerated, however, there are some concerns about the level of remuneration for care planning and case conferencing with GPs stating that they are complex, time consuming and poorly remunerated for the effort involved.

The complexity of the requirements for some elements of the programs, e.g. care plans was a barrier to uptake. In addition, keeping abreast of amendments to the programs and additional requirements is an ongoing and time-consuming administrative task.

Some EPCs such as care plans and case conferencing are not taken up as readily as they could be because of poor communication between GPs and other health professionals.

There is a lack of established formal and informal communication pathways.

GPs have a chronic lack of time. Ongoing practice commitments limit the time available to perform EPC. A recent survey demonstrated that GPs feel that the demand for acute care in their practice is often so high that they are unable to dedicate the time required for EPC.

Practice size is a critical factor in program uptake. Most components of PIP payments are proportional to practice size. Smaller practices do not have the efficiencies associated with economies of scale and administrative and nursing support .

In addition, PIP and EPC require initial investment that provides better returns if they are used by a large number of GPs.

Practice accreditation

Since January 2001, accreditation or registration for accreditation is compulsory for practices to claim the incentives²². When practice accreditation became compulsory for PIP in February 2002, more than 600 practices dropped out of the program²³. There is an initial cost and administrative burden that may be a barrier to accreditation.

Beliefs

A recent survey of 148 GPs found that 26.7% would not take part in the government's incentive program because they were "philosophically opposed to incentives-based payments". Some GPs also believe that these initiatives are further reforms to enhance the government's control over general practice⁵.

Some GPs consider that SIPs are 'an insult to the doctor's intelligence' because it implies that GPs are currently not treating their patients as they should. In particular, SIP and EPC are often negatively perceived for being "overly prescriptive", sometimes "clinically inappropriate" and "influencing the GPs clinical decision-making process" which most doctors find "offensive and inadequate". GPs resent having a framework imposed on their clinical practice and hence their ability to make appropriate clinical decisions. This framework often does not take into account the practice circumstance or the GPs clinical judgement.

Practice systems

Most GPs have a positive attitude to the EPC concept, however the systems and procedures required are complex to set up and to carry out. It is difficult for GPs to develop these systems and policies for introducing EPC and PIP items into their everyday practice.

Outcomes research

There is little or no data on the effectiveness of EPC and PIP/SIP items. Considering the time and administrative burden, some GPs are questioning the benefit in terms of positive outcomes.

Patient factors

Some doctors are concerned about patients' lack of awareness and understanding of the items and are worried that patients may feel threatened. This view is strengthened by the government's EPC evaluation project, which demonstrated that consumers were mostly

unaware of the new items until approached by their GP. There was almost no demand from patients for health assessments and care plan.

Enablers to Government incentives

Payments

Some GPs consider the financial incentives as a motivating factor to use the items (although most GPs were more strongly motivated by improved outcomes for patients and the chance to operate more effectively in a preventive health and multidisciplinary environment), and some GPs see the financial incentives as rewarding them for already good clinical practice.

Time

GPs are pleased that the new MBS items facilitate extra time to be spent on chronic conditions and complex needs.

Communication

GPs were supportive of the fact that EPC will enhance communication between GPs and other health professionals and GPs, their staff and other health providers agree that EPC will provide the opportunity for more holistic health care.

Patient satisfaction

Being a part of EPC conveys a greater involvement of the patient and GPs recognise an improved doctor-patient relationship and the potential positive effects on the patient's quality of life.

In particular, patient (and carer) satisfaction with health assessments is generally high. The EPC evaluation study reported that 86% of patients reported increased confidence in their GP, 89% a better understanding of self-management, 68% learnt something new and 74% gained a better understanding of their conditions. In addition, 64% of patients reported a better quality of life.

Professional practice

GPs recognise that EPC is all about formalising and receiving payment for good clinical practice. It also influences the way GPs approach their patients with chronic conditions.

New items

Introduction of a new chronic disease management item would potentially increase uptake of incentives. A survey of 148 GPs found that 57% would use a new Medicare item for chronic disease management. It has been suggested that GPs would be very supportive if some SIP items were replaced with generic disease management items.

Practice nurses

The practice nurse is critical to the successful implementation and integration of EPC items into practices and would facilitate GPs to increase the uptake of EPC and PIP.

Workload management

Employing extra staff, extending the hours of existing staff to assist with tasks has been shown to assist with EPC uptake. Better use of computer systems for recalls and reminders has also been shown to streamline procedures.

Administration

It has been suggested that simplification of PIP as recommended by the government's Red Tape Taskforce would improve EPC and PIP uptake. However a recent survey of 148 GPs found that only 6.7% of GPs thought that administrative changes to PIP would encourage them to participate.

Peer support and review

Peer support and review has been identified as a way to increase program uptake. GP groups overseas have experienced great success with the support of their peers through local 'GP collaboratives'.

Information technology

Better use of information technology would accelerate administrative tasks. For example the ability to complete and submit forms electronically would be seen as a positive progression.

Discussion

Any rehabilitation or intervention programme is likely to have psychological benefits as well as physical benefits, and these benefits are likely in turn to encourage greater adherence and more successful management of therapy. Lacasse⁵¹ reviewed evidence (up to 1996) for the benefits of components of pulmonary rehabilitation. He concluded that there was overwhelming evidence that muscle specific exercise training improved functional capacity and quality of life, and some evidence that psychosocial support could improve patient outcomes suitable option for the majority of COPD patients. This was certainly evidenced in this study where the major goal identified through the cue and response and subsequently on the care plans was the desire for an ability to improve exercise tolerance and physical functioning. The patients themselves identified the following:

“That I must keep up my exercise and work to my own capacity.”

“How important it is to take my medication and to talk about any change in my condition with my doctor.”

“Instead of being afraid of over-exerting myself, I realise exercise is beneficial and essential to a feeling of well being. I am very pleased to have taken part in the Rehabilitation course.”

“Medication control. Exercise benefit.”

“I now take my medication with greater confidence because I know a bit more now, which helps me to feel better in myself and not worry so much.”

Van den Boom *et al* showed that the likelihood of patients consulting for COPD respiratory symptoms is more strongly influenced by QOL than respiratory symptoms per se.⁵² The survey instruments used in this study also showed that the patients despite having moderate to severe airways disease focussed more on the QOL aspects and importantly again physical capacity. What this Demonstration Project study demonstrated was that patients with severe respiratory disease were able to improve their physical capacity and undertake (and want to undertake) supervised exercise programmes.

In terms of the risk of hospital readmission, it has been found to be significantly greater amongst patients with poorer QOL, and moreover this result was independent of lung function.⁵³ We did not have anyone in the study admitted to hospital during the course of the study, however one patient in the control group was admitted to a high level residential aged care facility. One patient in the control group fell and fractured both forearms.

Bosley reported that among 93 patients using domiciliary nebulisers low quality of life (as measured by the St George's Respiratory Questionnaire (SGRQ)) was associated with worse adherence to therapy.⁵⁴ An observation in this study from the Satisfaction with Medicines Scale was that most patients were managing their own medicines and only one

⁵¹ Lacasse Y, Guyatt GH, Goldstein RS. The components of a respiratory rehabilitation program: a systematic overview. *Chest* 1997; 111:1077–88.

⁵² van den Boom G, Rutten-van Molken MP, Tirimanna PR et al. Association between health-related quality of life and consultation for respiratory symptoms: results from the DIMCA programme. *Eur Respir J* 1998;11:67–72.

⁵³ Osman LM, Godden DJ, Friend JA et al. Quality of life and hospital re-admission in patients with chronic obstructive pulmonary disease. *Thorax* 1997; 52:67–71.

⁵⁴ Bosley CM, Corden ZM, Rees PJ et al. Psychological factors associated with use of home nebulized therapy for COPD. *Eur Respir J* 1996; 9:2346–50.

person in each of the arms of the study was utilising a dosette aid. In both cases these patients had the least understanding and knowledge of their medicines. Whilst this is a small sample it resonates with the findings of a recent study at the Bundoora Centre for Gerontological studies conducted this year which showed that use of dosette aids for medication administration diminished self capacity and knowledge about the individual medicines. Understanding nonadherence from erratic nonadherence, unwitting nonadherence, overuse and intelligent nonadherence is crucial to optimise outcomes from prescribed therapies. In a study in the Netherlands of adult patients with asthma and patients with COPD they found that 20% of the patients using pulmonary medications admitted that they did not know the prescribed daily dosage, 29% thought that their regular daily medication was to be used "short term" or as needed" Only 51% correctly perceived that their medications were to be taken regularly.⁵⁵ Also of note in the control group they used less combination inhaler products compared with the intervention group with no significant differences in compliance and knowledge about the products.

Asthma: certain forms of education and information, together with an individualised management plan, have been found to improve outcomes for children and adults. However, more generic education, without a link to individualised instruction, has not been found to be effective in improving outcomes.^{56,57} One study assessed the benefits of self management patients with fifty six COPD patients. It was found that antibiotic use was higher among the COPD patients with individualised self management plans, but no difference was reported when considering symptom days, dyspnoea or visits to GP.⁵⁸

Another economically based study reported that a personalised hospital practice programme for COPD patients (involving the receipt of illness specific education and management instructions) was followed by lower use of health services and hospital admission, and hence lower cost of care for patients.⁵⁹ After 12 months, COPD patients randomised to receive a management plan have significantly higher (better) scores on the SGRQ, have had significantly fewer GP visits and have used less bronchodilator medication.⁶⁰ In this Demonstration Project we have not been able to demonstrate a change in the SGRQ and it may be that we have insufficient numbers.

This evidence supports the proposition that the effectiveness of COPD education as provided by the RGH-DP comprehensive pulmonary rehabilitation programme can be enhanced with the support of an individualised self management plan using the Flinders model of self-management.

Self-management may improve asthma control and disease-related quality of life (QOL) among patients with asthma in a Dutch primary-care setting, compared with usual care, say researchers from The Netherlands. They evaluated outcomes for 193 such patients (aged 16–60 years) from 19 representative general practices randomized to self management (n = 98) or to usual care over a 2-year follow-up period. The self-management program involved tailored education "over 3 months and personalized written self-treatment instructions. Intent-to-treat analysis revealed that patients in the self-management group experienced a higher mean proportion of successfully treated weeks (78% vs 72% per patient) and fewer limited

⁵⁵ Dekker FW et al. Compliance with pulmonary medication in general practice. *European Respiratory Journal* 1993;6:886-890.

⁵⁶ Lahdensuo A, Haahtela T, Herrala J et al. Randomised comparison of guided self management and traditional treatment of asthma over one year. *BMJ* 1996; 312:748–52.

⁵⁷ Madge P, McColl J, Paton J. Impact of a nurse-led home management training programme in children admitted to hospital with acute asthma: a randomised controlled study. *Thorax* 1997; 52:223-8.

⁵⁸ Watson PB, Town GI, Holbrook N et al. Evaluation of a self-management plan for chronic obstructive pulmonary disease. *Eur Respir J* 1997; 10:1267–71.

⁵⁹ Tougaard L, Krone T, Sorknaes A et al. Economic benefits of teaching patients with chronic obstructive pulmonary disease about their illness: The PASTMA Group. *Lancet* 1992; 339:1517–20.

⁶⁰ Gallefoss F, Bakke PS. Impact of patient education and self-management on morbidity in asthmatics and patients with chronic obstructive pulmonary disease. *Respir Med* 2000; 94:279–87.

activity days (mean of 1.2 vs 3.9 when outliers were excluded). than patients in the usual-care group. There were no significant between-group differences in lung function parameters or general practitioner-diagnosed asthma exacerbations, although the self-management group used a significantly higher number of oral prednisolone courses than the usual-care group. Moreover, self-managed patients demonstrated statistically significant improvements from baseline in overall QOL (as measured using the Asthma Quality of Life Questionnaire [AQLQ]), compared with usual-care patients; a clinically significant between-group improvement was observed in the emotions domain of the AQLQ.⁶¹

Improving the overall management of these respiratory conditions such as COPD can only be achieved by combining the specialist expertise and investigations at secondary care level with the continuity provided by primary care, in a coordinated fashion.⁶² Pulmonary Rehabilitation now has an established role in the management of COPD⁶³ this needs to be marketed to GPs and resourced. Participants in the study from the outer urban parts of the Southern Division of General Practice greatly appreciated transport arrangements for the pulmonary rehabilitation program. All participants who needed transport for any assessments appreciated the assistance provided. This in the overall budget was a small cost but greatly enhanced the opportunity for these people who were already not “managing” and who had identified physical activity as a barrier. Addressing transport costs is an important factor in the success of the programme.

Exercise was an integral component of the rehabilitation/self management process for the patients. The rehabilitation program made them aware of the possibility of continued exercise even with breathlessness being a problem. It is important for the GPs to have access to the services available and this is to a key message in the forthcoming academic detailing service to the GPs.

Pulmonary Rehabilitation has shown clear improvements in exercise capacity and health status, including the 6 minute walk distance.⁶⁴ In this Demonstration Project a clinically significant improvement in the 6 minute walk was demonstrated at 6 and 12 months.

Importantly that 40% of patients are continuing to participate in organised exercise programmes after the intervention. A community based exercise programme was identified and this information was given to the patients with a referral form to be signed by the GP. The patients took the responsibility of informing their GP about the programme, getting the referral signed and then enrolling themselves in the program.

It has been shown in other studies that the improvement in health status associated with pulmonary rehabilitation does not occur in the absence of physical training – therefore successful rehabilitation needs individually prescribed physical exercise training as well as education.⁶⁵ This is a feature of the RGH-Daw Park pulmonary rehabilitation programme. There appears to be a dose-response relationship between physical training and improvement in exercise capacity – however this is not followed immediately by the gain in health status.⁶⁶ It has therefore been important to facilitate ongoing exercise following the conclusion of the rehabilitation programme. In other studies it has been shown that disease

⁶¹ Thoonen BPA, Schermer TRJ, van den Boom G, et al. Self-management of asthma in general practice, asthma control and quality of life: a randomised controlled trial. *Thorax* 2003 Jan; 58: 30-36.

⁶² Holmes WF; Macfarlane J. Issues at the interface between primary and secondary care in the management of common respiratory disease: Introduction. *Thorax* 1999;54:538-539.

⁶³ Morgan M D Singh S Calverley P M et al British Thoracic Society Statement on PR. *Thorax* 2001; 56 827-34
American Thoracic Society. PR – 1999. *Am J Respir Crit Care Med* 1999, 159 1666-82.

⁶⁴ Butland RJ Pang J Gross ER et al 2, 6 and 12 min walking tests in respiratory disease. *BMJ (Clin Res Ed)* 1982; 284: 1607-8.

⁶⁵ Toshima MT, Kaplan RM et al. Experimental evaluation of rehabilitation in COPD: short term effects on exercise endurance and health status. *Health Psychol* 1990 9 237-52.

⁶⁶ Green RH et al. A randomised controlled trial of 4 wks vs 7 wks of PR in COPD. *Thorax* 2001, 56: 143-5

education alone does not improve exercise capacity, health status or medication compliance, although it has been shown to modify bronchodilator use.^{67,68}

There have been several systematic reviews or overviews that reveal the weight of evidence in favour of comprehensive pulmonary rehabilitation for moderate and severe COPD. Most of the benefits have been observed in hospital-based programs, but there is increasing appreciation of the need to develop rehabilitation in the community.⁶⁹

A critical review of comprehensive pulmonary rehabilitation was published in 1999⁷⁰. From the previous 45 years of research, papers demonstrating good patient and outcome descriptors, use of control groups, and use of adequate statistical analyses, were selected for meta-analysis. Of 79 studies 42 had inadequate controls while a number of others had insufficient descriptions or lack of adequate exercise training, leaving 18 articles. There were some further inadequacies, but highly significant and homogeneous improvements in maximal exercise capacity and walking distance were found for up to 9 months after comprehensive PR. There were also homogeneous significant improvements in HRQoL, dyspnoea, fatigue, emotion and mastery. This meta-analysis extended the findings of an earlier meta-analysis⁷¹, though with some more homogeneous results, notably exercise capacity (influenced by starting spirometry heterogeneity in the earlier paper).

Since the 1999 meta-analysis a small number of randomised controlled and other trials have been published. Griffiths⁷² evaluated 200 patients with chronic disabling lung disease (a mix, but mostly COPD) randomly assigned to outpatient comprehensive PR or a "usual medical care" group. As a reflection of the severity of their conditions, 14 patients died before the one-year follow-up, and for some patients data were incomplete. Intention-to-treat analysis, however, showed significant treatment effects for all dimensions of generic and disease-specific health status and for exercise capacity immediately after PR, still significant at one year. There was also less hospitalisation and use of primary care resources over the year of observation.

Green⁷³ studied 44 patients with moderate COPD, randomised to either a condensed four-week or a full seven-week program of comprehensive PR. There were statistically greater benefits accrued over 7 weeks than over 4 weeks in HRQoL, with trends to more exercise capacity.

Finnerty⁷⁴ reported a randomised controlled trial of outpatient PR. There were 36 patients randomised to the active group, who had a 2-hour education and 1-hour exercise training session twice a week for weeks as well as voluntary patient support group attendance and follow-up exercise maintenance sessions at 8, 9, and 10 weeks. There were 29 controls who simply attended weekly outpatient clinical reviews. HRQoL improved in the treatment group

⁶⁷ Gallefoss F, Bakke PS. How does patient education and self management amongst asthmatics and patients with COPD affect medication? *Am J Respir Crit Care Med* 1999; 160:2000-5.

⁶⁸ Gallefoss F, Bakke PS, Rsgaard PK. QOL assessment after patient education in a randomised controlled study on asthma and COPD. *Am J Respir Crit Care Med* 1999; 159:812-7.

⁶⁹ Australian Pulmonary Rehab Standards, 1995.

⁷⁰ Cambach W, Wagenaar RC, Koelman TW, Ton van Keimpema ARJ, Kemper HCG. The long-term effects of pulmonary rehabilitation in patients with asthma and chronic obstructive pulmonary disease: a research synthesis. *Arch Phys Med Rehabil* 1999; 80:103-111

⁷¹ Lacasse Y, Wong E, Guyatt GH, King D, Cook DJ, Goldstein RS. Meta-analysis of respiratory rehabilitation in chronic obstructive pulmonary disease. *Lancet* 1996; 348:1115-1119

⁷² Griffiths TL, Burr ML, Campbell IA, Lewis-Jenkins V, Mullins J, Shiels K, Turner-Lawlor PJ, Payne N, Newcombe RG, Lonescu AA, Thomas J, Tunbridge J. Results at 1 year of outpatient multidisciplinary pulmonary rehabilitation: a randomised controlled trial. *Lancet* 2000; 355:362-368

⁷³ Green RH, Singh SJ, Williams J, Morgan MDL. A randomised controlled trial of four weeks versus seven weeks of pulmonary rehabilitation in chronic obstructive pulmonary disease. *Thorax* 2001; 56:143-145

⁷⁴ Finnerty JP, Keeping I, Bullough I, Jones J. The effectiveness of outpatients pulmonary rehabilitation in chronic lung disease. A randomized controlled trial. *Chest* 2001; 119:1705-1710

by well over the “minimal clinical effect”, but did not change in the controls. Small but clinically significant improvements were also seen in walking distance.

In New Zealand, Young⁷⁵ conducted an uncontrolled prospective longitudinal study of 51 patients with severe COPD enrolled in a “pragmatic” outpatient hospital-based PR program with multidisciplinary education group sessions and progressive aerobic exercise training. Significant improvements were seen in exercise capacity, perceived dyspnoea and HRQoL at 3 and 6 months after the program. Further, there were reduced hospital bed-days and courses of oral corticosteroids for exacerbations in the 6 months after completion than in the 6 months before PR.

Ries compared comprehensive PR to education alone in 119 patients with COPD, with an initial 8-week program followed by monthly sessions for one year in the comprehensive group, and good follow-up was obtained over 4 years. Significant benefits were described for exercise capacity, walking self-efficacy, and perceived breathlessness and fatigue at 2 months, with loss of all but exercise endurance and walking self-efficacy by 18 months, and essentially no difference between the groups by 2 years. Over 4 years there were no differences in survival, quality of life, depression, or hospitalisation.

Guell⁷⁶ conducted a randomised controlled trial of outpatient comprehensive PR with 30 COPD patients in the therapy group and 30 matched controls in a “usual care” group. By 3 months there were significant differences in dyspnoea, fatigue and emotional function, which then declined slightly by 2 years. There were reduced exacerbations in the PR group, but no differences were seen in hospitalisation. Importantly, only three patients needed to be treated to achieve significant benefit in HRQoL for one patient over 2 years.

After pulmonary rehabilitation patients should be confident to monitor and manage their lung condition more effectively so that they need to access emergency treatment only rarely, and their dependency level is reduced. Pulmonary rehabilitation should enable patients to collaborate in a more informed manner with their doctor and other health care providers in planning their own care. Their spouse or carers should also feel more confident and less restricted.

The feedback from the patients was that participation in the pulmonary rehabilitation was highly valued. The patients liked the camaraderie of being in the group, encouraged each other and were pleased to be helping in a study of this type. These elements seemed to assist the participants deal with barriers to rehabilitation and exercise such as fear and anxiety of the physical consequences of exertion.

This study linked the pulmonary rehabilitation programme with an ongoing care plan. This approach also linked the practice nurse into the process as a way of facilitating integrated service delivery. Different models were used in this study in which the practice nurse played a greater role in collecting information for the care plan via the cue and response and partners in health questions in one of the intervention practices. In the other practice in which the practice did not undertake this role it necessitated some patients attending two to three times for their GP to complete the EPC care plans. Some of the patients found this time consuming and perceived it as a barrier not dissimilar to what has been reported with the Asthma 3+ Visit plans.

⁷⁵ Young P, Dewse M, Fergusson W, Kolbe J. Improvements in outcomes for chronic obstructive pulmonary disease (COPD) attributable to a hospital-based respiratory rehabilitation program. *Aust NZ J Med* 1999; 29:59-65

⁷⁶ Guell R, Casan P, Belda J, Sangenis M, Morante F, Guyatt GH. Long-term effects of outpatients rehabilitation of COPD: A randomised trial. *Chest* 2000; 117:976-983

One of the GPs commented that his proficiency at doing the elements of the study such as PIH, Cue & Response, care planning and problems & goals assessment improved as he repeated the process with subsequent patients. A barrier is simply getting started and a perception that the current structure for EPC is too complex, piecemeal and administratively burdensome.

The processes used in the study when undertaken thoroughly led to a comprehensive management of chronically ill patients, however, accepting that it has been very time consuming upon the general practices. These tools if utilised effectively in general practice will enable a change away from episodic care to more planned care and GPs will embrace a preventive care model if the model addresses the demands of general practice. The use of the Flinders CCSM tools, (PIH and Cue and Response) provided insight into the social, emotional and physical health needs of the patients and these were incorporated into the care plans.

An essential element was the strong positive co-operation of the practice managers and practice nurses.

Study implementation points of learning:

- PIH and Cue & Response forms and Problems and Goals forms took 45 mins to complete by the GP. GPs found this time consuming and sought assistance in how to reduce the time involved.
- Medicare EPC payments for formulation of care plans changed in May 2002 and this was a major barrier for the project as the care planning/ case conferencing within the project was a pivotal aspect. It seemed that many GP practices were no longer interested in care planning.
- Practices found it helpful to have a patient letter template to put on their own stationary.
- The practice nurse attending to the PIH, Cue & Response and Problems and Goals Assessment was more suitable for some practices. 45min – 1hr appointment with the practice nurse proved feasible for some practices. Time to complete PIH – 5 –7mins, Cue & Response 20-30mins; Problems and goals – 10mins. The GP then completed the care plan with the patient at consultation.
- Other GPs valued the opportunity to go through the whole process with the patient even if it took 2 consultations – considered they needed to gather the information to best formulate the care plan. This highlights the need for a flexible model when making available a system for self-management in primary care.
- A practice nurse was involved in only one practice and she found doing care plans most beneficial for the patient as it was the patient's self-identified problems (medical/ social) that were addressed.

Two multidisciplinary CCSM workshops were organised within the project.

The participants of the first workshop were members from the pulmonary rehabilitation program (psychologist, nurses, clinical pharmacist and physiotherapist) and key workers from the Mental Health Project.

The second workshop was organised to accommodate both GPs and nurses from the intervention practices and other health professionals involved in the pulmonary rehabilitation program. (6 doctors, 6 practice nurses, 1 dietitian, 1 hospital nurse and 2OT's were present). The doctors had the 3hour instruction and the others had one additional session about the

formulation of care plans. There were positive comments about the workshop but most participants commented on the time factor commitment that was necessary. A constructive suggestion was made that the workshop content could be tailored to the individual general practices of the participants. CCSM workshops were a challenge to organise at a time and venue convenient to a group of practices.

This study revealed that the prevailing system a great deal of work is required to recruit, consent and maintain patients and general practitioners in a RCT assessing a multifaceted intervention for patients with chronic lung disease. Working with all the patients was very rewarding. It seemed that the patients who did the pulmonary rehabilitation program all benefited from education on CDSM. Some of these benefits seemed to vary for each individual. However, generally, exercise benefits were mentioned by the majority. I noticed that some patients were able to take ownership of their chronic disease health problems and work in partnership with their doctors. It is difficult to comment on the impact the study has had on the general practices involved and their attitude to CDSM.

Similar to other studies, a rehabilitation or intervention programme is likely to have psychological as well as physical benefits, and these benefits are likely in turn to encourage greater adherence to and more successful management of therapy. Lacasse⁷⁷ reviewed evidence for the benefits of components of pulmonary rehabilitation. He concluded that there was overwhelming evidence that muscle specific exercise training improved functional capacity and quality of life, and some evidence that psychosocial support could improve patient outcomes for the majority of COPD patients. However one proven draw-back of this type of intervention is that the effects of a standard 8-week course usually last for up to six months and benefits wane if patients do not maintain a regular exercise training regimen.

This innovative self management programme combined Pulmonary Rehabilitation with the Flinders Self-Management model within current Primary Care funding models in Australia.

The framework in which the proposed CCSM model was to be implemented was the Enhanced Primary Care (EPC) package introduced by the Commonwealth Government in the 1999-2000 Federal Budget. The new EPC item numbers were designed to encourage evidence-based care focussed on prevention and early intervention in chronic disease management. The stated objectives of the initiative, were to put an emphasis on care for the elderly and to ensure that health is community based and increasingly had a focus on prevention better coordinated and was directed at finding new and better ways to manage chronic illness. It was anticipated at the commencement of this project that the EPC items and the Asthma 3+ Visit plan would encourage and provide an incentive for more planned continuing preventive and comprehensive care and support a team approach to the delivery of patient care. However, utilization of the EPC items by GPs has met with mixed success and during the course of the study became a disincentive rather than an incentive for recruitment of GPs and practices to the project. The multi-tiered and itemised nature of the new payments created significant administrative burden for GPs and there was a perception that the rules for payment meant that they would not qualify for payment anyway. Across the time of the study in the southern region of Adelaide where the study was implemented a number of practice changes occurred with Corporate GP clinics being established. This heightened the need for clear business cases for such initiatives and was a barrier to enrolment of practices into the study. This has been reflected in the underutilisation and now declining uptake of the EPC item numbers more generally. However those practices and GPs who did enrol in the study were generally "early adopters" of the EPC items and this perhaps led to their willingness to participate in the study and may have led to the higher

⁷⁷ Lacasse Y, Guyatt GH, Goldstein RS. The components of a respiratory rehabilitation program: a systematic overview. *Chest* 1997; 111:1077-88.

than anticipated uptake of care plans in the control group as part of usual care in the second six months of the study. There was still a common view by GPs in the intervention arm of the study that the current levels of payment do not provide sufficient financial incentive for the increased administrative work required.

Improvements to the PIP and EPC payments are in development, including chronic disease management items at two levels, simplifying arrangements for PIP registration, and updating current requirements for IT and after-hours service payments.

The sustainability of the model which extends the improved physical functioning seen in this Demonstration programme through making available a system for self-management and builds capacity in primary care requires a funding model to support it.

Medication management is an important aspect of self-management of many chronic illnesses. In all cases where pharmacotherapy is used, additional attention to achieving genuine and durable adherence with treatment goals between doctor and patient is important to improve compliance and health outcomes. An interesting observation in the recent systematic review of self-management education programs in chronic disease was the increased effect of self-management education programs in diabetic and hypertensive populations where self-management was associated with improved medication compliance. In this study 79% of patients in the intervention group were on 5 or more medicines and 84% in the control group. Overall medicines remained largely unchanged across the study in both groups with the exception of the introduction of tiotropium bromide (Spiriva®) as PBS item after the study commenced. There was a differential uptake in Spiriva between the intervention and control groups. At baseline in the control group 1 patient was receiving Spiriva at 6 months this had increase to n=5 and at 12 months n=4. In the intervention group there were 2 patients at baseline and at 6 months n=12 and at 12months n=12. 40% of the intervention group received the combination long acting beta agonist and corticosteroid product, Seretide, compared with 15% in the control group which may reflect both GP and patient choice for particularly delivery devices. Also there was much greater use of prevention therapy for osteoporosis in the control group at 12 months (64% compared with 22% in the intervention group).

The 6 month results of this study were presented at national forums in 2004 including the Thoracic Society of Australia and New Zealand annual conference and the biannual National Medicines Symposium. The study has also been included in the South Australian Health Promotion Storybook 2004.