# Action on Health Inequalities: Early Intervention and Chronic Condition Self-Management

**HIRC PHC NETWORK**

**February, 2004**

ISBN:  1876504609

Published by the Health Inequalities Research Collaboration (HIRC), Primary Health Care Network

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This paper was produced with funding received from the Australian Government Department of Health and Ageing.  However, the views and opinions expressed in the paper are solely those of the authors and do not necessarily reflect the views of that Department.

# Contents

# 1. Executive Summary

This report has been developed by the Health Inequalities Research Collaboration (HIRC) Primary Health Care (PHC) Network. The report aims to review the evidence on the effectiveness of chronic condition self-management programs, with a special emphasis on *arthritis, asthma and diabetes*; and suggest a range of policy options to improve the health of disadvantaged communities and reduce health disparities. The consistently low health status and unequal burden of chronic disease experienced by a number of population sub-groups has meant that the focus of this report is on:

- *indigenous Australians;*
- *those who experience socio economic disadvantage;*
- *rural and remote populations; and*
- *culturally and linguistically diverse communities (CALD).*

The report also considers early intervention for the three conditions, but to a much lesser extent. This is due in part to the amount of literature to be reviewed on chronic condition self-management (CCSM), which meant that CCSM ended up being the major focus of the project and also because the initial search strategy yielded few articles in relation to early intervention.

A comprehensive model to address chronic conditions is one that embraces a population health approach across the continuum from primary prevention for well populations to early detection and intervention for population sub groups defined at being 'at risk' through to management and tertiary prevention for people with established disease. At each of these stages in the continuum, primary health care services play an important role and are the setting for a number of Australian Government initiatives.

Chronic condition self-management is primarily aimed at individuals who have been diagnosed as having a chronic condition and *"involves the individual with the chronic condition working in partnership with their carers and health professionals so that they can: know their condition and various treatment options; negotiate a plan of care; …..engage in activities that protect and promote health; monitor and manage the symptoms and signs…; manage the impact ….. on physical functioning, emotions and interpersonal relationships."[1]*

Whereas early intervention in the context of chronic conditions refers to that point in the history of the disease where secondary prevention activities are focussed. That is: "*early detection of biological abnormalities (biological risk factors) and their prompt treatment, to reduce morbidity and mortality*". [2]

The methodology involved a selected review of literature published since 1990 and available electronically, supplemented by 'grey' literature and interviews with project managers from four Sharing Health Care Initiative (SHCI) Demonstration Projects.

## 1.1 Major findings

The review identified that there is a range of CCSM programs being implemented both overseas and within Australia. The main approaches include patient education and training, community-based support groups and provider focussed methods. Elements important to their effective implementation include a collaborative approach between the patient and provider, self-management education and ongoing provider training, informed choice, behavioural and lifestyle changes, and monitoring. For disadvantaged groups, social support through the engagement of local community networks is also regarded as a crucial component. The review highlighted gaps in evidence around improving access to self-management programs by indigenous Australians, lower socio-economic groups, rural and remote populations and CALD groups. These include:

- difficulties in making comparisons between different types of self-management models in order to identify those that are more successful;
- little analysis of the impact of self-management interventions for disadvantaged populations in systematic reviews;
- limited generalisability of findings to the Australian context; and
- limitations in the strength of the evidence for disadvantaged groups.

It is noted that the National Evaluation of the SHCI, is looking at a range of self-management models in the Australian context, and will be reporting in late 2004.

With these cautions in mind, evidence of the effectiveness of self-management interventions included:

- the importance of multifaceted interventions, although it is often not clear from the literature which specific component/s contribute most to change;
- the evidence is strongest for short term change under trial conditions: it is less clear the extent to which the benefits are maintained over time;
- there is evidence of improvement in specific health outcomes: these include improved self efficacy (for asthma and arthritis), pain reduction (for arthritis), blood glucose control (for diabetes);
- for asthma and arthritis there is also evidence of reduced costs to the health system.

The major findings on the effectiveness of CCSM programs for each condition are summarised in the following table

| Condition | Findings |
|---|---|
| **Arthritis** | ▪ Ethnicity & health beliefs influence understanding of condition, choice of self-management strategies (SMS) & their efficacy, & greater use of complementary therapies, as an adjunct to mainstream therapies.<br>▪ Social networks are an important source of condition & treatment information.<br>▪ Provider communication skills important for appreciation of health beliefs.<br>▪ Low education levels and English language skills are not a barrier to good outcomes provided information & materials are tailored to address these issues<br>▪ Self efficacy is the biggest predictor of pain reduction. |
| **Asthma** | ▪ Low education & income levels are predictors of less effective SMS.<br>▪ Differences in information & education provided to English speaking versus non English speaking people / or for those who speak English as a 2nd language.<br>▪ Involvement of local communities/bilingual/indigenous health workers effective in improving knowledge and self-management strategies.<br>▪ Personal interaction between provider and patient an important component of care |
| **Diabetes** | ▪ Health literacy important – low literacy & education levels associated with poor glycaemic control & less adherence to treatment.<br>▪ Self efficacy associated with regular blood glucose monitoring.<br>▪ Involvement of local communities/bilingual/indigenous health workers effective in improving knowledge and self-management strategies.<br>▪ Cost barriers associated with self-management (eg blood glucose monitoring/access to healthy food).<br>▪ Patient education as a single strategy not effective.<br>▪ Automated telephone assessment, with nurse follow up and telemedicine overcome barriers to accessing care and education and improve health outcomes.<br>▪ Health benefits not sustained over time. |

Factors that have been shown to contribute to the success of self-management programs for disadvantaged patients across the three conditions have included:

- understanding the health beliefs and expectations of the groups involved and adapting programs to meet these beliefs;
- increasing levels of health literacy and tailoring information and materials;
- improving the communication skills of providers;
- working with the person with chronic condition/s, their carers, families and communities;
- addressing issues related to affordability in program design, so that it presents no barrier to take-up;
- addressing poverty and other environmental issues, such as access to fresh food;
- improving access to PHC services;
- employing people from the target group including Aboriginal health workers and bilingual health workers;
- ensuring that language barriers are addressed through the use of interpreters and translation of materials.

## 1.2 Policy implications

A two-pronged approach is required to provide effective self-management programs for disadvantaged groups:

a) a responsive health system that embeds self-management as an integral aspect of chronic condition management within a strengthened PHC system; and

b) a parallel focus on strengthening and supporting the person with the chronic condition, their carers, families and the wider community.

A model for chronic condition self-management which is responsive to the needs of disadvantaged groups must take into account both the supply (health system) and demand (patient driven) aspects. The literature review suggests that these aspects can be understood under four broad headings:

- *the beliefs* of both patients and health care providers on the causes of the health problem and action that can be taken to address it;
- *the level of knowledge and skill* that they have to take effective action;
- *the other competing demands* on their time and resources; and
- *their personal, social, economic and organisational resources* that will impact on their capacity to act.

### Policy approaches

A number of approaches are identified that would increase access of disadvantaged groups with chronic conditions to self-management services and programs as well as early detection and intervention strategies (the latter being aimed at behavioural and lifestyle changes, medication and monitoring). These approaches need to be embedded within broader strategies to ensure there is a strong and comprehensive PHC system in Australia which ensures access to high quality PHC for all groups within the population.

As there are a number of possible actions that can be taken for each level, we have purposely identified broad aims and objectives in the expectation that policy makers at the Australian government and state/territory level can decide on more specific action to take these approaches forward. These are summarised below, with greater detail outlined in Section 5.3 (see pages 63-66).

## Health system approaches

### Provider level:

***Aim:*** ***Health service providers have the capacity and resources to work effectively with patients and carers from disadvantaged backgrounds.***

***Objectives:***

- Increase the skills of all service providers to work with disadvantaged groups
- Provide easy access to evidence based tools on approaches that include a focus on working with disadvantaged groups.
- Strengthen opportunities for multidisciplinary team work.
- Ensure access to interpreters and bilingual/indigenous health workers.
- Provide policy support and funding incentives for PHC providers to participate in programs and interventions.

### Service delivery level:

***Aim:*** ***Service delivery systems are able to support health care providers to identify and work with patients, families and carers from disadvantaged background and monitor the reach and impact of CCSM programs and early intervention strategies.***

***Objectives:***

- Use practice based systems that will routinely identify and follow up patients who are at high risk or who have a chronic condition.
- Provide a comprehensive range of services and programs that are accessible to disadvantaged groups.
- Establish effective referral patterns to other services and ensure that these services are affordable and appropriate.
- Establish clinics or other structures that enable health service providers to undertake structured care programs.
- Enhance the system capacity to monitor screening and referral of high risk populations to relevant services;
- Increase accessibility of PHC services to disadvantaged groups.

### Regional or Division of General Practice level

***Aim:*** ***Systematically address the implementation of a comprehensive range of services and programs that support disadvantaged populations and overcome barriers to the effective use of CCSM programs and early intervention strategies.***

***Objectives:***

- Provide access to a comprehensive range of CCSM programs and early intervention strategies.
- Inform service providers on the range of services available within the community.
- Provide education and training for service providers on CCSM programs and early intervention strategies.

- Undertake needs assessments on the access of disadvantaged groups to existing CCSM programs early intervention strategies and take action to address gaps.
- Support the development of practice level systems that will allow for better identification and monitoring of high risk populations.
- Develop, adapt or provide local services with access to a wide range of health information and education materials.

### State/ National Level

***Aim*: Capacity across the system is developed to support the development of effective CCSM programs and early intervention strategies for disadvantaged populations.**

***Objectives:***

- Strengthen models that facilitate collaboration between State and Federally funded CCSM and early intervention approaches.
- Develop Australian government-State agreements that identify CCSM programs and early intervention strategies as agreed priority areas.
- Strengthen policy links between individual CCSM and early intervention strategies and population level approaches (e.g. SNAP).
- Invest in the development of an Australian evidence base for CCSM programs and early intervention strategies.
- Work with community leaders and non-government organisations (NGOs) to develop relevant and appropriate health education and media campaigns.
- Advocate within the health and other sectors to address underlying determinants of health.
- Provide education and training on CCSM programs and early intervention strategies as part of core undergraduate education programs.

## Patient and community approaches

Section 4.4 of the report highlights some case studies of these approaches that strengthen patient and community capacity to engage in CCSM programs.

### Patient and carer level

***Aim:* Strengthen the capacity of patients and their carers to take an active role in CCSM programs and early intervention strategies.**

***Objectives:***

- Provide patients with information and education that is culturally and linguistically relevant.
- Increase the skills and confidence of patients to participate in the management of their health risk factors and/or disease.
- Reduce the costs to patients in accessing services and programs and maintaining their self-management strategies.

### Community and support group level

***Aim:*** ***Increase the capacity of local communities, self help and other support groups to work effectively with disadvantaged groups.***

***Objectives:***

- Provide adequate funding to community organisations and groups to ensure that they can provide and contribute to programs that are sustainable, accessible and relevant to the needs of disadvantaged populations.
- Support health services to work with local communities to identify actions that could increase the availability, accessibility and appropriateness of CCSM programs and early intervention strategies.
- Support local communities to identify social, economic and environmental constraints/barriers to adopting healthy lifestyles and address through local and intersectoral actions.

### Social and economic level

***Aim:*** ***Reduce the impact of social and economic factors that limit access to, and the effectiveness of, CCSM programs and early intervention strategies.***

***Objectives:***

- Systematically address some of the underlying social determinants of health such as unemployment and poverty.
- Targeted programs to improve literacy levels amongst disadvantaged populations.

# 2. Introduction

## 2.1 Background to project

### Health Inequalities Research Collaboration & Primary Health Care Network

The Health Inequalities Research Collaboration (HIRC) was established in 1999 to develop a health inequalities research agenda within Australia and aims to be intersectoral and multidisciplinary. Its strategic objectives are to:

- increase national focus on reducing health inequalities;
- build national capacity and support for research and development in health inequalities;
- establish close collaboration among researchers, practitioners and policy developers; and
- promote the uptake of research findings in policy, practice and evaluation.

The Primary Health Care (PHC) Network is one of three research and development networks funded through the HIRC, the others focus on children, youth and families, and sustainable communities. Each network emphasises indigenous and rural and remote populations. The networks aim to enhance Australia's knowledge on the causes of, and effective responses to, health inequalities, and to promote the application of this evidence to reduce health inequalities in Australia.

In 2002 the PHC Network undertook a series of consultations across Australia to identify research priorities and capacity building issues to inform the development of a health inequalities research agenda in PHC. From these consultations a discussion paper was produced that identified five research priorities: three were specific population or health issues of indigenous health, rural health and oral health, with the other two being access to PHC services and the effectiveness of PHC interventions in reducing health inequalities [3]. Building on this work, the Network has continued to advocate for ongoing research into these areas in a number of fora. It is against this backdrop that the HIRC secretariat facilitated a meeting between the Network and key policy areas within the Australian Government Department of Health and Ageing.

### Aims and focus of the project

This project developed from discussions held in May 2003 between the HIRC PHC Network, the National Health Priority Action Council (NHPAC) secretariat and the Primary Care Branch of the Australian Government Department of Health and Ageing. The project aims to:

- recommend evidence-based interventions to improve the health of disadvantaged communities and reduce health disparities, which focus on early intervention and self-management of chronic conditions, with special emphasis on asthma, arthritis and diabetes; and to the extent possible,
- prioritise the interventions on the basis of their efficacy, feasibility, cost effectiveness, affordability and accountability within the context of the Australian health care system.

The major focus has been a review of Australian and international systematic reviews, Australian primary research and readily available "grey" literature in Australia on the effectiveness of chronic condition self-management (CCSM) and to a lesser extent, early intervention, in addressing health inequalities. This has included:

- identifying effective CCSM and early intervention strategies, a range of different models and elements of these models that assist in reducing health inequalities, and to the extent possible,
- undertaking further analysis and an iterative review of identified CCSM models and early intervention strategies, successively examining characteristics of models as applicable in the Australian setting, and developing a prioritised list of policy options likely to have the most significant impact on detection and early intervention in chronic conditions in disadvantaged communities in the Australian setting.

The scope of this project has been limited by the time and available resources and has focussed on three major chronic conditions:

- *osteo- and rheumatoid arthritis (generally older population);*
- *asthma (in children and adults); and*
- *type 2 diabetes mellitus (adults);*

and four population sub-groups.

- *indigenous Australians;*
- *those who experience socio economic disadvantage;*
- *rural and remote populations*; *and*
- *culturally and linguistically diverse communities (CALD).*

However it is recognised that many chronic conditions do not operate in isolation, and that many people experience co-morbidities, for example cardiovascular disease, stroke and diabetes.

## *2.2 Chronic conditions in Australia*

Chronic conditions … "are mostly characterised by complex causality, multiple risk factors, a long latency period, a prolonged course of illness, and functional impairment or disability" [4].

Despite clinical differences, for most conditions there are similar issues with which people and their families must grapple: behavioural changes; the social and emotional impacts of symptoms, disabilities and in some cases, approaching death; medications; and interaction over time with a multiplicity of health care providers [5].

Chronic conditions make an estimated 70% contribution to the burden of disease in Australia [6] and many of these conditions include a potentially modifiable behavioural component. In 2002, the Australian Institute of Health and Welfare (AIHW) produced a report entitled *Chronic Disease in Australia* [4]. This report examines the major chronic conditions affecting the population and includes a focus on the common behavioural risk factors and the risk profiles for the population and sub groups within it. The following section is predominantly a summary of the AIHW report in relation to arthritis, asthma and diabetes.

### Arthritis

The term arthritis covers a group of disorders in which there is inflammation of the joints that causes chronic pain, stiffness, disability and deformity. The two most common forms are osteoarthritis and rheumatoid arthritis. Osteoarthritis is a degenerative joint disease whereas rheumatoid arthritis is an auto-immune disease. Predisposing factors include genetics, age and sex. It is estimated that approximately 15% of the population have some form of arthritis: of these 1.2 million have osteoarthritis and 476,000 have rheumatoid arthritis. The disability burden is high, with just under 0.5 million people in 1995 reporting a disability due to arthritis, a total of 14% of all persons with a disability.

There is a strong relationship between arthritis and ageing and it is more prevalent in females at all ages, with over 65% of females and 50% of males reporting having arthritis by age 65 years. While there are few deaths ascribed to arthritis (86 from osteoarthritis and 135 from rheumatoid arthritis in 1998), rheumatoid arthritis is believed to be associated with an excess mortality, and contributes to deaths from respiratory and infectious disease and gastrointestinal disorders (the latter may be due to complications related to drug therapy [4].

Arthritis accounts for 2.4% of all problems managed in general practice, with management of osteoarthritis being ranked the 10th most common problem managed.

Hospital separations for osteoarthritis have increased by 42% over the past seven years.

Environmental and behavioural factors include joint trauma and injury, obesity, repetitive occupational joint use and physical inactivity [4].

### Population sub groups at risk

There is limited information on population sub-groups at risk. Identified group are females who have a greater risk of rheumatoid arthritis, older females at greater risk for osteoarthritis.

## Asthma

Australia has one of the highest prevalence rates of asthma in the world. Between 1989-90 and 1995, self-reported prevalence increased from 85 per 1,000 to 113 per 1000. There is significant geographical variation, with Queensland having the highest and Tasmania the lowest prevalence. In 1998, there were 701 deaths from asthma (0.5% of all deaths), with the death rate being higher for females. Reported death rates for asthma generally increase with age, although asthma mortality is known to be less reliable amongst older people, due to the presence of chronic obstructive pulmonary disease (COPD).

Asthma can have a major effect on quality of life, including physical and social functioning and general health, and interruptions to daily life including work, schooling and social participation. People with asthma are also major users of health services, with asthma being the 4th most common reason for hospital admission (and one of the most frequent admissions for young children), a frequent reason for visits to emergency departments, and the 5th most common condition managed in general practice.

Asthma often occurs in the presence of other allergic and respiratory conditions and its management is influenced by the presence of these other conditions. Predisposing factors include family history, age and excess weight. Known triggers include allergens, exercise, viral infections, weather changes, exposure to tobacco smoke, food, chemicals and drugs [4].

### Population sub groups at risk

- *Aboriginal and Torres Strait Islanders:* experience higher asthma mortality rates and higher prevalence of smoking, in addition to their higher representation in remote areas and limited access to health services. Reported rates of asthma vary between 17-23%, depending on age.[4]

- *Culturally and linguistically diverse groups*: where language and health beliefs can be barriers to effective management and whose length of stay in Australia may affect asthma prevalence.

- *Low socioeconomic groups:* socioeconomic inequality is evident in asthma symptoms, diagnosis, hospital admissions and management [7].

- *Remote and rural populations:* there is significant regional variation in mortality with an association between geographical remoteness and higher mortality. Contributing factors to this association include:
    - larger representation of indigenous communities with known increased mortality rates in rural and remote area;
    - limited access to emergency and primary care;
    - increased exposure to chemicals and pesticides [4]

## Diabetes Mellitus

Diabetes mellitus is a major cause of mortality, morbidity and disability and an important risk factor for several other chronic diseases including vascular and heart diseases, kidney disease and eye disease. Type 2 diabetes accounts for 85-90% of the incidence of diabetes. In 1998, the total number of deaths for diabetes (all types) as an underlying or contributory cause was 9,454 or 7.5% of all deaths. Diabetes is the eighth most common problem managed in general practice [4].

Risk factors for diabetes include genetic and environmental factors, with behavioural and biomedical factors including excess weight and obesity, impaired glucose tolerance (IGT), physical inactivity and poor diet and nutrition.

### Population sub groups at risk

- *Aboriginal and Torres Strait Islanders*: prevalence lies between 10-30% and is generally 2-4 times higher at any age than the general population, with an earlier age of onset [8]. The death rate for males is nine times that of all Australian males, and for females it is16 times that of all Australian females.

- *Culturally and linguistically diverse groups:* prevalence is higher amongst some migrant groups, particularly South Pacific Islanders, Indians, Chinese and Southern Europeans. [4],[8].

- *Low socioeconomic groups:* prevalence is almost two-and-a-half times as high amongst the lowest socioeconomic group compared to the highest group.

- *Older males:* prevalence increases from age 40 years on, but more so in males; in the 65-74 years age group diabetes is almost one-third higher among males than females [8].

- *Rural & remote:* prevalence between metropolitan, rural and remote communities is not significantly different [4]; however the death rates in rural and remote areas are two-three times higher [8]

## Summary of disadvantaged population sub groups at risk[i]

| Group | Asthma | Diabetes |
|---|---|---|
| **CALD** | ▪ Longer length of stay may affect prevalence<br>▪ Barriers to effective management (language & health beliefs) | ▪ Prevalence: higher among PI's; Indians, Chinese, Southern Europeans |
| **Indigenous** | ▪ Mortality: higher<br>▪ Higher prevalence of smoking | ▪ Prevalence: 2-4 times higher<br>▪ Earlier age onset<br>▪ Death rate: males - 9 times higher; females - 16 times higher |
| **Low Socio-economic** | ▪ Inequalities in relation to symptoms, diagnosis, hospital admissions, management | ▪ Prevalence: 2.5 times higher amongst lowest vs highest SE group |
| **Rural & Remote** | ▪ Regional variation in mortality associated with remoteness<br>▪ Increased exposure to chemicals & pesticides | ▪ Death rates: 2-3 times higher |

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[i] There was limited information on population subgroups at risk of arthritis, and none that were associated specifically with the disadvantaged groups that are the focus of this study.

## 2.3 Sharing Health Care Initiative

The Sharing Health Care Initiative (SHCI) is part of the Enhanced Primary Care (EPC) package for older Australians and those with chronic and complex conditions. The SHCI is aimed at "improving quality of life, improving the use of the health care system and for individuals, families and health care professionals to work together in the management of chronic conditions." [9]. Primary care is the foremost setting for the SHCI and a major element is a focus on self-management. The initiative comprises three major components:

- Demonstration projects testing a range of CCSM models in the Australian context.
- Education and training for health providers and consumers participating in the demonstration projects.
- A National Evaluation of the demonstration projects.

There are 12 demonstration projects (including five indigenous specific projects located in South Australia, Queensland and the Northern Territory), that are developing and testing a number of self-management models. In addition to the indigenous projects, several of the other demonstration projects have an explicit focus on disadvantaged groups: Canning Division of General Practice in Western Australia (*Healthpartners*) and South Western Sydney Area Health Service both focus on socioeconomic disadvantage; the Whitehorse Division of General Practice (*The Good Life Club*) includes a focus on Chinese people; and the Tasmanian project (*Whose Health is it Anyway?)* includes a focus on Polish clientele.

The Flinders Human Behaviour and Health Research Unit, at Flinders University in South Australia has been funded to develop and implement education and training to support the demonstration projects. This involves a post graduate chronic and complex diseases module and a variety of training programs for general practitioners, other health professionals, community workers, and Aboriginal Health Workers. The education and training includes:

- the benefits of self-management;
- empowering people and involving the community;
- discussions of various components of chronic conditions that can be self-managed;
- information on the psychological, emotional and social issues faced by people with chronic conditions; and
- ways to communicate with people who have a chronic condition and their families/carers. (http://www.chronicdisease.health.gov.au/educat.htm)

The Western Australian Royal Australian College of General Practitioners (WA-RACGP) has developed and implemented Chronic Conditions Self-management

Clinical Guidelines for general practitioners, nurses and allied health professionals involved in the demonstration projects.

A national evaluation of the SHCI is being conducted, and the major progress report for the six-month period July-December 2002 is available.

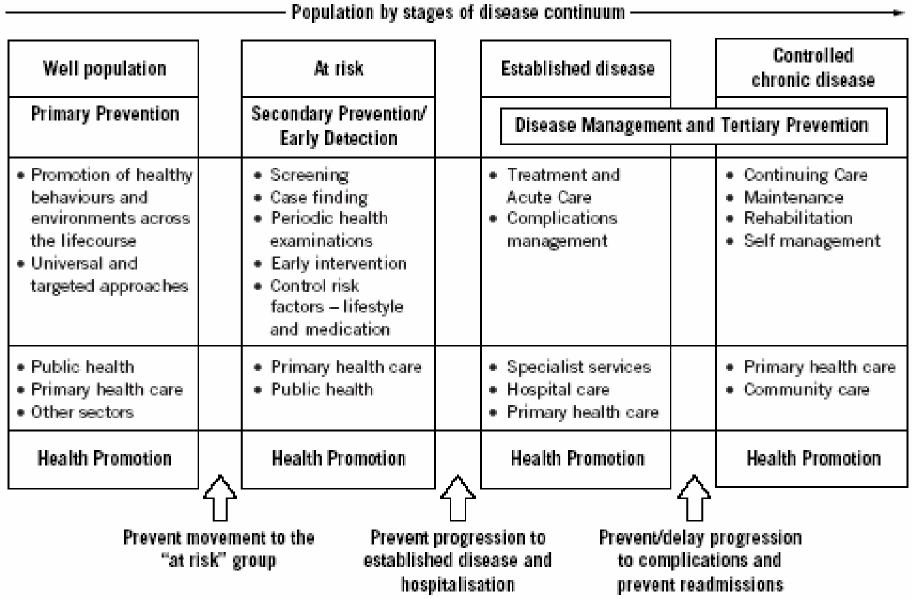
Other initiatives that have supported the SHCI include:
- commissioning of literature reviews by the WA RACGP and Flinders University;
- two national conferences (August 2000 and November 2003), and
- one ‘Early Wins’ workshop held in December 2002.

Details of the education and training programs, the clinical guidelines, the literature reviews and conference/workshop proceedings are available on the Department of Health and Ageing website as are the executive summaries of the regular reports being produced by the demonstration projects as part of the national evaluation. (http://www.chronicdisease.health.gov.au)

## 2.4 Definitions

A comprehensive model to address chronic conditions has been developed by the National Public Health Partnership, and is depicted in the following figure. This model embraces a population health approach across the continuum from primary prevention for well populations to early detection and intervention for population sub-groups defined at being ‘at risk’ through to management and tertiary prevention for people with established disease. At each of these stages in the continuum, primary health care services play an important role and are the setting for a number of Australian Government and state government initiatives. [6]

**Figure 3: Comprehensive model of chronic disease prevention and control**



| Well population | At risk | Established disease | Controlled chronic disease |
|---|---|---|---|
| Primary Prevention | Secondary Prevention/ Early Detection | Disease Management and Tertiary Prevention | |
| • Promotion of healthy behaviours and environments across the lifecourse<br>• Universal and targeted approaches | • Screening<br>• Case finding<br>• Periodic health examinations<br>• Early intervention<br>• Control risk factors – lifestyle and medication | • Treatment and Acute Care<br>• Complications management | • Continuing Care<br>• Maintenance<br>• Rehabilitation<br>• Self management |
| • Public health<br>• Primary health care<br>• Other sectors | • Primary health care<br>• Public health | • Specialist services<br>• Hospital care<br>• Primary health care | • Primary health care<br>• Community care |
| Health Promotion | Health Promotion | Health Promotion | Health Promotion |

**Early detection and intervention** refers to that point in the natural history of the disease where secondary prevention interventions are focussed. In an internal Australian Government Department of Health and Ageing paper written to clarify prevention terminology, “Secondary prevention refers to the measures available to individuals and populations for the early detection of departures from good health and prompt and effective intervention to correct them. Secondary prevention is therefore aimed at early detection of biological abnormalities (biological risk factors) and their prompt treatment, to reduce morbidity and mortality” [10].

**Chronic condition self-management** has been defined as involving: “[the person with the chronic disease] engaging in activities that protect and promote health, monitoring and managing of symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes” [11]

This definition of chronic condition self-management has been adopted in Australia in work commissioned by the Commonwealth Department of Health and Ageing [12]; and has been enhanced by Flinders University to embrace a partnership approach between the patient, their carer and health professional [13].

The term *chronic condition* is increasingly being used in place of *chronic disease* in part as a response to consumer concerns about being stigmatised and labelled. In this report both terms are used: *chronic condition* is the preferred term, however *chronic disease* is used where specific literature is being referenced that uses this term.

## Section summary

- In asthma and diabetes there is evidence of greater burden of disease amongst populations experiencing disadvantage, with increased mortality and morbidity.
- Major groups where there are health differentials for asthma and diabetes include indigenous Australians, CALD communities, socioeconomic (SE) disadvantaged groups, remote and rural communities.
- Common potentially avoidable behavioural risk factors for all three conditions include excess weight and obesity, physical inactivity, as well as smoking for diabetes and asthma.

# 3. Methodology

## Search of electronic databases

A search of the published literature was conducted using the following databases: MEDLINE; CINAHL; EMBASE; PubMed; EBM Reviews; Australasian Medical Index; Aboriginal & Torres Strait Islander Health; APAIS-Health; Social Science Index; PsycINFO; and the Cochrane library. An initial search was performed using search terms relating to *the three conditions* and a variety of terms relating to early detection/intervention, self-management and the disadvantaged population sub-groups. The titles and abstracts were obtained and screened for relevance. Reference lists of full texts were searched manually for additional articles.

A further MEDLINE search was done mid way through the project to identify additional published research in areas where there were major gaps in information in relation to chronic condition self-management and disadvantaged groups. This search yielded additional articles.

In the initial search, while articles relating to early detection were located, few articles of relevance were located on the effectiveness of early intervention strategies or programs specifically with disadvantaged groups in relation to the three conditions.

## Inclusion Criteria

Only published literature that was readily available on-line was included. Reviews of literature pertaining to early intervention and self-management were limited to those published since 1990; for models of behaviour change, selected literature published since 1980 was reviewed. Participant characteristics for the three conditions include people who belong to one or more of the following population sub-groups: of low socio-economic position; living in rural and remote areas; indigenous peoples; and/or of a culturally and linguistically diverse (CALD) background.

## Snowball sampling

Relevant materials were also drawn from several key resources to supplement material drawn from electronic searches:

- the Patient Education Research Center bibliography at Stanford University (http://patienteducation.stanford.edu/);
- the Improving Chronic Illness Care website (http://www.improvingchroniccare.org/resources/bibliography/self-mngmt.html);
- the Department of Health and Ageing (www.chronicdisease.health.gov.au); and
- the Flinders University self-management webpage http://som.flinders.edu.au/FUSA/CCTU/Home.html).

‘Grey’ literature as recommended by key contacts and the conference proceedings from the *Sharing Health Care ‘Early Wins’ National Workshop* in 2002 were also reviewed and included as supplementary information where appropriate.

## Targeted searches

Once strategic and snowball searches were complete, targeted searches were conducted in an attempt to fill any remaining gaps in the material. These included searches of additional databases (such as Sociological Abstracts) and specific journals that may not be included in the databases searched; for example the Australian Journal of Primary Health.

## Interviews

Telephone interviews (based on an interview schedule) were conducted with project managers for four of the SHCI Demonstration Projects that have an explicit focus on disadvantaged groups. These were *Healthpartners* in Western Australia; *The Good Life Club* in Victoria; *South Western Sydney Area Health Service* in New South Wales; and *Katherine West Indigenous trial* in Northern Territory. Notes taken during the interviews were written up and supplemented with information from the latest progress reports that each project is required to produce and that are available on the SHCI webpage. The interviews were then emailed back to the interviewees for any corrections and additions.

# 4. Findings

## 4.1 History & theoretical basis for CCSM

### Chronic condition policy context

A number of factors in the late 20th century have influenced the development of chronic condition self-management (CCSM) as an integral component of contemporary chronic condition care. These include the ageing of the population, better understanding of disease aetiology and improved early detection and intervention to halt or delay the progression of disease. These factors have led to an increase in the number of people living for longer with chronic diseases. Moreover, the greatest burden of disease falls upon the poor and others who are disadvantaged [14]. This increasing prevalence has led to an increase in health care costs and a recognition of the long-term consequences for the health system of caring for people living with chronic disease [14], as well as a conceptual shift in health policy from the tertiary to the community and primary care levels [15]. A rise in consumer expectations of the health system and a demand for responsive health care have also driven the provision of more patient-centred programs [16]. In an attempt to prevent a greater burden of disease on the individual, the community and the health system, governments are increasingly investing in research and development of chronic disease programs which will reduce health costs and improve quality of life [17]. The World Health Organisation has recognised that adherence to treatment for chronic disease is influenced by a multitude of factors, and that patient-tailored interventions are needed, supported by training for health providers, involvement of the patient, family, and community, and a recognition that long-term maintenance of chronic disease is a dynamic process [14].

### Early detection and intervention

Screening is a common method for early detection of potentially modifiable risk factors that are common for a number of chronic conditions: smoking, hypertension, high cholesterol, hyperlipidaemia and obesity. Screening can be organised for whole populations, at risk population sub groups, practice populations or for individuals in clinical settings as part of medical and health assessments.

The rationale for supporting early detection is that a) intervening early can prevent or delay the natural progression of disease; b) there are known and proven interventions that can delay/prevent progression; c) there are systems in place to link people into interventions; and d) interventions are cost effective.

Early intervention strategies for chronic disease risk factors commonly include a mixture of the following:

- preventive medication (e.g. cholesterol lowering drugs, nicotine replacement patches);
- regular monitoring of physiological signs and symptoms (blood/urine testing for sugar, peak flows); and
- modification of behavioural risk factors (dietary changes, increasing physical activity, cessation of smoking, avoidance of allergic triggers).

As with early detection, early intervention can occur at the population level (through for example legislation or regulations, as in the case of smoking or media campaigns designed to educate and change behaviour), at the individual level in primary health care settings, (through patient education and training) [10], or through a range of formal/informal community support networks.

## Chronic condition self-management

For those people with a chronic condition, self-management can be an integral component of effective chronic disease management. It is reliant on health system structures and community support systems which encourage the development of processes and relationships to support on-going monitoring, education, and intervention. Successful chronic condition management programs have demonstrated that effective interventions need to focus on the processes involved as much as the targets for intervention. Self-management programs include an additional focus on the participation and active involvement of the patient in monitoring and management processes [1, 18, 19].

## Theoretical underpinnings for chronic condition self-management programs

The theory underlining most CCSM programs is taken from the psychological and behavioural science literature, and refers primarily to the ability of individuals to take control of their health and effectively manage their chronic illness. Thus, there is a strong emphasis on self-efficacy [19-22], health literacy [23-25], and psychosocial and communication obstacles [26-29]. There are several main behavioural theories which are most commonly used to support research in this area [12, 30], including the Health Belief Model [31], the Transtheoretical Model of behaviour change [32], and Social Learning Theory [33].

The research literature shows a gap, however, within the theoretical foundations of chronic condition self-management, as the complexity of managing a chronic condition is influenced by factors other than the individual's ability or capacity to effect lifestyle and behaviour changes.

By way of illustration, Turrell and many others have convincingly argued that patterns of health inequalities can be understood by examining the factors within and between the levels which influence them [34]. These factors include:

- *upstream (macro level) factors*: the social, physical, economic and environmental determinants;
- *midstream factors:* psychosocial factors, health related behaviours and the role played by the health system; and
- d*ownstream (micro) factors*: changes to physiological systems and biological functioning bought about by the factors operating at the other levels.

Understanding these levels is useful for identifying where interventions are focussed and therefore what outcomes are possible and the range of issues that need to be considered. Thus while CCSM programs are focussed at the mid stream level, their effectiveness is influenced by factors operating at the upstream and downstream levels. For instance, people who experience social isolation and have few community networks and who face material deprivation have less access to those resources and opportunities that can support and help sustain health related behaviours.

The major findings of the Turrell et al review of the Australian research in relation to behaviour change interventions pertaining to socioeconomic inequalities were that:

- health promotion efforts are not as effective with people from disadvantaged backgrounds;
- a presumed lack of knowledge about health and health related behaviours was not supported;
- disadvantaged groups expressed a willingness to change and a desire for more information, but that they were constrained by their lack of time, money and space; and
- providing social support in addition to advice is more effective than providing advice alone. [34]

These findings are reinforced by the NHPAC in their draft discussion paper on dealing with disadvantage in the National Health Priority Areas (NHPAs), which reiterates the importance of considering the circumstances in which people live in any risk factor reduction interventions [35].

Many of the chronic condition self-management programs which are now in place internationally are based on the Lorig model. This model was based upon work begun by Halsted Holman and his colleagues at Stanford University in the 1970s, and has been widely disseminated in more recent years through publication of research by Kate Lorig and her colleagues, also at Stanford University. The Chronic Disease Self-Management Program (CCSMP), as it became, is based upon three main assumptions:

- "patients with different chronic diseases have similar self-management problems and disease-related tasks;
- patients can learn to take responsibility for the day-to-day management of their disease(s); and
- confident, knowledgeable patients practicing self-management will experience improved health status and will utilise fewer health care resources" [36].

Other assumptions underpinning the program are that:

- "patient self-management education should be inexpensive and widely available;
- trained lay persons with chronic conditions could effectively deliver a structured patient education program; and
- such lay instructors would be acceptable to both patients and health professionals" [36].

The main aim of the CCSMP is to empower patients to take control of their health care through group education with skilled lay trainers. The course itself is based upon the Self-Efficacy Theory of Bandura, and is a six-week training course on such topics as dealing with emotions, communicating with health professionals, and problem-solving and decision-making [36]. The course has been widely copied, in North America, Europe and Australasia, and is being used in the SHCI in Australia.

There is an on-going debate as to whether Lorig style courses can also be run by trained health professionals in addition to trained lay leaders. The UK version: 'The Expert Patient' program is being implemented by peer leaders, whereas in the Australian SHCI demonstration projects, Lorig style groups are being run by a mixture of peer leaders and health professionals.

The other major model in use within Australia is the Chronic Condition Self-Management program developed by Flinders University. The primary component of the Flinders model, is the emphasis on the role of health care providers in assisting patients to take control of their health. The Flinders model focuses on training and education for health care providers who will in turn encourage patients to self-manage their condition. Training for providers incorporates skill development in motivational interviewing, problem-solving and decision-making, and in recognising mental health symptoms and understanding stages of change which patients move through in making behaviour or lifestyle changes. The theoretical framework of the Flinders model is also based on theories of change and social learning [13].

The Lorig and Flinders models, addressing the education and training needs of either the patient or the provider, complement each other and can be used in conjunction with one another, as is being done within the SHCI.

## Key components of chronic condition self-management programs

### 1. Partnership

Collaborative care acknowledges the centrality of the client as principal managers of their own health [37] and *"...as key actors in the care process"* [38] and is based on the assumption that patients are more likely to benefit when there is a blending of their perspectives with those of the practitioners.

Von Korff et al (2002) suggest a number of principles of collaboration:
- "understanding of patients' beliefs, wishes, and circumstances;
- understanding of family beliefs and needs;
- identification of a single person to be the main link with each patient;
- collaborative definition of problems and goals;
- negotiated agreed plans regularly reviewed;
- active follow-up with patients; and
- regular team review." [39]

These principles form the foundation for self-management programs, which encourage the patient to take an active role in the management and monitoring of their condition, supported by a back-up team of health providers who will provide additional education, clinical assistance, and encouragement. As this moves providers outside of the traditional role of the clinician, collaborative care has implications for the ways in which health services and systems incorporate clients into the care process, including the removal of barriers within the health system which discourage self-management, and the integration of self-management principles into mainstream primary health care [19, 39]

### 2. Education

Medical treatment should be supplemented by educational and behavioural interventions in order to enable patients to play an active role in their care. A number of skills are required to take effective control of one's life. Clark et al (1991) have identified 12 skills included in self-management programs, including: recognising and acting on symptoms; using medication correctly; managing emergencies; managing diet and exercise; interacting effectively with health care providers; using community resources; adapting to work; managing relations with significant others;

and managing psychological responses to illness (quoted in [40]). "To summarize, two essential elements define self-management education: 1) patients learn problem-solving skills, useful at identifying problems from their own point of view and using action plans to find solutions; and 2) these skills are applied to three aspects of chronic illness: medical, social, and emotional." [18]

## 3. Informed choice

Lorig [41, 42] emphasised the notion of informed choice and the need for patients to adapt new perspectives and generic skills which can be applied in the context of their daily lives. However, Hibbard [38] suggests that patients need not only to be informed, but also to participate as co-producers and evaluators in their own care in order to influence the quality of care. In essence, informed choice is a concept incorporating several action stages for both provider and patient: providers need to provide information in ways in which patients can understand their options and the consequences of treatments, interventions, or lifestyle changes; and patients need literacy skills and a sense of self-efficacy in order to make informed decisions about their health. Much of the literature regarding self-management programs does not directly speak of informed choice but refers to *"problem-solving skills and decision making"* [19], *"health literacy"* [43], *"patient empowerment"* [18] and *"self-efficacy"* [20, 44], concepts which either presuppose or have an impact upon the ability to make informed choices, including behavioural and lifestyle changes. However, Schillinger et al. [25] suggest that health literacy is a marker for other factors influencing health status, including education level, ethnicity, and socioeconomic status.

## 4. Behavioural and lifestyle changes

Research has suggested that chronic disease progression and/or related risk factors can be modified or prevented by adopting lifestyle behavior changes such as diet, exercise and physical activity [45-47]. However, debate remains as to the long-term efficacy of behaviour change interventions outside of the environment of specialist clinics. To date, the strength of most existing behaviour change theories and models has been in their ability to explain why certain behaviours occur and to predict certain health behaviours on the basis of specific cognitive factors. The Lorig model recognises that the process by which chronic disease self-management is taught is as important, if not more important, than the content of the course itself [20, 48-50], and influences the effectiveness of patient's ability to make and sustain changes to their daily routines.

## 5. Monitoring

Maintenance of behavioural or lifestyle changes should be considered as part of the process of learning and emphasised from the beginning of any self-management course, as maintenance is an integral component of self-management, not an endpoint following an educational intervention [51]. Improving adherence, in the broadest sense of participating fully in treatment regimes and programs including self-management, is considered by some to be the single most important factor in improving population health outcomes [14]. Donaldson (2001) considers that the "key [to self-management] is the change to the individual's confidence and belief that they can indeed take control over their life despite the disease." This includes monitoring symptoms and responding to them accordingly, participating in regular follow-up consultations with health providers, and gaining an understanding of how ordinary life events and daily stressors affect the experience of the disease. The rigour required to monitor and maintain health and well-being while coping with a chronic disease should not be underestimated, and it is common for people to 'burnout' after several years of self-management, suggesting that long-term self-management programs will need to include flexible support systems which can change over time as patients' needs change [44].

## Section summary

♦ Chronic disease is of increasing concern worldwide, for the increasing burden of disease and associated health resource and social implications.

♦ The focus of most chronic disease interventions has been on individual behaviour and lifestyle change, including treatment adherence.

♦ Common components of chronic disease self-management include: informed choice and patient involvement in decision-making; collaboration between clients and service providers; lifestyle and behaviour changes particularly diet, smoking and exercise; patient education and ongoing provider training; medication and adherence to clinical treatments; development of self-efficacy; and ongoing support from health providers.

♦ Recognising the increasing burden of disease, there is a need for an approach to CCSM which recognises the larger social context in which people with a chronic condition live their lives.

## *4.2 Evidence of effectiveness of early intervention strategies and chronic condition self-management programs*

The three conditions under consideration in this report, diabetes, asthma, and arthritis, have differing etiologies and disease trajectories and these differences are reflected in the literature exploring effectiveness of interventions. However, there are commonalities for the treatment of chronic conditions, such as the types of interventions which are required (e.g. behavioural risk factor modification: diet, smoking, physical activity) and the goal of reducing hospital stays and clinic visits. The chart below summarises the nature of the evidence for effective interventions for the three conditions, as well as their similarities and their differences.

| **Asthma** | **Arthritis** | **Diabetes** |
|---|---|---|
| Early intervention (EI):<br>Can identify triggers in adults but equivocal for children. EI involves avoidance of triggers, lifestyle changes, monitoring & drugs. | Early intervention:<br>For RA early & assertive treatment with disease-modifying antirheumatic drugs (DMARDs) is recommended. Also, weight loss & moderate exercise for both RA & osteo. | Early intervention:<br>Lifestyle changes can prevent/delay onset. |
| CCSM:<br>▪ Improved outcomes & probably reduced costs, through reduced health service use (e.g. hospital admissions)<br>▪ For severe asthma, health benefits may not stretch to improved morbidity/mortality<br>▪ Improved self efficacy from improved knowledge | CCSM:<br>▪ Improved clinical outcomes & reduced costs through reduced health service use<br>▪ Improved self efficacy, well being & pain reduction | CCSM:<br>▪ Equivocal results re glycaemic control and clinical outcomes<br>▪ Improved compliance with treatment |

| **Commonalities for all conditions** | **Differences between conditions** |
|---|---|
| ▪ Multifaceted interventions are more effective than single component interventions (education, plus self-management skill development)<br>▪ Most evidence on effectiveness is short term & under trial conditions<br>▪ Unclear long term maintenance of behavioural changes<br>▪ Health benefits of CCSM shown | ▪ Self efficacy reported for asthma and arthritis<br>▪ Pain reduction is specific to arthritis<br>▪ Symptom monitoring & action plans reported to enhance self-management for asthma & diabetes<br>▪ Reduced costs for asthma and arthritis, through less use of health care although components of use differ for each. |

## Early identification/intervention strategies

There are few studies which relate specifically to the effectiveness of detection of risk factors for chronic disease, although much of the self-management literature refers to the importance of early detection. Early detection is primarily concerned with the identification and subsequent modification of (biological) risk factors for chronic disease through early intervention strategies.

## Arthritis

Studies indicate that initiating treatment with disease modifying antirheumatic drugs (DMARD) as soon as possible after diagnosis of rheumatoid arthritis produces significant clinical and functional benefits and appears to retard the progression rate of erosions. Delaying treatment by as little as 8 or 9 months sets the stage for damage that cannot be reversed [52-54]. Some researchers suggest that delaying treatment may be the main contributing factor for poor outcomes [55]. However, others argue that preliminary assessment is crucial to identify which patients will do better with rest and mild treatment regimens rather than with aggressive therapies [56].

The importance of early intervention, especially with exercise regimens, for osteoarthritis and the prevention of osteoporosis, particularly for women, has been stressed by some researchers [57]. On the other hand, excessive participation in high impact sports can increase the risk of osteoarthritis [58]. Other risk factors such as obesity, joint trauma and high-risk occupations point to the conclusion that much pain and disability from osteoarthritis is, theoretically at least, preventable [59].

Early detection and intervention differ for osteo- and rheumatoid arthritis. In rheumatoid arthritis it involves serology testing and X-rays for people with a family predisposition or in whom a clinical pattern is suggestive of the condition. Immunisation against influenza and pneumonia are recommended for people with RA given their excess mortality from respiratory and infectious diseases [4]. Early intervention for osteoarthritis risk factors include control of obesity, modifying occupational related joint stress and avoiding joint trauma. Weight loss and exercise are important strategies in the management of osteoarthritis as is the use of anti-inflammatory drugs [4].

As there is no cure for most types of arthritis, the goals of treatment are to provide pain relief, increase mobility and improve strength [4].

## Asthma

Asthma is a growing problem in Australia and it has been suggested that under-diagnosis and consequent under-treatment contributes to higher morbidity and mortality [60]. This points to the importance of early detection and intervention with regard to triggers/risk factors such as exposure to smoking. Screening for childhood asthma appears particularly important [61], although the difficulty of defining asthma means that it is possible that asthma is over-diagnosed in children who are experiencing normal, self-correcting developmental respiratory conditions [62]. Regular screening in the workplace may also assist adults who are exposed to occupational risks for asthma, allowing those who are affected to be removed from exposure to prevent further development of the condition [63].

In addition to early diagnosis and identification of triggers, early intervention and management of asthma for both children and adults involves medication for acute attacks and ongoing management of the condition. This includes identification and avoidance of triggers, other self-management strategies (monitoring lung function, medication use, a healthy diet and regular exercise), and regular medical consultations [4].

## Diabetes

Evidence (cited in [64] ) suggests that screening for high risk populations has a lower cost per case detected than screening opportunistically. [65] High risk groups for prevention and early intervention include people with impaired glucose tolerance (IGT) or gestational diabetes and those with other risk factors such as obesity and physical inactivity [8]. Early detection through screening of high risk groups is important because type 2 diabetes can remain asymptomatic for some time and complications may set in before the diagnosis is made. Early diagnosis and the control of blood sugar levels can delay the onset and progression of many diabetes related complications. In addition, early and aggressive treatment of risk factors such as hyptertension, hyperlipidaemia, and elevated albumin which may be present before a clinical presentation of diabetes, can delay the development of the disease [66]. Recognising that there is a continuum from minimal changes to impaired glucose tolerance to the development of diabetes [67], regular recall and monitoring may provide population health benefits by influencing health promoting behaviours [68].

There is Level 2 evidence that weight loss, healthy diet and physical activity in high risk groups can prevent or delay the onset of diabetes [8, 69]. Management of diabetes involves a combination of patient education, self-management and continuing support [4]. Pan et al. [70] found a reduction in the incidence of diabetes over a six-year period due to changes in diet and exercise, while Tuomilehto et al.[71] reported a 58% reduction in diabetes risk due to changes in lifestyle and the use of individualised counselling.

Dagogo-Jack [72] proposes ten strategies for primary care to prevent or reduce the development of diabetes, including provider education, patient education, risk factor reduction and surveillance, and goal setting. Several authors [73, 74] suggest that involving not only the family but the community is essential to change dietary and lifestyle patterns which can lead to diabetes; this can be of particular importance to children in high risk families or population groups in order to prevent or delay the onset of diabetes. Regular surveillance for microvascular complications and CVD risk reduction is a priority for newly-diagnosed people as it may prevent more serious complications from developing [67, 72]. This is particularly true for type 2 diabetes in young people [73, 75, 76], where the development of poor eating and lifestyle habits in childhood may have consequences later in life.

## Chronic condition self-management

Chronic condition self-management programs have demonstrated significant health benefits for diabetes [77], asthma [78], arthritis [79], and a heterogenous group of patients with a variety of chronic conditions [20, 36]. There is also evidence of the potential of well-designed CCSM programs to reduce health care use [22, 36, 50, 80, 81]. Collaboration between practitioners and patients, targeted goal setting, training and support, and follow-up have been identified as key elements to a successful CCSM program [82, 83], with an emphasis on evidence-based outcomes [84]. Symptom action plans and ongoing monitoring increase self-management practices such as preventative action and are widely recommended for asthma and diabetes [85, 86].

However, there are gaps in the literature with regard to methodology, definitions, and outcome measures which make it difficult to assess effectiveness of interventions outside of the study environment, with functional outcomes most often measured in place of clinical outcomes [87]. Weingarten et al's (2002) meta-analysis of 118 chronic disease management programs found that patient education (materials and instructions), reminders (prompts to perform specific tasks) and financial incentives (direct monetary payments, discounts or services for achieving specific goals) were all associated in improvements in disease control. However, the authors comment that the wide variety and number of interventions makes it difficult to compare interventions and assess the relative contribution of each intervention [88]. Eakin et al [89] propose an evaluation of efficacy under the domains of physiological, behavioural, psychosocial, knowledge, and other, recognising the difficulty of assessing outcomes from studies using varying outcomes measures. Moreover the long term evidence on the effectiveness of CCSM programs is unclear. This lack of evidence for maintenance of behaviour changes suggests that there may be important differences in the processes that govern initiation and maintenance of behaviour [90].

## Arthritis

Self-management programs are underused by health providers for arthritis [91] although they are available and can improve quality of life while delaying disability. An Australian self-management program reported increased knowledge and satisfaction among patients using an arthritis program although there were no significant changes in levels of pain, disability, or self-efficacy [48], while a British program found noticeable improvements in self-efficacy, psychological well-being, reduction in clinic visits, and reduction in pain which were maintained at 12-month follow-up [92]. Bodenheimer et al [18] concluded that self-management education can improve clinical outcomes. However, as with asthma, evidence of long-term benefits is equivocal [93] and it is unclear which interventions are more effective than others for particular forms of arthritis [94, 95].

## Asthma

Many studies and reviews of asthma self-management programs are inconclusive. The Grampian study found that there were no significant differences in the effectiveness of routine self-monitoring as opposed to conventional monitoring processes [96]. The authors suggest that while prescribing peak flow meters and giving self-management guidelines to patients with severe asthma may provide benefits it is unlikely to improve mortality or morbidity amongst those with mild to moderate asthma. However, this may depend on the type of patient education provided: a study involving personalised booklets show some improvement in terms of reduced hospital admissions and improved quality of life [97]. Another study found the use of a ‘credit card’ asthma self-management plan reduced the need for acute medical services [98]. A more recent study [99] found that, if peak flow monitoring was combined with written action plans and regular contact with health practitioners to reinforce self-management, airway reactivity was improved and use of health services was reduced. Guided self-management programs may be more cost-effective [78], increase knowledge of asthma among patients [100] and lead to greater self-efficacy [101].

One review has shown that patient education programs, especially for young people, can improve lung function, self-efficacy, and reduce school absenteeism, number of days of restricted activity, and number of visits to the emergency department [81]. However, a review of adult asthma programs concluded that critical characteristics of education programs are often not adequately described, making it difficult to assess what strategies or components of programs are most effective [102].

## Diabetes

A number of studies and strategic reviews highlight inconsistent results of many patient education programs and the difficulty of maintaining behaviour and lifestyle changes over time [103-105]. In their review, Renders et al [68] suggest that multifaceted professional interventions can enhance the performance of health professionals in managing patients with diabetes, and that the addition of patient-oriented interventions can lead to improved patient health outcomes. Although much research has been conducted with young people, the elderly also have special considerations and it may be that older adults in particular need targeted education and individualised programs [106]. Griffin & Kinmonth [107] have shown that including a systematic follow-up system within general practice provides the same quality of care as hospital follow-up, however the evidence is weak.

A systematic review by Norris et al (2001) of 72 randomised controlled trials of diabetes self-management education concluded that education interventions that consisted of multiple education sessions over time, with active participation of patients generally showed better short term outcomes; as opposed to single didactic interventions, which were ineffective. For those few studies which had long term follow up (i.e. longer than 1 year) the results were mixed; with positive studies either associated with intensive interventions or a high attrition rate, leaving only a small group at follow up. Few studies examined health service utilisation and no studies undertook cost benefit analysis [108].

## Section summary

- Early intervention for these three chronic conditions emphasises risk factor monitoring, behaviour and lifestyle modification, and patient education and self-monitoring – for asthma, triggers for attacks; for arthritis, the onset of pain; for diabetes, monitoring of glucose levels.

- CCSM research emphasises patient education and self-monitoring, however, there is a lack of consistency with regard to what each entails, and difficulty in measuring effectiveness.

- CCSM programs show improvements in health benefits, measured by clinical factors (blood glucose levels, asthma readings, reduction in arthritis pain) but it is not always clear which intervention has been most successful.

## 4.3 Effectiveness of chronic condition self-management programs for disadvantaged groups

While the evidence suggests that self-management programs within the general population are effective to at least some extent, the experiences of some disadvantaged groups points to the difficulties of providing services which are accessible and appropriate for a wide diversity of needs. The importance of organisational aspects of care such as multi-disciplinary teams, provider-client partnerships, culturally appropriate education tools, individualised treatment plans, and greater interaction with the community have been highlighted as aspects which might improve access to care by disadvantaged groups [109], [110], [111] and [112].

The literature review identified 35 articles which were a mixture of qualitative and quantitative research studies and literature reviews/opinion pieces on the effectiveness of self-management strategies primarily for the three conditions and selected population sub-groups. The majority of studies were conducted in the United States (19), with ten Australian studies and the remainder from New Zealand (3), the United Kingdom (2), and Canada (1). Most of the evidence from these studies is classified as *Level 5 evidence*, as per the following table, demonstrating the difficulty of measuring many of the cultural, socioeconomic and psychosocial factors impacting upon the provision of health services to disadvantaged populations.

| **Evidence Levels**[ii] | **Articles** |
|---|---|
| *Level 1:* Systematic review of all relevant RCTs | 0 |
| *Level 2:* Properly designed RCTs | 5 |
| *Level 3:* Well designed pseudo RCTs/comparative studies with controls | 1 |
| *Level 4:* Case studies, either post-test or pre-test/post test | 5 |
| *Level 5:* Expert opinion papers/descriptive studies | 24 |

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[ii] Levels 1-4 evidence levels based on NHMRC definitions [113]. Level 5 evidence based on definition from RACGP [114..]

## Summary of CCSM approaches

A range of CCSM approaches operating at a number of levels were identified from the literature. These are categorised in the following box.

**Patient education & training**
- Focus: 1:1, with carers/families, small groups
- Approaches: Counselling, motivational interviewing, skills development
- Delivered by: Peers, health professionals
- Settings: Clinical, community
- Delivery mode: Face to face, telephone, computer assisted
- Tools: Action plans, diaries, written/audiovisual materials

**Community-based support groups**
- Focus: Single/multiple conditions
- Approaches: Time limited/ongoing, formal/informal structure
- Delivered by: Trained personnel, group members
- Settings: Community

**Provider focussed**
- Focus: Education, training, ongoing support
- Tools: Clinical guidelines, educational resources

## Arthritis

There have been a number of studies examining attitudes, beliefs and self-management practices for people with arthritis in different disadvantaged population groups, including rural residents in the UK [115] where locally-based Lorig education programs for rural residents showed similar results to those for urban dwellers; as well as distinct ethnic groups including American Indians [116], Chinese-speaking Canadians [117], African Americans [118, 119] and Hispanic Americans [50]. Ethnicity and associated health beliefs were found to be important influences on the recognition and understanding of arthritis, as well as on the choice of self-care strategies which were used. American Indians were found to use a range of words to describe their arthritis which may not reflect the extent of pain or disability actually experienced, understating their symptoms [120]; in addition, beliefs about the nature of arthritis may effect the uptake of coping strategies or medical interventions [116]. Older African American women were found to have low levels of physical activity and higher morbidity than the general population, possibly due to cultural or social beliefs such as the value of rest and attitudes towards the body [121].

Zhang and Verhoef (2002) conducted in-depth interviews with Chinese immigrants in Canada and found that beliefs regarding Chinese and Western medical systems influenced patients' choices regarding treatment and their beliefs about efficacy. For instance, Chinese immigrants tended to choose Chinese medicine for treatment of chronic disease rather than Western medicine, seeing the latter as better able to treat acute and short-term problems. However, in Chinese medicine arthritis is not considered a serious disease, a belief which also influenced the length of time patients waited before seeking treatment, their use of self-treatments, and their beliefs about treatment efficacy. Social networks were important avenues for gaining information regarding treatments and healers. The authors developed a model which illustrates the way in which Chinese immigrants will use both Chinese and Western medicine depending on their perceived needs at the time. In particular, Chinese physicians were perceived to have a more holistic approach. Zhang and Verhoef concluded that Western physicians need to take into consideration ethnic cultural beliefs about medicine and health. It was considered important that physicians used clear communication and took time to explain treatment or medications with the patient: "even if lab results fail to show a problem, [the physicians] should still offer an explanation about the possible disease and the function of any medication being prescribed. Without clear statements and explanations, Chinese immigrants perceive physicians as not qualified and have little confidence in them" [117]. The importance of differing communication patterns between cultures and ethnic groups is often unrecognised by the health system [122].

The use of complementary medicines for the treatment of pain is widespread, and has been reported to be highest among suburban sufferers compared to their rural and urban counterparts in the United States [123], perhaps due to demographic factors such as age and income. Financial factors were found to influence the uptake of self-management strategies among older African Americans of low SES [119]. The use of complementary medicines is more widespread in most ethnic groups than in the general population [117, 118, 124, 125] and in some ethnic groups there is less faith in conventional western medicine and surgical therapies [117, 118]. African American men were shown by Ibrahim et al (2001) to rely more on self-care treatments and to undergo joint replacement less frequently than their white American counterparts. In none of the groups was complementary medicine used as a substitute for medical care, although delay in seeking medical help was found in American Indian groups [116]. Clearly self-management programs need to be sensitive to and cognisant of diversity in health beliefs and to use the traditional therapists in communities as both referral sources and as participants in programs.

Low education was found on the one hand to be associated with less use of conventional allied therapy modalities in rheumatoid arthritis [126], although it was not found to be a barrier to achieving good outcomes with formal self-management programs in Hispanics of low education [50] or elderly African Americans of low education [119]. Lorig et al.'s study of an arthritis self-management program designed for an American Hispanic community provides *Level 2 evidence* suggesting that self-help management programs are effective in minority groups when information and materials are provided in the group's preferred language. In another study, a mail delivered program was able to achieve good outcomes by ensuring materials were tailored to the education level of participants [22]. Lorig et al. (1999a) also suggest that specific interventions designed for particular community groups (in this instance, special exercises and information on the American health system) help ensure sustainable results. The results of this study demonstrated, more importantly, that self-efficacy was the biggest predictor of sustained pain reduction after one year [50].

The Lorig self-management program concept has been used in a number of countries and in a variety of settings. It has been reported to be an effective tool for self-management of arthritis when adapted to the needs of low-income urban older African American women [119], and with rural residents in England [115]. While the Challenging Arthritis course in the UK showed no significant different in results between rural and urban environments, interviews with rural participants suggested that in order to preserve mobility issues such as viable local transportation, support networks, and access to services have a heightened importance in rural areas. It should be noted that the definition of rural differs by country and even by research program: Barlow et al. in the UK used a definition of a population of 10,000, while Vallerand et al. (2003:923) in the United States defined rural as “communities with fewer than 25,000 residents and a population density below 1000 persons per square mile” The parameters for a definition of rural in Australia are likely to be much smaller, although the issues of transport, support networks, and access to services,, are likely to be even greater for rural Australian residents.

## Asthma

Poverty has been recognised as a factor influencing asthma, particularly in children, as it may impact upon a number of risk factors including environmental conditions [127], education levels and social class [128], and life stresses [129]. One study reported that predictors for lack of asthma self-management skills were: “less than a high school education, current smoking, lower median household income and no history of steroid use” [130] On the basis of interviews with patients attending emergency departments for acute asthma in the USA, Radeos et al. (2001) conclude that patients of low income with low education levels are more likely to present at the emergency department and are less likely to be connected to a primary care provider. The authors suggest that the emergency department may be the only opportunity to provide targeted asthma education interventions to this segment of the population.

A UK study looking Birmingham residents of either white European or Indian sub-continent background, from similar neighbourhoods of high ethnicity and high socio-economic deprivation, found that while both groups had been provided with information regarding use of medication delivery tools, fewer of those from the Indian sub-continent had been provided with more detailed information regarding medication, trigger factors and symptoms, or peak flow meters [131]. A further analysis of those of Indian background showed that people who had been born in the

UK had received more detailed information and demonstrated greater knowledge of self-management skills. Language barriers for migrants may play an important part in the management of asthma where the provision of information and the vigilance of the patient in monitoring their symptoms is crucial [131].

One study concluded that computer-based interventions may be more cost-effective than written materials with low SES, urban children, if staff time is reduced**.** However, in terms of clinical outcomes, both are effective [132]. Nevertheless, a systematic review of 22 randomised controlled trials on computerised patient education concluded that while it is a valuable supplement to face-to-face care, computer-based interventions are not a substitute for patient-GP interactions [133]. There is other evidence that suggests that personal interaction is generally an important component of effective care, with access to health care providers a first step for many disadvantaged groups. For instance, pharmacists are a key group in ensuring quality use of medicines by Arabic and Chinese communities as are herbalists in Chinese communities [134].

Indigenous communities, as has been noted earlier in this report, in general experience higher rates of chronic illness, including asthma. A New Zealand program designed in partnership between an academic medical team and Maori community health workers demonstrated (*Level 4 evidence*) a high rate of success in improving health outcomes and self-management. What is interesting about this program is that the health outcomes and self-management improvements were sustained after six years and extended beyond asthma morbidity [135]. The program consisted primarily of daily symptom diaries, use of peak flow monitors, and an asthma self-management plan, with follow-up support provided by community health workers. The program took place within local community centres rather than within a traditional clinic setting. The six year follow-up study reported by Ratima and his colleagues demonstrated improved self-management, increased quality of life and participation in sporting and other recreational activities, and increased community bonds. Participants reported that taking control of their asthma management had assisted them to take control of other aspects of their lives, including smoking, use of alcohol, and management of co-morbidities [135]. Four key benefits of the program were identified in addition to improved asthma management: “cultural affirmation; improved access to other health services; a greater sense of control over health; and a positive impact on the extended family” [135]. The authors conclude that working in partnership with indigenous communities and designing programs in accordance with the community’s traditions and in familiar, culturally acceptable locations, may provide a model for implementing similar programs in other indigenous communities.

A similar conclusion was also reached by a study by Chang et al. within Australian indigenous communities. This study found that a specialist respiratory service delivered in partnership with local indigenous health workers can improve the management of asthma in indigenous children and improve health outcomes, and the researchers argued for the incorporation of such partnerships within community-controlled health services [136].

Access to general primary care within the Australian indigenous community may be more of a priority than the quality of asthma management provided by the GP [137]. In its report NACCHO & the Chronic Disease Alliance advises that regular screening for smoking status be undertaken and that smokers be provided with brief interventions (including education, advice and counselling). They also stress that these individual focussed strategies need to be complemented by health promotion programs that focus on tobacco control [69].

While varying rates of asthma have been estimated within indigenous communities around Australia, a recent study of five Torres Strait communities (which involved a house-to-house approach for identifying children with asthma) indicated that prevalence rates were around 20%, higher than in the non-indigenous Australian community [138]. Higher rates of hospitalisation for asthma for indigenous people have been reported in Western Australia [139]. The distinct differences between indigenous communities in demographics, culture, employment and education status, resources, environment and access to health services make it difficult to estimate a national prevalence rate for asthma in indigenous communities.

## Diabetes

Diabetes management requires highly motivated patients on a sustainable long-term program [140]. Health literacy is particularly important for diabetes due to the wide range of complications which may arise. Health literacy has been associated with poor glycaemic control in American adult populations with diabetes, both English and Spanish-speaking adults, and is independently associated with socioeconomic status, educational levels, and ethnicity [25]. In particular, education levels have been demonstrated to correlate with health outcomes, with patients who had 13 or more years of education showing greater compliance to treatment regimens than those who had 12 years or less of education [140]. Those with higher educational attainment may also have gained higher levels of health literacy and self-efficacy. This educational differentiation between those with 13 or more years of education and those with less was also found by Katz [126] for people with arthritis.

Self-efficacy has been shown to have an association with regular blood glucose monitoring (BGM) among diabetic New Zealanders, across population groups of Europeans, Maori and Pacific Islanders [141].

However, more significant barriers to BGM demonstrated in the New Zealand study were the costs of, and access to, care, for instance in the purchase of glucose strips for testing, suggesting that those of lower socioeconomic status have more difficulty in maintaining a regular monitoring regimen. This was particularly true for people of Maori and Pacific Islander background, and Zgibor and Simmons (2002) suggest that the development of specific recommendations on self-management supports for people experiencing financial or access difficulties might assist people to continue monitoring practices. Hunt et al [27] in their study of Mexican American patient perceptions and assessments of self care behaviour also found that limited economic resources influenced patient treatment as well as lifestyle choices (for e.g. the cost of blood glucose monitoring strips and medications; the difficulties in following dietary recommendations for fresh fruit and vegetables which were more expensive than their usual purchases; pursuing regular exercise in the face of poverty and/or living in high crime areas where it is not safe to walk).

Barriers to accessing care also influence health outcomes for patients with diabetes, and these fall disproportionately on those of low socioeconomic status and ethnic and indigenous groups. A USA study (*Level 2 evidence*) on the use of automated telephone assessments of patients with diabetes and follow up by nurses, improved health outcomes, primarily by overcoming barriers such as perceived problems in accessing health services and worries about financial aspects of health care [29, 142]. The automated telephone calls, which were made on a bi-weekly basis to the patients, asked the patient to record verbally the results of their self-monitored blood glucose (SMBG) as well as other health status or symptom information. The high level of participation in the study over twelve months suggests that patients were comfortable with the system, and that it improved their perceptions of access to and support from the health system [142]. The results were the same for both English and Spanish speakers, the latter being provided with telephone texts in their native language. While the study was designed around structures within the American health system which are not directly applicable to the Australian context, the results of the study do suggest that simple measures to improve access to health professionals can positively influence health outcomes in a cost-effective manner. Piette (2000) suggests that public health services will need increasingly to consider how to serve a population with rising levels of chronic disease, through such mechanisms as telephone consultations to assist people who have difficulties navigating the complexities of the health system in accessing advice, information and support.

A similar study in the United States (*Level 2 evidence*) piloted the use of telemedicine facilities for the provision of diabetes education and showed that distance education was as effective and acceptable to patients as face-to-face education [143]. The education program was provided during three consultations with a diabetes nurse and a diabetes educator, and outcome measures at completion and three months indicated that glycaemic control had improved and was sustained. Both of these studies indicate possibilities for addressing access issues for rural and isolated patients, which are not cost prohibitive and appear to be acceptable to patients.

A contrasting Australian study explored the effectiveness of diabetes education in the Hunter Region of NSW and found that there were no significant differences between those who had received formal diabetes education through a 5-day residential course and those who had not [144]. The study also revealed a worrying lack of understanding regarding the disease and its consequences, and a lack of understanding amongst the sample about what constitutes good glycaemic control; as these results were shown across urban and rural residents, men and women, and age groups, it suggests the importance of ongoing evaluation of the effectiveness of education programs. Lowe and Bowen (1997) did identify single males and those living in rural areas as groups less likely to have received diabetes education and suggest that the provision of diabetes information through community pharmacies may be a way of reaching those who are less likely to attend medical or health facilities.

It may be that the frequency and quality of interaction with health workers impacts on the success of self-management programs. The provision of a bilingual community health worker in an American Hispanic community to assist patients to complete a diabetes education program has shown to have associated improvements in knowledge and self-care tactics at the end of the program [145]. Likewise, the use of Aboriginal health workers to run self-management programs for indigenous patients in Australia has been shown to have benefits in terms of knowledge and self-care [146].

Von Hofe et al. [122] suggest that effective models for diabetes self-management in culturally and linguistically diverse populations include culturally specific materials, make use of relevant cultural beliefs and attitudes in discussing diet and nutrition, and emphasise individual and community involvement. An Australian study which examined the diabetes education and knowledge among patients with Type 2 diabetes demonstrated that education, knowledge and self-management were lowest amongst the elderly, those not fluent in English, and indigenous Australians [147]. Exposure to and uptake of education programs and usage of information provided was lowest for these groups. The authors of this study, conducted in Fremantle where there is a high population of migrants from Southern Europe, argue for the development of targeted education programs which are appropriate for the various ethnic communities and indigenous Australians.

As a final note of caution, Eakin et al. [89] reviewed diabetes self-management programs for disadvantaged populations and noted that of the four which included long-term follow-up there were fewer differences between control and intervention groups, suggesting that short term differences were not usually sustained.

## Table of summary of research findings for each condition

| Condition | Findings |
|---|---|
| **Arthritis** | ▪ Ethnicity & health beliefs influence understanding of condition, choice of self-management strategies (SMS) & their efficacy, & greater use of complementary therapies, as an adjunct to mainstream therapies.<br>▪ Social networks are an important source of information on condition & treatment options.<br>▪ Health care provider communication skills important in understanding & appreciation of health beliefs.<br>▪ Low education levels and English language skills are not a barrier to good outcomes provided information & materials are tailored to address these issues<br>▪ Self efficacy is the biggest predictor of pain reduction. |
| **Asthma** | ▪ Low education & income levels are predictors less effective SMS.<br>▪ Differences in information & education provided to English speaking versus non English speaking people / or for those who speak English as a 2nd language.<br>▪ Involvement of local communities/bilingual/indigenous health workers is effective in improving knowledge and self-management strategies.<br>▪ Personal interaction between provider and clients/patient is an important component of care, especially in early stages. |
| **Diabetes** | ▪ Health literacy is important for effective self-management – low literacy & education levels associated with poor glycaemic control & less adherence to treatment.<br>▪ Self efficacy is associated with regular blood glucose monitoring.<br>▪ Involvement of local communities/bilingual/indigenous health workers is effective in improving knowledge and self-management strategies.<br>▪ Cost barriers associated with self-management (eg blood glucose monitoring/access to healthy food).<br>▪ Patient education as a single strategy not effective.<br>▪ Automated telephone assessment, with nurse follow up and telemedicine overcome barriers to accessing care and education and improve health outcomes.<br>▪ Health benefits not sustained over time. |

## Section summary

- For disadvantaged groups, organisational aspects of the structure of health care at the local and regional level may need to be addressed first, such as use of multi-disciplinary (and multi-lingual) teams, time for the development of patient-provider relationships, development of culturally specific materials, and community involvement.

- Condition specific issues such as the provision of information, access to and monitoring of medication, and on-going support need to be provided in a culturally appropriate manner.

- Health beliefs and self-efficacy issues may impact upon the perceived need for health services amongst disadvantaged groups, the choice and uptake of self- management strategies, and understanding of health.

- The financial costs of maintaining self-management treatment and lifestyle strategies are a particular constraint for people with diabetes.

- The most effective CCSM programs appear to be those with a high level of provider involvement or access to providers through follow-up (even by telephone or telemedicine); those which are developed in partnership with culturally acceptable health workers from within the particular community; and those which provide information in language tailored to the recipient's education and health literacy comprehension levels, and in the primary language for migrants.

## *4.4 Do disadvantaged people access chronic condition self-management programs? If not, why not - some case studies*

Research shows that disadvantaged groups do access self-management programs, but there are questions regarding the efficacy of generic programs for disadvantaged groups, and the need for targeted programs which address the barriers to accessing care. A recent Australian review into participation in CCSM programs found that despite marketing the course, people from disadvantaged backgrounds were less likely to participate [148]; thus reinforcing the evidence that generic programs have the potential to increase inequities in health. It has been suggested that addressing health inequalities in Australia requires commitment to five strategies at the policy level: "better data on inequalities, appropriate use of data, greater investment in prevention, local or regional initiatives to improve coordination, and funding mechanisms" [149].

**SHCI Case Study: South Western Sydney**

**The project is based in an outer urban area characterised by large pockets of socioeconomic disadvantage and an ethnically diverse population.**
A crucial aspect in enabling access to the program has been the recruitment of an Arabic-speaking community development worker who has had prior experience with the Arabic groups being targeted and who has developed trusting relationships with these groups. While the 6 week education/support program has been well attended; there are concerns that the most disadvantaged groups have not participated & that this may unintentionally contribute to widening health disparities.

Other demands on primary health care nurses have also meant that it cannot be assumed that this workforce has the capacity to sustain their involvement in the longer term.

## Issues influencing access to health care services

There are many barriers to health care for disadvantaged groups and, in particular, to the effective uptake of self-management programs. Some of the barriers include geographical access [150], availability of culturally appropriate education programs [122] or adequately resourced Aboriginal Community Controlled Health Services [151], lack of education [152], financial concerns [153], availability of interpreters [24] and other language barriers [134], and lack of relevant training for health providers working with disadvantaged groups [122][iii].

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[iii] Training in motivational interviewing as well as in counselling and coaching techniques as part of client empowerment approaches were identified as needs by 'The Good Life Club' project. Additional issues included provision of on-going support to providers for the implementation and sustainability of these new techniques as well as ways of interacting with clients.

Poverty and time orientation seem to be consistent barriers across racial, cultural and ethnic boundaries. "Poverty often forces people into a present time orientation, as the survival needs of the present become more important than looking to the past or the future. People in this situation are less likely to take preventative medications if the medication is expensive and they feel well." [154]

## Health literacy

People with low health literacy have a poorer knowledge of asthma and poor adherence to management guidelines [23], increased risk of hospital admissions [24, 155], and a disproportionate burden of diabetes-related problems [25]. Health literacy has been defined as "the achievement of the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health" [40]. Different types of literacy may be necessary in order to navigate the health care system and to manage chronic conditions effectively. Nutbeam [43] uses Freebody and Luke's three-fold classification of literacy based on the capabilities which it confers:

- *"Basic/functional literacy* – sufficient basic skills in reading and writing to be able to function effectively in everyday situations…;
- *Communicative/interactive literacy* – more advanced cognitive and literacy skills which, together with social skills, case be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances; and
- *Critical literacy* – more advanced cognitive skills which, together with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events and situations." [43].

Such a schemata recognises that people will differ in their ability to take in and process information about their health and about ways of managing their chronic condition. Inadequate health literacy has been independently associated with lower levels of chronic disease maintenance [25]. Low levels of literacy can be difficult to assess as people with literacy problems often hide their lack of ability from others [40]. The disparity in education levels which influence literacy (and it should be noted that this relationship is symbiotic: literacy levels can also influence educational attainment) can lead to an increased gap between patients who are well-educated and assertive in their relations with providers, and those who are unable to do so. Katz [126] focused on individuals with rheumatoid arthritis and a range of different educational levels, and found that "the association between education and performance of self-care activities was not linear", but concluded that "low education should not be viewed as the cause of increased morbidity and mortality, but as a proxy for a constellation of factors responsible for poor health outcomes." Nutbeam (2000) suggests that the relationship between education (in particular, literacy skills) and health is such that alliances between the sectors at the policy level as well as the local level should be considered to develop the levels of patient empowerment necessary for effective self-management.

Patient-related barriers such as a poor understanding of the need for treatment, insufficient confidence in the clinician or medication, psychological problems, or low motivation for behaviour change [156] may also impact upon an individual seeking treatment, or they may delay treatment until it requires acute medical care. Education appears to be a significant factor, with less educated individuals more likely to rely on clinicians to make management decisions for them than to self-manage [153].

## Psychosocial factors

Glasgow et al [28] found that two psychosocial barriers which influence levels of self-management and quality of life are low self-efficacy and low levels of family social support. Fear or distress concerning the disease and its complications, depression and health beliefs also impact upon self-management.

A recently published literature review identified a number of patient and physician barriers to patients' ability to be active participants in decision making. Factors influencing patients' unwillingness to actively engage are thought to include their feelings of intimidation about the complexity of choices, their anxieties about making the right choice, and their unfamiliarity with the concept of formally weighing costs and benefits. This lack of confidence can lead to patient's adopting a passive role, surrendering decision-making to the experts [38]. This is supported by Australian commentary from a prominent consumer advocate, who suggests that not all patients seek to be assertive and highly literate with regard to their illness, and that developing patient/provider relationships of trust and respect is the primary goal rather than developing more assertive patients [157]. Hibbard (2003) also cites a study by Roter et al on physician behaviour that involved audio-taping 46 physician-patient encounters. The analysis revealed that most information related to biomedical issues, that patient initiated talk and exchange on psychosocial issues was minimal, and that the physician's values and judgements tended to determine the treatment choice. These finding suggest that there are considerable challenges in implementing CCSM approaches that are patient centred and empowering and embedding these participatory approaches in every day practice. This has implications for practitioner training and education in communication skills and also for the way practices operate.

A patient-centred approach may improve patients' experience of care within consultations and programs [158], and patient participation in health care can improve compliance with self-management regimens. Successful interventions may include culturally and linguistically appropriate approaches, improved communications (including the use of interpreters), and involving the community [109]. Individual motivation and functional ability are also factors in adherence to treatment [159], as are educational programs which focus on empowerment and address psycho-social components of health [160].

## Culturally and linguistically diverse populations

Language can be a significant barrier to high quality health care and a risk factor for medication mismanagement. Language has been found to be a major barrier regardless of length of residency [134]. Significant positive associations have been shown between asthma knowledge and only speaking English, and non-significant positive associations with being born in Australia [161]. This correlates with a British study showing different self-management skills between UK-born and non-UK born participants within an ethnic population [131].

Culturally-specific treatments such as traditional Chinese medicine may be the first point of health care for migrants and people might delay seeking treatment from the biomedical health care system; however, attributing health beliefs solely to culture can be misleading, as a number of sociological attributes may contribute to the development of health beliefs [154].

Ashley [110] points out that some tasks associated with self-management include both abstract and concrete thinking, and that these tasks can be more difficult when they involve first making the judgement in one's native language (i.e. assessment of pain levels) and then translating that judgement into English. The experience of developing a Lorig course for Polish speakers in Tasmania demonstrated that while the course can be effective for CALD participants, it required a substantial resource investment in preparation and translation in order to make materials written in English accessible to non-native speakers [110].

Language issues including the availability of interpreters [24] and the cultural relevance of educational materials can also influence patients' capacity to develop health literacy and knowledge regarding self-management.

Hunt et al [27] conducted a qualitative study contrasting patient and practitioner perspectives among low income, low education and mostly unemployed Mexican Americans with type 2 diabetes. They concluded that differences in patient and practitioner perspectives regarding the illness and its requirements led to different approaches to treatment, including adherence and confidence in the other party. Key factors influencing patients' choices included the belief in the power of medication; the desire to feel and act normal and to avoid physical symptoms; and limited economic resources. The authors recommended that for groups experiencing significant levels of disadvantage, enhancing self care requires a multi-pronged approach including the following: paying attention to strategies to minimise costs, using patient empowerment strategies to assist patients to make optimal choices, incorporating open dialogue concerning ways in which patients are responding to their condition (with the assumption that there is a clear logic underlying self-care behaviour), and tailoring interventions to enable exploration of roles and social conflicts.

**SHCI Case Study: The Good Life Club**

**This project targets Chinese people with CVD & diabetes & involves 1:1 telephone counselling & a social support/education club.**
Training of & ongoing support for health professionals in telephone counselling & motivational techniques has been an important component. Capacity issues are impacting on the program: the limited number of bilingual workers restricts access to telephone counselling for Chinese speaking clients. This is also an issue for the Good Life Club, where Chinese interpreters are required. It has required considerable resources to develop language appropriate materials and provide interpreters. In response to these challenges, a recent initiative has been to collaborate with Australian Chinese Health Foundation.

## Indigenous populations

An obstacle to the improved health status of Aboriginal and Torres Strait Islander peoples has been their poor access to appropriate health services, including PHC services. Barriers include:

- ♦ the lack of provision of PHC services particularly in rural and remote areas;
- ♦ poor linkages (both horizontal and vertical) between the different parts of the health system;
- ♦ lack of a population health focus;
- ♦ poverty, which limits access to private health services, including fee-for-service general practitioners;
- ♦ cultural and social factors, such as cultural misunderstandings, poor communication and discrimination. [162]

Patient perceptions about their condition, including an underestimation of its severity, can affect uptake of services as well as the progression of disease.[iv] In indigenous groups this can contribute to higher prevalence rates, for instance with asthma, than in the non-indigenous population [163-165]. It should also be noted that there may be

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[iv] Interview with Robyn Mobbs, NT Indigenous SHCI demonstration project

an underestimation of the use of health services by Aboriginal people, due to discrepancies in information recording at the point of access [166].

The personal resources of an individual include social support and community connectedness, which are important concepts in indigenous communities. Aboriginal understandings of health and illness include an holistic approach [69]. The involvement of family members and the community is crucial in maintaining lifestyle changes and preventing complications from diabetes [122, 167].

> ***" Culture and tradition are pre-determinants to the introduction of the concept of self-management in indigenous communities and recognition of these pre-determinants can be utilised to influence the delivery of western medical solutions to chronic disease problems and the enhancement of health and well-being in a cross-cultural environment. Working within the traditional and cultural frameworks within a community instead of pulling an individual and family into a different unfamiliar social and cultural direction, opens communication between patients and service providers increasing a patient's capacity to self-manage."[168]***

Providing appropriate and relevant information requires awareness of appropriate language groups, as English is often a second or third language in rural indigenous communities [138, 169]. This is just one reason why Aboriginal health workers are best placed to provide self-management education, encouragement and support to indigenous communities, and should be part of any multi-disciplinary team considering self-management programs [167]. Provision of self-management should include a life skills component, such as budgeting and cooking, as these have an impact upon diet and nutrition [170]. Aboriginal health workers have been described as the "Praetorian Guard" of the Aboriginal Community Controlled Health Organisations [169], for their ability to mediate across indigenous and western cultures.

It has been suggested that a successful self-management program for indigenous communities should include the following components:

- Aboriginal health workers to take on a role of self-management coordination;
- links with existing health promotion programs;
- evaluation and quality tools which are appropriate to indigenous communities;
- continuing evaluation and clinical audit;
- ongoing training and education for health providers in chronic disease self-management;
- a multi-disciplinary approach which includes primary care practitioners and allied health providers. [146]

The above findings reinforce the importance of access to culturally appropriate PHC services, as represented by Aboriginal Community Controlled Health Services. These services improve access to health services for indigenous communities for reasons that include:

- local community ownership and control of the service;
- flexible and responsive service delivery, including the provision of outreach services;
- integrated and holistic service delivery through PHC approaches;
- cultural appropriateness of services, including information and education, that cater to the social and cultural needs of indigenous peoples in ways that are sensitive and inclusive. [171].

**SHCI Case Study: The Katherine West Health Board, Indigenous Project**

**This project involves 4 remote communities in central Australia.**
The model being used is underpinned by a community empowerment philosophy and involves two stages: community engagement and decision making (which takes on average 4-5 months); and 1:1 collaborative relationships between provider and patient, using goal setting approaches. Support groups are also being established in each community to support the program. Genuine community decision-making has been critical to get right before moving onto Stage 2. The Aboriginal community support workers have also been essential to the program's success and participation.

Challenges include the scarcity of additional support services & resources; lack of experience amongst heath professionals in community development approaches; and community attitudes towards chronic illness.

## Rural

Specific factors affecting rural communities include the distance required to travel to health and medical services, access to information, transport costs, and lack of provider/service choice [150].

Although it appears that rural communities have not been disadvantaged with regard to uptake of the EPC items by GPs, with rural uptake of health assessments 36% higher than urban uptake per full time GP [172], this is clearly not true of all areas and it is difficult to generalise about health access needs for rural and remote communities. Rural areas are not homogeneous, nor is access and availability to health services; health provision for rural indigenous communities may be far less than that provided to non-indigenous communities [172].

**SHCI Case Study: Healthpartners (WA)**
**This project targets people from low SES backgrounds and is focussed on healthy living.**

The program explicitly recognises the influence of the social determinants of health on the capacity of clients to self manage, and the social and economic barriers they face in their daily lives that need to be addressed before they can focus on their health. An appreciation of the difficulties disadvantaged groups face in navigating the health and welfare systems was the basis for using facilitators to assist and support clients to access other services. The need to continually appreciate that clients come into the program for a range of reasons and varied commitment to change their lifestyle behaviours has reinforced the importance of using the 'Stages of Change' approach in goal setting and action plans.

## Socioeconomically disadvantaged populations

The financial impacts of chronic illness disproportionately affect those of a low socioeconomic status. Concerns about costs of medications or treatment and implementing lifestyle changes may impact upon people's capacity to self-manage [153]; [27]. Programs targeting communities of significant SES disadvantage must take into account access to services and associated costs such as medications, nebulisers, and so forth. As an example, a greater degree of socioeconomic disadvantage has been reported in the slow-onset asthma group, with a greater number of hospital admissions, emergency department and GP visits, both urgent and usual, and a greater number of adverse psychological and behavioural effects in the event of an attack [173]. A high proportion of asthma sufferers in New Zealand reported that they would not call emergency services in the event of a slow-onset attack, indicating that "slowly developing attacks over a number of days are particularly prone to being inadequately managed and are therefore potentially more hazardous" [174]. Refer also to section 4.3 on diabetes for findings regarding financial impediments to self-management strategies.

> ***"….. we are trying to reach those in the community who are probably the most difficult to reach, those who have to get by on modest to minimal incomes, who are often isolated and have to confront their own ill-health, and must cope as best they can where the community support system seems to be already overburdened. We are using all available avenues to reach out and invite in to the program, those who would normally be invisible."*** [175]

## Summary of issues influencing access to CCSM interventions for disadvantaged groups

| | Arthritis | Asthma | Diabetes |
|---|---|---|---|
| **CALD** | ▪ Health beliefs can mean symptoms are underestimated<br>▪ Greater use of & respect for traditional therapies | ▪ Language barriers<br>▪ Use of pharmacists for information & advice | ▪ Access to bilingual health workers & culturally relevant information, (e.g. diet and nutrition) important |
| **Indigenous** | ▪ Little research in this area | ▪ Access to culturally appropriate PHC services important | ▪ Use of Aboriginal health workers<br>▪ Teaching of life skills, i.e. budgeting & cooking |
| **Low SES** | ▪ Greater reliance on self-care & complementary remedies<br>▪ Lower uptake of services | ▪ Poverty & environmental triggers<br>▪ Health literacy & self-management capacity<br>▪ Costs of medications | ▪ Information that is responsive to varying literacy levels<br>▪ Support for diet & lifestyle modification<br>▪ Costs of implementing & sustaining SMS |
| **Rural/remote** | ▪ Access to services, particularly early detection | ▪ Access to services, particularly in emergencies | ▪ Access to services<br>▪ Access to fresh and healthy food |

## Barriers or challenges and facilitators identified by informants from the SHCI demonstration projects

| Barriers or challenges | Facilitators |
|---|---|
| ▪ Lack of availability of specialist & support services.<br>▪ Lack of capacity within general practice to engage in multidisciplinary care planning & coordination.<br>▪ Lack of capacity within State-funded PHC services.<br>▪ Formal 6 week group courses not appropriate for people not used to participating in such groups.<br>▪ Lack of transport to participate in groups, compounded by problems of reduced mobility.<br>▪ Lack of access to bilingual staff and culturally and linguistically appropriate resources and services.<br>▪ Other more pressing concerns that are a greater priority than improving physical health e.g. domestic, financial stressors. This impacts on both capacity and motivation. | ▪ Locally based peer support groups that operate on a community development model.<br>▪ Trained bilingual workers & interpreters.<br>▪ Training indigenous workers.<br>▪ Use of workers who have pre-existing relationships with clients/carers (especially those where trust has developed) and also with GPs.<br>▪ Engagement of local community networks important for legitimacy of interventions, for provision of social support and for sustainability of interventions. |

## Section summary

- Many barriers to effective uptake of self-management programs have been identified which are common across groups and conditions.
- Health system issues include lack of availability of specialist and support services, lack of capacity within general practice & other parts of PHC.
- Patient/client related issues include health literacy, lack of motivation and competing pressures, health beliefs, psychosocial factors including self-efficacy and lack of social support.
- Enablers include provision of racially, culturally & linguistically appropriate services & resource materials, enhanced availability of services, ongoing training & support of providers, cost subsidies for treatment, services & equipment; interventions that are patient-centred, recognise & address psycho/social issues, engage carers/families & promote community involvement.

# 5. Discussion

## 5.1 Introduction

An ageing population, increasing prevalence of behavioural risk factors, and advances in treatment are increasing the prevalence of complex and chronic health conditions which in Australia, as in many other industrialised countries, are making a major contribution to the burden of disease. This burden of disease is shared unequally for many conditions with higher levels of disability, morbidity and mortality amongst groups in the community that experience disadvantage; whether this be by socio-economic status, location (rural/remote), ethnicity, Aboriginality or an interplay of a number of these factors. Primary care settings are a major focus for the management of chronic conditions. Over the last decade in particular there have been a number of Australia-wide initiatives that have aimed to improve the prevention (both primary prevention and the early detection of and intervention for potentially avoidable risk factors) and management of chronic conditions, including the development of the SNAP framework, the Coordinated Care Trials, EPC, and the Sharing Health Care Initiative with its focus on improving self-management. Improved management of chronic conditions has also featured in state initiatives, and most of the first round of bilateral agreements between the Australian government and state governments include objectives and initiatives to improve integration across and within primary health care services, especially in relation to diabetes and to a lesser extent, asthma. [176]

Central to the discussion of CCSM is understanding how chronic conditions are experienced by consumers and how they permeates the whole of life. These lived experiences include making significant life-style changes, the impact on family and employment, often involves substantial commitment by the carer, contains elements of uncertainty regarding future needs and recurrence, may fluctuate, be episodic and progressive, may be life threatening, and require ongoing, time-consuming and complex management. [177]

## *5.2 Evidence of effectiveness chronic condition self-management programs and early intervention strategies*

### CCSM programs

From the literature the major components of CCSM programs that can be identified are:

- *Partnership* or collaboration between the patient and the health service provider.
- *Education* with a focus on the patient developing self-management skills.
- *Informed choice* and involvement in decision-making through an understanding by the patient of the options and consequences. Adherence to medication and treatment regimes are also assumed by health professionals to be a central aspect of this element.
- *Behavioural and lifestyle changes*, especially in relation to diet, smoking and physical activity which are common risk factors.
- *Self-Monitoring* of symptoms and physiological measures.

The centrality of the 'active and empowered patient' reflects the psychological and behavioural science theoretical underpinnings. However, there is compelling international and Australian evidence that the patterns of health inequalities and greater burden of disease experienced by disadvantaged population sub-groups are as much, if not more so, a function of upstream social determinants of health as they are a consequence of individual behaviour and lifestyle. This evidence suggests that early intervention and CCSM initiatives for disadvantaged groups need to include as an additional central element:

- *Community involvement and engagement* that recognises the broader social context in which people live their lives.

There are a number of commonalities for all conditions in relation to the evidence for the effectiveness of CCSM programs:

- The importance of multifaceted CCSM interventions (which incorporate education PLUS social support, counselling, structural support, strengthening the capabilities of clients and their carers) is highlighted in a number of systematic reviews, although it is often not clear which specific component contributes most to change.
- The evidence is strongest for short term change under trial conditions.
- It is unclear the extent to which the benefits demonstrated in the studies are maintained over time.
- There is evidence of improvements in specific health outcomes, these include improved self efficacy (for asthma and arthritis), pain reduction (for arthritis), blood glucose control (for diabetes).

For asthma and arthritis there is also evidence of reduced costs to the health system.

## Early intervention strategies

Much of the literature on early intervention refers to its potential to delay/prevent the onset of diabetes and rheumatoid arthritis, but through different interventions:

- For *diabetes* the major focus is on behavioural and lifestyle changes amongst high risk groups with impaired glucose tolerance (IGT), or gestational diabetes.
- For people with *rheumatoid arthritis*, high risk groups are those with a family history or who have a suggestive clinical pattern, and early drug treatment appears to retard the joint damage.
- For *asthma*, identification of triggers in adults is the major focus for early intervention, with avoidance being the goal of intervention.

Thus for diabetes and rheumatoid arthritis in particular, the effectiveness of early intervention requires a primary health system that has the organisational capacity and systems to support the identification and screening of high risk groups as well as systems to support therapeutic interventions and lifestyle change programs designed to reduce behavioural risk factors.

## Discussion

The review has thrown up concerns related to the conceptualisation of issues that need to be addressed. Firstly there is often an assumption that people are not involved in self-management unless they are exposed to a specific intervention. In reality people are continually involved in day to day personal self care. [178], as part of their response to every day living, in order to maintain normal activities and relationships. The role of current patterns of self care and social support and their contribution to more formalised interventions need to be better recognised, acknowledged and strengthened.

Secondly, by focussing on literature related to three specific issues (arthritis, asthma, and diabetes) some more generic issues may have been missed, in particular the importance of co-morbidity, especially for disadvantaged groups. This is an important issue in the current context where the detection and management of chronic conditions can be vertically organised across the health system with little recognition that many people, especially in disadvantaged populations, have several conditions. They are also often living in households that are managing a wide range of acute and chronic health problems that stretch personal, social and economic resources. Evidence related to managing multiple, complex health problems associated with aging, disability and palliation may assist in understanding the challenges of developing effective and comprehensive early detection/intervention and self-management strategies for disadvantaged groups.

Finally, the review has also highlighted some significant gaps in evidence that would enable the identification of interventions to improve access and outcomes for disadvantaged groups through early detection/intervention initiatives and self-management programs:

- Difficulties in making comparisons between different types of interventions to identify those interventions (or their components) that are more successful.
- Little analysis of the impact of interventions for disadvantaged population sub-groups in systematic reviews.
- Limited comprehension of interventions that address known barriers to chronic condition self-management.
- Limited generalisability of research findings from other countries to the Australian context: of the 35 papers reviewed that had a specific focus on disadvantage, only 10 were Australian.
- Limitations in the strength of the evidence: most studies on disadvantaged groups were Level 5 evidence (i.e descriptive studies or expert opinion pieces/literature reviews).

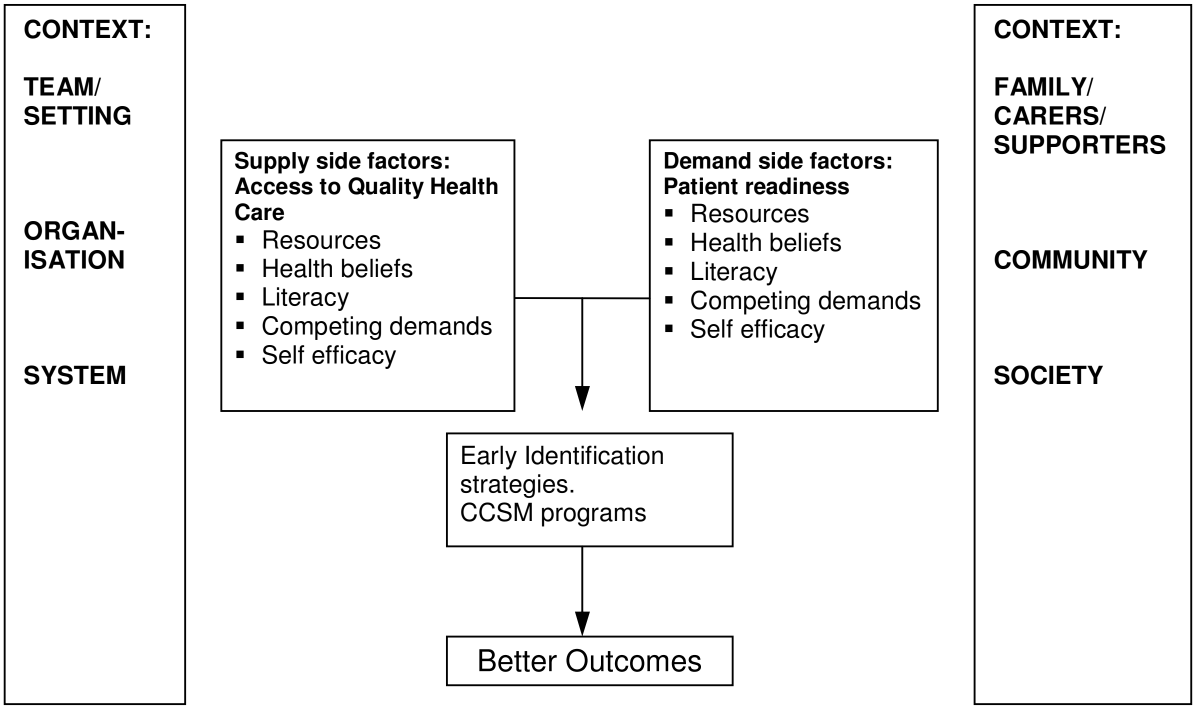
Despite these limitations, there are a number of factors that have been shown to contribute to the success of CCSM programs for disadvantaged patients. These include:

- Multi-faceted approaches.
- The importance of psychosocial support and working not only with the person with the chronic condition, but also their carers, families and communities.
- Addressing affordability in program design, whereby it presents no barrier to access or take up of self-management strategies.
- Addressing poverty and other environmental issues, such as access to fresh food, through intersectoral approaches.
- Increasing levels of health literacy, and tailoring information and materials.
- Understanding the health beliefs and expectations of the groups involved and adapting programs so that they are sensitive to these beliefs (which include a greater use of complementary therapies as an adjunct to mainstream therapies).
- Employing people from the target group including bilingual and indigenous health workers.
- Ensuring that language barriers are addressed through the use of interpreters and appropriate translation of materials.
- Improving the communication skills of providers.
- Improving access to PHC services and specialist back up and support.

## *5.3 Ways forward*

Despite the limitations, a number of clear lessons emerge from the review that can form the basis of a discussion on how health services can work more effectively with patients, their families and support systems and the community.

The diagram below looks at how the interaction between the patient and their health care provider needs to be understood in a wider ecological context. The patient needs to be seen in the context of their family, carers and supporters (including self-help groups), community and wider society. The health care provider needs to be understood in the context of the team or setting within which they work, their immediate organisational structures and the wider health care system. In this model, increasing the self-efficacy (the belief that they will be able to work together to successfully undertake self-management) of both the patient and the provider is seen as key to increasing self-management or to take steps that will enable early identification.



The literature review suggests that the issues to be addressed can be grouped under five domains:

- the availability of adequate resources;
- the beliefs of both patients and health care providers on the causes of the health problem and action that can be taken to address it;
- the level of knowledge and skill to take effective action;

- other competing demands on their time and resources; and
- personal, social, economic and organisational resources that will impact on the capacity to act.

The following table summarise the issues to be considered for each of these domains on both the demand and supply side in the development and implementation of effective and sustainable self-management initiatives for disadvantaged groups.

| | Supply (health system factors) | Demand (patient factors) |
|---|---|---|
| **Resources** | ▪ Availability of & access to quality interventions, research evidence, EBGs, practice systems to support ED & CCSM (e.g. patient registers, recall & reminder systems), community organisations & structures (e.g. support groups/networks).<br>▪ Availability of PHC & specialist services. | ▪ Availability of & access to a range of resources including equipment, medication, food, clothing, money, transport, social & environmental supports.<br>▪ Access to PHC & specialist services.<br>▪ Access to social support networks. |
| **Health beliefs** | ▪ Professionally mediated beliefs about health.<br>▪ Attitudes & beliefs about patient held health beliefs.<br>▪ Availability of culturally relevant programs, materials, information. | ▪ Culturally mediated perceptions about health.<br>▪ Sources of information about health. |
| **Literacy** | ▪ Access to opportunities to further develop competencies in communication, counselling & patient centred approaches.<br>▪ Access to interpreters & bi-cultural/indigenous health workers.<br>▪ Knowledge of local community networks. | ▪ Literacy levels.<br>▪ Health literacy.<br>▪ Problem solving & decision making skills. |
| **Competing demands** | ▪ Other priorities take over, e.g. hospital waiting lists, busy general practices, policy directives. | ▪ Other more pressing issues of poverty, financial, emotional, social crises. |
| **Self efficacy** | ▪ Belief that they will be able to work successfully with the patient. | ▪ Self confidence in their capacity to improve their health. |

It is suggested that a two-pronged approach will be required to provide CCSM programs for disadvantaged groups:

- a responsive health system that embeds early detection/intervention and CCSM as an integral aspect of patient management within a strengthened PHC system (i.e. the supply side); and
- a parallel focus on strengthening and supporting the patient, their carers, families and the wider community (i.e. the demand side).

## A responsive health system

The primary health care setting is the foremost setting in which the majority of the people at risk of /who have a chronic condition receive their ongoing care and support. Primary health care in Australia includes a combination of Australian Government and state government funded PHC services, as well as community-driven or locally-initiated self-help groups. Access to more specialised secondary and tertiary services, whether they be in community or hospital settings are also important for providers, patients and carers.

However, there are a number of challenges that impact on the capacity of the PHC sector to implement evidence-based early detection/intervention and CCSM interventions, not the least of which is the differing Australian Government and state government responsibilities for PHC and health reform drivers. The current focus of Australian Government chronic disease initiatives is aimed at improving population health and reducing the burden of disease through a range of GP-related initiatives. By contrast the major state-government drivers are to contain costs in the acute sector through earlier discharge policies and prevention of hospital admissions. This is impacting on the direction of community-based health services towards responding to acute health issues and away from early intervention and ongoing care and support for people with chronic conditions. It is apparent from the experiences of some SHCI demonstration projects at the service delivery level that these differing drivers and responsibilities are constraining the capacity of the PHC system as a whole and its component providers to engage in effective and sustainable CCSM programs.

Strengthening the PHC system requires action at many levels for both universal responses to chronic disease and also for additional/enhanced initiatives that target disadvantaged groups. Within primary health care, multi-disciplinary care teams can be supported, including the involvement of general practice. Clarifying the roles and responsibilities of especially primary/community health nurses, practice nurses and specific publicly funded allied health providers (e.g physiotherapists, occupational therapists and podiatrists) in relation to early detection/intervention and CCSM is also important. This could be assisted through consideration of incentives and other supports for state government funded PHC services to increase the involvement of, and focus on, self-management of people at risk of/with chronic conditions who are currently in community settings. The involvement of indigenous and ethno-specific health workers as part of the multi-disciplinary team is important. They have a significant bridging role between patients, their carers and the health system and are an important resource. Options for strengthening the PHC system need also to include Aboriginal Community Controlled Health Services as a matter of priority. Not only do they provide culturally appropriate services, many (41%) are located in areas that are classified as remote/very remote [179] and are the only health services provided. Through their accessibility and comprehensive PHC approach they have the potential to provide timely, ongoing and systematic early detection and interventions to prevent the onset of chronic disease as well as CCSM interventions for their communities.

A number of challenges are thrown up for health service providers in their role as facilitators of self-management. In part this has to do with what self-management means, to whom, whose definition prevails and what are the consequences[v]. Early intervention and CCSM is predicated upon notions of patient empowerment and preferences; yet there may be tensions between providers and patients over patient's preferences and priorities that do not accord with provider/guideline expectations. This has implications for the education and training of health workers in the theory and practice of patient centred approaches and exploration of differing perspectives. A good start has been made with the programs being offered by Flinders Human Behaviour and Health Research Unit for the SHCI demonstration projects.

Other challenges include practical concerns such as the extra time needed to build a relationship based on trust, the reluctance of patients to share preferences if they consider the health practitioner provider more powerful or knowledgeable, a lack of health practitioner interpersonal skills, practitioners who may wish to retain power imbalance [181] and their lack of technical skills and ongoing support for facilitating and supporting patients in their self-management[vii]. It was apparent from the interviews with SHCI demonstration projects specifically targeting disadvantaged groups that the skill set required by health practitioners to work in partnership with patients and their carers, for example in motivational interviewing and counselling, is different from (and sometimes at odds with) their current set of skills and competencies. Approaches which involve the patient and are based on genuine empowerment strategies might assist with effectiveness by building trust and relationships, and allowing exploration of adherence issues and understanding of obstacles to care. This might require workforce up-skilling in counselling and motivational interviewing techniques as well as a commitment to follow-up support and ongoing training for providers.

Consideration could be given to developing more individualised and flexible approaches which are sensitive to differing belief systems, health beliefs and personal capacity issues for disadvantaged groups. There could be an explicit recognition and

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[v] For example, Broom [180.] has identified several contradictions underlying the concept of self-management that relate to the differing patient/health system perspectives: autonomy vs victim-blaming, consumer & lived experience vs biomedical expertise/test results, long-term outcomes vs daily quality of life, patient empowerment vs cost efficiency, consumer responsibility vs provider control over access to resources.

[vii] For instance, while CCSM facilitators participated in a two-day motivational interviewing training program, they also required considerable ongoing support to implement their newly acquired skills.

consideration of equity issues in design and implementation of interventions through the use of health equity impact assessments.

In the short term at least health care costs may increase rather than decrease, while organisational and management systems are put in place, and also that due to the additional support needs of disadvantaged groups, there will be a need for greater investment. Systems that enable identification of high-risk patients and assist with follow-up and support of high risk groups might assist in bringing CCSM into mainstream health services. Systems to support CCSM include decision supports and clinical information systems that support quality care. Decision supports include evidence-based guidelines, protocols and education methods that specifically incorporate the evidence for disadvantaged groups and shared care protocols that integrate specialist care and primary care. Recall and reminder systems can be used to actively support CCSM by identifying specific patients who may require active follow up and support because of their disadvantage. Clinical information systems can also facilitate patient care planning and enable information to be shared with patients, their carers and other providers as part of coordinating care. These systems can also be used to monitor performance.

The variation in the distribution of primary medical services in remote and rural areas [182], coupled with a lack of publicly funded allied health professionals and long waiting lists also requires innovative and flexible models and responses, including the use of 'telehealth' and partnership approaches with other services and agencies.

## Strengthening and supporting the patient/carer/community

An important principle of effective CCSM is that it is a partnership approach; indeed the Australian program enshrines this in its title: *Sharing Health Care Initiative*. Implicit in this principle is the recognition that the majority of people are currently managing their chronic condition to a greater or lesser extent and in this they are supported by their health care providers and their families/carers. Exceptions are perhaps homeless people and those with a serious mental illness.

Programs targeting disadvantaged groups should include core components in relation to strengthening individual/family and communities and focus on creating supportive environments and developing public policies conducive to health; this may involve addressing social and environmental concerns which impinge on the well-being of the community. Family and community level interventions can also support diet, lifestyle and behaviour changes which can support healthy living. Interventions might include specific organisational and psychosocial supports, such as subsidies or financial support for self-management needs (i.e. equipment, medications, transport, etc), and interpersonal support for the development of self-efficacy and healthy beliefs. Individuals and communities may work together to find solutions to barriers such as accessing transport or facilities. Lay/peer educators in self-help initiatives are important community social support resources for facilitating recruitment into CCSM programs, in building trust and relationships, acting as role models, advocating for the self help group and so on. Finally the compelling evidence on the importance of health literacy requires concerted, multilevel and intersectoral approaches to improve functional and higher literacy levels, and enhance self-management skills and self confidence.

## *5.4 Approaches*

In this section a number of approaches are identified that would increase access of disadvantaged groups to early identification and intervention strategies and CCSM programs. These options need to be embedded within broader strategies to ensure there is a strong and comprehensive PHC system in Australia which ensures access to high quality PHC for all groups within the population. Refer to the recent report for the General Practice Partnership Advisory Council [176] which contains a number of recommendations on strengthening the PHC system.

This paper argues that any attempts to improve access to these services needs to address both supply (health system) and demand (patient and community) drivers within an ecological context. This involves seeing the health service provider as part of a team within a local service and as part of the wider health care system while acknowledging that patients live in a social context that includes family and carers, support groups, their local community within the wider social and economic environment.

### Policy approaches

A number of approaches are identified that would increase access of disadvantaged groups with chronic conditions to self-management services and programs as well as early detection and intervention strategies (the latter being aimed at behavioural and lifestyle changes, medication and monitoring). These approaches need to be embedded within broader strategies to ensure there is a strong and comprehensive PHC system in Australia which ensures access to high quality PHC for all groups within the population.

As there are a number of possible actions that can be taken for each level, we have purposely identified broad aims and objectives in the expectation that policy makers at the Australian government and state/territory level can decide on more specific action to take approaches forward.

## Health system approaches

### At the individual provider level:

***Aim:*** ***Health service providers have the capacity and resources to work effectively with patients and carers from disadvantaged backgrounds***

***Objectives:***

- Increase the skills of all service providers to work with disadvantaged groups through development of skills in:
    - Understanding the nature and causes of health inequality
    - Cultural competence (i.e. competencies to work with people from culturally diverse backgrounds)
    - Patient centred communication (that includes acknowledging health beliefs and healing philosophies and practices)
    - Approaches to strengthening personal capacity of patients to be involved in their care and undertake behaviour change, for example, motivational interviewing.
- Provide easy access to evidence based tools where they exist on approaches that include a focus on working with disadvantaged groups.
- Strengthen opportunities for multidisciplinary team work
- Ensure access to interpreters and bilingual/indigenous health workers.
- Provide policy support and funding incentives for PHC providers to participate in programs and interventions that increase the time available to spend with patients and promote continuity of care.

### At the service delivery level:

***Aim:*** ***Service delivery systems are able to support health care providers to identify and work with patients, families and carers from disadvantaged background and monitor the reach and impact of CCSM programs and early intervention strategies.***

***Objectives:***

- Use practice based systems that will routinely identify and follow up patients who are at high risk or who have a chronic disease, especially those from disadvantaged backgrounds.
- Work with other service providers to provide a comprehensive range of services and programs that are accessible to disadvantaged groups, for example Shared Care Programs for Diabetes.
- Establish effective referral patterns to other service providers and ensure that these services are affordable and appropriate to the needs of the patients.
- Establish clinics or other structures within the system that will enable health service providers to undertake structured care programs.

- On the prevention and early intervention side, enhance the capacity of local service delivery systems to monitor whether high risk populations are being screened, monitored and referred to relevant services, and increase accessibility of PHC services to disadvantaged groups by reducing financial barriers, employing flexible appointment and opening hours, enhancing and supporting flexible staff employment practices.

**At the regional or Division of General Practice level**

***Aim*: Systematically address the implementation of a comprehensive range of services and programs that support disadvantaged populations and overcome barriers to the effective use of CCSM programs and early intervention strategies.**

***Objectives:***

- Provide access to a comprehensive range of CCSM programs and early intervention strategies that are appropriate and acceptable to the local community, especially those who are most disadvantaged.
- Inform all service providers on the range of services available within the community. This should include health and non-health services (such as local self-help/support networks, community transport).
- Provide education and training for service providers on CCSM programs and early intervention strategies as part of continuing education programs. Engaging people with chronic conditions from disadvantaged population as teachers in continuing education programs (especially on their experiences and management of ill-health) should also be considered.
- Undertake needs assessments on the access of disadvantaged groups to existing CCSM programs early intervention strategies and take action to address gaps or problems, for example access to bilingual staff, lack of transport.
- Support the development of practice level systems that will allow for better identification and monitoring of high risk populations.
- Develop, adapt or provide access to a wide range of health information and education materials, appropriate to the literacy and other needs of disadvantaged populations, for local services.

**At the State/ National Level**

***Aim*: Capacity across the system is developed to support the development of effective CCSM programs and early intervention strategies for disadvantaged populations**

***Objectives:***

- Strengthen models that facilitate collaboration between State and Federally funded CCSM and early intervention approaches that meet the needs of disadvantaged populations in their community.

- Develop Australian government-State agreements that identify CCSM programs and early intervention strategies as agreed priority areas, with a focus on disadvantaged groups.
- Strengthen policy links between individual CCSM and early intervention strategies and population level approaches (eg SNAP).
- Invest in the development of an Australian evidence base for CCSM programs and early intervention strategies for disadvantaged groups.
- Work with community leaders and NGOs to develop health education and media campaigns that are relevant to the needs of disadvantaged populations.
- Advocate within the health and other sectors to address underlying determinants of health such as increasing food security and improvements in housing or transport infrastructure and improving literacy levels.
- Provide education and training on CCSM programs and early intervention strategies as part of core undergraduate education programs.

## Patient and community approaches

Section 4.4 of the report highlights some case studies of these approaches that strengthen patient and community capacity to engage in CCSM programs.

### At the patient and carer level

***Aim:* Strengthen the capacity of patients and their carers to take an active role in CCSM programs and early intervention strategies**

***Objectives:***

- Provide patients with information and education that is culturally and linguistically relevant.
- Increase the skills and confidence of patients to participate in the management of their health risk factors and/or disease.
- Reduce the costs to patients in accessing services and programs and maintaining their self-management strategies.

### At the community and support group level

***Aim:* Increase the capacity of local communities, and self help and other support groups to work effectively with disadvantaged groups**

***Objectives:***

- Provide adequate funding to NGOs, consumer groups, self help groups and other groups to ensure that they can provide and contribute to programs that are sustainable, accessible and relevant to the needs of disadvantaged populations.

- Support health services to work with local communities to identify actions that could increase the availability, accessibility and appropriateness of CCSM programs and early intervention strategies.
- Support local communities to identify social, economic and environmental constraints/barriers to adopting healthy lifestyles and address through local and intersectoral actions.

**At the wider social and economic level**

***Aim:*** ***Reduce the impact of social and economic factors that limit access to and the effectiveness of CCSM programs and early intervention strategies.***

***Objectives:***

- Systematically address some of the underlying social determinants of health such as unemployment and poverty.
- Targeted programs to improve literacy levels amongst disadvantaged populations.

# 6. Abbreviations

| | |
|---|---|
| AIHW | Australian Institute of Health and Welfare |
| BGM | Blood glucose monitoring |
| CALD | Cultural and linguistic diversity |
| CCSM | Chronic condition self-management |
| CCSMP | Chronic disease self-management program |
| COPD | Chronic obstructive pulmonary disease |
| CVD | Cardiovascular disease |
| DMARD | disease-modifying antirheumatic drugs |
| EBG | Evidence based guidelines |
| EI | Early Intervention |
| EPC | Enhanced Primary Care |
| GP | General practitioner |
| HIRC | Health Inequalities Research Collaboration |
| IGT | Impaired glucose tolerance |
| NACCHO | National Aboriginal Community Controlled Health Organisation |
| NGO | Non-Government Organisation |
| NHMRC | National Health and Medical Research Council |
| NHPA | National Health Priority Area |
| NHPAC | National Health Priorities Action Council |
| PHC | Primary Health Care |
| PI | Pacific Islander |
| RA | Rheumatoid arthritis |
| RCTs | Randomised controlled trial |
| SE | Socioeconomic |
| SES | Socioeconomic status |
| SHCI | Sharing Health Care Initiative |
| SMBG | Self monitoring of blood glucose |
| SMS | Self-management strategies |
| SNAP | Smoking, nutrition, alcohol & physical activity |

# 7. References

1. Flinders Human Behaviour and Human Research Unit, *What is Self-Management?* 2002, Flinders University.
2. Straton, J. and C. Sindall, *Perspectives and prevention terminology*. 2003 (unpublished), Population Health Division, Department of Health and Ageing,: Canberra.
3. McDonald, J., E. Harris, and J. Furler, *Health Inequalities Research Collaboration Primary Health Care Network Discussion Paper. Research priorities and capacity building issues.* 2002, Centre for Health Equity Training Research and Evaluation, University of Melbourne: Melbourne.
4. Australian Institute of Health and Welfare, *Chronic diseases and associated risk factors in Australia, 2001*. 2002, Commonwealth Department of Health and Aged Care: Canberra.
5. Wagner, E., *Care for chronic diseases.* British Medical Journal, 2002. **325**.
6. National Public Health Partnership, *Preventing Chronic Disease: A Strategic Framework Background Paper*. 2001, http://www.nphp.gov.au/publications/a_z.htm#p.
7. Commonwealth Department of Health and Aged Care, *National Asthma Action Plan*. 2001, Commonwealth Department of Health and Aged Care: Canberra.
8. Commonwealth Department of Health and Aged Care and Australian Institute of Health and Welfare, *National Health Priority Areas Report. Diabetes Mellitus 1998*. 1999, AIHW Cat. No. PHE 10. HEALTH and AIHW,: Canberra.
9. Commonwealth Department of Health and Ageing, *Sharing Health Care*. 2003, Department of Health and Ageing.
10. Straton, J. and C. Sindall, *Perspectives and prevention terminology*. 2003, Population Health Division, Department of Health and Ageing (unpublished): Canberra.
11. Gruman, J. and M. Von Korff, *Indexed bibliography on self-management for people with chronic disease*. 1996, Center for Advancement in Health: Washington DC.
12. Royal Australian College of General Practitioners, *Development of chronic disease self management guidelines for health service providers. Third report.* 2000, The Royal Australian College of General Practitioners Western Australian Research Unit: Perth. p. 1-17.
13. Flinders Human Behaviour and Health Research Unit, *Chronic condition self-management education and training manual.* 2003, Flinders University: Adelaide.
14. Sabate, E., *Adherence to long-term therapies: evidence for action*. 2003, World Health Organisation: Geneva. p. 211.
15. National Resource Centre for Consumer Participation in Health, *Consumer participation in Australian primary care: a literature review*. 2002. p. 1-67.
16. Shoor, S. and K.R. Lorig, *Self-care and the doctor-patient relationship.* Medical Care, 2002. **40**(4 Suppl): p. II40-44.
17. Reuben, D.B., *Organizational interventions to improve health outcomes of older persons.* Medical Care, 2002. **40**(5): p. 416-28.

18. Bodenheimer, T., et al., *Patient self-management of chronic disease in primary care.* JAMA, 2002. **288**(9): p. 2469-2475.
19. Donaldson, L., *The expert patient: a new approach to chronic disease management for the 21st century*. 2001, Department of Health: London. p. 38.
20. Lorig, K.R., et al., *Effect of a self-management program on patients with chronic disease.* Effective Clinical Practice., 2001. **4**(6): p. 256-62.
21. Clark, N.M. and F. Nothwehr, *Self-management of asthma by adult patients.* Patient Education & Counseling, 1997. **32**(1 Suppl): p. S5-20.
22. Fries, J., C. Carey, and D. McShane, *Patient education in arthritis: randomized controlled trial of a mail-delivered program.* Journal of Rheumatology, 1997. **24**(7): p. 1378-83.
23. Williams, M., et al., *Inadequate functional health literacy among patients at two public hospitals.* Journal of the American Medical Association, 1995. **274**(21): p. 1677-1682.
24. Baker, D.W., et al., *Use and effectiveness of interpreters in an emergency department.* Journal of the American Medical Association, 1996. **275**(10): p. 783-788.
25. Schillinger, D., et al., *Association of Health Literacy With Diabetes Outcomes.* JAMA, 2002. **288**(4): p. 475-482.
26. Gabe, J., M. Bury, and R. Ramsay, *Living with asthma: the experiences of young people at home and at school.* Social Science & Medicine, 2002. **55**: p. 1619-1633.
27. Hunt, L.M., J. Pugh, and M. Valenzuela, *How patients adapt diabetes self-care recommendations in everyday life.* Journal of Family Practice, 1998. **46**(3): p. 207-215.
28. Glasgow, R.E., D.J. Toobert, and C.D. Gillette, *Psychosocial barriers to diabetes self-management and quality of life.* Diabetes Spectrum, 2001. **14**(1): p. 33-41.
29. Piette, J.D., et al., *Use of automated telephone disease management calls in an ethnically diverse sample of low-income patients with diabetes.* Diabetes Care, 1999. **22**(8): p. 1302.
30. Nutbeam, D. and E. Harris, *Theory in a nutshell.* 1998, Sydney: University of Sydney.
31. Becker, M., *The Health Belief Model and personal behaviour.* Health Education Monographs, 1974. **2**: p. 324-473.
32. Prochaska, J. and C. DiClemente, *Stages and processes of self-change of smoking: towards an integrated model of change.* Journal of Consulting and Clinical Psychology, 1983. **51**: p. 390-395.
33. Bandura, A., *Social Learning Theory.* 1977, Englewood Cliffs: Prentice-Hall Inc.
34. Turrell, G., et al., *Socioeconomic determinants of health: towards a national research program and a policy and intervention agenda.* 1999, School of Public Health, Queensland University of Technology: Canberra.
35. National Health Priority Action Council, *Dealing with disadvantage in the National Health Priority Areas: A discussion paper for the National Health Priority Action Council (draft).* 2002, Commonwealth Department of Health and Ageing: Canberra.
36. Lorig, K.R., et al., *Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial.* Medical Care., 1999. **37**(1): p. 5-14.

37. Von Korff, M., et al., *Collaborative management of chronic illness.* Annals of Internal Medicine., 1997. **127**(12): p. 1097-102.
38. Hibbard, J.H., *Engaging health care consumers to improve the quality of care.* Medical Care., 2003. **41**(1 Suppl): p. I61-70.
39. Von Korff, M., R.E. Glasgow, and M. Sharpe, *Organising care for chronic illness.* British Medical Journal, 2002. **325**(7355): p. 92-94.
40. Levin-Zamir, D. and Y. Peterburg, *Health literacy in health systems: perspectives on patient self-management in Israel.* Health Promotion International, 2001. **16**(1): p. 87-94.
41. Lorig, K.R., P.D. Mazonson, and H.R. Holman, *Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs.* Arthritis & Rheumatism., 1993. **36**(4): p. 439-46.
42. Lorig, K., *Self-management education: more than a nice extra.* Medical Care, 2003. **41**(6): p. 699-701.
43. Nutbeam, D., *Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century.* Health Promotion International, 2000. **15**(3): p. 259-267.
44. Gonder-Frederick, L.A., D.J. Cox, and L.M. Ritterband, *Diabetes and behavioral medicine: the second decade.* Journal of Consulting and Clinical Psychology, 2002. **70**(3): p. 611-625.
45. Dishman, R.K., *Behavioral barriers to health-related physical fitness*, in *Epidemiology, Behavior Change, and Intervention in Chronic Disease*, L.K. Hall and G.C. Meyer, Editors. 1988, Life Enhancement Publications: Champaign, Illinois.
46. Gochman, D., *Health behaviour: emerging research perspectives*. 1988, New York: Plenum Press.
47. Lawrence, M., et al., *Prevention of cardiovascular disease: an evidence based approach*. 1996, London: Oxford University Press.
48. Simeoni, E., et al., *Evaluation of a community arthritis program in Australia: dissemination of a developed program.* Arthritis Care & Research, 1995. **8**(2): p. 102-7.
49. Lorig, K., *Chronic disease self-management: a model for tertiary prevention.* American Behavioral Scientist, 1996. **39**(6): p. 676-683.
50. Lorig, K., V. Gonzalez, and P. Ritter, *Community-based Spanish language arthritis education program: a randomized trial.* Medical Care, 1999. **37**(9): p. 957-63.
51. Wing, R., *Cross-cutting themes in maintenance of behavior change.* Health Psychology, 2000. **19**(1 (Supplement 1)): p. 84-88.
52. Emery, P., *Evidence supporting the benefit of early intervention in rheumatoid arthritis.* Journal of Rheumatology - Supplement., 2002. **66**: p. 3-8.
53. Pincus, T., *The case for early intervention in rheumatoid arthritis.* Journal of Autoimmunity., 1992. **5**(April Suppl.): p. 209-226.
54. Scott, D.L., et al., *The radiological assessment of rheumatoid arthritis.* Clinical & Experimental Rheumatology., 1997. **15**(Suppl 17): p. S53-61.
55. Machold, K.P., et al., *Early arthritis therapy: rationale and current approach.* Journal of Rheumatology - Supplement., 1998. **53**: p. 13-9.
56. Gremillion, R.B. and R.F. van Vollenhoven, *Rheumatoid arthritis. Designing and implementing a treatment plan.* Postgraduate Medicine., 1998. **103**(2): p. 103-6, 110, 116-8 passim.

57. Sharkey, N., N. Williams, and J. Guerin, *The role of exercise in the prevention and treatment of osteoporosis and osteoarthritis.* Nursing Clinics of North America, 2000. **35**(1): p. 209-21.
58. Saxon, L., C. Finch, and S. Bass, *Sports participation, sports injuries and osteoarthritis: implications for prevention.* Sports Medicine., 1999. **28**(2): p. 123-35.
59. Dieppe, P., *Strategies for the prevention of osteoarthritis.* International Journal of Tissue Reactions., 1993. **15**(3): p. 93-7.
60. van Schayck, C. and N. Chavannes, *Detection of asthma and chronic obstructive pulmonary disease in primary care.* European Respiratory Journal, 2003. **39**(supplement): p. 16s-22s.
61. Jones, A., *Screening for asthma in children.* British Journal of General Practice, 1994. **44**(381): p. 179-183.
62. Keeley, D.J. and M. Silverman, *Are we too ready to diagnose asthma in children?* Thorax, 1999. **54**: p. 625-628.
63. Balmes, J., *Surveillance for occupational asthma.* Occupational Medicine, 1991. **6**(1): p. 101-10.
64. Weeramanthri TS, E.K., *Northern Territory Preventable Chronic Disease Strategy – the Evidence Base.* 1999, Territory Health Services: Darwin.
65. Easton JL, S.L., *Opportunistic screening for diabetes.* Medical Journal of Australia, 1998. **168**(45).
66. Colwell, J.A., *Multifactorial aspects of the treatment of the type II diabetic patient.* Metabolism: Clinical & Experimental, 1997. **46**(12 Suppl 1): p. 1-4.
67. Ramlo-Halsted, B.A. and S.V. Edelman, *The natural history of type 2 diabetes. Implications for clinical practice.* Primary Care, 1999. **26**(4): p. 771-89.
68. Renders, C., et al., *Interventions to improve the management of diabetes mellitus in primary care, outpatients and community settings.* Cochrane Database of Systematic Reviews, 2003. **1**: p. 1.
69. National Aboriginal Community Controlled Health Organisation, *National guide for preventive health assessment in Aboriginal and Torres Strait Islander peoples*. 2003, National Aboriginal Community Controlled Health Organisation and Chronic Disease Alliance of Non Government Organisations.
70. Pan, X.R., et al., *Effects of diet and exercise in preventing NIDDM in people with impaired glucose tolerance. The Da Qing IGT and Diabetes Study.* Diabetes Care., 1997. **20**(4): p. 537-44.
71. Tuomilehto, J., et al., *Prevention of type 2 diabetes mellitus by changes in lifestyle among subjects with impaired glucose tolerance.* New England Journal of Medicine., 2001. **344**(18): p. 1343-50.
72. Dagogo-Jack, S., *Preventing diabetes-related morbidity and mortality in the primary care setting.* Journal of the National Medical Association, 2002. **94**(7): p. 549-60.
73. Burnet, D., et al., *A practical model for preventing type 2 diabetes in minority youth.* Diabetes Educator. 28(5):779-95, 2002.
74. Auslander, W.F., et al., *Community organization to reduce the risk of non-insulin-dependent diabetes among low-income African-American women.* Ethnicity & Disease, 1992. **2**(2): p. 176-84.

75. Haire-Joshu, D. and M.S. Nanney, *Prevention of overweight and obesity in children: influences on the food environment.* Diabetes Educator, 2002. **28**(3): p. 415-23.
76. Melnyk, M. and Weinstein, *Preventing obesity in black women by targeting adolescents: a literature review.* Journal of the American Dietetic Association, 1994. **94**(5): p. 536-40.
77. Norris, S., et al., *Strategies for reducing morbidity and mortality from diabetes through health-care system interventions and diabetes self-management education in community settings: a report on recommendations of the Task Force on Community Preventive Services.* MMWR Morbidity & Mortality Weekly Report, 2001. **50**(RR-16): p. 1-15.
78. Lahdensuo, A., et al., *Randomised comparison of cost effectiveness of guided self management and traditional treatment of asthma in Finland.* British Medical Journal, 1998. **316**(7138): p. 1138-9.
79. Hawley, D., *Psycho-educational interventions in the treatment of arthritis.* Baillieres Clinical Rheumatology, 1995. **9**(4): p. 803-23.
80. Gibson, P.G., et al., *Self-management education and regular practitioner review for adults with asthma.[update of Cochrane Database Syst Rev. 2000;(2):CD001117; PMID: 10796600].* Cochrane Database of Systematic Reviews, 2003. **1**.
81. Guevara, J.P., et al., *Effects of educational interventions for self management of asthma in children and adolescents: systematic review and meta-analysis.* British Medical Journal, 2003. **326**(14 June): p. 1308-1313.
82. Wagner, E.H., B.T. Austin, and M. Von Korff, *Organizing care for patients with chronic illness.* Milbank Quarterly., 1996. **74**(4): p. 511-44.
83. Coulter, A., V. Entwistle, and D. Gilbert, *Sharing decisions with patients: is the information good enough?* British Medical Journal, 1999. **318**: p. 318-322.
84. Williams, G.C. and A. Zeldman, *Patient-centred diabetes self-management education.* Current Diabetes Reports., 2002. **2**(2): p. 145-52.
85. Clark, N., et al., *Patient and family management of asthma: theory-based techniques for the clinician.* Journal of Asthma, 1994. **31**(6): p. 427-35.
86. Jones, A., R. Pill, and S. Adams, *Qualitative study of views of health professionals and patients on guided self management plans for asthma.* British Medical Journal, 2000. **321**: p. 1507-1510.
87. Walker, E.A. and J.A. Usher, *Understanding and enhancing adherence in adults with diabetes.* Current Diabetes Reports, 2003. **3**(2): p. 141-8.
88. Weingarten, S.R., et al., *Interventions used in disease management programmes for patients with chronic illness - which ones work? Meta-analysis of published reports.* British Medical Journal, 2002. **325**.
89. Eakin, E.G., et al., *Reaching those most in need: a review of diabetes self-management interventions in disadvantaged populations.* Diabetes/Metabolism Research Reviews, 2002. **18**(1): p. 26-35.
90. Rothman, A., *Toward a theory-based analysis of behavioral maintenance.* Health Psychology, 2000. **19**(1 (supplement1)): p. 64-69.
91. Hootman, J., J. Sniezek, and C. Helmick, *Women and arthritis: burden, impact and prevention programs.* Journal of Women's Health & Gender Based Medicine, 2002. **11**(5): p. 407-16.
92. Barlow, J., A. Turner, and C. Wright, *A randomized controlled study of the Arthritis Self-Management Programme in the UK.* Health Education Research, 2000. **15**(6): p. 665-80.

93. Riemsma, R.P., et al., *Patient education for adults with rheumatoid arthritis.* Cochrane Database of Systematic Reviews, 2003. **1**: p. 1.

94. Mulligan, K. and S. Newman, *Psycho-educational interventions in rheumatic diseases: a review of papers published from September 2001 to August 2002.* Current Opinion in Rheumatology, 2003. **15**(2): p. 156-9.

95. Bradley, L.A. and K.R. Alberts, *Psychological and behavioral approaches to pain management for patients with rheumatic disease.* Rheumatic Diseases Clinics of North America, 1999. **25**(1): p. 215-32.

96. Drummond, N., et al., *Effectiveness of routine self monitoring of peak flow in patients with asthma. Grampian Asthma Study of Integrated Care (GRASSIC).* British Medical Journal, 1994. **308**(6928): p. 564-7.

97. Osman, L.M., et al., *Reducing hospital admission through computer-supported education for asthma patients.* British Medical Journal, 1994. **308**: p. 568-571.

98. D'Souza, W., et al., *Trial of a 'credit card' asthma self-management plan in a high-risk group of patients with asthma.* Journal of Allergy & Clinical Immunology, 1996. **97**(5): p. 1085-1092.

99. Adams, R., et al., *A randomized trial of peak-flow and symptom-based action plans in adults with moderate-to-severe asthma.* Respirology, 2001. **6**(4): p. 297-304.

100. Abdulwadud, O., et al., *Evaluation of a randomised controlled trial of adult asthma education in a hospital setting.* Thorax, 1999. **54**(6): p. 493-500.

101. van der Palen, J., et al., *Behavioural effect of self-treatment guidelines in a self-management program for adults with asthma.* Patient Education & Counseling, 2001. **43**(2): p. 161-9.

102. Sudre, P., et al., *Objectives, methods and content of patient education programmes for adults with asthma: systematic review of studies published between 1979 and 1988.* Thorax, 1999. **54**: p. 681-687.

103. Huang, T.T.K. and M.I. Goran, *Prevention of type 2 diabetes in young people: a theoretical perspective.* Pediatric Diabetes, 2003. **4**(1): p. 38-56.

104. Peyrot, M., *Behavior change in diabetes education.* Diabetes Educator, 1999. **25**(6 Suppl): p. 62-73.

105. Valk, G.D., D.M.W. Kriegsman, and W.J.J. Assendelft, *Patient education for preventing diabetic foot ulceration.* Cochrane Database of Systematic Reviews, 2003. **1**: p. 1.

106. Rosenstock, J., *Management of type 2 diabetes mellitus in the elderly: special considerations.* Drugs & Aging, 2001. **18**(1): p. 31-44.

107. Griffin, S. and A.L. Kinmonth, *Systems for routine surveillance for people with diabetes mellitus.* Cochrane Database of Systematic Reviews, 2003. **1**: p. 1.

108. Norris, S.L., M.M. Engelgau, and K.M. Narayan, *Effectiveness of self-management training in type 2 diabetes: a systematic review of randomized controlled trials.* Diabetes Care, 2001. **24**(3): p. 561-87.

109. Cooper, L.A., M.N. Hill, and N.R. Powe, *Designing and evaluating interventions to eliminate racial and ethnic disparities in health care.* Journal of General Internal Medicine, 2002. **17**(6): p. 477-486.

110. Ashley, E. *Bi-cultural perspectives of the adoption of the Lorig course: experiences and issues for sustainability*. in *Sharing Health Care 'Early Wins' Workshop*. 2002. Hobart.

111. Mansfield, A., *Sustaining a 'secondary disease prevention' approach to chronic disease management: a chronically complex issue.* Australian Journal of Primary Health, 2003. **9**(2&3): p. 155-159.
112. Mobbs, R., H.T. Nguyen, and A. Bell, *The chronic disease self-management project at Katherine West Health Board Aboriginal Corporation in the Northern Territory: a report of the first year.* Australian Journal of Primary Health, 2003. **9**(2%3): p. 160-167.
113. National Health and Medical Research Council, *Using socioeconomic evidence in clinical practice guidelines*. 2002, Commonwealth of Australia.
114. Royal Australian College of General Practitioners, *Guidelines for Preventive Activities in General Practice. Updated 5th Edition*. 2001, RACGP.
115. Barlow, J.H., W. B., and W.C. C., *Patient education for people with arthritis in rural communities: the UK experience.* Patient Education & Counseling, 2001. **44**(3): p. 205-14.
116. Kramer, B., J. Harker, and A. Wong, *Arthritis beliefs and self-care in an urban American Indian population.* Arthritis & Rheumatism, 2002. **47**(6): p. 588-94.
117. Zhang, J. and M.J. Verhoef, *Illness management strategies among Chinese immigrants living with arthritis.* Social Science & Medicine, 2002. **55**(10): p. 1795-1802.
118. Ibrahim, S., et al., *Variation in perceptions of treatment and self-care practices in elderly with osteoarthritis: a comparison between African-American and white patients.* Arthritis & Rheumatism., 2001. **45**(4): p. 340-5.
119. Newman, A., *Self-help care in older African Americans with arthritis.* Geriatric Nursing, 2001. **22**(3): p. 135-8.
120. Kramer, B., J. Harker, and A. Wong, *Descriptions of joint pain by American Indians: comparison of inflammatory and non-inflammatory arthritis.* Arthritis & Rheumatism, 2002. **47**(2): p. 149-54.
121. Wilcox, S., *Physical activity in older women of color.* Topics in Geriatric Rehabilitation, 2002. **18**(1): p. 21-34.
122. Von Hofe, B., M. Thomas, and R. Colagiuri, *A systematic review of issues impacting on health care for culturally diverse groups using diabetes as a model.* 2002, Australian Centre for Diabetes Strategies and Multicultural Health Unit: Sydney.
123. Vallerand, A.H., J.M. Fouldbakhsh, and T. Templin, *The use of complementary/alternative medicine therapies for the self-treatment of pain among residents of urban, suburban, and rural communities.* American Journal of Public Health, 2003. **93**(6): p. 923-925.
124. Coulton, C., et al., *Ethnicity, self-care, and use of medical care among the elderly with joint symptoms.* Arthritis Care & Research, 1990. **3**(1): p. 19-28.
125. Bill-Harvey, D., et al., *Methods used by urban, low-income minorities to care for their arthritis.* Arthritis Care & Research, 1989. **2**(2): p. 60-4.
126. Katz, P., *Education and self-care activities among persons with rheumatoid arthritis.* Social Science & Medicine, 1998. **46**(8): p. 1057-66.
127. von Schlegell, A., E.N. Grant, and K.B. Weiss, *The burden of asthma: weighing the community risk against individual risk.* Thorax, 1999. **54**: p. 471-472.
128. Duran-Tauleria, E. and R.J. Rona, *Geographical and socioeconomic variation in the prevalence of asthma symptoms in English and Scottish children.* Thorax, 1999. **54**: p. 4786-481.

129. Bender, B., H. Milgrom, and C. Rand, *Non-adherence in asthmatic patients: is there a solution to the problem?* Annals of Allergy, Asthma, and Immunology, 1997. **79**(3): p. 177-186.
130. Radeos, M.S., et al., *Risk factors for lack of asthma self-management knowledge among ED patients not on inhaled steroids*1.* The American Journal of Emergency Medicine, 2001. **19**(4): p. 253-259.
131. Moudgil, H. and D. Honeybourne, *Differences in asthma management between white European and Indian subcontinent ethnic groups living in socioeconomically deprived areas in the Birmingham (UK) conurbation.* Thorax, 1998. **53**: p. 490-494.
132. Homer, C., et al., *An evaluation of an innovative multimedia educational software program for asthma management: report of a randomized, controlled trial.* Pediatrics, 2000. **106**(1): p. 210-215.
133. Krishna, S., et al., *Clinical trials of interactive computerised patient education: implications for family practice.* Journal of Family Practice, 1997. **45**(1): p. 25-33.
134. Bolton, P., S. Hammoud, and J. Leung, *Issues in quality use of medicines in two non-English speaking background communities.* Australian Journal of Primary Health, 2002. **8**(3): p. 75-80.
135. Ratima, M.M., et al., *Long-term benefits for Maori of an asthma self-management program in a Maori community which takes a partnership approach.* Australian and New Zealand Journal of Public Health, 1999. **23**(6): p. 601-605.
136. Chang, A.B., et al., *Asthma management in indigenous children of a remote community using an indigenous health model.* J Paediatr Child Health, 2000. **36**(3): p. 249-251.
137. National Health Priority Areas Action Council, *Are we ensuring that funding is used to improve care to Aboriginal patients and their families?* 2001 forthcoming, National Health Priority Areas Action Council: Canberra.
138. Valery, P.C., et al., *High prevalence of asthma in five remote indigenous communities in Australia.* European Respiratory Journal, 2001. **17**: p. 1089-1096.
139. National Aboriginal Community Controlled Health Organisation, *Barriers faced by Aboriginal community controlled health services in accessing the Asthma 3+ Plan Federal Budget Initiative*. 2003 forthcoming.
140. Goldman, D. and J. Smith, *Can patient self-management explain the SES health gradient?* PNAS, 2002. **99**(16): p. 19029-10934.
141. Zgibor, J.C. and D. Simmons, *Barriers to blood glucose monitoring in a multiethnic community.* Diabetes Care, 2002. **25**(10): p. 1772-1778.
142. Piette, J.D., *Perceived access problems among patients with diabetes in two public systems of care.* Journal of General Internal Medicine, 2000. **15**(11): p. 797-804.
143. Izquierdo, R.E., et al., *A comparison of diabetes education administered through telemedicine versus in person.* Diabetes Care, 2003. **26**(4): p. 1002-1008.
144. Lowe, J.M. and K. Bowen, *Evaluation of a diabetes education program in Newcastle, NSW.* Diabetes Research and Clinical Practice, 1997. **38**: p. 91-99.
145. Corkery, E., et al., *Effect of a bicultural community health worker on completion of diabetes education in a Hispanic population.* Diabetes Care., 1997. **20**(3): p. 254-7.

146. Ah Kit, J., et al., *Chronic disease self management in Aboriginal communities - towards a sustainable programme of care in rural communities.* Australian Journal of Primary Health, 2003. **9**(2&3).
147. Bruce, D.G., et al., *Diabetes education and knowledge in patients with type 2 diabetes from the community: The Fremantle Diabetes Study.* Journal of Diabetes and its Complications, 2003. **17**(2): p. 82-89.
148. Foster M, K.E., Dickson P, Chaboyer W, Hunter B, Gee T,, *Participation and chronic disese self-management: Are we risking inequitable resource allocation?* Australian Journal of Primary Health, 2003. **9**(2&3): p. 132-139.
149. Wilson, A.J., B.F. Oldenburg, and A.D. Lopez, *Targeted approaches for reducing inequities in chronic disease.* Medical Journal of Australia, 2003. **179**(5): p. 231-232.
150. Urbis Keys Young, *Access to after hours primary medical care by disadvantaged and marginalised groups*. 2002, Urbis Keys Young: Sydney. p. 79.
151. Deeble J, *Expenditures on Aboriginal and Torres Strait Islander Health*. 2003, NIEPH: Canberra.
152. Pincus, T., et al., *Social conditions and self-management are more powerful determinants of health than access to care.* Annals of Internal Medicine, 1998. **129**(5): p. 406-11.
153. Adams, R.J., B.J. Smith, and R.E. Ruffin, *Patient preferences for autonomy in decision making in asthma.* Thorax, 2001. **56**(2): p. 126-133.
154. O'Neill, C., et al., *Chronic illness and ethnicity.* Australian Journal of Primary Health - Interchange, 2000. **6**(2): p. 94-101.
155. Lee, P., et al., *National Divisions Diabetes Program. Optional Module 1 part A: Aboriginal and Torres Strait Islander Populations.* 1999, ISERU, Centre for General Practice Integration Studies UNSW and Centre for Health Equity Training Research and Evaluation: Sydney.
156. Bender, B.G., *Overcoming barriers to nonadherence in asthma treatment. [Review] [16 refs].* Journal of Allergy & Clinical Immunology, 2002. **109**(6 Suppl): p. S554-9.
157. Bastian, H., *Just how demanding can we get before we blow it?* BMJ, 2003. **326**(7402): p. 1277-1278.
158. Lewin, S.A., et al., *Interventions for providers to promote a patient-centred approach in clinical consultations.* Cochrane Database of Systematic Reviews, 2003. **1**: p. 1.
159. Fraenkel, L., S. Bogardus, and J. Concato, *Unwillingness of rheumatoid arthritis patients to risk adverse effects.* Rheumatology., 2002. **41**(3): p. 253-61.
160. Day, J.L., *Diabetic patient education: determinants of success.* Diabetes/Metabolism Research Reviews, 2000. **16**(1): p. S70-4.
161. Abdulwadud, O.A., et al., *The relationships between patients' related variables in asthma: implications for asthma management.* Respirology, 2001. **6**: p. 105 - 112.
162. The Office for Aboriginal and Torres Strait Islander Health, *Better Health Care: studies in the successful delivery of primary health care services for Aboriginal and Torres Strait Islander Australians.* 2001, Commonwealth Department of Health and Aged Care: Canberra.
163. Whybourne, A.M., et al., *Low rates of hospitalization for asthma among Aboriginal children compared to non-Aboriginal children of the Top End of*

*the Northern Territory.* Journal of Paediatric Child Health, 1999. **35**: p. 438-441.

164. Valery, P., *Asthma is not Prevalent in Aboriginal and Torres Strait Islander Children: A Myth.* J Paediatr Child Health, 2002. **38**(1): p. 105-106.
165. Bremner, P., et al., *Respiratory symptoms and lung function in Aborigines from tropical Western Australia.* American Journal of Respiratory Critical Care Medicine, 1998. **158**: p. 1724-1729.
166. Jackson Pulver, L., A. Bush, and J. Ward, *An analysis to determine the number of Aboriginal and Torres Strait Islander women using an urban obstetric hospital.* Australian Health Review., 2003. **26**(2): p. 19-25.
167. Couzos, S., et al., *Systematic review of existing evidence and primary care guidelines on the management of non-insulin dependent diabetes*. 1998, Kimberly Aboriginal Medical Services Council: Canberra.
168. Mobbs, R. *Creating community management of the CDSM project at Lajamanu*. in *Sharing Health Care 'Early Wins' Workshop*. 2002. Hobart.
169. Pollard, M., *Killers in the bush.* Australian Health Review., 2002. **25**(2): p. 16-19.
170. Couzos, S., et al., *Plain language summary systematic review of existing evidence and primary care guidelines on the management of non-insulin dependent diabetes in Aboriginal and Torres Strait Islander populations*. 1998, Kimberley Aboriginal Medical Services' Council: Canberra.
171. Bell K, C.S., Daniels J, Hunter P, Mayers N, Murray R,, *Aboriginal community controlled health services*, in *General Practice in Australia 2000*. 2000, Commonwealth Department of Health and Aged Care: Canberra.
172. Wilkinson, D., et al., *Variation in levels of uptake of Enhanced Primary Care item numbers between rural and urban settings, November 1999 to October 2001.* Australian Health Review., 2002. **25**(6): p. 123-130.
173. Kolbe, J., W. Fergusson, and J. Garrett, *Rapid onset asthma: a severe but uncommon manifestation.* Thorax, 1998. **53**: p. 241-247.
174. Kolbe, J., et al., *Assessment of practical knowledge of self-management of acute asthma.* Chest, 1996. **109**(1): p. 86-90.
175. Murphy, T. *I'm poor, I'm depressed and I'm sick, and you want me to manage my own illness?* in *Sharing Health Care 'Early Wins' Workshop*. 2002. Hobart.
176. Powell-Davies G, McDonald J, Hu W, Furler J, Harris M, Harris E., *Reviewing the contribution of General Practice to a well-functioning and comprehensive Primary Health Care System*. 2003, Centre for General Practice Integration Studies, UNSW: Sydney.
177. Carter M, W.C., Furler J., *Developing a shared definition of chronic illness. Implications and benefits for general practice*. 2002, GPEP Grant 843.
178. Walker C, *Putting 'self' back into self-management*, in *Chronic illness. New Perspectives and New Directions*, P.C. Walker C, Millen N, Martin C, Editor. 2003, Tertiary Press: Victoria.
179. Bell K, B.G., Couzos S, Daniels J, Huner P, Kehoe H, Mayers N, Murray R, Tynan M,, ed. *Aboriginal Community Controlled Health Services*. General Practice in Australia: 2004 (unpublished FINAL DRAFT). 2004.
180. Broom, D. *Living with diabetes: management and meaning*. in *National Chronic Disease Self-Management Conference: Sharing Health Care*. 2001: Commonwealth Department of Health and Aged Care.
181. Say, R. and R. Thomson, *The importance of patient preferences in treatment decisions.* British Medical Journal, 2003. **327**.

182. Commonwealth Department of Health and Aged Care, *General Practice In Australia: 2000*. 2000, Canberra: Commonwealth Department of Health and Aged Care.