Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach

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ABSTRACT

- Although emphasis on the prevention of chronic disease is important, governments in Australia need to balance this with continued assistance to the 77% of Australians reported to have at least one long-term medical condition.
- Self-management support is provided by health care and community services to enhance patients' ability to care for their chronic conditions in a cooperative framework.
- In Australia, there is a range of self-management support initiatives that have targeted patients (most notably, chronic disease self-management education programs) and health professionals (financial incentives, education and training).
- To date, there has been little coordination or integration of these self-management initiatives to enhance the patient–health professional clinical encounter.
- If self-management support is to work, there is a need to better understand the infrastructure, systems and training that are required to engage the key stakeholders — patients, carers, health professionals, and health care organisations.
- A coordinated approach is required in implementing these elements within existing and new health service models to enhance uptake and sustainability.

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The 2008–09 federal health budget places a renewed emphasis on preventive health care, with a focus on keeping all Australians healthy.[1] Undoubtedly, addressing the increasing prevalence of chronic diseases is of great importance if improvements in population health status are to be realised. However, this focus on prevention needs to be balanced with ongoing support to assist people currently managing chronic diseases across the community.[2] It is estimated that 77% of Australians have at least one long-term medical condition, defined as a condition that has lasted, or is expected to last, 6 months or more.[3] It is an exigent challenge to the currently acute care-focused systems across health care and community settings to adequately respond to the ongoing, complex and diverse needs of people with chronic health conditions.

This is particularly relevant in primary care, where clinicians regularly encounter new patients with complex chronic conditions and patients with existing chronic disease whose clinical status fluctuates. The impact of chronic disease was highlighted in a recent survey, which found that 15% of patients waiting for lower limb joint replacement for osteoarthritis rated their health-related quality-of-life equivalent as worse than death.[4]

Active participation by patients is paramount in the effective management of chronic conditions, which are long-term, variable and often degenerative. An example is osteoporosis, which does not significantly affect a patient until an incident fracture is sustained, after which time morbidity and associated costs can increase markedly.[5] Yet symptom onset and progression may be delayed in part through self-management practices.

Various self-management support initiatives have been generated to assist patients to optimise the management of their health, including a focus on chronic disease self-management education programs. Although there are formal and informal models, the objective of these programs is to provide patients with information and skills that enhance their ability to participate in their health care; for example, communicating with health professionals, identifying relevant information and adhering to treatment. In the case of osteoporosis, management of the condition may be enhanced if patients have information regarding appropriate diet, safe and effective exercise, adherence to bisphosphonate therapy (if applicable), and knowledge of how to access a network of professionals from whom further information can be sought. As such, self-management education programs are increasingly recognised not only as an essential component of chronic disease management, but also as part of secondary prevention and a way of reducing the burden of chronic illness on individuals and the community.[6]

Although there have been advancements in self-management support at policy and program levels, these initiatives have tended to remain separate from mainstream health care and have had insufficient coordination for effective and sustainable impact, particularly at the primary care level (eg, structured referral pathways for health care providers to refer patients to self-management education programs).[7] To improve integration, self-management support needs to be incorporated as an integral aspect of health service redesign in terms of infrastructure and systems to ensure appropriate uptake and utilisation by key stakeholders (patients, carers, health professionals and health care organisations). Without this, self-management support will remain on the periphery — delivering a small "therapeutic dose" that may be difficult to justify at the policy level, thereby limiting available funding and uptake.

Given that patients are the focus of health care resources, a patient-centred approach is particularly important when evaluating such resources. Yet in Australia, there has been little exploration from the patient's perspective as to how such support initiatives and programs influence relationships with health professionals and everyday strategies in managing their condition. Box 1 outlines various outcomes for patients, clinicians and policymakers.

We aim to provide an overview of current chronic disease self-management support within Australia, with a specific emphasis on interactions between patients, health care professionals and policy.

Self-management support

A distinction can be made between patient self-management and self-management support. The former comprises the actions individuals take for themselves.[8] The latter (the focus of this article) refers to the facilities that health care and social care services provide to enable patients to enhance management of their health. Self-management support encompasses several facets, outlined in Box 2.

1 Key stakeholder outcomes relating to effective self-management support

Patient-focused outcomes	Clinician-focused outcomes	Policy-focused outcomes
Diagnosis		
• Patients receive user-friendly information (eg, oral, written, multimedia) about their new or ongoing chronic conditions • Patients understand implications of their conditions for working, caring for others, family life and participation in society	• Patients understand the long-term and variable nature of chronic conditions, which require multidisciplinary input over time • Patients understand that they have the key role in the day-to-day management of their condition	• Establishment of patient-centred care and partnership approach • Foundations set for effective use of health professional time, including who to contact for further information about services available to them
Management		
• Patients know who their main (primary) health care professionals are, and what additional treatments or education they need • Patients feel safe and supported to undertake self-care activities (eg, blood glucose assessment, returning to work with back pain)	• Where necessary, multidisciplinary care is recommended and taken up • MBS items are considered and care plans implemented • Patients are empowered to engage in informed self-care	• Effective use of MBS items • The system provides an opportunity for patients to be empowered to engage in formal and informed self-care in an ongoing way
Outcome		
• Self-management is integrated into patients' day-to-day life • Health is optimised • Patients only access a health care professional for planned management or because of new events	• Patients have a highly developed understanding of their treatment, responsibilities, and how to optimise their self-management • Patients return to their clinics at appointed times for review or support	• Use of health care services optimised • Use of potentially unnecessary services such as emergency departments minimised • Overall cost of treatment reduced • Secondary prevention embedded in patient–clinician and community health interactions

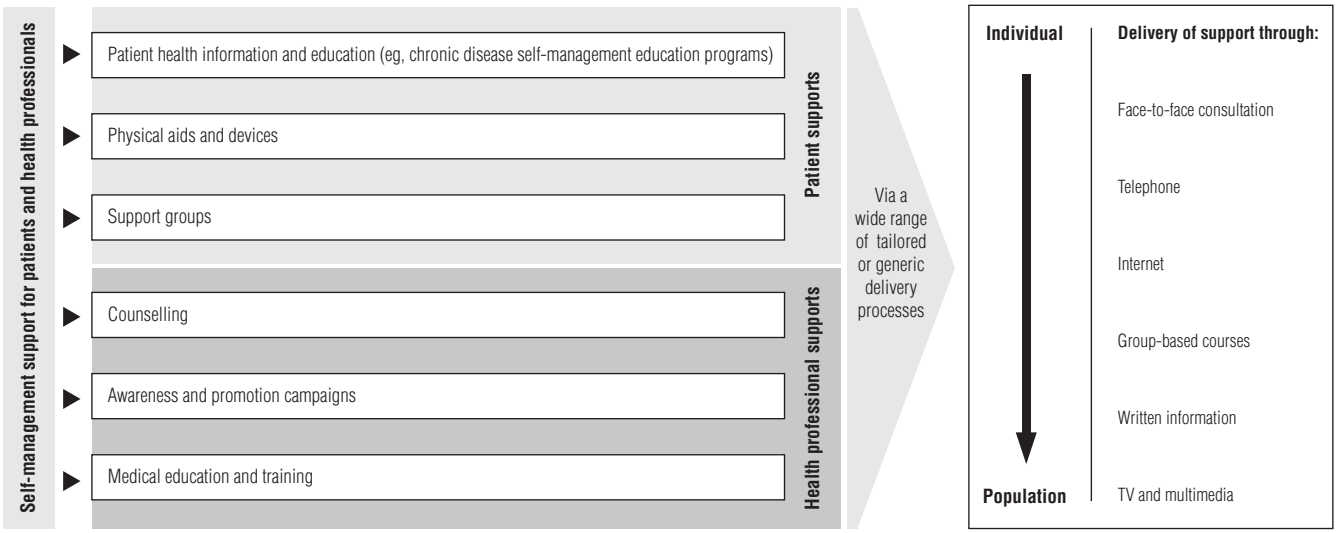
MBS = Medicare Benefits Schedule. ◆

At the policy level, self-management support in Australia has been concentrated on chronic disease self-management education programs through the National Chronic Disease Strategy and patient programs developed through the Sharing Health Care Initiative.[9] Although meta-analyses have examined the efficacy of self-management education programs, the interpretation of such reviews is limited by heterogeneity in populations and interventions, and the limited range of outcomes measured.[10-12] Few randomised controlled trials have found a reduction in health service utilisation, such as incidences of hospitalisation (in patients with chronic lung disease, heart disease, stroke and arthritis) and fewer hospital visits (in patients with chronic inflammatory bowel disease) as a direct outcome of attending an education program.[13-14] In Australia, the national quality and monitoring system for chronic disease self-management education programs has shown that one-third of patients who attended a community program reported substantial development of skills, techniques and self-monitoring.[15]

Another aspect of self-management support has focused on assisting health care professionals to provide self-management support through changes to the Medicare Benefits Schedule (MBS) in the form of care plans and multidisciplinary team support. For example, patients who meet certain chronic disease criteria may receive up to five MBS-subsidised allied health interventions per calendar year as part of the Enhanced Primary Care initiative. Although this represents a limited number of consultations within a 12-month period to achieve a significant change in the clinical status of certain conditions (eg, chronic back pain), these consultations provide an opportunity to introduce self-management practices to patients. From clinical efficacy and cost–benefit viewpoints, it is therefore imperative that clinicians are supported to introduce and deliver elements of self-management. With recent changes to the *Private Health Insurance Act 2007* (Cwlth), chronic disease management programs, including self-management provided by private practice clinicians and broader organisations, are eligible for funding by some health insurance companies,[16] again highlighting the importance for primary care clinicians to be aware of self-management education programs. Resources have also been directed towards education and training of health professionals through the Australian Better Health Initiative. Box 3 outlines the range of key stakeholders involved in self-management support and examples of initiatives undertaken in Australia.

While these developments are encouraging, self-management support initiatives for patients (education programs) and health care professionals (education and training, financial incentives, professional body endorsement) have largely been segregated, with no overarching coordination between the two and no recognition of their potential mutual reinforcement.[17] This is problematic, given the important role that the patient–health professional relationship plays in enabling and supporting self-care, providing a critical juncture for the exchange of information, and decision making.[6] A previous study found that the ability of health care professionals to engage in effective communication during a consultation can reinforce or discourage health actions that maximise a person's capacity to live positively with a chronic condition.[18] Thus, for self-management support to be effective and sustainable at the community level, it is imperative that initiatives simultaneously focus on supporting patients to engage in self-management and equipping health care professionals with the necessary resources to assist them.

2 The facets of self-management support for patients and health professionals, and possible modes of delivery



The patient–health care professional interaction

Overseas and Australian evidence highlights that for chronic disease self-management education programs to be effective, a "critical mass" of individuals interested in and capable of participating is required.[19] Reliance on social marketing strategies alone to promote these programs has failed to engage many community groups. As evidenced by the initial version of the Expert Patients Programme in the United Kingdom, social marketing strategies intending to promote the recruitment of patients to programs do not reach marginalised sectors of the community (eg, culturally and linguistically diverse groups), leading to concerns that self-management programs promoted though mass media may increase social inequities in health.[8,20-22] However, it is acknowledged that well structured mass media campaigns can be effective in motivating a societal shift in health care beliefs;[23] see also Buchbinder in this supplement (*page S29*).[24] In Australia, localised, tailored but resource-intensive recruitment strategies have had success in reaching marginalised groups.[25]

The primary health care professional is often the first point of contact for people with chronic conditions such as arthritis, back pain, diabetes and asthma. Such consultations provide the opportunity for information exchange and successful self-management practices to begin.[6] However, primary health care professionals often do not have the resources and are not aware of pathways to do this, particularly in terms of knowing the range, availability and access to local community self-management support services such as education programs. Moreover, it is difficult for practising clinicians to be cognisant of reliable government and non-government self-management education program initiatives, given the increasing breadth of services available and the demands of day-to-day practice. Therefore, it is necessary to not only disseminate high quality and up-to-date information about self-management programs, but also to foster confidence among health care professionals regarding the effectiveness and sustainability of these services if patient participation is to be enhanced. This needs to be established at a local level and involve networks and alliances across health agencies and professions assisted by structured referral and information management processes, including quality monitoring and evaluation with timely feedback. An example of such an initiative is the Early Intervention in Chronic Disease in Community Health in Victoria, which uses similar structures and partnerships among primary health care organisations to enhance patients' capacity to self-manage their condition by providing a range of community support services.

There has been a focus on engaging general practitioners and general practice nurses in self-management support through education, training and practice incentive payments. However, given the diversity of organisations and health care professionals involved, this focus should be expanded to include a broader range of health care professionals. This will ensure that patients are provided with consistent and effective messages relating to self-management practices appropriate for their condition across the sector.

Health literacy

Although it is important to ensure health care professionals and patients are aware of available self-management support, sustainability of these programs and services is founded on patients' capacity to participate. Initial and ongoing participation is likely to depend on a wide variety of patient-specific issues, ranging from ability to identify and understand health messages, access to information and services, and skills to decide what is useful information. Such skills are relevant to all chronic health conditions. Our previous work identified key impacts that an effective self-management intervention should deliver.[26]

A key rate-limiting step for gaining self-management skills and active participation in care is a patient's health literacy. Health literacy refers to a person's capacity to seek, understand and utilise health information to participate in decisions about their health.[27] Patients' health literacy is therefore central to their participation in their health care, and extends to knowing when to seek medical help, being able to effectively communicate with health professionals, and adhering to treatment and follow-up with other health services and supports.

Although patients accumulate extensive lay knowledge and experience in coping and managing their chronic condition on a daily basis, this does not necessarily mean they become aware of or have

3 Implementation of self-management support initiatives by key stakeholders

Government policymakers; funding providers

- Inclusion of self-management support in national strategic frameworks (eg, National Service Improvement Framework)
- Sharing Health Care Initiative
- Australian Better Health Initiative
- Early Intervention in Chronic Disease in Community Health (Victoria)
- Systematic evaluation for state-based chronic disease self-management courses (Western Australia)
- Medicare Benefits Schedule (chronic disease management items, Team Care Arrangements)
- Self-management interventions incorporated into national clinical practice guidelines

Non-government and broader community organisations

- Chronic disease self-management education programs
- Disease-specific information
- Telephone helplines
- Support groups

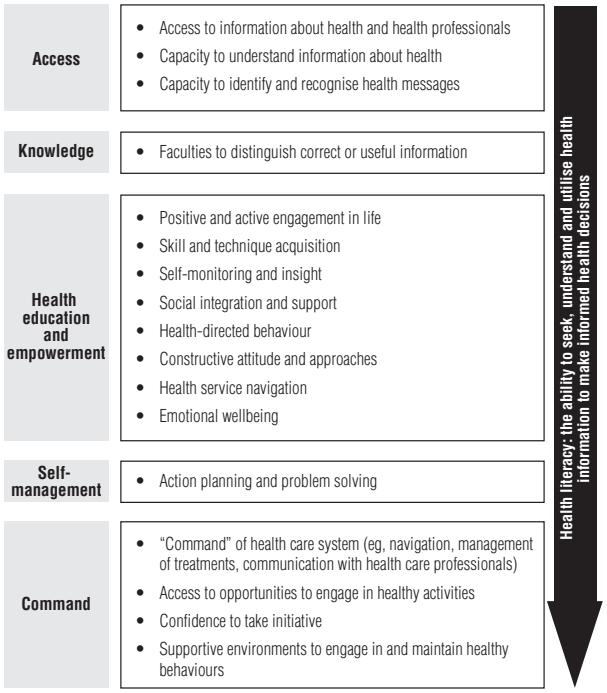
Health care professionals and professional associations

- Medicare Benefits Schedule
- Self-management curricula for undergraduate medical, allied health disciplines and postgraduate ongoing professional development programs
- Self-management interventions incorporated into clinical practice guidelines

Health care system managers and organisations

- Primary Care Partnerships (Vic)
- Self-management interventions incorporated into clinical practice guidelines ◆

4 Critical components for individuals to participate in the management of their chronic condition



the ability to access and use health information resources effectively to enhance self-management. Further, effective coping and management practices are not necessarily beneficial for their condition. For instance, patients with chronic conditions such as diabetes, hypertension and rheumatoid arthritis who had poor health literacy skills were also found to exhibit poor knowledge of the disease process and had poor self-management skills.[28] Similarly, patients with chronic low back pain may unknowingly develop maladaptive coping strategies, which often exacerbate their condition.[29] Further, there may be broader factors relating to financial, family, self-esteem, linguistic or cultural reasons that can preclude a patient from being able or willing to access particular programs or services. Box 4 identifies components necessary for patients to effectively engage with and participate in self-management.

A consultation is a key opportunity for the health professional to assess an individual patient's capacity to participate in self-management, against the social and cultural milieu, and with knowledge of the nature and value of locally available self-management interventions. It is an opportunity to gauge a patient's capacity and willingness to participate in health care, thus enabling the health professional to tailor care and education.

A systematic approach to self-management support

Seemingly, a systematic approach is required to integrate components of self-management support to optimise patients' capacity to self-manage their condition. In the UK, the WISE (Whole System Informing Self-management Engagement) model advocates change at three interrelated levels: patient, health care professional and structure of health care setting.[30] This includes ways to enhance patients' capacity for self-care through information processes, and how professional practice and service organisation can be modified to support self-management practices. In Australia, such a systematic approach to supporting self-management is yet to be realised, although opportunities may arise through the recently announced National Primary Health Care Strategy, which has a major objective of supporting self-management of chronic disease.[31] The UK experience suggests it is imperative that models of self-management care facilitate or augment current evidence-based practice, rather than attempting to provide an alternative or supplementary form of care.

In Australia, more work needs to be done to understand local community needs and coordination requirements and to support integration of self-management across the health care continuum (ie, acute to community) and enhance information dissemination among patients, health care professionals, health professional bodies, non-government organisations and industry.

At the policy level, the necessary components for a systematic approach to self-management support seem to have been identified. The Australian Government's ongoing Sharing Health Care Initiative is patient-focused in terms of creating opportunities to develop and implement a range of self-management education programs and other initiatives, with particular emphasis on reaching marginalised groups. Complementing this is the Australian Better Health Initiative, which is moving toward policy reform and health system changes and supporting health care professionals through education, training, clinical audit and financial incentives in enhancing coordination of chronic disease care. Of critical importance is coordination between programs from these respective initiatives,

particularly at the health professional level, in terms of information dissemination and training. Engagement with local professional associations will be an important means of facilitating this.

For chronic disease self-management support to have an effective and sustainable impact at individual and public health levels, a systematic approach that facilitates integration and enhances the interaction between the patient and health care professional is essential.

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Competing interests

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