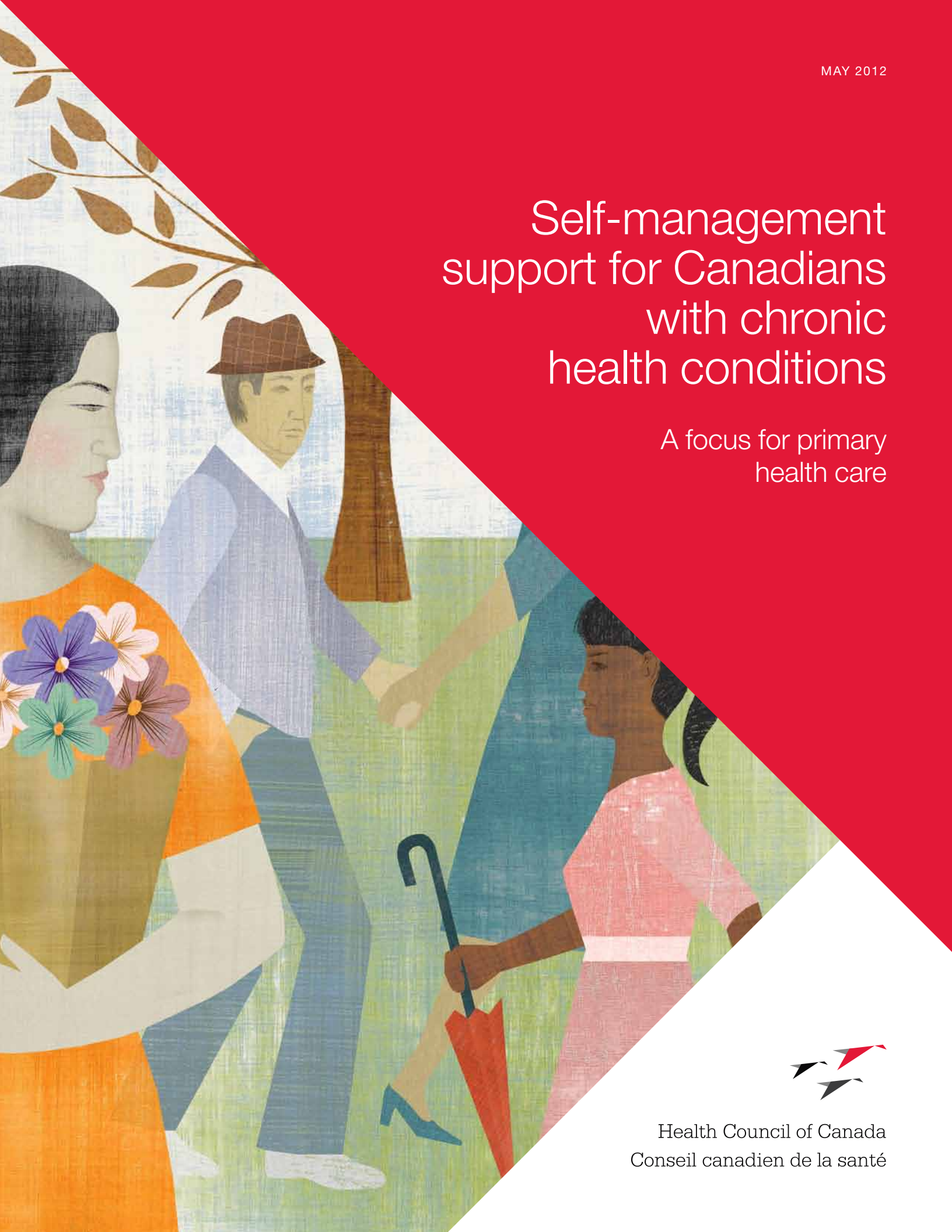


Self-management support for Canadians with chronic health conditions

A focus for primary
health care



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Approximately half of all Canadians are living with at least one chronic health condition, and more than one in four Canadians report having two or more chronic conditions.¹ Many will live well and long despite having a long-term health concern, but others will not. This report is about how we can ensure a better quality of life for all.

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Foreword

Across Canada and globally, there is a growing understanding that patients with chronic conditions benefit from being actively engaged in their own care. The health care system benefits too. Patients feel better and use health care services differently when they have the information, skills, and confidence to manage the physical and emotional impacts of their disease.

The process of helping patients become successful in this way has come to be known as self-management support and, appropriately, it is attracting attention as concerns mount about the rising rates of chronic disease. Failure to help more people with self-management will carry a hefty price tag. Chronic disease accounts for a large and growing portion of health care use. Patients with chronic conditions—particularly those with multiple chronic conditions—use emergency departments more and spend more time in hospitals than patients with other kinds of health care needs.²

While it is widely recognized that primary health care providers should be an ongoing source of self-management support, this role is not yet a routine part of care in Canada. For at least a decade, leading health care organizations in Canada have been calling for changes in practice and policy to ensure that patients with chronic disease receive self-management support according to need. In 2002, the Canadian Nurses Association, the College of Family Physicians of Canada, and several other health professional associations reported on a three-year collaboration to promote the role of primary health care in supporting

self-care, including self-management support.³ More recently, the advancement of self-management for complex and chronic disease care emerged as one of the key themes in a 2011 engagement exercise among Canadian health care leaders.⁴

A number of programs and approaches to self-management support have been tried and evaluated in recent years. Our report highlights the collective wisdom about what works, and where gaps remain. We are pleased to be able to profile some innovative practices in this area and to provide recommendations for moving forward.

Nonetheless, these are early days in understanding the role of primary health care in self-management support. There is a great deal to be learned about how to sustain the gains, reach more people, and ensure that health care is well organized and appropriately funded to deliver self-management support for Canadians with chronic conditions. Canadians should expect no less and, at the same time, become more engaged in their own care.

Sincerely,

Dr. Jack Kitts
Chair, Health Council of Canada

Executive Summary

What's the issue?

- People with chronic health conditions often need education, coaching, and other interventions to help them gain the confidence, knowledge, skills, and motivation to manage the physical, social, and emotional impacts of their disease. The systematic provision of this assistance by health care providers and others is known as **self-management support**.
- Self-management support is an increasingly important consideration in the delivery of health care for people with chronic disease, especially those with multiple chronic conditions. Evidence has shown that self-management support can help many patients manage their symptoms more effectively.
- It's widely recognized that primary health care providers should be an ongoing source of self-management support, but this role is not yet a routine part of primary health care delivery in Canada.

Why this report? Why now?

- Chronic disease costs Canadian society more than \$90 billion a year in lost productivity and health care costs.⁵
- Targeted investments to advance self-management hold potential to yield big wins on many levels—for individuals and their families (e.g., better quality of life); for health care providers (e.g., better outcomes for their patients); for the efficient, effective, and sustainable use of health care resources; and for a healthier, more productive Canada.
- This report highlights success factors, barriers, innovative practices, opportunities, and resources to advance the delivery of self-management support, through better integration with primary health care and community-based services and through continued research in key areas.

What helps patients succeed in self-managing?

- A number of group programs, such as the Chronic Disease Self-Management Program, are well-established and seem to work well for some people, but other Canadians are falling through the cracks. The underserved may be patients with lower incomes, less education, or more complex disease, or who are unable (for a variety of reasons) to join a group program.
- One-to-one interventions are emerging to fill some of these gaps. These programs reach patients by home visits, telephone, or individual coaching by trained peers (lay people with chronic disease), primary health care nurses and doctors, and other professionals such as social workers and pharmacists.
- Internet-based delivery of group and individual support holds promise to engage patients and caregivers in self-management and to expand program reach in remote areas or for people who cannot meet in person (as long as they have access to, and the ability to use the technology).

How can primary health care providers help patients succeed?

- Primary health care providers have considerable potential to offer greater self-management support to people with chronic conditions, both during routine office visits and by linking patients with community-based programs.
- Team-based care allows for efficient and innovative approaches to self-management support, but solo practitioners can also benefit from training to use self-management support tools and techniques, such as care-planning tools and communication strategies, that help patients overcome barriers.

- Some training is made available through ministries of health, regional health authorities, or independent organizations. Online courses are emerging; many toolkits and guides to help primary health care providers deliver self-management support are available free online.

How can policy-makers help patients and primary health care providers succeed?

- System-level strategies can play a vital role using funding, incentives, and other policies to enable health care providers to deliver self-management support and promote the delivery of community-based programs.
- In Canada, some provinces (Alberta and British Columbia are profiled in this report) have developed comprehensive chronic disease strategies that explicitly aim to advance self-management support as a focus for primary health care.
- Initiatives in other countries, notably the United Kingdom and Australia, provide additional models for an integrated, system-wide approach to advancing self-management support.

Recommendations

We recommend that health care systems across Canada move actively to provide self-management supports in a more systematic way. We see four key areas for action:

1) Create an integrated, system-wide approach to self-management support. Current efforts to promote, deliver, and evaluate self-management support are often fragmented. This report highlights several integrated approaches that we can learn from. Continued progress on the delivery and uptake of self-management support should be monitored against specific health system performance objectives, measures, and targets. Further research in key areas, such as cost-effectiveness and how best to sustain program effects in the longer-term, is also needed.

2) Enable primary health care providers to deliver self-management support as a routine part of care.

Many providers need education and training in effective techniques for self-management support. Appropriate funding models and support for practice redesign—to introduce interprofessional team-based care, for example—are also important to allow providers to spend the time needed with patients and to expand the range of services they provide to support patients with more complex conditions.

3) Broaden and deepen efforts to reach more Canadians who need self-management supports.

This can be accomplished by making existing, evidence-based programs more accessible (e.g., by adapting them for different cultures and languages and for patients with low literacy) and by facilitating newer approaches such as one-to-one interventions and peer support.

4) Engage patients and informal caregivers as a key part of any systematic approach. Individuals affected by chronic conditions have a personal stake in the quality of the Canadian health care system. Collectively, the system is finally beginning to appreciate the important asset that patients and caregivers represent through their unique perspectives on quality of care.

The full report includes more detailed recommendations (page 44). Building on Canada's strong foundation of primary health care, these actions would help create a sustainable path to enable patients with chronic conditions to help themselves.

1

Section One

Introduction



What is self-management?

Living with a **chronic condition**—such as arthritis, cancer, diabetes, depression, heart disease, asthma, or chronic obstructive pulmonary disease (COPD)—may mean coping with pain or fear, adapting to new physical limitations, or handling social or job-related stresses, in addition to dealing with disease-related symptoms.

The term **self-management** refers to “the tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions.”⁶

Self-management is both an outcome and a process. As an outcome, self-management means the positive behaviours that patients carry out, such as eating right, exercising, monitoring symptoms, taking medications, and knowing when to seek professional help. The process of self-management involves the actions people follow to make and sustain their behavioural changes. This includes steps such as setting goals, developing action plans, deciding how they might overcome barriers, and monitoring their progress in meeting their goals.

For many patients and their families, the journey into self-management starts with patient education—learning technical skills related to their specific conditions. For example, people with diabetes need to know how to monitor their blood glucose levels, and people with asthma may need to learn how to use emergency medication. This education might be provided one-to-one by a nurse who works with a family doctor, or in a group session at a clinic or community health centre with other patients who need the same information. Increasingly, patients and caregivers are using the Internet to augment this formal education, through information that is sometimes provided online by experts and sometimes by fellow patients or caregivers.

What is self-management support?

Self-management support goes further than traditional patient education. It aims to motivate patients to tackle the personal changes that will enable them to become successful self-managers. **Self-management support** is “the systematic provision of education and supportive interventions, by health care staff (and others), to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support.”⁶

Broadly speaking, self-management support is delivered in two ways: one-to-one by health care providers and through group programs (in person or online). In addition, policies within and outside of the health system can also play important roles in enabling self-management support. For example, policies can support the provision of tools to assist in the delivery of self-management support, and they can improve access to healthy food and opportunities for physical activity.

Why is self-management support important?

Many patients with chronic conditions will need both patient education and self-management support. Research with diabetes patients has shown that augmenting a traditional patient education program with added elements of self-management support can improve health outcomes.⁷

Patients who can self-manage have reduced disease-related effects and may change their use of health services because they monitor their symptoms and know how to prevent and respond to certain health-related problems. Some studies have shown:

- Arthritis patients who received self-management support reported reduced pain and disability.
- Diabetes patients had better control of their blood sugar levels.
- COPD patients had fewer hospital admissions.
- There is also some evidence, although more limited, that patients who receive self-management support can reduce their use of more costly (and less appropriate) health care services.⁸

Yet, despite growing evidence of positive outcomes for patients and the health care system, self-management support is not consistently a routine part of care for all Canadians with chronic conditions:

- In a 2008 survey, one-half to two-thirds of Canadians with chronic conditions said that their primary health care provider had asked about their health-related goals. Far fewer (one-quarter) were referred to a specific group or community program to help them cope with their condition.⁹

- In the 2011 Commonwealth Fund International Health Policy Survey, about two-thirds of Canadians with chronic conditions reported that a health professional had asked them to discuss their goals for their care, had helped them to make a treatment plan they could carry out in daily life, or had given them clear instructions about symptoms to watch for and when to seek further care. (These survey respondents were “sicker” adults, a sample described in our 2011 report, *How Do Sicker Canadians with Chronic Conditions Rate the Health Care System?*)

These survey data give only a partial picture but they do suggest that, although many Canadians are receiving at least some aspects of self-management support, we are also missing opportunities to reach many other people who would benefit.

Who is involved in self-management support?

Successful self-management depends on a partnership between patients and health care providers within a supportive health care system. In this report, we focus on three groups:

- **patients and families** affected by chronic disease;
- **primary health care providers**, including doctors, nurses, social workers, pharmacists, and other professionals, as well as lay community health workers who may also deliver self-management support, particularly in remote communities; and
- **health system managers and policy-makers.**

Many others may also be involved in supporting an individual's capacity to effectively manage chronic health conditions, including:

- **peers** (other people with chronic disease). We highlight this role in Section 2;
- **disease associations**, such as the Arthritis Society, the Canadian Diabetes Association, and the Heart and Stroke Foundation of Canada. They may deliver self-management programs and provide a wide variety of practical information for patients and caregivers (formal and informal). Some also support research that policy-makers can use—we describe some of this work in Section 4;
- **community organizations and volunteer groups;** and
- **private sector companies** such as employers and insurance companies.

“For my girlfriend to lose her job because I’m having seizures and she took too many days off work, I feel tremendous guilt. She’s been my flashlight through these dark times.”

Jordan B., patient

Themes in this report

In addition to our focus on primary health care, other themes run throughout this report:

- We live in an age of **patient engagement**, where the patient-provider relationship is shifting from patients accepting their doctor's advice without question to a partnership in which patients actively participate in their own health care.^{i,ii}
- **Multi-morbidity** (having multiple chronic conditions at the same time) is an emerging characteristic of an aging population like Canada'sⁱⁱⁱ and an important consideration in self-management support.^{iv}
- **Sustainability** of self-management supports is important from two perspectives. The first relates to the concern that too often resources are not put in place to ensure that successful strategies are sustained beyond the pilot phase. The second relates to sustained effects for patients.^v What is needed to help patients continue to succeed after their participation in a self-management program has ended?
- Better **integration** between primary health care and other settings that deliver self-management supports has great potential to sustain the impact of patient interventions on patient health and self-management skills, as well as to make referrals to group programs more likely.^{vi}
- The **determinants of health**—factors such as income, education, and community environment— affect patients' ability to self-manage chronic conditions. We recently reported that Canadians who have chronic conditions and who are in fair-to-poor health are more likely than the general public to be poorer, older, less educated, and living in rural areas.^{vii} Advice to join a gym or eat healthier food may be very challenging for these people to comply with. How can programs, services, and policies take these inequities into account so that more Canadians can benefit from self-management supports?
- The **Internet** holds promise as a method of delivering various kinds of self-management support. Many web-based tools and programs already exist, but there are concerns about a “digital divide” between patients and caregivers who are able to use this technology effectively and those who cannot for reasons of access, literacy, or health.
 - i. Health Council of Canada. (2011). *How engaged are Canadians in their primary care? Results from the 2010 Commonwealth Fund International Health Policy Survey. Canadian Health Care Matters Bulletin 5*. Toronto, ON: Health Council of Canada.
 - ii. Sarasohn-Kahn, J. (2009). *Participatory health: Online and mobile tools help chronically ill manage their care*. Oakland, CA: California Healthcare Foundation.
 - iii. Canadian Institute for Health Information. (2011). *Primary health care. Seniors and the health care system: What is the impact of multiple chronic conditions?* Ottawa, ON: CIHI.
 - iv. Corser, W. & Dontje, K. (2011). Self-management perspectives of heavily comorbid primary care adults. *Professional Case Management*, 16(1), 6–15.
 - v. Liddy, C., Johnston, S., Mill, K., & Shahidi, J. (2011). *Self-management support interventions: Technical paper on the sustainability of self-management supports for people with chronic conditions and the availability of self-management support programs for people with multiple chronic conditions* (Unpublished commissioned work for the Health Council of Canada). Ottawa: Élisabeth Bruyère Research Institute, C.T. Lamont Primary Health Care Research Centre.
 - vi. Williams, A.M., Dennis, S., & Harris, M.F. (2011). How effective are the linkages between self-management programmes and primary care providers, especially for disadvantaged patients? *Chronic Illness*, 7, 20–30. doi:10.1177/1742395310383339
 - vii. Health Council of Canada. (2011). *How do sicker Canadians with chronic conditions rate the health care system? Results from the 2010 Commonwealth Fund International Health Policy Survey of Sicker Adults. Canadian Health Care Matters Bulletin 6*. Toronto, ON: Health Council of Canada.

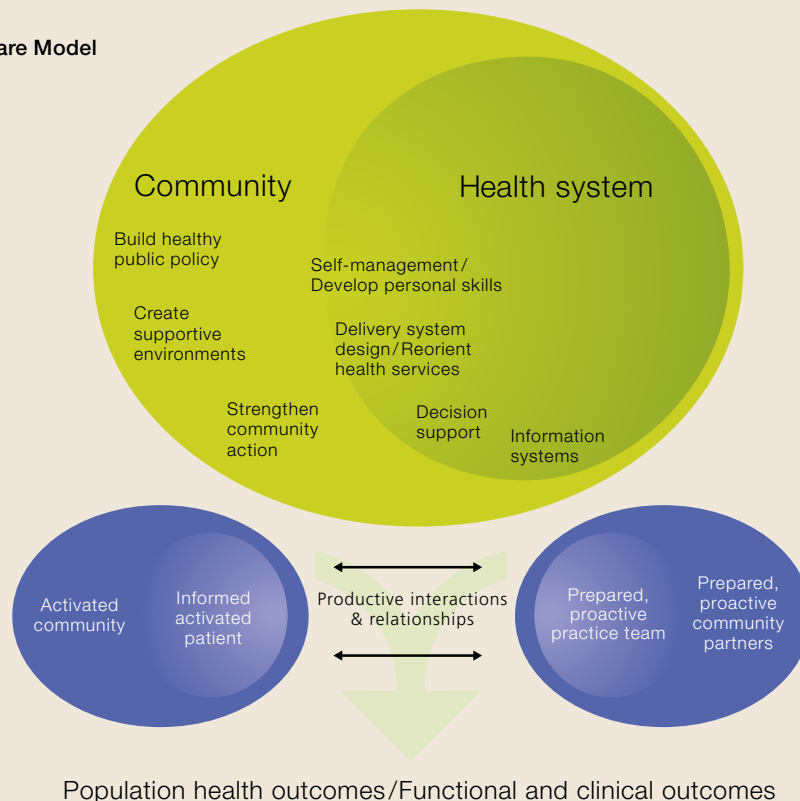
The **Expanded Chronic Care Model** (Figure 1) captures the “it takes a village” perspective on self-management support. This model depicts self-management support (straddling both the health system and the wider community) as a key element of a system-wide approach to improving individual and population health outcomes related to chronic health conditions.

The Expanded Chronic Care Model¹⁰ and the original Chronic Care Model,¹¹ which puts less emphasis on population health promotion, have been widely adopted in many countries including Canada. These models are commonly used by governments and health care providers¹⁰ when they plan how best to prevent and manage chronic disease. In the real world, it isn't always easy to define the boundaries of different elements of chronic disease care; in a fragmented health system, some elements (and therefore some patients) may fall through the cracks. But, as the models show, it is key to think of all the elements as interdependent and integrated—part of a whole system supporting high-quality patient care.

Primary health care: An anchor for self-management support

In Canada, 95% of adults with multiple chronic conditions have a regular primary health care provider¹²—a family doctor or nurse practitioner who provides a foundation for ongoing care. Increasingly across Canada, primary health care may also mean an interprofessional practice such as a family health team where patients can access a range of providers (e.g., pharmacists, social workers, dietitians) to help them manage and prevent health problems. In large part, this shift to team-based primary health care is responding to the rise in the number of people with complex chronic health conditions and a greater understanding of the complex nature of chronic disease.

FIGURE 1
Expanded Chronic Care Model



Source: Barr et al., 2003.¹⁰
Adapted with permission.

Ideally, primary health care is a hub for people with chronic conditions—the person or place that enables continuity of care, follows up with patients, and links them with community services and specialists as needed. Many Canadian reports have described this kind of vision, as well as the gap between vision and reality. For example, the Canadian Academy of Health Sciences (an organization that brings together academic leaders to study health care issues) recently concluded, after an extensive study, that “Canada is lagging behind other countries in performance and infrastructure to support people living with multiple chronic conditions, particularly in the critical primary health care sector.”¹³

Case studies of effective, team-based primary health care for chronic disease illustrate that patients benefit from being equipped with “the tools and resources necessary to be an active participant in their own care. CDM [chronic disease management] programs succeed when patients are at the heart of the initiative.”¹⁴ This lesson applies equally to solo practitioners and small-group practices.

We hope the tools and information highlighted in this report help bring Canadians closer to realizing this vision. We focus on the role of primary health care providers, not because they are the only or most important source of self-management support, but because an effective, system-wide approach to self-management support will not be possible without them.

About this report

This report provides practical information for patients, health care providers, and policy-makers on how to promote and provide self-management support for Canadians with chronic health conditions. For simplicity, and because this report is focused on primary health care services, we use the word “patients” to refer to people with chronic conditions. However, we appreciate that many health service agencies prefer to use other terminology such as “clients” or “individuals living with chronic disease.”

This is not a report about any particular chronic condition, but we use disease-specific examples to illustrate information. Neither is it a report about the prevention of chronic disease, although we recognize that health care providers and policy-makers generally view self-management support as part of a continuum of chronic disease prevention and management.

In developing this report, we received feedback—in particular from governments—that the need remains to examine the best ways to advance self-management support with First Nations, Inuit, and Métis people. A full examination is beyond the scope of this report, but we do make note of successful examples of cultural adaptations of community-based programs (page 19), and identify the potential role that community health workers can play in self-management support.

The structure of this report reflects three streams of self-management supports:

- programs and resources that **patients** use to get information and build their skills and confidence (Section 2);
- strategies and tools that **health care providers** can use in their clinical practices (Section 3);
- strategies that the broader **health system** can implement to support the delivery of self-management programs and policies more widely across Canada (Section 4).

Each of these sections also features an in-depth profile of an innovative initiative that illustrates self-management support in various contexts. These practices offer tools and ideas that can be adapted by governments and health systems across Canada.

We also look at the emerging area of Internet-based, self-management supports (Section 5) and conclude with our recommendations for moving forward. A wealth of resources addresses self-management support, and we encourage readers to make use of the resources listed in Appendix A.

2

Section Two

What helps patients
succeed in
self-managing?



“When I was first asked to join the Living Well with Chronic Conditions course ... I had no expectations that it would change anything. Wow, how wrong I was ... Listening to the experiences of others made me realize that I wasn’t the only person who suffered. By changing the way I thought about my condition and the way I coped ... I now think of things in terms of what I can do, rather than what I can’t.”

Dennis L., a First Nations participant in the Living Well with Chronic Conditions course*

Learning to be a successful “self-manager” can give a patient the best chance of living well with a chronic condition or multiple conditions.^{8, 15} In this section, we look at what helps patients succeed and what barriers they may face. We describe the types of programs being used to promote self-management, as well as some key factors that research has shown to be important to make these programs effective and accessible for as many people as possible.

What makes a good self-manager?

Good self-managers are patients who are actively engaged in their care and are able to make decisions that support their health, including knowing when they can manage on their own and when to seek professional help. Good self-managers are people who:

- are knowledgeable about their condition(s) and about the things they can do to improve their chances of having a good quality of life;
- are motivated to self-manage, using structured information and support;

- follow a personal care plan, developed in active partnership with their health care providers, including goals for their care and specific action plans they can carry out at home;
- actively share in decision-making with their health care providers;
- monitor and manage symptoms of their condition(s) between health care visits;
- know how to problem solve or seek help to manage the impact of the condition(s) on their physical, emotional, family, and social life;
- adopt lifestyles that promote health; and
- have access to support services and the ability to use them.^{8, 16}

With the right supports, ideally everyone with a chronic condition could become a good self-manager. But a number of personal and program-related factors can make it easier or harder for people to benefit from self-management supports.

* Living Well with Chronic Conditions course is a version of the Stanford Chronic Disease Self-Management Program profiled on page 18. Excerpted with permission from the UK-based Patient Voices project: Stories from the Saskatoon Health Region, 2008. View the digital story titled “Why Me?” (patientvoices.org.uk).

What barriers do patients face?

Patients have identified **personal challenges** to their ability to self-manage, such as financial difficulties, competing life priorities, and difficulty in achieving behavioural changes.¹⁷ Patients also recognize **system-related challenges** such as a lack of self-management programs tailored to their needs, access problems related to work hours, child care, transportation, and poor communication with their doctors.^{18, 19} In addition, **disease-related challenges** such as depression, pain, and mobility restrictions can make it difficult for some people to engage in self-management programs or summon the motivation to change health behaviours.²⁰

Having multiple chronic conditions brings additional challenges. These patients often have greater self-management learning needs,²¹ but the complexity of their health problems can also throw additional challenges into their path. Common problems include:

Drug interactions. Patients taking multiple drugs for multiple conditions report difficulties in getting adequate and reliable information to understand how to use their medications safely.²² Many Canadian seniors with chronic conditions take at least five prescription drugs at one time, and they are more than twice as likely to experience a side-effect requiring medical attention (13%) as those taking only one or two prescription drugs (6%).²³

Complex information. If patients have difficulty understanding how their multiple conditions can affect one another, this can lead to poor self-management. It may be hard for patients to recognize symptoms that might indicate worsening health problems.²⁴

Conflicting advice. Different health care providers may have different recommendations,²² different diseases require different medication regimens, and different priorities may lead to confusion about treatment plans. Some patients have developed coping strategies through trial and error and personal insight.¹⁷

What helps patients to successfully self-manage?

Research provides information about what enables patients to become good self-managers. Successful self-management supports will help patients develop these attributes. People are more likely to be able to self-manage when they are:

Ready to change. Exercising more, eating better, drinking less alcohol, finding healthy ways to reduce stress—these are some of the difficult challenges that people with chronic conditions typically face. Patients are considered ready to change if they have both conviction (that the change is important) and confidence (that they themselves can make the change).²⁵ Assessment tools are available to help patients and their health care providers understand where they are in terms of readiness to change. Health coaching by trained providers or peers can help patients move towards readiness.²⁶

Confident in their ability to self-manage. Evaluations of chronic disease self-management programs have shown that participants who gain confidence (“self-efficacy”) in their ability to self-manage have better health outcomes.²⁷ For example, arthritis patients with high self-efficacy manage their pain better, experience less depression, exercise more, and pursue more self-management activities than patients who are less confident about their ability to manage their arthritis.²⁸

Health literate. Low health literacy—the limited ability to access, understand, and act on health-related information²⁹—is pervasive in Canada, affecting about 60% of adults aged 16 and older, as measured by the 2007 International Adult Literacy and Skills Survey.³⁰ Many patients with limited health literacy have poor abilities to engage in self-management³¹ and are less likely to attend peer-led, self-management programs.³² Self-management programs and resources should be designed to take low health literacy into account.

“After all these years... it is a finely tuned balance of medications that support each other and minimize side effects. If I don’t take a certain medication for a day or two...it has a significant impact on my health and well-being.”

Lene A., a patient with rheumatoid arthritis

Supported by family, friends, or peers. Higher levels of social support are associated with better self-management for diabetes and other diseases,³³ and have been shown to be particularly important for people with multiple chronic conditions.³⁴ In fact, some experts question whether the roles of family and larger societal influences have been underestimated in many current approaches to self-management support (with their focus on individual self-efficacy).³⁵ For example, research in Australia is looking at defining a collective approach to self-management support that reflects the culture and beliefs of indigenous communities,³⁶ an issue also relevant to Canada.

Supported by a primary health care provider. People with chronic conditions benefit from an ongoing relationship with a primary health care provider,³⁷ not only for medical monitoring but also as a source of self-management support.³⁸ Section 3 looks at how primary health care providers can fulfill this role.

Breaking down barriers

In general, self-management support programs are more likely to be successful if they:

Motivate and build knowledge, skills, and confidence. Programs that focus on self-efficacy and teach self-management skills (such as active goal-setting and other behaviour-change strategies)—and do not focus on information/education alone—have been shown to be more effective in motivating sustainable behaviour change.^{8, 38, 39}

Are integrated with primary health care. Self-management support that is integrated into primary health care has been shown to have greater impact than when it is not integrated.³⁸ To be integrated, programs can be delivered in a primary health care setting, or they can be delivered in the community but also involve the patient checking-in regularly with health providers (e.g., to develop and monitor a personal action plan).⁴⁰ For example, asthma-related interventions can reduce the number of unscheduled visits and help patients avoid hospitalizations.³⁹

Address multiple chronic conditions. Many people with chronic disease are dealing with more than one chronic condition at one time. Disease-specific initiatives can be effective, but they may not fully serve people with multiple chronic illnesses, including mental health conditions.^{2, 41}

Include informal caregivers as a distinct client group.

Programs can play a role in nurturing this significant source of support by making self-management courses available to informal caregivers.⁴² Technology may also be instrumental in involving informal caregivers such as adult children who may live at a distance. For example, the CarePartners initiative of the US Veterans Health Administration provides a patient's chosen "care partners" with email updates about the patient's health (based on assessments made via interactive voice response telephone calls). Care partners also have access to a comprehensive website containing more detailed information about how they can help.⁴³

Target underserved populations. Numerous studies have identified difficulties in recruiting certain groups for chronic disease self-management programs (ethnic minorities, indigenous communities, rural residents, older people, and people with low income or lower education) and have raised concern that participation tends to drop off as the course progresses.⁴⁴ Some of the solutions proposed include:

- translating program materials not only in terms of language but also incorporating the patients' cultural context, including traditional beliefs about health and disease. This can be accomplished by working in partnership with community health workers, elders, or existing multicultural services;⁴⁵
- removing practical barriers to participation³⁸ by offering telephone-based interventions, varied meeting times, or locations with child care available;¹⁸
- training lay health workers from underserved communities to deliver self-management support, in partnership with primary health care teams³³ or as part of broader disease prevention programs;⁴⁶ and
- delivering programs online, but also considering that people with financial or literacy challenges may not have access to a web-enabled device or be comfortable using it.²⁰ (See page 39 for more information about the pros and cons of Internet-based self-management programs.)

Consider a mix of approaches. People with different conditions and individual needs may require different kinds of self-management support. For example, people with diabetes may need technical education about diet, exercise, and medications, in addition to more general self-management education about goal setting and problem solving. On the other hand, people with depression or chronic pain, who may not need a great deal of technical education, might benefit more from cognitive and behavioural interventions to help them cope with the emotional impacts of their conditions.⁸

What's out there?

The following types of group programs and individually-focused programs are the most common ways that patients learn about self-management and, in some initiatives, receive ongoing support. Group programs include the benefit of peer support and opportunities for interaction, but one-to-one services may be warranted for patients who cannot be, or prefer not to be, part of a group, or who need more intensive, individualized support.

GROUP PROGRAMS

The **Chronic Disease Self-Management Program** (CDSMP), also known as the Stanford Program, is a widely used and widely adapted group program that teaches patients generalized skills they can use to manage their chronic condition(s), regardless of their particular illness. Disease-specific versions of this program also exist. For more details and an example of how the Stanford model is being used in Canada, see our “leading practice” feature on page 18.

Other community-based group self-management programs may share components of the CDSMP, but their structure and content are determined locally, in order to serve particular populations.⁴⁴ For example, the Moving On After Stroke (MOST) program offered by Baycrest,

a geriatric care centre in Ontario, incorporates exercise into a program of self-management education with goal-setting activities and other types of support.⁴⁷ Other programs integrate volunteers as peer health educators. For example, the Airdrie (Alberta) Community Hypertension Awareness and Management Program (A-CHAMP), which used volunteer peer health educators to conduct blood pressure screening sessions in collaboration with pharmacists and family physicians, was effective in helping rural seniors control their high blood pressure.⁴⁸

Peer support groups (in-person and online) provide education, emotional support, and practical problem-solving assistance among people facing similar challenges. Peer support is associated with better self-management for diabetes and other chronic conditions,³³ and is a key component of many group programs for self-management education.

However, informal peer support groups or those that rely entirely on volunteers often face significant challenges to their sustainability, due to the ongoing need for recruitment, training, and coordination and other logistical issues.⁴⁹ Disease associations sometimes provide infrastructure for such programs; for example, the Arthritis Society of BC runs a telephone peer support program—Arthritis Answers Line—staffed by volunteers.

Shared medical appointments, also called group visits, combine clinical care, self-management support, and peer interaction in a setting integrated with primary health care. Health care providers come to the group (typically three to 30 patients) to take vital signs, discuss issues and

“I’ve seen my family members go through so many mood swings...

Many times I felt like my shoulders were collapsing from all the stress... Last year I took the Living Well with Chronic Conditions class, and following that I took the leadership training. I only wish I’d had this training before my family members died.”

Vicky W., a First Nations participant in the Living Well with Chronic Conditions course. Living Well with Chronic Conditions course is a version of the Stanford Chronic Disease Self-Management Program, profiled on page 18. Excerpted with permission from the UK-based Patient Voices project: Stories from the Saskatoon Health Region, 2008. View the digital story titled “Don’t Knock on My Door” (patientvoices.org.uk).

answer questions. Group visits are usually led by a physician or an advanced practice nurse, and sometimes include a nurse, social worker, pharmacist, or mental health professional. These professionals may conduct private or semi-private consultations, leading to individualized medication adjustments, referrals, and ordering of preventative services.⁵⁰

Compared to a typical one-to-one medical visit, group visits can improve access to primary health care services and allow more time for patient education and for addressing psychosocial issues; this can help build patients' confidence in their abilities to self-manage their conditions.⁵¹ This approach has been shown to decrease emergency room visits and increase patient and physician satisfaction, quality of care, and patients' quality of life. On the other hand, mixed results have been shown in studies that examined whether group visits have an impact on self-efficacy and self-management behaviours, perhaps due to the complexity of measuring these concepts.⁵²

ONE-TO-ONE PROGRAMS

In-home programs provide one-to-one self-management support for people unable to attend a group program. An example is the Quebec program designed for frail seniors with arthritis—called *I'm Taking Charge of My Arthritis! / Mon arthrite, je m'en charge!* (monarthrite.ca). The program consists of six weekly, one-hour home visits that focus on developing and carrying out an individual action plan, discussing other topics related to self-management, exploring community resources, and developing a coaching relationship.⁵³

Telephone programs typically involve a nurse providing proactive follow-up with patients to encourage self-monitoring and self-management.⁸ In Canada, some provinces have adopted telephone programs to provide self-management support, sometimes within a multi-faceted, chronic disease management intervention. For example, the Telecare Manitoba Program (demonstration phase) has seen positive outcomes for people with chronic heart failure. This program includes

telephone sessions with a nurse who helps the patient with education, action planning, ongoing monitoring, and other self-management support. It is also integrated with primary health care—health-line nurses regularly communicate with patients' family physicians.⁵⁴ Some observers feel that telephone-based initiatives may be a better forum than the Internet for people with limited health literacy.¹⁸

Peer coaching, also called peer health coaching or mentoring, engages trained volunteers who interact with other patients, either in person or by phone, to listen, discuss concerns, and provide support. This approach has been shown to be successful with people from various ethnocultural communities and for specific groups of patients such as those with breast or prostate cancer, post-partum depression, or HIV/AIDS. However, evidence of the effectiveness of peer mentor programs for people with certain chronic diseases, such as diabetes,³³ is still limited. Peers for Progress (peersforprogress.org), a global research network with a focus on diabetes, was initiated to address gaps in the current body of evidence concerning how peer support initiatives contribute to health.⁵⁵

Individual interventions by primary health care

providers involves delivering one-to-one self-management support during primary health care visits. Various models are available (described in Section 3), including some that integrate interventions for depression and anxiety with self-management support for other chronic diseases.

All of these group and individual approaches are designed to complement, not replace, regular support from primary health care providers, which is the focus of Section 3.

“As soon as I was able to connect with my peers and get that support, it changed my entire outlook and where I was mentally and emotionally with the disease, which is so huge when you're battling any type of illness.”

Daniel S., cancer survivor

LEADING PRACTICE***The Stanford Chronic Disease Self-Management Program**

Living well with chronic disease, regardless of the specific condition or conditions, is the focus of the widely used and studied Chronic Disease Self-Management Program (CDSMP). The program was originally designed to address generic issues typically faced by people with chronic disease, but adaptations have also been developed for a range of specific populations.

HOW DOES IT WORK?

Pairs of trained leaders—lay people and/or health care professionals—lead small groups of participants who meet weekly for six 2.5-hour sessions. People with any chronic condition can participate, as can their families, friends, and caregivers. The workshop leaders follow a set plan from a program manual; they do not provide medical advice. Instead, the workshops emphasize practical “how-to” techniques covering exercise and healthy eating; pain and stress reduction; using goals and action plans; problem solving; communicating with family, friends and health care providers; using medication; and dealing with emotions like anger and depression that commonly accompany chronic disease. Peer support among participants is a key component.

Developed and licensed by Stanford University in California beginning in the mid-1980s, the CDSMP has proven to be popular and flexible. Today, 24 countries worldwide deliver versions of the program, as do most Canadian provinces and territories (under many different local names; see Appendix B).

A CANADIAN EXAMPLE

In British Columbia, the CDSMP forms part of the provincial “Patients as Partners” strategy, which coordinates the planning and evaluation of self-management initiatives. Programs are delivered free of charge in community settings such as seniors’ centres, and are also available locally in the Chinese and Punjabi languages. BC is also delivering condition-specific versions for people with chronic pain, diabetes, or arthritis/fibromyalgia. In 2010–2011, 86% of BC residents living in communities with a population of 3,000 or more had access to one of six different self-management programs within 50 kilometres of their residence.⁵⁶

An online version of the generic CDSMP is also delivered in BC and is being considered for implementation in at least one other Canadian jurisdiction. This innovative approach enables people to participate if they cannot, or choose not to, attend in person. Participants can log on whenever they want, since the interaction happens through a bulletin board rather than through real-time chats. Evaluations show that the online version is a viable alternative to the small-group program, with positive outcomes similar to those in other CDSMP studies.¹²¹

WHAT IMPACT DOES IT HAVE?

Evaluations from its long, international history of implementation show that both the generic and disease-specific CDSMP can be effective, though with sometimes modest and variable results.^{57, 58} A 2011 review of 24 evaluations of the program

(including five BC studies) found small to moderate improvements in participants' self-efficacy (more confidence about self-managing), psychological health (less stress and depression), and health behaviours (better cognitive symptom management and communication with physicians). Many of these improvements were sustained for up to one year.⁵⁸

Like other group self-management programs, the CDSMP has had challenges in recruiting and retaining participants. A great deal of work has gone into adapting the program to reach more people. There is also debate about whether the program leaders should be health professionals or lay people. (Some programs are co-led by a lay person and professional working together; others are led by either one or the other.) Whereas professionals may be better equipped to deliver technical education about chronic disease and be more likely to attract referrals from primary health care providers, lay leaders can be role models for participants, cost less than professionals, and may be better able to address the non-medical concerns of living with chronic conditions. But recruiting, training, supporting, and retaining lay leaders has proven to be challenging.⁴⁹

These operational concerns highlight the need for continued adaptation and study of this program in all its variations.⁴⁴ In addition, it's important to consider that a single model for self-management support is unlikely to reach all underserved groups; therefore, a range of programs will probably be needed within a single jurisdiction.

CULTURAL ADAPTATIONS

BC and other jurisdictions have aimed to improve participation by involving targeted communities in the design, implementation, and evaluation of the programs. For example, First Nations adaptations have incorporated community customs into the program, added culturally meaningful content such as the medicine wheel, and worked with the community to determine how and where to train program leaders and recruit participants.^{59, 60} The University of Victoria worked with BC First Nations and Aboriginal communities between 1992 and 2009 on a series of six projects, testing modifications to the CDSMP based on local feedback.^{61, 62, 63} Using a similar approach, the CDSMP has been tailored for the Punjabi-speaking populations and is now being delivered throughout BC in that language.⁶⁴

FOR MORE INFORMATION

- on the Stanford Chronic Disease Self-Management Program, visit the Stanford Patient Education Research Centre (patienteducation.stanford.edu)
- on the Stanford model self-management programs being delivered across Canada, see Appendix B.

* The Health Council of Canada has established criteria to categorize innovative practices as emerging, promising, or leading (healthcouncilcanada.ca/innovativepractices).

3

Section Three

How can primary health care providers help patients succeed?



“There are definitely some consultations where things have gone more efficiently because of the skills I’ve learned... The training has helped me to think about how I can approach things differently and get a better outcome, rather than just going over old ground.”

Primary health care doctor in the UK, after training in self-management support⁶⁵

For a primary health care provider, the goal of self-management support is an informed and empowered patient with the skills and confidence necessary to manage his or her chronic conditions.^{66, 67} In this section, we focus on self-management support as a role for primary health care: what’s involved and what will help health care providers to successfully deliver these services.

By primary health care providers, we mean not only family doctors in solo or group practice, but also nurse practitioner-led clinics, doctors working with nurses in a primary health care practice, and interprofessional teams involving doctors, nurses, social workers, pharmacists, dietitians, and others. They may also include health care providers in disease-specific education clinics, and lay community health workers who may deliver chronic disease education and self-management support within their own ethnic, cultural, or geographic communities, ideally as part of a primary health care team.⁶⁸

In team settings, all members of the primary health care team should be involved in supporting self-management practices. Solo practitioners or those in small practices can also use many of the tools, techniques, and ideas we describe here. In fact, some of the resources listed in

Appendix A are designed for clinicians in solo or small-group practices, as well as those providing team-based care (see, for example, Partnering in Self-Management Support: A Toolkit for Clinicians on page 48).⁶⁹

Productive health care visits: A key to self-management support

Self-management support delivered by health care providers is sometimes called health coaching.⁷⁰ Health coaching can be both a function (all members of a primary health care team can integrate aspects of coaching into their interactions with patients) and a type of job (someone within or outside of the primary health care practice can be called a health coach).¹⁸

Underpinning self-management support is shared decision-making between patients and health care providers. This puts demands on health care providers to provide patients with complex information in clear and understandable terms and, when needed, to help patients develop skills in making decisions that support their physical and mental health.⁴⁰ For example, patients should know and be empowered to ask, whenever a new medication is introduced, “How will this new drug interact with my other medications?”

The health care visit is a central opportunity for these interventions. Some experts have proposed that providers and patients should think about “the visit” as more than just the time they sit in a room together. They suggest viewing each visit as having three phases—a pre- and post-phase as well as the visit itself (Figure 2).^{15, 71} A number of evidence-based principles have been identified as being important to implementing self-management support as a routine part of primary health care. These activities can take place over one or more phases of the visit:

Conduct a brief targeted assessment. Along with assessing clinical severity and functional status, this might include exploring the patient’s problems and goals, current self-management behaviours, readiness to change, and barriers to self-management. This information can then inform collaborative care planning and other interventions aimed at supporting behaviour change.

Provide disease-specific education and technical skills. Patient education is a foundational element of self-management support. It should not only teach patients about how to care for their specific conditions (e.g., how to manage multiple medications and avoid adverse interactions), but it should also promote skills development.

Support collaborative priority and goal setting. Providers and patients should collaboratively define problems and then develop realistic goals and a personalized action plan. Tools such as action plan templates are available (see Resources, Appendix A).

Encourage the development of problem-solving skills. Providers can teach patients how to use specific problem-solving strategies to overcome barriers to change.

FIGURE 2
A Cycle of Self-Management (SM)
Support in Primary Health Care



Source: Schaefer et al. 2009.⁶⁹
Adapted with permission.

Provide active follow-up and links to evidence-based community programs. Check-ins and reminders help sustain self-management behaviours and improve outcomes. Providers should also connect patients with community resources and services that can enhance social support and reinforce problem-solving skills.

Pursue multi-faceted interventions. Some patients, such as those with more complex chronic conditions, require several kinds of self-management support.^{8, 15} (See also *Multi-faceted approaches* on page 25.)

While many of these practices can be implemented by a single primary health care provider, they can also involve a number of different members of a care team. In fact, many successful practices find that a team approach optimizes their ability to deliver comprehensive self-management support.^{18, 72}

Productive primary health care practices: System changes to support self-management

In addition to what happens during visits with patients, primary health care providers can enhance their ability to deliver self-management support by improving various aspects of their practice environment. It's no coincidence that the focus of many of these efforts by various practices and jurisdictions correspond to components of the Expanded Chronic Care Model. Self-management support interventions that are grounded in this model—meaning they take a system-wide approach to chronic disease care and target multiple dimensions of care delivery—have been shown to lead to sustainable operations and improved longer-term outcomes. Some examples include:

Delivery system redesign. Making better use of all members of the health care team and implementing other changes in how care is organized can ease the time pressures felt by physicians in offering self-management support.⁷³ Offering shared medical appointments (described on page 16) and adopting an interprofessional team approach are common ways of achieving this.

For example, having nurses follow up with patients (by phone or in a face-to-face, check-in visit) may improve the practice's ability to spend the time that's needed to deliver effective support. To support the more complex needs of patients with multiple conditions, employing a care coordinator or case manager as part of the primary health care team has been shown to be valued⁷⁴ and effective.^{75, 76} Integrating a counsellor into the team can help patients cope with psychosocial issues that affect their ability to self-manage (see sidebar, *Tackling emotional barriers to self-management* on page 24).

Integrated program delivery. Group and one-to-one self-management programs like those profiled in Section 2 can be delivered directly in primary health care settings, an approach shown to lead to positive, sustained outcomes.⁷⁷ For example, a nurse-led group self-management program, established within a primary health care practice, supported patients with type 2 diabetes through assessing behaviour, setting goals, problem solving, and offering tailored information sessions. A dietitian and psychologist were also involved. Evaluation showed that patients had sustained their weight-reduction improvements 18 months after the program ended.⁷⁸ Integration has the potential to improve the overall delivery of care for patients with chronic conditions.⁷⁷ To this end, nurses, pharmacists, and others can also deliver health coaching in person or by telephone and serve as conduits to other primary health care providers, such as family physicians.

Tackling emotional barriers to self-management

A range of techniques is available to help primary health care providers tackle the social and emotional issues that often accompany chronic disease. Addressing these issues—depression, for example—is essential so that the patient can benefit from self-management education and skill building. This neglected aspect of self-management support has been successfully integrated into primary health care in a number of initiatives.

For example, the Hamilton (Ontario) Family Health Team has integrated mental health personnel into the offices of family physicians. Various team members (e.g., physicians, nurses, pharmacists) can refer patients to a counsellor—often a registered nurse or a Masters-level social worker with special training and experience—for help with mental health or addiction problems that may be associated with their chronic disease. Psychiatrists are also available for consultation with other team members. Counsellors often use special techniques such as motivational interviewing (described in “Tools and techniques”) or a depression screening tool (the patient health questionnaire 9, or PHQ-9) to identify the nature of problems, provide short-term counselling, and redirect patients who might need specialist care or other mental health services. Sometimes patients are referred to the family health team’s education and self-management support groups, leading to functional integration of emotional and physical health care.¹ This interprofessional approach is used in many family health teams, community health centres, and diabetes education programs across Ontario.

i. Kates, N., McPherson-Doe, C., & George, L. (2011). Integrating mental health services within primary care settings. The Hamilton Family Health Team. *Journal of Ambulatory Care Management*, 34(2), 174–182. doi: 10.1097/JAC.0b013e31820f6435

Linkage with community services. Similarly, it has been proposed that patient participation in community-based self-management programs will likely improve when primary health care practices have strong links with these programs. Structured information about community resources, as well as initiatives that instill confidence among physicians by conducting evaluations and publicizing the results, have been cited as ways to support this linkage.⁷⁹ For example, a community program run by volunteer peers was able to rely in part on family physicians and pharmacists to recruit participants, and the program in turn referred patients back to these health care providers. This link with primary health care provided an efficient mechanism for identifying, tracking, and managing large groups of people that could benefit from the program,⁴⁸ and illustrates how community programs can enhance and complement primary health care.

Information systems. Electronic information systems are identified as a key characteristic of primary health care practices that are able to deliver self-management support sustainably; the systems help practices document the support that patients have received and more effectively monitor their outcomes.⁸⁰ Electronic medical records also make it easier for practices to segment their patient rosters into risk categories, which allows them to optimize care delivery and provide the right level of self-management support.^{81, 82, 83} Electronic health records, which have the ability to incorporate health records from multiple points of care, have even greater potential to benefit self-management support because they can facilitate the sharing of patient information among providers in different locations. This will help to ensure integrated care not only for people with multiple chronic conditions but also for people in remote areas of Canada, such as many First Nations and Inuit communities whose care may involve providers from multiple jurisdictions.

Multi-faceted approaches. In our review of the research about what helps the sustainability of self-management supports, we found that the programs showing the greatest and most sustained effects combined two or more interventions, such as a group class in self-management and training for health care providers.^{84, 85, 86} These multi-faceted approaches have also been shown to be effective for patients with complex needs related to having multiple chronic conditions, such as pain and depression (a common combination).^{77, 87} For example, one study looked at the benefits of a primary health care initiative in which patients received antidepressant medication for three months, followed by six sessions (once every two weeks) of a pain self-management program. Active follow-up included continued support for up to one year by a nurse (called a care manager). Patients experienced reductions in pain and severity of depression.⁸⁷

Tools and techniques

Health care providers are being encouraged to provide self-management support by using behaviour-change strategies as part of a regular clinical visit. A variety of techniques have been developed and can be used singly or in combination.⁴⁹ Two comprehensive and well-evaluated approaches are described on this page (the 5As and the Flinders model), along with a popular communications technique (motivational interviewing) and several emerging approaches for patients with more complex conditions or challenges with self-management. Continued research is needed to identify how best to implement these interventions and to identify additional promising practices.^{8, 39}

The 5As is a set of well-tested behaviour-change techniques that health care providers can use to help patients develop realistic action plans and take other steps towards self-management.⁴⁹ By incorporating multiple types of self-management support, the strategy becomes greater than the sum of its parts and is more likely to lead to better outcomes for patients.⁸⁸ See our “promising practice” feature on page 27 for more detail.

The Flinders Program for Chronic Care Management, developed in Australia, gives health care providers a care planning approach and tools to support the assessment, planning, and motivation of patients with chronic physical or mental health conditions and co-morbidities. The program includes a number of tools for assessment, interviewing, and goal setting designed to help providers and patients collaboratively identify issues, formulate a care plan, and monitor and review progress.⁸⁹ While the Flinders program has been used with success in Australia, Alberta Health Services recently experienced difficulties in implementing it. Challenges included problematic time commitments, lack of buy-in by management and colleagues, logistical considerations (forms, flow, and communication), and the need for a Canadian adaptation.⁹⁰

“I have three neurologists. I have a rheumatologist. I have a hematologist, I have a cardiologist. They all need the same information, in a central location. In today’s day and age with technology, I shouldn’t have to carry a stack of papers and pass it to my doctors.”

Jordan B., a patient with multiple chronic conditions

Motivational interviewing (MI) is a patient-centred method of communication that helps patients explore and resolve their ambivalence about behavioural change and, as a result, become more motivated to change their health-related behaviours.⁹¹ Motivational interviewing is a component of the 5As strategy, described on page 27, although effectiveness studies of MI alone have found mixed results. For example, motivational interviewing was found to help patients improve some risk factors (body mass index, total blood cholesterol, systolic blood pressure) but not others (smoking, blood glucose levels).⁴⁹ The Health Foundation, a UK-based health care quality organization, has summarized the characteristics of effective training for motivational interviewing, but notes that there has been little research about what makes a good motivational interviewer.⁹²

Guided self-determination (GSD) is a structured coaching strategy designed for nurses to help patients with diabetes who struggle with blood sugar control. Designed for one-to-one and group settings, the method uses a series of worksheets and coaching techniques to address barriers to effective problem solving and to guide patients in setting goals.⁹³ Evaluation of the group GSD approach showed that patients improved their life skills, measured their blood glucose more frequently, and increased their sense of competence in managing their diabetes.⁹⁴ Researchers are continuing to evaluate the use of this method for other chronic conditions.⁹³

Guided care is a multi-faceted case management approach for patients with more complex chronic conditions. It involves a nurse working with a group of primary health care physicians as well as with patients and their caregivers. Through these collaborations, the nurse develops a care guide (for providers) and an action plan (for the patient/caregiver). The nurse also coordinates the roles of the various care providers involved, uses motivational interviewing techniques to coach the patient for self-management, provides a referral to a group self-management education program, smoothes the patient's transitions between sites of care, and provides education and support for family caregivers.^{75, 95} For more information, see guidedcare.org.

Education and training

Primary health care providers could improve outcomes for their patients by learning how to use behaviour-change strategies and other specific approaches and tools for self-management support that they can incorporate into their practices. There is good evidence for the effectiveness of communication skills training for health professionals, especially to support shared decision-making.^{8, 39} However, surveys have shown that some clinicians define patient involvement in decision-making and self-management narrowly, suggesting that additional work is needed to educate health care professionals about the value, scope, and skills needed for self-management support.⁸

In Canada, some training in self-management support techniques is organized for providers through provincial ministries of health or regional health authorities. Providers can also seek training on their own through independent organizations. Some, like the Choices and Changes course offered by the Institute for Healthcare Communication, are accredited for Continuing Medical Education (CME). Online training is emerging, such as courses offered through British Columbia's Practice Support Program and the online Self-Management Toolkit for Providers from the (Ontario) South West Local Health Integration Network (LHIN). In addition, quality improvement collaboratives, operating in a number of provinces (and described in Section 4), provide training in practice-level changes that support better chronic disease management.

This section has highlighted ways that primary health care providers can incorporate self-management support into routine care. In the next section, we look briefly at some policy initiatives in Canada and abroad that aim to help primary health care providers succeed in this role.

PROMISING PRACTICE*

The 5As: A how-to guide for primary health care providers to help patients help themselves

Assess, Advise, Agree, Assist, Arrange: these five steps make up a communication and action cycle known as “the 5As” that health care providers can use to help patients make challenging changes in their lives.⁹⁶

Originally developed as a smoking cessation strategy, this effective approach has been adapted, and widely adopted, in self-management support for a range of chronic health conditions from diabetes to depression. The 5As are endorsed by the Registered Nurses’ Association of Ontario (RNAO) as a clinical best practice for self-management support.⁸⁸

HOW IT WORKS

Nurse practitioner Cheryl Smith leads a primary health care clinic in a small community on the Bay of Fundy in Nova Scotia. In practice for 30 years, she learned the 5As just a few years ago. “I use it every day,” she told us in an interview. “It becomes second nature. It’s a good algorithm, a guideline to help you structure your visit.”

She described how she used the technique to help a young man who had phoned her unexpectedly at the clinic. He was in a serious mental health crisis—suicidal, in fact. The problem wasn’t new to him, but he was disillusioned with responses he had received in his previous attempts to get help.

“You always start with **assessing**,” she said. “What kind of need did he have? What were his goals? And, if this is the first visit (as it was with this young man), you also start by establishing rapport.” This means ensuring the patient has a chance to express his or her feelings and fears, and that the provider gets a sense of the patient’s readiness to take action.

Moving into **advising**, Smith talked with him about what they each could do to help him reach his goals of getting through this crisis and avoiding a repeat in the future. Communication techniques such as “ask-tell-ask” and “closing the loop”—in which both the patient and provider repeat key points in their own words—ensure that patients feel heard and have actually received important advice or information.

The third step is to **agree** on a set of specific, short-term actions. “He wanted counselling, so we agreed that I would refer him into the mental health system and he would keep a diary until our next visit.” A diary helps patients monitor themselves and creates a tool for ongoing communication.

In this case, the **assist** step was straightforward, since the young man was very motivated to get help. “Not everyone is committed to change when you first see them,” Smith said. For the “assist” step, the RNAO best practices guide recommends motivational interviewing, a counselling method designed to help people resolve their ambivalence about making changes in their lives.

The last task is to **arrange** follow-up. “I was able to get him a mental health appointment in three days, and we arranged to meet again in four days’ time,” Smith explained. Regular, sustained, and integrated follow-up is essential to long-term success in self-management. “As a primary care provider, it’s key that we know what’s available in the community so that we can connect people with those resources,” she said.

IT TAKES TIME

Smith spent over an hour with the young man that first day. “Because nurse practitioners are not paid on a fee-for-service basis, we have more time to work with patients on self-management strategies than a busier primary care office might have. Sometimes doctors refer people to us for this kind of support,” she explained.

* The Health Council of Canada has established criteria to categorize innovative practices as emerging, promising, or leading (healthcouncilcanada.ca/innovativepractices).

4

Section Four

How can policy-makers help patients and primary health care providers succeed?



“To adopt a self-management philosophy and embed self-management within current and future practice, it is necessary to make major shifts in cultures, attitudes, infrastructure, tools and practices.”

Queensland (Australia) Framework for Self-Management 2008-2015

Public policy plays a vital role in supporting the ability of patients to self-manage their chronic conditions, as the Expanded Chronic Care Model illustrates (page 10). At a provincial or national level, strategies might lay out health system goals that reflect a commitment to promoting and enabling self-management support. Policy could then prescribe the funding and other incentives needed to realize these goals—such as funding to deliver skill-building programs for patients, training providers in communication techniques and tools, and encouraging the expansion of primary health care teams. Beyond the health system, policy-makers at all levels can influence social and economic factors that contribute to patients’ ability to self-manage chronic disease, such as the availability and cost of healthy food. Policy can also drive evaluation research to measure results, listen to patients, and improve understanding of what works best to reduce the impact of living with chronic conditions.

How self-management support occurs at the system level in Canada

CHRONIC DISEASE STRATEGIES

We commissioned an environmental scan of chronic disease strategies across the provinces and territories

and found a range of approaches to promoting self-management support. Most provinces and territories have a strategy or action plan related to chronic disease prevention and management, which may include self-management support as an element. Sometimes disease-specific strategies address self-management support (e.g., provincial diabetes strategies are the most common ones).⁷⁷ Appendix D lists a sample of government strategies and policy documents related to self-management support.

Under these strategies, most provinces and territories fund community-based programs for patients in self-management education. Many of these are versions of the Stanford Chronic Disease Self-Management Program, operating under a range of local names (Appendix B); Appendix C lists examples of other types of programs for patients and providers in each jurisdiction. At the national level, the Canadian Diabetes Strategy sets self-management and self-management support high on its list of priorities; a variety of self-management initiatives were funded under this strategy in 2010 and 2011.^{97, 98}

Strategy statements from non-governmental organizations

Canada has numerous non-government organizations whose work is dedicated to the prevention and management of specific chronic conditions. Some of these organizations have developed strategy statements that emphasize the need for self-management support at the system level. For example:

- The 2008 **National Lung Health Framework** called for the promotion of patient empowerment and self-management, among other tactics, to improve the management of respiratory diseases in Canada. It also recommends greater use of interdisciplinary care models that include self-management plans, such as Quebec's Living Well with Chronic Obstructive Pulmonary Disease (COPD), a model of care used in local community service centres (Centres locaux de services communautaires, CLSC), home care, and hospitals. (lungframework.ca)
- The 2009 **Canadian Heart Health Strategy and Action Plan** highlights some promising practices and calls for a number of policies and tactics to promote self-management support as an integral part of primary health care for people with cardiovascular disease. Although it has not yet been implemented, the strategy highlights the value of engaging patients in the redesign of primary health care services and recommends that Canada's chronic disease organizations work together to communicate common messages, taking health literacy into account. (cchs.ca)

- **Diabetes: Canada at the Tipping Point—Charting a New Path**, a 2011 report from Diabetes Quebec and the Canadian Diabetes Association, advocates for a comprehensive secondary prevention strategy to help reduce the impact of diabetes. Such a strategy would require equitable access to services related to self-management, an information platform to share best practices across Canada, and additional efforts to standardize the quality of diabetes education. (diabetes.ca)

In addition, **cancer survivorship research** in Canada identifies self-management support as an emerging consideration for cancer survivors. Because of improved long-term survival rates, cancer is starting to be viewed as a chronic condition, and people who have survived cancer are benefitting from self-management education and empowerment in an integrated environment that includes both clinical and community support.ⁱ

i. Catton, P. (2008). Cancer survivorship research: Improving health, health care services and the health care system. In *Identifying priorities for cancer survivorship research: Proceedings of a pan-Canadian invitational workshop*, November 22–23, 2008. Vancouver, BC. Retrieved from <http://www.bccancer.bc.ca/NR/rdonlyres/E6F649B9-761C-4C51-89E0-C2F0834B8DCC/43097/CancerSurvivorshippriorities.pdf>

GROUNDING SELF-MANAGEMENT SUPPORT IN PRIMARY HEALTH CARE

Some provinces have developed comprehensive approaches to self-management support, as part of their broad (rather than disease-specific) strategies and policies on chronic disease. In this report we highlight the efforts of two provinces—Alberta and British Columbia—that feature primary health care prominently in their approach. (See sidebars, *British Columbia’s strategy* and *Alberta’s strategy*.) Other Canadian jurisdictions are also beginning to emphasize self-management support such as Ontario’s Self-Management Initiative, an investment in education and training for people with diabetes and their health care providers.

More generally, jurisdictions are piloting a variety of funding models, incentives, and quality improvement initiatives directed at primary health care providers to foster better management of chronic disease and improve access to care. A full discussion of these approaches is beyond the scope of this report, but one example is the use of “collaboratives.” Collaboratives bring together groups of health care professionals to develop solutions to challenges in specific areas of care, such as improving outcomes for patients with congestive heart failure or other chronic diseases. Collaboratives in the US have achieved positive results—for example, reducing hospitalizations by 50% among patients with congestive heart failure.⁹⁹

In Canada, collaboratives have been organized, supported, and funded by ministries of health or health quality organizations in a number of provinces to support the redesign of primary health care practice, often with a focus on improving chronic disease management. Organizations such as the Saskatchewan Health Quality Council,¹⁰⁰ Health Quality Ontario¹⁰¹ and Alberta AIM (the acronym stands for Access Improvement Measures)¹⁰² have spearheaded such initiatives.

Seen through the lens of the Expanded Chronic Care Model, collaboratives can be considered a multi-faceted approach to improving self-management support, since participants might receive training in methods to help them communicate better with patients, while also improving their clinical information systems (e.g., electronic medical

records) and trying out changes in the organization of care (e.g., the transition to team-based care or the use of shared medical appointments).⁷⁷ Associated supports include “practice facilitation,” in which primary health care providers receive hands-on support from a quality improvement coach or facilitator as they plan, test, and evaluate changes in the organization of care or use of clinical practice guidelines.^{103, 104}

MEASURING THE IMPACT OF SELF-MANAGEMENT SUPPORTS

Researchers have been trying to develop measurement frameworks and better health indicators to evaluate self-management supports more systematically, so that the performance of various interventions can be compared in a standardized way.

One result is a new indicator called “the patient activation measure,” which captures patients’ sense of their own confidence, knowledge, and ability to take action to maintain and improve their health.¹⁰⁵ BC has started to investigate the patient activation measure as one of several performance measures for self-management support programs in that province.⁶⁷ While the measure has been tested for its validity,¹⁰⁵ there are emerging issues about its use to compare ethnic and language groups.¹⁰⁶

An evaluation framework known as RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) has been employed in a wide range of health care studies to standardize the reporting of results and synthesize findings from various sources.¹⁰⁷ RE-AIM is often used to evaluate self-management support interventions, as well as to translate evidence into practice.¹⁰⁸ It could also provide the basis for a coordinated, cross-Canada approach to evaluating self-management support initiatives so that jurisdictions can learn from one another and build a stronger evidence base.

British Columbia's strategy

BC is developing the **Stepped Care for Self-Management Support: A Health Care Intervention** framework to integrate the various self-management support interventions emerging throughout the province. The plan is based on similar work done by the US Indian Health Service, with input from a BC Ministry of Health committee called "Integrated Primary and Community Care: Patients as Partners." The draft framework (Figure 3) has four levels that build progressively, from fundamental components of care and support that all patients with chronic conditions need to more advanced approaches for patients with more complex challenges:

- The foundation level focuses on honouring patients' culture, promoting health literacy, and fostering active self-management.
- The second level focuses on the use of core techniques that support behavioural change to help patients become successful self-managers.
- The third level captures advanced approaches that primary health care practices can use (e.g., motivational interviewing, case management, problem-solving therapy, shared medical appointments).

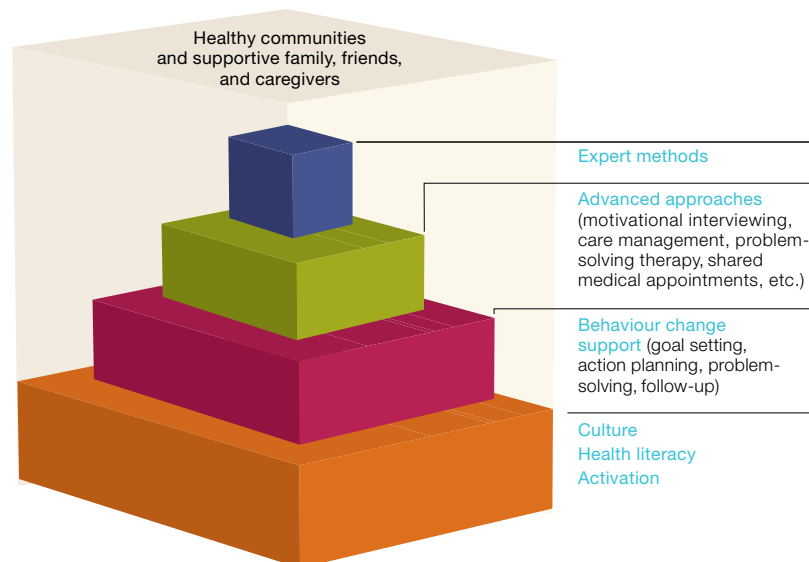
- The fourth level involves advanced training in self-management support for primary health care providers and access to specialty expertise (e.g., mental health specialists) to meet the needs of patients with more complex conditions.ⁱ

The framework is being developed to help the province deliver self-management support in a more systematic way and to help residents and health care providers understand the spectrum of methods and approaches available for patients at different stages or complexity of disease and with different desires and levels of readiness to participate.ⁱⁱ

i. British Columbia Ministry of Health. Personal communication, November 7, 2011.

ii. British Columbia Ministry of Health. (2011, October). Patients as partners: the key to health system transformation. Presentation session to the Health Council of Canada's National Symposium on Patient Engagement, Toronto.

FIGURE 3
British Columbia Draft Framework—Stepped Care for Self-Management Support: A Health Care Intervention



Source: BC Ministry of Health, 2011. Adapted with permission.

CURRICULA FOR THE EDUCATION OF HEALTH CARE PROFESSIONALS

Health leaders in several countries—such as Canada,¹³ the United States¹⁸ and Australia⁷⁹—have noted that the design of post-secondary curricula for health care professionals has a role to play in optimizing outcomes for people with chronic conditions. Health care professionals initially develop their core competencies, including those related to self-management support, during their pre-licensure education.

International examples of system-level strategies

Chronic disease is a global health problem. Canada is by no means the only country faced with the challenge of identifying the most effective ways to promote self-management support. We can—and are—learning from other countries' strategic approaches to making self-management support a focus for primary health care.

UNITED KINGDOM: INTEGRATED APPROACHES

Co-creating Health is a three-pronged initiative that integrates self-management education for patients, advanced training in self-management support for clinicians, and a process improvement initiative for primary health care.¹⁰⁹ To learn more, read our “emerging practice” feature, page 36.

Also being tested in the UK is a similar model called WISE (Whole System Informing Self-Management Engagement), which attempts to engage a health system to implement changes so that:

- patients can make better use of self-management support;
- primary health care providers can provide better self-management support; and
- the health care system can improve access to self-management support options.

The WISE model was developed by a team at the University of Manchester and is being implemented and evaluated in primary health care settings in England.¹¹⁰

A government-led initiative in Wales, developed in 2009, is the Framework for Supported Self Care.¹¹¹ It makes recommendations about how to coordinate services across the system to support self-management. Four key elements are skills training, peer support networks, assistive technology, and information.

AUSTRALIA: QUEENSLAND FRAMEWORK FOR SELF-MANAGEMENT

The Australian state of Queensland developed its Framework for Self-Management 2008–2015 as part of a 10-year chronic disease strategy to inform government investments in self-management support and to contribute to a shared vision and common language for the various sectors involved in supporting people with chronic disease. The framework targets four chronic disease groups, selected risk factors, and selected populations, including Aboriginal peoples, people from culturally and linguistically diverse backgrounds, people in low socioeconomic circumstances, and people from rural and remote areas. Various aspects of the framework are being evaluated.¹¹² To learn more, see “Chronic disease/Strengthening the system/Supporting self-management” on the Government of Queensland’s website (health.qld.gov.au).

Alberta's strategy

Strengthening the ability of primary health care teams to promote and deliver self-management support is an objective under Alberta's goal of *Building a Primary Care Foundation*, part of the Alberta Health Services 2011–2015 Health Plan.ⁱ The plan calls for the consistent implementation of evidence-based, self-management tools in primary health care and across the continuum of care. Some examples of initiatives are:

- Consolidating the province-wide delivery of the Stanford Chronic Disease Self-Management Program (CDSMP) under the trademarked name "Better Choices, Better Health" (launched in fall 2011). Leader training has enabled program delivery in more than 60 communities, in a variety of languages (e.g., French, Punjabi, Chinese) where numbers warrant.
- Leading a pilot of the online CDSMP in 2010, involving 270 Canadians. Research results will be available from Stanford University in December 2012. Based on preliminary data, Alberta is exploring ways to offer an online version of Better Choices, Better Health across the province.^{ii, iii}
- Launching a health portal (Myhealth.Alberta.ca), with information on more than 8,000 health topics including how to access self-management support programs in Alberta. In the future, the portal will evolve into a tool where individuals can enter personal health information (e.g., blood pressure readings) and receive personalized self-management tips, make appointments, request prescription renewals, and consult with physicians and other health professionals.^{iv}
- Increasing the ability of health care providers to support patient self-management through a variety of training opportunities. These include the Choices and Changes course, CDM 101 online (an introduction to chronic disease management and self-management support), and other online modules covering cultural diversity, health coaching, and motivational interviewing.^v

i. Alberta Health Services. (2011). *Alberta Health Services 2011–2015 Health Plan*. Edmonton: AHS. Retrieved from <http://www.albertahealthservices.ca/3238.asp>

ii. Alberta Health Services (2011, September 26). Chronic disease self-management program launches today. [Press release]. Retrieved from <http://www.albertahealthservices.ca/5785.asp>

iii. Alberta Health Services. Personal communication, January 24–25, 2012.

iv. Alberta Health Services. (2011, May). MyHealth: Alberta's newest health tool. *Apple Magazine*. Retrieved from <http://www.albertahealthservices.ca/apple/4571.asp>

GLOBAL: BUILDING BRIDGES—AN INTERNATIONAL FRAMEWORK FOR CHRONIC CONDITION SELF-MANAGEMENT SUPPORT

An international roundtable in 2009—with participants from Canada, Australia, New Zealand, the UK and the US—developed a framework in hopes of influencing policy, practice, and research in self-management support. The framework has two main goals: to promote the development and evaluation of effective interventions and support mechanisms that will enable the delivery of self-management support, and to encourage the integration of initiatives into health, social, and community settings. The roundtable group identified seven areas of strategic direction:

- Involve consumers;
- Expand services;
- Advance evidence;
- Improve quality;
- Strengthen linkages;
- Strengthen multi-sector commitment;
- Build infrastructure.

The roundtable also produced sample tactics to support these strategic directions and promote development at the local level.^{113, 114}

Long-term strategies needed

Researchers have indicated that a commitment to self-management support calls for policy that includes a long-term strategy, promotes programs to build skills for providers and patients, and aligns funding to ensure that primary health care services match what patients want and need. In this section, we looked briefly at the key types of policy interventions being used to promote self-management support in Canada and internationally, including some that are grounded in primary health care and some that involve more wide-ranging approaches.

Strategies that address the broader determinants of health are also important to improve and sustain people's capacity for self-management, although a discussion of specific approaches is outside the scope of this report. The Health Council of Canada discussed government strategies to reduce health inequities in its 2010 report, *Stepping It Up: Moving the Focus from Health Care in Canada to a Healthier Canada*.

“Patients ... often fail because the larger deck—their physical and social environment—is stacked against them ... A woman living in a crime-infested neighborhood lacking healthy food outlets [and other barriers] ... would have great difficulty controlling her diabetes no matter how perfectly the health care team manages the disease and teaches her the knowledge and skills needed for diabetes control.”

Moskowitz, D. & Bodenheimer, T. (2011). From evidence-based medicine to evidence-based health: The example of asthma. *Preventing Chronic Disease*, 8(6), A151. Adapted.

EMERGING PRACTICE***Co-creating Health: An integrated approach to self-management support**

In the UK, a patient self-management course called the Expert Patients Programme (a version of the Stanford Chronic Disease Self-Management Program profiled on page 18) had been widely delivered for some years. But the program was achieving only modest results.

With chronic conditions consuming an estimated two-thirds of all health care spending in the UK,¹⁰⁹ the Health Foundation—an independent non-profit organization dedicated to improving health care in Britain—began to examine how best to improve the lives of people living with chronic conditions while promoting the efficient use of National Health Service resources.

WHAT WAS THE BOLD IDEA?

The reviewers concluded that “self-management courses alone are of limited effectiveness if they are isolated from mainstream health services. Self-management support requires a whole-system approach.”¹¹⁵ The foundation’s answer was Co-creating Health—an ambitious, large-scale demonstration program with more than £7.5 million invested to date. The initiative aims to embed self-management support within mainstream health services across the UK by transforming the patient-provider relationship.¹⁰⁹

Drawing on the integrated approach depicted in the Expanded Chronic Care Model (page 10), Co-creating Health began in 2007 with local primary health care and specialist services in eight communities. Each site focuses on one of four conditions—diabetes, depression, COPD, or musculoskeletal pain—and participates in all three streams of the program:

- **Creating engaged, informed patients.** Patients take a seven-week course that develops knowledge and skills for self-management, as other courses do, but this one puts added emphasis on helping patients work effectively with health care providers. Courses are co-led by a patient and a health care professional, which gives participants a model of a patient-provider partnership.
- **Training clinicians in self-management support.** Health care teams take a multi-faceted program of training, including workshops, web-based learning, coaching and support, and “action learning,” in which they practice and get feedback from patients on the clinicians’ self-management support skills. Here, too, patients are co-trainers along with local clinicians. The course focuses on three “enablers” that are common to many models of self-management support—agenda setting (visits start with a collaborative question like “What do you want us to do today?”), goal setting (patients and clinicians agree on specific actions to address their concerns), and follow-up (someone from the clinic contacts the patient within 14 days to check progress on the patient’s goals).

- **Promoting system improvements.** Teams of patients and health care providers work together to identify and implement new approaches to service delivery—with the goal of removing any barriers to the effective partnership they are trying to create. One clinic decided to send the results of routine blood tests to diabetes patients ahead of their visits, so that patients come to the consultation informed and ready to discuss their priorities.

Although each of the three streams of this strategy is being used in Canada, what is innovative about the UK Co-creating Health initiative is its systematic linkage through primary health care: clinicians refer patients to the community-based, self-management education course, patients are engaged in process redesign with their primary health care providers, and their providers receive advanced training in communication tools and techniques to support the self-management process.¹¹⁵

IS IT MAKING A DIFFERENCE?

Results from an independent evaluation of the first phase of Co-creating Health suggest that the initiative's approach holds promise. The evaluation showed improvements to patient quality of life, activation and some condition-specific outcomes. In addition, health care professionals improved their use of three specific self-management support tools: setting an agenda for change, establishing behavioural goals for change, and goal follow-up. However, the evidence for improved use of a wider range of self-management support skills in clinician

practice was weak. There were also benefits to joint facilitation of all training courses by clinicians and people with chronic conditions.

The evaluation also presents recommendations to support a more broad implementation and integration of self-management support programs. The evaluation, however, was constrained by the inability to evaluate the impact of the initiative's integrated approach.

Phase 2 of the initiative has been designed to spread the Co-creating Health model to a wider population and to help the demonstration sites sustain their improvements through ongoing commitment from local authorities and providers. The phase 2 interventions reflect some of the lessons from the phase 1 evaluation, such as: creating a revised and updated clinician development program, and producing a change package to support service redesign around self-management support.¹¹⁶

FOR MORE INFORMATION

- on Co-creating Health, see The Health Foundation website and their Self-Management Support Resource Centre for health care providers and policy-makers (health.org.uk).

* The Health Council of Canada has established criteria to categorize innovative practices as emerging, promising, or leading (healthcouncilcanada.ca/innovativepractices).

5

Section Five

Internet-based self-management supports: Promise and pitfalls



“Smartphones are one of the key ways we’re going to get health information to people ... It’s already happening.”

Susan Frampton, president of Planetree*

Self-management support? There’s an app for that.

The explosive growth of online interaction through websites and social networking provides new opportunities for people with chronic conditions to share information and promote self-management among themselves and with health care providers.

But is the Internet just another communications channel? Or does it add new dimensions to self-management support, with potential to help people in ways that traditional approaches do not?

To better understand current thinking about the benefits and risks—the promise and pitfalls—of using the Internet as a medium for self-management support, we reviewed the topic both through commissioned work and our own information gathering. This section, which captures key findings from our review, has implications for the three streams of self-management support that we explored in Sections 2 to 4 of this report.

The promise

Canadians are already online and looking for health information. Health-related searches rank seventh among the top reasons Canadians use the Internet.¹¹⁷ Increasingly, the goal of those searches is to find help in managing

chronic disease. For example, the relative proportion of Canadians searching online for “diabetes app” jumped dramatically in recent years (Figure 4). But “the jury is still out in terms of how successful these self-monitoring apps are,” one stakeholder advised.

Mobile technology has potential to integrate self-management supports seamlessly into daily life.

Smartphone software that not only reminds patients about self-monitoring tasks but also sends the results directly to their medical team has seen some promising early results in Canadian clinical trials. Teenagers with diabetes checked their blood sugar more frequently (and were rewarded with iTunes store credits) when they used the “Bant” app developed by the Centre for Global eHealth Innovation at Toronto’s University Health Network (UHN).¹¹⁸ In another UHN trial, adults with diabetes and hypertension did better at controlling their blood pressure when they could send the results of regular self-monitoring directly to their family doctor wirelessly via mobile phone and a Bluetooth-enabled monitoring device.¹¹⁹

And age is not necessarily a barrier to using technology. A US study of older adults with moderate to severe chronic obstructive pulmonary disease compared an in-person program promoting exercise to reduce breathing difficulties

*Planetree is a US-based health care improvement organization, speaking at the Health Council of Canada’s National Symposium on Patient Engagement, October 2011.

with an Internet-based one that had participants using a hand-held device to record their daily exercise and symptoms. The study found that both approaches were equally effective in this population.¹²⁰

Online self-management resources and programs hold several inherent advantages. Many disease associations and governments host health information websites that include interactive self-management tools. (Figure 5 shows a Canadian e-tool.) In addition, online and telehealth versions of group programs for self-management education are becoming increasingly available or are being pilot-tested in Canada, and they seem to offer a number of benefits. Patients can control when and where they participate, and the technology can overcome isolation due to distance, weather, physical disability, family responsibilities, or discomfort with meeting in groups. Experts are optimistic about the potential of online self-management programs because the technology enables patients to access large amounts of information in a variety of formats, as well as provides opportunities for them to interact with peers and health care professionals.⁴⁴

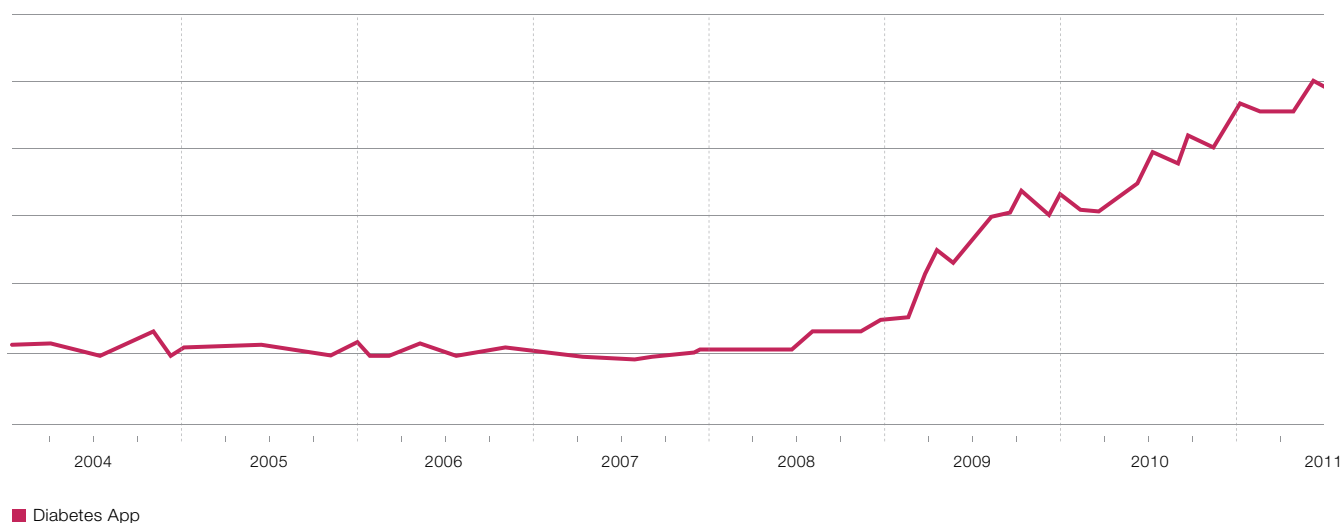
There is some evidence that online programs show promise for improving self-efficacy, health behaviours,¹²¹ and clinical outcomes.¹²² Having a live person easily reachable to answer questions and interact with through a website seems to be important in sustaining participation.²⁰

Beyond structured programs, online interactions can provide emotional support and information exchange.

Peer support and patient discussion forums are the focus of many online communities that are relevant to self-management support.²⁰ Some examples of forums with high uptake and sustained usage among people with a specific chronic condition include:

- Six Until Me (sixuntilme.com)—a popular blog by a diabetes patient and platform for story-telling and peer support among people with diabetes.
- RA Chicks (facebook.com/RACHicks)—a Facebook page for women with rheumatoid arthritis; it features pain-management strategies, stories and education about different kinds of arthritis, and references and links to evidence-based resources.
- Men and Health: It's a Guy Thing (itsaguythingblog.wordpress.com)—an online forum for men to share stories and strategies about dealing with depression, a condition still surrounded by stigma and often associated with other chronic conditions.
- Two popular peer-to-peer online communities for people with cardiovascular disease: the blog-site Pizaazz—Healthcare News & More (pizaazz.com) and Heart Disease News, Articles & Information (healthhubs.net/heartdisease), which posts links to academic research. Like other popular peer forums in this area, these sites appear to be sensitive to the reality of co-morbidities for many people with cardiovascular conditions.

FIGURE 4
Relative Proportion of Canadian Google Users Searching for “Diabetes App”: 2004 to 2011



The Internet opens doors to information and peer support that would otherwise be impossible to access without technology, especially for people with relatively rare chronic conditions. Online (and telephone) support from peers is also seen as a promising substitute when patients lack family members or friends nearby who could provide the social support that appears to be critical for successful self-management.³³ A variety of organizations are using social networks to promote self-management and patient engagement. Examples include the online communities PatientsLikeMe.com, e-patients.net, and the Society for Participatory Medicine (participatorymedicine.org).¹²³

Patient/provider portals are another emerging innovation in self-management support. Health portals are websites that may also provide secure online access to personal health records, linking patients and health care providers so they can make appointments, share test results and communicate electronically. For example, Kaiser Permanente's HealthConnect patient web portal (kaiserpermanente.org) has attracted interest in Canada.¹³

Canadian health portals and personal health records are in various stages of development and include:

- MyChart from Sunnybrook Health Sciences Centre in Ontario (sunnybrook.ca);
- Unani.ca from McGill University Health Centre in Quebec;
- MyHealth Alberta (myhealth.alberta.ca);
- Mydoctor.ca Health Portal operated by MD Physician Services, a subsidiary of the Canadian Medical Association;
- Mihealth, a made-in-Canada application designed for family practices, piloted in northern Ontario and now targeted for expansion to wider geographic markets (mihealth.com)
- MyOSCAR, a free, open-source personal health record software developed by McMaster University (myoscar.org); and
- New Brunswick Chronic Disease Self-Management Portal (<https://santenb.nbhealth.ca>).

These resources do not provide the kind of deliberate skill-building support that a structured program does, but they have potential to empower patients and enhance the patient-provider partnership by giving patients equal access to their health data.

FIGURE 5
Online Action Plan Tool for Canadians
with High Blood Pressure

The screenshot shows the 'My Blood Pressure Action Plan' website. At the top left is the 'Heart & Stroke ACTION PLAN' logo. The main title is 'My Blood Pressure Action Plan™' with a 'Sign in' link. A 'Welcome' message states: 'My Blood Pressure Action Plan can help you manage and control your blood pressure by offering useful information and easy-to-use tools.' Below this, it lists 'Some of the tools available include:':

- My Tracker:** Set goals and keep track of your blood pressure readings.
- My Medications:** Track your medication and get reminders about renewing prescriptions.
- My Appointments:** Schedule and manage upcoming appointments and activities.
- Learning and Lifestyle:** Access more than 50 articles written by the Foundation's experts.

There is also a section for 'Choose your preferred companion' with two profile pictures. At the bottom, a blue box asks 'Ready to give it a try?' and provides the text: 'My Blood Pressure Action Plan™ is free, confidential and simple to use, so why not register today?' with a yellow 'Register now' button.

Source: Heart and Stroke Foundation of Canada, 2012. heartandstroke.ca. Reproduced with permission.

The pitfalls

Despite their considerable promise, the proliferation of Internet-based self-management supports is also raising a number of concerns.

A socioeconomic “digital divide” might widen health inequities. People with lower incomes and less education are more likely to have chronic conditions, and they are also less likely to have access to, and comfort with, using computers. Although Internet use continues to expand across Canada, a 2010 Statistics Canada study found that close to 60% of Canadians in the poorest households (annual income of \$30,000 or less) used the Internet, compared to 94% of the wealthiest households (with incomes of more than \$87,000 a year).¹¹⁷ Living in a smaller community (under 10,000 people) and not having any post-secondary education are also associated with lower Internet use.¹²⁴ However, a recent US study found that people with a chronic disease were less likely to have Internet access than people without chronic health problems (64% versus 81%), but that once online they were just as likely to look for health information as Internet users with no chronic conditions.¹²⁵

These disparities suggest that financial and other barriers may prevent online self-management supports from reaching many of the people who need them. Sustained use of online self-management programs is highest among better-educated and higher-income patients, and a variety of incentives are being tested to engage disadvantaged participants and maintain their involvement.²⁰

Chronic conditions can prevent some people from effectively using the Internet. Cognitive decline and certain physical disabilities, such as chronic pain, can create barriers to using computers and engaging online.¹²⁵ (These conditions can also prevent patients from accessing in-person forms of self-management support). In this context, some online self-management programs struggle to retain participants; dropout rates are a concern across a number of conditions that we looked at—arthritis, cardiovascular disease,²⁰ and diabetes.¹²⁶

“Today I became the 24th member of the National Sarcoidosis Organization ... If only their website had existed in 1993, I would have been spared a lot of anxiety and uncertainty.”

Dave W., a patient advocate, New Brunswick

Most online self-management supports are not integrated with primary health care. Much like “offline” programs and resources, relatively few Internet-based self-management supports are integrated with patients’ usual primary health care, according to our key informant interviews. Exceptions are those that explicitly link patients and providers, such as the patient/provider portals and the trials of self-monitoring via smartphone described on page 39. However, clinicians may be reluctant to refer their patients to online tools without stronger evidence about their effectiveness or about the barriers that prevent patients from using them and ways to overcome those barriers. In addition, concerns about security of personal information and about the credibility of information from Internet sources makes some people reluctant to communicate online about their health.

Thumbs up or down?

It is still early days in the evolution of online tools for self-management of a chronic condition. As more and more of our world moves online, it seems inevitable that health-related activity will follow. Many creative ideas are being tried and tested with great promise, but researchers and policy-makers will need to be as nimble and imaginative as the technology itself.

Questions and concerns persist. For example, once the research is over, who will pay for smartphones and data plans for patients who could not afford to use them as self-management tools? How can we ensure that the technology truly enhances communication between patients and primary health care providers, rather than creating a virtual world where health care interactions are dehumanized?

For now, the prudent advice is not to assume that the Internet is the entire answer to delivering self-management support to everyone who needs it, but to continue to explore its potential while ensuring that vulnerable groups do not get left behind.

“In the ideal world, physicians would provide every patient with ‘here are the most reliable websites that I have personally reviewed related to this illness’ and ‘here are social media sites that you can also benefit from.’ Things that are recommended by the provider would have a bigger impact.”

John Sharp, Manager, Research Informatics, Quantitative Health Sciences, Cleveland Clinic, Cleveland, Ohio

Conclusions and recommendations

Faced with growing numbers of people living (and living longer) with chronic conditions, health care systems around the world are struggling with how best to respond. Canada is no exception. Undoubtedly, self-management supports should be a key component of any system's comprehensive plan to tackle the challenge of chronic disease.

At the same time, defining the recipe for success in self-management support remains a complex and evolving field. A number of well-established group programs seem to work well for some people but many other patients are falling through the cracks. The underserved are patients with low incomes, less education, or more complex disease, and people who are unable to join a group program, or who don't know about or have access to an appropriate resource in their community. It's also widely recognized that primary health care providers should be an ongoing source of self-management support, but this role is not yet a routine part of primary health care delivery in Canada.

In this report, we've highlighted a range of innovative approaches to group and individual interventions that are emerging to fill these gaps. The challenge now is how to build effectively on the current efforts and investments.

Recommendations

Governments across Canada have made forays into building self-management support into their chronic disease strategies. Most also fund community-based self-management programs. Some governments have gone further: they are beginning to integrate information and tools for self-management support into primary health care and to embed the principles of self-management support across their health systems. Reflecting on the definition at the top of this page, **we recommend that all health care systems across Canada move actively to provide self-management supports in a more systematic way.**

We encourage governments, health care providers, and chronic disease organizations to collaborate further and integrate their initiatives to reduce duplication, fill gaps in services, support continued research and evaluation, and learn from one another and from the patients and caregivers they serve. We make the following recommendations:

1) CREATE AN INTEGRATED, SYSTEM-WIDE APPROACH TO SELF-MANAGEMENT SUPPORT.

Current policies and strategies related to chronic disease prevention and management vary across the country. While some provinces and territories provide leadership in promoting and delivering self-management programs, what is needed in many parts of the country are efforts to reduce fragmentation and improve coordination between health care agencies and community organizations in a given geographic area.

At the same time, we don't know enough yet about the impact of specific components of online or in-person programs, or about the kind of ongoing support that will best help patients sustain their improvements long after an initial intervention has ended. Therefore, it's also critical that governments invest in an integrated approach to build the evidence base for chronic disease management. They will need to:

- Measure continued progress on the development, delivery, and uptake of self-management support, with links to health system performance objectives, indicators, and targets.
- Learn from promising models that aim to improve the reach and outcomes of public investments in self-management support, including initiatives using new technology.
- Support continued evaluation research and construct a national framework for evaluation of self-management support programs, in order to provide more standardized information on the impact of programs, including their cost-effectiveness, from a system-wide perspective.

2) ENABLE PRIMARY HEALTH CARE PROVIDERS TO DELIVER SELF-MANAGEMENT SUPPORT AS A ROUTINE PART OF CARE, ACCORDING TO PATIENTS' NEEDS.

Too often, primary health care is a missing link in what should be the systematic delivery of self-management support. In some cases, front-line providers are not aware of the programs we described in Section 2, and too few are delivering the kind of supports we described in Section 3, despite the range of promising models available.

Health ministries, regional health authorities, professional associations, and educational institutions can help forge that link in a number of ways:

- Invest in basic and ongoing education for providers in self-management support, including specific techniques they can apply in their practice. Given the growing importance of chronic disease in Canada, training to build competencies in self-management support should be embedded in curricula and continuing education for nursing, medicine, and other health care professions.
- Encourage the expansion of primary health care teams, which have been shown to improve the quality of care for patients with chronic conditions. Continued policy support for quality improvement initiatives and appropriate funding models can help achieve these changes and ensure that all team members are skilled in delivering self-management support. As well, continued research and evaluation of strategies for clinicians to foster self-management and engage patients should be supported.

- Facilitate the delivery of multi-faceted interventions in primary health care—in which self-management support is complemented by case management, medication management, care coordination, and other components—to meet the greater needs of people with complex and multiple chronic conditions. Nurses and other non-physician health professionals can provide many of these additional services, and practices may need to stratify groups of patients by disease severity or risk levels so that busy teams can effectively target their multi-faceted interventions.
- Create better linkages between primary health care providers and community-based self-management support programs. Some provinces are developing online portals where patients, caregivers and service providers will not only be able to get information about local resources but also, as the systems evolve, be able to communicate personal health information securely.

3) BROADEN AND DEEPEN EFFORTS TO REACH MORE CANADIANS WHO CAN BENEFIT FROM SELF-MANAGEMENT SUPPORTS.

A one-size-fits-all approach will not work because of the diversity of social and personal circumstances and disease-related challenges that patients and caregivers bring to their self-management efforts, and because of the diversity of client groups and settings in which self-management support is delivered across Canada. More specifically:

- Build on existing programs that have shown good outcomes, but also try new approaches, including one-to-one supports and multi-faceted interventions for people with multiple chronic conditions. Multi-faceted approaches combine more advanced support such as case management with fundamental self-management support such as goal setting and action planning.
- Make in-person group programs more accessible through cultural or low-literacy adaptations, or by delivering them in a wider range of settings such as workplaces and assisted-living residences.
- Pursue opportunities to provide self-management support online, but don't put all the eggs in the technology basket because that might risk leaving the most vulnerable patients behind. As online services continue to develop, research is needed to provide more evidence about their impact and ensure they are integrated with offline services.
- Target caregivers as a distinct client group, in addition to patients themselves, in all approaches to self-management support.
- Use the power of peers as an important component of self-management support initiatives.

**4) ENGAGE PATIENTS AND INFORMAL CAREGIVERS
AS A KEY PART OF ANY SYSTEMATIC APPROACH.**

Individuals affected by chronic conditions have a personal stake in the quality of the Canadian health care system. Collectively, the system is finally beginning to appreciate the important asset that patients and caregivers represent through their unique perspectives on quality of care.¹²⁷

In closing

We chose to report on self-management support because of its potential to yield big wins on many levels. If patients succeed in self-managing and sustaining their success, they and their families will enjoy a better quality of life. Primary health care providers will have the tools and time to help patients succeed, either by personally guiding them through behaviour-change strategies or by reinforcing what patients have learned in the community-based programs that the clinic has referred them to. Local specialists and hospitals will be able to shift their resources to treat people whose health has worsened, and resources that once went to treating preventable complications can be reinvested in a range of other critical services that support a healthy population.

As a country, we're moving in the right direction. Canada has a strong community of expertise in self-management support, and pockets of innovative and integrated approaches to delivering interventions are emerging. At the same time, there appears to be a lot we can—and should—learn from other countries about the development of national and regional systems of funded, sustainable programs to deliver self-management support for people with chronic conditions. We are confident that primary health care providers will embrace the opportunities provided by these measures to deliver more effective, systematic self-management support for patients with chronic disease. These professionals are a valued source of information for patients in Canada—and the vast majority (95%) of Canadians with multiple chronic conditions have a primary health care provider. Our health care systems need to build on this strong foundation to create a more integrated approach to helping patients with chronic conditions help themselves.

The opportunity to invest in self-management support at the individual and population health levels holds the promise of big dividends in improving the health of Canadians and the sustainability of our health care system. Let's seize this opportunity now.

Appendix A. Resources

A1. Resources for patients and caregivers

A sample of resources related to self-management support programs across Canada, as well as some examples of online tools for patients offered by provinces and disease-specific organizations. See also Appendices B–D for examples

of programs and strategies in each province and territory. More web-based resources (peer support communities and patient discussion forums) are listed in Section 5.

ORGANIZATION/RESOURCE	DESCRIPTION	LINK
Health Canada—Inventory of Chronic Disease Management Programs in Canada	An inventory describing the range of chronic disease management programs across Canada, with a focus on diabetes, hypertension, congestive heart failure, asthma/chronic obstructive pulmonary disease, arthritis, and depression.	Forthcoming
Heart and Stroke Foundation of Canada—eTools	Tools include a risk assessment tool that generates a customized report; action planning tools for controlling blood pressure (Figure 5, page 41) and achieving or maintaining a healthy weight; and an email support program that generates personalized emails with health tips and lifestyle changes based on an individual's risk assessment results.	heartandstroke.ca/ehealth
Canadian Diabetes Association—Diabetes and You	Resources include a video and downloadable checklist to help patients prepare for a diabetes-focused visit with their physician or other primary health care provider.	diabetes.ca
The Arthritis Society	Programs include, for example, an arthritis self-management education program and a chronic pain management workshop.	arthritis.ca
Canadian Lung Association	Resources include a national telephone hotline run by the BREATHWORKS National COPD Program, and information for people with asthma and their families such as a searchable database of asthma support programs.	lung.ca
The Asthma Society of Canada	Resources include an interactive e-learning module ("Taking Control of Your Asthma") and a template to develop a personalized Asthma Action Plan.	asthma.ca

A2. Resources for primary health care providers

A sample of toolkits, training opportunities, and other resources to help primary health care providers offer self-management support.

Toolkits

ORGANIZATION/RESOURCE	DESCRIPTION	LINK
Partnering in Self-Management Support: A Toolkit for Clinicians	Information and tools to introduce busy clinical practices to a set of activities that support patients and their families in the day-to-day management of chronic conditions.	improvingchroniccare.org
Alberta Health Services—Self-Management and Complex Care Planning Workbook	Designed to help family physicians and their teams incorporate self-management principles into care planning with their patients. The workbook aligns with Alberta's comprehensive annual care plan template for family physicians and can be adapted for use with other care plan templates.	albertahealthservices.ca
South West Self-Management Program (Ontario)—Self-Management Toolkit: A Resource for Health Care Providers	Three online modules for health care providers to learn the basics of self-management support and get started helping their patients become better self-managers.	swselfmanagement.ca
The College of Family Physicians of Canada—Primary Care Toolkit for Family Physicians	The "continuity of care" section of this toolkit includes an overview of chronic disease management.	toolkit.cfpc.ca

Toolkits (Cont'd)

ORGANIZATION/RESOURCE	DESCRIPTION	LINK
Registered Nurses' Association of Ontario—Strategies to Support Self-Management in Chronic Conditions: Collaboration with Clients, Nursing Best Practice Guideline	Provides evidence-based recommendations for registered nurses and registered practical nurses in self-management support across the continuum of care.	rnao.org
Group Health Cooperative—Group Visit Starter Kit	Step-by-step instructions on how to run <i>shared medical appointments</i> in primary health care.	improvingchroniccare.org
Canadian Diabetes Association—Best and Promising Practices in Diabetes Education	Identifies programs such as the MicoHealth Internet Diabetes Management Program. The CDA website also links to the association's tool kit and searchable database of clinical practice guidelines for diabetes care.	diabetes.ca/bestpractices
Canadian Public Health Association—Health Literacy Portal	This portal is targeted at health professionals, researchers, and interested individuals. It features the final report of the Canadian Expert Panel on Health Literacy as well as links to other health literacy resources.	cpha.ca
American Medical Association—Physician Resource Guide to Patient Self-Management Support	Links to many resources, including tip sheets and work sheets to help physicians support their patient to make healthy behavioral changes.	ama-assn.org

Training and self-assessment

ORGANIZATION/RESOURCE	DESCRIPTION	LINK
Institute for Healthcare Communication Canada—Choices and Changes Course	An online training resource for health care providers about the literature, theory, and techniques for promoting change in health behaviour, including a focus on patient motivation. This non-profit institute is sponsored by the College of Family Physicians of Canada, the Canadian Cancer Society, and Cancer Care Ontario.	ihcc.ca
Institute for Optimizing Health Outcomes (IOHO)—Health Coaching Training and Certification Program	A two-day workshop provides an overview of health coaching principles and skills, tools, and techniques. For certification, trainees participate in the Community of Practice for 12 months. Other training includes planning for integrating health coaching into health care delivery, among other topics.	optimizinghealth.org
Primary Care Resources & Supports for Chronic Disease Self-Management	A collection of quality improvement tools designed to help health care teams improve self-management support.	improveselfmanagement.org

Other resources for primary health care providers

ORGANIZATION/RESOURCE	DESCRIPTION	LINK
International Research Community on Multimorbidity	A virtual community that brings together researchers and health care professionals studying multimorbidity in primary health care. Hosted by the Université de Sherbrooke, Quebec.	usherbrooke.ca
Primary Care Insight	A quarterly e-newsletter for primary health care leaders, highlighting innovations in primary health care delivery and links to references and tools, and an online forum.	primarycareprogress.org

A3. Resources for policy-makers

A sample of resources for policy-makers and others wanting to learn more about self-management support at a system level.

ORGANIZATION/RESOURCE	DESCRIPTION	LINK
British Columbia Ministry of Health—Self-Management Support: A Healthcare Intervention	A report on BC's 10-year journey of actively supporting self-management, including an explanation of self-management support, how it is delivered and evaluated in BC, and the types of training undertaken by health professionals.	coag.uvic.ca
Respiratory Resources Canada	An open database providing brief descriptions of programs, projects, and initiatives across Canada to help the respiratory health community collaborate and increase its collective knowledge.	lunghealthframework.ca
The Health Foundation—Self-Management Support Resource Centre	Resources for policy-makers and health care providers to help promote and enable the delivery of self-management support, including a business case for self-management support, and videos and reports related to the Co-creating Health initiative.	health.org.uk
Observatory of Innovative Practices for Complex Chronic Disease Management—When People Live with Multiple Chronic Diseases: A Collaborative Approach to an Emerging Global Challenge	An interactive book designed to facilitate global collaboration to distill the best available knowledge on how to meet the challenges faced by people living with multiple chronic diseases. The book evolves as readers contribute to it.	opimec.org
New Zealand Health Navigator: Self-Management Support Toolkit	An online toolkit for health care providers and policy-makers.	healthnavigator.org.nz

Appendix B. Examples of Stanford Model Chronic Disease Self-Management Programs (CDSMP) in Canada

JURISDICTION	PROGRAM TITLE	PROGRAM TYPE
BRITISH COLUMBIA	Chronic Disease Self-Management Program	Generic
	Online Chronic Disease Self-Management Program	Online, generic
	Arthritis/Fibromyalgia Self-Management Program	Disease-specific
	Chronic Pain Self-Management Program	Disease-specific
	Diabetes Self-Management Program	Disease-specific
ALBERTA	Better Choices, Better Health	Generic and disease-specific, including chronic pain and diabetes
	Healthy Living Canada (online pilot)	Online, generic
SASKATCHEWAN	Live Well with Chronic Conditions Program	Generic
MANITOBA	Get Better Together	Generic
	Arthritis Self-Management Program	Disease-specific
ONTARIO	Living a Healthy Life with Chronic Conditions	Generic
	Telehealth Chronic Disease Self-Management Program (research pilot)	Telehealth, generic
	Arthritis Self-Management Program	Disease-specific
	Diabetes Self-Management Program	Disease-specific
	Chronic Pain Self-Management Program	Disease-specific
NOVA SCOTIA	Your Way to Wellness	Generic
	Chronic Pain Self-Management Program	Disease-specific
	You're In Charge	Youth, generic
NEW BRUNSWICK	My Choice—My Health	Generic
NEWFOUNDLAND AND LABRADOR	Improving Health My Way	Generic
	Arthritis Self-Management Program	Disease-specific
PRINCE EDWARD ISLAND	Living a Healthy Life	Generic
YUKON	Chronic Disease Self-Management Program	Generic (no longer offered)
NORTHWEST TERRITORIES	Live Well with Chronic Conditions Program	Generic (no longer offered)
NUNAVUT	(Information not available)	

Source: Adapted from Liddy et al., 2011⁷⁷

Note: This table is not intended to be a comprehensive list of self-management support programs available in each province and territory. Health Canada's *Inventory of Chronic Disease Management Programs in Canada* (forthcoming) includes more detailed information about some of these and additional programs.

Appendix C. Examples of self-management support initiatives other than CDSMP in Canada

JURISDICTION	PROGRAM TITLE	TYPE OF SELF-MANAGEMENT SUPPORT (SMS)
BRITISH COLUMBIA	Bounce Back: Reclaim Your Health Program	Depression and anxiety-specific
	Practice Support Program	Physician self-management support training, office redesign
ALBERTA	Integrated Community-Based Programming	Supervised exercising, education (e.g., 1:1 and group dietitian services), self-management; interdisciplinary teams deliver services
	Choices & Changes	Health care provider training in health coaching
	My Health Alberta	Consumer health portal, including self-management support program information
	CDM 101	Provider training: basics of chronic disease management including action planning and goal setting
	Diversity Training	Provider skill development in cultural safety and addressing emotional and cultural needs to support health and self-management of diverse and vulnerable populations
SASKATCHEWAN	Provincial Diabetes Plan	Diabetes self-management education and support
	Saskatchewan Chronic Disease Management Collaborative (Saskatchewan Health Quality Council)	Quality improvement initiative, including aspects of self-management support
MANITOBA	TeleCARE/TéléSOINS Manitoba (heart failure, type 2 diabetes)	Telephone support with self-management components (Monday to Friday, 8 a.m.– 8 p.m.)
	Dial-a-Dietitian	Telephone support for food and nutrition inquiries (Monday to Friday, 8 a.m.– 6 p.m.)
	Health e-Plan	Online health assessment and support tool
	Regional chronic disease and diabetes programs	Generic or disease-specific programs with provider teams incorporating self-management principles
ONTARIO	Primary Care Asthma Program ⁱ	Asthma management training, including self-management concepts
	Peer-to-Peer Support for People with Mental Illness	Peer-support program
	Choices & Changes	Physician training in health coaching
	Arthritis Rehabilitation and Education Program	Personalized assessment and education program
	Diabetes Education Centres	Nurse- and dietitian-led personalized assessment and education specific to diabetes
	Stand Up to Diabetes website (ontario.ca/diabetes)	Online information and self-management tools for patients and providers
	Medscheck for Diabetes	Pharmacist-led education and counselling specific to diabetes

i. To, T., Cicutto, L., Degani, N., McLimont, L., & Beyene, J. (2008). Can a community evidence-based asthma care program improve clinical outcomes? A longitudinal study. *Medical Care*, 46(12), 1257–1266.

Appendix C. (Cont'd)

JURISDICTION	PROGRAM TITLE	TYPE OF SELF-MANAGEMENT SUPPORT (SMS)
NOVA SCOTIA	You're in Charge	Youth self-management program
	Self-Management Support for Health Care Providers	Health care provider oriented education module to raise awareness and simple tools to support patients to self-manage
	Nova Scotia Chronic Pain Initiative	Provincial approach to chronic pain with an embedded chronic pain self-management program
	Health Link 811	24/7 telephone support and advice
NEW BRUNSWICK	TeleCare	24/7 telephone support
	Mindfulness Program	Self-management support for patients
	Chronic Disease Self-Management Portal (https://santenb.nbhealth.ca)	Secure consumer health portal, dedicated to self-management
NEWFOUNDLAND AND LABRADOR	West Coast Asthma Support Group	Peer-support—people living with asthma
	Pilot Programs for COPD, hypertension, and weight management	Programs with self-management components
	Minimal Intervention Training for Health Care Providers	Decision-support/training and education
PRINCE EDWARD ISLAND	Mindfulness-Based Cognitive Therapy for Depression	Depression-specific, self-management support
	Chronic Conditions Support Program	A multi-aspect program for patients and providers, with some elements of SMS
	Diabetes Education Centre	Diabetes education resource
YUKON	Diabetes Education Program	Diabetes-specific education
	Other disease specific programs	Disease-specific programs with elements of self-management including mental health programs
	Community Health Committees	Health priority setting
NORTHWEST TERRITORIES	Chronic Disease Clinics	Primary health care clinic
NUNAVUT	(Information not available)	

Source: Adapted from Liddy et al., 2011⁷⁷

Note: This table is not intended to be a comprehensive list of self-management support programs available in each province and territory. Health Canada's *Inventory of Chronic Disease Management Programs in Canada* (forthcoming) includes more detailed information about some of these and additional programs.

Appendix D. Examples of government strategies, frameworks, and plans relevant to self-management of chronic diseases in Canada

JURISDICTION	DOCUMENT TITLE	LINK
BRITISH COLUMBIA	Expanded Chronic Care Model (2003)	primaryhealthcarebc.ca
	BC Primary Health Care Charter	health.gov.bc.ca/library/publications/year/2007/phc_charter.pdf
	Patients as Partners (2007)	impactbc.ca
ALBERTA	Alberta's model for chronic disease management care (2009)	albertahealthservices.ca
	Vision 2020 (2008)	health.alberta.ca
	Becoming the Best: Alberta's 5-Year Health Action Plan, 2010–2015 (2007)	health.alberta.ca
SASKATCHEWAN	Provincial Diabetes Plan (2004)	health.gov.sk.ca
	Self-Management Support Action Plan (2006)	Not available online
MANITOBA	Self-Management in Primary Care in Manitoba: The Way Forward (2011)	gov.mb.ca/health
ONTARIO	Ontario's Chronic Disease Management and Prevention Framework (2005)	health.gov.on.ca
	Ontario Diabetes Strategy (2008)	health.gov.on.ca
NOVA SCOTIA	Nova Scotia Chronic Disease Prevention Strategy (2003)	gov.ns.ca/health
	Strategy for Positive Aging in Nova Scotia (2005)	gov.ns.ca/health
	Chronic Disease Management Action Plan (2011)	Not available online
	Action Plan for the Organization and Delivery of Chronic Pain Services in Nova Scotia (2006)	gov.ns.ca/health
NEW BRUNSWICK	Chronic Disease Prevention and Management Framework (2010)	gnb.ca
	Comprehensive Diabetes Strategy for New Brunswickers (2011)	gnb.ca
PRINCE EDWARD ISLAND	Healthy Living Strategy (2008)	gov.pe.ca
NEWFOUNDLAND AND LABRADOR	Improving Health Together: A Policy Framework for Chronic Disease Prevention and Management in Newfoundland and Labrador (2011)	health.gov.nl.ca/health
YUKON	Aging Well Strategy (under development)	Not available online
	Chronic Disease Prevention and Management Strategy (under development)	Not available online
NORTHWEST TERRITORIES	Chronic Disease Management Strategy (under development in partnership with the Canadian Health Services Research Foundation)*	Not available online
	Chronic Disease Prevention and Management Framework, based on the Expanded Chronic Care Model (under development)	Not available online
NUNAVUT	Public Health Strategy (2008)	hss.gov.nu.ca
FEDERAL	Canadian Diabetes Strategy (2005)	phac-aspc.gc.ca

Source: Adapted from Liddy et al., 2011⁷⁷

*For more information, see Leith, E., Kirvan, C., Verma, J.Y., Lewis, K., & Robertson, S. (2012). Re-imagining healthcare: The Northwest Territories transitions to an integrated chronic disease management strategy. *Healthcare Quarterly*, 15(1), 19–21.

References

- 1 Health Council of Canada. (2011). *How do sicker Canadians with chronic disease rate the health care system? Results from the 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults, Canadian Health Care Matters, Bulletin 6*. Toronto, ON: Health Council of Canada.
- 2 Fortin, M., Soubhi, H., Hudon, C., Bayliss, E.A., & van den Akker, A.M. (2007). Multimorbidity's many challenges: Time to focus on the needs of this vulnerable and growing population. *British Medical Journal*, *334*, 1016–1017. doi: 10.1136/bmj.39201.463819.2C
- 3 Canadian Nurses Association, The College of Family Physicians of Canada, Canadian Association of University Schools of Nursing, Association of Canadian Medical Colleges. (2002). *Supporting self-care: A shared Initiative—1999–2002* (ISBN: 1-55119-997-1). Ottawa, ON: CNA.
- 4 PricewaterhouseCoopers. (2012). *Canadian Health Services Research Foundation: National Health Leadership Survey on Ambulatory and Community Care – Final report*. Toronto, ON: PwC.
- 5 Mirolla, M. (2004). *The cost of chronic disease in Canada*. Ottawa, ON: Chronic Disease Prevention Alliance of Canada.
- 6 Adams, K., Greiner, A.C., & Corrigan, J.M. (Eds.). (2004). *The 1st annual crossing the quality chasm summit: A focus on communities* (ISBN: 0-309-54535-8). Washington, DC: National Academies Press.
- 7 McGowan, P. (2011). The efficacy of diabetes patient education and self-management education in type 2 diabetes. *Canadian Journal of Diabetes*, *35*(1), 46–53.
- 8 de Silva, D. (2011). Evidence: *Helping people help themselves. A review of the evidence considering whether it is worthwhile to support self-management* (ISBN: 978-1-906461-26-3). London, UK: The Health Foundation.
- 9 Health Council of Canada. (2010). *Helping patients help themselves: Are Canadians with chronic conditions getting the support they need to manage their health? Canadian Health Care Matters, Bulletin 2*. Toronto, ON: Health Council of Canada.
- 10 Barr, V.J., Robinson, S., Marin-Link, B., Underhill, L., Dotts, A., Ravensdale, D., & Salivaras, S. (2003). The expanded chronic care model: An integration of concepts and strategies from population health promotion and the chronic care model. *Hospital Quarterly*, *7*(1), 73–82.
- 11 Wagner, E.H. (1998). Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice*, *1*(1), 2–4.
- 12 Canadian Institute for Health Information. (2009). *Analysis in brief - Experiences with primary health care in Canada*. Ottawa, ON: CIHI.
- 13 Nasmith, L., Ballem, P., Baxter, R., Bergman, H., Colin-Thomé, D., Herbert, C., ... Zimmerman, B. (2010). *Transforming care for Canadians with chronic health conditions: Put people first, expect the best, manage for results* (ISBN: 978-0-9811589-7-6). Ottawa, ON: Canadian Academy of Health Sciences.
- 14 Health Council of Canada. (2009). *Getting it right: Case studies of effective management of chronic disease using primary health care teams*. Toronto, ON: Health Council of Canada.
- 15 Battersby, M., Von Korff, M., Schaefer, J., Davis, C., Ludman, E., Greene, S.M., ... Wagner, E.H. (2010). Twelve evidence-based principles for implementing self-management support in primary care. *The Joint Commission Journal on Quality and Patient Safety*, *36*(12), 561–570.
- 16 Battersby, M., Martin A., Hood, C., Lawrence-Wood, E., Lawn, S., Misan, G., ... Grimmer-Somers, K. (2007). *Educating future health care professionals to support people with chronic conditions to live better and live longer: A chronic condition self-management support tertiary education curriculum framework*. Adelaide, SA: Flinders University and Flinders Human Behaviour & Health Research Unit.
- 17 Schoenberg, N.E., Bardach, S.H., Manchikanti, K.N., & Goodenow, A.C. (2011). Appalachian residents' experiences with and management of multiple morbidity. *Qualitative Health Research*, *21*(5), 601–611. doi: 10.1177/1049732310395779
- 18 Bodenheimer, T., & Abramowitz, S. (2010). *Helping patients help themselves: How to implement self-management support*. Oakland, CA: California Healthcare Foundation.
- 19 Mead, H., Andres, E., Ramos, C., Siegel, B., & Regenstein, M. (2010). Barriers to effective self-management in cardiac patients: The patient's experience. *Patient Education and Counseling*, *79*, 69–76. doi:10.1016/j.pec.2009.08.003
- 20 Seeman, N., & Jaurai, X. (2011). *Self-management over the Internet (diabetes, cardiovascular disease, arthritis, depression, and key learnings)* (Unpublished work commissioned by the Health Council of Canada). Toronto: Health Strategy Innovation Cell.
- 21 Hitchcock Noel, P., Parchman, M.L., Williams, J.W., Jr., Cornell, J.E., Shuko, L., Zeber, J.E., Pugh, J.A. (2007). The challenges of multimorbidity from the patient perspective. *Journal of General Internal Medicine*, *22*(Suppl 3), 419–424. doi:10.1007/s11606-007-0308-z
- 22 Haverhals, L.M., Lee, C.A., Siek, K.A., Darr, C.A., Linnebur, S.A., Ruscin, J.M., ... Ross, S.E. (2011). Older adults with multi-morbidity: Medication management processes and design implications for personal health applications. *Journal of Medical Internet Research*, *13*(2), e44. doi:10.2196/jmir.1813
- 23 Canadian Institute for Health Information. (2011). *Analysis in brief - Seniors and the health care system: What is the impact of multiple chronic conditions?* Ottawa, ON: CIHI.
- 24 Jowsey, T., Jeon, Y.-H., Dugdale, P., Glasgow, N.J., Kljakovic, M., & Usherwood, T. (2009). Challenges for co-morbid chronic illness care and policy in Australia: A qualitative study. *Australia and New Zealand Health Policy*, *6*, 22. doi: 10.1186/1743-8462-6-22
- 25 Keller, V.F., & White, M.K. (1997). Choices and changes: A new model for influencing patient health behavior. *Journal of Clinical Outcomes Management*, *4*(6), 33–36.

- 26 Levich, B.R. (2007). Self-management in chronic illness. In J. Nuovo (Ed.), *Chronic disease management*. New York, NY: Springer Science+Business Media, LLC.
- 27 Marks, R., Allegrante, J.P., & Lorig, K. (2005). A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: Implications for health education practice (Part I). *Health Promotion Practice*, 6(1), 37–43.
- 28 Marks, R., Allegrante, J.P., & Lorig, K. (2005). A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: Implications for health education practice (Part II). *Health Promotion Practice*, 6(2), 148–156.
- 29 Canadian Public Health Association. (no date). *Health literacy portal*. Retrieved from <http://www.cpha.ca/en/portals/h-l.aspx>
- 30 Canadian Council on Learning. (2008). *Health literacy in Canada: A healthy understanding* (ISBN: 978-0-9809042-1-5). Ottawa, ON: CCL.
- 31 Johnston, L.L., Ammary, N.J., Epstein, L.G., Johnson, R., & Rhee, K. (2006). A transdisciplinary approach to improve health literacy and reduce disparities. *Health Promotion Practice*, 7(3), 331–335. doi: 10.1177/1524839906289378
- 32 Canadian Council on Learning. (2007). *Lessons in learning - Patient self-management: Health-literacy skills required*. Ottawa, ON: CCL.
- 33 Heisler, M. (2007). Overview of peer support models to improve diabetes self-management and clinical outcomes. *Diabetes Spectrum* 20(4), 214–221.
- 34 Bardach, S.H., Tarasenko, Y.N., & Schoenberg, N.E. (2011). The role of social support in multiple morbidity: Self-management among rural residents. *Journal of Health Care for the Poor and Underserved*, 22, 756–771.
- 35 Spence, M., Nagatani, A., & Koehn, S. (2010). *Self-management support for ethnocultural minority older adults: An annotated bibliography*. Vancouver, BC: BC Home & Community Care Research Network.
- 36 Kendall, E., & Rogers, A. (2007). Extinguishing the social?: State sponsored self-care policy and the Chronic Disease Self-management Programme. *Disability & Society*, 22(2), 129–143.
- 37 Starfield, B. (2010). Chronic illness and primary care. In L. Nasmith, P. Ballem, R. Baxter, H. Bergman, D. Colin-Thomé, C. Hebert, . . . B. Zimmerman (Eds.), *Transforming care for Canadians with chronic health conditions: Put people first, expect the best, manage for results - Appendices*. Ottawa, ON: Canadian Academy of Health Sciences.
- 38 Kreindler, S. (2008). *Lifting the burden of chronic disease: What's worked, what hasn't, what next*. Winnipeg, MB: Winnipeg Regional Health Authority Research & Evaluation Unit.
- 39 Coulter, A., & Ellins, J. (2006). *Patient-focused interventions: A review of the evidence*. London, UK: The Health Foundation and Picker Institute Europe.
- 40 Picker Institute Europe. (2007). *Patients make it better. Policy Research Primer*. Oxford, UK: The Picker Institute.
- 41 U.S. Department of Health & Human Services. (2010). *Multiple chronic conditions: A strategic framework. Optimum health and quality of life for individuals with multiple chronic conditions*. Washington, DC: U.S. Department of Health & Human Services.
- 42 Veteran Affairs Office of Research and Development, Health Services Research and Development Service. (2011, June). Enhancing support from informal caregivers: Diabetes Mellitus QUERI. *QUERI Update*. Retrieved from http://www.queri.research.va.gov/about/impact_updates/
- 43 Piette, J.D., Kerr, E., Richardson, C., & Heisler, M. (2008). Veterans Affairs research on health information technologies for diabetes self-management support. *Journal of Diabetes Science and Technology*, 2(1), 15–23.
- 44 Paterson, B., Kealey, L., MacKinnon, R., McGibbon, C., van den Hoonaard, D., LaChapelle, D., & Brewer, J. (2009). *Chronic diseases self-management practice in Canada: Patterns, trends and programs* (Unpublished paper commissioned by the Public Health Agency of Canada).
- 45 Dennis, S.M., Zwar, N., Griffiths, R., Roland, M., Hasan, I., Powell Davies, G., & Harris, M. (2008). Chronic disease management in primary care: From evidence to policy. *Medical Journal of Australia*, 188(8), S53–S56.
- 46 Paterson, B.L. (2009). *Assessment of the Health Canada Aboriginal Diabetes Initiative in selected First Nations and Inuit communities* (Unpublished paper commissioned by Health Canada).
- 47 Baycrest. (2012). Moving on After Stroke (MOST). Retrieved on April 10, 2012 from <http://www.baycrest.org/care-programs-73.php>
- 48 Jones, C., Simpson, S.H., Mitchell, D., Haggarty, S., Campbell, N., Then, K., ... Chambers, L.W. (2008). Enhancing hypertension awareness and management in the elderly: Lessons learned from the Airdrie Community Hypertension Awareness and Management Program (A-CHAMP). *Canadian Journal of Cardiology*, 24(7), 561–567.
- 49 McGowan, P. & Lorig, K. (2009). Delivery of self-management interventions. In S. Newman, L. Steed, & K. Mulligan (Eds.), *Chronic physical illness: Self-management and behavioural interventions* (pp. 78–97). Berkshire, England: Open University Press.
- 50 Davis, A.M., Sawyer, D.R., & Vinci, L.M. (2008). The potential of group visits in diabetes care. *Clinical Diabetes*, 26(2), 58–62.
- 51 Kallstrom, L. (2008). Group medical visits: Enhancing chronic illness care. *BC Medical Journal*, 50(6), 297.
- 52 Jaber, R., Braksmajer, A., & Trilling, J.S. (2006). Group visits: A qualitative review of current research. *Journal of the American Board of Family Medicine* 19(3), 276–290.
- 53 Laforest, S., Nour, K., Parisien, M., Poirier, M.-C., Gignac, M., & Lankoande, H. (2007). "I'm taking charge of my arthritis": Designing a targeted self-management program for frail seniors. *Physical & Occupational Therapy in Geriatrics*, 26(4), 45–66.

- 54** Botting, I., Katz, A., & the Provincial Health Contact Centre Congestive Heart Failure Steering Committee. (2009). *Moving forward in integrating chronic disease management with primary care – Final report. A summary of qualitative findings from the Chronic Disease Management of Congestive Heart Failure via Health Lines Demonstration Project*. Winnipeg, MB: Winnipeg Regional Health Authority Research and Evaluation Unit.
- 55** Boothroyd, R.I., & Fisher, E.B. (2010). Peers for progress: Promoting peer support for health around the world. *Family Practice*, 27, i62–i68. doi: 10.1093/fampra/cmq017
- 56** P. McGowan (personal communication, January 23, 2012).
- 57** Foster, G., Taylor, S.J.C., Eldridge, S., Ramsay, J., & Griffiths, C.J. (2007). Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database of Systematic Reviews*, 4, Art. No.:CD005108. doi:10.1002/14651858.CD005108.pub2
- 58** Centers for Disease Control and Prevention. (2011). *Sorting through the evidence for the arthritis self-management program and the chronic disease self-management program – Executive summary of ASMP/ CDSMP meta-analyses*. Atlanta, GA: CDC.
- 59** Jernigan, V.B.B. (2010). Community-based participatory research with Native American communities: The chronic disease self-management program. *Health Promotion Practice*, 11(6), 888–899. doi: 10.1177/1524839909333374
- 60** Public Health Agency of Canada. (2011). *Reducing health disparities related to diabetes: Lessons learned through the Canadian Diabetes Strategy Community-Based Program* (ISBN: 978-1-100-18786-0). Ottawa, ON: PHAC.
- 61** McGowan, P., & Green, L.W. (1995). Arthritis self-management in native populations of British Columbia: An application of health promotion and participatory research principles in chronic disease control. *Canadian Journal on Aging*, 14, 201–212.
- 62** McGowan, P. (2007). *Northern Aboriginal Communities Diabetes Self-Management Project* (Unpublished paper commissioned by First Nations and Inuit Health Branch, Health Canada).
- 63** McGowan, P. (2009). *Effectiveness of the Chronic Disease Self-Management Program*. (Unpublished paper commissioned by Aboriginal Diabetes Initiative, Health Canada).
- 64** McGowan, P. (2010). *Punjabi Chronic Disease Self-Management Program*. Unpublished report.
- 65** The Health Foundation. (2012). Co-creating health. Case study: I was pleasantly surprised by how useful I found Co-creating Health training. Retrieved on April 11, 2012 from <http://www.health.org.uk/areas-of-work/programmes/co-creating-health/co-creating-health-training>
- 66** Johnston, S.E., Liddy, C.E., & Ives, S.M. (2011). Self-management support: A new approach still anchored in an old model of health care. *Canadian Journal of Public Health*, 102(1), 68–72.
- 67** British Columbia Ministry of Health. (2011). *Self-management support: A health care intervention*. Victoria, BC: Government of British Columbia.
- 68** American Association of Diabetes Educators. (2010). *A sustainable model of diabetes self-management education/training involves a multi-level team that can include community health workers*. Chicago, IL: AADE.
- 69** Schaefer, J., Miller, D., Goldstein, M., & Simmons, L. (2009). *Partnering in self-management support: A toolkit for clinicians*. Cambridge, MA: Institute for Healthcare Improvement. Available at: www.lhl.org and www.improvingchroniccare.org
- 70** Wong-Rieger, D. (2011). *Health coaching for chronic conditions: Engaging and supporting patients to self manage*. Toronto, ON: Institute for Optimizing Health Outcomes.
- 71** Bodenheimer, T. (2005). Helping patients improve their health-related behaviors: What system changes do we need? *Disease Management*, 8(5), 319–330.
- 72** Health Council of Canada. (2009). *Teams in action: Primary health care teams for Canadians*. Toronto, ON: Health Council of Canada.
- 73** Johnston, S., Liddy, C., Ives, S.M., & Soto, E. (2008). *Literature review on chronic disease self-management*. Ottawa, ON: Élisabeth Bruyère Research Institute and Champlain Local Health Integration Network.
- 74** Matthias, M.S., Bair, M.J., Nyland, K.A., Huffman, M.A., Stubbs, D.L., ... Kroenke, K. (2010). Self-management support and communication from nurse care managers compared with primary care physicians: A focus group study of patients with chronic musculoskeletal pain. *Pain Management Nursing*, 11(1), 26–34. doi:10.1016/j.pmn.2008.12.003
- 75** Aliotta, S.L., Grieve, K., Giddens, J.F., Dunbar, L., Groves, C., Frey, K., & Boulton, C. (2008). Guided care: A new frontier for adults with chronic conditions. *Professional Case Management*, 13(3), 151–158.
- 76** Kahn, L.S., Fox, C.H., Carrington, J., Desai, U., Bartlett, D.P., Lyle, H., & Kowalski, M. (2009). Telephonic nurse case management for patients with diabetes and mental illnesses: A qualitative perspective. *Chronic Illness*, 5, 257–267. doi:10.1177/1742395309350229
- 77** Liddy, C., Johnston, S., Mill, K., & Shahidi, J. (2011). *Self-management support interventions: Technical paper on the sustainability of self-management supports for people with chronic conditions and the availability of self-management support programs for people with multiple chronic conditions* (Unpublished work commissioned by the Health Council of Canada). Ottawa: Élisabeth Bruyère Research Institute, C.T. Lamont Primary Health Care Research Centre.
- 78** Bastiaens, H., Sunaert, P., Wens, J., Sabbe, B., Jenkins, L., Nobels, F., ... Van Royan, P. (2009). Supporting diabetes self-management in primary care: Pilot-study of a group-based programme focusing on diet and exercise. *Primary Care Diabetes* 3, 103–109. doi:10.1016/j.pcd.2009.02.001
- 79** Jordan, J.E., Briggs, A.M., Brand, C.A., & Osborne, R.H. (2008). Enhancing patient engagement in chronic disease self-management support initiatives in Australia: The need for an integrated approach. *Medical Journal of Australia*, 189(10), s9–s13.

- 80** O'Toole, M.L., Brownson, C.A., Anwuri, V.V., Nalley, C.M., & Fisher, E.B. (2009). *Sustainability: A retrospective assessment of diabetes initiative projects*. St. Louis, MO: Washington University.
- 81** Clark, C.M. Jr., Snyder, J.W., Meek, R.L., Stutz, L.M., & Parkin, C.G. (2001). A systematic approach to risk stratification and intervention within a managed care environment improves diabetes outcomes and patient satisfaction. *Diabetes Care*, *24*(6), 1079–1086.
- 82** Bengoa, R., Martos, F., Nuno, R., Kreindler, S., Novack, T., & Pinilla, R. (2010). Management models. In A.R. Jadad, A. Cabrera, R.F. Lyons, F. Martos, & R. Smith (Eds.), *When people live with multiple chronic diseases: A collaborative approach to an emerging global challenge* (pp.89-115). Granada, Spain: Andalusian School of Public Health.
- 83** Hindmarsh, M. (2011, September). *Engaging and sustaining healthcare professionals in self-management support*. Presentation at the Coaching for Health Behaviour Change: Supporting Chronic Disease Self-Management conference, Caledon, ON.
- 84** Barcelo, A., Cafiero, E., de Boer, M., Mesa, A.E., Lopez, M.G., Jimenez, R.A., ... Robles, S. (2010). Using collaborative learning to improve diabetes care and outcomes: The VIDA project. *Primary Care Diabetes*, *4*, 145–153. doi:10.1016/j.pcd.2010.04.005.
- 85** Piatt, G.A., Anderson, R.M., Brooks, M.M., Songer, T., Siminerio, L.M., Korytkowski, M.M., ... Zgibor, J.C. (2010). 3-year follow-up of clinical and behavioral improvements following a multifaceted diabetes care intervention: Results of a randomized controlled trial. *Diabetes Educator*, *36*, 301–309. doi: 10.1177/0145721710361388
- 86** Svetkey, L.P., Pollak, K.I., Yancy, W.S., Jr., Dolor, R.J., Batch, B.C., Samsa, G., ... Lin, P-H. (2009). Hypertension Improvement Project. Randomized trial of quality improvement for physicians and lifestyle modification for patients. *Hypertension*, *54*, 1226-1233. doi:10.1161/HYPERTENSIONAHA.109.134874
- 87** Kroenke, K., Bair, M.J., Damush, T.M., Wu, J., Hoke, S., Sutherland, J., & Tu, W. (2009). Optimized antidepressant therapy and pain self-management in primary care patients with depression and musculoskeletal pain: A randomized controlled trial. *Journal of the American Medical Association*, *301*(20), 2099–2110. doi:10.1001/jama.2009.723
- 88** Registered Nurses' Association of Ontario. (2010). *Strategies to support self-management in chronic conditions: Collaboration with clients*. Toronto, ON: RNAO.
- 89** Flinders University. (2012). *The Flinders program*. Retrieved April 11, 2012 from <http://www.flinders.edu.au/medicine/sites/fhbhru/self-management.cfm>
- 90** Alberta Health Services. (2009). *The Flinders care planning model: Summary of comments from workshop evaluations and initial care plans*. Retrieved from <http://www.albertahealthservices.ca/hp/if-hp-summary-flinders-2009-10.pdf>
- 91** Rubak, S., Sandbaek, A., Lauritzen, T., Borch-Johnsen, K., & Christensen, B. (2009). General practitioners trained in motivational interviewing can positively affect the attitude to behaviour change in people with type 2 diabetes. One-year follow-up of an RCT, ADDITION Denmark. *Scandinavian Journal of Primary Health Care*, *27*, 172–179. doi: 10.1080/02813430903072876
- 92** The Health Foundation. (2011). *Research scan: Training professionals in motivational interviewing*. London, UK: The Health Foundation.
- 93** Zoffman, V., & Kirkevold, M. (2012). Realizing empowerment in difficult diabetes care: A guided self-determination intervention. *Qualitative Health Research*, *22*(1), 103–118. doi: 10.1177/1049732311420735
- 94** Zoffman, V., & Lauritzen, T. (2005). Guided self-determination improves life skills with type I diabetes and A1C in randomized controlled trial. *Patient Education and Counseling*, *64*(1-3), 78–86. doi: 10.1016/j.pec.2005.11.017
- 95** Boulton, C., Reider, L., Leff, B., Frick, K.D., Boyd, C.M., Wolff, J.L., ... Scharfstein, D.O. (2011). The effect of guided care teams on the use of health services: Results from a cluster-randomized controlled trial. *Archives of Internal Medicine*, *171*(5), 460–466.
- 96** Glasgow, R.E., Goldstein, M.G., Ockene, J.K., & Pronk, N.P. (2004). Translating what we have learned into practice: Principles and hypotheses for interventions addressing multiple behaviors in primary care. *American Journal of Preventive Medicine*, *27*(2 Suppl), 88–101. doi: 10.1016/j.amepre.2004.04.019
- 97** Health Canada. (2011, November 1). Speech by the Honourable Leona Aglukkaq Minister of Health for funding for community based projects under the Canadian Diabetes Strategy. Retrieved on April 11, 2012 from http://www.hc-sc.gc.ca/ahc-asc/minist/speeches-discours/_2011/2011_11_01-eng.php
- 98** Public Health Agency of Canada. (2011). Fact sheet: Diabetes community-based projects in the Atlantic Region. Retrieved on April 11, 2012 from http://www.phac-aspc.gc.ca/media/nr-rp/2011/2011_1110-nl-tnl-fs-fr-eng.php
- 99** Institute for Healthcare Improvement. (2004). The Breakthrough Series: IHI's collaborative model for achieving breakthrough improvement. *Diabetes Spectrum*, *17*(2), 97–101.
- 100** Health Quality Council (Saskatchewan). (2012). *Chronic disease management collaborative II* (ISBN: 13-978-1-897155-56-1). Regina, SK: Health Quality Council.
- 101** Quality Improvement and Innovation Partnership. (2010). *Learning Collaborative One, An Improvement Journey for Primary Healthcare Teams*. Hamilton, ON: QIIP.
- 102** Alberta AIM (Access. Improvement. Measures). (no date). *About AIM*. Retrieved on April 11, 2012 from <http://www.albertaaim.ca/aboutaim.html>
- 103** Safety Net Medical Home Initiative, Van Borkulo, N., & Coleman, K.A. (2011). *A practice facilitator's guide to visiting clinical teams* (1st ed.) Seattle, WA: Qualis Health and the MacColl Institute for Healthcare Innovation.
- 104** Baskerville, N.B., Liddy, C., & Hogg, W. (2012). Systematic review and meta-analysis of practice facilitation within primary care settings. *Annals of Family Medicine*, *10*(1), 63–74. doi:10.1370/afm.1312

- 105** Hibbard, J.H., Stockard, J., Mahoney, E.R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research, 39*(4), Part I, 1005–1026.
- 106** Wong, S.T. (2011, October). *Skills, knowledge and confidence in managing one's own health: Can patient activation be compared across ethnic and language groups in primary health care?* Paper presented at the Accelerating Primary Care 2011 Conference, Edmonton, AB.
- 107** National Cancer Institute. (2011). *About RE-AIM*. Retrieved on April 11, 2012 from <http://cancercontrol.cancer.gov/IS/ream/whatisre-aim.html>
- 108** Bakken, S. & Ruland, C.M. (2009). Translating clinical informatics interventions into routine clinical care: How can the RE-AIM framework help? *Journal of the American Medical Informatics Association, 16*(6), 889–897.
- 109** The Health Foundation. (2011). *Snapshot—Co-creating health: Building new relationships between people with long-term conditions and a supportive health service*. London, UK: The Health Foundation.
- 110** Kennedy, A., Chew-Graham, C., Blakeman, T., Bowen, A., Gardner, C., Protheroe, J., Gask, L. (2010). Delivering the WISE (Whole Systems Informing Self-Management Engagement) training package in primary care: Learning from formative evaluation. *Implementation Science, 5*, 7. doi:10.1186/1748-5908-5-7
- 111** Welsh Assembly Government. (2009). *Improving health and wellbeing in Wales: A framework for supported self care* (ISBN: 978-0-7504-5386-8). Cardiff, Wales: Welsh Assembly Government.
- 112** Queensland Government, Queensland Health. (2008). *Queensland strategy for chronic disease 2005–2015: Framework for self-management 2008–2015*. Brisbane, Australia: Queensland Government.
- 113** Chronic Condition Self-Management Support Framework and Community of Practice Project Team. (2010). *Building bridges: An international framework for chronic condition self-management support* (draft report). Vancouver, BC: British Columbia Centre of Excellence for Women's Health.
- 114** Mills, S.L., & Vanden, E. (2011). International roundtable on the self-management support of chronic conditions – workshop report. *Chronic Diseases and Injuries in Canada, 31*(4). Retrieved April 11, 2012 from <http://www.phac-aspc.gc.ca/publicat/cdic-mcbc/31-4/ar-07-eng.php>
- 115** The Health Foundation. (2008). *Briefing - May 2008: Co-creating health*. London, UK: The Health Foundation.
- 116** Wallace, L.M., Turner, A., Kosmala-Anderson, J., Sharma, S., Jesuthasan, J., Bourne, C., & Realpe, A. (2012). *Evidence: Co-creating Health: Evaluation of first phase. An independent evaluation of the Health Foundation's Co-creating Health improvement programme*. April 2012. London, UK: The Health Foundation.
- 117** Statistics Canada. (2011). Canadian Internet use survey, 2010. Retrieved on April 11, 2012 from <http://www.statcan.gc.ca/daily-quotidien/110525/dq110525b-eng.htm>
- 118** Dingman S. (2011, October 28). Can an app save billions in health-care costs? *The Globe and Mail*. Retrieved from <http://www.globeandmail.com>
- 119** Logan, A.G., Mclsaac, W.J., Tisler, A., Irvine, M.J., Saunders, A., Dunai, A., ... Cafazzo, J.A. (2007). Mobile phone-based remote patient monitoring system for management of hypertension in diabetic patients. *American Journal of Hypertension, 20*(9), 942–948.
- 120** Nguyen, H.Q., Donesky-Cuenco, D., Wolpin, S., Reinke, L.F., Benditt, J.O., Paul, S.M., & Carrieri-Kohlman, V. (2008). Randomized controlled trial of an Internet-based versus face-to-face dyspnea self-management program for patients with chronic obstructive pulmonary disease: Pilot study. *Journal of Medical Internet Research, 10*(2), e9. doi: 10.2196/jmir.990
- 121** Lorig, K.R., Ritter, P.L., Laurent, D.D., & Plant, K. (2006). Internet-based chronic disease self-management: A randomized trial. *Medical Care, 44*(11), 964–971.
- 122** Bender, J.L., Radhakrishnan, A., Diorio, C., Englesakis, M., & Jadad, A.R. (2011). Can pain be managed through the Internet? A systematic review of randomized controlled trials. *Pain, 152*, 1740-1750. doi:10.10106/j.pain.2011.02.012
- 123** McGowan, P., Lorig, K., Jadad, A.R., Armayones, M., Bender, J., Gil-Zorzo, E., Serrano, M. (2010). Patient education and self-management support. In A.R. Jadad, A. Cabrera, R.F. Lyons, F. Martos, & R. Smith (Eds.), *When people live with multiple chronic diseases: A collaborative approach to an emerging global challenge* (pp. 117-140). Granada, Spain: Andalusian School of Public Health.
- 124** Statistics Canada. (2011). Canadian Internet Use Survey, 2009. Retrieved on April 11, 2012 from <http://www.statcan.gc.ca/daily-quotidien/100510/dq100510a-eng.htm>
- 125** Fox, S. (2011). *Health topics: 80% of internet users look for health information online*. Washington, DC: Pew Research Center's Internet & American Life Project.
- 126** McKay, H.G., King, D., Eakin, E.G., Seeley, J.R., & Galsgow, R.E. (2001). The diabetes network internet-based physical activity intervention: A randomized pilot study. *Diabetes Care, 24*(8):1328–1334.
- 127** Health Council of Canada. (2012). *Turning what we know into action: A commentary on the National Symposium on Patient Engagement*. Toronto, ON: Health Council of Canada.

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