EDITED BY Alejandro R. Jadad Andrés Cabrera Renée F. Lyons Francisco Martos Richard Smith

> When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge



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Words cloud from chapter sections "Why is this topic important?" and "What do we know?" [Available at: http://www.wordle.net]

# When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge

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# When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge

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Chapter 5

# Patient education and self-management support

This chapter is continuously evolving at www.opimec.org

# Vignette: How it could be

Ten years ago, Thomas was 52 years old, approximately 70 pounds overweight, had type 2 diabetes, hypertension, and osteoarthritis in his knees and hips. For most of his life he had been very active in competitive sports like football and basketball. Up to the age of 40 years he had normal weight for men his height and build, but gradually gained additional weight. He started to have problems with his knees and experienced several injuries requiring arthroscopic surgery. He continued to play these sports because they were important to him but in a modified manner that didn't require running and quick starts and stops. However, he paid the price for continuing and experienced increased pain and mobility problems.

Five years ago he participated in a community self-management program and learned helpful skills and strategies. His priority concerns were how to lose weight and to eat in a way that didn't leave him hungry all the time. He was impressed by this program and became a leader and subsequently led the program four times. He told his doctor about the self-management program and was surprised that the doctor was already familiar with the key concepts such as action planning and problemsolving. His doctor also encouraged him to join an online program where he could take the selfmanagement program again, access his medical record, add certain types of information such as his latest HbA1c levels, communicate with peers, receive online newsletters, and find community resources.

Today Thomas continues to manage and cope with diabetes, but feels he has more control. He used the problem-solving process and found ways to get 30 minutes of daily exercise by parking three blocks away from the office and using the stairs instead of the elevator, and eating foods that are healthy and leave him satiated. For his home he bought a popular video fitness program and enjoys playing it with his wife and grandchildren, and he also joined an online chat room for

older men with diabetes. He has lost nearly 40 pounds, has much more energy and has a really great relationship with his doctor who also happy with the way Thomas is controlling his disease.

# Summary

- Effective self-management and patient education should be regarded as essential components of a high-quality, modern health system.
- The best type of educational activities for patients experiencing chronic health conditions should include: a) disease-specific information; b) general managing skills (e.g., problem-solving, finding and using resources, working with a health care team); and c) use of behavioral strategies that increase patients' confidence (i.e., self-efficacy) in their ability to engage in behaviors needed to manage their condition on a daily basis.
- Self-management support can take place on a one-to-one basis between the patient and health care professional or in group settings led by either health providers or lay persons, or by using interactive technology like the internet.
- When patients participate in evidence-based self-management programs and interact with health professionals who use self-management support strategies, they become more knowledgeable and have higher self-efficacy. This influences their behavior as well as the behavior of their health providers; patients attain better disease control leading to improved health outcomes and higher patient satisfaction; and better healthcare utilization takes place as well as improved workplace productivity and lower costs.
- Effective self-management support programs not only involve changes at the clinician-patient level but also require change at multiple levels: office environment, health system, policy, and environmental supports.
- Use of multiple modalities has been shown to lead to improved health behavior outcomes.
- Not all patients are willing or able to engage in self-management or educational activities. In these cases, the involvement of family and significant others could be beneficial.
- Modern interactive social networking technologies have a boundless potential for enhancing self-management support.

# Why is this topic important?

Over the last decade, a dramatic rise in the prevalence of chronic conditions has emerged, altering the way in which care is delivered and received. Presently, one in every three individuals will at some time in their life be living with a chronic condition (1, 2). Coupled with aging populations and rising health care costs, these chronic conditions will create a financial burden that is expected to overwhelm the finite medical and personnel resources of any given country. The reality of this global situation will mean that clinicians will be present for only a fraction of a patient's life and these people will be living for a long period of time and mostly outside the formal health care system. Importantly, such people have an integral role in managing because the pace of disease progression and nearly all health outcomes are mediated through their own behavior [3].

One promising approach to improving outcomes and reducing health care costs associated with chronic conditions is self-management, whereby individuals, in collaboration with health care professionals, assume greater responsibility for health care decisions. In the past, almost all health care and teaching was provided by health care professionals, but there is acknowledgement that many of the clinical functions (e.g., monitoring HbA1c, blood pressure and weight) and teaching activities can be effectively carried out by patients. An inherent philosophical re-orientation is taking place whereby health professionals are seeing their relationship with patients as partners and coaches.

The growing emergence of self-management support programs not only involves changes at the clinician-patient level but also requires change at multiple levels: office environment, health system, policy and environmental supports (4). The bottom line is that self-management is good medicine, and health care without a strong self-management component does not meet quality standards.

# What do we know?

To date there is no gold standard, universally accepted definition of **self-management**. Rather, several terms are used, sometimes interchangeably, depending on the context and focus of the discussion. Although generally they are meant to describe a similar phenomenon, the terms imply varying specification regarding attributes, roles and responsibilities of both people with chronic health conditions and health care providers. Adams, Grenier, and Corrigan (5, p.57) define self-management as the *tasks that an* 

individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with medical management, social management, and emotional management.

This definition envisions self-management as behaviors, but includes the notion of confidence and embraces clinical management as well as role and emotional management by the individual. Using this definition someone who is engaged in self-management:

- Has knowledge of his/her condition and/or its management.
- Adopts a care plan agreed and negotiated in partnership with health professionals.
- Actively shares in decision-making with health professionals.
- Monitors and manages signs and symptoms of his/her condition.
- Manages the impact of the condition on physical, emotional, occupational and social functioning.
- Adopts lifestyles that address risk factors and promotes health by focusing on prevention and early intervention.
- Has access to, and confidence in, the ability to use support services (6).

This definition of self-management provides clarity in that it focuses on the person with the chronic conditions, and further introduces the concept of self-management support, which specifies what health care providers can do to encourage self-management (5). Self-management support is defined as *the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment or progress and problems, goal setting, and problem-solving support (p.57).* 

By articulating self-management as behaviors and confidence to deal with medical, role, and emotional management and by using the term self-management support to describe what health care providers can do to facilitate this, Adams et al. (5) have brought greater clarity to the picture.

Another factor supporting the decision to use this definition of self-management is that it is congruent with the concept of self-management support incorporated into the Chronic Care Model (7) (Chapter 4).

The model involves two overlapping realms, the community and the health care system, with self-management support as one of the four essential components within the health care system (3). Self-Management / Develop Personal Skills refers to the support of self-management in coping with a disease, but also to the development of personal skills for health and wellness (8).

Ultimately, the model posits that when Informed, Activated Patients interact with a Prepared, Proactive, Practice Team the result is improved Functional and Clinical Outcomes. To encourage these outcomes, health authorities provide inputs to strengthen and maximize the efficiency of each component including Self-Management Support.

## Difference between patient education and self-management education

Traditionally, patient education has involved the provision of disease-specific information, teaching specific disease-related skills (e.g., how to monitor glucose levels and how to use asthma medication), and contingency planning (i.e., what to do if a situation occurs). Self-management focuses more on teaching generalized skills that patients could use to manage their condition and includes learning how to solve problems, using community resources effectively, working with one's health care team, and how to initiate new behaviors. The major differences between patient education and self-management education have been outlined by Bodenheimer, Lorig, Holman, and Grumbach [3]:

- Traditional patient education provides information and teaches technical diseaserelated skills whereas self-management teaches skills on how to address problems.
- Problems covered in traditional patient education reflect widespread common problems related to a specific disease, whereas the problems covered in self-management education are identified by the patient.
- Traditional patient education is disease-specific and offers information and technical skills related to the disease. In contrast, self-management education provides problem-solving skills that are relevant to the consequences of chronic conditions in general.
- Traditional patient education is based on the underlying theory that disease-specific knowledge leads to behavioral change, which in turn produces better outcomes. Self-management education, meanwhile, is based on the theory that greater patient confidence in his/her capacity to make life-improving changes yields better clinical outcomes.

- The goal of traditional patient education is compliance, whereas the goal in selfmanagement education is increased self-efficacy and improved clinical outcomes.
- In traditional patient education the health professional is the educator, but in selfmanagement education then educators may be health professionals, peer leaders or other patients.

Both activities are, however, essential in assisting patients achieve the best quality of life and independence. While necessary, traditional disease-specific patient education is generally not sufficient for people to manage a lifetime of chronic disease care (9-12).

It is important to emphasize, however, that modern approaches to patient education, particularly outside the English-speaking world, are practically indistinguishable from self-management. This, and the risk of confusion generated by the emergence of new terms, is illustrated by the coining of such expressions as «therapeutic patient education» (TPE), which is defined by the WHO as a set of structured activities which involves «helping the patient and his family to acquire knowledge and competencies on the disease and its treatment, in order to better collaborate with the caregivers, and to improve his quality of life» (13). While increasing knowledge is one important aspect of this approach, its main aim is to increase awareness of the issues that patients face and must manage, and to motivate them to incorporate self-management and selfcare behaviors in their daily lives, while addressing their own resistance to change and ambivalence and working with health professionals as partners and coaches. There is evidence that TPE can result in a number of benefits to the patient, including better quality of life, greater therapeutic compliance, a reduction in complications, decreased anxiety and a reduction in the number of acute or emergency situations (14). In any case, there is strong evidence that using behavioral strategies that teach self-directed goal-setting and action-planning, problem-solving, healthy coping, stress management, self-monitoring and skills to link to community resources improves outcomes (10, 15). There is also evidence that using more than one of these strategies increases program effectiveness (12, 15-17).

The evidence strongly makes the case that the best type of education for patients experiencing chronic health conditions should include: a) disease-specific education; b) general managing skills (e.g., problem-solving, finding and using resources, working with a health care team); c) use of strategies that increase patients' confidence (i.e., self-efficacy) in their ability to engage in behaviors needed to manage their condition on

a daily basis; and d) adequate peer role models and support networks that help in the initiation and maintenance of the desired behavioral changes.

## Delivering self-management support

Self-management support can take place on a one-to-one basis between the patient and health care professional, or in group settings led by either health providers or lay persons. These activities could take place in person or through Web-based interactive technologies.

In recent years, the main task of managing one's chronic health condition has been shifting to the patient, yet considerable responsibility still lies with health care professionals who can use their expertise to inform, activate and assist patients in the self-management of their condition.

Self-management interventions are delivered in a variety of settings; according to Barlow et al. (18) the most popular locations in which health professionals deliver programs are clinical settings (e.g., hospitals). Today a greater emphasis is being placed on health care professionals delivering self-management support and using behavioral techniques during routine clinical visits to enhance patients' abilities to be effective selfmanagers.

## Self-management support provided by health care professionals

## The 5As

One unifying conceptual framework used on a one-to-one basis or in groups by health care professionals is known as the 5 As construct (19). The 5 As are Assess, Advise, Agree, Assist and Arrange. Basically, this is a set of behavioral strategies to encourage patients to engage in self-management, including:

- Establishing rapport with patients to ensure that patients have opportunities to express their priority concerns.
- Setting a visit agenda with patients to ensure that both health professionals' and the patients' concerns are addressed in the visit.

- Getting patients to complete a Health Risk Appraisal at home to provide an opportunity for patients to obtain independent objective information about their health and what they need to do to address these concerns. The information can be discussed with the health professional.
- Assessing patients' readiness to enable the health professionals to use appropriate behavioral change strategies.
- Considering the Ask-Tell-Ask strategy, a technique to ensure that patients get the information they are after, or the Closing the Loop technique, to ensure patients understand the information provided by health professionals.
- Getting patients to make Action Plans is the process by which patients specify a particular behavior they will engage in.
- Teaching the Problem-Solving Process which gives patients a systematic approach to solve problems when they arise in their daily lives.
- Ensuring that follow-up takes place, facilitating the success of action plans.

These activities, which are not necessarily linear with each step following the other sequentially, have been applied to primary care interventions for a variety of behaviors (20-22).

The goal of the 5 As is to develop a personalized, collaborative action plan that includes specific behavioral goals and a specific plan for overcoming barriers and attaining those goals. The 5 As are interrelated elements and are not designed to be used in isolation, and better results will be achieved if a combination of interventions is employed, especially for complex cases (23).

Professional Associations and major hospitals have used the 5 As construct as the basis of their evidence-based best practice guidelines in providing self-management support to adults with chronic health conditions (24) and in caring for children experiencing chronic health conditions (25).

## Motivational Interviewing

Motivational interviewing (MI) is a patient-centered, directive method of communication used throughout self-management support with the goal of enhancing motivation to change behavior by exploring and resolving ambivalence (26, 27). With the widespread

dissemination of a complex innovation such as MI it is likely that reinvention may take place reflecting practitioners' particular understanding and style, and this reinvention may further add or remove critical elements. Miller and Rollnick (28) provide clarity with respect to what MI is and is not, specifically:

- MI is collaborative and person-centered.
- MI incorporates reflective listening to guide the resolution of ambivalence about change.
- MI is intended to enhance patients' motivation for change (change talk) and does not need to be based on the trans-theoretical model of change (i.e., Pre-contemplative Stage).
- MI honors the patients' autonomy and should never be used to coerce them into doing what you think they should.
- MI is a complex clinical skill that requires practice to increase proficiency, rather than a formula to be followed step by step.
- MI is a method to elicit solutions from the patient, rather than providing solutions for them in the belief that they lack something needed for success.
- MI is not necessary if the patient is ready for change.

A recent meta-analysis by Rubak (29) evaluated the effectiveness of using MI with patients who had various diseases. They found that MI produced significant effects in some areas (body mass index, total blood cholesterol, systolic blood pressure) but not in others (cigarettes smoked per day and A1C levels).

Lewin et al (30) recommended that MI be used to counsel patients/families on health behavior change. MI can be effective in brief encounters of fewer than 15 minutes, although the dose of effectiveness is individualized, assuming that increased use improves the likelihood of favorable outcomes (28). Meanwhile, some studies have shown greater efficiency when combined with other treatment methods (31). MI outperforms traditional advice-giving for a broad range of behavioral problems and diseases in approximately 80% of studies (29).

Studies show that any appropriately trained health professional (e.g., physician, nurse, psychologist or dietician) can successfully use MI skills with his or her patients (29). Miller and Rollnick (28) recognize that most health care professionals learn about motivational

interviewing through self-study or in short one- or two-hour workshops, and state that although this clinical method is simple, it is not as easy to master, requiring repeated practice with feedback and encouragement from knowledgeable guides to facilitate both skill and comfort of use.

Despite the promise that the technique holds for promoting behavioral change, there are few controlled studies evaluating its efficacy with health problems (32, 33). This point of view is consistent with that of Bodenheimer and Grumbach (34) that the effectiveness of MI in enhancing physical activity and managing chronic illness is still inconclusive.

## The Flinders Program (formerly the Flinders Model)

The Flinders Program (35) was developed at Flinders University in Adelaide, South Australia. This model enables the clinician to use measurement over time to track changes. It involves three main phases, namely:

- An assessment phase, which may involve using three tools: the Partners in Health Scale (36); the Cue and Response Interview, and the Problems and Goals Assessment Scale.
- The development of a self-management care plan where information elicited in the assessment is used to collaboratively develop an individualized self-management care plan. The plan includes the identified issues and key problem; the agreed-upon goals, interventions, a sign-off for patient and clinician and review dates.
- Monitoring and review, initiated by the clinician and using the self-management care plan as its basis. The purpose is to help the patient maintain motivation, assist the patient with problem-solving and make changes in the plan if circumstances change.

Research has investigated specific elements of the Flinders Program (36, 37), and demonstration projects have investigated effectiveness when using the complete version. These pilots, part of the Australian Statewide Chronic Disease Self-Management Initiative, investigated diabetes in rural aboriginal communities (38); mental health (39), and patients in respiratory rehabilitation (40) and found encouraging outcomes, both statistically and clinically.

# Self-management support provided by health professionals and patients

The most familiar and common way that evidence-based self-management support is delivered is through the specially designed programs that emerged during the last decade. These include both disease-specific and generalized programs led by health care professionals as well as by lay people (11, 41-43). A cursory review of recent literature reveals a growth in the development, scope, and evaluation of these programs and includes programs for: adults and children with asthma (44-46), cancer (47), COPD (48), HIV (49), bulimia nervosa (50), chronic kidney disease (51), congestive heart disease (52), dementia (53), low vision (54), macular degeneration (55), mental health (56), and stroke (57). In addition, the US National Council on Aging has also recommended several evidenced-based programs which include: Chronic Disease Self-Management Program (42), Enhanced Wellness (58), Enhanced Fitness (59), Active Choices (60), Active Living Every Day (61), Strong for Life, A Matter of Balance (62), Healthy IDEAS (63), Prevention & Management of Alcohol Problems in Older Adults: A Brief Intervention (64). These programs have been shown to be effective across a wide range of settings for people with many different types of disease and for people from different cultures and socioeconomic groups (65).

A comprehensive review of the strengths and weaknesses relating to program settings, using professional or lay leaders, using disease-specific or generic programs, and group or individual programs, has been published by McGowan and Lorig (66).

These self-management programs provide basic information, teach specific skills, and use strategies to increase patients' confidence in their ability to manage their condition (67). Specific skills include: a) Problem-solving (learning to identify a problem, generate possible solutions, implement a solution, and evaluate the results); b) Decision-making (learning how to identify warning signals when caring for their symptoms, having suitable guidelines to follow, and making appropriate choices to manage their symptoms properly; c) Resource utilization (learning how to find and use resources effectively); d) Patient provider relationships (learning how to build relationships with health care providers); and e) Taking action (learning how to implement a specific behavior in order to achieve a goal. Patients learn to do this by making short-term, realistic and achievable action plans). Action plans are a useful resource for acquiring knowledge and for promoting health-enhancing habits, particularly when they enable patients to identify key symptoms and interventions to relieve these, and include tips on how to solve common problems and to deal with crises.

Self-management programs usually employ several strategies to increase the patient's self-efficacy in implementing a specific behavior at a future point in time. Bandura (68) defined self-efficacy as people's judgments of their capabilities to organize and execute the courses of action required to attain designated types of performance (p.391). The key contention regarding the role of self-efficacy beliefs is that «people's level of motivation, affective states, and actions are based more on what they believe than on what is objectively true» (69). The process of developing long- and short-term goals, which is known as Guided Mastery, serves as the major means for developing and expanding behavioral competencies (68), and is an effective technique for raising individuals' self-efficacy. Other self-efficacy enhancing strategies used in the group programs include: modeling (i.e., persons with chronic health conditions leading the program); reinterpreting physiological signs and symptoms, and persuasion.

One comprehensive framework helpful in planning and evaluating the impact of selfmanagement programs and which considers several stages of knowledge development and dissemination is the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) framework (4, 70). The five dimensions of RE-AIM build on conceptual work by Rogers (71) and Green and Kreuter (72) and focus on the following:

- Reach (proportion and representativeness of the target population willing to participate).
- Effectiveness (impact of the program in terms of outcomes and quality of life).
- Adoption (proportion and representativeness of organizations and staff agreeing to deliver the program).
- Implementation (degree to which interventions are delivered consistently as planned across staff, patients, program components, and time).
- Maintenance (extent to which behavioral change is maintained over the longer term and, at the setting level, the extent to which the program is maintained by the organization).

Traditional evaluations have mainly focused on only one or two dimensions, from knowledge development to dissemination. Examining all five dimensions yields a more

thorough evaluation, thus giving decision-makers more information on which to base their decision to adopt or discontinue a program. The Stanford Patient Education Research Center has satisfactorily addressed the RE-AIM factors in that these programs have been around since the mid 1980s and are currently being delivered in approximately 20 countries. These self-management programs have undergone randomized controlled trials (41-42, 73), dissemination studies (74), follow-up and cost analysis studies (16), and have demonstrated external validity through successful implementation, producing similar results in different countries and with different populations (75-80).

# What do we need to know?

We need a better understanding of why some patients are unable to engage in or benefit from educational and self-management efforts (81). More attention should also be paid to the role that family or caregivers should play in these cases (82).

Another major question that has not been addressed relates to the process of selfmanagement, specifically the elements that bring about the beneficial outcomes. The recent evaluation of self-management support programs conducted by RAND (83) suggests a chain of self-management support effect, specifying that: a) as patients participate in evidence-based self-management programs and interact with health professionals who use self-management support strategies, they become more knowledgeable and have higher self-efficacy; b) this influences their behavior as well of the behavior of their health providers; c) patients attain better disease control leading to improved health outcomes and higher satisfaction levels; and d) better healthcare utilization takes place as well as improved workplace productivity and lower costs. Specific aspects within this chain of effect that need further investigation relate to why and how disease control and health outcomes are improved through self-management. It would also be worthwhile to explore the role that socioeconomic status, baseline educational level and ethno-cultural issues play in these cases.

The current understanding of how this process unfolds is that when patients acquire new knowledge and skills and gain higher self-efficacy in their ability to carry out behaviors to achieve goals, their health status and outcomes improve. The major question warranting further research is: what are the core components that are necessary to bring about this improvement? Most self-management research studies revealing positive results have utilized multiple strategies, making it difficult to delineate exactly which strategy has

been the most effective in contributing to the change in behavior or in bringing about the improvement in health status (84, 34, 85-87).

Other efforts have incorporated formal tools for the assessment of the degree of patient empowerment and «activation» for self-management. It would be important to validate those tools within the context of multiple chronic diseases (88-90).

Another area to be addressed is the development of realistic strategies and incentives for recruiting, training and retaining peer leaders for the community programs. Sponsoring organizations generally use a variety of recruitment strategies to encourage people to become peer leaders. The majority of prospective leaders then successfully complete the necessary training workshops and approximately 60% lead programs. Within this 60% of leaders approximately 10% remain involved and become program champions. While successful in some aspects, there is a need to develop strategies to retain this valuable cadre of trained and skilled volunteers.

The research design commonly used in evaluating self-management interventions has involved longitudinal randomized controlled or matched group pre- and post- program designs from base-line to four-six months. There has been little research providing information on the sustained effectiveness of these programs for longer periods of time, for example five to ten years. Having this valuable information would assist in determining the need for and types and scope of refresher and reinforcement programs.

The dissemination strategies used with self-management programs have been successful in reaching remote and rural communities and specific populations. However, these strategies may have problems with quality control and program fidelity. As with any program, trained peer leaders and health professionals may personalize and modify specific elements within the program, and observing and monitoring program delivery is difficult. Although quality control mechanisms can be implemented (e.g., program delivered by two leaders, four-day training workshops, and regular contact and support from program coordinators), there may be variation in the delivery. This is a serious concern because participants may not receive the benefits that occur when the intervention is delivered as it was planned.

From an organizational perspective there are the ongoing challenges of how to make self-management programs accessible and attractive to the target populations. Successful dissemination strategies can make the programs accessible but people may be reluctant to participate. Multiple venues (small group, telephone, mail, and internet) do exist for these programs but information is needed to determine the best combinations and concentrations given limited resources. Scenarios that may entice members of the target population to participate could include enhancing the choice of available programs (e.g., communities having a menu of self-management programs from which to choose such as: an Online Program, Chronic Disease, Chronic Pain and Matter of Balance, etc.). Another potential strategy may be to have health professionals recommend and encourage patients to participate. Research has demonstrated that the probability of participating in a community Arthritis Self-Management Program increased 18 times when recommended by a health professional (91). The process of deciding to participate in a program is complex and an examination of marketing strategies used in the business world may shed light in this area.

Community self-management programs and the provision of self-management support strategies by health professions need to be combined into the overall health system. The term integration is commonly used to indicate how this combination should take place. However, this term is not easily defined and means different things to those who use it. To some, integration means that health professionals should coordinate the process while to others it may mean a sharing of effort and information to ensure patients receive consistent information and acknowledgement that they play an integral role in managing their health. Focused research on the best ways to integrate self-management support activities into overall care would help boost overall effectiveness and ensure that selfmanagement is not considered a disparate and complementary service.

One concern related to the provision of self-management support by health professions deals with ensuring a sustainable remuneration and payment formula for health professionals who use practice time to provide these activities. Consistent and burgeoning research findings are indicating that disease control and health outcomes are improved with self-management support strategies, but a system that negatively impacts on one's practice and livelihood will not be welcomed or supported. Therefore the development of various administrative and organizational incentives for health professionals to engage in self-management support needs to be addressed.

# What innovative strategies could fill the gaps?

In addition to the increase of self-management support development and implementation activities, several innovative initiatives with promising potential are taking place. In the

United Kingdom, the Chronic Disease Self-Management Program (known as the Expert Patients Programme) is being delivered by the Expert Patients Programme Community Interest Company (EPP CIC), a not-for-profit social enterprise set up to meet a public need and to reinvest profits for the public good. The EPP CIC was established in 2007 to expand the work already undertaken across England in the area of self-care and self-management. The purpose is to establish the principle of individual self-management and self-care as a recognized public health measure, deliverable in a cost-effective and sustained manner, increasing the number of courses from 12,000 a year to over 100,000 by 2012. The name of the initiative derives from the belief that expert patients should be considered not only as health providers, but also as important contributors in the collective intelligence that must be developed if multiple chronic diseases are to be managed successfully (http://www.globalalliancesms.org/about-gasms).

Group Health Cooperative, an American consumer-governed non-profit health care system that coordinates care and coverage, is implementing new technology to facilitate remote participation in self-management.

The rapid penetration of the Internet and Web 2.0 resources, along with the convergence of mobile smart telecommunication devices and social networking tools, provides an unprecedented opportunity to foster global interventions to promote the sharing and adoption of successful experiences worldwide. The emergence «of one-to-many», «many-to-one» and «many-to-many» communication tools such as Facebook (http:// www.facebook.com), Twitter (http://twitter.com) and Google Wave (http://www.wave. google.com) is opening up new frontiers for self-management (92).

Online social networking technology is being applied directly to promote self-management and optimal levels of patient education. Organizations such as PatientsLikeMe (www. patientslikeme.com), MD Junction (www.mdjunction.com), WellSphere (www.wellsphere. com), WebMD (www.webmd.com), the Association of Cancer Online Resources, Inc. (www.acor.org) (93, 94), New Health Partnerships (www.newhealthpartnerships.org), e-Patients (www.e-patients.net) or the Society for Participatory Medicine, among many others, are creating unique opportunities for networked patients and their loved ones to become the main drivers of their health-related decisions (http://participatorymedicine. org/). Those responsible for health policy, patients' associations and caregivers have access to tools of immense power to engage in a true partnership with patients to make self-management support and education a global reality.

## Contributors

Patrick McGowan wrote the draft of this chapter in English. Kate Lorig provided valuable ideas about the structure and main messages for the chapter. Alejandro Jadad approved the draft before it was made available online through the OPIMEC platform. This draft received important contributions from Esther Gil-Zorzo and Antonia Herráiz (in Spanish); Manuel Serrano (in English and Spanish); and Jackie Bender, Jennifer Jones, Maria Carmen Griñán Martínez and Manuel Armayones (in English). Alejandro Jadad incorporated these contributions into a revised version of the chapter, which was approved by Patrick McGowan and the other contributors.

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## How to reference

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#### Abbreviations

| AAL: Ambient Assisted Living  | PACE: Pro       |
|---|-----------------|
| BMJ: British Medical Journal  | QALY: Qua       |
| CAM: Complementary And Alternative Medicine   | QRISK: Ca       |
| CCD: Complex Chronic Disease  | RE-AIM: F       |
| CCM: Chronic Care Model   | Maintenar       |
| CIRS: Chronic Illness Resources Survey  | SNOMED<br>Terms |
| CMPs: Case Management Programs  | SSPA: Sist      |
| CVD: Cardiovascular Disease   | TCAM: Tra       |
| DMPs: Disease Management Programs   | TPE: Ther       |
| EASP: Escuela Andaluza de Salud Pública   | VHA: Veter      |
| EPP CIC: Expert Patients Programme Community Interest<br>Company  | WHO: Wor        |
| GRIN: Genomics, Robotics, Informatics and Nanotechnologies  |                 |
| ICCC: Innovative Care for Chronic Conditions  |                 |
| ICD: International Classification of Diseases   |                 |
| ICED: Index of Coexisting Disease   |                 |
| IDS: Individual Disease Severity  |                 |
| MCCs: Multiple Chronic Conditions   |                 |
| MD team: Medical Doctor   |                 |
| MeSH: Medicines Medical Subject Headings  |                 |
| MI: Motivational interviewing   |                 |
| MPOWER: Monitor (tobacco use and prevention policies),<br>Protect (people from tobacco smoke), Offer (help to quit tobacco<br>use), Warn (about the dangers of tobacco), Enforce (bans on<br>tobacco advertising, promotion and sponsorship), Raise (taxes<br>on tobacco) |                 |
| NHIS: National Health Interview Survey  |                 |
| NHS: National Health Service  |                 |

OECD: Organization for Economic Co-operation and Development

**OPIMEC:** Observatorio de Prácticas Innovadoras en el Manejo de Enfermedades Crónicas Complejas PACE: Program of All-inclusive Care
QALY: Quality-Adjusted Life Year
QRISK: Cardiovascular disease risk score
RE-AIM: Reach, Effectiveness, Adoption, Implementation and Maintenance
SNOMED CT: Systematized Nomenclature of Medicine-Clinical Terms
SSPA: Sistema Sanitario Público de Andalucía
TCAM: Traditional Complementary And Alternative Medicine
TPE: Therapeutic patient education
VHA: Veterans Health Administration
WHO: World Health Organization

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## Chapter 1

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Words cloud from chapter sections "What do we need to know?" and "What innovative strategies could fill the gaps?" [Available at: http://www.wordle.net]

# When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge

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