

Section 5

5. Self-management, patient activation and health literacy

Basic concepts

This section is about self-management of chronic conditions, the patient activation and health literacy that people require to prevent and manage their health. We firstly look at each of these concepts, and the evidence for their value in the prevention and management of chronic disease.



Learning objectives

By the end of this section you will be able to:

- Describe the concepts of self-management, patient activation and health literacy as they relate to chronic disease prevention and management.
- Identify the evidence for the effectiveness of approaches to supporting self-management, patient activation and health literacy in achieving better quality of care and outcomes.
- Describe the issues and challenges in implementing these at the organisation and system level.

5.1 What are chronic disease self-management, patient activation and health literacy?

Self-management can be defined as the decisions and behaviours that patients with chronic illness engage in that affect their health [1]. Chronic illness management requires patients to take an active role in managing behaviours and risk factors, monitoring their condition, adhering to treatment plans, and using health services optimally. These require knowledge and skill and are underpinned by patient's self-belief in their capability or self-efficacy [2]. Lorig has developed self-efficacy scales related to specific conditions and self-management behaviours for assessing the impact of chronic disease self-management support programs [3, 4].

Patient activation is a related concept and involves knowledge, skill, and confidence to manage long-term conditions including engaging in positive health behaviours and management of their health conditions [5]. It is related to self-efficacy but is a more general description of the patient capacity to engage. The most widely used measure of patient activation is the Patient Activation Measure [6].

There are numerous definitions of health literacy. The Institute of Medicine in the USA uses the definition of health literacy developed by the National Library of Medicine [7]: *The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions*. The WHO uses the definition of health literacy proposed by Nutbeam and Kickbusch [8]: *The cognitive and social skills which determine the motivation and the ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health*. Nutbeam [9] described three levels of health literacy:

Basic or functional health literacy is the basic reading and writing skills needed to be able to function in daily life.

Communicative or interactive health literacy describes more advanced cognitive and literacy skills which combine with social skills to enable someone to participate in a range of activities and apply information to changing situations.

Critical health literacy describes more advanced cognitive and social skills that a person can use to exert more control over their lives.

5.2 Self-management support

Chronic disease self-management support is a key component of the chronic care model, [1] which supports patients to be more activated. There are a number of self-management support models and training programs that are well researched and evidence based, and which provide a good underlying understanding of chronic disease self-management support theory and principles [10]. The aims of self-management programs are to develop the knowledge, skills and confidence necessary to enable the person with chronic illness to manage their health [11]. This requires the

person to be empowered to self-manage their own health as well as to attain the knowledge and skills to make the most efficient use of the healthcare system. It also requires a fit with carrying out new activities within existing domestic arrangements and should build on a participant's access to social and cultural resources. Ideally self-management is also supported by health care providers who plan the provision of care with the patient. This partnership between health providers, patients and their carers and social networks is more effective where the provider recognises that the person can be an expert in their own condition [12]. The person is supported to develop the knowledge and skills to take an active role in self-management and to achieve their health goals in partnership with their health care team.

Self-management support (SMS) is a key component of the Chronic Care Model (CCM) as a means of providing chronic care and equitable access for vulnerable populations [1]. SMS is what health care givers do to assist patients to become good self-managers. The World Health Organization (WHO) describes a triad of care between the patient and their family, the community in which they live and their health care provider [13]. The Australian National Chronic Disease Strategy identified self-management as one of the four key policy directions for healthcare and it recognises a diverse range of strategies are required to optimise self-management for different population groups.

Most of the self-management initiatives have been built on different theories including social, cognitive, behavioural and self-efficacy. Such programs target the management of specific conditions [14] using multiple components such as drug management, symptom management, psychosocial management, lifestyle changes, social support, goal setting and the provision of information on how to access support services [15]. The Stanford Chronic Disease Self-management Program (CDSM) developed by Lorig and colleagues (Lorig Program) in the US is widely accepted internationally because it has been developed as a generic chronic disease self-management program that has often been implemented by lay leaders [16]. This model was developed based on self-efficacy theory and incorporates components aimed to enhance self-efficacy such as weekly action plans, behaviour modelling, different management techniques, group problem solving and individual decision making through goal setting and support.

CDSM programs have varied widely in the way they have been designed or delivered. In Australia the most widely used programs have been the Flinders program (<http://www.flinders.edu.au/medicine/sites/fhbhru/programs-services/flinders-program.cfm>) and the Stanford program developed by Kate Lorig et al (<http://www.selfmanagementresource.com/programs/small-group/chronic-disease-self-management>). Some programs have been disease specific and others have been more generic self-management across a range of chronic illnesses. The programs have been delivered in group or individual sessions either face to face or by telephone or via the internet. Programs have been provided by health professionals or peers with chronic illness themselves and offered in a limited number of languages other than English.

What is the effectiveness of self-management support programs?

CDSM programs have been found effective in improving clinical, behavioural and self-efficacy outcomes associated with asthma, arthritis, chronic pain, diabetes and hypertension. Lay-person led generic group self-management education programs are effective in improving the self-efficacy and quality of life of patients with chronic long-term conditions [17]. Participants experience social support from their peers, and this can also lead to the development of local social networks. They are well suited to the needs of older patients with a number of co-morbid conditions where focus on one condition would be inappropriate.

CDSM programs can reduce health care use and costs and have been found effective in both rural and urban and a number of different cultural settings [18]. A recent systematic review of CDSM found that support for self-management was the most commonly used and most effective intervention for chronic disease care [19].

A number of success factors for CDSM programs have been identified. These include a collaborative approach between clients and clinicians, self-management education, clients making behavioural and lifestyle changes, ongoing training for clinicians, motivation interviewing, and engagement of local community networks (particularly for disadvantaged clients) [20]. Class size was not an important factor but annual top-up sessions maintained the effect [21]. Patient self-management has been particularly effective in community settings such as community groups or church groups where it could be culturally specific and tailored to the needs of ethnic groups [22]. There is limited evidence for the effectiveness for patients with multimorbidity.

Barriers for CDSM programs reported by Australian studies include: cessation of the program if the coordinator leaves, insufficient resources, implementation of the program in the wrong area, insufficient program content, lack of recruitment of patients, unclear criteria for patient eligibility, inconvenient schedules for education sessions, and lack of affordable transport [23].

How are chronic disease self-management support programs implemented?

In a review of 145 studies that were related to self-management approaches for people with chronic conditions, Barlow et al found that the majority of self-management approaches have been undertaken related to asthma, diabetes and arthritis [15]. The initiatives were delivered usually by health professionals in a variety of settings (clinical, community, home) utilising group sessions, individualized approaches or a combination of both and the format and content of the approaches varies considerably but most approaches used lectures and a manual.

The literature reports only a few CDSM programs that have been modified for use in different cultures. The Lorig Program has been adapted for and found effective in improving health behaviours, health status and self-efficacy in Spanish speaking populations [24], and culturally acceptable in Chinese populations [25]. The Arthritis Self-Management Program (ASMP) has been used in many countries (the Netherlands, Australia, and Canada) and been adapted for Spanish speaking

populations where it has had similar improvements in outcomes for pain, self-efficacy and exercise compared to studies undertaken in the other countries.

The Australian Government Department of Health and Ageing implemented the “Sharing Health Care Initiative” in 2002-03, which funded 12 CDSM projects. These projects had discrete funding and were developed and supported locally by an Area Health Service, Division of General Practice, Aboriginal organisations or the Arthritis Foundation. Each reflected local needs, but all were required by the funding body to include the Lorig Program, the Stages of Change Model and telephone follow-up.

A qualitative study in 2007 explored the uptake and sustainability of CDSM within routine activities of primary health care clinicians involved in the implementation of a demonstration project within an Area Health Service in Sydney, NSW [26]. This found that there was widespread support by participating clinicians for CDSM, finding it valuable to themselves, their clients and the health system. However, the design of the Lorig Program which focuses on clients’ ability to speak and understand English presented many barriers for its implementation in cultural and linguistic diversity (CALD) communities and the program was less effective in engaging key members of the primary care team, in particular, general practitioners. The study highlighted system design issues including communication and continuity of care between service providers, workforce supply and demands of acute care delivery in the community that need to be addressed to achieve sustainable and effective CDSM.



Learning Activity 1

Look at the Self Management UK (Formerly Expert Patients Programme) website. What model of self-management are these courses based on? How are they implemented? What are some of the strengths and weaknesses of the implementation of this and other programs. <http://selfmanagementuk.org/>

5.3 Health Coaching

Health coaching aims to support people to self-manage or change their behaviours. It may use behavioural techniques such as motivational interviewing and goal setting. It has been defined as *“a patient-centered approach wherein patients at least partially determine their goals, use self-discovery or active learning processes together with content education to work toward their goals, and self-monitor behaviors to increase accountability, all within the context of an interpersonal relationship with a coach. The coach is a healthcare professional trained in behavior change theory, motivational strategies, and communication techniques, which are used to assist patients to develop intrinsic motivation and obtain skills to create sustainable change for improved health and well-being.”* [27]

Health-coaching interventions were delivered including individual or group, face to face, telephone or internet (including use of avatars). One systematic review reported similar outcomes for face-to-face or telephone coaching approaches, although most people preferred face-to-face contact [28]. Most effective coaching programs last at least six months. In NSW health coaching is most frequently delivered by nurses. However, it can be delivered by a range of health professionals, community health workers, trained peers.

5.4 Patient activation

The Patient Activation Measure (PAM) contains a series of 13 statements designed to assess the extent of a patient's activation. These statements are about beliefs, confidence in the management of health-related tasks, and self-assessed knowledge. Hibbard has defined four levels of patient activation:

1. Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.
 2. Individuals may lack the knowledge and confidence to manage their health.
 3. Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.
 4. Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors.
5. 67 (9.6 %) were PAM Level 1, 123 (17.7 %) were Level 2, 193 (27.8 %) were Level 3, and 312 (44.9 %) were Level 4.

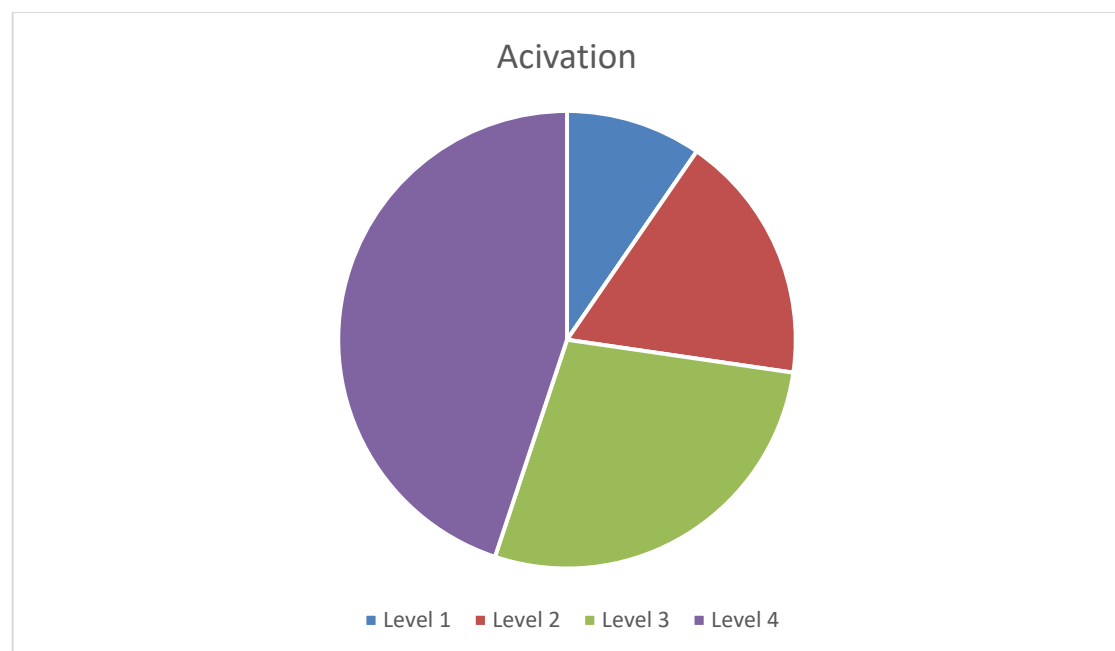


Figure 1: Levels of Activation of adults attending urban safety net hospital in Boston USA 2008-2010 [29]

Activated patients are more likely to engage in preventive behaviours, treatment and healthy behaviours. Less activated patients are less likely to self-manage, ask questions of their health providers and delay medical care.

Higher activation scores in patients with chronic conditions are positively correlated with better adherence to treatment and monitoring and appropriate health service use [30]. Patients with higher activation have lower rates of hospitalization and better patient experience [31]. Like self-management support, interventions aimed at raising levels of patient activation often focus on helping patients to develop skills

and confidence and on increasing patients' intrinsic motivation to engage and make decisions about their health care.

Interventions to engage patients in shared decision making and self-management also need to be tailored to patients' level of activation and motivation. This is important for coaching of patients with or at risk of long-term conditions. Patients whose coaching is tailored to their level of activation are more likely to improve their health behaviours than those who receive coaching that is not tailored [32].

Level 1	<p>Focus on building self-awareness and understanding behaviour patterns and begin to build confidence through small steps.</p> <p><i>What a coach might say: 'Let's not try to tackle everything right now. Let's just focus on one thing...'</i></p>
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Level 2	<p>Help patients to continue taking small steps, such as adding a new fruit or vegetable to their diet each week or reducing their portion sizes at two meals a day. Help them build up their basic knowledge.</p> <p><i>What a coach might say: 'You're off to a great start. Let's build on your success by reducing your portion sizes at lunch time too...'</i></p>
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Level 3	<p>Work with patients to adopt new behaviours and to develop some level of condition-specific knowledge and skills. Support the initiation of new 'full' behaviours (those that are more than just small changes – eg, 30 minutes of exercise three times a week) and work on the development of problem-solving skills.</p> <p><i>What a coach might say: 'You're making great strides. Do you think you're ready to take your efforts up one notch?'</i></p>
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Level 4	<p>Focus on preventing a relapse and handling new or challenging situations as they arise. Problem solving and planning for difficult situations to help patients maintain their behaviours.</p> <p><i>What a coach might say: 'You've had terrific success. Let's talk about how you can maintain that, even when life gets more stressful.'</i></p>

Figure 2: Tailoring coaching to patient activation levels [5]

Many interventions which target patient activation are focused support for patients with low activation levels to access health services [5]. Others attempt to tailor health care to the patient's level of activation.

5.5 Health literacy

Von Wagner and colleagues' review of health literacy introduced a framework on the associations between health literacy and health outcomes being mediated by three principal domains of health actions, namely access and use of health care, patient-provider interactions, and self-care (management of health and illness) [33, 34].

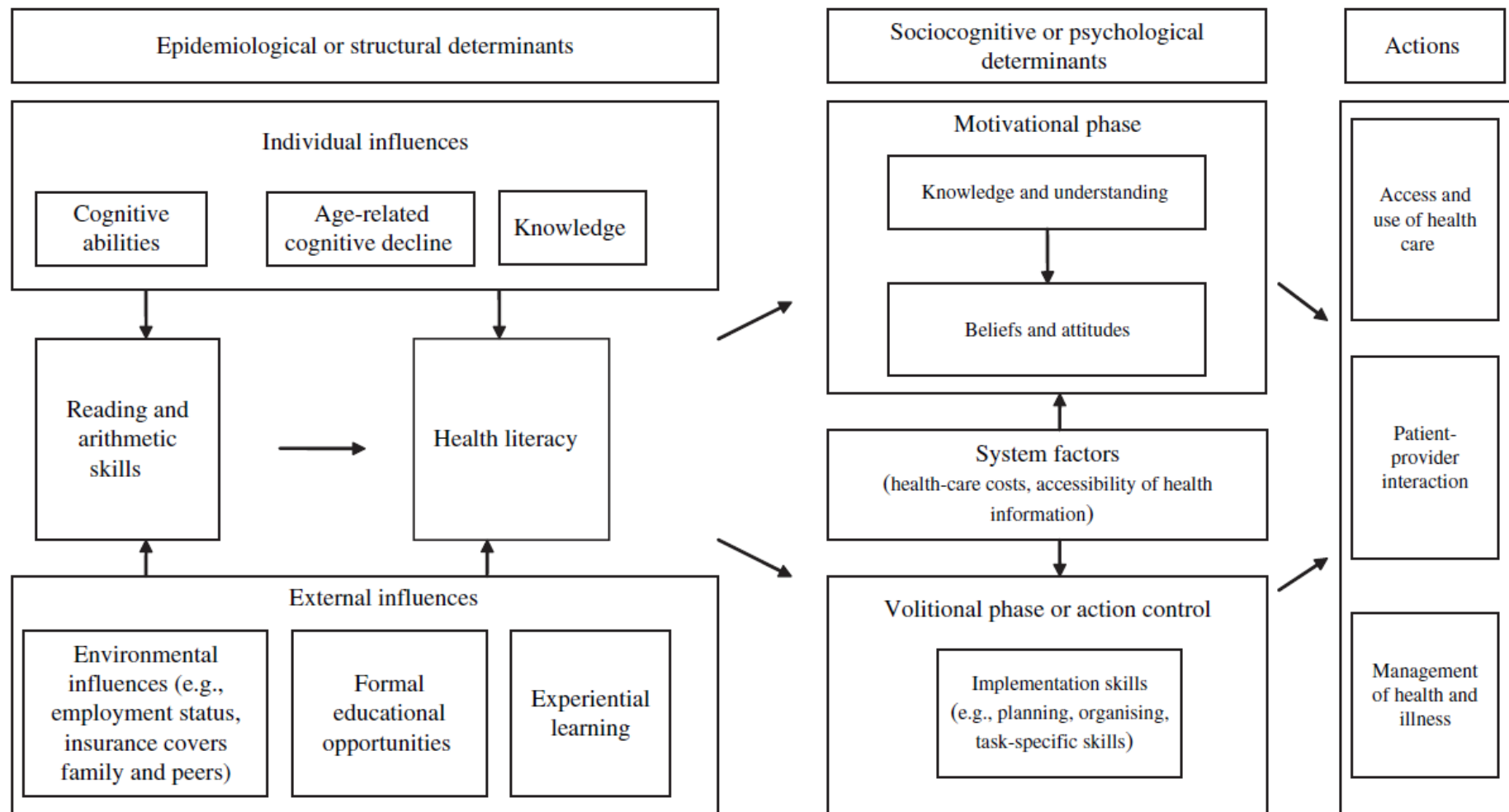


Figure 3: Framework for Health Literacy

Source: von Wagner, C., et al., Health literacy and health actions: a review and a framework from health psychology. *Health Educ Behav*, 2009. 36(5): p. 863.

In Australia, 59% of adults aged 15-74 years have health literacy that is below the minimum level regarded as necessary to understand and use information relating to disease prevention and staying healthy [35]. People with limited health literacy have: less knowledge of diseases and self-care [36]; worse self-management skills [37]; lower medication compliance rates [38]; and higher rates of hospitalisation. People with low health literacy also have lower levels of engagement in health promoting behaviours and are more likely to smoke especially in adolescence and as young adults [39].

Patients with limited literacy commonly experience access barriers such as: difficulties completing paperwork and navigation problems, delays in seeking care [40] and being less likely to receive preventive services [41]. Patients with poor health literacy are: less likely to ask questions, and providers incorrectly assume these patients are not interested or desire a less active role in their health care [42]. Providers communicate less well with patients with low educational attainment and poor health literacy, particularly in the domains of general clarity, explanation of a condition and explanation of processes of care [43].

Here are some suggested strategies for communicating to address poor health literacy in clinical practice [44]:

- Use plain- non-medical language when speaking with patients
- Speak clearly and at a moderate pace
- Limit content by prioritising what needs to be discussed and limit information to 3-5 key points
- Be specific and concrete in your conversation and repeat key points
- Draw pictures, use illustrations or demonstrate with models
- Encourage patients to ask questions and be involved in their decision making – ask *what questions do you have?* rather than *do you have any questions?*
- Confirm patients understand what they need to know and do by asking them to explain the key points. If they cannot remember accurately, repeat what you asked them, clarify your information and directions and then ask them to describe in their own words what they are going to do
- Follow up with patients to check progress and verify follow-through on referrals. Patient follow up can be supported by a reminder system. Methods for follow up can include another consultation, a phone call, email or letter. You will need to identify who will do the follow up – general practitioner, practice nurse, or other office staff.

There are a number of screening tools available for assessing patients' health literacy [45, 46].

Table 1: Screening questions for low health literacy [47]

A. How often do you have someone help you read hospital materials?				
1) Never	2) Occasionally	3) Sometimes	4) Often	5) Always
B. How often do you have problems learning about your medical condition because of difficulty reading hospital materials?				
1) Never	2) Occasionally	3) Sometimes	4) Often	5) Always
C. How confident are you filling out forms by yourself?				
1) Extremely	2) Quite a bit	3) Somewhat	4) A little bit	5) Not at all

Total scores greater than ten are categorised as low health literacy. Scores of ten or lower reflect adequate health literacy.

People with low health literacy often lack skills in navigating health services and programs. The term care navigation was developed as a way to address some of the factors thought to be responsible for poor rates of screening, adherence to follow-up, and treatment for cancer among disadvantaged communities [48]. Lay individuals were trained as patient navigators to identify patients' barriers to seeking care and to work with patients, care providers, and community resources to overcome these barriers.

Health literacy for navigation includes [49]:

1. An understanding of one's health, socioeconomic and cultural values and context
2. A clear sense of 'where we're going'. Why should I be healthy? Why should I be informed about my health? Every person's journey may be different, take more or less time, encounter different hurdles
3. A map – information in a form that is digestible, meaningful and easy to interpret. This may be a mix of verbal and written electronic and paper materials
4. A compass – health professionals, publications or the internet as helpful guides
5. A path – messages about health that are accessible, appropriate to individual needs, cultural and social backgrounds
6. Family and friends are essential in health. Health professionals, advocacy groups, community services – may all help build health literacy and provide a supportive environment for health.

The roles of the care-navigators are to provide intensive, personal assistance for patients in:

- Proactively identifying and addressing patients' barriers to seeking or receiving preventive care, particularly in relation to not understanding health information or not having the confidence to make lifestyle changes

- Linking patients into lifestyle modification programs or to allied health professionals in a timelier manner, and following up with patients to provide encouragement and support attendance at these services and programs
- Connecting patients to relevant medical and other community resources
- Helping patients negotiate the complex web of advice on how to stay healthy, at to set goals and targets for their own health choices, thereby fostering patient empowerment.

Care navigation has at its core relationship-building (building trust and providing emotional support) and instrumental assistance [50]. Families may also be involved in the care-navigation process if requested by the patient.

Health literacy also needs to be considered at the health service organisational level. For example organisations can work with consumers to make sure that the information and services they provide are easy to understand, use and act on [51]. The Institute of Medicine in the US has identified ten key attributes of health literate organisations [52]:

1. Leadership that makes health literacy integral to its mission, structure and operations
2. Integration of health literacy into planning, evaluation measures, service users' safety and quality improvement
3. Preparation of the workforce to be health literate and monitoring of progress
4. Inclusion of populations served in the design, implementation and evaluation of health and related information and services
5. The needs of populations with a range of health literacy skills are met while avoiding stigmatisation
6. Health literacy strategies are used in interpersonal communications and confirms understanding at all points of contact
7. Provision of easy access to health and related information and services and navigation assistance
8. Design and distribution of print, audio-visual, and social media content that are easy to understand and act on
9. Health literacy is addressed in high-risk situations, including care transitions, communications about medicines, etc.
10. Communicates clearly what health plans cover and what individuals will have to pay for services.



Learning Activity 2

Look at the web page on health literacy by the Australian Commission on Safety and Quality in Health Care. <https://www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/health-literacy/> and their National Statement on Health Literacy. <https://www.safetyandquality.gov.au/wp-content/uploads/2014/08/Health-Literacy-National-Statement.pdf>.

What aspects of health literacy are described? What strategies are proposed to deal with it?

Suggested further reading



Improving Chronic Illness Care. *Self-management support*. Available from:

http://www.improvingchroniccare.org/index.php?p=Self-Management_Support&s=39

Agency for Clinical Innovation. *Chronic Care Resources*. Agency for Clinical Innovation: Chatswood: Available from:

<https://www.aci.health.nsw.gov.au/resources/chronic-care>

For further information and tips on addressing health literacy you can access the US toolkit on health literacy at the following address:

<https://www.ahrq.gov/professionals/quality-patient-safety/index.html>

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